

Standing Committee on Social Issues

# **A Matter of Priority**

## Report on Disability Services

### Second Report

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## Terms of reference

- 1) That the Standing Committee on Social Issues inquire into and report on the provision of residential care and other services which support people with disability, including the following.
- 2) The tendering out of group homes currently operated by DOCS, including:
  - (a) how the decision was made, by whom and for what reason,
  - (b) the criteria for choosing which homes would be tendered out, how they were arrived at,
  - (c) the service planning and development that preceded the decision to tender out group homes, and in particular the following:
    - (i) arrangements for the provision of case work, clinical and allied health services for people with disability in accommodation provided by the non-government sector,
    - (ii) arrangements for the training and accreditation of staff working in non-government accommodation services,
    - (iii) arrangements for non-government infrastructure support and development generally.
  - (d) how the processes involved in tendering out group homes were arrived at,
  - (e) the level of consultation with people with disability, their families and carers prior to and during the process of tendering out the group homes, and organisations representing people with disability, especially including People with Disabilities (Inc), the NSW Council on Intellectual Disability, the NSW Safeguard Coalition and the Public Service Association,
  - (f) the appropriateness of the means by which people with disability and their families were informed of the decision to tender out group homes,
  - (g) whether during this process the government has breached the Disability Services Act in any way,
  - (h) the need for certainty of future accommodation for people currently residing in DOCS Group Homes, and future clients of what are now DOCS Group Homes,
  - (i) the particular impact on rural and remote families.
- 3) The provision of residential care and other services for people with disabilities, having regard but not limited to:
  - (a) current unmet need,
  - (b) the adequacy of the Government's response to unmet need to date, including:
    - (i) the provision of funding to address unmet need,
    - (ii) service planning,

- (c) the need and level of provision for respite care,
  - (d) the availability and distribution of supported accommodation, respite care and other disability services for people in rural and remote communities, needs of people with disabilities and their families in rural and remote areas, and the need for government to make particular provision for their needs,
  - (e) the security of ongoing funding arrangements for the non-government sector,
  - (f) the desirability or otherwise of a continuing role for Government in the direct provision of services for people with disability,
  - (g) the adequacy of administrative arrangements between the Ageing and Disability Department and the Department of Community Services in relation to the disability services provided by the Department of Community Services,
  - (h) the status of the implementation of the Disability Services Act (1993) in particular in respect to:
    - (i) the provision of funding to assist services to reach conformity to legislative requirements, and
    - (ii) the implementation of those provisions dealing with individualised funding arrangements.
- 4) That the Inquiry make specific and general recommendations about the matters inquired into,
  - 5) That in conducting the Inquiry specific steps be taken to consult as widely as possible with people with disability, their families and carers, and organisations representing people with disability, especially including People with Disabilities (Inc), the NSW Council on Intellectual Disability, the NSW Safeguard Coalition and the Public Service Association, having particular regard to the need to ensure people with disability are fully involved in decisions affecting their lives,
  - 6) That, in relation to the matters raised in paragraph 2 the Inquiry report to the Parliament no later than 30 November 1999,
  - 7) That until recommendations are made by this Inquiry, this House calls on the Government in the strongest terms to agree to a moratorium on the proposed changes to DOCS group homes, in order that it may respond positively to the Inquiry's outcomes,
  - 8) That the Government be required to provide to the House all Government papers in written or electronic form including the complete range of documents relating to the decision to tender out DOCS group homes, including papers from the Departments of the Premier, Treasury, Ageing and Disability and Community Services.

These terms of reference were referred to the Committee by the Legislative Council on the motion of the Hon John Ryan MLC on 16 September 1999 (Minutes of Proceedings No 6 page 63).

## **Committee membership**

Jan Burnswoods, MLC, **Australian Labor Party, Chair**

The Hon Doug Moppett, MLC, **National Party, Deputy Chair**

The Hon Dr Arthur Chesterfield-Evans, MLC, **Australian Democrats**

The Hon Amanda Fazio, MLC, **Australian Labor Party**

*from 11 October 2000*

The Hon Ian West, MLC, **Australian Labor Party**

*from 16 November 2000*

The Hon Henry Tsang, MLC, Australian Labor Party, served on the Committee from 25 May 1999 to 11 October 2000. Ms Fazio was appointed in place of Mr Tsang.

The Hon Andrew Manson, MLC, Australian Labor Party, served on the Committee from 25 May 1999 to 16 November 2000. Mr West was appointed in place of Mr Manson.

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## Chair's foreword

I am pleased to present this second report of the Committee's inquiry into residential and support services for people with disability. The first report, *The Group Homes Proposal*, was tabled in December 1999.

In this second part of the inquiry the Committee has identified three areas in need of urgent attention. The focus of the report on permanent supported accommodation, respite care and devolution of large residential centres is motivated by the Committee's desire to see substantial changes made to these services. The decision to deal with these aspects of our terms of references now was dictated by the need for action and also by the inter-relationship of these service areas. The Committee very strongly believes that with sustained investment and long-term planning in these areas, the disability services system in New South Wales could be a model for others to follow. Other important issues in disability services will be dealt with in a final report in 2001.

The importance of this inquiry's subject matter is demonstrated by the large number of submissions received, 309 since we began in September 1999, and by the high attendance at our community consultations. This interest is a testament to the profound commitment of parents, advocates and the peak organisations to ensuring that people with disability are treated with dignity and have access to quality services and support.

I would like to express my appreciation to all the individuals and organisations who participated in this inquiry. In particular I would like to thank the residents and staff of centres and the clients of services, who allowed us to visit them in their living and working environment. Committee members found these visits enlightening, moving and sometimes very sobering.

This report urges swift and effective action to address the more pressing matters in the delivery of disability services. The Committee believes that the State Government and its coordinating agency, the Ageing and Disability Department, have the commitment to greatly enhance the quality of life of people with disability. With the same dedication to planning and investment given to the Paralympics, the accommodation and support provided to people with disability in NSW can be similarly world-class.

Finally, I would like to thank Committee members for the commitment they have demonstrated and the sensitive way they have dealt with this important inquiry. I am extremely grateful to the staff of the Secretariat, Tony Davies, Beverly Duffy, Julie Langsworth and Heather Crichton. I would also like to thank student intern Thea Bray for her research and support during consultations.

I commend this report to the Government.



**Jan Burnswoods, MLC**  
**Chair**

## Executive summary

Systemic services to meet the need of people with disability are a prime responsibility for government in Australia. Historically, these services have failed to attract the necessary resources. There is a need for immediate action to assist those people in greatest need and to restore confidence in the disability services system.

There are three priority areas where immediate action is required: permanent supported accommodation, respite services and devolution of large residential centres.

The Committee notes that the government has progressively increased funding for disability services, with considerable growth funding allocated in the 2000 Budget. The Committee commends the government and its coordinating agency, the Ageing and Disability Department (ADD), for their commitment to renewed investment in the disability sector. The evidence to this inquiry has shown that extended investment in disability services must be maintained over a period of years to redress past neglect and to develop an efficient and equitable disability services system.

### ***Supported accommodation***

Permanent supported accommodation stands out as the area of greatest need for disability services in NSW. Other areas of unmet need cannot be effectively addressed unless demand for accommodation services is substantially reduced.

A relatively small but significant number of people with disability now live in unsustainable care arrangements that place them and their carers at risk. There is currently a substantial under-supply of permanent supported accommodation for these people. This unmet need for accommodation places extreme pressure on families, service providers and coordinating agencies.

The disability services system is focussed largely on crisis management as a result of this relentless pressure for accommodation. Services and resources intended to support a wide range of people (for example, respite) are consistently diverted to support a very small number of individuals whose informal care arrangements have broken down. This results in provision of temporary and inappropriate support to the small number of people who actually require permanent accommodation, and contraction of services needed to support a far wider range of people. The pre-occupation with crisis management over many years has impeded the development of a thoroughly planned, effective and equitable support system for people with disability in NSW.

Failure to provide permanent accommodation to the small number of people who are in critical need imposes immense human cost on people with disability and their carers. In extreme cases failure to access supported accommodation gives rise to relationship and family breakdown, physical injury and disability of care-givers, social isolation, inability to participate in the workforce, depression and poverty. This seriously undermines the dignity of people with disability.

Many carers currently see no prospect of their family member with disability ever achieving a permanent placement. An inevitable consequence of this is that the activities of caring come to be viewed as an overwhelming burden. This can translate into demand for permanent accommodation, even where alternative supports may better assist the people concerned.

A progressive increase in the supply of permanent accommodation is required to meet the needs of three main groups:

- A relatively small number of people in need of urgent and immediate out-of-home permanent accommodation because care relationships have broken down.
- People who require permanent out-of-home accommodation in the near future, but who with immediate and intensive support are able to remain within existing carer relationships. These people can be described as on the brink of, but not in crisis. This group needs immediate intensive assistance and assurance that permanent accommodation will be available when required.
- People whose current caring relationship is stable, but likely to deteriorate in the short or medium term. In many cases these are people whose carers are ageing.

Accurate information on the number of people who immediately require supported accommodation is currently not available. Similarly, there is no information on the rate of growth. A relatively small number of people require permanent supported accommodation when compared to the overall number of people reporting unmet need for some form of accommodation support or assistance. However, investment in providing accommodation for these people will have significant flow-on benefits for the disability services system as a whole.

The present situation is a result of historical factors, including lack of investment in service provision over a long period of time and changes to the way that accommodation services are provided to people with disability. It is likely that demand for accommodation will continue to outstrip supply for at least the medium term. A program of long-term investment, initially targeted to the very small number of people in extreme crisis, will have an immediate impact by assisting those in greatest need. Beyond that the program will build confidence in the capacity of the system to ensure that accommodation will become available when, and if, it is needed.

Recent initiatives, particularly over the past five years, have resulted in approximately 100 new supported accommodation places being created each year. This has reduced the level of unmet need, but has not been sufficient to meet increasing demand. In the 2000/2001 Budget, significant new funds were provided for permanent accommodation. Also, ADD has commenced a program of systemic reform of disability services in NSW, that will over time have a significant impact on the level of unmet need for supported accommodation. The government has also established a Service Access System that will allow central management of the most urgent requests for services. The Committee welcomes these additional measures but considers that further increases in the supply of supported accommodation are required to ensure that demand is reduced to a manageable level.

The **key recommendation** on supported accommodation is that:

- The Ageing and Disability Department should adopt a growth target of 200 additional permanent supported accommodation places for people with disability each year for five years from the date of tabling this report.

In addition, ADD should develop and publish targets for the number of residential places for people with disability per head of population as part of the planning process. Systems to allow collation and interpretation of data on the level, type and distribution of unmet demand for disability services including permanent supported accommodation should be developed and made public as part of the planning process.

### ***Respite services***

Respite services are vital to maintaining long-term informal support arrangements for people with disability. It is well recognised that investment in respite is a cost-effective and highly desirable way to provide on-going accommodation supports. Adequate provision of respite ensures that demand for permanent accommodation is minimised. Respite services can also provide important developmental opportunities for people with disability, including the opportunity to learn necessary skills for living outside the family home.

Demand for respite services greatly exceeds supply. Access to centre-based respite is particularly restricted because of the continuing problem of 'blockage' by people needing supported accommodation and crisis support. Regular planned respite is now almost unobtainable in some areas of NSW.

In February this year, the Respite Working Group identified a number of issues that need addressing, such as the need for increased funding for supported accommodation to unblock respite and prevent further blockage. The report identified the need for a clear policy framework and definition of respite to be developed to make it clear that respite is *planned support* for the carer relationship, not crisis support.

Since the release of the Working Group report, the government has announced a range of measures that are intended to address the current situation in respite. These include funding for a regionally based crisis support system, funding for permanent accommodation for people in long-term respite, the development of 1200 new flexible respite packages and the establishment of two new respite centres.

These initiatives will form the basis of widespread and beneficial reform to the respite system in NSW. However, they need to be supported over time by sufficient resources to ensure that respite services are not taken up by people with other service needs in the future.

Detailed recommendations for reform of the respite system have been developed by the Respite Working Group (see appendix 6) and therefore this Committee has not put forward detailed recommendations. The Committee's **key recommendations** on respite are that:

- The Ageing and Disability Department should implement all recommendations of the Respite Working Group.
- Within 6 months of the date of this report, the government should table a detailed response to the Report of the Working Group outlining what action it has taken or intends to take in relation to each recommendation of the Working Group.

## ***Devolution***

There are 2400 people with disability presently living in medium and large residential centres. All the research presented to the Committee demonstrates that community-based models meet the needs of residents far more adequately than congregate models. Large residential centres also fail to meet some of the most significant requirements of the *Disability Services Act 1993*. Regrettably, the only spare accommodation capacity exists in large residential centres, creating continued pressure to 'backfill' vacancies that arise in these services.

There are no benefits to government in retaining congregate accommodation models. Financial data provided to the Committee regarding large government centres shows that significant economies of scale are not achieved through congregate accommodation. Large non-government centres are often forced to operate on low levels of recurrent funding, which are based on historical funding models inherited from the Commonwealth. As a result, residents of these centres may receive a demonstrably lower level of service than people in community accommodation.

The accommodation support system must address the inequities presented by congregate accommodation. It is inequitable to keep people in an outmoded accommodation model when many people with disability live in community-based accommodation and all growth funding is for community-based models. It is necessary to remove the pressure to continually 'backfill' vacancies in large residential centres as the only means to assist families in crisis. This requires the establishment of an alternative system of crisis accommodation, greater access to respite accommodation and effective pathways to permanent supported accommodation.

The Committee considers that the 12-year time-frame for complete transition of large residential centres announced in 1998 is too long. Such a period dissipates the momentum that has built up in relation to devolution, and means unacceptable delays for people, many of whom have now been awaiting transfer to community accommodation for over a decade. However, given the complexity and importance of the task, the Committee has reluctantly accepted that the 12-year time-frame for final devolution of all services is realistic. A **key recommendation** of this report is that:

- All medium and large residential centres should be funded to complete transition to models that comply with the *Disability Services Act 1993* before 31 December 2010.

In the 2000/2001 Budget, funding was announced to enable 400 people to move out of medium and large residential centres into community accommodation by 2003. A **key recommendation** of this report is that:

- Further funding be identified now to ensure that 80% of residents of large centres transfer to appropriate community accommodation by 31 December 2005.

The planning for transition of *all* medium and large residential centres should commence immediately. Revised transition plans for these services should be finalised and made public within two years of the date of tabling of this report. The need to prepare plans for all services should not delay the transition of services that are capable of immediately commencing the process.

Intensive consultation with residents, families and staff regarding transition of large centres needs to commence immediately. To ensure adequate participation in the process, residents need to be provided with accessible information and properly resourced advocacy.

The Committee is particularly concerned for those family members who are apprehensive about changes to living arrangements for people in large centres. Their concerns must be fully recognised and addressed as part of the transition process. Therefore, a **key recommendation** of this report is that:

- The government should provide all residents who transfer from large government and non-government residential services to community-based accommodation with an unconditional life-time guarantee of service.

The Committee believes that there should also be a guarantee that appropriate medical, nursing and therapy services will be provided for residents with high medical support needs.

Existing staff of large residential centres will be vital to the success of the transition process and must be part of it. Staff need to support the transition process and help prepare residents so that they can respond positively to change. The Committee believes that, from the outset, staff should receive reassurance about continuity of employment. Existing skills and specific client knowledge should be recognised and deployed to minimise disruption to residents during the transition period. Where necessary, staff should be provided with training to gain additional skills.

There is a need for a substantial allocation of capital funding to assist the transition process. Overall, recurrent funding will need to increase as a result of transition. Where possible, existing assets of large residential centres in the government sector should be realised to assist the transition process. ADD should retain the proceeds of all government asset realisations for allocation to disability services.

### ***The group homes project***

The report briefly comments on the group homes project and the concerns about the expression of interest process. Feedback to date from parents and advocates suggests that many participants did not feel they had been properly consulted about matters such as who would be their service provider. While acknowledging that the process has been a positive experience for some residents, the Committee is particularly concerned that DoCS had only managed to submit an expression of interest for 1 of the 41 services. As ADD intends to finalise the process by the end of 2000, the Committee **recommends** that:

- As a matter of urgency, the Department of Community Services should submit Expressions of Interest for all services in the group homes project.

## Summary of recommendations

### **Recommendation 1** *Page 37*

The Ageing and Disability Department should adopt a growth target of 200 additional supported accommodation places for people with disability per year for five years from the date of this report.

### **Recommendation 2** *Page 37*

The Ageing and Disability Department should review the growth target of 200 places per year in the light of information provided by the Service Access System, provided accurate information on current and future unmet need is available within two years of the date of this report.

### **Recommendation 3** *Page 40*

The Ageing and Disability Department's regional and State plans for disability services should include numerical targets for growth in supported accommodation as outlined in Recommendations 1 and 2.

### **Recommendation 4** *Page 41*

The Ageing and Disability Department should develop and publish population-based targets for the number of residential places for people with disability as part of the planning process.

### **Recommendation 5** *Page 42*

Systems to allow collation and interpretation of data on the level, type and distribution of unmet demand for disability services, including permanent supported accommodation, should be incorporated into the Service Access System.

### **Recommendation 6** *Page 42*

Information on unmet demand for disability services derived from the Service Access System and other sources should be made public as part of the development of the planning process.

### **Recommendation 7** *Page 51*

The Ageing and Disability Department should act to implement all recommendations of the Respite Working Group.

### **Recommendation 8** *Page 56*

The Ageing and Disability Department should adopt a definition of respite for respite services that includes the following elements:

- planned support is provided to the family unit or other carer relationship
- the service is provided to people with disability who have existing informal support arrangements
- the service is not intended to be the primary source of support for a person with disability
- the service does not provide emergency care to individuals in crisis
- the service is flexible, individualised, culturally and age-appropriate and provides developmental opportunities to people with disability.

**Recommendation 9** *Page 57*

In developing services to separate crisis support from respite, the Ageing and Disability Department should develop funding guidelines for services that provide crisis support.

**Recommendation 10** *Page 57*

The Ageing and Disability Department should develop and implement population-based targets for respite services.

**Recommendation 11** *Page 57*

Funding allocations for respite services should be sufficient to support population-based targets for respite.

**Recommendation 12** *Page 58*

The Leader of the Government should table in the House a detailed response indicating what action the government has taken or intends to take in relation to each recommendation of the Respite Working Group, not later than six months after the date of tabling this report.

**Recommendation 13** *Page 74*

The government should provide all residents who transfer from large government and non-government residential services to community-based accommodation with an unconditional lifetime guarantee of service that conforms with the Objects, Principles and Applications of Principles of the *Disability Services Act 1993*.

**Recommendation 14** *Page 74*

The guarantee to all residents transferring from large residential services should explicitly acknowledge that appropriate levels of support will be provided as support needs of people with disability increase, including those of younger people who initially returned to the family home.

**Recommendation 15** *Page 75*

The guarantee of lifetime care referred to in Recommendation 13 should include an explicit commitment that people will receive appropriate medical and therapy services to meet their needs.

**Recommendation 16** *Page 75*

The funding packages for people who move to community-based services should include a component for medical and therapy services appropriate to their needs.

**Recommendation 17** *Page 77*

The Ageing and Disability Department should ensure that all residents of large residential centres who do not have advocates are provided with independent advocacy support as part of the devolution process, and that adequate funding for advocacy support is provided.

**Recommendation 18** *Page 77*

In consultation with people with disability, the Ageing and Disability Department should develop a communication strategy to ensure that residents have a clear understanding of the devolution project. The communication strategy should include provision of plain English information about the devolution project.

**Recommendation 19** *Page 78*

Specific steps should be taken to ensure that existing beneficial social networks are maintained for residents of large centres who move to the community.

**Recommendation 20** *Page 78*

Clear evaluation of resident compatibility should take place prior to transfer to community-based settings.

**Recommendation 21** *Page 80*

The Ageing and Disability Department should develop a staff strategy for devolution of large residential services to ensure that existing skills and knowledge are used and retained during the devolution process. The strategy should:

- make provision for continuity of employment of existing staff
- ensure that adequate resources are provided for staff training
- outline the obligations of existing staff to support and participate in the success of the devolution program
- enable the development of new skills, philosophy and approaches necessary to support people in the community.

**Recommendation 22** *Page 81*

The Department of Community Services, in conjunction with the relevant unions, should examine the staffing mix of large centres with a view to filling vacancies with appropriately qualified people and ensuring that staff can support the devolution process.

**Recommendation 23** *Page 84*

The Ageing and Disability Department should, in consultation with relevant interest groups, develop an overall strategic plan for devolution of large residential centres for people with disability. This plan should be made public.

**Recommendation 24** *Page 85*

All medium and large residential centres should be funded to complete transition to models that comply with the *Disability Services Act 1993* before 31 December 2010.

**Recommendation 25** *Page 86*

As part of the planning process referred to in Recommendation 23, funding should be identified now to enable 80 per cent of residents of large centres to transfer to appropriate community accommodation by 31 December 2005.

**Recommendation 26** *Page 86*

Within two years of the date of tabling of this report, revised transition plans for transfer to community living should be finalised for all large residential services.

**Recommendation 27** *Page 86*

As a matter of urgency, additional resources should be allocated to the Ageing and Disability Department to ensure that an expanded devolution project is effectively managed.

**Recommendation 28** *Page 87*

As part of the planning process referred to in Recommendation 23, the Ageing and Disability Department should define the specific types of support services that will be available to people who move to the community.

**Recommendation 29** *Page 88*

As part of the planning process, clearly understood procedures should be established for on-going review of the support needs of people who move to the community.

**Recommendation 30** *Page 89*

The Ageing and Disability Department should take, as a part of the consultative process, specific steps to encourage and facilitate contact between families of people engaged in current devolution projects and families of people who have moved to the community during past projects.

**Recommendation 31** *Page 90*

All proceeds from the sale of large government-owned residential centres should be retained within the Disability Services Program and managed by the Ageing and Disability Department.

**Recommendation 32** *Page 90*

The Ageing and Disability Department should implement a formal no admissions policy for all large non-government centres.

**Recommendation 33** *Page 96*

As a matter of urgency, the Department of Community Services should submit expressions of interest for all services included in the group homes project.

## **Plain English summary for people with disability**

*This is a plain English summary of this report. It is written for people with disability so they can read what we said in our report. This report has been written by a group of people called the Committee. We are 5 members of Parliament. We have talked to a lot of people about the things in this report, and also read the letters people have written to us.*

*This summary does not have all the information that is in the report. It does not include the recommendations or reasons for the recommendations. These are in the main report. If you are really interested in the report, it is a good idea to go through it with a support person, or you could call us to talk about it. Our telephone number is 02 9230 3078.*

### **Introduction**

Services for people with disability and their families are very important. It is mainly the job of the government to provide services for people with disability. This report looks at how the government can help people, especially with finding the right sort of place to live.

### **Chapter 1 – Impact of unmet need for accommodation**

Many people with disability live well without help from the government. But some people with disability need a place to live. This is very worrying for them and their carers.

Some carers are finding it hard to cope because they don't have enough support. This is causing problems for some families who do not have enough time for everyone in the family. Sometimes the problems are so bad that the family begins to break down.

Some carers told us they are worried about getting older and not being able to look after their family member with disability. They said they loved their children very much but they didn't think all the work they have to do now is fair on them or their children.

Some parents of younger children with a disability also need lots of help. Some of them told us they were very tired because they didn't have much help to take care of their child every day. Other carers were very worried about where their child would live when they grow up.

Some people in country towns are finding it hard because there is not very much support. Carers living in the country told the Committee that some people don't understand what they need.

It is very important to people with disability to have a proper place to live. Lots of people told us that people with disability feel much better when they are able to spend time away from the family. Some people with a disability are very annoyed that they can't leave the family home because there are no services to help them.

The Committee thinks that there should be much more help given to people with disability and their carers. We think there should be more support for people with disability to be away from the family for some of the time. Lots of people told us they thought this would help everyone in the family.

## **Chapter 2 – Supported accommodation**

The Committee looked at the need for more supported accommodation, such as group homes, for people with a disability when they move out of their family home.

At the moment we do not know how many people there are in New South Wales who need supported accommodation. We think the government needs to find out how many people with disability need supported accommodation.

The Committee knows there are lots of people who really need help because they can't live at home any more.

We think that the government needs to provide more supported accommodation for people with disability. At the moment the government provides 100 new places each year to help all those people still waiting for somewhere to live. We don't think this is enough. The Committee wants the government to make sure

there are 200 more places made available each year for the next 5 years. We think that this will help people who really need accommodation outside their family home.

Lots of people told us that it is important for the government to have a long-term plan about providing supported accommodation. The Committee thinks that a clear plan might help and stop people from worrying about where they will live when they leave the family home. We think that the government should show the plan to people with disability and their families and ask them to help make the plan.

Some people from towns told us that they have problems finding supported accommodation and other services. People from other cultures, including Aboriginal people, also have problems finding the right kind of place to live. The Committee will look at this in our next report on disability services.

The Committee is sure that the government can find a way to help people with disability to find the right sort of supported accommodation. We have to make sure that there is enough money for places, and a good plan.

### **Chapter 3 – Respite services**

The Committee knows that most respite care is done by family and friends. In this chapter we look at the other kind of respite provided by different organisations.

Lots of people told us that respite is very important to people with disability and their families. The Committee knows that every family needs to have a break from each other now and again. People feel much better if they can leave the family home for a while. We know that people with disability need to have different experiences and be able to make their own friends.

Carers also need to have a break away from their family member. Some older carers told us they need a break so they can have a rest. Some younger parents said they needed to have some time for themselves and for other children in the family.

The Committee thinks there is not enough respite care for people with disability and their families and carers at the moment. Lots of people told us they could not find a place when there was a problem in the family and they really needed a break. Other people told us they couldn't plan for a holiday because there was not enough respite care.

The government and other groups have written reports on the problems with respite care. The main problem is that some people are staying in respite places because they have nowhere else to live. The Committee thinks that one way to get more respite care is for the government to make sure there is more permanent accommodation for people with disability, so people don't have to live in respite places.

The government is trying to find ways to help improve respite services. The Committee thinks that the government needs to find out how many people need respite care in New South Wales. They also need to plan for the future needs of people. The Committee thinks that respite care is very important and will help to keep families together.

#### **Chapter 4 - Devolution**

Many people with disability still live in large institutions or residential centres. They don't get a lot of the things that people in the community get.

Most people believe people with disability are better off if they live in the community with staff who can support them. That way they can have more freedom to live the way they want to. The Committee has spoken to many people who are glad they have moved from a centre to the community.

The government has a plan to move people with disability from large institutions to the community by the year 2010. This plan is called devolution.

The Committee thinks devolution should happen sooner so that most people can move to the community by 2005.

Some people are nervous about moving somewhere different. Some families and staff are also very worried.

So the Committee has asked the government to make sure that people with disability and their families have lots of support when they move. For example, people in the centres should have an advocate to help them choose where to live. They should also be able to keep in touch with their friends and the staff from the centre.

The Committee believes that people in centres should receive a guarantee or promise that they will always have somewhere to live and people to help them.

## **Chapter 5 – Conclusion**

In this report the Committee has said that the government will need to spend some more money to help people with disability.

We also think that there needs to be a better plan for helping people with disability to find out what they need and what their families need.

In 1999 the government had a plan to ask different organisations to look after people living in DoCS group homes. Some people with disability and their families were worried that this might mean they would have to move somewhere else. Our Committee thinks the government should make sure DoCS puts in its ideas before anything happens.

Next year, we will look at things like education, the need for day programs and jobs, the services people with disability need when they get older and support for people who do not speak English. We will print another report late in 2001.

## Introduction

This is the second report of the Committee's inquiry into residential and support services for people with disability. The first report, issued in December 1999, focussed on the proposed tendering out of group homes. This report concentrates on some of the most urgent needs of people with disability. The final report will be released late in 2001.

Systemic services to meet the needs of people with disability are a prime responsibility for government in Australia. Historically, these services have been provided in an uncoordinated and unplanned manner and have failed to receive the necessary resources. This has led to significant unmet need for services and imposed immense human cost on people with disability and their families. A crisis of confidence now exists in the ability of the disability services system to help those in extreme need of support. This crisis is most apparent in accommodation and related support services, where there is presently a significant shortfall. While parents and advocates express their own desperation and anger, they often perceive a profound sense of inertia on the part of government.

The Committee has released this interim report to highlight the need for immediate action to assist those people in greatest need and to restore confidence in the disability services system. Planning has now commenced to produce a strategy that will gradually transform the disability services system. Very significant financial initiatives were also announced in the May 2000 State Budget. It is clear, however, that investment in disability services must be sustained over a period of years. This extended investment is required to redress past neglect by State and Commonwealth governments from both sides of politics, and to develop an efficient and equitable disability services system for the future.

## Immediate priorities

The Committee has identified three priority areas where sustained investment is required.

- *Permanent Supported Accommodation.* There is a critical need to increase the number of supported accommodation places for people with disability.
- *Respite Services.* Urgent action is required to facilitate the development of an effective and accessible system of respite care based on the needs of people with disability and their carers.
- *Devolution of Medium and Large Residential Centres.* There is a clear imperative to finalise the transition from outmoded congregate forms of accommodation to community living arrangements for people with intellectual disability.

The three priority areas are inter-related. For example, respite services play a significant role in managing demand for permanent accommodation. These services support the informal carer relationships that provide the majority of support to people with disability. In turn progressive increases in the supply of supported accommodation are required to prevent blockage of respite places.

Similarly, the only current spare capacity for permanent accommodation exists in large residential centres. This creates continual pressure to 'backfill' vacancies as they arise. However, large residential centres do not conform to legislative standards, fail to meet the basic needs of residents and cannot be justified on other grounds such as cost-effectiveness.

The Committee has found that beyond the current Budget, there is a need for significant investment in the disability sector, strategically targeted to areas of greatest need as outlined in this report. An effective disability services system must first ensure that families and people with disability in crisis have access to sufficient supports to prevent breakdown of the carer relationship. Secondly, when people with disability are no longer able to live with their family, or in other voluntary care arrangements, there must be a genuine prospect of obtaining permanent supported accommodation that is appropriate to their needs. Equally important is the need to ensure that people who live in substandard accommodation are able to move into appropriate community living arrangements.

The Committee notes that the government has progressively increased funding for disability services, with considerable growth funding allocated in the 2000 Budget. The Committee commends the government and its coordinating agency, the Ageing and Disability Department (ADD), for their commitment to renewed investment in the disability sector. While there have been worrying delays in the implementation of some initiatives, the Committee has been assured by the department that substantial service growth will take place by June 2001.

In line with this emerging commitment to disability services, the Committee has made specific recommendations for additional funding, beyond growth funds presently identified by the government, for the areas of priority identified in this report.

## **Structure of the report**

The report consists of five chapters.

**Chapter 1** addresses the effects of unmet need for permanent accommodation on people with disability and their carers. The chapter draws upon the direct experience of people who have made submissions, given evidence and attended the Committee's public consultations. On the basis of these consultations, the Committee considers that there is a compelling need for action to address the needs of people with disability throughout the State.

**Chapter 2** examines the level of unmet need for out-of-home accommodation for people with disability. The chapter notes that specific information on the level of unmet need is not available, and better information must be developed regarding need. In the meantime, it is imperative to develop and implement clear targets for accommodation growth over successive years. This growth is necessary to meet the needs of people in crisis and develop confidence in the disability services system.

**Chapter 3** considers reform of the respite care system. The chapter examines the importance of respite care in NSW and outlines concerns over the continuing problem of respite 'blockage'. The Committee notes that the recent report of the Respite Working Group contains recommendations that can provide a permanent solution to problems regarding respite in NSW. The Committee therefore urges the swift and complete implementation of the recommendations.

**Chapter 4** highlights the continuing inability of governments from both sides of politics to finalise the transition of people with disability from large residential centres into community-based facilities. The

chapter considers past reports on the issue of devolution as well as arguments in favour of retaining large centres. The chapter then makes a range of recommendations regarding devolution of large centres.

**Chapter 5** provides concluding remarks on the issues raised in this report. Issues covered include resource implications of service growth and lessons to be drawn from the recent group homes project. The chapter also considers the implications in terms of departmental resources of the changing focus of ADD from policy development and service monitoring to active development and management of new services.

### ***Terminology***

In this report, the terms *supported accommodation* and *accommodation supports* are used for different purposes. *Supported accommodation* is used to refer to permanent out-of-home accommodation for people with disability, for example, group homes or semi-independent living in a house or unit. *Accommodation supports* refer to a far broader range of in-home and out-of-home supports that enable people with disability to maintain their current living environment such as Home and Community Care (HACC) services and respite services. People in need of supported accommodation form a relatively small sub-group of people who need accommodation support. Most figures on demand for accommodation refer to demand for accommodation supports, not supported accommodation.

A distinction is usually drawn between *demand* – which is seen as a person's reported understanding of their need – and *need* – which is seen as a person's actual need. For example, a person who demands supported accommodation may be assessed by a departmental officer or support planner as actually needing some other type of service, such as additional respite. The Committee has generally not drawn such a distinction in this report because it deals with people who have an extremely high level of need.

In this report *informal* care or support arrangements are those where support for people with disability is provided by family and/or friends. *Formal* services are those that are provided by paid carers.

### ***Names***

To preserve peoples' privacy, the report does not name participants who spoke at public and private consultations. These details have been retained by the Committee for administrative reasons only. In all cases substituted names are used in quotations from the consultations.

## **Background to the inquiry**

The Legislative Council referred the inquiry to the Committee on 16 September 1999. The first part of the inquiry examined the decision of the Government to seek tenders for the operation of Department of Community Services (DoCS) group homes. The first report, *The Group Homes Proposal, Inquiry into Residential and Support Services for People with Disability*, was released on 2 December 1999 and tabled in the Legislative Council on 6 December 1999. The government's response to the recommendations of the first report was due but not delivered on 6 June 2000. The Committee regrets that the government has not yet tabled a response to the first report.

The second part of the terms of reference asked the Committee to investigate the broader issues of residential and support services for people with disability. The terms of reference for this second stage of the inquiry are:

1. *That the Standing Committee on Social Issues inquire into and report on the provision of residential care and other services which support people with disability, including the following.*  
...
3. *The provision of residential care and other services for people with disabilities, having regard but not limited to:*
  - (a) *current unmet need,*
  - (b) *the adequacy of the Government's response to unmet need to date, including:*
    - (i) *the provision of funding to address unmet need,*
    - (ii) *service planning,*
  - (c) *the need and level of provision for respite care,*
  - (d) *the availability and distribution of supported accommodation, respite care and other disability services for people in rural and remote communities, needs of people with disabilities and their families in rural and remote areas, and the need for government to make particular provision for their needs,*
  - (e) *the security of ongoing funding arrangements for the non-government sector,*
  - (f) *the desirability or otherwise of a continuing role for Government in the direct provision of services for people with disability,*
  - (g) *the adequacy of administrative arrangements between the Ageing and Disability Department and the Department of Community Services in relation to the disability services provided by the Department of Community Services,*
  - (h) *the status of the implementation of the Disability Services Act (1993) in particular in respect to:*
    - (i) *the provision of funding to assist services to reach conformity to legislative requirements, and*
    - (ii) *the implementation of those provisions dealing with individualised funding arrangements.*
4. *That the Inquiry make specific and general recommendations about the matters inquired into,*
5. *That in conducting the Inquiry specific steps be taken to consult as widely as possible with people with disability, their families and carers, and organisations representing people with disability, especially including People with Disabilities (Inc), the NSW Council on Intellectual Disability, the NSW Safeguard Coalition and the Public Service Association, having particular regard to the need to ensure people with disability are fully involved in decisions affecting their lives.*  
...

This report presents the Committee's initial consideration of the issues raised by sub-paragraphs 3(a), (b), (c), (d) and (h). The Committee's final report on disability services will be released late in 2001. While the majority of evidence taken so far in this inquiry refers to the needs of people with intellectual disability, the Committee is aware that issues relating to supply of accommodation and respite are equally important for many people with physical disability and acquired brain injury.

## **Scope and process of the inquiry**

The Committee formally commenced this second part of the inquiry in January 2000. In gathering evidence for this part of the inquiry, the Committee has called for submissions, taken oral evidence and conducted site visits to services in metropolitan, regional and rural areas. The Committee also conducted community consultations in regional areas with people with disability, families, advocates and service providers. The Committee is grateful for the significant contribution to the inquiry by so many people.

### ***Submissions***

The Committee has received a total of 309 written submissions from individuals and organisations. While the Committee received 171 written submissions for part one of the inquiry into the group homes proposal, many of these submissions also dealt with the broader issues in the delivery of disability services. The majority of submissions came from parents, relatives, guardians and advocates. A small number of submissions came from people with disability. Other submissions to this inquiry were provided by peak organisations representing people with disability, church and welfare organisations, and the government. A list of people and organisations who provided submissions is included in appendix 1.

### ***Public hearings***

The Committee heard formal evidence from 36 witnesses during this part of the inquiry. Witnesses included people with a disability and their parents and relatives, representatives of peak organisations and representatives of government agencies. The list of witnesses can be found in appendix 2.

### ***Site visits***

During this part of the inquiry, the Committee visited a range of services for people with disability, including six large residential centres operated by DoCS, four residential services operated by non-government organisations and two employment services. At most services, the Committee had the opportunity to consult with residents and their relatives as well as staff. Details of Committee site visits appear in appendix 4.

### ***Community consultations***

The Committee conducted eight public meetings in regional centres to consider disability services in NSW. These meetings were attended by a total of 351 people, many of whom had the opportunity to speak directly to Committee Members. In addition, a public meeting was held Narrabri, which was attended by the Deputy Chair, the Hon Doug Moppett MLC. These meetings provided valuable information regarding the needs of people in regional, rural and remote areas of NSW.

The Committee also held two meetings with people with disability and their families, facilitated by disability advocacy groups, and several meetings with regional service providers.

Details of these consultations appear in appendix 5.

## **Future plans**

The Committee is conscious that many issues raised in submissions and consultations are not addressed in this report. These include: issues relating to people with physical disability or acquired brain injury; people from non-English speaking and Aboriginal and Torres Strait Islander backgrounds; transportation issues; access to education, early intervention and therapy services; day programs; problems faced by people with disability as a result of fragmentation of responsibility across several departments and agencies; and issues related to accommodation of ageing people with disability. The Committee has also not considered matter raised by sub-paragraphs 3(e), (f) and (g) of the terms of reference, including the continuing role of DoCS in the direct provision of services at great length in this report. These issues will be considered in greater detail in the final report. The Committee will also be taking some limited additional evidence from groups who have not yet been properly represented in the inquiry.

## Chapter 1 Impact of unmet need for accommodation

There is a broad range of need for disability services, and it is difficult to isolate particular priorities for action to address unmet need. Areas of unmet need include early intervention for children with disability, therapy services, day programs, supported employment services, supports for people with physical disability, and programs to address the needs of people with disability who are ageing.

However, the evidence presented to this inquiry indicates that the area of greatest immediate need is for permanent supported accommodation, particularly for people who are in crisis. The strain placed on the disability services system as a whole by unmet need for accommodation means that other areas of need cannot be addressed unless demand for accommodation services is reduced. The ability of people with disability to benefit from other services, such as day programs, is limited when basic needs for safe accommodation are not met. The Committee has been deeply moved and at times shocked by the gravity of the situation facing some people with disability and their carers. In order to reduce the immense human cost of unmet need for accommodation, action is needed to permanently place those people whose support arrangements have broken down or will break down in the near future.

While the impacts described in this chapter, which reflect just some of the experiences related during consultations, are so significant that they warrant immediate action, the Committee emphasises that disability should not be viewed negatively. The majority of people with disability and their families live positive and fulfilling lives without formal assistance from government. The negative experiences discussed in this chapter are not a result of people's disability but of the lack of sufficient support to help people in extreme need.

This chapter outlines the impact of unmet need for accommodation on people with disability and their families. The next chapter contains the Committee's recommendations regarding demand for out-of-home supported accommodation.

### How support is currently provided

**1.1** People with disability make up a significant proportion of the NSW population. As stated in the government submission to this inquiry:

People with disabilities constitute 15% of the NSW population aged between 5 and 64 years of age and 13% have a specific restriction arising from their disability. People with a profound/severe core activity restriction constitute 3.9% of the population between 5 and 64 years of age or 199,800 people. In contrast, the disability service system (including Employment services funded by the Commonwealth) provided services for 16,063 people ... <sup>1</sup>

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<sup>1</sup> Cabinet Office of NSW, Submission 225.

Data from the most recent *Report on Government Services*<sup>2</sup> suggests that the proportion of people with severe or profound core activity restriction now constitutes 4.1% of the population of people aged 5-64. Fifty-seven percent of all people with disability reported a need for assistance with one or more activity, of whom 96% stated that their need was fully (64%) or partly (32%) met, leaving 4% with needs that were not met at all. These figures do not indicate the types of service required to assist people with various activities,<sup>3</sup> but they indicate that only a relatively small proportion of all people with disability have an unmet need for all services, including supported accommodation.

- 1.2** The majority of accommodation support for people with disability is provided by unpaid carers through informal arrangements. Using 1993 data, the Australian Institute of Health and Welfare (AIHW) estimated in 1996 that 91.9% of people with disability living in households received assistance from family and friends. For people with profound or severe handicap, 'the main provider of assistance with self-care activities was an informal carer usually resident in the same household'.<sup>4</sup> Typically, the principal carer of a person with disability is a woman, and the caring relationship will be long-term, often spanning decades.<sup>5</sup>
- 1.3** The Committee appreciates that family members, usually parents, provide the principal support structures for people who require assistance with the tasks of daily living. This support is provided at little or no cost to government. For parents who care for a son or daughter with disability, the long-term nature of the relationship means that the work involved in providing care greatly exceeds that in raising a child without disability. Caring for a son or daughter with very high support needs greatly increases the intensity as well as the duration of the work involved in parenting.
- 1.4** A small proportion of people with disability live in circumstances of crisis where their informal support structures have broken down, or are under such pressure that they are at imminent risk of breaking down. As outlined in the next chapter, a proportion of these people require permanent accommodation. Lack of appropriate services for these people means that resources intended to support a broad range of people are diverted into crisis management for a relatively small number of individuals. This enforced focus on crisis management prevents the disability services system from providing efficient and effective support to a wide range of people in need.

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<sup>2</sup> Steering Committee for the Review of Commonwealth/State Service Provision, *Report on Government Services 2000* (report on Government Services 2000). The Report uses data from the 1998 Disability Ageing and Carers Survey conducted by the Australian Bureau of Statistics.

<sup>3</sup> The Australian Bureau of Statistics defines 'core activities' as being communication, mobility and self-care: Australian Bureau of Statistics, *Caring in the Community*, 1998 (ABS 1998), p. 46

<sup>4</sup> Australian Institute of Health and Welfare, *Demand for Disability Support Service in Australia: Size, Cost and Growth*, Canberra 1997, (AIHW 1997) p. 18

<sup>5</sup> Ibid

## What does 'crisis' mean?

I am yet to identify what a crisis is....After 30 years getting up every morning is a bit of a crisis. Is a crisis when someone in the family dies or when someone breaks a leg? It seems that that is the only time that families can get any sort of break.<sup>6</sup>

**1.5** Definitions of crisis generally focus on the risk to a person with disability or their carer. In relation to unmet need for accommodation, the Committee considers people to be in crisis when:

- they live in an environment where they are currently subject to physical or mental abuse, or there is a high probability of such abuse
- their support arrangements place their carer at risk of injury or breakdown
- their family or other informal supports have broken down or are at imminent risk of breaking down
- they are homeless or are at imminent risk of becoming homeless.

**1.6** Living in such conditions can have profound effects on the physical and mental well-being of a person with disability and their carer. Lack of services can lead to family breakdown, the social isolation of people with disability and their carers, violence, and physical breakdown of the carers. The Committee has been particularly struck by evidence and submissions from a number of carers who had acquired a disability as a result of the physical demands of caring for a family member with disability.

**1.7** Ageing of carers is a well known factor that can result in a person moving into crisis. Other people move into crisis due to an increase in challenging behaviour, particularly when a person with disability leaves school at age 18 and loses access to the supports available for children with disability. The unremitting demands of caring for a person with extremely high physical and/or medical support needs may also contribute to crisis.

**1.8** The Committee has spoken to a number of long-term carers of people with disability who are now 'just coping' with the circumstances of caring for a family member. These people may not initially present as being in crisis, but the support that they provide to their family member is at imminent risk of breaking down. Such breakdown may be precipitated by relatively minor changes in circumstances such as the temporary ill health of a carer.

**1.9** One example presented to the Committee is where a primary carer needs to undergo a voluntary medical procedure, but is unable to do so because they have no alternative care arrangements for their family member with disability. As a result, the carer's medical condition deteriorates to the point where they are physically unable to continue to care for their family member. It is particularly important that these people are recognised as being in crisis, alongside the more visible cases of family breakdown and homelessness. People with disability living in these circumstances do not necessarily see themselves as being in

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<sup>6</sup> Public consultation, Ballina, 22 August 2000.

crisis, but the fragility of their care arrangements will often mean that they need permanent accommodation arrangements in the very near future.

## **Impact on carers**

**1.10** The Committee is deeply concerned about the impact of unmet need on carers of people with disability. Whilst the primary focus of initiatives in the disability services system must always be on providing appropriate supports to people with disability, this will often be dependent on meeting the present and future needs of carers. For many, the experience of being a carer can be rewarding. However, some circumstances can leave carers in a state of crisis. The AIHW has noted that within the disability services system:

- the role of carers must be sustained, because of its huge value; and
- carers' rights to participate in society must also be recognised.<sup>7</sup>

**1.11** All carers of people with disability who spoke to the Committee emphasised that they loved the person for whom they cared and that their family member with disability was valued equally with other family members. However, the impact of caring for a person with disability on carers and their families is significant:

Documented effects of caring for people with disability include experiencing frequent sleep interruptions, losing touch with friends, strain on family relationships, giving up work to take on the caring role, and diminished social activity. These effects fall mainly on women aged 30 and over.<sup>8</sup>

The AIHW has noted that the long time span of the care distinguishes it from other caring roles. Using 1993 data, the AIHW estimated that almost half of the carers aged over 65 had been caring for the person with disability for over 30 years.

## **Impact on family relationships**

**1.12** While the impact of caring will normally be greatest for the individual carer, having a family member with disability will often have a significant impact on the entire family:

We have changed our lives totally to support David. Our whole family, there are six of us plus boyfriends and grandchildren, support David very well, considering the lack of services. ... We revolve around David. Our whole lives revolve around David and I am tired of that. My other children resent David, what David has done to the family. They all love David, but they resent what he has done to the family. They cannot have their friends in. We cannot just have a party. I cannot just duck into the car to go down to the shop to buy a carton of milk. ... So far as I and my family are concerned he is a priority, but it should not be like that. Six people suffer because of one person. It has made for a very dysfunctional family.<sup>9</sup>

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<sup>7</sup> AIHW 1997, p.19

<sup>8</sup> Ibid

<sup>9</sup> Parent consultation, Western Sydney, 10 May 2000

I have one family where the grandmother is the respite carer and the mother and daughter can never go out together as a family because one of them has to look after the child and he has got really challenging behaviour; you really cannot just take him anywhere.<sup>10</sup>

- 1.13** A number of parents highlighted the difficulty they have in meeting the needs of all their children due to the need to primarily focus on the child with disability. Older carers felt that their other children had missed out on significant aspects of their childhood as a result of the unavoidable demands of caring for a child with disability. This led to feelings of guilt and anxiety on the part of the parents and resentment on the part of their other children. One mother told the Committee that she had to neglect one child to look after the other and that her son who does not have a disability:

...has grown up to be a very angry young man...I believe that once he gets to high school, I will virtually have lost him.<sup>11</sup>

Another parent told the Committee about his experience of bringing up several children:

It was a hell of a job for us – we are a family of four – to ensure that my son was not disabled because of my daughter’s disability ... I looked after my daughter and my wife looked after my son. We tried to ensure that there was no conflict, so that as they get older there is always respect.<sup>12</sup>

- 1.14** A number of older carers also expressed frustration at their inability to be involved with their grandchildren because of the needs of their family member with disability.

My son and daughter-in-law ring us before they come home. We have two grandchildren. If they come home when my daughter is going through one of her bipolar depressions, those two children are frightened and we do not want to create that. That upsets us. It upsets my wife more and creates depression because she cannot look after the grandchildren.<sup>13</sup>

I have six children altogether. This has affected my other children growing up. I now cannot do the grandmotherly role because I have to watch [my son]. ... These are people who have grown up with this all the time. Now they are in their 30s and they are still being affected by the lifestyle we have lived since we have been married.<sup>14</sup>

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<sup>10</sup> Service provider comment, public consultation, Parkes, 21 March 2000

<sup>11</sup> Public consultation, Newcastle, 4 July 2000

<sup>12</sup> Parent consultation, Western Sydney, 10 May 2000

<sup>13</sup> Parent consultation, Western Sydney, 10 May 2000

<sup>14</sup> Parent consultation, Western Sydney, 10 May 2000

### **Relationship breakdown**

- 1.15** The strain that unmet need places on family relationships will inevitably lead to increased incidence of relationship breakdown. The Committee spoke to many carers, generally women, who attributed failed marriages or other relationships to the difficulties in finding adequate support for their children with disability:

Now I find that I am single – my marriage broke up due to the stress of having a disabled child.<sup>15</sup>

Having a disabled child in the family is very disruptive. It is very easy to cause a marriage to fall apart.<sup>16</sup>

- 1.16** However, men were not immune from the pressures of caring for a child with a disability without support:

I think the other thing too that needs to be said is that males are very unsupported. ... When our son lost his sight at age 19 my husband had a breakdown after living with a profoundly intellectually handicapped child.<sup>17</sup>

A number of other carers reported that the demands of caring for a family member with disability caused serious damage to their relationship, increasing the chance that it would fail. Apart from exerting a serious emotional toll on all family members, marital breakdown will often remove the family support structures available to primary carers. The impact of unmet need for sole carers of a person with disability is therefore greatly magnified by relationship breakdown.

### **Ageing carers**

- 1.17** One of the main factors propelling the rising demand for accommodation is the ageing of carers. Older carers are likely to have been looking after their family member with disability for a significant period, and will often be increasingly concerned about their declining capacity to care for that person.

At nearly all the meetings we have been to - and we have been to quite a lot of them – they ask what is the main worry and we all say that ....our main worry is what will happen to our children after we die.<sup>18</sup>

I am the parent of a 42 year-old young lady with multiple disabilities, including intellectual and physical disabilities. I am 65 years old and now I am also caring for my husband who is 78 and has an asbestos related disease. My daughter lives at home with us because there is no accommodation for her. We have been fighting for years and years to get it. One of my problems ... is my growing

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<sup>15</sup> Public consultation, Wollongong, 11 May 2000

<sup>16</sup> Public consultation, Broken Hill, 10 July 2000

<sup>17</sup> Ibid

<sup>18</sup> Public consultation, Newcastle 4 July 2000

inability to care for her in the way [she] should be cared for. At the moment I am just going through the motions. Her development in that case, of course, is very limited. I am very sorry and sad about that but there is no accommodation for her.<sup>19</sup>

I think that is the fear of anyone who has a handicapped child. I mean, we are not getting any younger and they are not getting any younger; what will happen afterwards? My husband cannot look after her because he has had a triple bypass. He has a bad heart.<sup>20</sup>

I know a family who have a 43 year old daughter with Down's syndrome. Dad has advanced Alzheimer's, he is 85, and mum is on a walking frame, she is 82. They have one of their other daughters come in to basically do the whole family because dad is no longer with it at all and the mother is quite incapacitated because of her age and the walking frame and whatever, but that lady has never ever been into respite, not one night. She has been in the family home. 25 years ago they came to Dubbo and they live in town. When mother and father go, the daughter's whole world is going to fall apart because she has no outside network of any sort at all. She herself is beginning to have inappropriate behaviour and hygiene issues and whatever and the rest of the family are not prepared to take that on board.<sup>21</sup>

- 1.18** Submissions and consultations have indicated that the main concern for ageing carers is the need for certainty of accommodation for their son or daughter. While increased levels of in-home assistance and respite may assist ageing carers in the short term, their basic need is to obtain permanent supported accommodation for their family member with disability. For some ageing carers, their need is for certainty that accommodation will be available at some time in the future when it is required. For others, who are having difficulty coping, the need for accommodation is far more immediate. The Committee believes that it is not reasonable to expect people who themselves are becoming increasingly frail to provide full time care to their adult children with disability.

### **Interruption to life plans**

- 1.19** A number of ageing carers who spoke to the committee expressed their wish to rest and enjoy their retirement after decades of providing full-time care to their son or daughter. Like other parents, their initial expectations were that their child would at some stage move out of home and live in the community as an adult, allowing the parents an opportunity to meet their own needs. The reality for many parents has been that they have had to retire early from employment to provide care for their son or daughter:

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<sup>19</sup> Public consultation, Wollongong, 11 May 2000

<sup>20</sup> Consultation with clients of Disability Advocacy Services Hunter, 4 July 2000

<sup>21</sup> Sanders evidence, 20 March 2000

My husband is over 60. I am closer to 50 than 60. I am told that will catch up quick. My husband has retired. When do we get on with retirement? We cannot because he has to look after [my son]. He has to help me look after [my son].<sup>22</sup>

**1.20** Many of these carers feel they have contributed substantially to their child's well-being for a very long period. They are increasingly concerned that they will have to care for their son or daughter until they themselves become incapacitated by age. In consultations, many of these carers expressed their frustration at the apparent lack of action to assist people in their circumstances:

I am a mother of two retarded sons. I am also a widow. At the age of 57 I have less time not more, and I wonder just what I am leaving my family to deal with. The outlook is very bleak and, like all other carers, I am tired - tired of seeking to find things that can change situations, tired of going to consultations, which cost precious money and resources and no notice is taken of them anyway. There is not even a databank kept to reflect the outcomes.<sup>23</sup>

### **Case Study – Unmet Need**

During a visit to a regional centre, the Committee was provided with information about 'John', a man with disability who is in extreme need of accommodation. Service providers in the town were unaware of John's existence until shortly before the Committee's visit. John is aged in his late forties and lives with his father who is in his late eighties. John has not ventured outside the family home since the time of his mother's death over twenty years previously. John has not seen a doctor or had dental treatment during this period. Neither John nor his father access any form of accommodation support; all care for John is provided by his father. John's father has difficulty with mobility and requires a knee and hip replacement, however he is concerned about finding alternative care for John while he is receiving treatment. There is evidence that John has on at least one occasion assaulted his father, resulting in injury. Professional assessment of John's circumstances indicated that his father was no longer able to provide care for John. John was unable to live without support and therefore required supported accommodation. A submission for urgent accommodation funding for John was prepared and submitted to ADD but was unsuccessful. At the date of this report Committee understands that John remains at home with his father without support.<sup>24</sup>

The Committee understands that this case while extreme is not an isolated example, the Committee was advised that there were several others in the town who were in similar circumstances. Similar accounts were also given in other regional centres visited by the Committee.

<sup>22</sup> Parent consultation, Western Sydney, 10 May 2000

<sup>23</sup> Drewe evidence, 23 March 2000

<sup>24</sup> Submission 289

## Injury to care-givers

**1.21** Caring for a person with disability can place significant physical demands on carers. This in turn can lead to injury and/or disability on the part of carers. These problems are compounded as children with disability become adults and their carers age. According to one carer:

Sometimes my back gives out and I cannot care for him (my son) for a short period so my wife, who has severe osteoarthritis, carries him around.<sup>25</sup>

Another carer told the Committee:

I am 75 and I have been looking after my son for 54 years. My son cannot walk and he is blind. I have ... an incurable lung disease. I have arthritis in my shoulders and a severe back problem.<sup>26</sup>

A carer who had originally been promised accommodation in 1988 told the Committee:

[My daughter] is a welcome part of the family. But in the past three or four years my wife has become sick to the point that she now walks with a frame. ... Since my wife has become sick I have become the principal carer. At half past five this morning I was donning my wetsuit because [my daughter] woke up and she wanted a shower. Then my wife had to have a shower and I have to help my wife have a shower because she cannot have a shower on her own. After cleaning the bathroom, et cetera, I thought I might as well have a shower myself. By seven o'clock this morning I had had three showers. It becomes very demanding. I can assure you that if my wife was not sick I would not be here.<sup>27</sup>

**1.22** Injury can also occur as a result of the stress and exhaustion resulting from the demanding role of a carer. The impact of caring for a person with disability has been recorded in the Australian Bureau of Statistics Report *Caring in the Community*. This report found that over half of the primary care-givers to a person with an intellectual disability spend 40 or more hours per week looking after this person.<sup>28</sup> This enormous commitment is adversely reflected in the physical and emotional effects primary carers experience. 71.2 % reported suffering some kind of physical or emotional effects, including a high proportion suffering from a loss of well-being, lack of energy and depression. In addition to this 44.1% reported sleep interruption and 42.5% indicated that they needed more support.<sup>29</sup>

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<sup>25</sup> Public consultation, Ballina 22 August 2000

<sup>26</sup> Ibid

<sup>27</sup> Parent consultation, Western Sydney, 10 May 2000. The Committee has viewed medical evidence to show that this carer suffers from a significant medical condition. The Committee understands that his daughter has now been promised support through the Service Access System and is awaiting placement.

<sup>28</sup> ABS 1998, p. 27

<sup>29</sup> Ibid p. 30

MDAA is aware of several incidents of carers ending up in hospital because of burnout and because no-one picked up on that before the carers reached that point. As a result, persons with disabilities go into nursing homes and residential care. That really is the stark reality. Another issue for carers is that they can end up acquiring a disability after a long period of caring for a person with disability. Often, that can be a physical disability, or stress or mental health problems.<sup>30</sup>

- 1.23** In some cases, carers are placed at physical risk by the challenging behaviour of their son or daughter. One mother who spoke to the Committee recounted a recent incident where her son became violent as a result of frustration:

A few weeks ago I was on my own. He got a bit agitated and I moved away when I saw him getting agitated. This young man of 18, who is bigger than I am and taller than both of us, raced down the hall. I was not quite expecting it, because he has been my better autistic child, or I thought so. He bit me on both arms. They were bleeding. I was bruised from my elbow down to my wrist. I put my head down between my legs and the thought went through my mind that I could be dead. I got myself out into the backyard ...

He is OK sometimes but there will always be periods like that. ... I put his name down as a person who may need a group home. I do not even know if there is a waiting list. I do not even know whether his name is down on the waiting list. I want him to move into a home with a couple of other people. I want it to happen sooner rather than later.<sup>31</sup>

- 1.24** It is particularly difficult for carers to manage people with complex and challenging behaviour. Even younger carers who are in good health may therefore be unable to support family members with difficult behaviours in their own homes.

### **Withdrawal of care**

- 1.25** Where accommodation is not available, some carers feel that they are faced with no alternative but to cease caring for their family member. The Committee is aware of the anguish that this causes to families and appreciates that such actions reflect the desperation of people who are unable to continue to support their family member:

I got to that point of ringing the manager in Lismore and saying "Enough is enough. I will have to bring my daughter down to your office and pack a suitcase." At that point I sat down, my hands shaking, and had a cup of tea, wondering whether I had made the right decision. Lo and Behold! At 10.30am the phone rings and DoCS had found some crisis money so that we can now have some care.<sup>32</sup>

When you talk about bringing your daughter down to their office they talk about abandoning your child. In fact, nothing could be further from the truth...I want

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<sup>30</sup> Qian evidence, Multicultural Disability Advocacy Association, 10 February 2000

<sup>31</sup> Parent consultation, Western Sydney, 10 May 2000

<sup>32</sup> Public consultation, Ballina, 22 August 2000

to get her into a situation where she is properly cared for in the community. And I want to do it now while I can, not when I am so frail aged myself that I cannot do it.<sup>33</sup>

Last year I became sick, I had to do something; I could not continue. I was not able to block the beds because they were already blocked. ... I did actually pack his bags and throw him out the door ... It was early on a Saturday morning. I could not phone DoCS because they were not there on the weekend. ... After half an hour I went out and he was still there. He had not gone off by himself. Nobody had picked him up and taken him away in the car, so I had to bring him home again, bring him back into the house and unpack. I have no choice but to look after him. I am trying to make light of it.<sup>34</sup>

**1.26** It is not uncommon for people who are unable to continue caring to leave a family member in respite, resulting in a blocked bed. During consultations, the Committee was repeatedly told that people believed that the only way to obtain permanent accommodation was to abandon someone in respite. During one public consultation, the father of a person with disability described the circumstances in which his family felt forced to leave a young man in respite:

I am the parent of a severely disabled child. He is not a child, he is a young man. He turns 24 in July. A month ago my wife and myself made the hard decision to leave him in respite care because of his disability. It is like having a baby for 24 years. He is a grown up adult but he is still a baby. It has got harder for us to look after him at home. So our only need is that there is just no planning by the government or the departments. ... What has happened to us is that we have taken a respite care bed, which I did not want to do but was forced to do so because of our health within the family. Now somebody in the community will miss out on respite care because we have taken that bed. ...

He was in day programs approximately six hours per day. He would go in the morning, come back just after three, half past two sometimes. Then we are back looking after him, putting him on the floor, changing his nappy, feeding him, getting ready to bath him. When personal care comes in they undress him, we put him in the toilet, he comes out, they bathe him, he comes out, then we feed him again. It is continuous, the same thing all weekend. It is a continuous cycle. Everything we did with [our son] was timed. Every three hours we had to do something with him. It was actually every two hours because we would take him out of the chair, leave him sitting in the chair for an hour, take him out, put him down and then the cycle would start all over again. It is very draining physically and mentally. It gets to the point where you just give up.

My son is in crisis and is awaiting a bed. I do not know when he will get a bed. It may be two to three years down the track, it might be in a month's time, we do not know, we have no idea. There should have been a plan where residential beds are made available. You cannot continue to give us respite care, it just does not work all the time. We are only getting little blocks of respite care to revitalise

<sup>33</sup> Ibid

<sup>34</sup> Parent consultation, Western Sydney, 10 May 2000

ourselves. Four days respite care and you are back again looking after the child or young adult. It is quite draining.<sup>35</sup>

- 1.27** The decision to leave someone in respite can irreparably damage family relationships, leading to feelings of guilt and shame on the part of parents, and feelings of confusion, abandonment and depression on the part of the person with disability. Parents also have to face hostility and allegations of ‘queue jumping’ from other carers who need respite or permanent accommodation for family members. Nevertheless, when the difficulties seem insurmountable some people believe they have no option.

### **Parents of younger people with disability**

- 1.28** While ageing carers are readily associated with demand for out-of-home accommodation, the Committee is also aware of the impact that lack of service has on parents of younger people with disability. From very early on in the lives of children with disability, parents learn that they will have difficulty in obtaining sufficient support. Whilst the need for services for younger people – particularly early intervention and therapy – will be addressed in the Committee’s final report, the Committee understands that uncertainty about their child’s future accommodation is a major source of concern for carers of younger people. These fears were articulated by a young mother during a public consultation:

I am the mother of a 5 year old. I have listened to the parents – mothers and fathers – of 20 to 30 year old people talk today and I am scared. I am absolutely terrified. The most important thing for all of us are our children. They are so precious and ... we are hearing people discarding the parental love not because they chose to but because the job is so hard. It is hard because of all the constraints in our lives. We have no support to get us past those constraints.

I am looking down a barrel. I do not want ‘Helen’ to be my crusade. I want her to be my daughter. I want her to enjoy her life, her peers and her mother’s love. Instead of spending time with our children we are at meetings and writing submissions and letters. My friends are astounded at the amount of mail I get in my home. All I am doing is answering all these letters, writing submissions, speaking to people and for what end? I do not know. I just sit here and think there is no end. I think there is no hope for me. I do not know why I am bothering, except I am ‘Helen’s’ mother.<sup>36</sup>

- 1.29** Lack of confidence that accommodation will be available when it is needed in the future contributes to a sense of despair and cynicism amongst carers:

I am the father of a 16 year old boy with severe cerebral palsy, and I underscore the word “severe”. I hold out no hope in the immediate or long-term future that there will be any services that will enable him to function socially or in any other way outside the family home. When he was young we got very good respite care. ... When he was eight years old we moved from Sydney to this area and did not reach out for any type of service. We were managing okay notwithstanding the burdens. When he was 13, he had an operation and my health started to break

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<sup>35</sup> Public consultation, Wollongong, 11 May 2000

<sup>36</sup> Public consultation, Wollongong, 11 May 2000

down. I thought I would reach out for some services and that is when I discover that for one reason or another ... he was in the too-hard basket. ... My wife and I are now resigned to the fact that we will be looking after him for decades to come. What happens when we die? ... [H]e relates well and I thought he would somehow integrate into the community via some supportive network. I do not believe that that exists now and I have no hope that it will in the future ...<sup>37</sup>

- 1.30** Parents of younger people with extremely high support needs may require urgent accommodation for their family members. As a result of medical advances many more children with high levels of disability are able to survive for longer periods than was previously the case. Whilst it is well recognised that children with disability should be supported to live with their family where possible, there are some cases where this is not possible. The Committee spoke to a number of parents suffering extreme stress as a result of the constant demands of looking after young children with very high support needs. Appropriate out-of-home supports are required for these people.

### **Financial impacts**

- 1.31** Caring for a person with disability can have significant financial consequences for families. The Australian Bureau of Statistics (ABS) report *Caring in the Community* revealed that, of carers of people who were aged and/or had a disability, 59% of those of working age had jobs, but less than half of employed primary carers had full-time work. Of employed primary carers, 22% reported that their weekly working hours had to be decreased because of their role as carer, and 24% had to regularly take time off work. Primary carers reported that there were a range of barriers to workforce participation, the most common being 'a lack of alternative or suitable care arrangements'.<sup>38</sup> As a consequence of this, it was found that 49% of carers were dependent on government support for their income.<sup>39</sup>

- 1.32** Providing full-time care to people with high support needs generally creates financial difficulties. The Committee has been informed of many instances when carers had to reduce their work hours or leave their paid employment in order to fulfil their caring role. The loss of paid employment greatly affects the financial situation of carers.

In 1991 I had to drastically reduce my work role when our son left school and my husband gave up work in 1994 in order to help me with support, both physical and emotional (as I was no longer able to cope). As a result we are both on a Carer's pension, although not by choice.<sup>40</sup>

- 1.33** The ABS study found that 46% of carers reported that their financial situation had been diminished due to their role. Parents who were the primary carers were the most likely to be financially affected. The reasons were mainly the cost of specialist equipment required

<sup>37</sup> Public consultation, Ballina, 22 August 2000

<sup>38</sup> ABS 1998, p. 7

<sup>39</sup> Ibid

<sup>40</sup> Submission 222, Mrs E Norris

or a loss of income.<sup>41</sup> Carers who spoke to the Committee also pointed out that medicine and therapy often involve substantial and continuing out-of-pocket payments by families.

**1.34** Sole carers of people with disability, for example, single parents can be particularly disadvantaged by being unable to work and thus reliant on income support.

**1.35** As with other groups in society, taking time off work to care for a person with disability reduces a carer's chance of returning to paid employment. A parent told the Committee of the implications of her husband losing his entitlement to a pension after several years:

My husband is 60 in January and the prospects of him getting work are not very good...he is not overly physically well, he is extremely worried. It is causing a great deal of stress.<sup>42</sup>

### **Social isolation**

**1.36** The time-consuming role of caring for a person with disability, often spanning decades, leaves little or no time to establish and maintain social relationships. Isolation may also derive from the stigma sometimes associated with disability. An inability to work can also drastically reduce a carer's level of social contact.

For carers, what happens in their lives is two things that we know for sure: they lose choice and they become isolated themselves ... the overwhelming sense of carers is social isolation. It becomes a profound problem for them and that would indicate that they are not accessing work opportunities. In fact we know that.<sup>43</sup>

**1.37** Social isolation can be compounded by living in a rural area where geographical distance makes accessing services and support difficult.

[N]o one seems to want to help you, you really are isolated. I lived 20 kilometres out at Trangie for fifteen years of [my daughter's] life and got no help or assistance from any department or organisation during those years before I moved.<sup>44</sup>

Often the parents of the child with a disability need to quickly access a teaching mode that they may not previously have been asked to exhibit. In other words, first of all, when someone sees your child with a disability they immediately go into a grief mode, they do not know how to cope, so they move back from you. You need to have the ability to walk up to them and say, "This is upsetting, this breaks my heart and I can see it is breaking yours too and that is okay", and then deal with the parent, you know, your friends. These are your friends, these are parents of what would normally be your child's peer group, and this only happens early in the case because your child does not have a peer group as he or she gets

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<sup>41</sup> ABS 1998, p. 8

<sup>42</sup> Public consultation, Ballina, 22 August 2000

<sup>43</sup> Fitzgerald evidence, Community Services Commission, 22 February 2000

<sup>44</sup> Richardson evidence, 20 March 2000

older. You deal with the grief of that person, but still it does not stop them really drawing back from you. It is as your child gets older and they see the differences - your child does not ride around the paddock on a mini-bike as theirs does - that you really notice the isolation.<sup>45</sup>

- 1.38** Some families have reported that within a rural context some people find it difficult to accept difference because of a lack of experience or prior contact. This can create isolation for both the person with disability and the carer.

In my circumstances, before I had my children, I was on many committees: Red Cross, Tennis, anything. I was the secretary actually. I had children and had my first four boys and they were all perfect and, "Oh, Marieann and these wonderful little boys". Then I had Julie and word got around. We are on party lines on the phones, so they are all getting their wires crossed, but one minute I had an autistic child and the next minute I had a "spastic" child. All these people I knew once, no one was talking to me, but they were all keen when I came to town to peer in the car - "Got one missing, oh" - and they would walk on. They all wanted to see this spastic child. I sort of feel how popular I was and now I am not very popular. I did not have anyone to turn to.<sup>46</sup>

The Committee is aware that similar problems, often arising out of inexperience and misconceptions, can lead to isolation of people in urban areas.

- 1.39** Coming from a non-English speaking background can also limit people's access to services and support. Culturally appropriate services are essential to ensure that people from culturally diverse backgrounds are informed about services available to the person they care for.

One can imagine caring for someone with a disability 24-hours a day. You do not know what respite care is. A lot of people do not even know what the word is. You do not have the energy to look for any service and you cannot communicate unless you use an interpreter. How hard is it now to use an interpreter? I am not surprised when I come across cases like, for example, three weeks ago I talked to a mother. I had the luxury to use an interpreter. She said, "No, we do not use respite care. My son has multiple disabilities. He has sleep disturbance as well. I have not slept for 26 years. She said "I am really sorry, I can speak very little English". Guess why? The husband had to do double shifts because he has to pay the extra costs so there is no money for the family to pay for a car so there would be no way for someone like this family to attend meetings and get anywhere. A lot of these people have lost the energy to get anywhere.<sup>47</sup>

## Impact on people with disability

- 1.40** It is essential for the well-being of people with disability that they are recognised as valued members of their family and society. Unlike their carers, some people with disability are not

<sup>45</sup> Berry evidence, 20 March 2000

<sup>46</sup> Richardson evidence, 20 March 2000

<sup>47</sup> Public consultation, Wollongong, 11 May 2000

in a position to express their needs or to communicate to others the impact of living in a situation of crisis. Lack of sufficient supports means that some people will ultimately be viewed as a 'burden' on their carers. This seriously undermines the dignity of people with disability and can irreparably damage family relationships. As one mother of a person with disability told the Committee:

For his own sake he needs to be away from the family. He is at the bottom of the ladder in our family. ... For his sake he needs to be away because our family has got to the stage where we resent the time, energy and emotion it takes from us.<sup>48</sup>

- 1.41** For people with high support needs, lack of accommodation supports will prevent them from having the opportunity to live independently of their families. Like other members of the community, many people with disability would not choose to remain living at home for their adult lives if there was a realistic alternative.

It is not very dignified for people – adults with a disability – to have to live with their mum and dad and have no life of their own.<sup>49</sup>

Our son [26 years old] would like to live as independently as possible – not to have to [go] away now and then when we can't cope!!<sup>50</sup>

A young 19-year-old man in this area had a disagreement with his mother – what is new! She did not like the way he and his friends were behaving in the house. So, he left home, which is fine except this boy is quadriplegic. He went to stay with friends, who obviously could not meet his physical needs. There was panic and trying to patch up needs. He is back home again, still fighting with his mum, which is probably normal for that age, but he does not have the choice other kids have. That is really sad.<sup>51</sup>

Our goal was to provide such care until [our daughter] reached adulthood, then, like any other child, seek independent supported accommodation for her in an environment as near to normal as possible – a standard suburban home with 3 or 4 other residents and 24 hours care support.<sup>52</sup>

- 1.42** The lack of opportunity for independent living exacerbates the pressure families are already living under. A mother told the Committee that the behaviour of her son, who no longer wishes to live at home, has 'escalated to such an extent that we are now a family in crisis'.<sup>53</sup>

- 1.43** At best, many people with disability are denied the social and developmental opportunities that come from leaving the family home and living with their peers:

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48 Parent consultation, Western Sydney, 10 May 2000

49 Public consultation, Ballina, 23 August 2000

50 Submission 222

51 Public consultation, Wollongong, 11 May 2000

52 Submission 224

53 Public consultation, Ballina, 23 May 2000

My son has been in the community and he likes going out. He likes being part of things. Half our trouble is that he wants to go out on the weekend. He walks quicker than us and he does everything quicker than us. He does not want to be home with us two old fogies. He wants to be doing things.<sup>54</sup>

People with disability who are forced to remain in the family home through lack of services may be denied the opportunity to participate in society as adults. Lack of opportunity to live with and interact with peers can also lead to profound social isolation for people with disability.

- 1.44** In the worst cases, when support arrangements are under pressure, people with disability may be forced to live in circumstances that threaten their safety. People with disability living in these conditions are highly vulnerable, and may be powerless to change their living conditions. Regrettably, the pressures placed on families by lack of appropriate accommodation can be highly conducive to abuse of people with disability:

some of the children return to the accommodation service with bruises, hair missing, pressure sores, missed or over-dosed medication. This is due to families just not coping with the demands of their children with disabilities as opposed to families who are not loving their children.<sup>55</sup>

- 1.45** While the Committee has received no specific evidence of instances of abuse of people with disability by their carers, a number of people have referred to cases where they believe abuse has occurred. Even more disturbing are references to threats of 'murder/suicide' where carers believe that they have no viable alternatives:

I have been to suicide and back with my children and it is not a nice place to go to.<sup>56</sup>

#### **Case Study - My other son has not had a social life....**

...my other son has not had a social life. He cannot go to outings. After school [my husband] gets home at 3pm and 'Andrew' gets home at 3.30 pm. Right away Andrew requires a tube feed. We cannot go to normal places like everybody else. We cannot go to the cinema as Andrew makes too much noise. We cannot go to the beach because he eats the sand. We cannot leave Andrew in his wheelchair for any length of time because he gets fidgety and distressed.... Andrew gets his nappy changed every hour. He is virtually fed every hour and a half because it takes half an hour to feed him.

The mothers' room at the shopping centre does not cater for larger children. I can not change Andrew's nappy there. The disabled toilet is of no use to us whatsoever. So I have to put him on the floor of the toilet, which I do not do. I take him back to the station wagon and I have to change his nappy in the car park. Then I go back and do the rest of my shopping.

<sup>54</sup> Parent consultation, Western Sydney, 10 May 2000

<sup>55</sup> Submission 266, Mercy Centre Lavington Limited

<sup>56</sup> Public consultation, Dubbo, 20 March 2000

I am virtually a prisoner in my own home because it is just too difficult to get out...We hear so many times...about the funding side of it...I do not want to know about that side of it. I have enough worries trying to look after that little boy and trying to keep the rest of my family unit together...But whatever you do, get it right very soon. I have not slept for a week as Andrew has been sick. I am up and down to him three times a night. I am tired and I am angry, I am sorry to say. I am just about talked out. I think most parents are talked out.<sup>57</sup>

## Systemic effects

- 1.46** Lack of capacity in the disability services system to provide accommodation for people in crisis has an impact on the system as a whole. The level of unmet need for accommodation places unreasonable pressure on families, service providers and coordinating agencies. To a great extent, the disability services system is forced to operate on the basis of crisis management, as service providers and funding bodies attempt to meet the needs of those in most urgent crisis. This impedes the development of a planned, effective and equitable system of supported accommodation for people with disability in NSW.
- 1.47** Lack of readily available permanent accommodation for those in urgent need results in diversion of resources from other forms of disability support. This reduces the availability of preventative supports with the result that increased numbers of people move into crisis. The clearest example of this is the problem of blockage in respite services, where accommodation of people in crisis in respite services drastically reduces services for people who need support but are not yet in crisis.
- 1.48** As outlined in chapter 3, preventative supports, particularly respite services, are essential to prevent people from moving into crisis. Over the longer term such supports greatly reduce demand for out-of-home accommodation. However, unless the supply of permanent accommodation for people in crisis is increased, any attempts to increase availability of respite will be thwarted by continued blockage. Preventative supports only operate effectively if the number of people in urgent need of accommodation is reduced to a manageable level.

## Conclusion

- 1.49** The individual accounts given to the Committee in submissions, hearings, meetings and public consultations – only some of which have been presented here – combine to present a grim picture of the impact of unmet need for accommodation on people with disability and their carers. A number of people who spoke to the Committee live in circumstances that are beyond the comprehension of most people in NSW. Their accounts are not the product of exaggeration or distortion; they represent the day-to-day effects of living in crisis without sufficient support. These effects are well-documented in research and policy documents and have been aired repeatedly in numerous consultative processes, including that undertaken by this Committee. Taken together they suggest that there are huge social costs in failing to act quickly. These effects were succinctly outlined by disability

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<sup>57</sup> Public consultation Newcastle, 4 July 2000

administrators in a background paper prepared for Commonwealth and State Ministers early in 1999:

- Increased incidence of family breakdown due to family stress and lack of opportunities for nurturing and sustaining relationships.
- Potential for inadequate attention to, and care of, other family members causing particular problems for siblings (contributing to longer term personal and social problems).
- Physical and emotional breakdown in the health of carers (with inevitable health care costs to the community).
- Diminished opportunities for people with disabilities to develop their full potential to participate meaningfully in the community of which they are a part.
- Diminished opportunities for carers to participate in the workforce because of their full-time caring responsibilities resulting in increased reliance on income support.
- Increased use of more intrusive and resource intensive measures such as Guardianship and Administration applications because of lack of less restrictive options.
- Increased offending and imprisonment rates of people with disabilities who lack appropriate support and supervision. ...
- Increased victimisation and exploitation of people with severe or profound disabilities because of inadequate supervision and support.

Each of these problems associated with breakdown carries a cost that is borne by the community. The incidence of social problems attributable to the breakdown in private caring arrangements of people with severe and profound disabilities is not differentiated in data on other social problems and is therefore likely to represent a hidden social cost.<sup>58</sup>

**1.50** Moving beyond these social impacts, the Committee considers that the effectiveness of the disability services system as a whole is dependent on reducing the level of unmet need for permanent accommodation to a manageable level. Recommendations to address this need are outlined in the next chapter.

**1.51** It is a matter of regret to the Committee that this chapter has documented only the negative aspects of living with disability and caring for a person with disability. This is because without appropriate supports, it can become increasingly difficult for people with disability and their carers to focus more than briefly on the many positive aspects of their lives. Adequate support services are essential to enable people with disability to live safe and fulfilling lives as valued members of the community.

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<sup>58</sup> Background Paper for Commonwealth/State Ministers, *Supporting Australians with Severe or Profound Disabilities: A Service Partnership*, Prepared by Disability Administrators, March 1999, p. 22

**Case study – Mr and Mrs ‘Wilson’**

“Ten years ago we were encouraged to put our son in a place. It was supposed to be a nursing home. We found out it was just a mini institution and provided no nursing home care whatsoever. I will never, ever forget that whole experience until the day I die. He was abused. We believe probably they tried to rape him but because he is autistic he does not like to be touched and, fortunately, at that time he could run. He was in there 24 hours a day for six years. We put him in that place because we had reached the point where we could not cope any longer with him and knowing that his health was going to deteriorate we thought it was the right place.

“The day I left him there a part of me died and it is still dead. We had to get him out of there six years later because he had progressed to such a state that he was like an animal. We tried over that period to get that place to put in support systems. We had to try to teach them about autism to get them to understand what it is like to have an intellectually disabled son. The manager was a psychiatric-trained person and had no idea about people with intellectual disabilities. It was a private place. I had even to battle to get our family doctor in there to try to get medical support not only for ‘William’ but I thought we could get it for others as well. Mothers were too afraid to even change over their doctor because that place just had one doctor.

“I almost killed myself trying to get help for those people in that place. There were many issues over duty of care. We got a group together. That place had powerful people in there that had legal backgrounds. We had to stand up to them. It was absolutely horrific. In order that I survived we had to get him out. We had nowhere to put him, but we lobbied another organisation to try to get him into a group home. There was some funding; it was just at the stage when they were changing over funding from the Commonwealth to the State. We put a submission into DoCS and that got lost in the system.

“We had to bring William home and [my husband] had to take early retirement to help care for him because I was totally wiped out after battling this place. For a man that has worked 32 years to do that at that stage of our lives was very difficult. Our superannuation was affected and our future years of having some superannuation. We were getting two hours sleep a night. We had to work shift work. He had to be totally rehabilitated and we had no support whatsoever.

“I phoned DoCS, which was involved in this organisation, this place he was in, to try to get some services. I phoned desperately six months after we brought him home and said, “Can you help us?” and they said, “We have nothing to offer you.” We have struggled for the last seven years trying to support him, trying to find doctors who will support us and support him. Several submissions have been lodged with ... [DoCS] but we have recently discovered that they have not been getting through the proper channels and over to the Ageing and Disability Department. For nine years we have been trying to get something.

“I have a whole record of events from August 1987 to now of things that we have been involved in, and that is not everything, to try to get funding and try to care for our son. The way things are going are not acceptable. Due to lack of funding and appropriate services for people with high support needs, the level of stress placed on every member of our family is enormous, not only individually but within our relationships. We are just surviving, living lonely and isolated lives, struggling with constant demands of caring, which has taken its toll physically, emotionally, mentally and financially. Now, as William's health deteriorates, we are expected to be not only parents and carers but nurses as well. As his general practitioner has just advised, William has now become a palliative care patient. We cannot continue at this pace. We are exhausted and in deep anguish about our future.”<sup>59</sup>

<sup>59</sup> Mother, Parent Consultation, Western Sydney, 10 May 2000

## Chapter 2 Supported Accommodation

The immense human cost of unmet need for accommodation for people with disability demands urgent action to provide supports for those in greatest need. This chapter considers the extent of need for supported accommodation in NSW and makes recommendations for strategies to address unmet need. The chapter is focussed solely on those people who require permanent accommodation because they, or their carers, have reached a point where no amount of additional in-home support, or respite, can maintain existing informal care arrangements. Carers may be in this situation because of ageing, their own disability, or because the accumulated impact of insufficient support in the past means that they are unable to maintain support arrangements. Most of the evidence heard by the Committee has been in relation to the needs of people with intellectual disability. However the Committee is aware that many people with physical disability, acquired brain injury or other forms of disability experience similar or greater difficulty accessing accommodation services. There is a clear need to ensure that additional supported accommodation is provided equitably across all disability types.

The Committee notes that the government has recently announced a range of measures that will greatly assist people with disability and their families. These initiatives are largely focussed on preventative services, such as respite, in-home supports and crisis intervention, that are intended to prevent breakdown of existing support arrangements. The Committee supports this approach and believes that in addition to significantly reducing demand for supported accommodation, preventative measures can assist people who would prefer to remain in existing informal support arrangements. However, these measures can only work if there is sufficient permanent supported accommodation for people who cannot remain in informal care arrangements. The recommendations in this chapter are therefore intended to complement current policy directions. The Committee's views on respite, a key preventative support, are outlined in the next chapter.

### Measuring demand for accommodation

- 2.1** It is difficult to accurately measure the level of need for supported accommodation in New South Wales. In part, this is because of difficulties in identifying people who need services and gathering data about their requirements. The Committee is aware that for a range of reasons, many families with a member who has a disability do not request assistance, and in some cases are unwilling to reveal to others that they have a family member with disability. Such factors may result in under-reporting of the number of people who require accommodation or other services.
- 2.2** A further problem is that there has been no work undertaken to ascertain exhaustively the number of people who require permanent accommodation, provided outside of the family home, rather than in-home accommodation support. Most available data relates to the total number of people who require accommodation support, that is, assistance with the tasks of daily living, rather than the sub-group who require out-of-home support. In the past, service provision for people with disability, particularly people with intellectual disability, has focussed on support models such as group home accommodation, with the result that figures on demand for accommodation support are frequently interpreted as figures on demand for group home (or similar) accommodation. This can lead to the perception that demand for out-of-home accommodation is immense and beyond the

resources of government to meet. In turn, this may lead to the mistaken belief that targeted initiatives to build service capacity are little more than a 'drop in the ocean' and incapable of having a significant impact on unmet need. This misconception has also engendered unfounded wariness of 'opening the floodgates'.

- 2.3** Provided that sufficient in-home or other supports are available to those who need assistance, demand for out-of-home accommodation will be significantly lower than overall demand for accommodation support. It is therefore not correct to say that all people who report some level of need for accommodation support are in crisis, or in urgent need of accommodation. Some of these people urgently require supported accommodation, but others need less intensive forms of support.

### **Estimating the number of people who are in crisis**

- 2.4** It is difficult to accurately determine the number of people in crisis who need immediate out-of-home accommodation, or the number in a situation of imminent crisis who are likely to need accommodation in the very near future. There are no statistical indicators of the number of people in crisis as a proportion of the general population. The nature of each individual crisis is unique. It is only possible to identify general indicators of conditions likely to precipitate crisis, for example ageing carers, or increased challenging behaviours. Reliable information on the number of people likely to move into crisis over time is not currently available.
- 2.5** Essentially, people or families in crisis must identify themselves to service providers or be identified by members of the community. However, until very recently there has been no system for recording details of people in crisis. While some services maintain waiting lists, there has been no formal coordination of these lists. The Committee was also advised that many people have not registered on service waiting lists because their need is immediate rather than at some time in the future. For these people, there is no reason to join a waiting list that is unlikely to produce any result in the foreseeable future.
- 2.6** DoCS holds some limited information on people in crisis. The department assists some people in crisis to make funding submissions to ADD and also provides some crisis accommodation to people with disability. Departmental respite services also provide long-term accommodation to people in crisis who do not have a permanent placement. In February of this year, the department advised the Committee that approximately 60 people per year entered the DoCS system as crisis admissions.<sup>60</sup> As outlined below, the 2000/2001 State Budget contains funding to accommodate 197 people in crisis known to DoCS, including people 'blocking' respite. However, DoCS has not been able to provide the Committee with data on the total number of people known to the department to be in crisis and in need of permanent accommodation.
- 2.7** Concerns have also been raised during consultations about the lack of adequate systems to ensure that information held by DoCS is transferred to ADD. This may mean that the details of people known to DoCS who require permanent accommodation are not always provided to ADD. As well as having very real consequences for people who fail to gain

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<sup>60</sup> McAlpine evidence, Department of Community Services, 22 February 2000

funding through administrative oversight, such communication failures undermine the reliability of data held by both departments.

**2.8** At present therefore, information on the total number of people with disability in New South Wales who need out-of-home accommodation is largely anecdotal. The lack of a properly coordinated system to record and manage requests for accommodation assistance was highlighted during the Committee's consultations and has recently been the subject of comment by the Audit Office of NSW. The Audit Office noted that there were 'shortcomings in policy, systems and information on vacancies and unmet demand' which constrain ADD's ability to prioritise resources and plan for service development and innovation.<sup>61</sup> The Committee is similarly concerned that the lack of clear information on actual needs restricts the ability of ADD to effectively plan for service provision. In particular it is difficult to define clear outcomes that can be achieved through provision of funding and the development of programs. Committee members are aware that the lack of clear information about unmet need is a problem throughout Australia. One consequence of this is that action to address unmet need may be deferred while further studies of the extent and cost of unmet need are carried out.

**2.9** The Committee is aware that a range of initiatives, including the population group planning project being undertaken by ADD and the new Service Access System (see below), will mean that better information will become available over time. However, it is important to act immediately to assist people who are in crisis, rather than wait for further information. Through its consultations, the Committee has been made graphically aware of the profound damage sustained by people with disability and their families through lack of accommodation. When available, clearer information can be used to adjust programs and strategies that have already commenced.

### **Studies of demand**

**2.10** Over the past decade there have been several studies of demand for supported accommodation in New South Wales. Departmental planning processes as well as evaluation of projects also provide some information about the level of need for out-of-home accommodation. Findings of key studies are outlined below:

- In 1994, a study by NSW Council for Intellectual Disability reported that at least 1,051 people with disability were in need of accommodation, 585 in critical need. The study, which was based on a survey of DoCS regions, also found that by 1999 a further 1,649 people would need community-based accommodation. Included in these figures were people who lived in inappropriate accommodation such as respite services, boarding houses, nursing homes or large residential centres, as well as people living with ageing carers.<sup>62</sup>

<sup>61</sup> Audit Office of NSW, *Performance Audit Report: Ageing and Disability Department – Group homes for people with disabilities in NSW* (Performance Audit 2000), June 2000, p. 71

<sup>62</sup> NSW CID, Submission 255

- In 1997, the Accommodation Task Force established by ADD reported that between 4,050 and 7,750 people with disability in NSW would require accommodation support by the year 2011.<sup>63</sup>
- In 1997, the Australian Institute of Health and Welfare (AIHW) reported that for 1996-97:
  - at least 13,400 people nationally required accommodation, support and respite services; approximately 33.5% of these people lived in NSW, giving a figure of about 4,490 for the State.
  - within this group nationally, there were an estimated 1,500 people with high support needs who wanted but did not receive formal support services. The Institute assumed that 750 of these people required out-of-home accommodation, giving a figure of approximately 250 for NSW.<sup>64</sup>
  - The number of parents aged 65 years or over who were the principal carers for people with a profound or severe handicap was projected to increase from 7,700 in 1993 to 9,000 in 2003,<sup>65</sup> roughly 3,000 ageing carers in NSW.

The AIHW noted that these figures were a conservative estimate of need.

- In 1997, an evaluation of the *300 places initiative* by the NSW Community Services Commission found that DoCS areas had identified 1,216 people in need of accommodation of whom 290 received placements.<sup>66</sup> ADD's 1997 review of the initiative also reported a significant shortfall of allocated places for people who met the eligibility criteria for accommodation. The criteria for placement under the initiative required people with disability to have ageing carers (in most instances) and be in urgent need of accommodation. Whilst the department's review did not provide exact figures, the shortfall in places for 'eligible consumers' was in excess of 250.<sup>67</sup>
- In early 1997, ADD published its 1996 Regional Plans for Disability and Home and Community Care Services. Included in the plans were tables outlining the top 10 priorities for disability services in each of the DoCS regions in NSW. Twelve of the 20 regions nominated supported accommodation as the highest priority for the region and all regions included supported accommodation in their

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<sup>63</sup> NSW Accommodation Taskforce for People with Disability and Older People, *Final Report to the NSW Government*, November 1997, pp. 20-24

<sup>64</sup> This figure is based on the AIHW's 'assumed service response' of group home accommodation for 750 people.

<sup>65</sup> AIHW Op Cit, 1997, p. xii

<sup>66</sup> Community Services Commission, Submission 226

<sup>67</sup> Ageing and Disability Department, *Review of the 300 places initiatives: Analysis of the processes and implementation protocols for the 300 individual accommodation support packages*, 26 May 1997, p. 73. The figure of 250 was derived by adding up the minimum reported shortfall for each of the 16 areas. Thus the actual shortfall was likely to be significantly higher than 250.

top four priorities. Nineteen of the 20 regions attempted to quantify the number of people in need of accommodation. The Committee understands that these figures are in addition to placements provided under the *300 places initiative*. The total number of people across all disability types identified as being in need of accommodation either at the time of the plan or within five years of the plan was 1990 (see Table 1). This figure is approximate due to inconsistencies in the way data was collected and presented by each region. In particular, the data does not reliably distinguish between people in crisis who urgently require accommodation and those who are not in crisis but would nevertheless benefit from accommodation, nor does it accurately differentiate between people who require in-home supports and people who require out-of-home accommodation.

**Table 1: No of people in need of accommodation - ADD 1996 Regional Plans**

<b>Region</b>	<b>No. of people in need of accommodation</b>
Hunter Valley	20 (over 3 years)
Newcastle	40 (over 2 years)
Central Coast	60 (urgent)
Cumberland/Prospect	54 (urgent)
Hornsby/Ryde	88 (no time-frame provided)
Nepean	96 (over 1 year)
Warringah	200 (based on waiting list data, 5 year time-frame)
Eastern Sydney	160 (17 people over the first year)
Inner West	220 (over 2 years)
Macarthur	43 (over 1 year)
Southern Sydney	131 (over 1 year)
South West Sydney	24 (urgent)
Far North Coast	200 (over 4 years)
Mid North Coast	176 (over 3 years)
New England	62
Illawarra	200 (over 1 year)
Southern Highlands	42 (over 5 years)
Central West	100 (over 1 year)
Orana/Far West	74 (over 2 years)
Riverina/Murray	(no figure provided)
<b>Total</b>	<b>1990</b> (approximate)

Note: Figures for each region were derived by adding up reported accommodation need for all disability types. Figures do not include need for home-based accommodation support.

**2.11** While these studies provide an indication of the dimensions of the problem of unmet need, the reported level of need varies significantly between studies. Thus they do not provide a reliable index of the number of people who require accommodation either immediately or in the near future. However, the Committee notes that ADD's analysis of the *300 places initiative* suggests that in 1996/97, following allocation of the 300 places, a minimum of 250 people were known to ADD and DoCS to be in urgent need of accommodation. This minimum figure corresponds to the AIHW's conservative estimate in 1997 that 750 people nationally, equating to 250 people in NSW, required group home accommodation. At the upper level, ADD's 1996 plans for disability services produced a very approximate figure of 1990.

### **Growth in demand**

**2.12** The figures cited above are several years old. The Committee has not received any up-to-date information on the number of people currently known to ADD or DoCS as requiring accommodation. It is well recognised that demand for accommodation is not static. Demographic projections indicate that there is likely to be significant growth in the number of people with disability over the next few years, particularly in the older age groups. For example, in 1997 the Australian Institute for Health and Welfare predicted that by 2003 the total number of people with a severe or profound handicap would increase by 13.7% to 109,200 people nationwide. The bulk of this rise is attributable to a rapid increase in the number of people aged 45 years or over.<sup>68</sup> As the NSW Respite Working Group noted, the "baby boomer" generation represents the first to include a substantial number of people with disabilities'.<sup>69</sup> These people are likely to require increased supports over time, and some will require out-of-home accommodation as support arrangements break down.

**2.13** Ageing of carers is a significant driving force behind demand for out-of-home accommodation. The Australian Institute of Health and Welfare explicitly stated that its projections that there would be 3,000 primary carers of people with disability in NSW aged 65 and over by 2003 are conservative. It is therefore reasonable to assume that there are now more than 3,000 people in these circumstances. Some of these people are already likely to be experiencing difficulties caring for their family member with disability and, even with significant in-home assistance, may not be able to continue to provide support for much longer.

**2.14** While demographic information such as that provided by the AIHW indicates that the number of people in need of accommodation continues to rise, this is difficult to translate into accurate figures to determine the number of people who need services. However, as noted, 60 people per year enter DoCS as crisis admissions, suggesting that the number of people urgently requiring accommodation increases by at least this number of people each year. The Committee is aware that a considerably higher number request urgent accommodation but do not receive it. Most of the carers in crisis who spoke to the Committee were, at the time of the consultations, unable to access crisis accommodation

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<sup>68</sup> AIHW, *Op Cit*, 1997, p.:xi

<sup>69</sup> Respite Working Group, *Report to the Minister: Reshaping the NSW Respite System for People with Disabilities and their Families and Carers*, (Respite Working Group 2000) Ageing and Disability Department, February 2000, p. 24

from DoCS. The Committee has also received information from non-government service providers and advocacy groups from around the State detailing individuals who are likely to move into crisis in the near future. It would therefore be reasonable to expect that well in excess of 100 families enter into crisis each year and require permanent supported accommodation for family members.

- 2.15** The Committee has not received any information about the rate at which vacancies arise in existing accommodation. Accommodation vacancies may arise through death of residents or movement to other types of service. While the rate of turnover of clients in existing services would have some impact on the level of unmet need, the Committee believes that relatively few vacancies arise each year in existing services. One reason for this is the increasing life expectancy of people with disability. It is unlikely that the rate at which residents are currently vacating accommodation services has a significant impact on unmet need.

#### **Past initiatives to meet demand for out-of-home accommodation**

- 2.16** Between 1995 and 1999, there were several initiatives to increase the supply of out-of-home accommodation for people with disability. In 1995, the government announced the *300 places initiative* for people in urgent need of accommodation. Despite some delays, the Committee understands that these placements are now all allocated. In 1998/99 funding was allocated to provide 85 packages for people with disability in crisis.<sup>70</sup> These initiatives have been accompanied by other programs to improve accommodation for people with disability, such as the boarding house reform program which aims to relocate 310 people living in inappropriate accommodation and the creation of 100 attendant care packages for people with disability.<sup>71</sup> Taking into account new attendant care places, these initiatives have resulted in the creation of almost 500 new places for people with disability since 1995, 385 of these places being out-of-home packages for people in urgent need of accommodation.

- 2.17** The Committee considers that these past initiatives have been important in addressing the problem of unmet need. In very approximate terms, supply of supported accommodation increased by 100 places per year between 1995 and 1999. While there have been concerns raised about the allocation of places and the exact level of growth, these initiatives have provided service for a large number of people who were in urgent need of accommodation. However, they have not been sufficient to meet the needs of all people in crisis. As noted above, at the time that places were allocated during the *300 places initiative*, at least 250 people who were identified as meeting the criteria did not receive placements, and all other studies suggested that the shortfall was considerably greater. Increases in the supply of accommodation since 1995 may possibly have kept pace with the increase in demand for out-of-home accommodation, but they are unlikely to have reduced the size of the backlog.

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<sup>70</sup> Community Services Commission, Submission 226

<sup>71</sup> Cabinet Office, Submission 225

**Recent initiatives**

**2.18** Since this inquiry commenced, there have been a range of important initiatives to address the accommodation needs of people with disability. In the 2000/2001 Budget, the government announced the following programs relating to accommodation and associated supports:

- \$20 million to fund permanent accommodation for 197 people identified by DoCS as being in crisis, including 74 people living in blocked respite beds.
- \$10.4 million in 2000/2001, part of \$54 million over 4 years, to fund additional permanent accommodation for people with disability.
- \$5 million in 2000/2001, or \$21.5 million over 4 years, to support the development of a crisis support system intended to provide an immediate response for people who move into crisis.
- \$5 million per year to provide preventative supports intended to stop existing informal support arrangements for people with disability from breaking down.
- development of a new Service Access System that will enable people to formally register their need for accommodation support with ADD. This will enable the department to prioritise and manage the needs of people with disability whose circumstances place themselves, their support arrangements or their current level of independence at risk.<sup>72</sup>

**2.19** The Committee acknowledges that these measures will greatly assist many people with disability and their families. The additional funding will ensure substantial growth in places for those people in greatest need of accommodation. It is likely that the growth funding for supported accommodation will be sufficient to provide on-going supported accommodation for approximately 300 people with disability. While a proportion of this funding will go to people who effectively already have out-of-home accommodation – for example, long-term residents of blocked respite services – it can be expected that a large number of people currently living in difficult or untenable circumstances will soon be able to access supported accommodation. Increased investment in crisis and preventative supports, along with the freeing of respite places, will also reduce the rate of growth in latent demand for permanent out-of-home accommodation.

**2.20** However, while the Committee considers that these measures will reduce the backlog in demand, it is clear that increased recurrent funding for out-of-home accommodation identified in the current Budget will need to be supplemented by future increases in recurrent funding for supported accommodation. This is the only way to reduce demand for urgent accommodation to manageable levels.

**2.21** The Committee is also concerned that there have been some delays in the delivery of these services to people who have a demonstrable need for permanent accommodation. At the

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<sup>72</sup> Hammerton briefing, Ageing and Disability Department, 9 June 2000

date of this report, very few people have actually moved into permanent arrangements. In November, ADD advised the Committee that the department's strategy has been 'not to rush people into permanent solutions' but to put temporary arrangements in place while final arrangements are carefully worked out.<sup>73</sup> Placements have also been delayed by the need to ensure that the Service Access System was functioning prior to allocation of new funding. Despite these delays, ADD has advised the Committee that all places in the current round of funding will be allocated by June 2001. While appreciating that careful planning is essential to all accommodation placements, the Committee notes that delay in allocating current funding may threaten future funds. This will result in significant human suffering. There is therefore a need to ensure that any unnecessary delay in placing people is eliminated, and that systems are in place within the department to ensure that growth funding is allocated to people as quickly as possible.

### **Service Access System**

**2.22** The development this year of the new Service Access System (SAS) is a significant initiative. The Committee considers that the SAS will for the first time enable the systematic central collection of information on unmet need for disability services, including supported accommodation. The SAS will enable ADD to prioritise and manage the needs of people whose needs are not currently met.<sup>74</sup> This system is intended to provide assistance to people who:

- are at significant risk themselves,
- have support arrangements that are at risk, or
- are at risk of losing their current level of independence.<sup>75</sup>

**2.23** In essence, the SAS is intended to enable people with disability or their carers to provide information about their needs to ADD with the help of a professional 'support planner'. Where people are accepted as meeting the entry criteria for the SAS, ADD will attempt to formulate an appropriate service response to meet their needs. The SAS has replaced the former ad hoc submission-based approach to service provision. The Committee considers that, provided sufficient funding is available to support the system and deliver appropriate services, the SAS has the potential to provide a reliable pathway to support services, including out-of-home accommodation for people with disability.

## **Addressing demand for accommodation**

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<sup>73</sup> Milligan briefing, Ageing and Disability Department, 20 November 2000

<sup>74</sup> Hammerton briefing, Ageing and Disability Department, 9 June 2000

<sup>75</sup> Ageing and Disability Department, *Directions Paper: Developing a Formal Service Access System for People with Disabilities in New South Wales*, May 2000, p. 14

- 2.24** The Committee accepts that it would not be possible to immediately provide permanent accommodation for all people in urgent need. Delays in allocation of current funds show that expansion of the disability accommodation system is a complex task and the capacity of the sector to rapidly absorb new residents is finite. There is a particular need to ensure that the non-government sector is assisted to develop sufficient infrastructure to support large numbers of new clients.
- 2.25** Growth in the absolute number of people living in supported accommodation is also taking place in a sector where many people live in accommodation that urgently requires upgrading or closure, such as large residential centres or boarding houses. These programs are necessary but obviously have an impact on the capacity of the sector and ADD to increase the overall supply of accommodation. Supply of supported accommodation will therefore need to be progressively increased to accommodate those currently in urgent need as well as those people who move into crisis over the coming years.
- 2.26** It is clear that the recent growth rate of approximately 100 places per year has not been sufficient to reduce the backlog in demand for accommodation. The Committee therefore considers that the level of growth in out-of-home accommodation should be increased to at least 200 supported accommodation places per year.
- 2.27** While noting that this target is conservative, the Committee believes that an increase of 200 places per year is within the capacity of ADD and the disability services sector to manage. The Committee is aware that the paucity of data on unmet need means that some may consider this level of growth to be insufficient to meet current and future demand. Others may criticise the figure as being insufficiently justified by reliable data on unmet need.
- 2.28** The Committee has been advised by ADD that the department is currently not in a position to identify precise targets for growth in supported accommodation due to lack of information about the extent and nature of unmet need. The department also advised the Committee that targets for supported accommodation may be inappropriate because some people who report need for out-of-home accommodation may actually require a different type of service. It may therefore be wrong to assume that permanent accommodation is the only service response to situations of crisis.<sup>76</sup>
- 2.29** While acknowledging the difficulty faced by the department, the Committee is concerned with the needs of people who are beyond other forms of intervention. There is a demonstrable need to provide permanent accommodation for these people and this type of support may be more efficient (and appropriate) than other forms of on-going support such as intensive in-home care. Given the importance of immediate action to assist people who require accommodation, and the desirability of a sense of security and certainty amongst families, the Committee considers that there is a need to establish and meet clear and unambiguous targets for growth.
- 2.30** ADD has advised the Committee that better data on unmet need will become available when information from the Service Access System is combined with data from the Population Group Planning project.<sup>77</sup> In view of the concerns raised by ADD the

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<sup>76</sup> Milligan, Mitchell briefing Ageing and Disability Department, 20 November 2000

<sup>77</sup> Mitchell briefing, Ageing and Disability Department, 20 November 2000

Committee considers that the figure of 200 places per year should be reviewed after two years, provided that accurate data on the level and rate of growth of unmet need for accommodation becomes available through the Service Access System.

**2.31** The Committee emphasises that it is necessary to maintain sustained investment in new supported accommodation over a substantial period of time. The importance of adopting a long-term strategy of growth in accommodation is manifested by:

- projected growth in the number of people with disability as a proportion of the population, and the ageing of carers;
- the need to reduce the backlog of unmet need while absorbing growth in the number of people who need accommodation;
- the need to provide assurance to ageing carers and other people who are unable to provide informal supports indefinitely that permanent supported accommodation will become available when it is needed;
- the need to ensure that preventative strategies designed to maintain existing informal care arrangements are underpinned by sufficient out-of-home supported accommodation to meet the needs of people who cannot remain in informal care arrangements;
- the need to provide a lasting solution to the problem of respite blockage;
- the need to remove the current pressure to 'backfill' vacancies as they arise in large residential services (see chapter 4).

Subject to any revision in growth targets resulting from data collected through the Service Access System, the Committee considers that the target of 200 additional supported accommodation places per year should be maintained for a minimum of five years.

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### **Recommendation 1**

The Ageing and Disability Department should adopt a growth target of 200 additional supported accommodation places for people with disability per year for five years from the date of this report.

### **Recommendation 2**

The Ageing and Disability Department should review the growth target of 200 places per year in the light of information provided by the Service Access System, provided accurate information on current and future unmet need is available within two years of the date of this report.

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**2.32** The Committee appreciates that out-of-home supported accommodation is just one component of a broader service response to unmet need for accommodation support. The

government's new *Living in the Community* strategy, outlined in the 2000/2001 Budget, emphasises the provision of flexible supports to maintain existing living arrangements where possible. This new policy direction moves beyond the past focus on group home accommodation as the only support model. Ultimately, this will enable the disability services system to assist a greater range of people and reduce the number of people who require permanent supported accommodation. However, this new strategy can only work effectively if sufficient accommodation is provided to assist those people whose situation is such that they can no longer live in informal support arrangements.

### **The problem of disappointed expectations**

- 2.33** A particular concern regarding past accommodation programs such as the *300 places initiative* is that they have appeared to many people to be 'one-off' measures designed to meet the most urgent needs of people with disability, rather than being part of a progressive and planned pattern of investment in disability services. People who failed to gain accommodation under the initiatives, particularly those who met the eligibility criteria but did not get a place, received no information about future initiatives. This has led to considerable distress on the part of carers and contributed to the perception that permanent out-of-home accommodation for people with disability is unobtainable. The Committee is particularly aware that the stress of a carer who is having difficulties caring for a person with disability is considerably magnified by the belief that there is no reasonable prospect of that person ever obtaining supported accommodation.
- 2.34** The Committee spoke to a number of carers of people with disability who felt that they have 'missed out' on a place for their family member and have little confidence that support will be provided. This in turn generates suspicion about the process, hostility towards ADD and DoCS and resentment towards those who obtain service. It also encourages the belief that the only way to obtain accommodation is to abandon a family member in respite.
- 2.35** These disappointed expectations greatly exacerbate the stress that lack of support places on people with disability and their carers. One carer who initially believed that she and several other parents had obtained placements for their children under one of the past initiatives described to the Committee the impact of learning that they had not obtained accommodation:
- I felt totally betrayed by everyone at that stage, and I just had a total breakdown six months later. One of the mothers whose child was to go into the original place was 72 at the time and she had a major heart attack and was rushed to Westmead Hospital. Another mother had a total breakdown. I was the only one left standing to scream and yell and jump up and down. But nothing happened. I had the breakdown six months later.<sup>78</sup>
- 2.36** Some long-term carers of people with disability who spoke to the Committee also felt that they were continually bypassed by more 'urgent' cases each time that limited places became available. As they have aged, this has led to increasing concern about their own future and

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<sup>78</sup> Parent consultation, Western Sydney, 10 May 2000

that of their family member with disability, as well as cynicism about the motives of government. As one carer told the Committee:

one of the tragedies is that governments know nothing about us. They do not want to know anything about us because they take advantage of the carers who look after their children. We have been looking after our daughter for 37 years.<sup>79</sup>

### **Planning for disability service provision**

**2.37** The need for long-term sustained investment in supported accommodation highlights the lack of a clear plan for delivery of disability services in NSW. The need for a plan has been highlighted in submissions, in formal evidence by witnesses such as the Commissioner for Community Services, and by many carers who attended public consultations. While the Government has developed policy objectives for delivery of disability services, the Audit Office's review of group homes recently noted that

there is still some way to go before ADD translates these policy objectives into a clear strategic framework for the provision of disability services.<sup>80</sup>

**2.38** The overwhelming view presented to the Committee is that publication of an effective plan for disability services will at least give many people confidence that action is being taken to address the problem of unmet need. This in itself will greatly reduce the level of anxiety and distress felt by many people with disability and their carers:

In the same way that the community has shown it will wait for many years to see a dual highway built from Melbourne to Brisbane as long as there is a vision and plan, a commitment and progress, with the worst bottlenecks and trouble spots addressed first, we believe that the disability community will not be unreasonable with their demands if they can receive the same assurances and see the same evidence of commitment and intelligent progress.<sup>81</sup>

Planning engenders confidence in disability administrators by indicating a demonstrable commitment to the disability services sector. Proper long-term planning is also necessary to ensure that service growth occurs equitably and efficiently:

The lack of longer term planning inevitably places the Government in a position of responding to crisis and allocating money in an unprioritised, rushed and inefficient manner.<sup>82</sup>

**2.39** The Committee is aware that regional planning processes within ADD have been under way for some time and are likely to be finalised in the near future. It is therefore not appropriate to comment extensively on the planning processes until the final report.

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<sup>79</sup> Ibid

<sup>80</sup> Performance Audit 2000, p. 71

<sup>81</sup> Western Sydney Intellectual Disability Support Group, Submission 230, p. 9

<sup>82</sup> Ibid p. 7

However, in the context of accommodation, the Committee considers it important to include clear growth targets for supported accommodation in plans for disability services.

**2.40** Many submissions have highlighted the absence of benchmarks for the provision of disability services. In contrast to the aged care sector, NSW does not have targets for the provision of disability services on a per capita basis. This lack of population-based service provision targets has been highlighted by the Audit Office which has noted that, for example,

the United Kingdom currently provides 122 residential places for people with intellectual disability per 100,000 of the adult population (over 16 years of age), and has a target of achieving 155 places per 100,000 of adult population.<sup>83</sup>

While direct comparisons may be difficult, the Committee notes that on the best available information, NSW presently provides approximately 111 accommodation support places per 100,000 of the adult population. To achieve the current UK residential placement rate, an extra 537 places would need to be provided. In order for NSW to match the UK's target of 155 places per 100,000 of the adult population, an extra 2,196 places would be needed.<sup>84</sup> The Audit Office has therefore recommended that ADD:

- develop and publish targets for the level of residential services for people with disability
- benchmark these targets against appropriate jurisdictions
- monitor progress in achieving these targets.

**2.41** The Committee agrees that there is a need to develop service provision targets as suggested by the Audit Office. Such targets are necessary to ensure orderly development of the disability services system and to ensure that disability services are funded equitably by comparison to other government services.

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### **Recommendation 3**

The Ageing and Disability Department's regional and State plans for disability services should include numerical targets for growth in supported accommodation as outlined in Recommendations 1 and 2.

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<sup>83</sup> Performance Audit 2000, p. 71

<sup>84</sup> Residential placement rate is based on the Productivity Commission's snap shot data in *Report on Government Services 2000, Volume 3*. Information for supported accommodation is for all people with disability. The population of NSW is from *ABS 2000 New South Wales Yearbook* and is of the adult population of NSW of adults 15 years and older as at June 1998.

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### **Recommendation 4**

The Ageing and Disability Department should develop and publish population-based targets for the number of residential places for people with disability as part of the planning process.

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**2.42** During consultations, the Committee was made aware of additional difficulties faced by people in rural and remote areas, people from non-English speaking backgrounds and people from Aboriginal and Torres Strait Islander backgrounds in obtaining services. People from these groups have problems accessing service because of geographical and/or cultural isolation, with the result that they are significantly under-represented amongst those who are able to obtain services. While these issues will be dealt with more fully in the final report, the Committee notes that current planning process need to take account of the specific needs of each of these groups.

### **Data collection**

**2.43** This chapter has highlighted the lack of accurate data on the level and nature of unmet need for disability services in NSW. The lack of data hampers service planning and must be rectified as part of the on-going program of reform of disability services in NSW. The Audit Office has noted that ADD needs to develop systems to:

- assess the level, type and distribution of unmet demand for disability services in NSW [and]
- determine eligibility and priority of access.<sup>85</sup>

**2.44** The Audit Office also identified problems with the way that ADD managed accommodation vacancies, including a lack of systems to keep it informed of vacancies within the sector and insufficient oversight of the way service providers filled vacancies when they arose. The Office therefore stated that there was 'an urgent need for ADD to develop a system to manage vacancies across both DoCS and the non-government sector.'<sup>86</sup>

**2.45** Since the publication of the Audit Office's report, the Service Access System has commenced operation. The Committee has been advised that the SAS will ultimately provide a system for managing vacancies in accommodation services and will therefore address one of the key concerns of the Audit Office.<sup>87</sup> It is too early to comment on the operation of the SAS, but the Committee notes that its efficacy depend on the use of consistent and reliable needs assessment tools and the development of clear criteria for access to various types of service.

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<sup>85</sup> Performance Audit 2000, p. 72

<sup>86</sup> Ibid, p. 73

<sup>87</sup> Milligan briefing, Ageing and Disability Department, 20 November 2000

- 2.46** Because it will provide a single system for registering and assessing requests for service, the SAS will potentially enable accurate information to be collected about the level, type and distribution of unmet need in NSW. It is therefore important that appropriate systems are in place to collate and interpret individual requests received through the SAS. This information will greatly assist the planning process, and in particular will enable ADD to develop and monitor appropriate population-based targets for accommodation provision. This information will also enable funding models to be developed that are linked to real reported need in the community. To enable full public input into planning processes, the Committee considers that such information should be made public.

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**Recommendation 5**

Systems to allow collation and interpretation of data on the level, type and distribution of unmet demand for disability services, including permanent supported accommodation, should be incorporated into the Service Access System.

**Recommendation 6**

Information on unmet demand for disability services derived from the Service Access System and other sources should be made public as part of the planning process.

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**Conclusion**

- 2.47** Ultimately, access to accommodation services should reflect rights rather than privileges. The Committee is aware that considerable work is required before the disability services system is able to provide accommodation to all those who require it. The first step towards achieving this goal is to ensure that a constant supply of supported accommodation becomes available for those in extreme need. Despite several initiatives to increase supply, there remains a significant backlog that places considerable pressure on disability services and related programs in NSW. Demographic trends mean that this backlog will continue to grow as carers age and the number of people with disability as a proportion of the population increases. Accurate data on the number of people who currently require out-of-home accommodation is not available, however there is no evidence to suggest that the level of unmet need for accommodation has decreased since the mid 1990s. On the contrary, all parties who have appeared before the Committee agree that demand for new places greatly exceeds supply. Recently announced measures have the potential to stem the increase in demand, but to effectively address the problem of unmet need for people in crisis, these measures will need to be supported by successive increases in the supply of accommodation.
- 2.48** The Committee does not believe that demand for supported accommodation is so great as to be unmanageable or beyond the resources of government. As stated previously, the majority of people with disability who need assistance with accommodation do not require out-of-home supported accommodation. A program of sustained new investment in supported accommodation, targeted to those people in greatest need, will gradually reduce unmet need for those in crisis to a manageable level.

## Chapter 3 Respite services

Chapters 1 and 2 dealt with those people who require permanent accommodation because their existing support arrangements cannot continue. This chapter deals with a larger group for whom accommodation at home is appropriate, but who require additional support to maintain existing accommodation arrangements and prevent a situation of crisis developing. Evidence and submissions have indicated that the most effective way to meet the needs of this group is through provision of effective respite care.

The Committee considers that the respite system in NSW is in need of reform if it is to fulfil its potential within the disability services system. This chapter considers the key issues in relation to respite and makes recommendations for reform.

### Overview of the respite system

**3.1** The majority of respite is provided informally by friends and relatives of people with disability or their carers.<sup>88</sup> This chapter, however, focusses on formal respite services provided by government and non-government agencies. Formal respite services are increasingly provided in a variety of ways but usually they fit within one of three broad categories:

- In-home respite – where support is provided to a person with disability in the home, enabling the person with disability to carry on normal activities and providing the carer(s) with the opportunity to carry out other activities such as shopping or to take a break.
- Out-of-home, daytime respite – where people with disability are supported outside their house during the day.
- Centre-based overnight respite – where overnight supported accommodation is provided to people with disability outside the family home.<sup>89</sup>

**3.2** Formal respite care for people with disability is available from a wide range of service providers and is funded through a variety of funding programs. In-home respite is often provided through the HACC (Home and Community Care) program, either through the Home Care Service of NSW or by funded non-government organisations. In-home and out-of-home respite may also be provided on a voluntary basis by host family support organisations and peer support networks. These organisations may receive limited funding through a range of programs.

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<sup>88</sup> Respite Working Group 2000

<sup>89</sup> Daytime out-of-home respite is also frequently referred to as 'centre-based' respite, but the term centre-based respite in this report refers only to overnight support provided outside the family home.

- 3.3** Overnight respite care is generally funded through the NSW Disability Services Program. The Department of Community Services is the main provider of centre-based overnight care, although non-government providers have an increasing role. The Commonwealth also funds a range of respite programs aimed at people with disability and ageing people, including Carer Respite Centres that provide information on respite and broker emergency accommodation for people with disability.
- 3.4** In this report, the Committee is principally concerned with the centre-based respite services. The demand for these services is more clearly linked to demand for accommodation than the demand for other service types. As outlined below, evidence to the Committee has indicated that people in carer relationships that are under stress, or that involve large commitment of time, require the substantial and sustained breaks that are only adequately provided through centre-based respite. For these people, availability of in-home and/or daytime services will often not be sufficient to prevent them from moving into crisis. Lack of centre-based respite contributes to carer burnout and dramatically escalates demand for out-of-home supported accommodation.
- 3.5** Provision of adequate and effective respite is a very significant factor in managing demand for more intensive forms of support, such as out-of-home accommodation. It is widely acknowledged that respite is a highly cost-effective strategy to support people with disability. Respite also meets the needs of the many families who want to continue to care for a family member with disability within the family home.

## **Benefits of respite**

- 3.6** Respite services support ‘families and people with disability in the natural experience of time away from each other’,<sup>90</sup> allowing people with disability and their carers to take a break from each other so that relationships are strengthened and replenished.<sup>91</sup> The break greatly reduces the stresses that are inherent in many long-term informal support arrangements. As one mother told the Committee:

My whole life revolves around my son. I have no freedom. When he goes into respite ... I get 12 to 15 days for three months. When he goes into respite I am continually amazed at the feeling I have of freedom. It amazes me every time. It should not because I know it is going to happen, but it is the feeling of freedom you get, of being able to do what you want, when you want without having to consider someone else first, of being able to be a person, of being able to sleep.<sup>92</sup>

- 3.7** The need to give much needed attention to their other children was a major impetus for parents to seek respite care:

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<sup>90</sup> Submission 255, Council for Intellectual Disability

<sup>91</sup> Submission 208, Interchange Respite Care Inc

<sup>92</sup> Parent consultation, Western Sydney, 10 May 2000

There are three other children...it is so important to give them your time and a holiday and for us too as carers.<sup>93</sup>

**3.8** The NSW Council for Intellectual Disability notes that respite should be viewed as:

part of a range of activities and experiences which contribute to the growth of community participation, interdependence, autonomy and self-determination.<sup>94</sup>

**3.9** The developmental benefits of respite services for people with disability are very important, and should be recognised in the planning of services. Quality respite can enable people with disability to develop social networks and independent living skills, and experience challenges outside of the family environment.

This can assist future transition to full time supported accommodation:

We have a couple of aging parents in town now ... We found that if the ... child can get into respite they can get a bit of an idea of what these communal homes are going to be like, ... if they have been in that home two or three times in the past 12 months, that makes it easier on the home...(and) it gives the parents a little bit of satisfaction that if they drop off the planet there is going to be some sort of arrangement that will fit into place.<sup>95</sup>

## **Barriers to accessing residential respite**

**3.10** Participants at all of the Committee's consultations spoke of the significant barriers to accessing residential respite. In most cases respite must be booked well in advance of the required date, so the opportunity for spontaneity is virtually non-existent:

You can only book your respite care three months in advance...You can do nothing spontaneously; you have to plan everything and suddenly if you do want to go away for a weekend, you try to get respite and there is no way. It is completely full.

**3.11** However, an advance booking is no guarantee of a place and carers are often let down at the last minute:

A friend booked her child into a group home, was planning a holiday and at the last minute there was a crisis situation and she was asked to remove the child. This is happening more and more. <sup>96</sup>

**3.12** In some areas, centre-based respite is more readily available for children than adults, leading to significant problems when people turn 16 or 18:

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<sup>93</sup> Public consultation, Parkes, 21 March 2000

<sup>94</sup> Submission 255, Council for Intellectual Disability

<sup>95</sup> Public consultation, Broken Hill, 10 July 2000

<sup>96</sup> Public consultation, Wollongong 11 May 2000

We have got five children at the moment who in 18 months will turn 18. There are no services that I can refer those families on to for respite in the future and some of these children are severely to profoundly disabled.<sup>97</sup>

My daughter will be 16 soon. Once she turns 16 there is absolutely no place for her to go at all for respite in the Nowra area.<sup>98</sup>

- 3.13** The quality of respite care was a concern for some carers, especially parents of children with profound disability:

My experience with respite care has not been terribly good we have had three incidents of abuse in care in this region that have been confirmed <sup>99</sup>

- 3.14** As outlined below, the difficulties in accessing centre-based respite reported to the Committee during consultations have also been identified in a number of reports that have considered respite services in NSW.

## **Demand for respite**

- 3.15** Measuring demand for respite is less complex than measuring demand for supported accommodation because specific information on demand has been gathered by agencies such as the Australian Bureau of Statistics. However, data on the level of need for respite services varies significantly between studies and therefore only provides an indication of the magnitude of unmet need rather than precise and reliable figures. This is also true of estimates of need for supported accommodation.

### **AIHW demand study**

- 3.16** In 1996 the Australian Institute of Health and Welfare (AIHW) reported that nationally, there were 7,000 carers of people who wished to obtain respite but were unable to do so because the service was not available. This equates roughly to 2,300 people in NSW.<sup>100</sup> The AIHW also reported that 58,845 people nationally did not use respite because they did not know (or did not know enough) about respite services, suggesting that the potential need for respite was significantly greater than reported need.

### **Community Services Commission review**

- 3.17** In 1997/1998 the Community Services Commission conducted a major review of the centre-based respite system in NSW. The review indicates that the overall size of the user

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<sup>97</sup> Public consultation, Parkes, 21 March 2000

<sup>98</sup> Public consultation, Wollongong, 11 May 2000

<sup>99</sup> Public consultation, Albury, 23 March 2000

<sup>100</sup> AIHW, *The demand for disability support services in Australia*, 1996, p.70. The AIHW demand study was based on the Australian Bureau of Statistics' 1993 Disability Ageing and Carers Survey.

group for respite in the period was 8,000 people. The Commission found that 3,500 people were able to access some centre-based respite in 1997. However, at least 4,500 people were unable to have their request for a respite service met. The review noted that the majority of unmet requests for respite (91%) were for scheduled respite, with the remainder being for temporary crisis accommodation.<sup>101</sup>

- 3.18** The Commission's review provides useful information on the level of demand for centre-based respite. Increases in the population of people with disability and ageing of carers indicate that the potential user group would have increased since then although it is not possible to say by how much. Demand for respite varies significantly: some people need frequent respite while others may only need occasional access. At present, information about the total level of demand, expressed in service hours or an equivalent measure, is not available. All available information, however, indicates that demand for centre-based respite greatly exceeds supply.
- 3.19** The review highlighted the problem of blocked places, or 'blockage'. In 1998, 149 people had been in respite for over 90 days continuously, on average for 3.3 years each. A further 343 people did not occupy a respite service continuously but were intensive users of respite, on average for 149 days each per year, effectively blocking a further 140 beds. Consequently of the 363 respite beds available, 80% were occupied by just 14% of the total population of respite users. In effect, this left 74 beds free to meet the needs of the remaining thousands of potential users.<sup>102</sup>
- 3.20** The Commission found that if permanent accommodation were provided for the 149 people living in respite, then each of the 4,500 people who did not receive any respite could have received 7 days a year while the 3,500 receiving some respite could have received an additional 7 days. The review noted that similar gains could have been achieved if action were taken to provide more appropriate service to the 343 people who used respite intensively.<sup>103</sup>
- 3.21** The review makes it clear that blockage is one of the key reasons why demand for respite has exceeded supply. It is clear that inappropriate use of respite by a relatively small number of users prevent the use of support arrangements by many thousands of people under stress and at risk of breakdown. Of course, many permanent or frequent users of respite do so only because their informal support arrangements have broken down and there are no permanent accommodation alternatives available to them. This highlights the argument in chapter 2 that provision of supported accommodation for a relatively small number of people will have systemic benefits for a far greater number of people.
- 3.22** Since the review, some action has been taken to reduce blockage and increase the overall supply of respite. However consultations have indicated that blockage continues to be a

<sup>101</sup> Community Services Commission, *Respite Care – a system in crisis: Summary*, 1998, pp. 8, 17

<sup>102</sup> The Commission's findings on blockage were supported by 1999 data from DoCS which found that 40% of the Department's respite places (145 places) remained blocked. Source: Respite Working Group 2000 p. 19. The Committee understands that corresponding data on the level of intensive use in 1999 was not collected.

<sup>103</sup> Ibid

problem in respite services, and many people continue to experience difficulty accessing sufficient centre-based respite.

**3.23** The figures on demand and usage in the review demonstrate that centre-based respite services have operated as a crisis support system rather than a genuine respite system providing continuing support. The government submission to the inquiry also notes:

Respite is frequently used in place of supported accommodation. It is estimated that more than half of respite beds are being used continuously (“blocked”) or intensively by a small number of people with disabilities. In addition, respite beds are often used for emergencies and are then not available for the very important function of planned support.

The effect of current patterns of usage of respite beds is to: reduce the capacity of the respite system to make places (beds) available to large numbers of potential respite consumers; and to divert resources away from meeting needs that are medium to long term.<sup>104</sup>

**3.24** The Committee appreciates that it is essential to ensure support is provided to people in crisis. However, curtailing regular respite to meet crisis admissions is likely to be counter-productive in the longer term because more people will move into crisis as a result of insufficient support. The separation of the respite and crisis support systems can break this cycle.

## Respite Working Group

**3.25** Following the release of the Commission’s review, the government established the Respite Working Group<sup>105</sup> to consider the issues raised by the review and the options for developing a more flexible and effective respite system in NSW. The Working Group finalised its report earlier this year, making a series of recommendations for comprehensive reform of the respite system with particular emphasis on residential respite. The report noted that reform of the respite system will be largely dependent on wider systemic reform. The report’s key findings are as follows:

- While the actual level of unmet need for respite is unknown, all available indicators show that the real level of unmet need is very high and continues to increase.
- There is a need to properly define respite. Respite should be a flexible support response that is tailored to the needs of the person with disability and their carer or family. Respite should only be provided to people who have a carer. Respite should be available as *planned* support, not emergency or crisis care or long-term supported accommodation.

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<sup>104</sup> Submission 225, Cabinet Office

<sup>105</sup> The membership of the Respite Working Group (RWG) included representatives from the Federal Department of Health and Aged Care, NSW Department of Community Services, the Community Services Commission, and a range of disability advocacy and support groups.

- Respite is funded through a range of programs and there is a lack of coordination between Commonwealth and State programs. Some people receive assistance from multiple providers and under several programs, raising the potential for inequity of access. Funding particular categories of service under different programs restricts flexibility and has created a fragmented system of services, particularly for people with complex needs who require more than one type of service.
- Better assessment, service planning, improved systems for quality control and monitoring systems are required, as well as carer involvement for service users.
- A clear policy framework for respite and standardised management tools are required to ensure equitable distribution of services.
- Respite services are being taken up for other needs.

Respite services have generally become a catch-all area, absorbing unmet needs for other services such as emergency accommodation or direct personal care. ...

Funding for respite and other services is inadequate. Despite an increase in respite funding this financial year, people in need of respite will not have access to services while it is used as a substitute for other services.<sup>106</sup>

The need for respite would be reduced by increased availability of services such as supported accommodation, day programs, and emergency care and specialist support for people with challenging behaviour. The report notes that “[t]he disability system and the respite system appear to be crisis driven with a lack of early intervention and preventative support.”<sup>107</sup>

- There is no current comprehensive data on use of respite and ‘consistent data about the use of respite services, particularly for residential respite and in tracking “blocked beds” is badly required’.
- Action is required to address the needs of a number of groups in the community who are particularly disadvantaged by lack of access to respite and other supports. These include people of Aboriginal and Torres Strait Islander background, residents in remote areas and people from non-English speaking background.
- Growth funding sourced from both the State and the Commonwealth is being made available and will go some way to meeting the deficit in respite services. However, little improvement can be expected unless structural reform is undertaken both in respite and the wider disability services system.

<sup>106</sup> Respite Working Group 2000, p. 22

<sup>107</sup> Respite Working Group 2000, p. 23

**3.26** These findings are consistent with the views expressed in submissions, evidence and consultations during this inquiry. The Working Group made a number of recommendations to address the identified problems. Key recommendations include:

- Respite should be freed by
  - providing permanent family-based support options for all children in long-term respite, including state wards
  - relocating adults in long-term respite to permanent community-based supported accommodation and preventing future use of respite for long-term accommodation
  - providing appropriate support, including permanent accommodation where necessary, for adults who are using respite intensively
  - developing intensive family support packages for children who use respite intensively or are at risk of long-term placement in respite
  - establishing regionally based funding within ADD for emergencies and crises (Recommendation 1).
- Residential respite should be made more appropriate by
  - relocating all respite places in large residential centres to community-based accommodation
  - separating respite care from supported accommodation
  - ensuring children and adults are not accommodated in the same facility at the same time
  - redesigning children's residential respite places to suit the particular needs of the small number of children who will continue to use residential respite (Recommendation 2).
- ADD should investigate and pilot non-residential models with a view to promoting flexible and viable services in rural and remote areas. Funding formulae should be adjusted to take travel costs into account in remote areas (Recommendation 10).
- ADD should, with NSW Treasury, develop a funding model which is based on population group planning characteristics – similar to the Commonwealth planning ratios for aged care. Under such a model a set level of recurrent funding would be allocated for a proportion of the population projected to have a profound or severe handicap (Recommendation 14).

**3.27** Other recommendations deal with the need to develop culturally appropriate service models for people from different backgrounds, the need to develop appropriate services for children, the need for an overall disability plan, and the need to reform the specialist support system for people with challenging behaviour and high support needs. The recommendations are reproduced in full in appendix 6.

**3.28** The Committee endorses the recommendations of the Working Group and supports the suggested strategy for reform. It is clear that a multi-faceted response to the widely acknowledged problems with respite will deliver clear benefits to the disability services system as a whole. Central to this approach is the need to break the nexus between respite

and crisis accommodation, and ensure that respite service reform is supported by increased availability of supported accommodation. Over the longer term, reform needs to be supported by overall strategic planning for disability services in NSW and a population-based approach to funding disability services.

- 3.29** The Committee is aware that some action has already been taken to implement the report of the Working Group. The Committee therefore considers that, within six months of the date of tabling this report, the government should provide a detailed response outlining the action that it has taken, or intends to take, in response to each recommendation of the Respite Working Group.

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### **Recommendation 7**

The Ageing and Disability Department should act to implement all recommendations of the Respite Working Group.

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## **Recent government initiatives**

- 3.30** Since the release of the Community Service Commission's report in 1998, there have been a number of initiatives that will have an impact on the respite system in NSW. The government has also endorsed the general direction outlined in the recommendations of the Respite Working Group. Many of the initiatives outlined in this section are informed by the work of the Working Group.
- 3.31** In the 1999/2000 Budget, additional funding was announced to establish two new respite centres in regions currently inadequately served. The government has also stated that it will fund an additional 1,200 flexible respite packages over the coming parliamentary term (ending in March 2003).<sup>108</sup> The Committee was informed that each package will provide families with the equivalent of three weeks out-of-home respite each year.<sup>109</sup> As this initiative will take place over three years, the Committee understands that an additional 400 families will be able to access respite for the three-year period.
- 3.32** The Commonwealth has also provided \$50 million over two years to provide support to ageing carers of people with disability. The Committee understands that this funding will soon be applied to new services.<sup>110</sup>
- 3.33** Significant action is also about to be taken to address the problem of blockage. As outlined in chapter 2, the 2000/2001 State Budget contained funding to provide permanent accommodation for the 74 people presently blocking respite services. The Committee

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<sup>108</sup> Submission 225, Cabinet Office

<sup>109</sup> Hammerton evidence, Ageing and Disability Department, 17 February 2000

<sup>110</sup> Milligan briefing, Ageing and Disability Department, 20 November 2000

understand that some of these funds have now been allocated to some individuals and work is under way to assist their move to permanent accommodation.

- 3.34** Concerns have been raised with the Committee about apparent lack of progress to date in moving people from long-term respite into alternative permanent accommodation. In November this year, officers of ADD acknowledged to the Committee that there has been some delay but emphasised that many people living in long-term respite have complex needs, and providing the appropriate place takes some time to finalise. ADD has advised the Committee that most of these people should be in permanent places by 30 June 2000.<sup>111</sup> The Committee considers that it is imperative, both for those people currently living in respite services and for the many people who require respite, to ensure that blocked places are freed as soon as possible.
- 3.35** Successful implementation of the recent measures will significantly increase the effective supply of centre-based respite. However, the level of unmet need for services, particularly accommodation and respite, means that there is a risk that centre-based respite services will again become blocked over time. Consequently, the long-term value of these measures will depend on strategies and resources being put in place to maintain the availability and effectiveness of respite. The next section outlines the Committee's views in this regard.

## **Ensuring the long-term efficacy of respite**

### **Permanent supported accommodation**

- 3.36** The Respite Working Group highlighted the link between lack of supported accommodation and respite blockage. Blockage occurs when informal support structures break down and people have no alternative place to live. When the breakdown is irreversible, the only appropriate response is permanent accommodation, which needs to be provided as soon as possible both to minimise trauma and to ensure respite for others is still available.
- 3.37** As chapters 1 and 2 have noted, a factor contributing to breakdown of support arrangements is the belief that permanent accommodation will never become available. The Committee's consultations revealed the widespread belief amongst carers, advocates and service providers that the only way to obtain permanent accommodation was to preemptively block a respite bed. The inappropriate use of respite can only be eased through a planned program of moderate but progressive increases in the supply of permanent supported accommodation. The demographic factors driving demand for disability support services suggest that the trend towards blockage is likely to accelerate unless there is an alternative and effective pathway to permanent accommodation for those who need it. The Service Access System has the potential to provide this pathway *provided* that sufficient new accommodation continues to be made available for people in genuine need. The Committee therefore emphasises that the recommendations in the previous chapter relating to supported accommodation underpin reforms to the respite care system. This view is supported by the findings of the Respite Working Group.

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<sup>111</sup> Ibid

### **Out-of home and centre-based support**

**3.38** The type of respite service provided must be appropriate to the needs of both the person with disability and the carer. Current policy directions in respite emphasise the importance of flexibility and the need to tailor services to best meet the needs of the carer relationship. This reflects recognition that the value of respite is measured by the effect on the carer relationship rather than the way in which service is delivered.

**3.39** In evidence, officers of ADD have indicated that the department is currently exploring options for more flexible provision of respite services to meet the individual needs of people with disability and their families. The Committee is aware that many families will continue to need access to centre-based overnight respite. This is particularly the case for families supporting adults with disability. As the Commissioner for Community Services told the Committee:

the word “flexibility” in the area of respite is a double-edged sword. On the one hand, it is quite clear that parents and carers generally do want more flexibility in the nature of the care, but some of that actually does involve centre-based care.

In other words one of the dangers, I think, is that we might move to the all-or-nothing principle, where we say, no longer will we have centre-based respite – it will all be in the home.

... interestingly, in respite, parents go through very noticeable and defined changes. When the children are very young, they only want people coming into their home, they only want home based respite. By the time they are about 18 or 19 they only want the person to go elsewhere, into another home or residential.<sup>112</sup>

**3.40** As a person with disability and their carer grow older, they are more likely to need access to out-of-home respite. This results from changes associated with maturation of people with disability as well as the ageing of their carers. Adults have different support needs to children that cannot always be met within the family environment. Some of these needs are developmental and some relate to the physical inability of older carers to provide full-time care to their adult son or daughter. Out-of-home respite is particularly important when it is likely that a person will need to move to permanent accommodation in the near future.

### **People with high support needs and/or challenging behaviours**

**3.41** Centre-based respite remains important for people with high support needs and/or challenging behaviours. Informal support arrangements for this group are most at risk of breaking down due to the intensity of the work involved in providing care. Paradoxically, people in this group often face the greatest barriers to obtaining respite and related services. The need to reform the system of support for people with challenging behaviours and/or high support needs was also highlighted by the Respite Working Group.<sup>113</sup>

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<sup>112</sup> Fitzgerald, Commissioner for Community Services evidence, 22 February 2000

<sup>113</sup> Respite Working Group 2000, Recommendations 17, 25

**3.42** A significant issue raised by carers during consultations was that service providers have limited or withdrawn services to people when their physical support needs increased, or they exhibited challenging behaviour. Service providers have also advised the Committee that funding constraints often prevented them from providing adequate service to people with high support needs and/or challenging behaviour. Some carers also felt they had been denied access to centre-based respite because staff feared that they would block a bed.

**3.43** A number of carers of people with high support needs advised the Committee that in-home support was not sufficient. Carers of people who need assistance with mobility found that occupational health and safety requirements restricted staff in carrying out physically demanding tasks, such as lifting, with the result that the carer had to assist the service provider:

We had an hour and a half Home Care or personal care coming in a day – half an hour in the morning and an hour of a night ... [W]e are expected to be there to help bathe and dress [our son]. So we did not really get a break because the services did not want to put a second person in to help the first person. We became the second person and we never got a break. It does not matter how much personal care you get into a home, you are expected to help them.<sup>114</sup>

We get some in-home services. I have just had a big 1 1/2 hour meeting with Home Care and I was told that [my son's] care is too demanding for their workers.<sup>115</sup>

**3.44** Service hours were often insufficient to enable carers to take a genuine sustained break. The overwhelming view presented in submissions and consultations was that service hours for people with high support needs and/or challenging behaviours had declined as a result of budgetary and occupational health and safety constraints.

**3.45** Communities that are highly reliant on voluntary networks, such as host family support, face particular problems providing respite for people with complex support needs. During regional consultations, a number of service providers and carers stressed that it was unreasonable to expect volunteers to provide respite services to people with high support needs or challenging behaviours:

I do not leave him long with a host family in the community. He will stay there for a couple of hours a week. These people, who are volunteers, are lovely people, but if anything was to happen I really do not know whether they would be able to cope with it.<sup>116</sup>

**3.46** A carer in Narrabri described her involvement in the 'host family' scheme. She is paid \$16.85 to care for a young boy for four nights per week and this amount has not changed since 1996, despite increases in the cost of living. She believes that the small amount of

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<sup>114</sup> Public consultation, Wollongong, 10 May 2000

<sup>115</sup> Public consultation, Newcastle, 4 July 2000

<sup>116</sup> Public consultation, Newcastle, 4 July 2000

money paid to such carers demonstrates a lack of commitment to quality care for disabled people.<sup>117</sup>

- 3.47** The Committee considers it particularly important to ensure that sufficient and appropriate respite is provided to people who have high support needs or who exhibit challenging behaviour. These people often require access to centre-based respite and may need to access these services frequently. They may also need access to specialist support services such as intensive behaviour management programs. Special provision therefore needs to be made to ensure that sufficient service is provided to maintain carer relationships for this group of people, and to prevent them drifting to more expensive forms of service such as permanent supported accommodation.

### **Rural and remote areas**

- 3.48** Submissions and consultations have shown that access to respite is especially difficult for people in rural and remote areas. Centre-based respite services are generally limited to major regional centres, so that people living in rural and remote areas may have to travel a significant distance to services, incurring substantial travel expenses and restricting the useful time available to carers.
- 3.49** In recognition of these difficulties, the Respite Working Group highlighted the need to develop alternative respite models, to meet the needs of people who live a long distance from regional centres. The use of local and/or mobile resources to provide respite in close proximity to the family home is at the core of these proposals. The Committee endorses the need to ensure that the benefits of respite to people with disability and their carers are not dissipated by the barriers to access experienced by people in rural and remote areas.

### **Clarifying the role of respite**

- 3.50** Until now, the centre-based respite system has operated largely as a crisis support system and its ability to provide regular scheduled care to people with disability has been severely curtailed. In a situation where demand for accommodation and respite greatly outstrips supply, it is inevitable that crisis support will overwhelm regular scheduled respite.
- 3.51** The Respite Working Group recognised that a clear distinction needs to be made between respite, which is planned support, and crisis support. The Committee endorses this view and notes that funding to establish a separate crisis support system for people with disability was included in the 2000/2001 Budget. It is too early to evaluate the efficacy of this system but the Committee notes that the crisis support system will need to:
- ensure that an immediate response is provided to people in crisis in a way that does not limit other users' access to respite. This involves providing supports, including short-term accommodation, outside the respite system;

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<sup>117</sup> Transcript of public meeting in Narrabri, 24 August 2000 attended by Hon Doug Moppett MLC, Deputy Chair

- identify high intensity/long-term users of respite who are at risk of blocking respite places and provide alternative support arrangements, including where necessary permanent supported accommodation.

**3.52** Exclusion of people in crisis from respite services will significantly improve the system of respite care and must be backed by increased levels of supported accommodation for people with disability. Given that centre-based respite services at present operate predominantly as crisis accommodation, re-configuration of these services to provide reliable and effective respite will considerably reduce unmet demand for respite.

**3.53** To achieve these outcomes, alternative services for people in crisis will have to be developed. To date, the Committee has not received details of the types of services that will be used. There is likely to be a need to build service capacity, particularly in regional and remote areas, to provide crisis support outside the existing respite network. In this regard, the Committee notes that the Respite Working Group identified opportunities to link into the Commonwealth Carer Respite Centre network. The Committee considers that there is a need to develop clear funding guidelines for crisis support services to ensure that funding is targeted to services that deliver appropriate outcomes.

**3.54** The Respite Working Group noted that there is a need for a clear definition of respite to remove the confusion of roles that currently exists between respite and crisis support, and also between respite services and permanent accommodation. The definition of respite should encompass the developing understanding of respite as a service that provides planned support to people who are in informal care arrangements and their carers. The definition should also encompass the need for respite service to be age-appropriate and meet the needs of people from culturally diverse backgrounds.

**3.55** The Committee considers that funding guidelines for respite services adopted by ADD should reflect the approach suggested by the Respite Working Group.

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### **Recommendation 8**

The Ageing and Disability Department should adopt a definition of respite for respite services that includes the following elements:

- planned support is provided to the family unit or other carer relationship
- the service is provided to people with disability who have existing informal support arrangements
- the service is not intended to be the primary source of support for a person with disability
- the service does not provide emergency care to individuals in crisis
- the service is flexible, individualised, culturally and age-appropriate and provides developmental opportunities to people with disability.

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**Recommendation 9**

In developing services to separate crisis support from respite, the Ageing and Disability Department should develop funding guidelines for services that provide crisis support.

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**Planning and data**

- 3.56** The lack of clear information about the level of demand for respite makes it difficult to plan service provision. Absence of reliable data means, for example, that while it is clear that unblocking existing respite places will dramatically increase the availability of respite, there is no certainty that such action will release sufficient centre-based respite to meet the needs of the total user group.
- 3.57** As with permanent accommodation, the Committee considers that lack of detailed information should not prevent immediate action to reform respite service provision. However, as outlined by the Respite Working Group, reliable data must be collected to provide clear information about the level of demand for respite, so as to determine the adequacy of existing services and to inform future service provision.
- 3.58** The Working Group also highlighted the need to adopt a population-based funding model for disability services. The Committee endorsed this model in relation to permanent supported accommodation and agrees that population-based service targets should be established for respite services. Targets should be worked out both for centre-based respite services and flexible forms of respite. In the absence of accurate data on the level of demand for respite, the Committee considers that the benchmarks should be established by reference to available indirect information. These benchmarks should be adjusted as better information on demand becomes available over time.

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**Recommendation 10**

The Ageing and Disability Department should develop and implement population-based targets for respite services.

**Recommendation 11**

Funding allocations for respite services should be sufficient to support population-based targets for respite.

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**Conclusion**

- 3.59** The critical role that respite plays in supporting people with disability and their families, and reducing demand for more resource-intensive services such as permanent accommodation, means that action must be taken immediately to ensure that the respite system operates effectively and efficiently. Apart from the specific matters referred to

above, the Committee has not made detailed recommendations regarding reform of the respite system in NSW. This is because the problems in respite service are well recognised and have been dealt with comprehensively in the recommendations of the Respite Working Group.

- 3.60** The Committee endorses the recommendations of the Working Group and urges their swift implementation, supported by adequate resources. The Committee is aware that some action has already been taken to implement them. The Committee therefore considers that, within six months of the date of tabling this report, the government should provide a detailed response outlining the action that it has taken, or intends to take, in response to each recommendation of the Respite Working Group.

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### **Recommendation 12**

The Leader of the Government should table in the House a detailed response indicating what action the government has taken or intends to take in relation to each recommendation of the Respite Working Group, not later than six months after the date of tabling this report.

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## Chapter 4      Devolution

The Committee supports devolution of large residential centres for people with disability and firmly believes that action must be taken as soon as possible to finalise the transition from all large centres. Although congregate accommodation for people with disability has been condemned as outmoded and inappropriate, these facilities provide care for close to half of all people in supported accommodation. Failure in the past to achieve even modest devolution targets has resulted in gross inequity within the disability service system and has impeded the development of a coherent system in NSW. Given the overall situation of chronic under-supply of accommodation, vacancies which arise in many large residential centres continue to be filled.

Internationally, almost universal support exists for the devolution of large residential centres into appropriate community-based supported accommodation services. In NSW, large residential centres do not conform to the *Disability Services Act 1993* and are incapable of doing so. This is because they fail to meet the needs of residents for a safe, secure and stimulating living environment. Residents of large centres are isolated from the community and are unable to exercise basic choice in relation to their day-to-day life. The majority of research demonstrates that movement to community living greatly improves the quality of life of most people with disability.

Over the past decade, all funded residential services have been required to develop transition plans for transfer into community-based services that meet the basic 1993 legislative requirements. Yet approximately 2400 people or 43% of all people in supported accommodation, still live in large residential centres.<sup>118</sup>

The Committee welcomes the recent announcements by the government of a renewed commitment to devolution of large residential centres. The recommendations of this chapter are intended to strengthen these current policy directions. Areas of particular importance include ensuring the development of an overall plan for devolution which will provide certainty for residents, families and staff; ensuring that appropriate processes for devolution are in place; establishing effective management of the process within ADD; and ensuring that the concerns of residents, families and staff who are opposed to devolution are properly addressed.

Evidence provided to the inquiry by departmental officers, peak groups and some staff of large residential centres strongly supported the devolution of large residential centres. However, many staff and families of residents are opposed to devolution. They are often most anxious about the processes for devolution, concerned about choice and quality of care for residents and frustrated at the continuing uncertainty about the future of large residential centres. These concerns must be acknowledged and addressed as part of the continuing devolution process.

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<sup>118</sup> Report on Government Services 2000. There were 5568 users of accommodation support services on the snapshot day in 1999 (Table 12A.28). 57.2% of these people received community-based services (Table 12A.9), indicating that 42.8%, or 2383 people, live in large residential centres.

## Background to devolution

### Underlying principles of community living

- 4.1** Congregate forms of accommodation were once the main model of supported accommodation for people with disability in Australia and overseas. Since the 1960s, it has been acknowledged that congregate accommodation is inappropriate for people with disability just as it is for other members of the community. Since that time there has been an international movement to close large residential centres and provide alternative accommodation within the community for people with disability.
- 4.2** Following the publication of the *Richmond Report*<sup>119</sup> in 1983, the NSW government made a commitment to support people with intellectual disability to move from large residential services into supported accommodation in the community. All subsequent governments have re-stated this commitment to community living, which is based on the following principles:
- The medical model of care provided by large residential centres does not meet the needs of people with disability. People with disability are not ill, although they may have specific medical needs. Accommodation services should provide support that enables people to maximise their potential, rather than focussing on a single aspect of their needs.
  - People with disability have a right to live as citizens in the community and receive support that maximises opportunities for community participation.

New support models therefore recognise the 'rights of people with an intellectual disability to experience the same outcomes as ordinary citizens through increased community integration and improved personal competencies.'<sup>120</sup>

What political organisations of people with disabilities are demanding is not to have their needs defined by others but rather the right to appropriate services to meet their own self defined needs. Service delivery in this model derives not from need and philanthropy but from equal citizenship as a means of self determination.<sup>121</sup>

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<sup>119</sup> NSW Department of Health, *Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled*, March 1983

<sup>120</sup> Audit Office of NSW, Community Services Commission, *Performance Audit Report: Large residential centres for people with a disability in New South Wales* (Performance Audit 1997), June 1997, p. 6

<sup>121</sup> New South Wales Law Reform Commission, *Report 91: Review of the Disability Services Act 1993 (NSW)* (NSWLRC 1999), July 1999, p. 23

## Implementation

- 4.3** Implementation of the various government commitments to devolution has been sporadic, and has lacked a clear comprehensive strategy. Since the first commitment in the mid 1980s, people have gradually moved from large centres into the community but progress has been slow. Some large centres have been closed, including the Riverglade Centre, Collaroy Hospital and the Watagan Centre, while the population of others, such as the Stockton Centre, Peat Island and the Rydalmere Centre, has been reduced.
- 4.4** During the 1980s, plans and time-frames were established for the devolution of most government-owned centres. For example, the 1985 draft state-wide plan for developmental disability services proposed that 1476 of the 2374 people with disability living in large government centres would move to community-based accommodation by 1989/90, leaving 898 people living in large centres.<sup>122</sup> The 1988 statewide plan nominated four services for closure by June 1988, including Macquarie Hospital (the Lachlan Centre), Strathallan Centre, Riverside Centre and Collaroy Hospital.
- 4.5** It is a matter of record that these objectives were not met. In 1991 there were approximately 1900 people living in large residential centres operated by DoCS.<sup>123</sup> There are now approximately 1800 people in large government centres. The 1985 draft plan indicated that 72 people with disability lived in the Lachlan Centre (Macquarie Hospital); exactly the same number of people were living there when the Committee visited in January this year. Only two of the very large residential centres operated by the government actually closed, the most recent being Riverglade Centre in 1994.<sup>124</sup> For a number of people, therefore, the Richmond program resulted in a considerable improvement in their quality of life, but for many the program raised expectations that were never met.
- 4.6** Similarly, many medium and large residential services operated by non-government organisations continue to exist. Some non-government services have successfully moved from congregate to community models. However, many large non-government centres remain, largely because they do not have sufficient funding to implement transition to a community-based model.

## Disability Services Act 1986 (Commonwealth)

- 4.7** The Commonwealth was originally directly responsible for funding non-government services, so these services were not officially within the scope of the Richmond program. However, the Commonwealth *Disability Services Act 1986* reflected the same underlying philosophy of citizenship and community participation. Government funding for these services was originally intended to supplement other funding sources such as charitable fund-raising and has never fully covered operating costs. Following the transfer of direct responsibility for funding accommodation to the States under the 1991 Commonwealth/State Disability Agreement (CSDA), a limited amount of transition

<sup>122</sup> NSW Department of Health, *Developmental Disability Services - Draft Statewide Plan*, January 1985, p. 31

<sup>123</sup> Performance Audit 1997

<sup>124</sup> Ibid, p. 19

funding was provided by the Commonwealth to fund service improvements. There have been some excellent examples of transfer to community-based services. However it is now well accepted that the amount provided was insufficient for a widespread shift to community living. Many non-government services continue to receive funding based on historical allocations that are not sufficient to meet current running costs, let alone fund service improvements.

### **Disability Services Act 1993 (NSW)**

**4.8** In 1993 the *Disability Services Act 1993* (DSA) was passed by the New South Wales Parliament with universal support. The Act gave legislative weight to a rights-based approach to service provision for people with disability, including the exercise of full rights of citizenship and rights to live within and actively participate in the community. The primary object of the Act is to:

ensure the provision of services necessary to enable people with a disability to achieve their maximum potential as members of the community.<sup>125</sup>

**4.9** It is widely accepted that congregate accommodation models do not and cannot conform to the requirements of the Act.<sup>126</sup> The Act was intended to ensure that over a period of time all funded disability services, including congregate residential services operated by government and non-government organisations, would conform to the Act. Transfer of all people living in large residential centres into community accommodation was one of the expected outcomes.

**4.10** The DSA imposes a duty on the Minister to ensure that funding for disability services is provided in conformity with the Objects, Principles and Applications of Principles of the Act.<sup>127</sup> Following the introduction of the DSA, services were assessed for conformity with the Act. Those that did not conform were required to develop transition plans outlining how and when full conformity would be achieved. In the interim, these services were required to conform as closely as possible to the requirements of the Act.<sup>128</sup>

**4.11** The Act stipulated that conformity of all services should be achieved within three years.<sup>129</sup> In its 1999 review of the Act, the NSW Law Reform Commission (NSWLRC) noted that the 'three year period proved to be somewhat unrealistic, with many services remaining in transition today.'<sup>130</sup> Using 1998 self-assessment data provided by ADD, the NSWLRC noted that 390 out of 1005 non-government services had transition plans:

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<sup>125</sup> s3(a)

<sup>126</sup> Performance Audit 1997, NSWLRC 1999

<sup>127</sup> s6(1)

<sup>128</sup> s7(4)

<sup>129</sup> NSWLRC 1999, p. 84

<sup>130</sup> Ibid

[o]f those, 25 (7%) had been completed, 216 (56%) had commenced working towards achieving the goals in the plans, 85 (22%) were awaiting transition plan funding and the status of 57 (15%) was unknown.<sup>131</sup>

Similarly, of the 509 government services that had transition plans:

27% (5%) had been completed, 357 (71%) had commenced and 124 (24%) were waiting for transition plan funding.<sup>132</sup>

In relation to both types of service, the Commission noted that

In some cases, considerable funding is required, especially where buildings need to be reconfigured and people integrated into the community.<sup>133</sup>

- 4.12** The Committee is aware that these figures, because they relate to all types of service, rather than just accommodation in large residential services, give the impression that a sizeable proportion of large residential services have been funded for transition. However, reductions in the numbers of people living in congregate accommodation have been relatively modest, suggesting that large residential centres figure prominently amongst those that have not completed transition.

## Critical reports 1996-1999

- 4.13** From the mid 1990s increasing concern about the lack of satisfactory progress in devolving large residential centres has been reflected in a series of reports by government advisory bodies.

### Community Services Commission inquiries

- 4.14** The Community Services Commission has investigated practices in a range of large residential services operated by both government and non-government agencies. Invariably the Commission has found that the services have not met the needs of residents in a number of significant ways and has recommended that funding be provided to enable residents to move into the community. Key reports include: *Peat Island: A report to the Minister* in 1996, which examined allegations of abuse of residents and inaction to prevent sexual assault of residents; the *Lachlan Reports* in 1995 and 1998,<sup>134</sup> which examined alleged poor practices; and a series of reports into the quality of care provided by large centres that

<sup>131</sup> Ibid, p. 86

<sup>132</sup> Ibid, p. 87

<sup>133</sup> Ibid

<sup>134</sup> Community Services Commission, *Lachlan Report: exclusionary time out or solitary confinement?*, 1995; Community Services Commission, *The Lachlan Inquiry 1998: Assessment of the standard of care at the Lachlan Residential Centre and of progress since the 1995 investigation*, 1998

provide accommodation to children.<sup>135</sup> In each case, the Commission recommended that funding for transition be provided as a matter of urgency.

**4.15** Taken together, these reports have outlined structural problems in the operation of large residential centres. In particular, they have repeatedly highlighted:

- the inability of large residential centres to prevent abuse of residents, including sexual assault, by other residents or in some cases staff
- difficulties in recruitment, training and motivation of staff
- a tendency for centres to provide whole-of-life services for people with disability
- limited opportunity to access or participate in community activities, resulting in segregation of residents from the general community
- embedded resistance to change
- lack of privacy; and
- inappropriate medical and/or nutritional practices.

In some cases the reports have presented a devastating picture of the life led by people living in some large residential centres.

### **Performance Audit of Large Residential Centres**

**4.16** In response to the first *Lachlan Report*, the Minister for Disability Services commissioned a performance audit of large residential centres for people with disability in NSW. It was conducted jointly by the Audit Office of NSW and the Community Services Commission and was finalised in mid 1997. The performance audit examined practices in several government and non-government services and made the following findings:

- Institutions<sup>136</sup> are unable to meet the needs of residents and cannot provide services in *full conformity* with the Objects, Principles and Applications of Principles of the Disability Services Act, or meet the requirements of the government's Accommodation Support Policy and international human rights instruments.

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<sup>135</sup> See for example, Community Services Commission, *Suffer the Children: The Hall for Children Report*, 1997

<sup>136</sup> The Committee acknowledges that use of the term 'institution' to refer to large residential centres can be controversial and has not used the term extensively in this report. The term was used in the performance audit report.

- The failure to fund transition has further delayed the movement of residents from institutions into alternate models of care, and prevented residents from receiving community-based accommodation services.
- The absence of both funding and a deadline for the devolution of all institutions has created an uncertain future for all parties. The centres have been in a 'holding pattern' while awaiting funds to devolve. Accommodation has been allowed to deteriorate because buildings are due to be vacated and have not been refurbished. Centres have had difficulty retaining and attracting staff.
- At the time of the audit, practices in large residential centres were deficient in a number of ways including the following:
  - Continued use of restrictive practices (chemical and/or physical restraint) to manage challenging behaviour.
  - An inability to address challenging behaviours resulting in risk of assault to residents and others.
  - Inadequate response to incidents of aggression, leading to resident injury. The risk of injury was increased by features of institutional living such as poor staff to resident ratios, the mix of residents, the number of residents in a service and the configuration of the accommodation. Across all centres, the largest category of reported injury resulted from resident-to-resident aggression, or self-injurious behaviour.
  - Inadequate control of medication, including the prescription of psychotropic medication in the absence of other strategies such as behaviour intervention.
  - Problems managing the nutrition, health and hygiene of residents.
  - Limited opportunities for residents to participate in community activities, with most of their time spent in the grounds. Access to family and friends was not supported and the institutional atmosphere discouraged visits and extended contact.
  - Lack of privacy and systems to promote resident dignity. Residents were rarely able to have personal property due to the risk of theft or damage. Most residents chose to leave their possessions in the family home or did not have any personal possessions. Resident dignity was compromised by lack of control over their day-to-day life (such as what to eat, what to watch on TV, who to live with, what training and education to undertake), limited freedom of movement in some units, and poor practices in relation to the management of sexuality and allegations of sexual assault.
  - Limited opportunities for skill development.
  - Poor safety practices, particularly in relation to fire safety.
  - Under-developed systems for handling concerns or complaints.<sup>137</sup>

**4.17** Apart from specific policies and practices in the centres, the audit found that a range of factors contributed to the unsatisfactory state of large residential centres, as follows:

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<sup>137</sup> Performance Audit 1997, pp. 25-47

- *Recruitment and staff development* – Overall, staffing arrangements were designed to provide basic supervision to large groups of people rather than individual support. The audit found that there was wide variation in staffing ratios across the centres and differences in the type of staff employed within centres. Industrial arrangements in government centres were found to bear little relationship to the needs of residents. Government centres were only able to employ nursing staff, who did not necessarily possess all the core competencies required to work with people with disability. Timing of resident activities was linked to shift arrangements rather than resident needs, and excessive costs resulted from overtime, penalties and allowances related to the nurses award. While noting that some residents needed medical care, the audit revealed that large government centres needed the flexibility to determine the mix of skills and backgrounds to best meet the individual needs of residents.

Non-government centres were found to face significant difficulties recruiting staff. Staff were often employed without any experience in disability and received limited formal training or induction. Some centres experienced high staff turnover resulting in employment of inexperienced workers and consequent poor practices and risk to resident safety. The Committee also notes that staff employed in non-government centres receive lower pay and less generous conditions of employment.

- *Resources* – Funding for both government and non-government centres was found to be based on past allocations to the centres and bore no relationship to the current needs of residents, resulting in inequities and inadequate services.
- *Physical Condition* – The audit found that large residential centres have become run down with ‘a consequent impact on resident safety’. In general the buildings were old, poorly laid out and in need of substantial maintenance. The expectation that residents would soon transfer to community-based accommodation has made maintenance a low priority.<sup>138</sup>

**4.18** The report acknowledged that practices in large residential centres could be improved, leading to a better quality of life for residents, but noted that there are factors inherent to large residential centres that are difficult to remedy:

These include the whole of life, umbrella approach to the delivery of services, the custodial and impersonal nature of care, the segregation of institutions from the community, the inability of institutions to adequately address the physical, emotional, social and skill development needs of residents.

These features mean that even if centres met the requirements of basic safety and rights, institutions could never meet the individual needs of people with a disability or provide the quality of life envisaged by the Disability Services Act 1993.<sup>139</sup>

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<sup>138</sup> Performance Audit 1997, pp. 16-74

<sup>139</sup> Ibid, p. ix

**4.19** In conclusion, the report made key recommendations along the following lines:

- The government fund the transition of large government and non-government residential centres for people with an intellectual disability to enable service to be provided in *full conformity* with the ... *Disability Services Act 1993*,
- A target date of seven years from the date of the report be considered for complete transition of all centres.
- An implementation timetable should be prepared to diminish the effect of uncertainty that currently exists and allow centres to properly plan service delivery up to and following movement to the community.
- As a priority, the government should consider the movement of children under the age of 18 years to community-based settings that match individual need.
- The government consider a policy to ensure that no more people are placed into these (non-conforming) institutions (government and non-government centres), even on a respite or crisis basis.<sup>140</sup>

**4.20** Recognising that the transition process would take considerable time, the audit recommended a range of immediate service improvements for current residents, including:

- improved monitoring of services,
- reducing congregation by limiting the size of resident groups and promoting alternative accommodation models within existing facilities,
- providing better opportunities for skill development as well as for off-site activities, and
- developing better funding models for government and non-government centres to ensure equitable and rational funding according to the actual assessed needs of residents.<sup>141</sup>

### **Law Reform Commission review of the Disability Services Act**

**4.21** In 1999, in its review of the DSA, the NSW Law Reform Commission re-iterated concerns raised by other bodies regarding the continued failure to implement the policy of devolution. Noting that the 'objectives of the DSA will only be effective if sufficient funds

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<sup>140</sup> Ibid, pp. xi-xii

<sup>141</sup> Ibid, p. xii

are made available to implement them'<sup>142</sup> the NSWLRC drew attention to the inherent inefficiency of the transition planning process:

Lack of transition funding has led to inefficiency because services are required to prepare transition plans which they do not have the resources to implement. The plans consequently become out of date, leaving the service and its users in an uncertain position.<sup>143</sup>

**4.22** These observations are consistent with views expressed during the Committee's consultations. The Committee understands that considerable resources were devoted at various times to the preparation and assessment of transition plans for large residential services. However, resources were not made available for their implementation. The Committee has been informed that many of these plans, which officially remain in force, are now out of date and would need considerable revision before they could be acted upon.

**4.23** During consultations, a number of people noted that the process of transition planning had raised expectation that funding would be provided to allow transition to community-based living. Transition planning also raised concerns among some people who did not support a shift from congregate to community-based accommodation. The subsequent failure to implement many transition plans has led to great disappointment for those who expected to move and continuing apprehension for those opposed to transition. This has contributed to a climate of continuing doubt and suspicion about the long-term future for people live in large residential centres, low staff morale, difficulties in recruiting and retaining staff and general neglect of the physical and human infrastructure of large residential services.

### **The Committee's view**

**4.24** The Committee has visited a range of centres around the State and spoken at length to residents, staff, relatives and advocates. The Committee has also taken substantial evidence on the importance of devolution from departments and peak bodies. The bulk of the evidence is consistent with other findings about the need to finalise devolution. Early this year, the Committee heard the following evidence about conditions in one large residential centre:

Without a doubt, the paid advocates have been utterly shocked, angered and appalled at the conditions that they see living in the Western Sydney Developmental Disability Service. The more they get to know people's lives, the more they see the absolute degradation of just living in a situation where people do nothing, day in and day out. I will read from one of the advocate's notes. "The occupational services room is a rather bare place. Apart from a few tables and chairs, there is nothing. One resident was lying on the floor and another was walking around the empty outside courtyard. [The resident she was supporting] walked around and around and around, occasionally picking up the one and only toy in the room which she would throw onto the floor. Occasionally the resident

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<sup>142</sup> NSWLRC 1999, p. 13

<sup>143</sup> Ibid p. 89

from the courtyard came into the room and knocked over a chair and then walked out. After 30 to 40 minutes of nothingness, I said goodbye to him.”<sup>144</sup>

- 4.25** The Committee endorses the views of the Community Services Commission that the institutional form of care provided by large residential centres for people with disability is no longer appropriate or necessary:

We have seen in our models of care an increasing isolation of many of those people with disabilities, particularly in relation to those within institutional care. We have created a model where we have removed all the normal community support and replaced that by a professional layer of support in an isolated institutional environment...

This is not what people with disabilities either require or have a right to and yet within the system, with more than around 50 per cent of people still in institutional care, that continued isolation exists.<sup>145</sup>

- 4.26** Apart from the scarcity of developmental opportunities available to residents, the nature of congregate accommodation is such that the privacy, dignity and physical safety of residents cannot be assured. There is consequently a need for immediate, clear and unambiguous commitment to the devolution of large residential centres for people with disability.

## Renewed commitments to devolution

### Service improvements

- 4.27** The Committee is aware that considerable improvements have been made to the large residential services since the performance audit in 1997. In particular, a program of extensive refurbishment has commenced in large government centres. Dormitories have been broken up into smaller units that provide residents with their own rooms, giving them much-needed privacy and the opportunity to have their own possessions.
- 4.28** Government and non-government services have also acted to improve resident privacy and dignity using existing resources. Examples include moving people into existing houses in the grounds of large centres and providing support along the lines of group home accommodation. Action has been taken to improve people’s quality of life through a range of other measures, such as increased community access and more readily available therapy services.
- 4.29** These steps have led to demonstrable improvements in residents’ quality of life. As one witness stated:

Instead of being housed in dormitory-style accommodation, they have gone into units. Where my son is, there are already six boys. It is as attractive as possible taking into account it is an old building that needs upgrading. They have attractive

<sup>144</sup> Stelc evidence, Western Sydney Intellectual Disability Support Group, 10 February 2000

<sup>145</sup> Fitzgerald evidence, Commissioner for Community Services, 22 February 2000

surroundings, attractive furniture and they have their own things around them... They have more outings now than before. They are taken to a pub for a counter lunch and there are all sorts of things that improve the quality of their lives. There are minibuses that they take them out in, and all around the improvement has been tremendous.<sup>146</sup>

**4.30** In large government centres, refurbishment has helped to reduce the difficulties of centres in attracting and motivating staff. The Committee was told that:

it is a huge improvement to what existed prior to us being able to get some funds for this and it has in some instances regenerated the commitment and involvement of the staff because they can see something happening for the clients.<sup>147</sup>

**4.31** The Committee welcomes these interim moves, and welcomes any moves to improve the quality of life for people living in large residential centres. These initiatives are consistent with the recommendations of expert bodies and have the potential to assist staff and residents to gain skills that support a shift to community living. Nevertheless, the program of refurbishment in large government centres has generated controversy because it has not taken place in the context of proper planning for medium or long-term devolution of the centres. There is also a perception that refurbishment has involved expenditure of funds that might have helped support a shift to community accommodation. As the Commissioner for Community Services has noted:

if it is the situation that a number of the large campus-based or large institutions are not to close for a period of time, then it is absolutely appropriate that we take steps to improve the quality of care, including the live-in accommodation arrangements.

The Commission is not opposed to the changes that are taking place in the large institutions, provided that we could be sure that this is part of a well thought through, longer term strategy where, ultimately, those facilities move off site.<sup>148</sup>

In the absence of a clear long-term devolution strategy, the refurbishment of services can give the impression that some or all of the large residential centres are to be retained as long-term accommodation for people with disability. The Committee notes that this impression, whether correct or not, has raised significant and legitimate concerns.

### **Recent announcements**

**4.32** In October 1998, the government made a commitment to devolve all remaining large residential centres within 12 years, with priority being given to children. To date detailed plans have not been released. As part of the 2000/2001 Budget, funding was announced to support movement to the community of approximately 400 people living in large centres

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<sup>146</sup> Consultation with friends of residents at Stockton Centre, 4 July 2000

<sup>147</sup> O'Reilly evidence, Department of Community Services, 22 February 2000

<sup>148</sup> Fitzgerald evidence, Commissioner for Community Services, 22 February 2000

by 2003. The process for transfer to community living has now commenced in a number of centres. The Committee has been advised that 11 services have been selected for the first stage of the devolution project: Gower Street, Marsden Rehabilitation Centre, York Road, Strathallen, Wenona, Cram House, Greystanes, Whitehall, Mannix and Jennings Lodge. Eighty-seven of the 400 people are children.<sup>149</sup> The Committee has also been informed that a program of 'incremental' devolution has commenced in some other large centres.

- 4.33** To date, no residents of these centres have moved into the community. However, time-frames have been established for several of these centres for people to begin to move early in 2001. The Committee was advised that these time-frames were established following consultation with residents and families. The department has assured the Committee that by June 2001 the transition process for the services will be well advanced, with substantial movement to the community having taken place.<sup>150</sup>

## Concerns of residents and families

### Family opposition to devolution

- 4.34** Families of residents at several centres visited by the Committee expressed strong opposition to devolution. Their concerns illustrate problems with past devolution processes and point out potential pitfalls to avoid in current processes. Opposition to devolution stems from a lack of clarity about the current devolution program, restricted information flows, past disappointments and the continuing insecurity about the stalled transition process. Above all, families were concerned to ensure that their family member with disability received the best possible care and that any changes to the type or location of service would not reduce the quality of care. The Committee considers that these concerns must be addressed to ensure that the current devolution program succeeds.
- 4.35** The Committee notes that not all families are opposed to devolution. The Committee has heard evidence that there are many families who are:

fearful, angry and desperate for their sons and daughters because of the conditions of life that those people have witnessed their sons and daughters living in institutions year after year after year. For example...“My son has been institutionalised for 26 years...in this environment, he has no opportunity, let alone equal opportunity, no training, no expectation – because he was not considered high functioning enough – and no quality of life.” None of those situations is going to change because he now has his own bedroom. That nothingness, the nil expectations, that poor and abusive quality of life which he actually experiences will still go on, even though now he does not sleep with four men in the same room and he has his own bedroom.”<sup>151</sup>

<sup>149</sup> Ageing and Disability Department briefing, 20 November 2000

<sup>150</sup> Ibid

<sup>151</sup> Stelc evidence, Western Sydney Intellectual Disability Support Group, 10 February 2000

**4.36** There are also many people in large residential centres who do not have any family or who have very limited family contact. It would be inappropriate for these people to be denied the opportunity to live in the community on the basis of opposition from families of other residents.

**4.37** The Committee believes that the concerns raised by families opposed to devolution do not constitute sufficient reason to retain the existing large residential centres. Research on devolution demonstrates that community living not only creates better outcomes for residents, but usually produces increased family satisfaction once the process has been completed.<sup>152</sup> This is consistent with the Committee's consultations with family members of people who have already moved into the community:

I believe personally that people who have intellectual disabilities who live in our large residential centres on the whole should be given the opportunity to have a different life in the community. In our case, our son's life has been very enriched as a result of living in a group home and so we are very satisfied with that service and we are happy for him. He is happy and contented. At the time, a lot of people thought that he would not make it in the community so I understand the fears that families have in regard to transferring their loved ones.<sup>153</sup>

**4.38** The genuine and serious concerns of families indicate the great importance of a carefully thought-out devolution strategy, since unless these concerns are properly addressed, it is likely that the devolution program will falter. The importance of satisfying family concerns was demonstrated during the Committee's examination of the decision to seek expressions of interest for DoCS group homes in part one of this inquiry.

### **Life-long guarantee of care**

**4.39** The most important issue for residents, families and advocates is ensuring people with disability receive an on-going guarantee of service, that is, that they will continue to receive continuous and sufficient support for the rest of their lives. Given the extremely high level of unmet need for accommodation, people are concerned that changes to service provision will result in a lessening of support, and once that support is lessened there will be no going back. Any change to the way that a service operates must be accompanied by explicit and genuine guarantees of service.

**4.40** During consultations, families expressed concerns that insufficient support will be provided in the community:

...put yourself in a parent's position, as we have been put through hell in the past five years. One moment our children are secure and the next moment we are told they are to go into the community. We are not happy with the cottage situation and have seen retarded people neglected when they are put in cottages. Some

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<sup>152</sup> See for example, Griffin & Dew, *Evaluation of the closure of the Hall for Children*, Interim Report, Centre for Developmental Disability Studies, November 1999; Stancliffe, *Watagan Project Evaluation*, Draft Report, Centre for Developmental Disability Studies, August 1997; Griffin & Dew, *ADD Transition Project*, Centre for Developmental Disability Studies

<sup>153</sup> Consultation with friends of residents at Stockton Centre, 4 July 2000

seem to work but even they are not satisfactory. For as soon as possible the staffing is reduced and then unqualified staff come in and then part time staff. The Government would like to see the back of retarded persons. Politically they mean trouble... As parents we would like to see this situation here continue and to be told by the government that our son can stay here we would have peace of mind. It is close to our homes which at our age, I am nearly 80, we are all getting on.<sup>154</sup>

People walk out and they say they cannot afford to look after the cottage as it should be looked after. What happens then? We have changes of government. Will the next government do the same with our kids as the previous government? Do we know all this?<sup>155</sup>

The possibility that their son or daughter will not receive sufficient support is particularly worrying for older parents. Many parents have also expressed anxiety that their son or daughter will not be able to access alternative supports in the event that their initial placement fails.

**4.41** These concerns partly result from a perception that the Richmond program was little more than a cost-saving measure that resulted in withdrawal of services for people with disability. This perception is incorrect. Follow-up research of former residents of large centres in NSW has clearly demonstrated that people continue to receive sufficient support in community-based accommodation and have gained significant improvements to their quality of life.<sup>156</sup> The concerns also reflect an awareness of unmet need for accommodation, and a belief that government is not actively and systematically working to address this problem.

**4.42** In 1995, the government gave a guarantee of lifetime care to all permanent residents of government-operated large residential services. The then Minister for Community Services, the Hon. Ron Dyer MLC, announced:

Let me be absolutely clear about this: I guarantee that when the large residential centres are closed down over the next several years we will not desert our responsibility to provide on-going care and support to clients.<sup>157</sup>

The current Minister, the Hon Faye Lo Po' MP, has confirmed that this guarantee is still in place.

**4.43** The performance audit of large residential centres noted, however, that no such guarantee has been given in respect of residents of non-government services.<sup>158</sup> Given the level of concern expressed by families, the Committee considers it important that a clear lifetime

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<sup>154</sup> Consultation with families of residents of Peat Island meeting, 4 July 2000

<sup>155</sup> Consultation with friends of residents at Stockton Centre, 4 July 2000

<sup>156</sup> Griffin & Dew, op.cit, November 1999.; Stancliffe, op.cit, August 1997

<sup>157</sup> The Hon R. D. Dyer MLC, Hansard 21 November 1995. See Chapter 7 of the *Group Homes Proposal* for further discussion of the guarantee.

<sup>158</sup> Performance Audit 1997, p. viii

guarantee of residential care for all people who move out of large residential centres into community accommodation should be provided. This guarantee should ensure that people will receive support that is appropriate to their needs and is provided in accordance with the Objects, Principles and Applications of Principles of the Disability Services Act. There should be no distinction between government and non-government service providers.

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### **Recommendation 13**

The government should provide all residents who transfer from large government and non-government residential services to community-based accommodation with an unconditional life-time guarantee of service that conforms with the Objects, Principles and Applications of Principles of the *Disability Services Act 1993*.

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- 4.44** The Committee understands that some younger people living in large centres will be able to return to the family home, with intensive family support. This is a highly desirable outcome for many younger families, but in some circumstances these families may not be able to provide long-term care to children who have returned home. The guarantee should therefore ensure that fully supported out-of-home accommodation will be provided if living arrangements break down.
- 4.45** More generally, there is a need for the guarantee to explicitly acknowledge that support needs for some people will increase over time, and that additional support will be provided as needs increase.
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### **Recommendation 14**

The guarantee to all residents transferring from large residential services should explicitly acknowledge that appropriate levels of support will be provided as support needs of people with disability increase, including those of younger people who initially returned to the family home.

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### **Medical needs**

- 4.46** Many people with disability living in large centres have medical needs that require continuing professional management. For this reason, some people favour the medical model of care for people with disability who have high medical needs. The availability of trained nursing staff in government centres is therefore seen as particularly beneficial. While the Committee does not agree that medical imperatives should override social, developmental and other needs, it is important to ensure that people's medical needs are fully met in a community setting. As the Commissioner for Community Services noted:

There is an absolute role for medical specialist care and nursing care for many people with disabilities. It does not have to be delivered for most in an institutional environment.

We now have examples from every State, including our own State, to show that high-medical-support-need people can be provided with good quality service not in an institutional setting.<sup>159</sup>

- 4.47** Many residents of community-based services have high medical needs that are met appropriately in the community setting. As one staff member from a large residential service for children told the Committee:

I have been in group homes here. There is one for those who are medically frail. The parents say that their children have thrived, I guess, because they are getting more interaction. Some of the kids that are gag fed, they buy McDonald's and blend it and the kids love it.<sup>160</sup>

- 4.48** As noted below, there will be a continued need for people with nursing skills and qualifications to work in disability services in order to properly support people. Where people have specific medical needs, staffing arrangements will need to be structured to ensure that professional nursing support continues to be available.

- 4.49** In addition to nursing support, many people are likely to require access to doctors, dentists and a range of therapy services to meet their medical needs. Provided appropriate funding is available for such services, it is possible that they may be more readily accessible in the community.

- 4.50** The Committee considers that the lifetime guarantee of care referred to in Recommendation 13 should include a guarantee that people will receive appropriate medical care and therapy to meet their needs.

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### **Recommendation 15**

The guarantee of lifetime care referred to in Recommendation 13 should include an explicit commitment that people will receive appropriate medical and therapy services to meet their needs.

### **Recommendation 16**

The funding packages for people who move to community-based services should include a component for medical and therapy services appropriate to their needs.

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## **Consultation and information exchange**

- 4.51** Thorough consultation, careful preparation and provision of clear information are essential elements of any strategy to devolve large residential centres. A lack of clarity about what is proposed for particular services heightens concerns about security. Family members who

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<sup>159</sup> Fitzgerald evidence, Commissioner for Community Services, 22 February 2000

<sup>160</sup> Public consultation, Wollongong, 11 May 2000

spoke to the Committee indicated that they were uncertain about the devolution processes and unsure exactly what was proposed for their service:

It is not knowing. If somebody can come in and say, "This is going to happen. You have chosen this, it will happen on this day", it would make it much easier, but nobody can do that.

Nobody has ever come and said, "This is what we envisage for 'Bob'." This is very intimidating for parents, especially as they get older. We do not know what the future holds for them.<sup>161</sup>

**4.52** Evidence to the Committee regarding past devolution processes has emphasised the importance of properly resourced consultation processes that actively engage residents and families in the project. In evidence, officers of ADD responsible for the devolution project outlined the department's commitment to empowering residents and families in the process:

a site officer from ADD meets every family to actually work through the process, to talk with them about the implications of it, to talk to them about what their plans are for the future, plans for their relative and then comes back to a group meeting at which the group decides on the time-frames for the relocation of that particular centre. So that is done collaboratively ... and the families and residents themselves, where possible, have actually had a part in the decision making around the time-frame.<sup>162</sup>

**4.53** This commitment to consultation and openness should provide the basis for a successful outcome. However, the Committee has reservations about whether the department has sufficient resources, in terms of personnel, to carry out sufficient consultation. As the department has noted, consultation with residents and family is a time-consuming process that does not allow for short-cuts. The adequacy of departmental resources is dealt with below.

### **Advocacy**

**4.54** A number of relatives raised with the Committee the issue of advocacy for people who do not have family support. The Committee believes that this is a particularly significant issue given that many people who live in large centres, and who have little or no family contact, have not lived in the community for a long time. They have very little experience on which to make choices about where they will live. Lack of information about choices is particularly difficult for residents who have family or staff who oppose moves to community living:

if people will be there who can help the family, help the person with the disability, to work through the issues until their particular issues and their concerns are

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<sup>161</sup> Consultation with families of residents of Cram House, 11 May 2000

<sup>162</sup> Riddiford, Ageing and Disability Department briefing, 20 November 2000

solved for them, in moving forward for their son or daughter. That is the kind of support that is not always clearly there, to enable people to move forward.<sup>163</sup>

- 4.55** The Committee's first report on disability services, *The Group Homes Proposal*,<sup>164</sup> highlighted the importance of effective and well-resourced independent advocacy support for residents when changes to living arrangements are proposed. Such advocacy support has a significant role when residents and families express different views about how and where they would like to live. The Committee notes that lack of such support to ensure that residents are able to effectively participate in the devolution process could result in funding decisions being made that are not in accordance with the Disability Services Act.
- 4.56** To support resident involvement in the decision-making process, there is a need to provide clear and accessible information. The Committee considers that ADD should develop and implement a communication strategy as soon as possible to ensure that residents have a clear understanding of the devolution process. This strategy should be developed in consultation with people with disability. As part of the communication strategy, ADD should develop and distribute to all residents of large centres a clear and comprehensive plain English information package that outlines the devolution project.

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### **Recommendation 17**

The Ageing and Disability Department should ensure that all residents of large residential centres who do not have advocates are provided with independent advocacy support as part of the devolution process, and that adequate funding for advocacy support is provided.

### **Recommendation 18**

In consultation with people with disability, the Ageing and Disability Department should develop a communication strategy to ensure that residents have a clear understanding of the devolution project. The communication strategy should include provision of plain English information about the devolution project.

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## **Maintenance of social relationships**

- 4.57** Long-term residents of large centres are likely to have developed close social relationships with other residents and with staff. During consultations with the Committee, families and staff expressed concern that movement to the community would destroy these networks, resulting in social isolation of former residents of large centres. The Committee is also aware, however, that people in large centres often live with people who they would prefer not to live with. At times, such incompatibility results in assault and injury.

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<sup>163</sup> Epstein-Frisch briefing, Disability Safeguards Coalition, June 2000

<sup>164</sup> Standing Committee on Social Issues, *Report 19: The Group Homes Proposal – Inquiry into residential and support services for people with disability, First Report*, NSW Legislative Council, December 1999

- 4.58** Resident compatibility and maintenance of appropriate social relationships are vital issues in accommodation for people with disability. Research on past devolution processes has suggested that careful attention needs to be given to the compatibility of residents. Similarly, the research has shown that some people who move to community settings miss former social contact with both staff and residents.<sup>165</sup> Past devolution processes have not always taken these factors into account with the result that some placements have not succeeded. The Committee considers that specific steps should be taken to ensure that placement decisions consider compatibility and maintenance of existing social networks as major factors contributing to successful placements.

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**Recommendation 19**

Specific steps should be taken to ensure that existing beneficial social networks are maintained for residents of large centres who move to the community.

**Recommendation 20**

Clear evaluation of resident compatibility should take place prior to transfer to community-based settings.

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**Staff concerns**

- 4.59** The Committee was impressed by the dedication of staff who spoke to the Committee during visits to large centres. Within the constraints of large settings and limited funding, staff clearly do their best to provide the best possible environment for people in the centres. Many of the improvements in recent years have been initiated by staff.
- 4.60** Like families, staff were concerned about the future of current residents and worried that a shift to the community would lead to reduction or withdrawal of support. Staff expressed concern that their existing knowledge of resident needs and their friendship with residents would be lost following transfer to the community. Nursing staff from some government centres were particularly concerned that residents would receive insufficient medical care in community-based settings. Staff were also quite legitimately anxious about their job security.
- 4.61** Existing staff bear a clear responsibility to ensure that the devolution process succeeds. The Committee has been informed that the staff of large residential centres should be an integral part of the transition process:

Particularly I think with Richmond the problems or the views of the unions and the employees within the system, which should have been taken on board and were not taken on board, and subsequently in our view certainly were part of the reason why the process did not in fact work very well.<sup>166</sup>

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<sup>165</sup> See for example, Stancliffe R, *Watagan Project Evaluation*, Draft Report, Centre for Developmental Disability Studies, August 1997

<sup>166</sup> Moore Council of Social Services of NSW briefing, 1 June 2000

**4.62** Staff need to support the process and help prepare residents so that they can respond positively to change. The existing skills of staff should be recognised and harnessed so as to assist residents to prepare for transition and to minimise disruption. Devolution provides an opportunity for staff to contribute to a process that will result in considerable improvements in the quality of life of people whom they currently support. Through this process, staff should be able to gain new skills and develop new ways of working with people. The Committee acknowledges that some staff may need to develop a different philosophical approach to their work so as to properly support people in the community.

**4.63** A strategy needs to be developed to support and assist current staff of large residential centres during the transition process. This strategy should clearly address concerns about security of employment. The Committee expects that most current staff will be able to continue working in the sector if they choose to do so, even if they do not remain with their current employer. Community-based services will need to be developed to support people moving from large centres and these service will need experienced staff. ADD has advised the Committee that:

We have a key objective that we do not want to lose those skills from the service system. ... [T]he people who have been working in large residential centres we see as a very core skills component in the disability system and ... we do not want to lose those skills.<sup>167</sup>

**4.64** The Committee supports this emphasis on retaining people with valuable knowledge and experience within the sector. From the outset staff should receive reassurance about continuity of employment. Where they are not able to remain with their current employer, processes should be established to help staff find placements in other services. Many staff will need additional training to develop new skills, philosophy and approaches required to support people in the community, so the strategy should provide for proper resources to support staff training. The strategy should also set out the responsibilities of staff to support the transition process.

### **Retaining nursing expertise**

**4.65** As already noted, adequate support needs to be maintained for people with high medical needs. The Committee believes that nursing skills will continue to be required within the far broader range of skills needed to support people with disability moving into the community. The Committee is aware that trained nurses currently work as residential care workers in community-based services and use their nursing skills to help people with specific medical needs. However, nursing staff of large centres have indicated that such arrangements do not provide appropriate recognition of nursing skills. The Committee is also aware that there is currently no training available for nurses that leads to a speciality in disability. The lack of specialist training has led to staff shortages in those large centres that, due to industrial arrangements, are not permitted to employ non-nursing staff in direct care positions. The lack of specialist nursing training is also indicative of a lack of on-

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<sup>167</sup> Riddiford Ageing and Disability Department briefing, 20 November 2000

going training, which has contributed to poor morale amongst nursing staff and a belief that they are being de-skilled in their current positions.<sup>168</sup>

- 4.66** There is clear merit in employing trained nurses to provide community-based medical support to people with disability. It may be appropriate for DoCS to continue to employ nurses following the closure of large centres, in order to provide community-based nursing support to people in both government and non-government services. As part of the devolution project, nursing staff in large centres should therefore receive support and training.

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### **Recommendation 21**

The Ageing and Disability Department should develop a staff strategy for devolution of large residential services to ensure that existing skills and knowledge are used and retained during the devolution process. The strategy should:

- make provision for continuity of employment of existing staff
  - ensure that adequate resources are provided for staff training
  - outline the obligations of existing staff to support and participate in the success of the devolution program
  - enable the development of new skills, philosophy and approaches necessary to support people in the community.
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### **Broadening the mix of skills in DoCS centres**

- 4.67** The Committee believes that recruitment and staffing practices in large DoCS centres should account for future transfer to the community. It is appropriate that people with skills and experience now working in community-based services should be able to work within the large centres so that knowledge and skills can be exchanged. This point was raised by a recent review of nursing in DoCS centres.<sup>169</sup>

- 4.68** The review also noted that a number of DoCS centres experience difficulties recruiting nursing staff, with the result that the centres are understaffed. The Committee is aware that in some centres it has been routine for nursing staff to work double shifts, or for staff to be brought in from hospitals to work additional shifts. Apart from the occupational health and safety risks to staff, such practices are unlikely to contribute to quality care for residents. The Committee is also aware that as recently as this year, staff in some centres

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<sup>168</sup> Department of Community Services, *Nursing Review in Residential Centres: Draft Final Report for Consultation*, October-December 1999

<sup>169</sup> Department of Community Services, *Nursing Review in Residential Centres: Draft Final Report for Consultation*, October-December 1999

wore nursing uniforms. At one centre visited by the Committee, some staff still referred to residents as patients.

- 4.69** In view of current staff shortages and the need to ensure that the centres are working towards a community-based model of care, it would be appropriate to employ residential care workers to fill vacancies. While this could pose difficulties under current arrangements, it is important that industrial agreements advance the interests and developmental opportunities of both residents and staff. Clearly, such arrangements should not be structured so as to impede the interests of residents.

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### **Recommendation 22**

The Department of Community Services, in conjunction with the relevant unions, should examine the staffing mix of large centres with a view to filling vacancies with appropriately qualified people and ensuring that staff can support the devolution process.

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## **Cost-effective service delivery**

### **Cost-effectiveness – government centres**

- 4.70** Although large centres do not provide appropriate accommodation for people with disability, some people argue that by comparison with community-based models such as group homes, large centres are a cost-effective form of supported accommodation. It is suggested that the centres can support a greater number of people for a given amount of funding than other models.
- 4.71** In relation to government services, available data does not support this view. Financial information provided to the Committee suggests that economies of scale are not achieved through congregate accommodation. In February 2000, DoCS provided the Committee with the following comparative cost projections:

#### **Projected annual recurrent expenditure per resident of DoCS services 1999/2000– large residential services and group homes<sup>170</sup>**

<b>Location</b>	<b>Large residential service</b>	<b>Group home</b>
Hunter Region	\$78,927	\$85,733
Western Sydney	\$84,571	\$85,733

- 4.72** Recurrent expenditure per resident for large government centres is only slightly lower than expenditure for group homes. This is despite the fact that direct care staffing ratios are considerably lower in large residential centres than in departmental group homes. Staff in all centres visited by the Committee noted that insufficient staffing was one of the primary

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<sup>170</sup> O'Reilly, Department of Community Services evidence, 22 February 2000.

reasons that they were unable to better provide for the needs of residents, for example through provision of meaningful daytime activity, more individualised support and frequent community access.

**4.73** The Committee is aware that direct cost comparisons between large residential centres and community-based services can be misleading because they do not take into account the different support needs of residents. It has been argued that residents of large residential centres have higher support needs than residents of DoCS group homes and that they would need higher and more costly levels of support in a community setting. However, accurate data on the support needs of residents in large residential centres and group homes is currently not available, making comparisons between the service types difficult. The Committee is aware that there are a large number of people in DoCS group homes who have high support needs. Similarly, staff of a number of large residential centres visited by the Committee stated that a proportion of residents did not have high support needs and remain in the centres largely as a result of historical accident.

**4.74** Apart from staffing costs, large residential centres also incur significant fixed running costs related to factors such as the size and age of the buildings.

**4.75** The Committee considers that residents can be moved from congregate services run by DoCS to community-based services that provide a similar or better level of support without significant cost increases. Recurrent support costs may increase, but not to a great extent, and these increases could be offset by proceeds of asset realisation (see below).

#### **Cost-effectiveness – non-government centres**

**4.76** Very different considerations apply in relation to large non-government centres. As noted at the beginning of this chapter, funding allocations to these centres do not cover running costs and are based on historical allocations. Non-government centres are funded at a considerably lower level than government centres. For example in 1997/98, large non-government centres received on average \$27,388 per resident while government centres received \$72,927. During the same period, community-based non-government accommodation services received \$33,767 in funding per person.<sup>171</sup> While non-government services have their own fund-raising activities, the low levels of funding available to large non-government centres means that residents receive demonstrably lower levels of service than people in community accommodation. The Committee is aware that current funding levels do not provide a sufficient basis for transition to community living. Submissions and confidential communications from the management of large non-government centres acknowledge the need to move to community-based models, but indicate that this is hampered by a lack of resources.

**4.77** It is likely, therefore, that devolution of large non-government centres will result in increased expenditure by government. This is appropriate given that large non-government centres are generally substantially under-resourced, and in many cases unable to provide appropriate or adequate care for residents.

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<sup>171</sup> Ageing and Disability Department, *Annual Report, 1998/99*, pp. 24-25

### **Linking costs to outcomes**

- 4.78** The Performance Audit in 1997 noted that funding for both government and non-government services is not linked to outcomes expressed in terms of quality of service for residents. Cost-effectiveness of services can only be measured by reference to defined outcomes: that is, quality of services must be taken into account when considering whether one model of service delivery is more economical than another. Monitoring systems for both large centres and community-based services currently do not do this.<sup>172</sup>
- 4.79** The Committee considers that if the relative efficiency of large centres and community-based services was measured by reference to clear performance indicators – such as level of compliance with specific Objects, Principle of Applications of Principles, of the Disability Services Act – then large centres would be demonstrably less efficient than community-based services.

## **Planning and implementation**

### **Need for strategic planning**

- 4.80** Previous chapters have highlighted the need for planning in relation to permanent accommodation and respite services. Similarly, there is a need for a comprehensive plan for devolution of all large services. The Committee is aware that the current devolution process has only just commenced. However, feedback from the disability sector indicates that there is some confusion and concern about how the process is unfolding. These concerns can be allayed by the presentation of a clear statement that outlines the overall strategy for complete devolution of large centres.
- 4.81** To date, the Committee has not seen a formal planning statement. However, ADD has advised the Committee that devolution is currently in its first phase, focussing on the 11 centres identified in paragraph 4.32. Features of the current process include:
- consultation with and empowerment of residents and families regarding options and time-frames for transition to the community for each centre
  - discussion of a range of flexible support options for current residents, rather than a focus on specific accommodation models such as group homes
  - a clear commitment to retaining skilled staff
  - avoidance of high-profile announcements regarding specific centres or the devolution project as a whole, on the grounds that such announcements have previously created excessive anxiety

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<sup>172</sup> Performance Audit 2000

- building the infrastructure and capacity of the whole disability services system so that services are in place to support the devolution program.<sup>173</sup>

The Committee was informed that the inherent flexibility of this process means that it is difficult to outline a clear and detailed plan for devolution of large residential centres.

**4.82** The Committee appreciates that there are complexities in developing an overall plan for devolving large residential services. Nevertheless, the disadvantages of proceeding without a clear and public strategic framework are significant. Successive governments have been committed to devolution for a substantial period, but have failed to meet expectations and anxiety about the future is entrenched in large residential centres. This contributes to poor morale and opposition to change. General anxiety is heightened in circumstances where people are aware that devolution has commenced in other centres, but have received no information about what is proposed for their own centre. A clear message that has emerged from consultations with families and staff of the large centres is that the future of all large centres needs to be clearly resolved, whatever the outcome might eventually be. The Committee therefore believes that an overall plan for devolution of large residential centres should be developed urgently in consultation with relevant interest groups including residents, families, staff and peak bodies, and be made public.

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### **Recommendation 23**

The Ageing and Disability Department should, in consultation with relevant interest groups, develop an overall strategic plan for devolution of large residential centres for people with disability. This plan should be made public.

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### **Time-frame**

**4.83** The 12-year time-frame announced in 1998 would mean that all people living in large centres would move to the community by 2010. During this inquiry, the time-frame has been criticised as being too long. It has been argued that some people have now been waiting for 15 years, and further delay would mean a wait of a quarter of a century before some people actually moved to the community. As an alternative it has been suggested by peak bodies that the seven-year time-frame recommended by the performance audit in 1997 should be adhered to, with the result that complete transition would be finalised by 2004.

**4.84** The Committee is aware that attempts to drive the devolution process too rapidly can be counter-productive. The original time-frame established under the Richmond program, and then the three-year time-frame outlined in the Disability Services Act, were overly optimistic. Failure to meet these time-frames generated cynicism and hostility. Evidence from both DoCS and ADD has emphasised the importance of ensuring that the pace of devolution in each centre is not forced, but rather, driven by the needs of residents and

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<sup>173</sup> Riddiford briefing, Ageing and Disability Department, 20 November 2000

families. Setting rigid targets for transition of services could therefore undermine the process by building resistance in centres that have been targeted for transition.

- 4.85** The Committee appreciates the importance of ensuring that the devolution process is driven by the needs of residents and families, but considers that the current time-frame is too long. The people in large centres are ageing and further substantial delays in movement to the community raises the real prospect that a large number of older people with disability will move from one form of institutional care in the disability services system to another in the aged care system. The long time-frame could also dissipate the momentum in relation to devolution, possibly leading to the abandonment of the process.
- 4.86** Given the complexity and importance of the task, the Committee has nevertheless reluctantly accepted that the 12-year time-frame for *final* devolution of *all* large residential services by 2010 is realistic.

### **Scope of the project**

- 4.87** Within this time-frame, the Committee considers that the majority of people living in large centres should be able to move to the community within a far shorter time, and targets should be established accordingly. The difficulties identified by ADD can be overcome by expanding the scope of the project so that the consultation and planning process commences in a larger number of centres. Stage one of the current devolution project applies to 11 services housing approximately 400 people. This represents a substantial commitment by the government that has been well received within the disability community. However, stage one excludes approximately 2000 people and no time-frames have been established for extension of the project to services. The Committee considers that a substantially greater number of people should be included in the initial stages of the devolution project.
- 4.88** As part of the planning process, the Committee considers that funding should be identified now to enable 80 per cent of residents of large centres to transfer to appropriate community accommodation within five years of this report. The initial processes of consultation and planning with residents, families and staff need to commence as soon as possible. Work needs to commence on preparation or revision of transition plans for all services so the process of transition can move forward as soon as possible. This planning process should take place within the consultative framework provided by the Disability Services Act. The Committee believes that revised transition plans should be finalised within a two-year period. The Committee recognises that this time-table would require the establishment of a number of teams equipped with the same resources as that working on the current 400 places initiative. The next section discusses the need for extra departmental resources.

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### **Recommendation 24**

All medium and large residential centres should be funded to complete transition to models that comply with the *Disability Services Act 1993* before 31 December 2010.

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**Recommendation 25**

As part of the planning process referred to in Recommendation 23, funding should be identified now to enable 80 per cent of residents of large centres to transfer to appropriate community accommodation by 31 December 2005.

**Recommendation 26**

Within two years of the date of tabling of this report, revised transition plans for transfer to community living should be finalised for all large residential services.

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**Departmental resources**

- 4.89** Concerns have been raised about the human resources available within ADD to manage the devolution project. Devolution, along with boarding house reform and the group homes project, is managed by the department's Community Living Development Unit (CLDU), which consists of eight staff. While the Committee has received very positive feedback from the sector about the quality and expertise of staff in the CLDU, the Committee believes the unit currently has insufficient resources to provide the intensive management required for the devolution project. The time-consuming nature of the planning and consultation involved for each service raises the real possibility that departmental staff will be spread too thinly, and thus unable to drive the process properly in each centre while establishing confidence in the process. The Committee believes that it is imperative to ensure that additional departmental resources are provided to support the devolution process, possibly through the establishment of additional teams to manage devolution in various services.

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**Recommendation 27**

As a matter of urgency, additional resources should be allocated to the Ageing and Disability Department to ensure that an expanded devolution project is effectively managed.

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**Flexible support options**

- 4.90** Rather than focus on specific service types, ADD has emphasised the importance of ensuring that community-based supports are matched to the individual needs of residents. Unlike past devolution projects, where residents of large centres have almost all moved to group homes, the department intends to broaden the options available to residents. One example provided to the Committee is that children with disability may be provided with intensive family support that will enable them to return to the family home.

**4.91** The Committee accepts that the department's approach is fundamentally correct. Group home accommodation is not always appropriate as a long-term accommodation option for people with disability and group homes can reproduce aspects of institutional care. Children in particular require specific services that are adapted to their needs and suffer as a result of the failure of the disability services system to differentiate between the needs of adults and children.<sup>174</sup>

**4.92** However, the process to date has suffered from a lack of clarity about exactly what types of services will be provided. Given the high level of anxiety among families about certainty of service, this could damage the devolution project. The Commissioner for Community Services has noted that in order to establish confidence in the process:

perhaps the government needs to be a bit more definitive about what it sees as acceptable options, even if it narrows the field, as a first step in the devolution process. ... I think that we are probably going to have to, as always in these things, compromise a little in narrowing the initial range of options in order for devolution to be achieved in a timely manner, and then hopefully ... as people's needs and aspirations change over time, the system can accommodate those changes.<sup>175</sup>

The Committee agrees that there is a need to clearly define the service options that will initially be available to people with disability who move into the community. This should occur as part of the overall planning process. Lack of clarity about support options generates hostility to the process amongst parents:

... what they are endeavouring to say to us is that our children should be coming back to our home and to have the individual looked after in our home. That is no different to the people ... who have their children at home now, and have had for a long time, and who are asking for respite care or whatever it might be. They are not getting the funding. How can it be offered to those parents who do not have their children at home if you cannot fund the children already in that situation?<sup>176</sup>

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### **Recommendation 28**

As part of the planning process referred to in Recommendation 23, the Ageing and Disability Department should define the specific types of support services that will be available to people who move to the community.

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**4.93** Research on past devolution projects has shown that continued flexibility is desirable following transfer to the community and that some people benefit by moving through a range of service types. For example, some residents of large centres may benefit by initially moving to group homes where they can gain independent living skills. Some of these people may then choose to move to more independent forms of accommodation where

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<sup>174</sup> See generally, Community Services Commission, *Inquiry into the practice and provision of substitute care in NSW: New Directions – from substitute to supported care*, November 2000, Chapter 4.

<sup>175</sup> Fitzgerald briefing, Commissioner for Community Services, 15 November 2000

<sup>176</sup> Public consultation, Ballina, 22 August 2000

support is provided that meets their needs and skills. Flexibility is an important part of the longer term devolution process.

- 4.94** In order to work effectively, flexible support options require guaranteed backup and long-term service planning to ensure that additional service becomes available if required. For example, children who are assisted to move to the family home from large centres will, as adults, need different types of support, which for social and developmental reasons may need to be provided outside the family home. By this stage their parents will be older and perhaps be less physically able to provide support. Unless alternative support such as permanent accommodation is available as a matter of right, these people may find themselves in the same situation of crisis as people currently without service at all (see chapter 1).
- 4.95** The Committee considers that clearly understood procedures should be established for on-going review of the support needs of people who move to the community.

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### **Recommendation 29**

As part of the planning process, clearly understood procedures should be established for on-going review of the support needs of people who move to the community.

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### **People with challenging behaviour**

- 4.96** Careful attention needs to be given to establishing appropriate forms of support to people who have challenging behaviour. Large government centres accommodate a number of people with challenging behaviour who require appropriate specialised support. One of the reasons for continuing admissions to large government centres has been breakdown of family care arrangements or group home accommodation due to challenging behaviour.<sup>177</sup> While movement to the community may result in overall improvements in people's quality of life, research suggests that challenging behaviours do not necessarily decrease.
- 4.97** Existing community-based services, like large centres, do not always deal appropriately with challenging behaviour. As noted in chapter 3, the Respite Working Group has already highlighted the need to develop an effective support system for people with challenging behaviour. The Committee notes that such a system is also necessary in the context of devolution of large residential centres.

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<sup>177</sup> The Department of Community Services has advised the Committee that roughly half of the 13 admissions to large centres in the first six months following the imposition of a no-admissions policy for large government centres were a result of breakdown of alternative accommodation due to challenging behaviour. Correspondence, Department of Community Services, 10 May 2000.

### **Building on earlier success**

- 4.98** The department advised the Committee that an important component of the current devolution strategy is to ensure that the first phase is successful, so that confidence in the transition process is established amongst people who are worried about the shift to community living. Further stages of devolution can then build upon initial success. The Committee agrees that sufficient positive examples of the shift to community living must be achieved to gain acceptance of devolution amongst those who currently oppose it. However, there are already many examples of successful and beneficial transition to community living.
- 4.99** The Committee has met many people who have moved successfully into the community from large centres since the 1980s. Many of these people have very high support needs. Despite recent improvements to large centres, the Committee's observations have been consistent with research that has shown that people living in the community have a demonstrably better quality of life than people in large centres. The Committee also met a number of parents who said that they were initially deeply opposed to devolution, but having witnessed the positive outcomes from movement to the community, they now fully supported community living.
- 4.100** One of the best ways for the department to build upon the achievement of past devolution projects would be by encouraging and facilitating contact between families engaged in the current process and families of people who have moved to the community during past projects. The Committee considers this would be most beneficial during early stages of the consultation process.

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### **Recommendation 30**

The Ageing and Disability Department should take, as a part of the consultative process, specific steps to encourage and facilitate contact between families of people engaged in current devolution projects and families of people who have moved to the community during past projects.

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### **Asset realisation**

- 4.101** The Committee is aware that some of the large government centres, particularly in the Sydney metropolitan area, are on highly valuable land. This has led to the belief by some that past and present devolution projects are motivated solely by a desire to sell these assets. The Committee acknowledges this concern but considers it to be unfounded. Supporting people in the community, as in the large centres, involves considerable recurrent expenditure, and past devolution processes have demonstrated the government's commitment to maintaining appropriate expenditure levels for people who have moved to the community.
- 4.102** Retaining the existing large centres is a very poor example of asset management. The centres are expensive to operate and maintain and do not provide an effective service to

residents. In order to provide a better level of service, considerable capital works would be required and staffing levels would need to be increased substantially. The capital tied up in the centres could be far more effectively used to help provide quality community-based disability services.

**4.103** In February of this year, the Committee was advised that the government intends to retain the proceeds of all asset sales within the disability services sector.<sup>178</sup> This commitment means that asset realisation may be an important component of a strategy for devolution, but is not the driving force behind devolution. The Committee considers that the ADD should manage all proceeds of asset realisation.

**4.104** The Committee is aware that ownership of sites is divided among different departments. Negotiations would need to take place to ensure that proceeds from asset realisation of all sites used for disability services are retained within the Disability Services Program.

**4.105** In some cases, several different services for people with disability are co-located on the one site. For example, the Grosvenor campus in Ashfield contains early childhood services as well as several forms of accommodation. Clearly, sites with multiple use present difficulties in terms of asset realisation. As part of the asset realisation process, there is a particular need to ensure that funding is identified to enable other services for people with disability to move off site and to continue operation.

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### **Recommendation 31**

All proceeds from the sale of large government-owned residential centres should be retained within the Disability Services Program and managed by the Ageing and Disability Department.

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### **No admissions policy in all large centres**

**4.106** While the devolution process has started in several centres, the Committee is concerned that a formal 'no admissions' policy has not been implemented for all large government and non-government centres. Presently, a formal policy is only in place for government centres. The Committee considers that all new admissions to permanent accommodation should be to community-based services that conform fully with the Disability Services Act. Further admissions to large centres will merely delay their ultimate devolution. Furthermore, in an environment where overall supply of accommodation is increasing, there should be no justification for further admissions to large centres.

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### **Recommendation 32**

The Ageing and Disability Department should implement a formal no admissions policy for all large non-government centres.

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<sup>178</sup> Hammerton evidence, 20 February 2000

## Chapter 5 Conclusion

The Committee is aware that the recommendations of this report have broad implications for the development of disability services in NSW. The recommendations have been made in a State government funding environment that is far more favourable to disability services than when the Committee commenced the inquiry. However, further investment in future Budgets will be required in order to achieve lasting benefit to people with disability in NSW.

The Committee notes the significant commitment of this government to the provision of quality services for people with disability and their families. This is demonstrated by many of the initiatives in the areas covered by this report, such as the development of the Service Access System to enable the systemic collection of information on unmet need. Many of these initiatives are now beginning to move beyond the planning stage to actual delivery of services. It is hoped that by mid-2001, people will begin to see progress in the areas of supported accommodation, respite and devolution. Given that many of these initiatives are only just commencing, the Committee is not in a position to finalise its views on these areas. The Committee has therefore decided to defer its final report on all of the terms of reference until late 2001.

This final chapter contains brief comments on important matters that have been raised during the Committee's consideration of this report.

### The link between unmet need and devolution

**5.1** During consultations it was suggested that action to address unmet need for accommodation will be undermined by moves to devolve large residential services. Some people have argued that people in large centres receive some form of service and it would be inappropriate and unnecessary to devote further resources to these people while there are so many people who are in desperate need of service. This view suggests in effect that the current generation of people living in the centres should remain there without any opportunity to live in the community. Some people have also suggested that spare capacity in the centres should be used to address the urgent problem of unmet need. These arguments have more often been put to the Committee by people who are connected to the centres and opposed to their devolution, rather than by people who are currently without service.

**5.2** The Committee believes that effective action to address unmet need for accommodation can only take place in conjunction with the devolution of large centres. The only spare accommodation capacity that is available exists in large residential centres. The high level of unmet need means that there is constant pressure to 'backfill' vacancies in the centres. As a result the population of large centres has remained relatively stable over the last decade. The Committee notes that despite the official no admissions policy in government-run centres, the lack of appropriate services for people with special needs, such as challenging behaviour, increases the pressure on large centres to continually admit people whose alternative placements break down. Growth in the supply of community-based

accommodation and respite services is therefore needed to create a climate in which final devolution of the centres can take place.

- 5.3** The continued existence of large centres perpetuates extreme inequities within the disability services system. At present, differences in the way that services are provided to individuals are a result of where they live rather than the type of support that they require. A rational and effective disability services system requires the level of funding and type of service received by individuals to be linked to their support needs. In general terms, people with equal types and levels of need should receive similar service. The continuing existence of large centres, despite their acknowledged obsolescence, prevents the development of a clear, rational and equitable accommodation support system for all people with disability in NSW.
- 5.4** All new supported accommodation places are now provided in the community. People with support needs that are similar to those of many people in large centres now receive community-based accommodation that enables them to enjoy a superior quality of life. The Committee considers that such persistent inequity can no longer be justified. The Committee is also aware that there are many people with disability who have no accommodation support whatsoever, and the lack of services for these people is grossly inequitable. In the longer term, it may be desirable to move towards a system of automatic entitlement to services based on defined support needs.

## **Financial implications**

- 5.5** The Committee is aware that the recommendations of this report require a substantial funding commitment by government. For example, supported accommodation for some individuals with high support needs may cost in excess of \$100,000 per year. Similarly, additional funding will be required to finalise devolution of all large centres. In some cases however, the cost to government may be relatively moderate. For example, a person with ageing parents may have low or moderate support needs and may be able to live semi-independently with drop-in support.
- 5.6** The recommendations of this report have not been made lightly, and the Committee recognises that the government has finite resources. The present need for significant increases in recurrent funding is a consequence of the accumulated effects of past failure by both State and Commonwealth governments to adequately fund disability services. Further delays will result in unjustifiable human cost and will ultimately increase the level of funding required to support an effective disability services system.
- 5.7** Without clear data on the extent and nature of unmet need, or the full cost of supporting current residents of large centres in the community, it is not possible at this stage to accurately determine the cost of addressing unmet need. In November 1997, the Accommodation Task Force advised government that:

current expenditure would need to grow by approximately 5.67% per annum until 2011 to properly address unmet need for accommodation.<sup>179</sup>

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<sup>179</sup> NSW Accommodation Task for people with disability and older people, *Final Report to NSW Government*, November 1997, p. 5

The Committee considers that such an increase may be a useful starting point for future Budget allocations.

- 5.8** It is worth noting that while significant increases in funding are likely to be required in the short or medium term, current initiatives by ADD are likely to reduce the overall cost of disability services in the longer term. The current situation of extreme need results from the fact that many people have been living without adequate in-home support for decades and are beyond the point where in-home support can help. Current work in the areas of early intervention, therapy supports and the provision of on-going support to families will reduce future expenditure on accommodation.
- 5.9** The Committee acknowledges that the State is not solely responsible for funding accommodation services. While the Commonwealth/State Disability Agreement provides that States are responsible for direct administration and funding of accommodation services, the Commonwealth provides a proportion of the funding for these services. The government has advised the Committee that Commonwealth transfers to NSW have declined over the past several years, with the result that there is now a cumulative shortfall in Commonwealth funding of \$80-100 million. While there may be arguments about the exact level of the shortfall, this report has highlighted the fact that continued under-funding for accommodation services results in substantial human suffering and social cost.
- 5.10** The Committee notes that it is the responsibility of both tiers of government to ensure that adequate funds are available for disability services in NSW. To address the problem of unmet need, both the Commonwealth and the State must increase the level of recurrent funding that they each provide for disability services. It is particularly important to ensure that this joint responsibility is not used by either tier of government as a reason to restrict its own contribution to accommodation services for people with disability.

## **The changing role of the Ageing and Disability Department**

- 5.11** Chapter 4 outlined the Committee's concerns about the resources available to ADD to manage the devolution project. This project is taking place in the context of a significant and, it is hoped, continuing expansion of accommodation services for people with disability. For the first time in some years, the 2000/2001 State Budget included a significant amount of funding for new services, which will lead to an increase in the supply of supported accommodation. The department has also established the Service Access System to properly manage requests for support.
- 5.12** These developments will inevitably present challenges to the department. They involve a significant shift in focus from policy development, funding and monitoring to active management of an expanding accommodation support system, and to some extent individual case management. The department is now simultaneously coordinating several large and urgently needed projects, which are far greater in scale than any previous projects that it has undertaken. It is important to ensure that sufficient resources are available within ADD to effectively manage these processes.
- 5.13** Delays in implementing some of the measures announced in May as part of the 2000/2001 Budget have already led to concern within the disability sector about the resources available within the department to manage these projects. The Committee is therefore strongly of

the view that further core funding for the department is required to enable it to properly administer reform in the three areas covered by this report. There is little point allocating additional funding for direct service delivery if the department does not have sufficient resources to 'roll out' the funding.

## **The Service Access System**

**5.14** This report has already noted the significance of the Service Access System. The System has only just commenced operation and it is not yet possible to comment on its efficacy. However, some concerns have emerged about the limited scope of the System. The Community Services Commission has noted that the System is currently set up to allow entry only when people are at 'risk' of crisis. The System does not coordinate access at an earlier point so as to prevent a situation of crisis developing. There is a risk that the existing 'crisis driven' approach to service provision will persist under the System.<sup>180</sup>

**5.15** In addition, the System is capable of performing a more central role in the management of disability services. At present the System cannot be accessed by people who already have accommodation arrangements in place. The Commission has suggested that the System could be made available to people in inappropriate care arrangements, such as young people in nursing homes or people in large residential services.

**5.16** The preliminary view of the Committee is that it would be beneficial for the Services Access System to develop into a more general system that allows access to a range of supports, rather than remaining as a system of crisis intervention. There would also be significant benefits in extending the role of the system so that it allows mobility between different types of service as required. This will be the subject of further investigation by the Committee leading up to the final report.

## **Disability and ageing**

**5.17** Ageing of people with disability is an issue at the intersection of State and Commonwealth responsibility. At present, there are no clear guidelines or protocols in place regarding services for people with disability who are ageing. Chapter 4 noted that delays in devolution of large centres mean that the population of the centres is ageing. Some people in the centres now require different types of community-based support to those envisaged under past devolution programs. Careful attention needs to be given to the types of service provided to these people, to avoid the risk that they will be moved from one type of congregate institution to another. Many people living in the community also face challenges associated with ageing. The Committee is aware that work is now under way to develop policy on these issues. Issues associated with ageing are clearly important and will be dealt with in the final report.

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<sup>180</sup> Fitzgerald, Community Services Commission briefing, 15 November 2000

## Planning

**5.18** This report has highlighted the need for planning in the specific areas covered. There is an urgent need for an overall plan for the effective and efficient delivery of disability services in New South Wales. The Committee is confident that with a medium and longer term planning strategy, the current government and its coordinating agency, the Ageing and Disability Department, can build confidence within the disability sector. A clear plan for delivery of disability services will provide people with disability and their families and carers with a degree of certainty. The Committee believes that the planning and provision of disability services is central to the well-being of many people in this State.

## The group homes project

**5.19** The decision by the NSW government to seek expressions of interest for DoCS group homes was first made public in the context of the State Budget on 22 June 1999. The decision to seek expressions of interest for the services was considered in the Committee's first report, *The Group Homes Proposal*, which was released in December 1999. In the report, the Committee noted that at the time of the announcement in the Budget, this initiative amounted to a clear policy decision to transfer a proportion of government services to the non-government sector. As of 20 November 2000, the expression of interest process for 41 DoCS group homes and community support teams had not been finalised. The outcomes of the group homes project are relevant to paragraph 3(f) of the Committee's terms of reference and will be considered in the final report. However, the Committee has received feedback from participants in the process during recent consultations and considers that comments should be made on some matters in this report.

**5.20** In general, feedback from parents and advocates has not been supportive of the process. Particular concerns have been raised about the requirement for all participants to name two preferred service providers. Many participants indicated to the Committee that they only wished to nominate one service provider and felt coerced into nominating a second provider that they did not actually want to use. Participants also indicated that they did not appear to have any role in making final decisions about who will be their service provider. This has led to considerable apprehension that people who nominate DoCS as their preferred service provider will not be able to remain with the department. While not able to comment on the expression of interest process until it is finalised, the Committee believes that the stated wishes of residents and their advocates should be central to any decisions made about accommodation and support services. As noted in *The Groups Homes Proposal*, the stated aim of the project was to provide people with the opportunity to exercise greater choice about their service provider.

**5.21** A matter of further concern to the Committee is that as of 20 November 2000, DoCS had only managed to submit an expression of interest for 1 of the 41 services.<sup>181</sup> The Committee was also advised that ADD intends to finalise the process by the end of 2000.<sup>182</sup> Failure by DoCS to submit an expression of interest in time to be included in the process

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<sup>181</sup> Ageing and Disability Department briefing, 20 November 2000

<sup>182</sup> Ibid

for each of the 41 services would be highly problematic. Approximately 210 of the 250 people involved in the process have named DoCS as one of their two preferred service providers. Failure to include DoCS in the process would seriously undermine the project and is likely to lead to unnecessary distress on the part of residents, families and advocates. The matter must be addressed as a matter of urgency.

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**Recommendation 33**

As a matter of urgency, the Department of Community Services should submit expressions of interest for all services included in the group homes project.

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- 5.22** The Committee notes that the expression of interest process has been a positive experience for some residents of the 41 services. As a result of the process, 40 people have chosen to leave the DoCS system after considering the range of other alternatives.<sup>183</sup> In consultations, some people have indicated that they were dissatisfied with the department and appreciated the opportunity to change services.<sup>184</sup> Other people have reiterated their determination to remain with DoCS.
- 5.23** The need for the disability services system to provide for mobility between service providers is an important issue. It is possible that the Service Access System has the potential to allow such mobility, thus eliminating the need to seek expressions of interest each time a change in provider is required. These matters will be considered in the Committee's final report.

**Other issues**

- 5.24** Consultations and submissions have indicated that, in building a better accommodation and support system for people with disability, there are a range of service gaps that must be addressed. Apart from the matters discussed above, the Committee intends to address the following issues in the final report:
- the needs of people from non-English speaking and Aboriginal and Torres Strait Islander backgrounds;
  - access to early intervention, education and therapy services;
  - service gaps experienced by people when they reach different age milestones;
  - access to affordable transportation;
  - the need for day programs;
  - services for people with physical and/or sensory disability and acquired brain injury;
  - advocacy services.

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<sup>183</sup> Ibid

<sup>184</sup> Consultation with clients, parents & advocates of Ballina Accommodation Support Service, 22 August 2000

# **Appendix 1**

## Submissions Received

<b>No</b>	<b>Author</b>
<b>1</b>	The Cabinet Office, Mr Roger Wilkins, Director-General
<b>2</b>	Confidential Submission
<b>3</b>	Western Sydney Intellectual Disability Support Group Inc, Ms Lisa Stelc, Executive Officer
<b>4</b>	Tamworth & District Respite & Advocacy Group <i>in conjunction with</i> Statewide Disability & Advocacy Coalition, Mrs Marie Cowling, Honorary Co-Ordinator
<b>5</b>	Manly Warringah Families and Friends of People with Disabilities, Ms Christine Agius
<b>6</b>	Multicultural Disability Advocacy Association of NSW Incorporated, Ms Barbel Winter, Executive Director
<b>7</b>	People with Disabilities (NSW) Inc, Mr Phillip French, Executive Officer
<b>8</b>	Disability Council of NSW, Ms Leonie Manns, Chairperson
<b>9</b>	Ms Rhonda M Hodges
<b>10</b>	Community Services Commission, Ms Edwina Pickering, Community Visitor Coordinator
<b>11</b>	Inner-West Group Homes Parents and Friends Association, Mr John Eager, President, & Ms Darleen Fawl, Secretary
<b>12</b>	Community Services Commission, Mr Robert Fitzgerald, Commissioner
<b>13</b>	Mid North Coast Area Disability, S J Rooth, Chairperson
<b>14</b>	Action for Citizens with Disabilities Ltd, Ms Ruth Robinson, Executive Officer
<b>15</b>	Westmead Hospital and Community Health Services, Mr Robert Moen, Social Worker & Team Leader FAACT Team
<b>16</b>	Dare to Care, Ms Christine Regan, Chairperson
<b>17</b>	Public Service Association, Ms Janet Good, General Secretary
<b>18</b>	Statewide Disability Coalition (NSW), Mr Jim Laird, Chairperson
<b>19</b>	Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc, Ms Judy Ellis, Director
<b>20</b>	Far North Coast Disability Action Team, Mr Tom Gorman, Committee Member
<b>21</b>	Jewish Community Services, Ms Freda Hilson, Manager Disability Services
<b>22</b>	Intellectual Disability Rights Services Inc, Ms Melissa Bellanta, Solicitor
<b>23</b>	ACROD NSW Division, National Industry Association for Disability Services, Mr Graham Catt, Executive Officer
<b>24</b>	New Horizons Enterprises Limited, Mr Stephen Kinkead, Executive Manager
<b>25</b>	Autism Association of NSW, Ms Imelda Dodds, Executive Director
<b>26</b>	Uniting Church in Australia, NSW Synod, Ms Lindy Kerr, Disability Education & Services Officer
<b>27</b>	Disability Advocacy Service Hunter (DASH) Inc, Mr Mark Grierson, Co-ordinator
<b>28</b>	Hunter Intellectual Disabilities Advocates, Ms Yiota Rae, Spokesperson

<b>29</b>	The Samaritans Foundation, Mr Cec Shevels, Director
<b>30</b>	The Housing Connection (NSW) Inc, Ms Anne Louise Hickey, Manager
<b>31</b>	Life Activities Inc, Ms Lyn Dowling, Social Worker
<b>32</b>	Catholic Women's League, Warialda Branch, Mrs A Jones, Secretary
<b>33</b>	Council of Social Service of NSW (NCOSS), Mr Gary Moore, Director
<b>34</b>	The NSW Council for Intellectual Disability, Ms Helena O'Connell, Executive Officer
<b>35</b>	The Disability Safeguards Coalition
<b>36</b>	Baringa Parents and Friends Association, Mr C R Peters, President
<b>37</b>	Stockton Hospital Welfare Association Inc, Ms Lorna Morris, Secretary
<b>38</b>	Confidential Submission
<b>39</b>	Confidential Submission
<b>40</b>	Access Community Education Services (ACES), Ms Beth Sawilejskij, Co-ordinator
<b>41</b>	Blue Mountains Disabilities Forum Inc, Mrs Marilyn Dibbs, Secretary
<b>42</b>	St Anthony's and St Joseph's Centre of Care, Mr Kevin Howard, Chief Executive Officer
<b>43</b>	Confidential Submission
<b>44</b>	Confidential Submission
<b>45</b>	Ms Maria Pappalardo
<b>46</b>	Mrs Dorothy Harrington, OAM & Mr Frederick Harrington
<b>47</b>	Confidential Submission
<b>48</b>	P J Collins
<b>49</b>	Mrs D Sammut
<b>50</b>	Ms Lorraine Yudaeff
<b>51</b>	Ms Marie Heaney
<b>52</b>	D E & M I Allen
<b>53</b>	Mr Ian Firth
<b>54</b>	Mr Garry Hancock
<b>55</b>	Mr A R Williams
<b>56</b>	Ms Yiota Rae
<b>57</b>	Mrs Dorothy Knight
<b>58</b>	no name – address supplied
<b>59</b>	Mrs L S Blyth
<b>60</b>	Lee Francis
<b>61</b>	Mr Tom O'Keeffe & Ms Deirdre O'Keeffe
<b>62</b>	Mr David Baker
<b>63</b>	Mr Terry Fawl

<b>64</b>	Confidential Submission
<b>65</b>	Mr A Holey & Mrs B Holey
<b>66</b>	Mrs Darleen Fawl
<b>67</b>	Miss M W Bowles
<b>68</b>	Checkpoint, Ms Maxine Brem, Convenor
<b>69</b>	Mrs Stephanie Robinson
<b>70</b>	Ms Maree Walz
<b>71</b>	Ms Darrell Evans
<b>72</b>	Mr Laurence See
<b>73</b>	Ms Pamela Morris
<b>74</b>	Confidential Submission
<b>75</b>	Mrs Betsy Hilton
<b>76</b>	Mrs Eva Nagy
<b>77</b>	E de Heer & Sheila de Heer
<b>78</b>	Nardy House Committee, Ms Denise Redmond and Ms Betsy Hilston, Secretary
<b>79</b>	Ms Meryl Harding & Mr Ian Harding
<b>80</b>	Mr Keith Manning
<b>81</b>	Mr Peter Hutten
<b>82</b>	Mr Eric Walters
<b>83</b>	Lower Hunter Temporary Care Inc., Ms Fiona Smith, President
<b>84</b>	Confidential Submission
<b>85</b>	Mr John Collins & Mrs Shirley Collins
<b>86</b>	Ms Helen Pitcher
<b>87</b>	Mrs E Studholme
<b>88</b>	B & P Hammett
<b>89</b>	Mr Francis Baker & Mrs Janet Baker on behalf of Mr Matthew Baker
<b>90</b>	R E & P Walsh
<b>91</b>	Mr John Eager & Ms Janet Eager
<b>92</b>	Confidential Submission
<b>93</b>	Ms Margaret Gorman
<b>94</b>	Mr Mark Gorman
<b>95</b>	S P O'Brien
<b>96</b>	Bonnie Johnson
<b>97</b>	Mrs Kerry Stratton
<b>98</b>	Confidential Submission
<b>99</b>	Confidential Submission
<b>100</b>	Mrs Wanda Osborn

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<b>101</b>	Mr James Condren
<b>102</b>	Mrs M Booth
<b>103</b>	Mrs A Eshman
<b>104</b>	Ms Melissa Athinson
<b>105</b>	Ms Jennie Adam
<b>106</b>	Ms Gaye Essex
<b>107</b>	G Baddock
<b>108</b>	Mr Ian Dunlop & Ms R Dunlop
<b>109</b>	Ms Anne Elysee
<b>110</b>	Mr Christopher Peters & Ms Jayne Peters
<b>111</b>	Mrs Marie T Clair
<b>112</b>	Ms Deborah Maher
<b>113</b>	P H & L L Driscoll
<b>114</b>	Confidential Submission
<b>115</b>	Ms Christine Smith & Mr Scott Smith
<b>116</b>	Ms Thelma Morris & Mr Bert Morris
<b>117</b>	Ms M Brem
<b>118</b>	Ms Dora Perdikaris
<b>119</b>	M Leousis
<b>120</b>	Mr Paul Jones & Ms Anne Jones
<b>121</b>	Ms Jenny Coughlan
<b>122</b>	Ms Barbara Spode
<b>123</b>	Confidential Submission
<b>124</b>	Mr Trevor Carter & Ms Mary Lou Carter
<b>125</b>	Mr Trevor McLennan & Ms Veronica McLennan
<b>126</b>	Ms Yvonne Snow
<b>127</b>	Ms Beverly Buckridge
<b>128</b>	Ms Monica Johnson
<b>129</b>	Mr Mohan Das & Mrs Barbara Das
<b>130</b>	Ms Pascale Carratt
<b>131</b>	Mrs Evelyn Shoemith
<b>132</b>	Mr Bert Redding & Ms Kath Redding
<b>133</b>	Ms Rhonda Brettschneider
<b>134</b>	Ms Maria Heaton
<b>135</b>	Ms Jeanette Moss, AM
<b>136</b>	W G & C R Packman
<b>137</b>	Hunter Region Disabled Lobby Group, Ms Melina Middleton, Co-ordinator

<b>138</b>	Drs K & R Frank
<b>139</b>	Ms Margaret Shepherd
<b>140</b>	Mr John Collins & Ms Shirley Collins
<b>141</b>	P & D McDonald
<b>142</b>	Ms Shirley Martin & Mr Gregory Martin
<b>143</b>	Confidential Submission
<b>144</b>	Ms Marcia McLennan
<b>145</b>	Ms Joan Marr
<b>146</b>	Mrs R Chapman, Mrs D Woodhill, Mrs T Dyson, Mrs M Dearn
<b>147</b>	Kirinari Community Services, Mr Gary Roberts, Chief Executive Officer
<b>148</b>	Allenby & Marjorie Bolte
<b>149</b>	Mr Richard Radcliffe Walton
<b>150</b>	Confidential Submission
<b>151</b>	Armidale Pathways Committee, Ms Mary Devine, Armidale Community Care Co-Ordinator
<b>152</b>	Ms Pamela Pearse
<b>153</b>	Families First Macarthur Parent Support Group, Ms Karyn Ingram, Vice-President
<b>154</b>	NSW Nurses Association Stockton Centre Branch, Mr Andrew Batcheldor, Branch Secretary
<b>155</b>	Access Plus Spanning Identities Inc, Ms Annie Parkinson, President
<b>156</b>	Armidale Disabilities Interagency, Ms Jan Roads, Chairperson
<b>157</b>	J F Brett
<b>158</b>	Mr John M Mowbray
<b>159</b>	Macarthur HACC Forum, Ms Linda Margrie, Macarthur HACC Development Worker
<b>160</b>	Mr Paul Race & Ms Lorraine Race
<b>161</b>	Macarthur Disability Network, Ms Julie Deane, Chairperson
<b>162</b>	Interchange Bega-Eden Respite Care Inc., Pat Jones, Co-ordinator
<b>163</b>	Ms Moya Smith
<b>164</b>	Mr Tom Kenny
<b>165</b>	Rights Forum, Ms Kim Walker, Community Educator
<b>166</b>	The Association of Childrens Welfare Agencies Inc., Mr Nigel Spence, Chief Executive Officer
<b>167</b>	New England Early Childhood Intervention Co-Ordination Committee, Ms Jane Rudd, Chairperson
<b>168</b>	Caring Together Ipswich, Mr Stephen Attwood
<b>169</b>	Ms Jennifer Conden
<b>170</b>	Mrs Frances Lanteri

<b>171</b>	Families In Partnership Committee, Ms Vicki Meadows, Parent Representative, Ms Annamaria Wood, Macarthur District Family Temporary Care, Professor John McCallum, Dean, Faculty of Health, University of Western Sydney, Macarthur
<b>172</b>	Uniting Church in Australia (NSW Synod), Ms Lindy Kerr, Disability Education and Services Officer
<b>173</b>	The Spastic Centre of New South Wales, Mr Richard Spencer, Chief Executive Officer
<b>174</b>	Ms Kim Walker
<b>175</b>	Mr Sydney Fernandes
<b>176</b>	Mrs Josie Bugeja
<b>177</b>	Jewish Community Services, Ms Freda Hilson, Manager Disability Services
<b>178</b>	Mrs Mary Cheney
<b>179</b>	Mrs J M Symonds
<b>180</b>	Lee Frances
<b>181</b>	Ms Deborah S Maher
<b>182</b>	Mr Robert Campbell & Ms Elizabeth Campbell
<b>183</b>	Chris Marsh
<b>184</b>	Confidential Submission
<b>185</b>	Ms Rosa Bartolo
<b>186</b>	Ms Barbara Satherley
<b>187</b>	The Disability Safeguards Coalition, Ms Belinda Epstein-Frisch
<b>188</b>	Ms Moya Clarke
<b>189</b>	Mrs Enid Darling
<b>190</b>	Lesley Freedman
<b>191</b>	Mrs Avelyn Gogos
<b>192</b>	Confidential Submission
<b>193</b>	Mrs Marie Clair
<b>194</b>	Hunter Consumer Unit, Ms Karen O'Hara, Consumer Liaison Co-ordinator
<b>195</b>	Mrs Dorothy Harrington, OAM
<b>196</b>	Mr Alan Kennedy
<b>197</b>	Mr Bert Morris & Mrs Thelma Morris
<b>198</b>	Mr Michael Hanretty
<b>199</b>	Mr Ian Leneham
<b>200</b>	Stockton Hospital Welfare Association Inc, Mrs Lorna Morris, Honorary Secretary
<b>201</b>	Parkes Post School Options, Ms Janet O'Donoghue, Co-ordinator
<b>202</b>	Confidential Submission
<b>203</b>	Inner-West Group Homes Parents and Friends Association, Ms Darleen Fawl
<b>204</b>	Mrs Margaret Chadwick

<b>205</b>	Carers NSW Inc, Ms Joan Hughes, Executive Director
<b>206</b>	Mr E Kearney
<b>207</b>	Action for Citizens with Disabilities Ltd, Ms Ruth Robinson, Executive Officer
<b>208</b>	Interchange Respite Care (NSW) Incorporated, Ms Jacqueline Parmenter, Executive Officer
<b>209</b>	Confidential Submission
<b>210</b>	Ms Margaret Shepherd, Ms Denise Shepherd, Ms Christine Smith
<b>211</b>	Hunter Mental Health Service, Ms Tina Smith, Co-Ordinator, Hunter Mental Health Supported Accommodation Project
<b>212</b>	Mr Ian Dunlop
<b>213</b>	Lachlan Centre Parents and Friends Forum, Ms Annette Guterres
<b>214</b>	Citizen Advocacy Western Sydney Incorporated, Ms Annette Jones
<b>215</b>	Mr Ken Benson & Mrs Jan Benson
<b>216</b>	The Lorna Hodgkinson Sunshine Home, Mr Jim McMenamin, Chief Executive
<b>217</b>	Professor Lindsay Gething, Director, Nursing Research Centre for Adaptation in Health and Illness, Faculty of Nursing, The University of Sydney
<b>218</b>	Community Services Commission, Ms Christine Carter, Community Visitor
<b>219</b>	The Australian Quadriplegic Association Ltd, Mr Mark Relf, Acting Chief Executive
<b>220</b>	Ms Dorothy McNamara
<b>221</b>	Ms Jennifer Lane
<b>222</b>	Mrs E P Norris
<b>223</b>	R.E.D. Inc., Mr Allan Ellis, President
<b>224</b>	Mr Allan Ellis & Ms Fran Ellis
<b>225</b>	The Cabinet Office, Mr Roger B Wilkins, Director-General
<b>226</b>	Community Services Commission, Ms Joanna Quilty, Manager, Service Monitoring and Policy
<b>227</b>	Council of Social Service of NSW (NCOSS), Mr Gary Moore, Director
<b>228</b>	Statewide Disability Coalition Inc. (NSW), Mr Jim Laird, Chairperson
<b>229</b>	Physical Disability Council of New South Wales, Mr John Moxon, President
<b>230</b>	Western Sydney Intellectual Disability Support Group
<b>231</b>	Mid North Coast Area Disability Committee, Mr S J Rooth
<b>232</b>	Disability Network – Hunter Inc., Ms Valerie Shevels, President
<b>233</b>	Mr Bernard Fitzpatrick & Mrs Rhonda Fitzpatrick
<b>234</b>	Confidential Submission
<b>235</b>	Confidential Submission
<b>236</b>	Office of the Public Guardian, Mr John Le Breton, Director
<b>237</b>	Mrs Josephine Bugeja
<b>238</b>	Brain Injury Association of NSW Inc., Mr Kevin Marron, Executive Officer

<b>239</b>	ACROD NSW Division, National Industry Association for Disability Services, Mr Graham Catt, Executive Officer
<b>240</b>	Multicultural Disability Advocacy Association of NSW Incorporated, Ms Barbel Winter, Executive Director
<b>241</b>	Deaf Blind Association (NSW), Janne Bidenko
<b>242</b>	Ms Heidi Roland
<b>243</b>	Public Service Association of New South Wales, Ms Janet Good, General Secretary
<b>244</b>	Intellectual Disability Rights Service Inc, Ms Paula Rix, Co-ordinator
<b>245</b>	SPICE Consulting, Ms Deborah Fullwood, Principal Consultant
<b>246</b>	Mr John Jacobsen
<b>247</b>	Ms Beverley O'Reilly
<b>248</b>	Mrs Gloria Banks
<b>249</b>	Ms Elizabeth Plant
<b>250</b>	Ms Barbara Spode
<b>251</b>	Far North Coast Disability Action Team, Ms Faye Druett, Committee Member
<b>252</b>	Action For Citizens With Disabilities, Ms Ruth Robinson, Executive Officer
<b>253</b>	Mrs Joan Marr
<b>254</b>	Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc, Ms Judy Ellis, Director
<b>255</b>	The NSW Council for Intellectual Disability, Ms Helena O'Connell, Executive Officer
<b>256</b>	HunterPlus, Ms Kay Meehan, General Manager
<b>257</b>	Sutherland Shire Carer Support Project, Ms Sue Roach on behalf of the Parent's Working Party for Permanent Accommodation
<b>258</b>	Ms Sandra Milling
<b>259</b>	Jemalong Retirement Village, Mr A J Reichelt, Chief Executive Officer
<b>260</b>	Bob Freda & Scott Drinkwater
<b>261</b>	Mr & Mrs A Jones
<b>262</b>	Ms Annette Jones
<b>263</b>	Mrs E P Norris on behalf of the Norris family
<b>264</b>	Mr John Shearer
<b>265</b>	Trundle Central School, R T Kingwill, Principal
<b>266</b>	Mercy Centre Lavington Limited, Sr Patricia Weekes, Chief Executive Officer
<b>267</b>	Mrs Helen Byrne
<b>268</b>	Mrs Dawn Henderson
<b>269</b>	Ms Rosemary Symon
<b>270</b>	Lachlan Centre Parents and Friends Forum, Ms Annette Guterres
<b>271</b>	Ms Judith Kleeman

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<b>272</b>	Hastings Foundation Limited, Mr Peter Merrotsy
<b>273</b>	Ms Karen Denny
<b>274</b>	Mrs Marlene Horn
<b>275</b>	Disability Advocacy Service Hunter (DASH) Inc, Mr Mark Grierson, Co-ordinator
<b>276</b>	Ms Irene Glassop
<b>277</b>	Mrs Lorraine Spieler
<b>278</b>	Parkes Shire Council, Mr Brian Matthews, Director of Corporate Services
<b>279</b>	Greenacres Association, Mr Neil Preston, Chief Executive Officer
<b>280</b>	Mr John Bilboe & Mrs Margaret Bilboe
<b>281</b>	Greenacres Association, Mr Neil Preston, Chief Executive Officer
<b>282</b>	Ms Enid Darling
<b>283</b>	Mr Ken Gibbon
<b>284</b>	Disability Assistance for Shoalhaven Inc., Mr George Mackenzie, President
<b>285</b>	Life Activities Inc, Ms Kay Tierney, Chief Executive Officer
<b>286</b>	Mr Ches Penfold
<b>287</b>	Mr Noel Morris & Mrs Lorna Morris
<b>288</b>	Ms Dianne Beatty
<b>289</b>	Confidential Submission
<b>290</b>	Central West Brain Injury Action Group Inc., Ms E Sewell, Secretary
<b>291</b>	Mr Ian Dunlop & Ms R Dunlop
<b>292</b>	Mr Roy Duffy
<b>293</b>	D J & E F C Graham
<b>294</b>	Ms Michelle Tang
<b>295</b>	Mrs Ann Melbourne
<b>296</b>	Confidential Submission
<b>297</b>	Mr Carl Ferguson
<b>298</b>	Mrs Claire Symonds
<b>299</b>	N.E.T. Kirkland Research and Education on the Holistic Approach to Schizophrenia, Ms Odette Nightsky
<b>300</b>	Stockton Hospital Welfare Association Inc, Ms Lorna Morris, Secretary
<b>301</b>	Confidential Submission
<b>302</b>	Confidential Submission
<b>303</b>	Mrs Rochelle Jang
<b>304</b>	Caringa Support Services, Ms Vicki deVaurno, Services Administrator
<b>305</b>	Mrs Margaret Gorman
<b>306</b>	Ms Jan Bowan
<b>307</b>	Kerry Pascoe

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**308** Confidential Submission

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**309** Muscular Dystrophy Association of NSW, Mr Martin Lavery, Chief Executive Officer

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## **Appendix 2**

### Witnesses at Hearings

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9 February 2000

**Mr Phillip French** Executive Officer  
People With Disabilities (NSW) Inc

9 February 2000

**Ms Wendy Potter** President  
People With Disabilities (NSW) Inc

9 February 2000

**Ms Helen Seares** Chairperson  
New South Wales Council for Intellectual Disability

9 February 2000

**Mr Gary Moore** Director  
Council of Social Service of NSW (NCOSS)

9 February 2000

**Ms Christine Regan** Policy Officer  
Council of Social Service of NSW (NCOSS)

10 February 2000

**Ms Diana Qian** Chairperson  
Multicultural Disability Advocacy Association

10 February 2000

**Ms Barbel Winter** Executive Officer  
Multicultural Disability Advocacy Association

10 February 2000

**Ms Lou-Anne Lind** Systemic Advocate  
Multicultural Disability Advocacy Association

10 February 2000

**Mr Maurie O'Sullivan** President  
Public Service Association

10 February 2000

**Ms Ayshe Lewis** Senior Industrial Officer  
Public Service Association

10 February 2000

**Ms Carol Yarovy** Delegate and Hunter Area Representative  
Public Service Association

10 February 2000

**Ms Belinda Epstein-Frisch** Advocate  
Disability Safeguards Coalition

10 February 2000

**Ms Pamela Morris** Advocate  
Disability Safeguards Coalition

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10 February 2000	<b>Ms Jane Fraser</b>	Advocate Disability Safeguards Coalition
10 February 2000	<b>Ms Judith Ellis</b>	Director Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc
10 February 2000	<b>Ms Jeannette Moss, AM</b>	Chairperson and Secretary Western Sydney Intellectual Disability Support Group
10 February 2000	<b>Ms Anne Elysee</b>	Vice-Chairperson Western Sydney Intellectual Disability Support Group
10 February 2000	<b>Ms Lisa Stelc</b>	Executive Officer Western Sydney Intellectual Disability Support Group
17 February 2000	<b>Ms Marianne Hammerton</b>	Acting Director-General Ageing and Disability Department
17 February 2000	<b>Ms Sharon Campbell</b>	Manager, Planning Unit Ageing and Disability Department
17 February 2000	<b>Ms Pamela Riddiford</b>	Manager, Community Living Development Ageing and Disability Department
17 February 2000	<b>Mr John Le Breton</b>	Director Office of the Public Guardian
22 February 2000	<b>Mr Robert Fitzgerald</b>	Commissioner Community Services Commission
22 February 2000	<b>Ms Joanna Quilty</b>	Manager, Service Monitoring and Policy Unit Community Services Commission
22 February 2000	<b>Mr Gary Dawson</b>	Manager, Complaints Investigations and Reviews Unit Community Services Commission
22 February 2000	<b>Mr Brendan O'Reilly</b>	Deputy Director-General Department of Community Services

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22 February 2000

**Ms Ethel McAlpine** Director, Disability Services  
Department of Community Services

20 March 2000

**Ms Judy Sanders** Member  
Statewide Disability Coalition

20 March 2000

**Ms Jennifer Berry** Member  
Statewide Disability Coalition

20 March 2000

**Ms Marieann Richardson** Member  
Statewide Disability Coalition

20 March 2000

**Ms Kirstin Mills** Regional Co-Ordinator  
The Northcott Society

23 March 2000

**Ms Susan Pringle** Co-Ordinator  
Coinda Family Support Group

23 March 2000

**Ms Robyn Raine** Committee Member  
Coinda Family Support Group

23 March 2000

**Ms Rosemary Drewe** Committee Member  
Coinda Family Support Group

23 March 2000

**Mr Michael Jarrett** Co-Ordinator  
Disability Advocacy & Information Service Inc

23 March 2000

**Ms Loretta Caunt** Advocacy Worker  
Disability Advocacy & Information Service Inc

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# **Appendix 3**

## Committee Briefings

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9 February 2000

**Ms Janeen McClellan**

Director, Quality Assurance Systems, Provincial Monitoring Group  
Victoria, British Columbia, Canada

9 February 2000

**Ms Jennifer Keilty**

Consultant, Provincial Monitoring Group  
Victoria, British Columbia, Canada

17 February 2000

**Dr Roger Stancliffe**

Centre for Developmental Disability Studies  
University of Sydney

20 March 2000

**Ms Debra Ryan**

Mother of a child with a disability living in regional New South Wales

23 March 2000

**Ms Marlene Kidman**

Manager  
Department of Community Services, Griffith

23 March 2000

**Mr Wayne Carroll**

Health Co-Ordinator  
Koori Health Post, Griffith

23 March 2000

**Ms Desma Newman**

Aboriginal Health Worker  
Griffith Community Health

23 March 2000

**Ms Ngjaran Williams**

Trainee  
Koori Health Post, Griffith

1 June 2000

**Mr Phillip French**

Executive Officer  
People With Disabilities (NSW) Inc

1 June 2000

**Mr Gary Moore**

Director  
Council of Social Service of NSW (NCOSS)

1 June 2000

**Ms Belinda Epstein-Frisch**

Advocate  
Disability Safeguards Coalition

1 June 2000

**Ms Helen Seares**

Chairperson  
New South Wales Council for Intellectual Disability

9 June 2000

**Ms Marianne Hammerton**

Director-General  
Ageing and Disability Department

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9 June 2000

**Mr Warwick Neilley**

Senior Policy Advisor to the Hon. Faye Lo Po'

9 June 2000

**Ms Janet Milligan**

Director, Program Performance  
Ageing and Disability Department

9 June 2000

**Ms Megan Mitchell**

Director, Strategic Planning and Policy  
Ageing and Disability Department

15 November 2000

**Mr Robert Fitzgerald**

Commissioner  
Community Services Commission

15 November 2000

**Ms Michelle Hayter**

Disability and Policy Liaison Officer  
Community Services Commission

20 November 2000

**Ms Megan Mitchell**

Director, Strategic Planning and Policy  
Ageing and Disability Department

20 November 2000

**Ms Janet Milligan**

Director, Program Performance  
Ageing and Disability Department

20 November 2000

**Ms Pamela Riddiford**

Manager, Community Living Development Unit  
Ageing and Disability Department

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# **Appendix 4**

## Committee Visits

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<b>31 January 2000</b>	<b>Crowle Foundation, Ryde</b> Tour of facilities and consultation with management and staff <b>Lachlan Centre, Macquarie Hospital, North Ryde</b> Tour of facilities and consultation with staff
<b>01 February 2000</b>	<b>Marsden Rehabilitation Centre, Parramatta</b> Tour of facilities <b>Rydalmere Centre, Rydalmere</b> Tour of facilities and consultation with residents and staff
<b>20 March 2000</b>	<b>Orana Far West Office, Department of Community Services, Dubbo</b> Consultation with staff <b>Carinya Children's Respite Unit, Dubbo</b> Tour of facilities and consultation with staff <b>Westhaven Association, Dubbo</b> Tour of facilities and consultation with residents and staff
<b>21 March 2000</b>	<b>Central West Area Office, Department of Community Services, Orange</b> Consultation with staff <b>Riverside Centre, Orange</b> Tour of facilities and consultation with families and staff
<b>23 March 2000</b>	<b>Woodstock Centre, Albury</b> Tour of facilities and consultation with staff <b>Friends of Woodstock Auxillary Inc</b> Consultation with members
<b>10 May 2000</b>	<b>Western Sydney Intellectual Disability Support Group Cottage 1, Rydalmere Centre, Rydalmere (Western Sydney consultation)</b> Consultation with parents of people with disability
<b>11 May 2000</b>	<b>Cram House, Wollongong</b> Consultation with management and staff Consultation with families of residents
<b>04 July 2000</b>	<b>Stockton Centre, Stockton</b> Consultation with staff Consultation with relatives and friends of residents Tour of facilities
<b>04 July 2000</b>	<b>Newcastle Workers Club, Newcastle (Newcastle consultation)</b> Consultation with clients of Disability Advocacy Service Hunter
<b>05 July 2000</b>	<b>Peat Island Centre, Brooklyn</b> Tour of facilities and consultation with parents and staff

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<b>10 July 2000</b>	<b>Broken Hill Post School Options/ATLAS Centre, Broken Hill</b> Consultation with service providers Consultation with service users
<b>11 July 2000</b>	<b>Silverlea Employment and Training Service, Broken Hill</b> Tour of facilities and consultation with clients and staff <b>Silverlea Accommodation and Education Service, Broken Hill</b> Consultation with staff
<b>19 July 2000</b>	<b>Coledale Community Centre, Tamworth</b> Consultation with ADD Aboriginal Planning and Advisory Group Consultation with service providers Consultation with staff from Ageing and Disability Department
<b>22 August 2000</b>	<b>Ageing and Disability Department, Ballina</b> Consultation with regional staff from ADD <b>The Gorman Family, Mullumbimby</b> The Committee met with Mr James Gorman and members of his family in his home in Mullumbimby <b>Far North Coast Disability Action Team (FNCDAT), Byron Bay</b> Consultation with members of the Far North Coast Disability Action Team. <b>Accommodation Network, Ocean Shores</b> Consultation with management <b>Ballina Accommodation Support Service (BASS)</b> Consultation with staff, clients and advocates

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# **Appendix 5**

## Community Consultations

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<b>20 March 2000</b>	<b>Dubbo Community Consultation</b> Dubbo Civic Centre, Dubbo
<b>21 March 2000</b>	<b>Parkes Community Consultation</b> Coachman Hotel Motel, Parkes
<b>23 March 2000</b>	<b>Albury Community Consultation</b> Albury Commercial Club, Albury
<b>11 May 2000</b>	<b>Wollongong Community Consultation</b> Cram House, Wollongong
<b>04 July 2000</b>	<b>Newcastle Community Consultation</b> Newcastle Workers Club, Newcastle
<b>10 July 2000</b>	<b>Broken Hill Community Consultation</b> Post School Options/ATLAS Centre, Broken Hill
<b>19 July 2000</b>	<b>Tamworth Community Consultation</b> Coledale Community Centre, Coledale
<b>22 August 2000</b>	<b>Ballina Community Consultation</b> Ballina RSL Club, Ballina

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## **Appendix 6**

Ageing & Disability Department  
Report to the Minister for Disability  
Services

Reshaping the NSW Respite System  
for people with disabilities and their  
families and carers

Recommendations for action

Respite Working Group February 2000

## **2.1 Improving the current respite system**

### **Recommendation 1**

Respite services should be freed up for respite by:

- (a) moving all children who are in long term continuous respite to more appropriate family-based care options using intensive family support packages (there are 35 children in this category in DoCS facilities in 1999; as well as those in non-government facilities) on the basis of family-focussed comprehensive assessment;
- (b) establishing long term family-based alternate care placements for those children who are state wards (11 of the 35 identified above – DoCS 1999);
- (c) relocating adults in long term continuous respite care to appropriate, permanent, community-based supported accommodation, on the basis of comprehensive assessment. Respite places should no longer be used for supported accommodation (110 adults in DoCS facilities in 1999, as well as those in non-government facilities);
- (d) on the basis of comprehensive assessment, providing appropriate support including supported accommodation if required, for adults who are using respite intensively (343 adults – CSC 1997);
- (e) providing comprehensive, family-focussed assessment and comprehensive support planning for all adults and children using respite continuously or intensively (non continuously). Ongoing communication should be maintained with families and carers to ensure their involvement in decisionmaking, support planning and transition planning. Transition planning should be informed by recent devolution experience (for example, CDDS evaluation of the Hall For Children), addressing the need for compatibility and specialist support for challenging behaviour;
- (f) developing intensive family support packages, which include respite, for children who are using residential respite intensively or who may be at risk of placement in residential respite on a long-term continuous basis (158 children – CSC 1997);
- (g) establishing a regionally based contingency fund within ADD, using additional funds, for emergencies and crises. Guidelines should be developed to differentiate the use of contingency funds from Carer Respite Centre brokerage funds. In the longer term, ADD should develop a coordinated emergency support system with the Commonwealth which is informed by wider disability reform. ADD should also encourage the development of local area protocol between service providers to allow cooperative responses to people in crisis, including situations where placements break down.

### **Recommendation 2**

Residential respite should be made more appropriate by:

- (a) relocating all respite places in large residential institutions into small houses in the community;
- (b) wherever viable, separating respite care from supported accommodation facilities;
- (c) ensuring that children are not accommodated in the same respite facility at the same time as adults (except in the case of families);
- (d) redesigning the remaining children's residential respite places, for children with severe physical disabilities or with very challenging behaviour, according to the particular needs of the small number of children who will continue to use residential respite (after most children have been

moved out of residential respite and children's respite is separated from adult respite). This may involve selling existing stock and the procurement of more appropriate environments.

### **Recommendation 3**

A policy and guidelines for respite should be developed across DSP and HACC and include a new definition of respite and guidelines for priority of access. Respite should be promoted as: support for the person with a disability and their family or carer/s; a planned, preventive service, not a crisis service; and one part of a total coordinated range of support services for people with disabilities. ADD should negotiate the development of a common definition and terminology for respite with the Commonwealth Departments of H&AC and FaCS, and seek to have this actioned at the national level through the HACC Officials group and at State level through the Disability Services Planning Officials group.

### **Recommendation 4**

ADD should establish effective control over respite services provided across both the government and non-government sectors through effective monitoring of the quality and appropriateness of services provided.

### **Recommendation 5**

ADD and respite service providers should work with Carer Respite Centres to improve the availability of disability respite information.

### **Recommendation 6**

ADD should continue to work towards improving data consistency between agencies to ensure the future ability to improve planning and resource allocation.

### **Recommendation 7**

A flexible approach to respite provision should be promoted through:

- (a) the 9 of Interest (EOI) process for the allocation of growth funds. A new respite definition, principles and examples of flexible practice should be included in the information package. The 'intention to offer flexible services' should be included in the criteria for the allocation of funding;
- (b) empowering families through peer support and mentoring between families, and providing information to consumers, families and carers about the concept of flexible respite options;
- (c) the promotion of mentoring between conforming and nonconforming respite services to encourage good practice;
- (d) developing an information package for respite providers (including a checklist and information on accredited competency-based training) to promote good practice. The package should promote ideas such as those in the Victorian "Making a Difference" program;
- (e) reviewing the use of the new respite package after 2 years.

**Recommendation 8**

Coordination should be promoted between service providers and Carer Respite Centres (CRCs); and between Commonwealth and ADD funded respite programs and initiatives.

**Recommendation 9**

ADD should consult with people from non-English speaking backgrounds (NESB) to investigate ways to make respite more accessible, culturally appropriate and acceptable and promote respite to NESB groups. ADD should also adopt the following strategies to improve access:

- (a) new respite packages should be designed and targeted to people from a NESB background (in recognition of the size of the population in NSW who speak a language other than English – 16.8% of the total population);
- (b) funding contracts should require service providers to adopt strategic access targets for people from NESB, based on local population statistics and to demonstrate progress towards the achievement of those targets;
- (c) respite information should be developed in the major community languages and centrally updated (for example, on the Internet); and
- (d) ADD should provide funding to non-government service providers for the use of interpreters.

(Note that service reforms for Aboriginal people and Torres Strait Islanders are at Recommendation 16 in section 10.4 because they refer to disability support rather than respite as such.)

**Recommendation 10**

In recognition of issues in remote areas, ADD should investigate and pilot non-residential respite models (family-based support for children, intensive in-home support, and in particular – multi-service/colocation model and motel model) through a selective tendering process, with a view to promoting flexible, viable service models. Funding formulae should be adjusted to take travel costs into account in remote areas.

**2.2 Financing the respite reforms**

The current level of unmet need for respite and supported accommodation (see section 8), the need to address problems in respite service provision (see section 9), and the projected increase in the disability population (see section 10) represent a significant resource challenge for the NSW Government. While initiatives such as the new approach to service planning and provision through the Population Group Planning (PGP) mechanism, and efficiency gains through improved co-ordination will assist, there is no doubt that additional resources will also be required (Kennedy 1996).

**Recommendation 11**

In recognition of the above, and in order to finance the reforms, ADD should bid for additional funds as well as harness existing funds.

Additional funds for supported accommodation will be required to unblock respite beds.

In order to prevent respite beds from reblocking, additional funds will be required for supported accommodation and for: a contingency fund for emergency support; intensive family support; and an accessible specialist support system for people with challenging behaviour.

Existing funds should also be harnessed under the following initiatives:

- (a) 1200 respite packages;
- (b) additional respite funds under the CSDA;
- (c) growth funds for supported accommodation;
- (d) growth funds for Alternate Care placements/Family Options project;
- (e) DoCS Child and Family funds;
- (f) opportunities arising from the devolution of large, children's residential respite facilities; and from the devolution of large residential facilities which include some respite places.

### **2.3 Managing the respite reforms**

Many of the current problems in the respite system have emerged largely as a result of ad hoc service development. Respite reform will require careful planning and collaboration between ADD, DoCS and non-government service providers. However respite reform will not be achieved without public endorsement by the Minister and a dedicated capacity within ADD, as the lead agency, to fund, drive, coordinate, monitor and review the reform strategies.

#### **Recommendation 12**

A distinct respite unit should be established within ADD to: oversight the implementation of the reforms; and to manage the provision of HACC and DSP funded respite care for people with disabilities in NSW. The goal of the unit would be to achieve a coordinated, consistent and planned approach to respite care provision for people with disabilities in NSW.

Functions of the unit would include:

- (a) establishing a collaborative framework and protocols with DoCS and non-government service providers and other key stakeholders to implement the reforms;
- (b) strategic and operational policy development and review;
- (c) strategic and operational planning and service development;
- (d) consistent and reliable data collections;
- (e) development of a mechanism to track access to, and usage of, respite services (including 'blocked beds') by people with disabilities, including people within the following target groups:
  - remote communities;
  - Aboriginal people and Torres Strait Islanders;
  - people from non-English speaking backgrounds; and
  - young people and children in residential respite for periods beyond 28 days in a single year;
- (f) ongoing implementation and evaluation of respite reform; and
- (g) integration of respite reforms with other ADD initiatives.

## **2.4 Reshaping the disability support system**

### **Recommendation 13**

ADD should, with adequate stakeholder consultation: develop an overall coherent plan and process for disability reforms in NSW; and clearly identify the connections between the many current policy developments and reforms under consideration. These reforms include: the NSW Adult Training, Learning and Support program; the policy for Children and Young People with Disabilities; Local Area Coordination; support coordination; devolution; comprehensive assessment; criteria for determining priority of access to services; vacancy management; the new regional planning framework; and respite reform.

### **Recommendation 14**

ADD should, with NSW Treasury, develop a funding model which is based on population group planning characteristics – similar to the Commonwealth planning ratios for aged care. Under such a model a set level or recurrent funding would be allocated for a proportion of the population projected to have a profound or severe handicap (CSDA target group). Such a funding model would aim to build on ADD's Population Group Planning model and address unmet need. The development of such a model would require continuation of ADD discussions with the Commonwealth on the linkages between ageing and disability programs.

### **Recommendation 15**

ADD should establish or foster disability networks between disability service providers in local areas to improve coordination of service provision and increase access for service users. This may be achieved by providing enhancement funding for coordination tasks to an existing, identified service provider in each local area or could be included in the tasks of a local area coordinator if such a model is funded in future.

### **Recommendation 16**

Funding should be pooled across funding programs and service types to establish and design flexible disability support services (as opposed to distinct service types such as respite) for Aboriginal people and Torres Strait Islander (ATSI) with disabilities consistent with the model recommended in the 1998 Family Dreaming report and the pilot project currently being established in the Nepean area.

- (a) A set of principles should be adopted to guide ATSI disability services (see draft principles in Family Dreaming report).
- (b) A mentoring program should be offered to new Aboriginal services with other disability service providers for management and administrative support where needed.

### **Recommendation 17**

Additional resources should be allocated to restructure and reform the specialist support system for people with challenging behaviours, in conjunction with government and non-government providers. Such a system should:

- (a) be locally accessible;

- (b) have a component for people and families with the most complex needs; and
- (c) examine the possible benefits of a telephone help line for families and carers.

**Recommendation 18**

ADD should establish a formal link with the Commonwealth Department of H&AC on the new respite initiative for people with challenging behaviours.

**Recommendation 19**

ADD should promote staff training in the prevention and management of challenging behaviour. Current funding agreements between ADD and service providers require service providers to comply with relevant ADD policies and guidelines – in this case, the Positive Approach to Challenging Behaviour Policy and Guidelines, and Standards in Action, both of which include the requirements for adequate staff training. ADD should ensure that the monitoring process includes compliance in this area and promote the range of training resources available.

**Recommendation 20**

ADD should develop information for families and carers to help them in the prevention and management of challenging behaviour at home. This should include information on the relationship between the physical environment and challenging behaviour (ADD).

**Recommendation 21**

Support coordination should be made increasingly available for all consumers with high/complex needs who require it. This strategy should be informed by: the implementation of the major coordination initiative across all human service departments; and possibly the formal evaluation of ADD's support co-ordination pilots (due for completion by end of 2001).

**Recommendation 22**

ADD should promote good practice in support planning for people with a disability. The effectiveness of the practice and monitoring of Individual Service Plans as a tool for achieving consumer outcomes should be evaluated.

**Recommendation 23**

Priority of access criteria should be introduced for all disability services, and area or regional vacancy management should be introduced for supported accommodation.

**Recommendation 24**

Subject to trial, evaluation and review of lower-cost community living options (cotenancy, individual or shared accommodation with low level drop-in support), these options should be promoted for people with low support needs who may be in long term respite because of carer death, illness or breakdown.

**Recommendation 25**

ADD should further investigate (refer to ADD's 1997 study), trial and review alternative specialised support models (including supported accommodation) for young people with high support needs (particularly autism and challenging behaviour), as current models do not appear to meet their needs.

**Recommendation 26**

ADD should develop, fund and promote a range of flexible support options for children with disabilities using a whole-of-family approach and family support packages.

**Recommendation 27**

In partnership with DoCS, ADD should promote policy and service development in the Child and Family service system to respond more appropriately to the needs of children with disabilities.

**Recommendation 28**

ADD should investigate current fee charging practices for disability services and develop fee guidelines which protect the rights of people with a disability and their families and carers and promote equity of access to services.

**Conclusion**

Over time, as these reforms are implemented:

- the focus of respite should shift away from residential care towards a range of flexible in-home and out-of-home community based respite services; and
- the focus of disability service provision should shift away from service types towards the needs of the unit of the person with a disability and their family or carer.

## **Appendix 7**

### **New South Wales Performance Audit Report**

### **Large Residential Centres for People with a Disability in New South Wales June 1997**

Executive Summary and Recommendations

## Executive Summary

### The Audit

A performance audit into the provision of residential services for people with an intellectual disability was undertaken by The Audit Office with the Community Services Commission. The audit was suggested by the Commission and requested by the Minister for Community Services following the release of the Lachlan Report (which identified poor practices in a large disability residential centre).

The audit reviewed policies and practices in large government and non-government residential centres to determine if policies and practices protected the human and legal rights, safety and dignity of residents.

The audit was conducted in seven government institutions and three non-government institutions.<sup>185 186</sup> The audit focussed attention on ten practice areas considered critical to protecting the legal and human rights, safety and dignity of residents and assessed the policies and practices in institutions against these criteria.

### Moving from Institutions to the Community

There is broad recognition that institutions are outmoded models of care. Successive state governments have indicated a commitment to closure of large residential centres and their substitution with community based facilities. But the population in these institutions remained more or less the same, providing accommodation for approximately 2,388 people with a disability.

There is now the danger that in these institutions, which are marked for transition to community based facilities, the services and protection will continue to decline due to the lack of attention and funding, thus further aggravating the already poor state of affairs. It is for this reason staff in the centres say "*close us down don't run us down.*"

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<sup>185</sup> The term institution has been used in this context to describe large residential accommodation centres for people with an intellectual disability that were viewed as part of the audit.

<sup>186</sup> These institutions provided services which were not in *conformity* with the Objects, Principles and Applications of Principles of the Disability Services Act 1993 and had not received funding to implement transition plans.

**Government  
Policy  
Disability  
Services Act**

The NSW Disability Services Act was introduced in 1993 along with ten Disability Service Standards. These Standards are based on an interpretation of the Objects, Principles and Applications of Principles set out in Schedule 1 of the Act.

The Disability Services Act 1993 requires disability services, whether funded (non-government services) or provided by the Minister for Community Services, to be provided in *conformity* with the Objects, Principles and the Applications of Principles of the Act. Services which do not *conform* are required to prepare a transition plan of strategies to be employed by the service to achieve *full conformity* and the funding required to fully implement the plan.

Large residential centres by their very nature can never provide services in *full conformity* with the Objects, Principles and Applications of Principles of the Act. Transition plans for institutions focus on the process of transferring people with disabilities from the existing facility to community based settings (that comply with the requirements of the Government's Accommodation Support Policy of no more than six residents per dwelling).<sup>187</sup>

However, none of the residential centres visited by audit had received funding to implement transition plans. While awaiting funding, these centres are required to *conform as closely as possible* with the Act.

**Service  
Standards**

The Disability Service Standards provide an interpretation of *conformity* with the Act. Disability services that claimed to be providing services which meet the requirements of the Act were assessed against these Standards and the Objects, Principles and Applications of the Principles of the Act.

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<sup>187</sup> The NSW Accommodation Support Program states that:

It is recognised that in a small number of cases, there might exist circumstances that require the consideration of service configurations which vary slightly from those stated. In such cases, the Minister will consider these special circumstances before deciding whether or not the proposed accommodation support service is eligible for funding under this program. Such special circumstances will be based on the second of Government's fundamental accommodation goals, that persons with disabilities have the right to choose their own lifestyle, as well as have access to the information necessary to allow informed choice.

(Ageing and Disability Department *NSW Accommodation Support Program* 1996 page 5).

In contrast, there is no definition, nor measurable criteria for *conforming as closely as possible* until funding for transition is received. Nor are there any criteria which establish the basic requirements for resident safety and protection from abuse. This means that while the Act and the Standards provide measures for the overall quality of service, there are no measures to determine when a centre is simply unacceptable because it is unsafe.

**Operational  
Policies in  
Government  
Centres**

Policies guide practices. Government centres use the Department of Community Services *Policies for Working with People with Disabilities*, released in January 1996, as centre policies. These policies represent an important development in establishing guidelines for the provision of services for people living in government centres.

Policies cover critical areas necessary to protect human and legal rights, safety and dignity of residents but are deficient in two areas of interest to this audit, fire safety and the management of critical incidents including resident accidents and injuries.

Audit found significant differences in how government centres had approached and progressed the implementation of these policies and the degree of practice compliance with policy directions. However, there are structural limitations in institutional settings which prevent the successful implementation of all Department of Community Services' policies (and thus prevent institutions achieving *conformity* without reconfiguring the accommodation).

**Operational  
Policies in  
Non-government  
Centres**

Non-government centres face the same difficulties and limitations as government centres in providing quality services in an institutional setting. However beyond this, none of these centres had developed a set of operational policies which was adequate to protect residents. Some non-government service providers had developed a few policies, but they were deficient in coverage (they did not cover the ten critical practice areas) and, or content (did not provide adequate guidance to staff).

**Government and  
Non-government  
Centres**

In most centres, there were deficiencies in the approach to the implementation of policy; staff were either unaware of the existence and content of policies or had not received training to support the implementation of policy.

**Ageing and  
Disability  
Department**

In 1995, the Government established the Ageing and Disability Department, responsible for policies and programs for people with disabilities. The change separated strategic policy, planning, funding, monitoring and evaluation of disability services from service delivery; all were undertaken at the time by the Department of Community Services.

To date, minimal assistance has been provided by the Ageing and Disability Department to guide both government and non-government centres in the development of policies, particularly in critical practice areas.

**Monitoring  
Service Delivery**

Information regarding the performance of large residential centres is not readily available. There are no indicators of service delivery or benchmarks against which large residential centres can be judged.

**Centre Based  
Monitoring**

Current systems for monitoring residential centres in terms of accountability and ensuring practices comply with policies and Standards are not effective. Accordingly, there is no assurance that deficiencies would be identified by centre management or those external to the centre with the power to intervene.

**Practices in  
Residential  
Centres**

To compare practices to operational policies, the Disability Service Standards and legal requirements, the audit focussed on practices in the ten critical areas. Findings are outlined in Table 1.

<b>Table 1: Summary of Key Findings in Practice Areas</b>	
<b>Practice Issue</b>	<b>Government and Non-Government Centres</b>
<b><i>Behaviour Management</i></b>	The effectiveness of behaviour management in institutions is limited. Even where management plans are prepared, centres often only achieve behavioural control of residents through medication and containment rather than long term behavioural change.
<b><i>Management of Incidents Including Injuries and Assaults</i></b>	Incidents are inconsistently defined, reported, monitored, analysed and are generally not well managed. The largest category of injury to residents is reported to result from resident to resident aggression. The risk factors are poor staff to resident ratios, resident mix, number of residents in the centre, configuration of accommodation, the effectiveness (or existence) of behaviour intervention plans and the centres ability to identify and implement preventative strategies.
<b><i>Medication Controls and Consent</i></b>	In government centres, controls over the administration of medication often fail and the legal requirements for gaining consent are often breached.  In the non-government centres, medication controls were either non existent or ineffective and the legal requirements for gaining consent for medical treatment were poorly understood and often breached. Across all centres, failure to gain consent for medication, particularly psychotropic, was a problem.
<b><i>Nutrition, Hygiene and Health Care</i></b>	All centres had systems for monitoring resident health but recording and monitoring of this information was unreliable and did not assure timely and appropriate intervention. Two non-government centres received donated foods to supplement the menu. Few centres had arrangements for therapy services or nutritional assessments.
<b><i>Community Access</i></b>	Community access is still dominated by diversional activities such as group bus rides and group outings with no focus on community integration.
<b><i>Promoting Access to Family and Friends</i></b>	In most centres there are no restrictions on visiting hours or formal practices that would prevent family contact and in most cases family contact is supported and promoted by the centre. However, the nature of institutional services mitigates against extended contact.
<b><i>Privacy and Dignity</i></b>	Dormitories, open plan bathrooms, common dining and sitting rooms deny residents an acceptable level of privacy. The features of institutional living do not protect and promote dignity.
<b><i>Individual Service Planning and Skill</i></b>	Most centres are structured to meet management, staff and organisational requirements not the needs of residents. Even when individual plans are prepared, the plans are not always used to provide support to meet the needs of residents. Opportunities for skill development are limited in institutional settings.
<b><i>Safety</i></b>	The risk of injury is a major factor affecting resident safety. There is no policy for fire safety procedures in government centres resulting in varied approaches to (and success in) risk reduction. The general response by centres to environmental safety risk facing residents is containment.
<b><i>Dealing with Complaints and Concerns</i></b>	Not all centres had established effective procedures for investigating and managing complaints, and families (and residents) were unsure of their rights. Data on complaints is not monitored by Ageing and Disability Department. Families and staff indicated a fear of retribution if they raised concerns or made complaints to service providers.

**Assessing Services**

Because there was no evaluation methodology for assessing service delivery in large centres, The Audit Office developed criteria and a methodology to test practices in each of the critical areas. This methodology has and will be used by the Community Services Commission and other agencies to conduct evaluations of service delivery.

It was not possible to complete the review of all areas that were included in the original scope of the performance audit. The areas that were not reviewed were staffing levels, competencies and the recruitment of staff to institutions, the management of consumer finances and the audit of service delivery in group homes.

The Audit Office would consider a request to complete the review of the outstanding areas subject to audit commitments and funding.

**The Hall for Children**

The Hall for Children was one of the centres visited by the audit. As a consequence of that review, The Audit Office agreed to the release of working papers prior to the tabling of this report so that the Community Services Commission could complete an Inquiry into that centre. Following that Inquiry, the Minister for Community Services decided to close the centre.

**Factors Contributing to Service Delivery Staffing Issues**

A number of other factors were identified as having an impact on service delivery.

Government institutions are a medical model of care and employ only nurses. There is no flexibility to match the mix of staff with the needs of residents. Work arrangements such as shift patterns (and associated costs) have impacted negatively on service delivery and client outcomes.

In non-government centres, recruitment practices can result in inexperienced staff providing residential support to people with an intellectual disability.

**Resources**

There are no principles to guide resource allocation decisions. The amount of funding an institution receives is based on historical factors not measures such as inputs (eg. needs of residents, salaries, rent, operating overheads), outputs (centre related products) or outcomes (related to the achievement of outcomes).

The effects of this is seen in differing standards of accommodation, staff to resident ratios, access to specialist services, provision of staff training and the provision of day activities.

**Physical  
Condition of  
Accommodation**

The Department of Community Services 1997 property condition audit of its major assets (buildings) identified that large residential centres are in a poor condition and required significant funds (estimated by it to be \$22m) to bring them to an acceptable standard. A number of the problems identified relate to resident safety and the basic condition of their accommodation.

This is consistent with audit findings that the physical condition of buildings accommodating residents in large government centres varied from impoverished to acceptable (although still inappropriate).

**Respite**

People with an intellectual disability can be placed in institutions on a respite or crisis basis.<sup>188</sup> These people, because of their specific needs, can have a detrimental impact on other residents and conflicts can arise.

**Advocacy**

People with an intellectual disability need access to advocacy support to participate in decision making about the services they received.

There is significant unmet demand for advocacy services by residents of large centres. The inability of these residents to articulate their feelings, needs and wants without assistance, renders them voiceless and potentially vulnerable consumers.

**Guardianship**

There are residents in institutions who require the appointment of a guardian to protect their interests. Sometimes the person responsible for making decisions on behalf of the resident has little contact with the resident.

**User Pays**

Some centres are reluctant to use residents' funds to improve the quality of a resident's life. There appears to be some confusion about which services and goods should be provided by centres and which should be purchased by residents.

**Guarantee of  
Service**

It was noted during the course of the audit that a guarantee of continuing care was provided by the Government, through the Minister for Community Services in 1996 to residents of government institutions that were to move to the community. In contrast, residents of non-government institutions did not receive any guarantee of continuing care from the Government.

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<sup>188</sup> Respite refers to a short term and time limited break for families and caregivers of people with intellectual disabilities, to assist in supporting and maintaining the primary caregiving relationship, whilst providing a positive experience for the person with a disability.

## **Conclusions**

The report indicates that practices in both government and non-government centres fail to protect adequately the human and legal rights, safety and dignity of residents.

Factors contributing to this situation are the absence of minimum criteria for the protection of residents' human and legal rights, safety and dignity, inadequate policies to direct service delivery, the absence of staff training to reinforce practices, low levels of supervision and the absence of effective monitoring systems to trigger a response to service deficiencies.

Even where policies have been developed to guide practices, the nature of institutional care (the environment renders some policies ineffective), inadequate implementation, inadequate monitoring of practices and lack of compliance results in the centre's failure to protect people living there.

Other factors which are more difficult to remedy are those inherent to institutional models of care. These include the whole of life, umbrella approach to the delivery of services, the custodial and impersonal nature of care, the segregation of institutions from the community, the inability of institutions to provide a home-like environment and the inability of institutions adequately to address the physical, emotional, social and skill development needs of residents.

These features of institutional care mean that even if centres met the requirements of basic safety and rights, institutions could never meet the individual needs of people with a disability or provide the quality of life envisaged by the Disability Services Act 1993.

Even though community opinion on the movement of people from institutions to community based settings is polarised, the Government's position on providing services for people with an intellectual disability is to provide services necessary for people to achieve their maximum potential.

The Government recognises that people with an intellectual disability can not achieve their maximum potential while they remain in an institution.

It is acknowledged that considerable cost is involved in implementing the recommendations of this audit. The cost involved in moving people from institutions to community based settings is substantial. In the meantime, while people remain in institutions it will be necessary to ensure that they live in a safe environment. This too will involve considerable cost.

The findings of this audit make it clear that the safety of people with an intellectual disability is jeopardised when living in institutions. Service providers and the Government have a legal duty of care to take all reasonable steps to protect these people from foreseeable harm. The failure to do so leaves them exposed to legal actions for damages. For this reason too, it is imperative that the Government act urgently on the recommendations of this report to protect the rights and safety of people with an intellectual disability. In the short term, the immediate safety of people residing in institutions must be addressed as soon as possible.

It is the mark of a developed and just society that provides care for those who can not care for themselves.

### **Recommendations**

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The recommendations of this report, unless otherwise indicated, concern large government and non-government residential centres for people with an intellectual disability providing services which do not *conform* with the Objects, Principles and Applications of Principles of the Disability Services Act 1993 and have not received funding for transition.

The recommendations present both long term changes for large residential centres (awaiting funding for transition) and short term, interim measures to address service deficiencies while awaiting transition.

Transition to *full conformity* for a large residential centre can take from 5 to 7 years to complete as indicated by their transition plans. In order to protect the human and legal rights, safety and dignity of residents during that time, recommendations should be implemented immediately concerning:

- mechanisms to protect people living in institutions including service improvements to reduce the congregate nature of the accommodation and to monitor service quality
- the reduction of service inequities.

The Community Services Commission has indicated that it will follow up and monitor the implementation of recommendations of this report.

### **Reconfigure Institutions**

**In regard to transition of large residential centres, it is recommended that:**

#### **Funding**

1.1 The Government fund the transition of large government and non-government residential centres for people with an intellectual disability to enable services to be provided in *full conformity* with the Objects, Principles and Applications of Principles of the Disability Services Act 1993.

1.2 By way of Regulation to the Disability Services Act 1993, a target date of 7 years from the date of tabling this report be considered for the complete transition of all institutions.

An implementation timetable should be prepared to diminish the effect of uncertainty that currently exists in centres targeted to reconfigure to community based accommodation, and allow centres properly to plan service delivery up to, and following, moving to the community.

#### **Children's Services**

1.3 As a priority, the Government consider the movement of children under the age of 18 years currently in institutional care to community based settings that match individual need.

### **Interim Recommendations for Service Improvement**

**The following are interim but essential measures to address deficiencies while awaiting transition:**

#### **No Admissions Policy**

2.1 The Government consider a policy for institutions, to ensure that no more people are placed into these (non-conforming) institutions (government or non-government), even on a respite or crisis basis.

The Ageing and Disability Department should ensure that any persons needing crisis or respite accommodation should be assisted to obtain admission to non-institutional residential centres.

As an immediate safeguard to protect the rights of any person for whom institutional placement is proposed, such decisions should only be made by the Guardianship Board (as an independent substitute decision maker) in the case of adults, and by the Minister for Community Services in the

case of children, where it can be demonstrated that such placement is the only available option to meet the person's needs. This decision making authority should not be delegated, and should be provided through legislative amendment if necessary.

### ***Service Standards***

**In regard to protecting the rights, safety and dignity of resident in large residential centres, it is recommended that:**

#### **Conforming as Closely as Possible**

2.2 The Ageing and Disability Department define the requirements for large residential centres to *conform as closely as possible* to the Objects, Principles and Applications of Principles, pending implementation of transition plans. This definition should:

- include baseline criteria for the protection of residents basic human and legal rights, safety and dignity in the 10 critical practice areas detailed in Appendix 7. Centres must be required to meet this criteria within 12 months
- a staged approach reflecting progressive service improvements each year.

The definition of *conforming as closely as possible* should not be restricted to service enhancements that are cost neutral.

#### **Funding Agreement**

2.3 The baseline criteria for resident safety and protection be included in the 1997/98 funding agreements with non-government centres and service contracts with the Department of Community Services. These criteria should be used to judge service delivery and where centres do not meet the baseline criteria within 12 months, funding should be withdrawn.

Progressive service improvements which allow centres to *conform as closely as possible* should be identified by the centre (involving residents and their families) in conjunction with the Ageing and Disability Department and incorporated into annual funding agreements or service contracts.

2.4 Ageing and Disability Department consider the application of the baseline criteria for resident safety and protection to all accommodation services (institutional or community based) through funding agreements.

<b><i>Protection for Individuals</i></b>
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**It is recommended that:****Guardianship**

2.5 Service providers identify and refer to the:

- Guardianship Board residents who may need a guardian. Attention should be paid to those residents whose behaviour or medical needs require significant or intrusive treatment, and residents who have no involved family who can act as “person responsible”.
- Department of Community Services any children who have not had substantial contact with their parents over the past 12 months.

Community Visitors should monitor individual needs in relation to guardianship, and report to the Community Services Commission where appropriate action has not been taken.

**Advocates**

2.6 The Ageing and Disability Department ensure that there are sufficient advocacy services to meet the needs of people living in institutions. The provision of additional services should be considered in the context of the NSW Advocacy Development Plan.

<b><i>Centre Policies</i></b>
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**It is recommended that:****Policy Development**

2.7 The Ageing and Disability Department:

- provide policy guidance on baseline criteria referred to in 2.2
- assist centres to develop their own policies that reflect the baseline criteria
- review policies developed by centres to ensure they meet baseline criteria.

**Policy Gaps**

2.8 The Department of Community Services include in its *policies for people with disabilities* practice requirements regarding:

- fire safety
- reporting and investigating critical incidents and injuries involving residents.

**Monitoring Service Delivery****It is recommended that:****Ageing and  
Disability  
Department**

2.9 The Ageing and Disability Department establish:

- baseline criteria for service delivery described in 2.2 to be stipulated in funding agreements with non-government organisations and service contracts with the Department of Community Services
- requirements for information in relation to consumer outcomes and the performance of services against the baseline criteria and progressive service improvements. These requirements should be stipulated in the funding agreements and the service contracts
- a program of independent audits of large residential centres to enable the Department to verify self assessments
- a system for independently reviewing and monitoring the use of psychotropic medication in large residential centres
- a system to enable the Department to monitor complaints about service delivery in large residential centres.

2.10 In relation to the institutions reviewed as part of the audit, the Ageing and Disability Department should monitor the implementation of service improvements to meet the deficiencies identified by audit.

2.11 The Government undertake a review of the effectiveness of service monitoring by the Ageing and Disability Department within 2 years from the date of tabling this report.

2.12 Information on individual centre practices and systemic issues arising from the functions of the Community Services Commission including Community Visitors should be provided to the Ageing and Disability Department. Such information should be used to monitor services and considered in assessing annual funding.

**Residential  
Centres**

2.14 Each residential centre establish a system of monitoring service delivery that consists of:

- collecting and analysing data on practices in critical areas
- regular reporting to key stakeholders on key aspects of service delivery including performance against funding criteria and practices in critical areas
- positions descriptions that clearly indicate to staff responsibility and accountability for the quality of care.

### ***Service Improvements***

#### **It is recommended that:**

#### **User Pays**

- 2.15 Ageing and Disability Department provide policy guidance which:
- clarifies the goods and services to be provided by the centre within the fee structure
  - outlines a process for centres to employ for identifying user pay options
  - outlines accountability mechanisms for the use of consumer funds.

#### **Service Improvements**

- 2.16 Large residential centres should implement steps to meet better the needs of individuals, while awaiting implementation of transition plans, such as:
- reducing congregation by limiting the size of resident groupings for activities and promoting alternate accommodation models using existing facilities
  - moving day activities off site into the community or arrange for residents to attend community based day activities
  - providing greater opportunities for resident skill development through improved training programs and access to facilities to practice skills acquired.

#### **Resident Rights**

2.17 Centres should provide printed information to residents, family members, advocates and other representatives which outline the obligations and responsibilities of the centre, and the legal rights and responsibilities of residents and their representatives. This information should include the details of organisations who can provide further assistance.

### ***Improving Equity in Service Delivery***

**In order to rectify some of the inequities developed over the years, as a consequence of financial assistance to residential centres being determined by historical grant levels without regard to equity or the results of service provision, it is recommended that:**

#### **Allocation of Resources**

2.18 The Ageing and Disability Department introduce a funding system for non-government centres which allocates funds according to the assessed needs of residents and agreed outcomes to be achieved.

Funding to non-government centres should be reviewed against this model and adjusted accordingly.

**Addressing Inequities**

2.19 The Department of Community Services should develop a rational approach to the distribution of funds to its government centres.

2.20 The Department should also review the allocation of funding to each large government institution to address inequities in:

- staff to resident ratios
- access to specialist services
- condition of accommodation
- resources available for staff training
- provision of day activities.

**Accommodation Standards in Government Centres**

2.21 The Government, as a priority, make available sufficient funds to implement recommendations in the Department of Community Services' property condition audit that relate to issues of resident safety and the basic condition of accommodation in large residential facilities.

2.22 In determining priorities for refurbishment of large residential centres, consideration be given to:

- bringing the standard of accommodation for residents to an acceptable level
- decreasing resident groupings to reduce congregation within large residential centres. This includes the size of the groups in shared sleeping arrangements, size of groups using same living facilities (bathrooms, dining areas, sitting rooms).

However, further expenditure should be avoided where it would prolong the existence of institutions as a model of care.

<b><i>Improving the Effectiveness of Service Delivery</i></b>
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**It is recommended that:**

2.23 The Department of Community Services examine the opportunities for improving service delivery in large residential centres that would result from:

- changes in staffing arrangements from 8, 10 and 12 hour shifts to 8 hour shifts in all centres
- changes in staffing mix (nurses are employed in large government residential centres when employment of residential care workers or assistants would sometimes be appropriate).

## **Response to the Report**

The Public Finance and Audit Act 1983 stipulates that at least 28 days before tabling a performance audit report, the Head of the authority and the responsible Minister are to be provided with a summary of findings and proposed recommendations in relation to the audit.

In accordance with the Act a full copy of the proposed report was provided to the Directors-General of the Departments of Community Services and Ageing and Disability and to the Minister for Community Services and Minister for Disability Services, as the responsible Minister, on 21 May 1997.

In subsequent discussions with the Minister's Office, The Audit Office was advised that the Minister's Office would coordinate a response to the report. On 13 June 1997 the Chief of Staff of the Minister's Office advised The Audit Office that there will be no response from either the Minister's Office nor the Departments.