Standing Committee on Social Issues

Making It Happen

Final Report on Disability Services

Ordered to be printed 14 November 2002

New South Wales Parliamentary Library cataloguing-in-publication data:

New South Wales. Parliament. Legislative Council. Standing Committee on Social Issues
Making it happen : final report on disability services / Standing Committee on Social Issues. [Sydney, N.S.W.] : The Committee, 2002. – xxviii, 179 p. ; 30 cm. (Report 28, November 2002) (Parliamentary paper ; no. 247)

Chair: Jan Burnswoods

“Ordered to be printed 14 November 2002”.

ISBN 0-7347-6469-3

Disabled—Services for—New South Wales.
Handicapped—Services for—New South Wales.
Title
Burnswoods, Jan.
Series: New South Wales. Parliament. Legislative Council. Standing Committee on Social Issues. Report ; 28
Series: Parliamentary paper (New South Wales. Parliament) ; no. 247

362.409944 (DDC21)

How to contact the Committee

Members of the Standing Committee on Social Issues can be contacted through the Committee Secretariat. Written correspondence and enquiries should be directed to:

The Director
Standing Committee on Social Issues
Legislative Council
Parliament House, Macquarie Street
Sydney New South Wales 2000
Internet www.parliament.nsw.gov.au
Email socialissues@parliament.nsw.gov.au
Telephone 02 9230 3078
Facsimile 02 9230 2981

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 James Samios, MLC, **Liberal Party, Deputy Chair**
from 20 June 2002

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 late Hon Doug Moppett, MLC, National Party, served as Deputy Chair on the Committee from 25 May 1999 to 14 June 2002. Mr Samios was appointed in place of Mr Moppett.

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.

Table of Contents

Figures and Tables

Chair's Foreword

I am pleased to present this third and final report for the inquiry into residential and support services for people with disability. The first report, ***The Group Homes Proposal***, was tabled in December 1999, and the second report, ***A Matter of Priority,*** in December 2000.

At the outset I would like to thank every person who participated in the inquiry by writing a submission, giving evidence, or attending a consultation. We are particularly grateful to all the people with disability who took part. Each of you has made a vital contribution to the inquiry and to the crucial task of improving disability services in New South Wales.

The inquiry has been about people's lives. While this report is focused on systems and structures, it is really about ways to improve those systems so as to create an inclusive society, a society where people with disability have the same opportunities as other people.

For too long people with disability in New South Wales have been waiting for a system that meets their needs and which supports them to fulfil their potential. This report calls on the Government to deliver that system, to 'make it happen' now.

During the past three years we have had the opportunity to meet with a range of people with disability, and the many parents, advocates and peak organisations who are in daily contact with the disability service system. These meetings have had a profound effect on Committee members and staff.

This report could not have been produced without the dedication of Committee members and I thank them for their commitment to the inquiry. On behalf of the Committee I would also like to thank the members of the Secretariat - Tony Davies, Merrin Thompson, Julie Langsworth, Beverly Duffy, Heather Crichton and Victoria Pymm - for all their work, and their unfailing courtesy and good humour.

This report is the third that the hard-working Social Issues Committee has tabled within a month. As in the other two, we pay tribute to our previous deputy chair, the late Hon Doug Moppett, MLC, who worked tirelessly on this inquiry. Doug had a longstanding commitment to improving services for people with disability and constantly reminded us of the needs of people in rural and regional places where services are few and far between. We miss his wisdom.

The recommendations in this report are made with considerable thought and after extensive consultation. I urge the Government to consider these recommendations in the light of the urgent need to provide people with disability in this State with a system that will afford them the dignity and quality of life that is their right.

I commend this report to the Government.

Jan Burnswoods, MLC
Chair

Executive Summary

This is a plain English Executive Summary. It is written for people with disability so that everyone can read what we said in our report. This report has been written by a Committee of 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. We have also released 2 other reports about disability services. If you want copies of our other reports call us and we will send them to you.

This inquiry has been about making sure people with disability have the same rights and opportunities as every other member of the community. This final report is about making it happen. The report is in two parts.

Part 1: Equity of Access

There are some groups of people with disability who find it harder than other people with disability to obtain support. These include people from other cultures, Aboriginal people, and people who live in country areas. People with physical disability and those people with acquired brain injury also have difficulty accessing services. We have also looked at the needs of people with disability who are getting older. Part 1 of the report looks at ways to help these groups of people get more support.

Part 2: Building the System

The second part of the report looks at ways to make things better for all people with disability. People have told us that they have difficulty finding somewhere to live. We also heard that more should be done to help people who live in institutions to move into the community. We have suggested ways to help these people. We also think that there is a need for more respite care to help people with disability and their carers.

We believe that the disability service system needs to change.

At the moment it is very hard to get support. People have to be in a lot of trouble before they can get help. Many people don't know where to go to get some help.

When people with disability need help they should be able to get it quickly. Many people and their carers also need a person to help them choose what type of support they need.

We think DADHC should set up a new system to make it easier for people with disability to get help. We have called this a **general intake and support coordination system**. This system would help people with disability and their carers to get help. It will also make sure that DADHC is better at managing disability services. Some people would use it to get information. Other people would use it to get services like supported accommodation.

We have also suggested ways to help children with disability and their families. It is important that people and their families get help as early as possible. Parents with disability often need help to look after their children. We think it is very important that parents with disability get plenty of help.

People told us that they want much more choice about how they live. Many people want to live independently and need help to do this. We think that DADHC should find new ways to support people with disability who want to be more independent.

Lots of people told us that the Government should have a long-term plan for people with disability. We think that a plan will help people to understand what the Government is trying to do to help people with disability. The Government should talk to people with disability about what they need and then make a plan. The plan should show people what the Government is going to do to support people with disability. The plan should be called the **State Disability Plan**.

More money is needed to help people with disability. We think that the Government should find a way to make sure that enough money is available to help people with disability.

Summary of Recommendations

Part 1: Equity of Access

Recommendation 1 ***Page 10***

The Department of Ageing, Disability and Home Care should, in consultation with representative groups, establish Departmental targets for equitable service access by people from culturally and linguistically diverse backgrounds.

- Targets should be established for vacancy management, service growth within existing programs and in new programs
- Performance against the targets should be monitored reported upon in the Department's annual report, and
- An implementation plan should be developed that outlines the specific steps that will be taken to meet the targets.

Recommendation 2 ***Page 11***

The Department of Ageing, Disability and Home Care should adopt a culturally competent approach to disability services which includes:

- The development of explicit NESB access strategies as an essential and ongoing component of all its programs and services
- A systematic approach to consultation with culturally diverse groups in order to inform policy and program development and implementation
- The implementation of mechanisms such as service guidelines, performance measurements and monitoring systems to ensure that funded service providers deliver culturally inclusive disability services.

Recommendation 3 ***Page 12***

The Department of Ageing, Disability and Home Care should establish a cultural diversity working party comprising representatives of people with disability from culturally and linguistically diverse communities to assist the Department with the development and implementation of policy and programs for people from diverse backgrounds.

Recommendation 4 ***Page 12***

The Department of Ageing, Disability and Home Care should undertake a comprehensive information and education campaign for culturally diverse communities to raise their awareness about and access to the range of services for people with disabilities, their families and carers.

Recommendation 5 ***Page 12***

The Department of Ageing, Disability and Home Care should routinely publish information in key community languages at the same time as it does so in English.

Recommendation 6 ***Page 12***

The Department of Ageing, Disability and Home Care should adequately resource the services it funds to undertake translations and utilise interpreting services.

Recommendation 7 ***Page 16***

In consultation with representatives of the Aboriginal community, the Department of Ageing, Disability and Home Care should develop a policy framework for Aboriginal service delivery. The policy framework should outline specific strategies to address:

- the need for autonomous Aboriginal disability services
- the mechanisms that can be put in place to support communities in their governance of services, for example training for boards of management as well as workers who will work in partnership with them
- potential mechanisms to achieve a better balance between accountability and flexibility
- appropriate levels of funding for holistic and community-focused services.

Recommendation 8 ***Page 16***

The Department of Ageing, Disability and Home Care should undertake a survey of need within Aboriginal communities to determine the level of need for disability services.

Recommendation 9 ***Page 19***

The Department of Ageing, Disability and Home Care should, in consultation with the Department of Transport, develop a rural transport strategy to improve the availability of community transport for people with disability in rural and remote areas. The strategy should include:

- A process for identifying demand for community transport at a regional level
- Population-based funding benchmarks for the provision of community transport.

Recommendation 10 ***Page 23***

The Department of Ageing, Disability and Home Care and NSW Health should develop a comprehensive rural and regional therapy strategy to improve the availability and effectiveness of therapy services in regional areas. The strategy should:

- Ensure that policy and eligibility criteria for access to therapy is consistent across DADHC Regions and Area Health Services and that services gaps are eliminated
- Provide specific funding to cover therapist travel time
- Examine ways to maximise the use of available therapist time and skills through greater use of consultancy models of therapy and recruitment of local therapy assistants
- Address the need for incentive measures to attract therapists to live and work in non-metropolitan areas.

Recommendation 11 ***Page 26***

The Department of Ageing, Disability and Home Care should develop a rural and remote area service delivery strategy to enhance the level of support available to people with disability and their carers in rural and remote communities. The strategy should be developed in consultation with relevant stakeholders, including people with disability, indigenous groups and regional advocacy organisations. The strategy should:

- Ensure that planning and resource allocation for rural and remote services takes sufficient account of the costs of service provision in those areas
- Clarify the role of government and non-government services in providing services in rural and remote areas, and the level of support provided to non-government services in these areas

- Examine ways to promote innovation and flexible service delivery in rural and remote areas.

Recommendation 12 ***Page 29***

The level of subsidy provided under the Taxi Transport Subsidy Scheme should be increased by 5 percent per year over a period of five years until it reaches a level of 75 percent.

Recommendation 13 ***Page 30***

The Department of Ageing, Disability and Home Care should immediately review the process for allocation of attendant care packages in order to remove delays and ensure that existing packages are allocated as soon as possible.

Recommendation 14 ***Page 30***

The Department of Ageing, Disability and Home Care should, in consultation with relevant user groups and workforce representatives, undertake a review of personal care funding and services to identify ways to improve their accessibility, efficiency and flexibility. The review should specifically examine ways to ensure that adequate safeguards for people with disability and workers are retained within a more flexible support structure.

Recommendation 15 ***Page 31***

The Government should provide adequate funding for personal care, aids and appliances and therapy services, using population-based formulas that estimate need.

Recommendation 16 ***Page 32***

The Department of Ageing, Disability and Home Care and NSW Health should develop joint models of support for people with complex care needs which comply with the *Disability Services Act 1993*, and which are delivered through the disability service system.

Recommendation 17 ***Page 37***

The New South Wales and Commonwealth Governments should collaborate to develop an agreed process and funding arrangement to address the inappropriate placement of younger people with disability in nursing homes. As a first step, they should develop and pilot joint funding models for priority groups of current residents.

Recommendation 18 ***Page 40***

The Commonwealth Government should allow people with disability to become eligible for Commonwealth ageing programs from age 55.

Recommendation 19 ***Page 40***

The Department of Ageing, Disability and Home Care, in collaboration with the Commonwealth Government, should develop a plan of action to address the diverse needs of people with disability who are ageing. This should be based on principles of flexibility and collaboration between the aged care and disability sectors and include the establishment of jointly funded models of support.

Recommendation 20 ***Page 45***

The Department of Ageing, Disability and Home Care should acknowledge people with acquired brain injury as part of the target group for the Disability Services Program.

Recommendation 21 ***Page 45***

The Department of Ageing, Disability and Home Care, in collaboration with the Motor Accident Authority, Workcover, NSW Health and Treasury, should develop a funding and policy framework for strategically addressing the needs of people with brain injury across New South Wales, in order to improve their access to the range of disability and mainstream support services, and to brain-injury specific services. In particular, this framework should consider:

- Living skills and behaviour/social skills development services
- Accommodation, respite, case management, meaningful day activities, education and employment supports.

Part 2: Building the System

Recommendation 22 ***Page 49***

The Department of Ageing, Disability and Home Care should, in consultation with stakeholders, identify those recommendations of the Committee's earlier reports, *The Group Homes Proposal* and *A Matter of Priority*, that remain relevant and progress their implementation.

Recommendation 23 ***Page 57***

Taking into account existing information about unmet demand for accommodation and respite services, the Department of Ageing, Disability and Home Care should fund additional respite services.

Recommendation 24 ***Page 57***

Following the introduction of new Minimum Data Set collection procedures, the Department of Ageing, Disability and Home Care should undertake a survey of the supply and demand for respite services in New South Wales to measure the effect of recent reforms and to provide a basis for planning for service growth. The survey should:

- Be undertaken on a regional basis
- Determine whether there is an appropriate balance between flexible and centre-based respite services
- Examine the extent to which respite services meet the needs of people from culturally and linguistically diverse backgrounds, people with physical disability and people with acquired brain injury.

Recommendation 25 ***Page 61***

The devolution project should be managed on a centre by centre basis and provide residents of each centre with the opportunity to remain with a single service provider. Where appropriate, existing services should be funded to support residents in the community, provided that:

- Residents who do not wish to remain with their current service provider are able to move to another service provider
- Flexibility within the system is maintained so that people have the opportunity to change their support arrangements following their initial move into community living.

Recommendation 26 ***Page 62***

As a matter of urgency, residential care workers should be employed to work alongside nursing staff in large Department of Ageing, Disability and Home Care residential centres.

Recommendation 27 ***Page 63***

The next stage of the devolution project should commence immediately. Identification of services to be included in the second round of devolution should be based on consultation and include those services that are strategically placed to move forward rapidly on the devolution project.

Recommendation 28 ***Page 63***

A devolution unit should be established within the Department of Ageing, Disability and Home Care to manage the devolution process. Resources and staffing for this unit should be sufficient to ensure that all large residential centres for people with disability are able to complete their transition into community-based services that conform to the *Disability Services Act 1993* before 2010.

Recommendation 29 ***Page 65***

The Department of Ageing, Disability and Home Care should establish a structured consultation framework to support the devolution process. Key elements of the framework should include:

- A State Devolution Reference Group to provide strategic support to the devolution process
- A Local Reference Group for each centre to support devolution at a service level.

Recommendation 30 ***Page 66***

The Department of Ageing, Disability and Home Care should establish a process to enable residents of large residential centres that are not currently engaged in the devolution project to move into community-based accommodation as soon as possible.

- Where necessary, funding of large centres should be quarantined to ensure their viability
- All residents of large residential centres, and their families or advocates, should be advised that they have the opportunity to register an interest in moving to community-based accommodation.

Recommendation 31 ***Page 83***

The Department of Ageing, Disability and Home Care should establish a general intake and support coordination system for people with disability. The functions of the system should include:

- Receipt of requests for support and assistance
- Assessment and prioritisation of requests
- Referral and information provision
- Support coordination
- Case management
- Vacancy management.

The general intake system should provide a point of contact with other human service systems such as health, education, community services and aged care.

Recommendation 32 ***Page 83***

The Department of Ageing, Disability and Home Care should develop a comprehensive communication strategy to ensure that the community is aware of the existence and the scope of the new general intake and support coordination system. This strategy should take into account the communication needs of people with disability including people from diverse cultural linguistic backgrounds and people in rural and remote areas.

Recommendation 33 ***Page 83***

The Department of Ageing, Disability and Home Care should establish an implementation group with representation from key stakeholders, and in particular people with disability, to assist with the design and implementation of the general intake and support coordination system.

Recommendation 34 ***Page 84***

Additional funding should be provided to the Department of Ageing, Disability and Home Care to support the implementation of a general intake and support coordination system. In particular resources are necessary to support:

- The development of information and business systems to support the system
- Additional staffing to support the intake process and support coordination roles
- The formal separation of regional offices from the Department of Community Services.

Recommendation 35 ***Page 84***

The Department of Ageing, Disability and Home Care should ensure that clear and transparent policy and decision-making guidelines are developed to support the operation of the system and that an accessible system for review and appeal is established.

Recommendation 36 ***Page 89***

The Government should clarify its role as a direct provider of services to people with disability with reference to the following principles:

- Existing clients of the Department of Ageing, Disability and Home Care services should be able to remain with the government provider if they choose to do so
- The government provider should not exclude people who would otherwise be within their target group but who do not have an intellectual disability
- The government provider should provide community-based support options for people with high or complex support needs, risky behaviours or offending behaviours
- The government provider should support people with disability who are unable to find alternative supports, including people in rural and remote areas who cannot access other services
- Guidelines for access to therapy, behavioural and other allied supports provided by the Department of Ageing, Disability and Home Care should be developed to ensure that access to these services is provided on an equitable basis to people with disability.

Recommendation 37 ***Page 90***

Specific steps should be taken to ensure that there is a clear structural separation between the general intake and support coordination and the service delivery operations of the Department of Ageing, Disability and Home Care. Consideration should be given to separating the management of clinical services, including therapy and behavioural intervention, from the supported accommodation and respite services provided by the Department.

Recommendation 38 ***Page 95***

The Department of Ageing, Disability and Home Care should, in consultation with service users, advocates and representatives of non-government services, develop a new funding model for non-government services so as to:

- Provide an equitable and consistent cost base for service delivery
- Support the autonomy of service users and their ability to exercise choice about their living arrangements
- Promote the long-term sustainability of non-government organisations
- Provide a basis for greater flexibility in the use of funding to support people with disability.

The new funding model should identify the additional cost of service delivery in rural and remote areas so as to provide a basis for additional funding for these areas.

Recommendation 39 ***Page 95***

The Department of Ageing, Disability and Home Care should undertake a review of existing funding to non-government service providers to ensure that all clients of non-government disability services are funded in a consistent manner.

Recommendation 40 ***Page 99***

The Department of Ageing, Disability and Home Care should review the use of expressions of interest to purchase services and develop a new approach to service procurement.

Recommendation 41 ***Page 100***

The Department of Ageing, Disability and Home Care, in consultation with relevant stakeholders, should prepare an industry development plan for non-government service providers. The plan should address:

- The need for funding reform referred to in Recommendation 38
- The need for a new approach to procurement referred to in Recommendation 40
- Ways to support the infrastructure needs of smaller organisations and the need to maintain a mix of large, medium and small organisations within the sector
- Ways to support services in regional, rural and remote areas
- Strategies to address the needs of people who are under-represented within the service system, including people with physical disability and acquired brain injury and people from culturally and linguistically diverse communities
- The role of the Department of Ageing, Disability and Home Care in supporting the non-government sector
- The relationship between the intake, support coordination and direct service delivery roles of the Department of Ageing, Disability and Home Care and non-government service providers.

Recommendation 42 ***Page 101***

As part of the industry plan referred to in Recommendation 41, the Department of Ageing, Disability and Home Care should develop an agreed strategy to address the training needs of non-government organisations. The strategy should ensure that:

- Services have the capacity to provide ongoing training and development for staff as part of their core business
- Adequate training can be accessed in rural and remote areas

- Services are able to obtain appropriate management training
- Funding to support the costs of training is incorporated into the funding base of non-government providers.

Recommendation 43 ***Page 107***

The new Department of Ageing, Disability and Home Care service-monitoring system should be designed around the measurement of client outcomes and client satisfaction.

- Performance indicators should be developed that reflect the Principles and Applications of Principles of the *Disability Services Act 1993* and measure qualitative outcomes for individuals rather than narrowly conceived service outputs
- Monitoring processes should ensure that service user views and satisfaction are actively canvassed as part of routine service monitoring
- Monitoring processes should be consistent across government and non-government service providers
- Specific steps should be taken to ensure that there is a clear structural separation between the monitoring, service access and service delivery operations of DADHC
- To promote transparency, consideration should be given to whether some or all aspects of service monitoring should be undertaken by an external body as recommended by the Law Reform Commission
- Systems should be developed to ensure that information collected through monitoring activities is acted upon at an individual level and is also used systemically as part of the planning, policy and industry development responsibilities of the Department
- Resources for monitoring should be adequate and linked to the level of funding provided for direct service delivery.

Recommendation 44 ***Page 107***

Funding methodology for Community Visitors should be developed that links the number of visitable hours to the number of clients of visitable services. Remuneration for Community Visitors should automatically be adjusted to reflect wage increases for public sector employees

Recommendation 45 ***Page 107***

Consideration should be given to either extending the coverage of the Community Visitor Scheme to respite, semi-independent living and other accommodation support services funded by the Department of Ageing, Disability and Home Care or developing a similar client-focussed monitoring scheme for these services.

Recommendation 46 ***Page 110***

The Government should review the NSW Disability Policy Framework as a means of achieving a whole of government approach to policy and service delivery for people with disability. In particular the review should consider:

- The extent of progress in achieving the objectives outlined in the Framework
- Whether the Framework is effective in addressing service gaps for people with disability
- Whether the current reporting and accountability requirements of the framework are an appropriate means to achieve compliance with section 9 of the *Disability Services Act 1993*.

Recommendation 47 ***Page 110***

In order to enhance the whole of government commitment to support people with disability, immediate consideration should be given to implementing Recommendations 13, 14 and 15 of the New South Wales Law Reform Commission, Report 91, *Review of the Disability Services Act 1993 (NSW).*

Recommendation 48 ***Page 111***

The Department of Ageing, Disability and Home Care should develop formal Memoranda of Understanding with all relevant departments, including NSW Health and the Department of Community Services, to clarify their responsibilities to support people with disability and ensure that there is a continuum of service across program boundaries.

Recommendation 49 ***Page 113***

As part of the negotiation for the forthcoming Commonwealth State Territory Disability Agreement, the Government should:

- Seek additional funding from the Commonwealth as a matter of urgency both to address unmet need and to accommodate cost increases in disability services
- Seek to develop an approach to funding under the CSTDA that links growth funding from the Commonwealth to identified unmet need
- Specifically seek additional funding for supported employment programs.

Recommendation 50 ***Page 113***

In negotiating the forthcoming Commonwealth State Territory Disability Agreement, the Government should seek to ensure that the new agreement provides greater clarity about the respective roles of the States and the Commonwealth to fund specific programs and services and to fund increases in the cost of providing services.

Recommendation 51 ***Page 119***

The Department of Ageing, Disability and Home Care should develop an appropriately resourced model of holistic support to provide planned and responsive support to children with disability and their families, which includes the following elements:

- The development of care plans for children with disability within their family unit
- Support coordination that focuses on the needs of the whole family
- Access to appropriately resourced early intervention services
- Behaviour management support
- Planned access to additional support during key life transitions
- Provision of flexible short-term care for the children.

Recommendation 52 ***Page 121***

The Department of Ageing, Disability and Home Care and the Department of Community Services should jointly develop an agreed and consistent approach to the funding and support of children with disability in out-of-home care.

Recommendation 53 ***Page 121***

The Government should amend the *Disability Services Act 1993* to include a part for children and young people with disability in accordance with recommendations 30, 31, 32, 34, and 35 of the New South Wales Law Reform Commission's review of the *Disability Services Act 1993 (NSW).*

Recommendation 54 ***Page 122***

The Department of Ageing, Disability and Home Care and NSW Health should complete the implementation of the Care for Carers Program. The outcomes of the Care for Carers Program should be evaluated to determine whether it is an effective program and whether it is sufficiently resourced.

Recommendation 55 ***Page 126***

The State and Commonwealth Governments should develop a joint and cooperative approach to meeting unmet need for meaningful daytime activity. This approach should be based on the following principles:

- Growth funding from both the Commonwealth and the State will be required to address unmet need for meaningful daytime activity
- The primary emphasis should be on supporting people with disability to access employment
- People with disability who are not able to access supported employment services should have guaranteed and continuing access to day programs.

Recommendation 56 ***Page 127***

Additional recurrent funding should be provided to the Department of Ageing, Disability and Home Care to ensure that the Disability Service Program has sufficient capacity to support people with lower needs.

Recommendation 57 ***Page 130***

The Department of Ageing, Disability and Home Care should in consultation with the Department of Community Services, the Cabinet Office and other relevant agencies develop and fund a support strategy for parents with disability. The strategy should include the following elements:

- The development and provision of training for Department of Community Services child protection caseworkers on ways to support parents with disability and their children
- Provision of additional funding to the Parent Access Program to enable it to operate on a full-time basis
- Development of service access guidelines to ensure that parents with disability receive priority access to Home Care services and support
- State-wide implementation of the Home Learning Program as a support model for parents with disability
- The establishment of a residential supported accommodation service to provide short, medium and long-term support for parents with disability.

Recommendation 58 ***Page 135***

The Department of Ageing, Disability and Home Care should establish an innovation unit with quarantined funding to develop and pilot innovative support and funding models, including models that involve substantial self-management of funds, for people with disability.

- The unit should be directly accountable to the Department's Executive
- Procedures should be established to ensure that the outcomes of evaluation are assessed, disseminated and where appropriate, incorporated into the operational policy and programs of the Department

- Details of projects that are funded and the outcomes of evaluation should be made public
- An Expert Advisory Panel on Innovation should be appointed to assist the Department in this regard.

Recommendation 59 ***Page 136***

The Department of Ageing, Disability and Home Care should establish a clear and transparent research agenda to foster innovation, best practice and leadership within disability services. The research agenda should include:

- A program of annual disability research grants
- An annual scholarship program to support further study by staff of government and non-government services.

Recommendation 60 ***Page 139***

The Government should, in consultation with relevant stakeholders, develop a State Disability Plan for New South Wales. The Plan should identify the long-term vision for people with disability and identify the outcomes that both generic and specialist disability services should achieve for people with disability in New South Wales. The plan should also outline a process for achieving the complete implementation of the *Disability Services Act 1993*.

Recommendation 61 ***Page 143***

In consultation with people with disability and other relevant stakeholders, the Department of Ageing, Disability and Home Care should develop and publish a comprehensive forward plan for specialist disability services. The plan should address:

- The type and mix of services that will be provided to support people with disability
- The level of demand for these services and the level of supply required to meet this demand
- Pathways for access to services and eligibility criteria for services
- Policy for service development and service provision
- What the role of the various participants in delivering these services should be, in particular what the respective roles of the government and non-government sectors should be
- Points at which disability services intersect with other service systems, such as health, education and aged care, and protocols to ensure that service gaps do not exist
- Workforce development for disability services
- How the system will be administered and funded
- Population-based funding benchmarks for disability services
- Arrangements for quality assurance, monitoring and review
- Performance indicators to evaluate the effectiveness of the system as a whole.

Glossary

ABI	Acquired Brain Injury
ACAT	Aged Care Assessment Team
ACROD	ACROD is the national industry association for the non-government sector
ADD	Ageing and Disability Department, incorporated into the Department of Ageing, Disability and Home Care in April 2001
AIHW	Australian Institute of Health and Welfare
ATLAS	Adult Training Learning and Support - A program to assist people with disability to access employment and education
CSTDA/CSDA	Commonwealth State Territory Disability Agreement, formerly known as the Commonwealth State Disability Agreement
CYPCP Act	*Children and Young Persons (Care and Protection) Act 1998*
DADHC	Department of Ageing, Disability and Home Care
Devolution	In this report devolution refers to the process of transforming services that provide congregate accommodation into community-based accommodation services that conform to the *Disability Services Act 1993*
DoCS	Department of Community Services. The disability services operations of DoCS were transferred to the DADHC in April 2001
DSA	*Disability Services Act 1993*
ECICP	Early Childhood Intervention Coordination Program
EOI	Expression of interest. EOIs have been used extensively by government as a competitive method of purchasing services from the non-government sector
LAC	Local Area Coordination (Western Australia)
LRC	New South Wales Law Reform Commission
LSC	Local Support Coordination (New South Wales)
MDS	Minimum Data Set
NESB	Non-English speaking background
NGO	Non-government Organisation
PADP	Program of Aids for Disabled People
PDCN	Physical Disability Council of New South Wales
PGP	Population Group Planning. The population group planning process is intended to provide a more equitable spread of services across the State by directing new funding into regions that have a relatively low level of services

SACS Award	Social and Community Services Employees (State) Award
SAS	Service Access System
Semi-independent living	A support model in which people with disability live independently with periodical support from professional support staff. Also referred to as 'drop in support'
HACC	Home and Community Care
PSO	Post School Options
ATSI	Aboriginal and Torres Strait Islander
MDAA	Multicultural Disability Advocacy Association
NCOSS	New South Wales Council of Social Service

Chapter 1 Introduction

This is the final report of the Committee's inquiry into residential and support services for people with disability. The report concentrates on the need for greater equity, better systems and more effective planning to deliver workable supports to people with disability in New South Wales. While acknowledging the challenges ahead, the Committee believes that it is possible in this State to develop a service system that is sustainable, equitable, cost effective and above all delivers the supports that people with disability and their families actually want and need. This report is the Committee's contribution to achieving these outcomes.

Background to this report

1.1 The inquiry was referred to the Committee by the Legislative Council on 16 September 1999. The terms of reference for the inquiry are in two parts. Initially, the Committee was asked to examine a decision in 1999 to seek expressions of interest for the operation of certain Department of Community Services (DoCS) group homes. Secondly, the Committee was asked to examine more broadly the need for accommodation and related supports for people with disability in New South Wales. The terms of reference for the inquiry are reproduced in full at page iv.

1.2 Two interim reports in this inquiry have been released by the Committee: *The Group Homes Proposal* and *A Matter of Priority*.

The Group Homes Proposal

1.3 The first report, released in December 1999, focussed on the proposed tendering out of 41 group homes and accommodation support services. The report noted that the proposal to seek expressions of interest for DoCS group homes raised considerable concern within the disability community. These concerns largely related to the way the proposal was announced and its subsequent implementation. Some participants also raised concerns about a possible withdrawal of government from the direct provision of services to people with disability.

1.4 The report found that there was very little opposition to the concept of allowing people with disability to consider whether they wanted to change their current living arrangements. The Committee made a number of recommendations aimed at improving the process to ensure that effective consultation occurred, that clients and their families were able to exercise genuine choice of service provider and there would be no diminution in the level of service provided to people who chose to change service provider.

1.5 The initial group homes project is now largely complete and its outcome is discussed in Chapter 8 of this report. The recommendations from the first report are reproduced in Appendix 4.

A Matter of Priority

1.6 The second report, released in December 2000, focussed on urgent priorities for reform. Three areas were identified as requiring immediate action:

- Provision of additional permanent accommodation for people with disability
- Reform of respite services to increase their availability
- Devolution of large residential centres.

1.7 The report found that the disability service system was focussed largely on crisis management and had little capacity to meet even the most urgent needs of people with disability. This focus has resulted from the significant and growing level of unmet demand for accommodation and related support services. Unmet need for these forms of support has been a long-term concern within the sector, which is a product of historical factors including the uncoordinated and unplanned development of accommodation services for people with disability and the failure by successive State and Federal governments to adequately resource the sector.

1.8 Preoccupation with crisis management has impeded the ability of the system to develop preventative supports that are more attuned to the needs of people with disability and their families and will, over the longer term, reduce the need for intensive support such as out-of-home permanent accommodation.

1.9 The report recommended immediate action to address the critical need for accommodation and respite services. While acknowledging that significant additional funding had been committed to the sector in the 2000-2001 State Budget, the report found that sustained investment in the sector over a period of years would be required to redress past neglect. The Committee noted that strategically targeted investment in the three priority areas of permanent accommodation, respite and devolution of large residential centres would be required to allow the disability service system to move out of crisis.

1.10 Key recommendations in the report included:

- The [then] Ageing and Disability Department (ADD) 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 the report
- ADD should develop and publish targets for the number of residential places for people with disability per head of population
- ADD should act to implement all recommendations of the Respite Working Group (established by the Government to advise it on ways to overcome the problem of blocked respite places)
- Respite services should be defined and funded separately to services that provide care to people in crisis
- ADD should develop and implement population-based targets for respite services

- 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

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

1.11 Other recommendations referred to the need for planning, effective communication and consultation, guarantees of care, and staffing issues. Appendix 5 contains the full list of recommendations from *A Matter of Priority*.

Structure of this report

1.12 This report is divided into two parts. Part One, *Equity of Access*, examines issues relating to people who are under-represented within the disability service system. These groups include people from culturally and linguistically diverse backgrounds, people who live in rural and remote areas, people with physical disability and people with acquired brain injury.

1.13 Part Two, *Building the System*, looks at the need to develop a coherent and accessible disability service system in New South Wales. Chapter 8 reviews progress in the areas covered by our previous reports and outlines ways to enhance the performance of the Department. There has been a clear consensus in evidence that the Department of Ageing, Disability and Home Care (DADHC) needs to develop better ways to manage the delivery of new services. Central to this task is the need to establish a general intake and support coordination system to manage requests for support, expansion of the disability service system and reform of existing services. The development of such a system is outlined in Chapter 9.

1.14 Chapter 10 considers the role of DADHC as a direct service provider while ways to develop a more sustainable non-government sector in disability services are discussed in Chapter 11. Systemic issues such as the need for a greater whole of government commitment to support for people with disability, service monitoring and the need to resolve outstanding issues under the Commonwealth State Territory Disability Agreement are addressed in Chapter 12.

1.15 Support for children with disability and their families, as well as the need to enhance the independence of people with disability, are considered in Chapter 13. Chapter 14 outlines the importance of fostering innovation and research within disability services.

1.16 Underpinning all of these issues is the need for comprehensive and open planning for disability services over the medium and long term. In Chapter 15, the Committee notes that a clearly articulated plan for the continuing delivery of accommodation and support services for people with disability is essential if the system is to move away from the current focus on crisis management to a focus on planned and preventative lifelong supports.

Departmental changes and initiatives

1.17 Over the period of this inquiry several important initiatives have been commenced and there have been significant changes to the structure of the government departments responsible for disability services.

1.18 Some of the key initiatives relevant to the inquiry include:

- The announcement in May 2000 of what is now referred to as the *197 places program*. The program is intended to provide permanent accommodation to 197 people known to be in crisis, including approximately 70 people living in blocked respite beds
- The establishment of the Service Access System (SAS) as a central point of access to support for people with disability whose circumstances place themselves, their support arrangements or their current level of independence at risk
- Funding to provide crisis support and longer-term assistance was also identified in the 2000/2001 Budget
- The allocation of funding in the 2000/2001 Budget to support the movement to the community of approximately 400 people living in large centres by 2003.

1.19 Two major changes to departmental structures have also occurred since the inquiry commenced in 1999. When the inquiry commenced, DoCS was a major provider of services to people with intellectual disability. DoCS services for people with disability included accommodation, therapy, behavioural support and case management. Some in-home supports for people with disability were also provided by the Home Care Authority of New South Wales. Funding, monitoring and policy development for disability services were provided to DoCS and non-government providers by the Ageing and Disability Department (ADD).

1.20 In April 2001 ADD, the disability services arm of DoCS, and the Home Care Authority were amalgamated to form a new Department of Ageing, Disability and Home Care (DADHC). Following the amalgamation, DoCS no longer has a role in the provision of disability services. The new Department initially consisted of three directorates: the Strategic Planning and Policy Directorate – which assumed the functions previously undertaken by ADD; the Disability Services Directorate – which took over the disability service provision role of DoCS; and the Home Care Directorate – which provided home care services.

1.21 In mid 2002, a restructure of DADHC commenced. The Department will consist of a Policy and Planning Directorate, an Operations Directorate and the Regions. The new structure is intended to create a stronger regional presence and will involve the integration of the DSD, the former Home Care Service and the service delivery aspects of the former ADD.[1] Some of the implications of these changes are discussed in the report.

---

[1] Ageing and Disability Department, *Fast Facts*, Edition Nine, 13 September 2002.

Scope and process of the inquiry

1.22 Since commencing the inquiry in September 1999, the Committee has consulted widely within the disability community. The Committee has received a total of 316 written submissions from people with disability, family members, advocates, service providers, workers, peak bodies and government departments. A list of people and organisations who provided submissions is included in Appendix 1.

1.23 The Committee heard formal evidence from 135 witnesses at hearings. Evidence was taken from a range of people including people with disability, parents, advocates, academics, peak organisations and relevant government departments. Hearings were held in Sydney and at various regional locations. A list of witnesses is included in Appendix 2.

1.24 During the inquiry the Committee visited a range of services and facilities for people with disability. Visits were made to services in western Sydney over three days as well as to Newcastle and Wollongong. The Committee also travelled to Ballina and Broken Hill. The Committee established a sub-committee, consisting of three Committee members, to undertake visits to regional locations in New South Wales. The sub-committee travelled to seven locations including Albury, Dubbo, Newcastle, Orange, Parkes, Peat Island and Tamworth. Details of Committee visits are included in Appendix 3.

1.25 Community consultations were held during the Committee visits to regional and rural areas of New South Wales. These consultations were attended by a total of 555 people. Many attendees had the opportunity to speak directly to Committee members and the consultations provided valuable information regarding the needs of people with disability in regional, rural and remote areas of the State. Details of these consultations appear in Appendix 4.

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

Part 1: Equity of Access

A persistent message received over the course of the inquiry has been that the disability service system serves some groups better than others. Against an overall background of unmet need, some groups receive demonstrably lower levels of service than others. This part of the report addresses calls to make the disability service system more representative of the full community of people with disability.

Chapter 2 examines the significant under-representation of people from culturally and linguistically diverse backgrounds within the specialist disability system and outlines strategies to improve access to services by people from a diverse range of cultural backgrounds. The specific needs of people from Aboriginal and Torres Strait Islander backgrounds are considered in Chapter 3. We note that support strategies for people from culturally and linguistically diverse backgrounds must be integrated into planning for all aspects of disability supports.

The needs of people with disability living in rural and remote communities are addressed in Chapter 4. Particular issues for people in these areas include the need for better access to transport and the significant undersupply of therapists. In addition to specific recommendations for these two areas, we note that there is a need to develop a comprehensive rural service delivery strategy for rural and remote areas.

Support for people with physical disability and people with acquired brain injury and intersections between the specialist disability and the aged care systems are considered in Chapters 5, 6 and 7. Presently, these two groups are poorly served by the disability service system with the result that younger people with higher needs are living in nursing homes. There is also a need to develop an effective response to the needs of people with lifelong disability who are ageing. We therefore make recommendations aimed at improving the interaction between the disability and aged care systems.

Chapter 2 Cultural and linguistic diversity

This chapter considers issues for one of the most significant groups of people who are under-represented within accommodation and other disability services, people from culturally and linguistically diverse communities. The needs of other groups who are also less well supported by the disability service system are considered in the following chapters. In keeping with the Committee's view that people of non-English speaking backgrounds (NESB) should be routinely considered in all disability service planning, the needs of diverse communities are also integrated into subsequent chapters on various aspects of the disability support system.

Access to disability services

2.1 People from culturally and linguistically diverse communities make up a substantial and growing proportion of the New South Wales population. Approximately one quarter (24 percent) of all people in the State come from a background where they, or at least one of their parents, were born overseas and have a non-English speaking background.[2] Close to 19 percent of people in New South Wales speak a language other than English at home.[3] There is no evidence to suggest that the prevalence of disability in NESB communities is lower than that of the general community.

2.2 By contrast, in May 2002 the Department of Ageing, Disability and Home Care (DADHC) reported to the Committee that on the basis of available data, 3 percent of disability service users were of NESB.[4] While there is an overall shortage of services that affects all cultural groupings, these figures indicate that people with disability who do not have an Anglo-Saxon or Anglo-Celtic background are substantially under-represented in their access to disability services.

2.3 In the Multicultural Disability Advocacy Association's (MDAA) view, the lack of participation by people from NESB in disability services means that the service system is racist in its operation:

> People with disability from NESB continue to be one of the most marginalised and vulnerable groups in our society simply because the issues are not understood or addressed … There is very little understanding within government, the community sector and the general population about disability and cultural issues … Both Commonwealth and State governments have failed to provide adequate resources, effective monitoring and policy direction to address the problems faced by people from NESB with disability. We estimate that three out of four people from NESB with a disability missed out on a service simply because they are from NESB. That is on top of current unmet needs.[5]

---

[2] Multicultural Disability Advocacy Association, *Less Talk, More Action: Advancing Cultural Diversity and Disability in* 21st Century NSW, June 2000, p. 37

[3] Australian Bureau of Statistics, 2001 Census of Population and Housing, New South Wales

[4] Griew evidence, 9 May 2002

[5] Qian evidence, 10 February 2000

2.4 Some of the systemic barriers to service for people with disability from NESB, which may be either language or culturally based, include:

- A lack of accessible information about essential services; in particular very little information is provided in languages other than English, so that people may simply be unaware of the services available or how to go about accessing them

- The lack of culturally appropriate services that reflect the different preferences of people from various cultures

- Poor knowledge on the part of service providers about how to ensure their services are culturally inclusive

- Discrimination by service providers.[6]

2.5 Underlying these barriers to access is that, in the past, there has been little action specifically to consult with or plan for the needs of people with disability from NESB when developing services and programs. As a consequence, the disability service system is culturally specific, being oriented towards the mainstream Anglo-Australian cultural group at the expense of other cultural groupings.

2.6 In addition, barriers to service use may emanate from NESB communities themselves, including culturally driven views about who should provide care and support. The isolation of many NESB families may also hinder them from keeping up with evolving social expectations of people with a disability.

2.7 Recent immigrants with disability may be further disadvantaged by the Commonwealth requirement that they wait 10 years before they become eligible for the disability support pension. Eligibility for that payment is an essential pre-requisite for access to a range of disability services including HACC, PSO/ATLAS and PADP.

2.8 Despite the Disability Services Act's explicit requirement that programs and funded services take cultural needs into account, all of the barriers outlined above affect the disability service system of New South Wales.

Progress to improve access in New South Wales

2.9 In recent years there has been greater acknowledgment at a policy level of the need to address the under-representation of people from NESB within disability services in this State. For example, a diversity unit was established within ADD in 2000 to guide policy in relation to NESB and issues related to cultural diversity. This unit has been retained within the new Department. MDAA told the Committee that DADHC has shown a welcome philosophical commitment to ensuring that people from NESB have the same opportunity to access services as other community members.[7]

---

[6] Submission 240, Multicultural Disability Advocacy Association

[7] Winter evidence, 4 July 2001

2.10 This commitment is still to be translated into practical outcomes. According to MDAA, implementation of strategies to increase the accessibility of services to people from all cultural backgrounds has been haphazard:

> [It] is vital that DADHC moves beyond the big picture, broad policy focus and starts to focus on an implementation process which is thought through, coherent, consistent, well developed and consultative. … In terms of operational guidelines for making decisions or guiding principles (such as access and equity principles), there is a clear lack of direction, guidance and consistency.[8]

2.11 According to MDAA, no funding for service growth has been allocated specifically to address the under-representation of people from NESB in disability services. There have been delays in making information available in community languages and no systematic attempts to consult with members of NESB communities about their needs. Furthermore, the Committee was told that the needs of culturally diverse communities have not been an integral aspect of the planning and development of key initiatives such as the Service Access System or devolution.[9]

2.12 In May 2002 DADHC advised the Committee that it was funding two key strategies to help improve access to services among people of diverse cultural backgrounds: cultural awareness training for service providers and individual advocacy targeted at people with disabilities of NESB living in rural and remote areas.[10] The Committee welcomes these measures.

Redressing the imbalance

2.13 We support the goal of equal access to disability services for people of NESB and consider that further action should be taken to achieve this. Australia is an increasingly diverse society and essential services should be constructed in such a way as to ensure that people are not excluded because of cultural or linguistic differences. This section considers key areas that need to be addressed to overcome the current imbalance.

Targets

2.14 We consider that people from culturally and linguistically diverse backgrounds should be able to access a share of services that is approximately equal to their proportion in the broader community. DADHC should pursue this goal as a priority.

2.15 The Committee considers that targets for service uptake by people from NESB should be established as a means to equitable access to disability services. The targets should apply to the management of vacancies in existing services, as well as to service growth and new programs. To encourage accountability and transparency, actual performance against the

---

[8] Submission 240, Multicultural Disability Advocacy Association, Supplementary Submission

[9] Winter evidence, 4 July 2001

[10] Allison evidence, 9 May 2002

targets should be reported on in the Department's annual report. To be effective, the targets must be supported by appropriate policy, and an implementation plan that outlines what steps will be taken to ensure that the targets are met. Key aspects of implementation are outlined in the following sections.

Recommendation 1

The Department of Ageing, Disability and Home Care should, in consultation with representative groups, establish Departmental targets for equitable service access by people from culturally and linguistically diverse backgrounds.

- Targets should be established for vacancy management, service growth within existing programs and in new programs
- Performance against the targets should be monitored reported upon in the Department's annual report
- An implementation plan should be developed that outlines the specific steps that will be taken to meet the targets.

Culturally competent service provision

2.16 If equal access is to be achieved, MDAA, along with all peak disability groups, have argued that there is a need for a fundamental shift to a culturally competent model of service delivery that actively accommodates cultural diversity and so minimises cultural and linguistic barriers to service:

> What needs to happen is a large systemic shift where people from NESB need to be not on the margin but need to be part of, a quarter of, the picture.[11]
>
> We ask for nothing more than for governments and bureaucracies to face reality, a reality which is made up of a diverse community, a community in which people from NESB make up one quarter of the population.[12]

2.17 A culturally competent service system would have two key elements:

- Enhanced capacity of all mainstream services to provide appropriate services as a matter of course to people from NESB. Such culturally diverse mainstream services, where an inclusive approach is integral to all service delivery, would be able to service the needs of people from all backgrounds, rather than only people from English-speaking backgrounds as is currently the case.
- Development of culturally specific services for groups that have very specialised requirements. Such services would form the exception rather than the norm and

---

[11] Winter evidence, 4 July 2001

[12] Submission 240, Multicultural Disability Advocacy Association, Supplementary Submission

would have to be justified on grounds that particular ways of working are more appropriate to people of a particular cultural group (as with Aboriginal specific services discussed in Chapter 3).

2.18 Ensuring that mainstream services develop their capacity to accommodate cultural diversity within their client group is particularly important. Both government agencies and disability service providers must move beyond treating NESB issues as peripheral to treating them as core business, fully integrated from the outset. We consider that DADHC should not only pursue more actively inclusive policy and planning, it must also establish mechanisms to assist disability services, whether they are funded or delivered by the Department, become culturally inclusive. For example in most tender processes at present service providers must articulate how they propose to address the needs of culturally diverse clients,[13] yet there are no mechanisms in place to ensure that such needs are actually addressed. The potential for service monitoring to take a greater role in achieving such outcomes is discussed in Chapter 12.

2.19 The Department should also invest in a more systematic and comprehensive approach to consultation with NESB communities in acknowledgment of the diverse interests of these groups and in order to develop a greater understanding of their needs and preferences. Such consultation will yield valuable practical information on how to achieve culturally inclusive services and will also inform decisions about areas where culturally specific services should be established. We consider that a cultural diversity working party comprising representatives of people with disability from NESB and other relevant stakeholders should be established to assist the Department with policy development and to ensure that effective consultation with people from culturally diverse communities is built into the routine operations of the Department.

Recommendation 2

The Department of Ageing, Disability and Home Care should adopt a culturally competent approach to disability services which includes:

- The development of explicit NESB access strategies as an essential and ongoing component of all its programs and services
- A systematic approach to consultation with culturally diverse groups in order to inform policy and program development and implementation
- The implementation of mechanisms such as service guidelines, performance measurements and monitoring systems to ensure that funded service providers deliver culturally inclusive disability services.

---

[13] Allison evidence, 9 May 2002

Recommendation 3

The Department of Ageing, Disability and Home Care should establish a cultural diversity working party comprising representatives of people with disability from culturally and linguistically diverse communities to assist the Department with the development and implementation of policy and programs for people from diverse backgrounds.

Information provision

2.20 The information needs of people with disability from NESB, their families and carers must be actively considered in all program planning and implementation. Addressing the lack of accessible information about the disability service system is one of the most basic and achievable improvements required for people from NESB. Information-based strategies to improve awareness about and access to services include:

- The development of education and information campaigns for NESB communities about disability issues
- Translation of program and service information into key community languages
- Allocation of funding, backed up by properly monitored contractual obligations, to services for the translation of written material into community languages and for the provision of interpreters as required.

2.21 Again it is important that the Department pursue improvements on two fronts by both addressing its own information strategies and also developing ways to ensure that service providers routinely address the information needs of diverse communities.

Recommendation 4

The Department of Ageing, Disability and Home Care should undertake a comprehensive information and education campaign for culturally diverse communities to raise their awareness about and access to the range of services for people with disabilities, their families and carers.

Recommendation 5

The Department of Ageing, Disability and Home Care should routinely publish information in key community languages at the same time as it does so in English.

Recommendation 6

The Department of Ageing, Disability and Home Care should adequately resource the services it funds to undertake translations and utilise interpreting services.

Chapter 3 Aboriginal and Torres Strait Islander people with disability

In the previous chapter the Committee recommended an approach to disability services that 'mainstreams' culturally appropriate services by enhancing the capacity of all services to support people with disability from all backgrounds, with limited culturally specific services for groups with highly specialised requirements. Within this approach, Aboriginal and Torres Strait Islander people are a key group that in the Committee's view has both particular needs and a unique status that warrant a culturally specific service delivery framework.

Over the course of this inquiry the Committee consulted with a range of Aboriginal representatives and gathered evidence that while Aboriginal people with disability, their families and carers face many of the same challenges in living with disability and accessing support services as other people, their Aboriginality adds a distinctive layer of complexity to the experience of disability, which government must understand and address if indigenous people are to receive an equitable and effective share of resources. This section explores several key issues facing government with regard to disability support services for Aboriginal communities, including culturally appropriate service delivery, funding arrangements and autonomy.

Rates of disability and access to services

3.1 There is little data available on rates of disability among Aboriginal and Torres Strait Islander (ATSI) people, however, the Australian Institute of Health and Welfare (AIHW) suggests that rates of disability are higher for indigenous people than for the whole population, perhaps more than twice as high.[14] In addition, compared with other people, Aboriginal people with disability report higher support needs.[15] It has been suggested that these estimates reflect higher rates of poor health, congenital conditions, birth trauma, accidents and substance misuse among the ATSI population.[16]

3.2 Issues of disability and care have an added complexity in Aboriginal communities for a range of reasons including the multiple disadvantages reflected in high rates of poverty, poor living standards, poorer health across their lifetime and reduced life expectancy. These complexities are increasingly recognised in disability policy, for example, under the Home and Community Care Program, Aboriginal people aged over 45 are eligible for aged care services.

3.3 Historically poor access by Aboriginal people to a range of community services has been widely acknowledged, as has the role of direct and indirect discrimination in this outcome. There is some question, however, as to whether Aboriginal people are currently accessing their fair share of disability services. According to the AIHW, 2.6 percent of disability

---

[14] AIHW, *Australia's Welfare 1999*, p. 223

[15] AIHW, *Australia's welfare 2001*, p. 289

[16] Yeatman, A., 1996 cited in Submission 226, Community Services Commission

service users across Australia identify as being of ATSI descent, a figure approximately equal to their proportion of the population. The AIHW notes that ATSI representation varies markedly across disability service types, with their access to respite services being higher than other service types.[17] We note however, that 2.6 percent may not reflect the disproportionate rate of disability among Aboriginal people, or their greater disability-related needs.

3.4 Reflecting evidence gathered across the disability population, Aboriginal representatives reported to the Committee unmet need for services including respite, accommodation support, day programs, aids and equipment, appropriate supports for people with challenging behaviour and flexible supports which respond to the individual needs and preferences of clients and carers. As with the general population, issues of access in rural and remote areas were also raised.

3.5 Over and above these general access issues, the Committee heard from a number of Aboriginal communities about the unique cultural issues affecting take-up of disability services by indigenous people. These included a reluctance to engage with community services due to the legacies of a racist welfare system, taboos relating to the provision of services such as personal care, and an emphasis on family 'taking care of their own'.

Culturally appropriate services

3.6 Aboriginal groups told the Committee that fundamentally, ATSI people with disabilities want to be with their own people. They and their carers want services which both reflect and respect their cultural practices and which are delivered by Aboriginal staff. The Committee heard instances where creation of an Aboriginal-specific service increased service use:

> It is very important for Aboriginal people to remain with their own communities. So a family would not even consider if there was a vacancy in a non-Aboriginal group home, one, and out of their own community, two, to even think about it. But once people start to know there is such a thing as an Aboriginal group home are now keen to say, 'Well, we would like to think about this'.[18]

3.7 Where ATSI-specific and ATSI-provided services are impractical, culturally sensitive knowledge and practice are vitally important.

3.8 Representatives also highlighted the need for staff with links to the community, who have the community's trust. They stressed the need for outreach work into communities, with staff building awareness of services and working with families and carers to overcome their anxieties about accessing supports.

---

[17] This data is from the 2000 snapshot day for CSDA-funded services across Australia, AIHW, *Australia's Welfare, 2001*, p.288

[18] Community consultation, 23 March 2000

Funding and accountability

3.9 Issues of cultural appropriateness are also reflected in funding and monitoring systems. The Committee has been advised that the nature of service provision in Aboriginal communities is fundamentally different to that in mainstream communities. It takes time and resources to work effectively:

> We know when they talk to your people one client might take a whole day because they have a holistic approach and while you are there, get my cousin in and you are going to do this then do that. That is what goes on, and we have to deal with that.[19]

3.10 Respecting and working with cultural differences is essential to effective service delivery and to positive outcomes for Aboriginal people with disability, their families and carers. However, this approach sits in tension with government systems of funding and monitoring which draw boundaries around types of need and which are increasingly moving towards standardised costs and outputs.

3.11 Participants in consultations noted that distinctions between health, disability and ageing services are difficult to make within Aboriginal communities and that different funding and accountability requirements can raise particular problems for service providers. Current systems of funding and administration of services may themselves be culturally inappropriate for Aboriginal communities.

Autonomous services

3.12 Perhaps the ultimate expression of Aboriginal self-determination in community services is autonomous services, that is, services which are independent and are controlled and managed by an Aboriginal community. These are a reasonably common and valued element of the health system, but to date are not widely established in the disability field.

3.13 During consultations, a number of Aboriginal community representatives raised their desire for autonomous services. The Committee considers that a system where an Aboriginal community makes its own decisions about service delivery not only validates their right to control their own affairs, but is also more likely to achieve effective outcomes.

The way forward

3.14 There is a need for a considered and forward-looking framework for the provision of disability services in Aboriginal communities which is underpinned by the principles of self determination and respect for cultural difference, and which is developed in collaboration with Aboriginal people. We understand that the Department of Ageing, Disability and Home Care (DADHC) recently established an Aboriginal Policy Unit and plans to develop a policy framework for Aboriginal services.

---

[19] Community consultation, 19 July 2000

3.15 To guide the policy development process, there is a need for better data about service use and levels of need for disability services within Aboriginal communities to guide planning and resource allocation. The Committee considers that DADHC should undertake a survey of need within Aboriginal communities to determine the level of need for disability services.

Recommendation 7

In consultation with representatives of the Aboriginal community, the Department of Ageing, Disability and Home Care should develop a policy framework for Aboriginal service delivery. The policy framework should outline specific strategies to address:

- The need for autonomous Aboriginal disability services
- The mechanisms that can be put in place to support communities in their governance of services, for example training for boards of management as well as workers who will work in partnership with them
- Potential mechanisms to achieve a better balance between accountability and flexibility
- Appropriate levels of funding for holistic and community-focused services.

Recommendation 8

The Department of Ageing, Disability and Home Care should undertake a survey of need within Aboriginal communities to determine the level of need for disability services.

Chapter 4 Rural and remote areas

A significant challenge for all human service agencies is how to ensure equitable and accessible service delivery in rural and remote areas. Over the course of this Inquiry, the Committee met with communities across New South Wales to discuss the experiences of people with disabilities and their families living in isolated areas. While many of the issues raised in rural and regional areas are consistent with those raised in metropolitan areas, it is clear to the Committee that people in rural and remote communities face additional barriers to receiving the supports they need, and correspondingly, that service providers face unique demands in delivering supports to isolated areas. This chapter identifies the challenges of disability service provision in rural and remote areas and explores the various roles for DADHC in ensuring equitable and effective supports across the State.

Unmet need and service sparsity

4.1 While unmet need is a feature of the disability service system across the State, difficulties accessing to services are particularly acute in rural and remote areas. A key factor is simply the sparsity of services across less populated areas.

4.2 Evidence put to the Committee highlighted poor access in rural areas to the full range of generalist and specialist disability services including respite, supported accommodation, ATLAS/PSO, day programs, recreation, employment services and behavioural support. In some areas services are simply not available. The absence of supported accommodation and day programs generates additional demand for supports such as respite. The Committee heard that it is especially difficult for people with complex support needs, such as those arising from challenging behaviour or dual diagnosis, to access supports like respite because services are not resourced to meet their additional needs:

> There is no point if you put your child into respite and you go away and you worry, is he going to be injured, because it is not respite … I would love a break. I do not have any family at all – no mother, father, whatever – so I do not have anybody to lean on. …[My son] is quite a bit bigger than me and he does have some behaviour issues.[20]

4.3 Therapy services emerged as major area of unmet need in rural areas. The Committee was told of one instance where a 15 year old girl had to attend a primary school because no physiotherapy or occupational therapy was available through the local high school, despite its purpose-built facilities for these services. Elsewhere, the only speech therapist in a town had an employment agreement stipulating that he did not assist children with cerebral palsy or intellectual disability. In Broken Hill, the early intervention service could only access a speech therapist who visits from Mildura once a term.

4.4 In addition, the lack of specialist medical practitioners with disability expertise in rural and regional areas means that families often have to travel to Sydney for diagnosis and ongoing advice:

---

[20] Community consultation, Dubbo, 20 March 2000

> To get any real help we had to go to Sydney and of course you go to Sydney and get a pretty good idea of what the story is and they tell you that you need things like regular speech therapy and then you come back to the country and find out that you do not get therapy in the country, they do not have time, because they have one person in say Forbes who services the whole of the Western region so they just confine themselves to assessments.[21]

Distance and transport

4.5 Intrinsically linked to issues of access in rural and remote communities are distance and transport. People with disability and their families routinely have to travel significant distances in order to access services. The Committee was advised, for example, of parents driving from Parkes to Orange to use respite, and of another mother who makes a 5 hour round trip with her 4 year old daughter three times a week in order to get specialised medical services. Such travel has obvious financial and time implications, which may make accessing a service unaffordable as well as disruptive to other commitments such as work, school and family activities. Some people cope with distance by moving to a regional centre in order to access services, thereby relinquishing ties to family, friends and others who play a vital informal support role.

4.6 Where people with disability have especially high needs, they may be placed in a service hundreds of kilometres away from home. This places significant added strain on families and makes their participation in care very difficult, as illustrated in the following case study:

> Susan is a single mother of a 26 year old son who was placed in a DoCS group home in his teen years because of unmanageable behaviour at home. However the group home is in another country town 300 km from Forbes, where she lives. She rarely sees him because it is too far for her to travel very often. She feels that their relationship has deteriorated and she would like to be able to be part of his life. She fears moving closer to him as she is dependent on her income as a school cleaner … and is worried that if she moves closer to her son she may not be able to get another job.[22]

4.7 Travel costs also create pressures for service providers. Their budgets may restrict their capacity to conduct outreach work, to visit outlying areas, to provide in-home services, or to subsidise the transport of service users. The Committee spoke with a service based in Parkes that has clients from Forbes and Condobolin, which pays what it describes as 'huge sums' to cover the shortfall in the taxi subsidy, which then affects the number of hours of service that clients receive.

4.8 Along with the significant costs associated with taxi transport, even when subsidised, service users and providers reported insufficient levels of transport services including specialist transport, wheelchair accessible taxis and public transport. The need for more community transport was frequently raised with the Committee.

---

[21] Community consultation, Parkes, 21 March 2000

[22] Submission 228, Statewide Disability Coalition

4.9 The ability to access transport affects a person's capacity to take up services as well as their ability to participate in community life. Transport plays a vital role in preventing social isolation among people with disabilities, their families and carers, and in maintaining their quality of life.

4.10 Consultations have indicated that community transport programs[23] form a vital part of the service network in rural and regional areas. Community transport programs assist a range of people within rural communities, including people with disability, and are generally inexpensive for users to access. Community transport helps people with disability living in informal care arrangements to access the community and to obtain necessary services. Adequate transport provision can therefore dramatically reduce the demand for more intense services. Similarly, community transport schemes assist people living in supported accommodation to access other services such as day programs, as well as the general community. These programs significantly reduce the infrastructure costs for the smaller services that tend to predominate in rural and regional areas.

4.11 Availability of community transport is, however, limited in many areas. The Committee considers that the Department of Ageing, Disability and Home Care (DADHC) should, in consultation with the Department of Transport, develop a rural transport strategy to improve the availability of community transport in regional areas. As part of the strategy, we consider that DADHC should develop regional indicators of need for community transport and population-based funding benchmarks for community transport. These benchmarks should be used to identify the level of resources required for community transport and be weighted appropriately to take into account the differing costs of providing transport services in different regions. This weighting is necessary to ensure that, for example, the additional costs of providing a community transport scheme in far western New South Wales where significant distances may be travelled by comparison to a coastal region are taken into account.

Recommendation 9

The Department of Ageing, Disability and Home Care should, in consultation with the Department of Transport, develop a rural transport strategy to improve the availability of community transport for people with disability in rural and remote areas. The strategy should include:

- A process for identifying demand for community transport at a regional level
- Population-based funding benchmarks for the provision of community transport.

---

[23] Direct administration of community transport programs is undertaken by the Department of Transport but funding decisions and services allocation is the responsibility of DADHC, Department of Transport evidence, 24 September 2001

Service provision

4.12 In speaking with a broad range of service providers across the State, it was clear to the Committee that those in rural areas feel stretched in their capacity to deliver quality services to people with disability and their families in the face of high demand and large catchment areas. A number of factors contribute to this situation including funding, organisational and infrastructure issues, and staffing.

Funding

4.13 The evidence cited above of service gaps and unmet demand suggests the need for greater funding for services in rural and remote communities. Service providers spoke to the Committee of the frustration they face reconciling their levels of funding with unmet need:

> We have been able to squeeze our budget so that we are currently providing four weekends a month and school holidays but it is very tight.[24]
>
> I work part time and part of the problem is that each service is usually given so few hours that it is very difficult to get through all of the things that you need to do.[25]

4.14 Others were frustrated by the rigidity of program and funding arrangements:

> It is not flexible enough to meet the changing needs. The needs in the community can change reasonably rapidly sometimes and by the time you put together an argument or whatever and send it away, the needs could have changed. It is not responsive enough.[26]

Organisational and infrastructure issues

4.15 Linked to the issue of adequate funding are a number of other organisational issues for service providers in dispersed communities. A key concern relates to the capacity of providers for flexible service delivery. According to the Community Services Commission, non-government providers in rural and regional areas are often small, poorly resourced and likely to be catering to both children and adults with a broad range of disabilities and high and low needs. In these circumstances it can be difficult to provide an individualised and flexible approach to all service users.[27] Similarly, it can be very difficult to prioritise performance improvement and innovation in the face of the strong demand, yet both are highly desirable in such an environment. On the other hand, as NCOSS has pointed out, and as the Committee witnessed, out of necessity services in rural areas often cooperate

---

[24] Community consultation, Parkes, 21 March 2000

[25] Community consultation, Parkes, 21 March 2000

[26] Community consultation, Broken Hill, 10 July 2000

[27] Submission 226, Community Services Commission

and coordinate in a more flexible way than those in metropolitan areas.[28] This was particularly the case for some services that provide support to people from Aboriginal and Torres Strait Islander backgrounds.

4.16 A number of representatives raised the issue of infrastructure among small service providers, who do not have the same economies of scale as larger providers and may face proportionately higher administration and other costs that may not be taken into account in their funding. As one person in Parkes put it:

> It's harder because you are so small … we have to meet the same standards as large organisations but with a tiny amount of funding.[29]

4.17 Another issue related to infrastructure concerns volunteers, upon whom many rural and remote services are especially reliant for service delivery, given their funding constraints. Evidence from both service providers and volunteers themselves raises the question of whether the system is going beyond the boundaries of fairness in what it asks of volunteers. Others have noted that volunteers can constrain service delivery because, for example, they may not be prepared or skilled to work with people with high needs. As a person working for a Host Family Respite service told to the Committee:

> We have to use volunteers, we are only funded to use volunteers and that is great, we have some wonderful volunteers but we can only provide a service to some people … volunteers are not very keen on providing care to people who have high support needs and challenging behaviour.[30]

Therapy

4.18 As with other human services, the significant shortage of therapists and specialised medical personnel in rural and regional areas stems from the difficulties of attracting suitably qualified and experienced staff to non-metropolitan areas. Where these professionals do exist, they often face excessive workloads, isolation and a lack of professional support; thus employers may have trouble retaining them.

4.19 A considerable percentage of paid therapy time is also taken up by travel, and the Committee heard that restrictions on travel allowances, funding for overnight accommodation and overtime can restrict the actual hours of therapy delivered outside major regional centres.

4.20 As the Committee heard in its inquiry into Early Intervention into Learning Difficulties, inequities in access to therapy also arise from a lack of consistency in the way different Area Health Services and DADHC regions allocate and prioritise resources for therapy.[31]

---

[28] Submission 227, NCOSS

[29] Community consultation, Parkes, 21 March 2000

[30] Community consultation, Parkes, 21 March 2000

[31] Standing Committee on Social Issues, *Foundations for Learning: A new vision for New South Wales?* Issues Paper, March 2002

Some of the problems could be resolved by agencies co-locating or co-funding therapy services, but as the Department of Education and Training advised the Committee:

> Attempts to negotiate the issue between key government departments and non-government organisations have been largely unsuccessful, frustrated by differences in regional boundaries, eligibility criteria, availability of therapy services, particularly in country areas, and a lack of interagency commitment.[32]

4.21 Given the critical shortage of therapy services in rural and remote areas, the Committee considers that the government should develop a rural and regional therapy strategy to improve the supply and efficacy of therapy in regional areas. Given the significant involvement of both NSW Health and DADHC in providing therapy in regional and rural areas, the strategy should be developed jointly by the two departments. The strategy should ensure that policy and eligibility criteria for access to therapy services are consistent across regions and Area Health Services and that service gaps between the two departments are eliminated.

4.22 A core objective of the strategy should be to ensure that outreach strategies that take professional services to smaller communities are more effectively organised and delivered. Specific strategies to improve outreach include:

- Building a significant travel component into the budget of therapy services in large regional centres so that allocations of therapy time to rural towns include a full allowance for travel and therapy time is not reduced

- Making greater use of consultative and team-based models of therapy to maximise the use of available therapist time and skills

- Use of locally recruited therapy assistants to provide direct therapy support to people with disability under the supervision of qualified therapists. This approach may be particularly useful for Aboriginal communities

- Use of communications technology, such as video-conferencing to provide remote access to therapists.

4.23 There is also a need to consider options for attracting therapists to rural and regional areas. For example, it may be appropriate to provide financial incentives to therapists to move to regional areas and scholarships for people who undertake to work in regional areas for a set period of time.

---

[32] Submission 18, Department of Education and Training, Inquiry into Early Intervention into Learning Difficulties

Recommendation 10

The Department of Ageing, Disability and Home Care and NSW Health should develop a comprehensive rural and regional therapy strategy to improve the availability and effectiveness of therapy services in regional areas. The strategy should:

- Ensure that policy and eligibility criteria for access to therapy is consistent across DADHC Regions and Area Health Services and that services gaps are eliminated
- Provide specific funding to cover therapist travel time
- Examine ways to maximise the use of available therapist time and skills through greater use of consultancy models of therapy and recruitment of local therapy assistants
- Address the need for incentive measures to attract therapists to live and work in non-metropolitan areas.

Other issues affecting service provision in rural and remote areas

Effective planning

4.24 The widespread presence of service gaps in rural and remote areas suggests the need for improved planning in disability services. In the case of therapy services, as discussed above, interdepartmental negotiations to address gaps and boundary issues will prove a significant step forward in planning and resource allocation.

4.25 The Committee recognises the significant challenges associated with achieving an equitable distribution of resources between and within geographical areas. We are aware that DADHC's uses the Population Group Planning (PGP) model to achieving regional equity over time. In addition, DADHC has undertaken regional planning to identify local needs and service gaps.

4.26 The evidence before this inquiry does, however, raise the question as to whether current planning mechanisms are adequately taking account of the additional transport, infrastructure and other costs that accompany service provision in rural and remote areas.

4.27 The Committee notes that while several rounds of regional planning have been undertaken, no plans have been publicly released since 1996. The Director General has told the Committee that new regional plans will be released before the end of 2002,[33] and we commend this as an important step in restoring the confidence of many communities in the Department's planning processes.

---

[33] Allison evidence, 9 May 2002

4.28 The Committee is also mindful of the challenges of operationalising resources into accessible and effective services on the ground. These challenges highlight the responsibilities of government that go beyond the role of planner and funder in rural and remote areas.

Government service provision

4.29 Both the NSW Council for Intellectual Disability and NCOSS have argued that there is a need for the New South Wales Government to make particular provisions for people with disability and their families living in rural and remote communities by ensuring an ongoing role for government in service provision. Two related reasons are cited for this. The first relates to the issue of choice in communities that do not have the capacity to sustain a number of agencies, stressing that the continued presence of DADHC as a provider of disability services in many rural and remote areas is essential to safeguarding the principles of choice in the Disability Services Act. Secondly, government providers have a greater capacity to bear the infrastructure and other costs of rural and remote service provision that would render many non-government providers unviable.

4.30 The Committee supports the view that government must maintain a strong service provider presence in rural and remote areas in order to ensure both access to services and respect for rights. We note that the Director General indicated a commitment to this position in evidence before the Committee:

> We are also now in a position to be able to design a coordinated intake system that provides coherent pathways for clients and their families and to provide services in small and remote communities where non-government providers do not operate.[34]

4.31 The Committee also acknowledges behaviour intervention and support services along with Community Support Teams as areas of strength in DADHC service provision, and underscores their importance in supporting regional communities to provide services to people with disability.

Funding and supporting non-government providers

4.32 At the same time, the Committee notes that non-government providers have a significant role in rural and remote communities. DADHC as both a funder and leader of disability service provision need to implement strategies that support non-government organisations to operate in rural areas, for example through industry development strategies such as management committee training and staff education.

4.33 We note the increasing tendency for government to fund large organisations to provide services in isolated and dispersed areas that do not necessarily have strong ties to those communities. While the Department may be motivated by perceived efficiencies in using larger providers, the Committee is aware that in many cases, the most effective services are those which are initiated by and embedded within local communities. We encourage

---

[34] Allison evidence, 9 May 2002

DADHC to invest in and adequately support small local organisations, for example through the development and cooperative implementation of new models for providing infrastructure, such as multi-service outlets and multi-purpose services.

4.34 Recommendations for the role of the Department in supporting and resourcing non-government providers, including those in rural and remote areas, are set out in Chapter 11.

Encouraging flexibility

4.35 Innovative service models are greatly needed in rural and remote communities. The Committee supports the suggestion of NCOSS, the Council for Intellectual Disability and others that DADHC invest in the development of locally managed and individualised service models as a means of addressing the challenges of service provision in rural and remote communities. We also support their suggestion that DADHC provide a team of experienced people to work in partnership with communities to develop and implement these models.[35]

4.36 One way to achieve this is the Local Area Coordination (LAC) model, which was initially developed in Western Australia to assist people with disability in rural areas. Local Area Coordinators work with people with disability and their carers to build support network within the community using informal supports, generic services and specialist disability services. DADHC has recently introduced a similar Local Support Coordination program to some regional areas and is gradually expanding the program. In Chapter 9 we recommend the development of a regionally based general intake and support coordination system for disability services. The Committee considers that the systemic introduction of Local Support Coordination, as part of broader reform of the disability service system will have significant benefits for people in rural and regional areas.

4.37 Difficulties providing services in rural areas were also raised by the Australian Institute of Health and Welfare[36] (AIHW) in its recent review of unmet need. A range of suggestions to provide more effective support were noted by the AIHW, including joint service organisations, greater use of communications technology and joint pooling of funds between agencies such as health and disability services.

Developing a rural and remote disability service delivery strategy

4.38 Underlying the difficulties faced by people with disability in rural and remote areas is the high cost of service delivery in these areas. The additional cost of service delivery, compared to metropolitan areas, should be taken into account when funds are provided to support people living in rural and remote locations. We therefore consider that a rural and remote service delivery strategy should be developed to enhance the level of support for people in these areas. The strategy should ensure that planning and resources allocation

---

[35] Submission 255, NSW Council for Intellectual Disability; Submission 227, NCOSS. Recommendations for supporting innovation are provided in Chapter 14

[36] Australian Institute of Health and Welfare, *Unmet Need for Disability Services: Effectiveness of Funding and Remaining Shortfalls*, AIHW, 2002

should take proper account of the additional costs of service delivery in rural and remote places.

Recommendation 11

The Department of Ageing, Disability and Home Care should develop a rural and remote area service delivery strategy to enhance the level of support available to people with disability and their carers in rural and remote communities. The strategy should be developed in consultation with relevant stakeholders, including people with disability, indigenous groups and regional advocacy organisations. The strategy should:

- Ensure that planning and resource allocation for rural and remote services takes sufficient account of the costs of service provision in those areas
- Clarify the role of government and non-government services in providing services in rural and remote areas, and the level of support provided to non-government services in these areas
- Examine ways to promote innovation and flexible service delivery in rural and remote areas.

Chapter 5 People with physical disability

Evidence presented to the Committee about equity of access has not simply been concerned with whether certain groups are receiving their fair share of supports through the disability service system. Issues of access are much broader and concern participation as full and equal members of the community, as well as physical infrastructure and the ability to access mainstream services. A key issue for people with physical disability is ensuring that their basic physical needs are met so that they are able to participate in community life. Some people with physical disability have complex care needs that require specialised supports in an appropriate environment. This chapter examines the needs of people with physical disability and considers ways to improve supports for this group.

Defining physical disability

5.1 The term 'people with physical disability' refers to people who have long-term disabilities that arise from a physical cause or that impact on the person's ability to perform physical activities, for example difficulties with mobility.[37] Many people with physical disability use a wheelchair which imposes particular constraints on their ability to access places and services that others take for granted.

5.2 Physical disability is attributable to a range of causes including spinal injury, degenerative conditions such as muscular dystrophy or multiple sclerosis, or lifelong conditions like cerebral palsy. People with physical disability may also have related medical and allied health needs or rely on a range of supports like nursing and physiotherapy to maintain their quality of life. Many people with intellectual disability also have physical disabilities.

5.3 The Physical Disability Council of New South Wales (PDCN) has highlighted the close link between ageing and physical disability and the many common physical needs that arise. Correspondingly, PDCN has pointed out the often arbitrary distinction in programs that target people with needs arising from physical disability and those arising from age.[38] The intersections between disability and ageing are explored further in the following chapter.

Participation and access

5.4 As with other people with disability, key concerns for people with physical disability relate to their independence and participation in the community. For PDCN, the starting point is that people with disability have the right to engage in social life on the same basis and to the same extent as other citizens. Correspondingly, society has a responsibility to ensure that barriers to participation are eradicated by ensuring physically accessible built environments, infrastructure and mainstream services.[39] Barrier-free public places and buildings are vital:

---

[37] Australian Institute of Health and Welfare, *National Community Services Data Dictionary: Version 2*, 2000

[38] Moxam evidence, 4 July 2001

[39] Submission 229, Physical Disability Council of NSW, Supplementary Submission

> If you cannot get in, you cannot participate. It is a bit hard to be part of the party if you are out on the footpath and the party is inside.[40]

5.5 A lack of accessible transport is often cited as the most significant barrier people face because mobility is a key requirement of participation in all activities, whether work, leisure, study, or use of services.[41] While significant progress has been made to improve the accessibility of public buses and trains, they are not yet widely accessible and the private transport system is even less so. Medium and long-term targets have been set for improved access, however PDCN's view is that these are unreasonably far off. In addition, the high cost and limited availability of accessible taxis are matters of concern for people with physical disability.

5.6 Physical access is often an issue in essential mainstream services such as health and education, whether school, TAFE or university. An inability to make use of these services means that people with disability are unable to fulfil their potential and are further excluded from community life.

5.7 Accessible housing is a basic requirement for people with physical disability. The Committee heard from the Department of Housing that people with disability are considered high priority for public housing and accordingly, a significant proportion of new housing stock (around 45 percent) is built to accessible standards. In addition, around 10 percent of existing public housing has been adapted to meet the physical requirements of tenants.[42] The desirability of more appropriate housing, whether through the public or private markets, and the importance of home modification schemes for people with physical disability, are acknowledged by the Committee.

5.8 PDCN have pointed out that accessibility and inclusion pay dividends not just for the person with the disability, but also the community more generally.

> With an equitable sharing of resources and good management, people with a physical disability can and will participate in their communities and lead productive, fruitful lives, more so than they do now. That is, with appropriate personal support, equipment, education, transport, accessible buildings, people with a physical disability will be much more likely to gain and hold employment.[43]

5.9 The Committee considers that accessibility of services and the physical environment should continue to be an important goal for both government and the community. As the lead agency for people with disability in New South Wales, DADHC has a key role in coordinating a whole of government approach to ensuring that people with disability can access necessary services. Issues of inclusion and participation for all people with disability are explored in more detail in Chapters 12 and 13, including the role of the Disability Policy Framework in realising those goals.

---

[40] Moxam evidence, 4 July 2001

[41] Submission 8, Disability Council of NSW, Supplementary Submission; Submission 229, Physical Disability Council of NSW, Supplementary Submission

[42] Vevers evidence, 24 September 2001

[43] Moxam evidence, 4 July 2001

5.10 We note that access to affordable transport is a significant issue for all people with disability. People with disability generally have lower incomes than the general population but their transport costs may be higher. PDCN have therefore argued that the level of subsidy under taxi-transport subsidy scheme be increased from its current level of 50 percent of the fare to 75 percent. The Committee is aware that provision of affordable transport enhances independence and reduces people's reliance on more intensive and costly forms of disability support. We therefore consider that the level of subsidy should be increased progressively to 75 percent over a period of five years. The progressive level of increase will ensure that the effect of the increase in any one budget year will not be too onerous.

Recommendation 12

The level of subsidy provided under the Taxi Transport Subsidy Scheme should be increased by 5 percent per year over a period of five years until it reaches a level of 75 percent.

Access to enabling supports

5.11 The ability to access mainstream services and the built environment is largely a matter for generic government agencies and the broader community. A range of other essential supports which enable people with physical disability to participate in community life, including personal care, aids and appliances and therapy, fall within the domain of disability services.

5.12 Having one's basic physical needs met is essential for dignity and quality of life, as is the ability to make use of aids, equipment and therapies that maximise one's independence. A number of groups representing people with physical disabilities have raised with the Committee the extent of unmet demand for services that meet these needs, including through the Attendant Care Program, the Home Care Service, the Program of Appliances for Disabled Persons (PADP) and a range of therapy services.

5.13 Both the Attendant Care Program and the Home Care Service of New South Wales support people with high needs living in the community with personal care such as assistance with bathing, dressing and eating. The Committee has been informed of unmet need for these services as evidenced in waiting lists, 'closed books' and unequal access across the State. In addition, there have been reports of inaccurate assessment of individual needs and extensive delays between assessment and approval of funding. Concerns have also been raised about substantial delay in the allocation of support packages following their approval. When they cannot access these supports, many people are highly dependent on family members or have no choice but to live in inappropriate settings such as hospitals and nursing homes. There is also significant unmet need for attendant care supports for people while they attend school, university, work and other activities.[44]

---

[44] Submission 229, Physical Disability Council of NSW, Supplementary Submission; Submission 219, Australian Quadriplegic Association

5.14 PDCN has emphasised to the Committee the seriousness of unmet need for personal care services and the sense of impasse that now exists in relation to accessing both Home Care's High Needs Pool and the Attendant Care Program. The Committee has been advised that waiting lists for these services are at a standstill. While the funding available for personal care is a critical issue, PDCN has also questioned the need for two separate personal care programs, and has suggested that there is potential for both greater flexibility and efficiency in the delivery of personal care.

5.15 The Committee considers that there should be a review of personal care services with a view to modernising the programs so as to make services more individually controlled and efficient, as well as more equitably available. While acknowledging the need for greater flexibility and individual control, we note that individual and flexible approaches should not place an excessive responsibility for service management on people with disability and their families, and that they should not be required to take on the risks associated with employment of support workers. Similarly, flexible arrangements must not result in unreasonable working conditions for disability workers. The review should therefore ensure that adequate safeguards for people with disability and workers are established within a more flexible approach.

5.16 More immediately there is a need to ensure that delays in the administration and allocation of existing attendant care packages are eliminated.

Recommendation 13

The Department of Ageing, Disability and Home Care should immediately review the process for allocation of attendant care packages in order to remove delays and ensure that existing packages are allocated as soon as possible.

Recommendation 14

The Department of Ageing, Disability and Home Care should, in consultation with relevant user groups and workforce representatives, undertake a review of personal care funding and services to identify ways to improve their accessibility, efficiency and flexibility. The review should specifically examine ways to ensure that adequate safeguards for people with disability and workers are retained within a more flexible support structure.

5.17 According to PDCN and the Australian Quadriplegic Association, issues of access to personal care are mirrored in the PADP scheme administered by NSW Health, which provides a range of aids such as hoists, wheelchairs and prostheses. While significant improvements have been made in the administration of the program since 2001, disability groups have reported to the Committee that there is continued unmet demand for PADP, waiting periods for equipment and inconsistent access across the State. In addition, some people find the level of co-payments required unreasonable.

5.18 Similarly, the Committee was told that children with physical disabilities have also been denied access to departmental therapy services when DoCS had responsibility for government service provision on the grounds that the government provider's target group is people with intellectual disability.[45] As a consequence, parents with sufficient income pay for private therapy services while others can not.[46]

5.19 The consistent evidence of unmet demand across all these programs suggests both the need for more adequate funding for personal care, aids and appliances and therapy, as well as for better planning and administration to ensure equitable access across the State. The Committee notes the centrality of these services to the quality of life of people with physical disability. There are significant social and long-term financial benefits that flow from maximising the independence of people with physical disability and reducing their dependence on high intensity specialist services.

Recommendation 15

The Government should provide adequate funding for personal care, aids and appliances and therapy services, using population-based formulas that estimate need.

People with complex care needs

5.20 Some people with physical disability require intensive medical assistance in an accommodation setting. These people may, for example, be dependent on a ventilator for breathing, require intravenous medication, or be fed through a central line.

5.21 In program terms, these people require supports that have traditionally been structured separately through the health and disability systems, and which pose particular challenges for policy and service delivery. As noted in a recent discussion paper:

> The medical needs of people fall under the jurisdiction of NSW Health. Support services to people with disability are generally provided in the community or through DADHC disability services. Where people have high medical needs it is unclear whether the primary responsibility falls with NSW Health, DADHC or both.[47]

5.22 As DADHC has acknowledged, the devolution process for large residential centres has highlighted this tension,[48] as many people with medical needs currently reside in institutional settings. This tension stands against a general backdrop of unmet need for accommodation support noted in the previous reports of this inquiry.

---

[45] Mills evidence, 20 March 2000

[46] Submission 229, Physical Disability Council of NSW, Supplementary Submission

[47] Brain Injury Association of NSW, MS Society, MDAA, NSW Council for Intellectual Disability, NCOSS, People with Disabilities and PDCN, *Younger People with Disability Out of Nursing Homes: A Discussion Paper*, September 2002, p.4

[48] Allison evidence, 9 May 2002

5.23 The Committee considers that the disability service system, through DADHC, should have overall responsibility to coordinate support for these clients for two related reasons: firstly, because the full range of needs of people with disability are more likely to be appreciated and met in the disability service system; and secondly, because that system is subject to disability service standards. Nevertheless, the Committee considers that NSW Health shares responsibility for meeting medical needs, and therefore we encourage the development of jointly funded models of support. We therefore welcome DADHC's endeavours to commence collaborative work with NSW Health to address the need for additional services for people with complex care needs.[49]

5.24 It is important that any joint support models that are developed comply with the Disability Services Act and focus on inclusive community-based models. As noted in our previous report, *A Matter of Priority*, it is both desirable and possible to support people with high medical needs in a community setting.

Recommendation 16

The Department of Ageing, Disability and Home Care and NSW Health should develop joint models of support for people with complex care needs which comply with the *Disability Services Act 1993*, and which are delivered through the disability service system.

5.25 A striking indication of the current absence of appropriate support options for people with both disability and medical needs is the number of younger people with disability living in residential aged care facilities. The following chapter explores the reasons for their inappropriate presence in these settings and suggests a number of policy directions consistent with those set out in this chapter. There is further discussion of people with complex care needs in Chapter 7, which focuses on people who have an acquired brain injury.

---

[49] Allison evidence, General Purpose Standing Committee No. 2, 25 June 2002

Chapter 6 Ageing and disability interfaces

The previous chapter outlined the Committee's view that accommodation that combines medical care with supports designed to maximise the quality of life of people with disability should be more widely available, and that this should be delivered in a community setting via the disability service system. The critical need for more supports of this type is illustrated by significant numbers of younger people with disability currently living in residential aged care settings. At the same time, people with longstanding disability who are ageing are emerging as a group with particular needs that traverse the ageing and disability service systems, and for whom the Commonwealth has significant responsibilities. The interface between ageing and disability policy, funding and service delivery is an area that requires collaborative solutions from the State and Commonwealth if effective outcomes are to be achieved. This chapter explores the diverse needs of younger people in nursing homes and people with disabilities who are ageing, and identifies key directions for policy with regard to both groups.

Younger people with disability living in nursing homes

6.1 There is general agreement among government agencies, parents, advocates and people with disability that residential aged care facilities or nursing homes are highly inappropriate places for younger people with disability to live. Despite this agreement, the lack of appropriate accommodation options for this target group has emerged as an area of significant need in jurisdictions across Australia.[50]

6.2 Younger people tend to be placed in nursing homes when there are no other accommodation options for them. This is especially likely to occur when they have complex needs arising from acquired brain injury, from conditions such as advanced multiple sclerosis or muscular dystrophy, or from the combination of both intellectual and physical disability.

6.3 The Committee was advised by DADHC in May 2002:

> Just under one percent of the residential aged care population in New South Wales are less than 50 years, point nine of a percentage point. The figure that is most often quoted is 1,316 people aged under 60 live in residential aged care facilities, that is 2.8 percent. 883 of those are aged 50 to 60 years. 433 are aged 50 years or less. Of those aged 50 or less, one in ten have an intellectual or developmental disability, one in three have a brain injury, two in three require high levels of care. … 36 people are aged 30 years or less and 50 percent of this group have a brain injury or damage. 80 percent of those people require high levels of care.[51]

---

[50] The Young People in Nursing Homes National Consortium, *Creating a Pathway from Aged Care to Appropriate Care: Report on the National Summit for Young People in Nursing Homes*, 2 May 2002

[51] Griew evidence, 9 May 2002. Subsequent information indicates that as at 31 July 2002, 420 people aged under 50 were living in nursing homes and 929 people aged between 50 and 59 living in nursing homes: Correspondence from Ms Janet Milligan, DADHC, October 2002

6.4 According to a coalition of New South Wales organisations who have mobilised around this issue, made up of the Brain Injury Association, the MS Society, the Multicultural Disability Advocacy Association, the NSW Council for Intellectual Disability, NCOSS, People with Disabilities and the Physical Disability Council of NSW, some of the reasons why younger people have entered residential aged care facilities include:

- An absence of other accommodation and support alternatives
- Ageing carers 'bringing along' a family member with a disability when moving into the nursing home
- Aged care facilities being seen as the only 'secure' alternative
- An aged care facility being the only setting situated near family members
- Expectations of high quality medical and nursing care from nursing homes
- Aged care facilities being seen as the 'only alternative' for people with complex needs.[52]

6.5 Younger people with disability generally find living in an aged care facility extremely isolating. As one younger woman told the Committee:

> It is horrible in the home. I have been there two years already and I do not like it. Everyone else is so old and they cannot communicate. Some are deaf and they cannot talk or speak. So there is not much communication.[53]
>
> I would rather be with younger people than older people. I am not against older people but I just like to have people my own age to talk to.[54]

6.6 The Committee heard evidence of individuals who were the sole younger person in a facility, of most other residents having dementia, of extensive periods of residency, and of individuals' inability to access community activities. Underscoring all instances was a concern for the quality of life of the person with disability.

6.7 NCOSS have documented a number of related reasons why such placements are inappropriate. These include that aged care facilities use a model of care which runs counter to government policy of non-institutionalisation for people with disability, and that nursing homes are not subject to the protections and standards afforded by the Disability Services Act. Younger nursing home residents with disability are unlikely to receive the individualised assistance they need to maximise their potential and to live as independently as possible. Similarly, they are unlikely to be offered opportunities comparable to those of

---

[52] Brain Injury Association of NSW, MS Society, MDAA, NSW Council for Intellectual Disability, NCOSS, People with Disabilities and PDCN, *Younger People with Disability Out of Nursing Homes: A Discussion Paper*, September 2002

[53] Community consultation, Newcastle, 4 July 2000

[54] Ms Y, resident of a nursing home in the Hunter area, 4 July 2000

their peers who do not live in an aged care facility. Finally, nursing homes are intended to provide a service for people at the very end of their lives.[55]

6.8 As the coalition of agencies including the Brain Injury Association have said:

> … in a residential aged care facility environment the focus is clearly on maintenance, prevention and slowing of further deterioration. This is clearly different from the dominant focus in disability service provision, which is on identifying and developing people's ability and potential, and re-assessing and adapting this over time. Such a system of maintenance for many younger people with disability may result in a decrease in skills and abilities.[56]

6.9 This kind of outcome is powerfully illustrated in the following case study:

> Amanda is 21 and she has a moderate to severe intellectual disability as a result of a birth injury. She is using a wheelchair and has high physical care needs but no nursing needs. Amanda was placed in a residential aged care facility on leaving a residential 'special' school she had been attending.
>
> The nursing home has over 100 residents. Amanda is the only person under 50 years of age. In the three years since her admission to the facility there has been an appreciable deterioration of her abilities and skills. Amanda has lost self-caring skills and now exhibits challenging behaviours. Amanda has little to stimulate her and she is clinically depressed.
>
> It is the opinion of all professionals involved that Amanda's deterioration is due to the inappropriate environment she is living in.[57]

6.10 Due to increased life expectancy, accommodation of younger people with disability in nursing homes is likely to mean decades of life away from the community and their peers. The Committee considers that age appropriate accommodation combining medical care with supports designed to maximise the independence and quality of life of people with disability should be more widely available, and that this should be delivered via the disability service system. In keeping with the findings of the second report of this inquiry, the Committee emphasises that such accommodation should occur in a community rather than institutional setting. As the disability service system currently lacks the capacity and infrastructure to meet this need effectively, we consider that new accommodation and support models that cater to the specific needs of people with disability who have complex care needs must be developed.

---

[55] NCOSS, *NCOSS response to the Review of the NSW Nursing Homes Act 1998: Younger People with Disabilities in Nursing Homes*, September 2000

[56] Brain Injury Association et al, September 2002, p.8

[57] Brain Injury Association et al, September 2002, p.9

Addressing the issue: Commonwealth and State commitment

6.11 As with people with physical disability who have high needs, there is a lack of clarity as to who is responsible for younger people with disability living in nursing homes. While both State and Commonwealth Governments agree that younger people with disability are better off outside nursing homes, to date they have not reached agreement as to how this problem can be addressed.

6.12 The central issue of the need for Commonwealth/State collaboration on this matter was highlighted at the National Summit on Young People in Nursing Homes held in May 2002. The Summit's call for action sought commitment between tiers of government in resolving the issues, measures and resources built into the Commonwealth State Territory Disability Agreement (CSTDA), and Commonwealth leadership in achieving change.[58]

6.13 DADHC sees the presence of younger people in nursing homes as part of a bigger picture of poor interface between the disability and aged care systems. As the Director General told the Committee:

> Yes it is true that we have younger people with disability in Commonwealth funded residential aged care and that they are inappropriate solutions. Equally, in fact more so, within the disability system in New South Wales we have very many people who are older, who are quite frail and have very significant support needs for whom the Commonwealth residential aged care system does not currently provide a response. Now, there are people who on all other criteria would clearly be eligible for residential aged care, but the system has not engaged with them particularly well because they have an underlying disability. That is a matter of some conversation we are having with the Commonwealth in the context of negotiating the next Commonwealth/State Disability Agreement because it seems to us as well as issues of individual rights to access appropriate services, there is also a very real question of cost shifting. So at the moment because a lot of older people in our system are, with improved medical care etc, living longer lives, there are not the exit points to aged care systems at the moment. At the same time we are providing a very intensive level of care for many of those people.[59]

6.14 In recognition that both jurisdictions share a responsibility for younger people with disability currently in residential aged care, the Committee encourages the Commonwealth and New South Wales Governments to develop a collaborative response to addressing the inappropriate placement of these individuals.

6.15 In order to develop the most appropriate support models, the Committee notes that along with DADHC, other New South Wales government agencies should be involved, particularly NSW Health, given its responsibility for people with medical needs, as well as the Department of Housing, Planning NSW, Transport NSW and local government.

6.16 The Committee considers it vital that the State and Commonwealth Governments reach agreement on both funding and a process for the movement of younger people in nursing homes to the disability supported accommodation sector. In the short term, the Committee

---

[58] The Young People in Nursing Homes National Consortium op cit., p. 8

[59] Allison evidence, 9 May 2002

believes it would be valuable for both jurisdictions to develop and pilot joint funding models to address this need. For example, the Commonwealth could contribute the equivalent funds for the level of care that a group of individuals is currently receiving in an aged care setting and the State Government could top this up with the funds required to place that group in a community setting. Alternatively, they could negotiate a 'trade' of funding responsibility for the group of younger people with disability in nursing homes with an appropriate selection of people with longstanding disability who are ageing and who need such care.

Recommendation 17

The New South Wales and Commonwealth Governments should collaborate to develop an agreed process and funding arrangement to address the inappropriate placement of younger people with disability in nursing homes. As a first step, they should develop and pilot joint funding models for priority groups of current residents.

People with longstanding disability who are ageing

6.17 A clear position in this and the previous chapter is that people with disability are best supported by the disability service system as it is underpinned by principles and safeguards which protect the rights of people with disability to live with safety, to participate in the community and to develop their full potential.

6.18 In our view, this position holds true throughout the lifetime of people with disability. Thus while we agree with the Director General that the Commonwealth has a responsibility towards older people with disability, and that it should fulfil this responsibility by providing appropriate resources, we strongly endorse the view that services and supports for people with disability who are ageing, particularly accommodation supports, should be delivered through the disability service system. This view both responds to the need of people with disability for certainty and continuity, and accords with the principle of 'ageing in place' that now underpins the provision of aged care.

6.19 The Committee does, however, acknowledge that as people with disability age they may benefit from accessing the services and expertise of the aged care sector.

6.20 People with longstanding disability who are ageing are a newly emerging group that sits somewhat uneasily at the interface of the disability and ageing service systems. This diverse group poses new challenges for the State and Commonwealth Governments in terms of policy, resources and service provision.

6.21 These challenges will continue as the population of people with disability is both growing in number and becoming more advanced in age. The AIHW estimates that between 2000 and 2006, the population of people with disability aged less than 65 will grow by 9 percent, those aged 15-64 years will grow by 12 percent and those aged 45-64 will grow by 19.3

percent.[60] This trend is a reflection of the ageing of the broader population and of greater longevity among people with disability.

6.22 The needs of people with disability acquire additional complexity as they age, with medical needs, whether associated with physical or cognitive decline, potentially increasing. People with disability may experience the effects of ageing earlier than other members of the community. They may also experience secondary disability or health complications arising out of the long-term effects of their disability. As a result, people with disability who are ageing may require more intensive supports at an earlier age than people without disability.[61] For these reasons, a number of people have argued that the defining age of an older person with disability should be 55, in the same way that 45 has been used for Aboriginal people.[62] In effect, this would mean that people with disability become eligible for programs such as Community Aged Care Packages, and that the Commonwealth would assume a level of responsibility for their needs, from age 55.

6.23 People with disability may also have new social needs as they grow older, for example, as they make the transition from work or day programs to retirement and perhaps seek new leisure and recreational activities. The Committee has been told, for example, of people with disability having no choice but to continue to attend a day program, despite the fact that they are of retirement age, because there are no staff where they live during the day.[63] The families and carers of ageing people with disability also have evolving needs associated with both their own ageing and that of the person with disability. As the Committee heard from a service provider in Broken Hill:

> We are just starting to find that the children are now older people and carers are old old people and you have got complex issues there as to what happens if the carer is not around or needs to find a permanent residential placement. You need to look at the carer's personal needs as well as the child who is ageing and who quite often has not learned the living skills.[64]

6.24 This range of additional needs is placing new and increasing demands on the disability service system to provide flexible, responsive and appropriate supports, and to assist with transitions in lifestyle and service usage. While there is an important service and skills base in the ageing sector that could clearly benefit older people with disability, and to which that group has a legitimate claim, the Committee has been told that the interface between the

---

[60] AIHW, *Unmet Need for Disability Services*, 2002, p. 196

[61] According to the AIHW, international studies have shown that dementia occurs at markedly higher rates among people with an intellectual disability than among the general population, with some people with an intellectual disability developing dementia around 50 years of age: AIHW, *Disability and Ageing: Australian Population Patterns and Implications*, AIHW, 2000; cf NSW Industry Group on People Ageing with Disability, *Issues Paper: People with a Longstanding Disability Who Are Ageing*, ACROD, Aged and Community Services Association and NCOSS, October 2001

[62] The Nucleus Group, *Review of Current Responses to Meeting Service Needs of People with a Disability and the Effectiveness of Strategies to Support Families: Final Report*, June 2002

[63] Sweeney evidence, 17 April 2002

[64] Community consultation, Broken Hill, 10 July 2000

ageing and disability service systems is poor, with innovative and responsive models of support few and far between.[65] According to the NSW Industry Group on People Ageing with Disability:

> Government needs to support linkages between the disability services, residential aged care and community care service sectors, via flexibility in funding arrangements and service access guidelines. This includes funding for cross-sector initiatives and training; interdepartmental collaboration and training; and a clear understanding of individual needs.[66]

6.25 The Industry Group holds that the lack of integration is a result of limited planning by both State and Commonwealth agencies and service providers. At present DADHC has no plan or policy for how the needs of ageing people with disability are to be met.[67] As was indicated in the previous section, responsibility for those in this group who have high support needs is currently a matter of discussion between the State and Commonwealth Governments.

6.26 As the Director General has made clear, the issue of older people with disability living in disability services is now critically linked in policy and resource terms to the issue of younger people in nursing homes. In both cases, a long-term collaborative solution is required from the State and Commonwealth Governments.

6.27 We consider that in cooperation with the Commonwealth, DADHC should develop a plan of action for people with disability who are ageing that affirms an integrated, collaborative approach to people with disability across the ageing and disability service systems.

6.28 Examples of collaborative models consistent with the principle of ageing in place could include:

- When a resident of a group home turns 55 the Commonwealth Department of Health and Ageing assumes full or part funding responsibility for that person and makes the appropriate transfer of funds to DADHC, so that the person's living arrangements are unchanged

- A person with disability aged 55 receives a Community Aged Care Package that supports them to continue living in the community by funding their existing service provider

- A Home and Community Care Program funded respite centre runs a program targeting people with disability who are ageing, following specific staff training

- A joint Commonwealth/State funded specialist ageing/disability assessment team is established to assist with the devolution of a residential centre.

---

[65] Regan evidence, 17 April 2002

[66] NSW Industry Group on People Ageing with Disability, *Survey Summary for the Issues Paper: People with a Longstanding Disability who are Ageing*, March 2002, p.3

[67] NSW Industry Group on People Ageing with Disability, *Issues Paper*, October 2001

6.29 The Committee supports the suggestions of the Industry Group as to the way forward in this area:

- Developing responsive, integrated models of service provision that support collaboration and address transition issues
- Ensuring access to ongoing comprehensive assessment for people with complex care needs so as to ensure optimal responses to changing needs
- Providing long-term and transitional planning for people with disability who are ageing, along with the families and carers
- Ensuring the provision of flexible, appropriate and timely services by both the aged care and disability service sectors through the provision of training for disability services in understanding the ageing process and conditions such as dementia, as well as training for aged care providers in understanding the nature of longstanding disabilities
- Access to advocacy services to ensure access to both information and services.[68]

Recommendation 18

The Commonwealth Government should allow people with disability to become eligible for Commonwealth ageing programs from age 55.

Recommendation 19

The Department of Ageing, Disability and Home Care, in collaboration with the Commonwealth Government, should develop a plan of action to address the diverse needs of people with disability who are ageing. This should be based on principles of flexibility and collaboration between the aged care and disability sectors and include the establishment of jointly funded models of support.

---

[68] NSW Industry Group on People Ageing with Disability, *Issues Paper*, October 2001, NSW Industry Group on People Ageing with Disability*, Survey Summary for the Issues Paper: People with a Longstanding Disability Who Are Ageing*, March 2002

Chapter 7 People with acquired brain injury

People with acquired brain injury comprise a high proportion of people with disability who have complex care needs requiring intensive medical support. As such they are highly represented among younger people currently living in nursing homes. However, people with brain injury have a broad range of support needs, depending on the types and severity of disability they acquire through their injury. A key finding of this inquiry is that within a general situation of unmet need for disability services, people who require responses from more than one system, or who have not historically been defined within the target group of the Department of Ageing, Disability and Home Care, generally have difficulty gaining access to disability services despite having similar support needs. People with brain injury commonly experience this situation and this chapter explores issues of equity in relation to that group.

Defining brain injury

7.1 Acquired brain injury (ABI) refers to an injury to the brain that results in deterioration in cognitive, physical, emotional or independent functioning. It can result from traumatic causes such as car accidents, falls and assaults, or from non-traumatic causes such as stroke, hypoxia (insufficient oxygen), infection, tumour, substance misuse and degenerative neurological diseases. Resulting cognitive, physical and sensory disabilities vary in their severity, may be temporary or permanent and often exist in combination. The nature and severity of disability will be influenced not only by the type and level of damage to the brain, but also by other medical, personal and social factors.[69] Most commonly, younger people acquire their injury through trauma, especially as a result of car accidents, while older people are more likely to experience a stroke.

7.2 There is some variation in estimates of the number of people with acquired brain injury. In 1998 an estimated 103,000 people in New South Wales had an impairment arising from head injury, stroke or brain damage, with long-term effects restricting everyday activities. Of this group, an estimated 56,000 were aged less than 65 years.[70] Less recent figures developed by the AIHW are somewhat higher probably because of the definitions used, with 1993 estimates of 113,000 for people with an ABI-related disability, of whom an estimated 60,500 were aged below 65 years.[71]

7.3 It is only in the last decade or so that brain injury has been recognised as a distinct disability type. People with ABI were previously hidden as a group and incorrectly classified as having either a physical, psychiatric or intellectual disability. Advances in life saving medical technology as well as improvements in driving safety measures which have increased

---

[69] Fortune and Wen, *The Definition, Incidence and Prevalence of Acquired Brain Injury in Australia*, Australian Institute of Health and Welfare, Canberra, 1999; Submission 238, Brain Injury Association of NSW

[70] ABS, *Disability, Ageing and Carers: Disability and Long Term Health Conditions*, 2000, Catalogue no. 4433.0 p. 21-22

[71] Fortune and Wen, 1999, p. 94

survival rates from accidents mean that the incidence of brain injury is growing and will continue to grow over time.

Needs arising from brain injury

7.4 Just as the type of disability arising from brain injury varies from person to person, depending on the nature and severity of their injury, so too do resulting support needs. Generally speaking, people with brain injury may require any of the broad range of disability supports from accommodation, personal care, day programs and respite to assistance with employment. The ABS estimates that 64 percent of those with a brain injury experience a severe or profound restriction in the core activities of daily living (that is, self care, mobility and communication).[72] People with severe injury and complex care needs are likely to require intensive medical assistance in an accommodation setting, while those with physical disability will require the same range of supports as discussed in Chapter 5. As traumatic brain injury commonly affects people in early adulthood and often has little effect on lifespan, people may require support over many years.

7.5 Those without severe injuries nevertheless face notable challenges associated with the cognitive and emotional difficulties that result from brain injury such as memory loss, depression, aggression, mood swings and disinhibition. They, their families and others in their social networks may require specialist supports to help them adjust to their changed circumstances and achieve optimum independence.[73]

Service funding and provision

7.6 Of course, immediately after a brain injury occurs, a person's acute care needs are addressed in a hospital setting, following which they will generally undertake a period of physical, cognitive and social rehabilitation. These supports are primarily provided through the health system, with the state-wide network of Brain Injury Rehabilitation Services co-funded by the Motor Accidents Authority (MAA), in recognition of car accidents as a major cause of ABI.

7.7 The MAA also funds a range of other rehabilitation, trauma and community support projects that assist people with re-integration into the community and long-term care. These projects tend to be limited in scope and are generally not recurrently funded.

7.8 Post-rehabilitation, people with brain injury increasingly look towards the disability service system overseen by DADHC to meet their long-term needs. A number of factors have combined to increase demand for disability services among this group. These include greater rates of survival, the contraction of the long-term care role of the health system, and greater identification of brain injury with disability.

---

[72] ABS, *Disability, Ageing and Carers: Disability and Long Term Health Conditions*, 2000, p. 25

[73] Fortune and Wen, 1999, p. 1-4

Access to services

7.9 The Committee was told that there is a need for greater investment in rehabilitation services for people with ABI[74], and a recent paper from the Royal Ryde Rehabilitation Centre highlighted the need for more living skills development services and behaviour/social skills development programs to enable people with brain injury to maximise their independence, quality of life and participation in the community.[75]

7.10 The Committee also heard evidence from the Brain Injury Association and others that people with ABI struggle to gain access to both mainstream and disability services. In particular, they have unmet need for accommodation, respite, case management, meaningful day activities, education and employment supports.[76]

7.11 As noted in the previous chapter, the presence of significant numbers of people with brain injury living in nursing homes is an indicator of substantial unmet need for appropriate accommodation for people with complex care needs arising from brain injury.

7.12 Factors affecting access by people with brain injury to the full range of disability services include: a lack of appropriate services; means testing, which often excludes people who have received compensation in respect of their injury; a lack of funding; poor awareness of services; physical inaccessibility; and a lack of understanding on the part of service providers of the needs of people with ABI.[77] In addition, the challenging behaviour of some people excludes them from many services. These barriers are exacerbated in rural and regional areas, where there are inevitably fewer services and where transport itself is a significant barrier. Access to respite is perhaps typical of issues across a range of services:

> People who have had a brain injury have complex individual needs and require a range of services to meet these needs, respite care being a crucial service. Yet people with an acquired brain injury receive almost no respite within the current community infrastructure. What has been provided has been ad hoc, focused on metropolitan regions and provided seemingly without reference to need or demand.[78]

7.13 Particularly disadvantaged, according to the Brain Injury Association, are people with ABI who have non-traumatic injury or who have a traumatic injury but who are non-compensable. As these groups have received no compensation they generally have less capacity to pay for services. The Committee has been told that contrary to many people's

---

[74] Submission 238, Brain Injury Association

[75] Pryor, J., Mott, S. and O'Reilly, K., *People with Acquired Brain Injury: Post Inpatient Rehabilitation Service Needs*, Rehabilitation Nursing Research and Development Unit, Royal Ryde Rehabilitation Centre Sydney and University of Western Sydney, Monograph Series No. 6

[76] Submission 238, Brain Injury Association

[77] Ramsay and Hilson, 1995, cited in Fortune and Wen, 1999, p. 4

[78] Submission 238, Brain Injury Association

assumptions, these two groups make up a significant proportion of people with brain injury.[79]

7.14 In the view of the Brain Injury Association, this poor access to generalist disability services stands alongside a lack of brain injury specific services. The Association argues that greater ABI-specific services are required in order to provide supports that are optimally tailored to the unique, complex and individual needs of this target group.

Policy issues

7.15 Underscoring both unmet need and barriers to access are two interrelated systemic policy issues. The first is a reluctance on the part of DADHC to embrace brain injury as one of its areas of responsibility, despite the inclusion of ABI in the target group for the Commonwealth, State, Territory Disability Agreement (ASTDA) the significant disabling effects of brain injury and the support needs that many people with ABI share with other disability groups:

> It is very much a poor relation disability to the others and it is an area that … I have found the Department very much wants to keep at arms length because it knows that to give some adequate resources and to further develop some specialist services in the community that can support people with a brain injury is going to cost more money …[80]

7.16 In the interests of equity, the Committee considers that DADHC should acknowledge people with ABI within the target group of the disability services it funds and provides. Correspondingly, the Committee considers that in keeping with its role as the government agency with primary responsibility for disability services in New South Wales, DADHC should have overall responsibility for funding and providing post-rehabilitation supports for people with brain injury, including accommodation supports. The Committee does, however, emphasise that other agencies such as NSW Health and the Motor Accidents Authority share responsibility for this target group and that particular efforts are required to improve collaboration between all relevant agencies in order to ensure that people with brain injury have access to the range of supports that they require. There is also a need to consider joint funding by responsible agencies.

7.17 The second policy issue underlying poor access by people with ABI to services is the absence of a comprehensive framework for addressing their needs. A Brain Injury Action Plan was jointly developed in 1994-95 by the Motor Accidents Authority, NSW Health, Workcover Authority, Department of Community Services and Treasury. Since that time the disability landscape has changed markedly, most notably with the establishment of the then Ageing and Disability Department and now DADHC. In addition, the numbers of people with brain injury have grown significantly over that period and many of the issues informing the Action Plan remain unaddressed.

---

[79] Marron evidence, 19 October 2001

[80] Marron evidence, 19 October 2001

7.18 The Committee considers that a new policy framework should be jointly developed by these agencies which considers the full range of current and future needs of people with brain injury, and which articulates the roles and responsibilities of relevant agencies for funding and service provision across the stages of recovery, rehabilitation and long-term support. It should also give consideration to the most appropriate mix and spread of mainstream, disability and brain injury specific service provision. Such a framework would, in our view, address the need for systematic policy and planning for people with ABI, thereby helping to achieve equity of access for this group.

Recommendation 20

The Department of Ageing, Disability and Home Care should acknowledge people with acquired brain injury as part of the target group for the Disability Services Program.

Recommendation 21

The Department of Ageing, Disability and Home Care, in collaboration with the Motor Accident Authority, Workcover, NSW Health and Treasury, should develop a funding and policy framework for strategically addressing the needs of people with brain injury across NSW, in order to improve their access to the range of disability and mainstream support services, and to brain-injury specific services. In particular, this framework should consider:

- Living skills and behaviour/social skills development services
- Accommodation, respite, case management, meaningful day activities, education and employment supports.

Case Study – Acquired Brain Injury

Jim is a 38 year old man living in the Illawarra Region. He sustained a brain injury in a motor vehicle accident in 1990, just after his 28th birthday. After leaving a rehabilitation unit Jim went to live with his parents in the area, with plans to move out as soon as he was 'better'. Jim had lived independently since he was 18, out of the region. It was a huge challenge for Jim and his parents to be living together again. He had no social contacts, and there was limited support available in the area.

Jim required a lot of supervision and guidance in his daily activities. He was no longer able to drive, and his memory, balance and sensory problems meant that going for a walk alone became a traumatic and confusing experience. He also relied heavily on his parents' supervision for meal preparation, budgeting and monitoring his behaviour. Jim found this reliance on his parents enormously frustrating, and this, combined with the decreased control over his emotions, led him to become verbally abusive towards his parents, after which he would experience a period of depression. His parents were struggling to cope with the situation and had faced a loss in financial stability since they had reduced working hours to care for Jim and deterioration in their health due to the long hours and stress of caring.

There are no respite services in the area to provide Jim and his family with a break. There are no accommodation support services available so that there is no opportunity for Jim to live independently again. The local generic services (HACC funded and independent) are under-resourced and in great demand. They are unable to offer any hours of in-home support.

(Edited extract from Brain Injury Association Submission)

Part 2: Building the system

When this inquiry commenced, the lack of resources for service expansion was seen by inquiry participants as the key issue for the disability service system. While the need to properly resource the sector remains an important issue, the emphasis has shifted to the effectiveness of systems for delivering new services and the need for medium and longer-term planning to address predictable growth in demand. Following the injection of new funding in May 2000, the specialist disability support system in New South Wales commenced a period of significant expansion and reform. Two years on, questions have emerged about the efficacy of reform in some areas and there have been increasing concerns about delays in the establishment of important new services and supports.

This part of the report examines systemic and organisational issues that need to be addressed in order to build a more effective and accessible disability service system in New South Wales. Chapter 8 reviews progress to date in the key priority areas and initiatives considered in our previous two reports and makes some specific recommendations relating to these areas. The chapter notes that many of our early recommendations remain relevant. Our conclusion from this review is that the Department must develop new systems to improve on its past performance and allow a greater focus on individual outcomes. A way to achieve this is outlined in Chapter 9, which recommends that a general intake and support coordination system be developed to form the basis for effective management of the disability service system. This system is necessary to make the existing service structure work more effectively and to provide for more responsive, flexible and sustainable disability services.

Chapters 10 and 11 consider the direct service provision roles of DADHC and the non-government sector. We note that, with the amalgamation of the government's funding and service delivery roles into a single agency, there is a need to clearly define the direct service delivery role of government. There is also a need to ensure that the non-government sector is sustainable over the longer term. Key recommendations include the comprehensive review of funding arrangements for the non-government sector and the development of an industry plan.

Chapter 12 examines other systemic issues within the current system that must be resolved in order to improve services for people with disability. These include the need to develop an effective service monitoring framework that focuses on individual outcomes to ensure the quality of existing services and to support the development of more responsive service structures; enhancing a whole of government commitment to people with disability; and the resolution of longstanding difficulties arising out of the Commonwealth State Territory Disability Agreement. It is increasingly accepted that in order to achieve a sustainable response to the problem of unmet need, the current structure and focus of disability services must change. The system must move beyond its current focus on crisis management to develop a flexible and proactive approach to support that emphasises the strengths and capacity of people with disability.

Chapter 13 discusses the critical importance of supporting children, families and independent living. There should be a greater focus on preventative supports that commence early in life and carry through over the life course of people with disability. This is followed by discussion in Chapter 14 of a way to promote innovation and flexibility within disability services.

Underpinning all of these issues is the need for comprehensive and open planning for disability services over the medium and longer term, as well as greater clarity about the respective roles and obligations of the State and Commonwealth Governments in funding disability services. The Committee notes that a clearly articulated plan for the continuing delivery of accommodation and support services for people with disability is essential if the system is to move away from the current focus on crisis management to a focus on planned and preventative lifelong supports. We therefore make a number of recommendations around planning in Chapter 15.

Chapter 8 Progress in priority areas

This chapter examines progress in the three priority areas of permanent accommodation, respite and devolution identified in the Committee's previous report. The Committee maintains its view that effective delivery in these three areas is essential for the development of the specialist disability service system as a whole. We have therefore closely followed developments in these areas since the release of our second report, *A Matter of Priority*, in December 2000. The chapter also briefly considers the outcome of the group homes project, which was covered in the Committee's first report, *The Group Homes Proposal* in December 1999. We note that many of the recommendations of our two earlier reports, and particularly those within *A Matter of Priority*, remain relevant. We therefore consider that the DADHC should, in consultation with stakeholders, identify those recommendations of previous reports that remain relevant and progress their implementation.

Recommendation 22

The Department of Ageing, Disability and Home Care should, in consultation with stakeholders, identify those recommendations of the Committee's earlier reports, *The Group Homes Proposal* and *A Matter of Priority*, that remain relevant and progress their implementation.

Permanent accommodation

Background

8.1 It is well recognised that demand for permanent out-of-home accommodation for people with disability poses the greatest challenge faced by the disability service system. This demand is driven by a number of factors including the ageing of carers, the increasing lifespan of people with disability and the development of a rights-based approach to disability service provision.

8.2 In New South Wales, as in other States, there has been significant new funding for supported accommodation in recent years,[81] but growth in the supply of accommodation has not yet been sufficient to meet even the most acute level of demand. During consultations, the Committee was made keenly aware of the immense human cost of unmet need for accommodation.

8.3 *A Matter of Priority* noted that the needs of people in extreme crisis and who require permanent accommodation must be addressed to allow the system to move away from its current focus on crisis and to develop a better balance between intensive supports like permanent accommodation and less intense preventative supports such as respite. To build confidence in the system, the Committee recommended that the supply of permanent accommodation be progressively increased by 200 places per year for five years. The

---

[81] *Unmet need for disability services: Effectiveness of funding and remaining shortfalls*, Australian Institute of Health and Welfare, Canberra, July 2002, Chapter 3

Committee also recommended that the government establish population-based targets for the number of residential places for people with disability per head of population, in the same way that planning is undertaken for other areas of human services such as health and aged care places.

Progress to date

8.4 Funding for what has become known as the *197 Places Program* to assist people known to DoCS as being in crisis was announced in the May 2000 Budget. In addition, funding to support people in crisis through the Service Access System was allocated in May 2000, with further funding allocated in May 2001.

8.5 Allocation of this funding was warmly received by the sector as providing vital 'breathing space' for those in most desperate need. However, concerns have been expressed over the time it has taken for people to move into permanent places. Concerns were initially raised with the Committee by peak groups in November 2000 and again in mid and late 2001 and early 2002.

8.6 In May 2002, DADHC advised that the number of people included in the program had risen to 215 through the inclusion of individuals involved in related programs. Executive Director of Policy and Planning, Mr Robert Griew, told the Committee that:

> Of the 215, 74 individuals are in alternate accommodation, 22 individuals are in long-term accommodation within disability services and 41 children are receiving support in home or in alternative placements, which is a total of 137 you could say have a robust long-term solution through that system. 54 additional clients are in disability services in some form of care, so they are not without care but there is still work being done, and there are 26 remaining proposals with other providers in combination with other programs like SAS.[82]

8.7 While it is pleasing that the process has been finalised for a proportion of people, delays remain of concern. DADHC advised the Committee that some of the delays are a result of the very complex needs of people who are in the program and the difficulty in developing solutions that are appropriate to their needs. The Committee notes that the move into permanent out-of-home accommodation for people with disability can be a time-consuming and difficult process. This is particularly so for people in the highest level of crisis, because they often have needs that are complex and difficult for service providers to meet adequately. We therefore acknowledge the significant challenges faced by the Department in providing suitable accommodation for some of these people. The need to develop support models and policy for people with complex needs is discussed further in Chapter 12.

8.8 While the current program will ultimately provide accommodation for a defined number of individuals, the Government has not yet stated a target for the number of additional permanent places that will be delivered over the medium to longer term. Similarly, no population-based targets for permanent out-of-home accommodation appear to have been established. There is a need, as part of a broader planning process, to clarify exactly what

---

[82] Griew evidence, 9 May 2002

level of projected growth in permanent accommodation is likely to be provided to manage growing demand. This issue is considered further in Chapter 15.

The Service Access System

8.9 Perhaps the most significant recent initiative has been the establishment of the Service Access System (SAS). The SAS is intended to provide a clearly defined way to access supports for people who are in or at imminent risk of crisis. While the system is not intended to act solely as a point of entry to permanent accommodation, the Committee noted in *A Matter of Priority* that the SAS should provide a clear path to permanent accommodation for those who need it.

8.10 There has been considerable support within the sector for the SAS. The SAS provides, for the first time ever, a clearly defined system that people in crisis can use to seek assistance. Importantly, the SAS provides a valuable opportunity for the consistent collection of data on the needs of people with disability in New South Wales. Such data can assist DADHC to plan systemically, and on an individual basis, for the needs of people with disability.

8.11 While it is recognised as being sound in principle, there has been a significant level of concern about the implementation and scope of the SAS. Some of the major issues include:

- Delays have been experienced at every stage of the process – including allocation of support planners, preparation and submission of support plans, approval of plans, establishment of interim support arrangements and provision of permanent support

- The system was not properly 'advertised' to the community meaning that it is poorly understood. In particular, there have been delays in developing communication strategies for people from culturally and linguistically diverse communities

- The system's focus on people with the highest level of need is too narrow. People with lesser needs who are assessed as ineligible for support through the SAS do not have a central point of access to services – this limits the development of preventative capacity within disability services as a whole

- People who receive some level of support but who are inappropriately supported, for example young people in nursing homes, cannot access more appropriate support through the SAS, even where their current level of support is demonstrably inadequate

- While the system was originally intended to provide individualised support to people with disability, the reality has been that the main model of support has been group homes. This has led to continuing delay for individuals who have been unable to move into permanent support arrangements until they are matched with a group of people with similar needs

- The centralised operation of the SAS and complex planning and approval processes have contributed to significant delays.

8.12 It is generally accepted that the Department did not anticipate the initial level of demand for the SAS. As such it commenced operation without sufficient staff and resources in place to manage the number of applications that have been received.

8.13 A key reason for the high level of demand has been the lack of clear alternative pathways to support for people who are not in crisis or at imminent risk of crisis. In the absence of systems to register future need, to request access to preventative supports like respite, or to seek changes to current support arrangements, the SAS has been viewed as the closest thing that there is to a general intake system. As the Director General of DADHC told the Committee:

> The Service Access System was established to provide … an entry point in the system for people who were at imminent risk of losing their community placement. However, in the absence of other articulated entry points in the service system, it became, in a de facto sense, the entry point …
>
> [T]here is in fact a wide diversity of people seeking service through SAS and to some extent some of the more complex problems in SAS actually relate to people who are perhaps not well serviced at the moment by other service systems. For example, we do have quite a high number of people applying for SAS who have very high and complex medical support needs who may at the moment be in, say, rehabilitation units in hospitals or spinal units following an injury. There have been people who have gone into nursing homes … There are people who have been in the criminal justice system and who need some specialised support but whose primary issues relate to their offending behaviour. There are people who are the adult children of ageing carers and those ageing carers in many cases do not immediately want service for their family member but are saying to the department, "Some time within the next couple of years I will need to place my son or daughter because we're getting old, we're not as capable as we once were of providing the service", so there is a future registration of need. There is a significant group within SAS who have an existing service but wish to enhance or top-up that service in some way.[83]

8.14 The most recent figures from DADHC indicate that:

- Approximately 2,400 people have applied for support through the SAS, of whom 2,315 have been assessed and 891 have been deemed eligible for support[84]
- By May 2002, 619 people had received assistance through the SAS, of whom 39 had received a permanent or recurrent support package and 580 were being provided with interim support

---

[83] Allison evidence, 9 May 2002

[84] Griew evidence, General Purpose Standing Committee No.2, 25 June 2002

- As of May 2002, 123 of the 580 people receiving interim support were in the process of finalising recurrent support packages; [85] by June 2002 this figure had risen to more than 150.[86]

8.15 According to DADHC, many of those currently receiving interim support have complex needs and require considerable work in order to finalise their support. The Department is currently working through the backlog of people requiring permanent support and is looking at ways to streamline processes in the future. The Committee understands that the system now receives approximately 20 applications per week.[87]

8.16 Substantial reform of the SAS has now commenced. In May, the Director General acknowledged that the Department needs to be more timely in the way it determines SAS eligibility, the way that it determines what services will be provided to people, and the way that it responds to those needs.[88] Ms Allison advised that the system will move from a centralised to a regional operation and decision-making processes will be streamlined. The Department also intends to use staff within the operational sections of the Department, rather than external contractors, to prepare support plans for people using the SAS.

8.17 To be effective, these changes need to occur as part of comprehensive reform of the Department's intake processes. An effective crisis support system must operate as part of a more general intake system with the capacity to direct people to a range of support options depending on the level and urgency of their needs. In the next chapter, we therefore recommend that a general intake and support coordination system be established.

Respite reform

Background

8.18 *A Matter of Priority* noted that an effective system of respite support for people with disability is essential to ensure that:

- Crisis-driven demand for permanent out-of-home accommodation is minimised through an emphasis on preventative supports
- People with disability and their carers are able to remain in informal support arrangements that they wish to maintain
- People with disability are able to have the natural developmental experience of time away from their family. Quality respite services support people with disability

---

[85] Griew evidence, 9 May 2002

[86] Hon Faye Lo Po' MP evidence, General Purpose Standing Committee No.2, 25 June 2002

[87] Allison evidence, 9 May 2002

[88] Allison evidence, 9 May 2002

to develop independence, new relationships and the skills to help them in their transition to life outside the family home.

8.19 From the outset, the problem of blocked respite places was identified as a key concern for this inquiry. Problems accessing sufficient respite, particularly in rural areas, western Sydney, the Illawarra and Hunter regions, were consistently raised during the Committee's consultations. People told the Committee that respite was being made available less frequently, for smaller amounts of time, and that planned respite was often cancelled due to crisis admissions to respite services.

8.20 To resolve these issues, the Government established a Respite Working Group, which reported in early 2000. Key recommendations were that permanent accommodation should be provided to people who lived permanently in respite services and that crisis accommodation should be separated from respite. The recommendations of the Working Group were endorsed by this Committee in *A Matter of Priority*, which noted that the preventative and developmental benefits of respite cannot be achieved if respite services are preoccupied with crisis support.

Progress to date

8.21 The Government has acted on many of the recommendations of the Working Group. In May 2002, DADHC advised the Committee that the number of blocked respite beds had been reduced from 149 to 73 and that 34 new respite services have been funded.

8.22 There has also been an expansion in the overall supply of respite services, through the allocation of 1,200 flexible respite packages over three years and the funding of new centre-based respite services. According to DADHC, funding for respite services has been the largest area of growth in recent years, with $6.5 million in additional growth funding allocated for respite in the 2001-2002 Budget.[89]

Flexible respite

8.23 An important policy direction has been the shift from traditional centre-based respite, to more flexible models that enable respite to be provided in a variety of settings. For example, a service provider may provide support to a person in their family home enabling their regular carers to go away for the weekend. Moves to develop flexible services tailored to the needs of clients and families are welcome, but some concerns have been raised about current directions.

8.24 In particular, a number of people have commented that there is an increased emphasis on in-home support which may not suit all families. Some families find in-home support very intrusive, particularly when they are under stress. A common comment was that in-home support is often available for relatively short periods, meaning that carers do not get a sufficient break to recuperate. Several carers also told the Committee that they were unable to leave the house when in-home support was provided because they were needed to assist with tasks such as lifting.

---

[89] www.dadhc.nsw.gov.au/aboutus.htm

8.25 A particular concern for carers of people with high support needs and ageing carers is that they require more support than that offered by in-home or other types of flexible respite services. Out-of-home respite therefore remains important for people with high needs and must be readily accessible.

8.26 Another comment was that the types of 'flexible' services currently offered are relatively inflexible, meaning that people with disability and their carers are not able to develop support options that suit their needs. This is illustrated by the following comment on the allocation of a flexible respite package to a person in a rural area:

> [W]e often find that the guidelines of those things are quite rigid. That exact thing has become available to a colleague. She has $1,500 a year to use on behalf of her son who is 18 and still lives at home. But the only way she can use that money is to pay for a motel room and a carer. She does not want her son to go to a motel in town for a weekend. She would rather use the money to provide someone to come to the house. He goes to the local high school. He has very high support needs. She would like some of his mates to come out to the house to spend a weekend with him and have a paid carer there while she and her husband go away. But they cannot use the money for that.[90]

8.27 There is no doubt that flexible respite services are an important part of the range of support options available to people with disability and carers. Flexible respite should offer genuine flexibility to people with disability and be provided in ways that maximise the benefits to clients and carers. Flexible respite services should also be provided within a framework that provides out-of-home support as required.

Summary

8.28 It is pleasing to note the progress that has occurred in relation to respite. Action is continuing to unblock beds, and the service system has expanded. But it is not yet possible to assess the extent to which these initiatives have had an impact on demand for respite. Data about the extent to which access to respite has increased in terms of either the number of users or the frequency of use is presently not available.

8.29 DADHC has advised the Committee that accurate data about the capacity of the respite system in New South Wales will become available through the implementation of a new Minimum Data Set (MDS) later this year. The new MDS will require services to provide more accurate data about service usage and will assist the Department to gauge the capacity of respite services.

---

[90] Sweeney evidence, 10 September 2001. The Australian Institute of Health and Welfare's (AIHW) recent study of unmet need noted similar concerns about the continued need for out-of-home respite, the limitations of in-home respite and the relative inflexibility of flexible respite packages: AIHW, *Unmet need for disability services: Effectiveness of funding and remaining shortfalls*, Canberra, July 2002, Chapter 4

Unmet need for accommodation and respite

8.30 *A Matter of Priority* noted that it is difficult to determine the exact level of unmet need for accommodation and respite services. Demographic information indicates that demand for these services remains high. According to Australian Institute of Health and Welfare (AIHW) data, 11,500 people with disability in Australia who had high needs were unable to access any respite or accommodation services in 2001. A further 10,700 people with high needs were unable to access a sufficient level of accommodation or respite support. Assuming that one third of these people live in New South Wales, the figures equate to approximately 3,830 people and 3,570 people respectively for this State. These estimates were produced using conservative methodology, which tends to underestimate need. For example, they exclude people who are inappropriately placed in nursing homes.[91]

8.31 The service growth that is now taking place through the *197 Places Program* and the SAS can be expected to address the needs of some of these people. However, the figures indicate that the substantial demand for accommodation and respite services will require continuing investment.

8.32 The AIHW estimates do not distinguish between people who need respite and those who need permanent accommodation. In part, this is because it is difficult to measure the demand for either service separately; the availability of respite has a direct effect on demand for permanent accommodation. Respite and permanent accommodation form part of a continuum of supports for people with disability and their carers. However, the current disability service system distinguishes between respite and permanent accommodation and information about actual demand for each type of service is necessary to accurately plan for service growth to meet demand.

8.33 In the absence of clear data about the breakdown of demand, the Committee considers that the target of 200 additional permanent accommodation places per year recommended in our previous report remains a reasonable and conservative approach to meeting part of the demand identified by the AIHW.

8.34 Continued growth in supply of respite is also necessary to address the level of demand identified by the AIHW. We note that the rollout of respite services to new users is also considerably less complex than the provision of permanent accommodation. Provision of additional respite services is an essential strategy to manage demand while the disability service system as a whole is undergoing a period of significant reform.

8.35 There is a need for better information about the extent and nature of need for respite services to inform medium to longer term planning. Building on the information that should become available through the implementation of the new MDS, the Committee considers that DADHC should undertake a survey of the current capacity of respite services in New South Wales and the level of demand for these services. The survey should be undertaken on a regional basis and consider whether there is an appropriate balance between flexible and centre-based respite services in these regions. The survey should also consider the extent to which current respite services meet the needs of groups who are currently under-represented in the disability service system including people from

---

[91] AIHW, 2002, Chapter 6

culturally and linguistically diverse communities, people with physical disability and people with acquired brain injury.

Recommendation 23

Taking into account existing information about unmet demand for accommodation and respite services, the Department of Ageing, Disability and Home Care should fund additional respite services.

Recommendation 24

Following the introduction of new Minimum Data Set collection procedures, the Department of Ageing, Disability and Home Care should undertake a survey of the supply and demand for respite services in New South Wales to measure the effect of recent reforms and to provide a basis for planning for service growth. The survey should:

- Be undertaken on a regional basis
- Determine whether there is an appropriate balance between flexible and centre-based respite services
- Examine the extent to which respite services meet the needs of people from culturally and linguistically diverse backgrounds, people with physical disability and people with acquired brain injury.

Devolution of large residential centres

Background

8.36 The third main issue discussed in *A Matter of Priority* was the continuing use of congregate residential services to accommodate a significant number of people with disability. Despite attempts to improve the quality of accommodation offered, these services are based on an inappropriate institutional model of care that is incapable of conforming to the requirements of the *Disability Services Act 1993*. While there has been longstanding commitment to the devolution of these services into fully supported community-based accommodation, the population of these centres remained relatively stable over the 1990s.

8.37 The Committee found that the congregate care model provided few benefits, financial or otherwise, to the disability service system and raised significant issues of inequity between government and non-government providers and between people who lived in congregate accommodation and those who lived in community-based services. It was noted that the continuing existence of congregate services as significant providers of supported accommodation has prevented the development of an equitable and planned system of supported accommodation. *A Matter of Priority* made a series of recommendations aimed at speeding up the process of devolution and ensuring that devolution occurred through a planned and effective process.

8.38 The relative levels of government funding to large residential and community-based supported accommodation across Australia is outlined in Table 1. While we acknowledge the possibility that DADHC centres support people with higher needs than non-government centres, the table demonstrates that there are persistent inequities between the funding provided to people in non-government centres and to all other clients of accommodation services. These inequities occur in most other jurisdictions.

Table 1: Average government funding for accommodation support at 2001-02 prices by State and Territory ($)

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT
Government large residential	97,079	72,977	106,503	69,731	64,181	NA	NA	NA
Government Community	95,649	72,305	83,597	81,230	44,401	61,322	75,483	NA
Non-government large residential	35,024	39,517	21,743	25,089	23,281	31,421	NA	NA
Non-government community	60,145	53,226	29,771	55,551	25,820	48,797	22,728	72,800
AVERAGE funding	77,062	67,272	47,775	61,492	45,234	50,616	61,765	68,612

Source: AIHW 2002, Table 3.10

Progress to date

8.39 In 1998, the Government made a commitment to transform all remaining congregate accommodation services into community-based services within 12 years. Funding was allocated for the first stage of this process in May 2000 to enable the movement of 400 people living in 11 large centres to community-based accommodation by 2003. The initial centres selected included those that supported children, and reflected the widely accepted view that children should be the first priority in the devolution program. Earlier this year, the devolution project was expanded to include Mannix Children's Home.

8.40 While this renewed commitment to devolution has been welcomed by the sector, issues have arisen about aspects of the process. Some of the key points include:

- Progress in assisting people to move into community-based accommodation has been very slow, leading to concerns that the target of complete transition within 12 years of the original announcement will not be achieved

- Some of the processes used have been cumbersome and unclear to residents, families and service providers

- There has been a lack of clarity about what options for community accommodation are available for residents and their families to consider. Residents and families were initially offered considerable choice about support options, but did not receive support to make the choice. This has lead to considerable uncertainty for residents and their families about the security of future options

- Opportunities have not yet arisen for residents in other centres who wish to move to community-based accommodation to do so
- No plans for significant extension of the devolution project beyond the initial 11 centres have been publicised, leading to uncertainty for residents, families and staff of other centres and an apprehension that the project will not extend beyond the initial centres.

8.41 Initial progress with devolution of identified centres has been slower than anticipated. In May 2002, the Committee was advised that community-based arrangements had been finalised for 43 people and by June this figure had risen to 68.[92] According to departmental estimates, a further 227 people will move into community living between July 2002 and June 2003.[93]

Promoting certainty

8.42 Lack of certainty about the process and support options has impeded progress. The department initially emphasised flexibility and individual choice for residents and their families. As such, it was not automatically assumed that residents would move into established service models, such as group homes, or that they would remain with their current service provider. This approach has been confronting for residents and their families, especially those who were familiar with their current service provider and resistant to change.

8.43 Earlier this year, the Commissioner for Community Services noted that there is a need for DADHC to review the approach that it takes to devolution in order to promote certainty and clarity:

> [W]e tried to do three things at once: devolve the service, increase choice and increase contestability between providers. It is clear now that that is stifling the ability to devolve in any way within the time that we would regard as appropriate.
>
> I think devolution will have to be reconstructed so that institutions are devolved perhaps either within the existing agencies or to other agencies but recognising that the choice may become more limited for the individuals in that process. We recognise that that is unsatisfactory in the long term. If a person moves from a large institution into a group home, it is imperative that the system allows flexibility beyond that point, such that in a few years time when a person makes the choice to know they can do so. It is equally true that the current emphasis on trying to meet and give maximum choice to individuals is in fact providing no

---

[92] Griew evidence, 9 May 2002, General Purpose Standing Committee No 2, Budget Estimates 2002-2003, Answers to Questions on Notice

[93] General Purpose Standing Committee No 2, Budget Estimates 2002-2003, Answers to Questions on Notice

> choice. They are simply locked into those current services and the devolution process is undoubtedly being stalled.[94]

8.44 The Commissioner suggested that devolution should proceed on the basis that residents would stay with their existing service provider, which would be funded to support them in community-based settings provided that:

- Residents who do not wish to remain with their current provider are able to 'opt-out' by changing to another provider
- The system should be flexible enough to respond to changing needs of people after their first move, so that:

> We are not simply moving people from an institution into a group home in which they forever become trapped.[95]

8.45 In evidence, the Director General acknowledged these concerns and advised that DADHC is reviewing devolution processes.[96] We understand that the Department intends to adopt a project management approach to devolution and will work systematically with each centre to manage the transfer to community-based living on a centre by centre basis.

8.46 The Committee agrees with the view of the Commissioner for Community Services that devolution processes need to be clarified and that it is appropriate in the short term to trade off flexibility for certainty. We therefore consider that the move by the Department towards specific project management for each centre is appropriate.

8.47 In many cases, the best way to achieve devolution will be to proceed on the basis that people will remain with their current service provider, which would then support them in the community. We note that this may provide greater continuity for residents and families, and in particular will enable positive social networks that exist within large centres to be maintained.

8.48 We also support the two provisos suggested by the Commissioner. People who wish to leave their current service provider should not be forced to remain with that service. Similarly, the accommodation system should allow for further change as people's needs and skills change. During our consultations, we met a number of people who had moved from an institution through a group home to semi-independent living. For these people, life in a group home was a valuable first step towards more independent arrangements that reflected their personal choices about how they wished to live. For other people who had moved out of institutions, group homes provided stable and effective long-term support arrangements. Systems therefore need to be established to allow support arrangements to change as people's needs and wishes change following movement to the community.

---

[94] Fitzgerald evidence, 17 April 2002

[95] Fitzgerald evidence, 17 April 2002

[96] Allison evidence, 9 May 2002

8.49 The provisos suggested by the Commissioner provide important safeguards around resident choice within the devolution process. We consider that the establishment of a general intake and support coordination recommended in the following chapter will provide a means by which these safeguards can be achieved.

Recommendation 25

The devolution project should be managed on a centre by centre basis and provide residents of each centre with the opportunity to remain with a single service provider. Where appropriate, existing services should be funded to support residents in the community, provided that:

- Residents who do not wish to remain with their current service provider are able to move to another service provider
- Flexibility within the system is maintained so that people have the opportunity to change their support arrangements following their initial move into community living.

Residents of DADHC centres

8.50 Approximately 1,400 people live in large residential centres operated directly by DADHC.[97] In order to achieve significant progress with the devolution of these centres, a decision needs to be made about the future role of the Department as a provider of supported accommodation.

8.51 A strategy that is being used for the devolution of Marsden Rehabilitation Centre (MRC) has been to set up a new non-government organisation, Community Living, to support residents when they move to the community. All residents were offered the option of either remaining with DADHC or joining the new organisation. While most residents have chosen to move to the new provider, a number of people with high medical support needs chose to remain with DADHC. Positive aspects of this approach are that it addresses the need for certainty and continuity while providing a degree of choice to residents. Most other DADHC centres are significantly larger than MRC, and translation of this approach to those centres would require a significant commitment to develop and resource non-government providers.

8.52 The role of DADHC as direct service provider is discussed in Chapter 10, however we consider that the devolution of the larger centres will be achieved more quickly if current residents are given the option of remaining with the Department.

---

[97] The Budget Papers indicate that the number of people in DADHC centres declined from 1,463 in 1999/2000 to 1,402 in June 2002 and is projected to reduce to 1,361 by mid 2003: *Budget Estimates 2002-03, Budget Paper No. 3 Vol. 1*, p 5-44. In October 2002, the Committee was advised that 1395 people live in large DADHC residential centres: correspondence from Ms Janet Milligan, DADHC, October 2002

Staffing mix in DADHC centres

8.53 Our previous report highlighted the shortage of staff in large DADHC (then DoCS) residential centres. A key reason for this shortage is that current industrial arrangements only permit qualified nursing staff to support residents. The report noted that to help the centres to work towards a community-based model of care, it would be beneficial to employ residential care workers to work alongside nursing staff in DADHC centres.

8.54 Staffing issues remain a critical concern in DADHC centres. There is currently an international shortage of nurses. Demand for qualified nurses is extremely high in New South Wales. Qualified nursing staff are simply not available to fill positions in DADHC centres and vacant positions are therefore not filled. Current industrial arrangements place excessive demands on existing workers, create significant occupational health and safety concerns and result in a demonstrably lower level of support to residents.

8.55 In view of the continuing staff shortages and the need to begin the transition process in all large DADHC centres, the Committee considers that residential care workers should be recruited to work in DADHC residential centres. Such an approach is clearly in the best interests of residents. The need to retain specialist medical, nursing and allied health skills within DADHC following transition to community living was highlighted in *A Matter of Priority*.

Recommendation 26

As a matter of urgency, residential care workers should be employed to work alongside nursing staff in large Department of Ageing, Disability and Home Care residential centres.

Expanding the devolution project

8.56 Continuing delay in the process of reforming services so that they meet legislative standards and current community expectations is of concern to the Committee. We acknowledge that experience has also shown that devolution of individual centres is a time-consuming process that cannot be rushed. We consider that the new approach adopted by DADHC is likely to achieve better outcomes and will reduce delay. Provided this approach is properly implemented, it is now possible that stage 1 of the devolution project will be complete by the end of 2004. This will be a significant achievement, but unless further services are included in the devolution project, approximately 2,000 people will remain in government and non-government accommodation that does not meet legislative requirements more than a decade after the Disability Services Act was passed and more than six years after the twelve year timeframe for complete devolution was first announced.

8.57 Stage 2 of devolution is not scheduled to commence until 2005, however we understand that a comprehensive plan for the management of future stages of devolution is currently being prepared.[98] Given the time-frames involved in successfully managing the transition of

---

[98] General Purpose Standing Committee No 2, Budget Estimates 2002-2003, Answers to Questions on Notice

large services, it is not appropriate to wait for the completion of the initial round before commencing the further devolution of large residential centres.

8.58 We consider that as the new approach develops, there should be a progressive increase in the number of centres included in the devolution project. The selection of these centres should be based on strategic consultation with the sector. We are aware that there are a number of large services that are prepared for devolution and employ staff who have participated in previous devolution projects. Many of these services are known to DADHC and should be included in the next round of devolution.

Recommendation 27

The next stage of the devolution project should commence immediately. Identification of services to be included in the second round of devolution should be based on consultation and include those services that are strategically placed to move forward rapidly on the devolution project.

Departmental resources

8.59 It is important to ensure that there are sufficient resources within the Department to manage devolution on a project basis. Devolution of each centre requires intensive project management over a long period of time. This in effect means that a properly staffed project team will need to be established for each centre. Planning resources are required now within the Department to enable the second stage to commence earlier than the currently scheduled date of 2005.

8.60 In *A Matter of Priority* we raised concerns about the lack of sufficient staffing within the Department to manage devolution and recommended that additional resources be allocated for this purpose. Lack of staff within the Department to manage devolution properly has contributed significantly to the delays experienced to date. We remain concerned that unless appropriate resources are made available to plan for and manage devolution projects, the objective of complete transition of all large centres by 2010 will not be achieved.

8.61 The Committee considers that a devolution unit should be established within DADHC to manage the devolution project. Staffing of the unit should be sufficient to ensure that complete devolution of all medium and large residential centres can take place by 2010.

Recommendation 28

A devolution unit should be established within the Department of Ageing, Disability and Home Care to manage the devolution process. Resources and staffing for this unit should be sufficient to ensure that all large residential centres for people with disability are able to complete their transition into community-based services that conform to the *Disability Services Act 1993* before 2010.

Case study – Devolution

I am writing as an advocate for 'William', a man with an intellectual disability who lived in 'Bellevue', a large congregate facility in Sydney. William died last Wednesday, and I have just returned from his funeral.

William's greatest wish was to move from Bellevue into a house of his own. He knew exactly what he was missing out on by living in an institution. It is a different sort of tragedy when people do not understand what they are missing, but William was very clear on what he wanted from life.

His three goals were to be able to sit on his own verandah, to have a hall table on which to keep his keys, and to be able to walk up the street and watch the lawn bowls. None of these goals are exotic or particularly costly. Meeting those goals would have meant that William could finish his life in dignity, knowing that he was valued and respected.

I am deeply frustrated by the waste of William's life and by the ways in which he was constrained and limited by the place in which he lived. When I first met him nearly five years ago, William told me he had been living at Bellevue since 1968 - and he said "and every morning I wake up and think how much I hate it here". Over the last five years, things have changed at Bellevue, and the new management of the service listened to William's complaints, and agreed with him that he should indeed be able to expect his own place in the community. However, this never became a reality.

Last Friday, William took issue with the manager of the service, asking her whether she was "going to get me out of here before I conk out". Five days later he died, angry and frustrated with the service that could not provide him with the support he so much wanted and needed.

I am pleading with you to make the funds available for the people who still live at Bellevue to move into the community. They have, without exception, endured abuse, degradation of their dignity and exploitation of their rights over the past twenty to thirty years they have lived in an institution. Please let me be clear that the current management and staff do their best to provide those who live at Bellevue with the best possible care. However, we owe a debt to all the older people who have lived in institutional settings for many years. They have lived through the worst sort of service provision – it is so important that we find a meaningful and concrete way to show them that they are valued and valuable human beings, and that they deserve living conditions and support that recognises their worth and dignity.

Today, I sat with ten others who live at Bellevue, and wept for the loss of William. I also cried for the fact that they too will die in an institution unless something is done.
(Edited extract from confidential submission)

Consultation and participation

8.62 Responsibility for the success of devolution does not lie solely with DADHC. The project-based approach opens the way for service users, family members, advocates, staff and service providers to collaboratively plan for and implement devolution plans in each centre. There is considerable expertise and commitment to devolution within the sector. In order to successfully expand the devolution project, DADHC will need to develop processes that engage stakeholders in its implementation.

8.63 The Disability Safeguards Coalition has proposed a consultation framework consisting of a State devolution reference group to provide strategic support to the devolution process. This would be supported by a local reference group to assist the implementation at each centre.[99] The Committee notes that this approach was used successfully in the devolution of the Hall for Children. This approach would provide an opportunity for DADHC to harness existing knowledge and skills within the sector to support devolution and to ensure that structured consultation and information provision take place within each centre.

Recommendation 29

The Department of Ageing, Disability and Home Care should establish a structured consultation framework to support the devolution process. Key elements of the framework should include:

- A State Devolution Reference Group to provide strategic support to the devolution process
- A Local Reference Group for each centre to support devolution at a service level.

Including residents of all services

8.64 While there is resistance to change within many large centres, there are also many residents who, with the support of their families or advocates, would like to move into the community. At present these people do not have the opportunity to participate in the devolution project unless they live in a centre that has been identified for complete transition to community living.

8.65 A number of witnesses have noted that this represents a missed opportunity to enhance the success of the devolution project. The current focus on devolution provides an ideal opportunity to give existing clients of large services a way to change their support arrangements to better meet their individual needs and aspirations. The Committee therefore considers that a mechanism should be developed to enable current residents of large centres who wish to move into community living to do so as soon as possible.

8.66 We are aware that progressive reduction of resident numbers could pose viability issues for service providers, particularly those non-government services that operate from a low recurrent funding base. If the funding that previously supported a single resident within a large centre is withdrawn, then the service may not be able to continue supporting remaining clients. It may therefore be necessary to quarantine funding for large services that lose clients during the period prior to undergoing transition. Such arrangements would be temporary, remaining in place until a new funding base for community-based living is established when the service undergoes transition. Large services of questionable viability should also be targeted for devolution sooner rather than later.

---

[99] Submission 187, Disability Safeguards Coalition, Supplementary Submission

Recommendation 30

The Department of Ageing, Disability and Home Care should establish a process to enable residents of large residential centres that are not currently engaged in the devolution project to move into community-based accommodation as soon as possible.

- Where necessary, funding of large centres should be quarantined to ensure their viability
- All residents of large residential centres, and their families or advocates, should be advised that they have the opportunity to register an interest in moving to community-based accommodation.

The group homes project

8.67 It is now more than three years since the decision was taken to seek expressions of interest for the support of residents of 41 DoCS group homes. Our first report, *The Group Homes Proposal*, examined that decision in detail and our second report commented on progress as at December 2000.

8.68 The process is nearing completion. Of the 218 residents who were included in the project, 43 have moved,[100] and a further 35 intend to move, to a non-government provider.[101] We note that over the period since the decision was announced, the number of departmental group homes has actually increased from 276 in 1999/00 to 282 in 2001/02 and is projected to increase to 299 by July 2003, due to devolution and other initiatives.[102]

8.69 Feedback to the Committee about the group homes project has been highly critical. The decision was announced in the context of the Budget and was accompanied by forward estimates that outlined expected cost savings from the project. This created an enduring perception that the process was motivated largely by the desire for cost savings rather than the interests of residents. Departmental documents provided to the Committee indicate that Treasury was advised of possible difficulties associated with the decision, but this advice was not acted upon.

8.70 Evidence to this inquiry has been marked by continuing concern about the way the project has been managed and the persistent delays in finalising the transfer process. It is clear that the cost to government of managing the fallout from the decision has outweighed any cost savings. The controversy surrounding the group homes project unnecessarily diverted resources from more pressing issues such as addressing unmet need and devolution.

---

[100] www.dadhc.nsw.gov.au/aboutus/htm

[101] Allison evidence, 9 May 2002

[102] Budget Estimates 2002-03, *Budget Paper No.3 Vol.1*, p 5-44

8.71 The damage to relationships between the Department and people with disability, families, service providers and peak bodies arising out of the project has been extensive and has impacted upon the ability of the Department to implement positive initiatives such as devolution and the SAS. An effective relationship between government and the sector is necessary to support the reform and development of the disability service system. These relationships are only now being re-established.

8.72 On the positive side, we note that approximately a third of the residents who were required to participate in the project have indicated a desire to change their support arrangements. This points to a need for greater flexibility within the disability service system and for a process to be established whereby all residents of accommodation services are able to voluntarily seek changes to their living arrangements.

Conclusion: common themes

8.73 Drawing on recent experience, the following issues have emerged about the Department's past management of accommodation programs:

- Processes for allocating or reforming accommodation services have not been clearly defined. Families and service providers told us that communication about individual cases as well as strategies for reform have been infrequent and unclear

- Information provision by the Department has been sporadic. There is no comprehensive communication strategy about services and supports for people with disability. There have been delays in establishing appropriate communication strategies for people from culturally and linguistically diverse backgrounds

- Insufficient staff resources within the Department have been provided to properly manage reforms

- Effective case management has not been provided resulting in families having to negotiate the system with limited assistance

- Approval processes have been over-centralised and have involved multiple layers of management, resulting in substantial delays

- The Department has commenced a range of reform projects with different funding streams, accountability requirements and processes; these programs are intended to deliver similar outcomes, but their diversity creates complexity within the sector

- Time frames for completion of some projects have been overly optimistic, resulting in failure to deliver stated targets.

8.74 We acknowledge that the Department faces considerable difficulties achieving reform and delivering outcomes. Support services for people with disability in New South Wales have developed over a long period of time and in an uncoordinated manner. Previous attempts at reform and coordination of the service system, such as the Richmond Program or the implementation of the original Commonwealth State Disability Agreement, have met with only partial success. This has resulted in a fragmented sector where funding for individuals is based largely on what program they were originally funded under rather than on their current level of need. Inequities that have built up over time have been particularly hard to address.

8.75 In managing the roll out of new funds the Department has also faced various and at times competing imperatives. To meet the considerable backlog in unmet need, the Department has been under significant pressure to roll out new programs as fast as possible. There has also been pressure to develop new flexible support options that reflect the individual needs of people with disability rather than fit people into predetermined models such as group homes. In the devolution program, the Department has also had to manage resistance to change from some families and from staff of some services.

8.76 Having acknowledged these constraints, it is clear that the Department must significantly improve its systems for service delivery. Allocation of accommodation and related supports, and programs such as devolution, should be more timely to reduce the continuing backlog of unmet need.

8.77 We note that there has been a consistent flow of new funding for all forms of specialist disability service covered by the CSTDA. Table 4 shows that, when adjusted for inflation, State funding for disability services has increased from $442.8 million in 1995-96 to $732.0 million in 2000-01. Table 3 indicates that considerable growth in funding for unmet need has occurred in over the last two years. On a per capita basis, Table 2 shows that New South Wales spending on disability services under the CSTDA has increased from $71 (in 2001 dollars) to $112 over the same period. Nevertheless, it is clear that this increased expenditure has not always achieved the best possible outcomes for people with disability.

8.78 The evidence to this inquiry has consistently demonstrated that the roll out of new services and reform of existing services are complex processes that require effective and continuous management by the Department. DADHC needs to develop structures and adequately resourced systems to effectively manage the continuous provision of new services to new clients. Allocation of support services needs to become part of the routine ongoing operations of the Department. There is also a need to ensure that greater flexibility is built into the disability service system. A system in which this can be achieved is outlined in the next chapter.

Table 2: Per capita expenditure on CSTDA services in 1995-96 and 2000-01 at 2001 prices ($)

	Expenditure 1995-96 adjusted $2001	Population June Quarter 1996	Funding per capita adjusted $2001	Expenditure 2000-01	Population June Quarter 2001	Funding per capita $2001
NSW	442,845	6,190,200	71	731,966	6,532,500	112
Vic	478,992	4,541,000	105	705,674	4,829,000	146
Qld	177,552	3,354,700	53	268,016	3,627,800	74
WA	145,589	1,762,700	83	204,010	1,909,800	107
SA	142,762	1,479,200	97	170,298	1,502,400	113
Tas	59,885	473,400	126	63,242	470,300	134
ACT	20,384	307,500	66	30,904	314,200	98
NT	11,663	177,700	66	17,877	197,600	90
Cth	251,085	18,289,100	14	289,493	19,386,700	15

Source: AIHW 2002, Table 3.2; Australian Bureau of Statistics, Cost Price Index, All groups, weighted average of 8 capital cities, *6401.0, June 1996 to June 2001; Australian Bureau of Statistics,* Australian Demographic Statistics*, 3101.0. Note: Figures for States and Territories include the Commonwealth contribution to each State or Territory.*

Table 3: Reported unmet need expenditure 2000-01 and 2001-02 by jurisdiction ($Million)

	2000-01 ($M)			**2001-02 ($M)**		
	Commonwealth	State	Total	Commonwealth	State	Total
NSW	16.840	93.410	110.250	33.680	148.491	182.171
Vic	12.300	50.400	62.700	25.150	56.850	82.000
Qld	9.100	9.000	18.100	18.300	18.000	36.300
WA	4.905	9.538	14.443	9.810	16.008	25.818
SA	3.625	4.842	8.468	8.276	6.000	14.276
Tas	1.315	1.500	2.815	2.960	4.800	7.490
ACT	0.131	1.832	1.963	2.333	2.300	4.633
NT	0.605	0.652	1.257	1.224	1.210	2.434

Source: AIHW 2002, Table 3.1 Note: (a) Unmet need exp[enditure figures for 2001-02 reflect the reported cumulative increase in recurrent funding since 1999-00. (b) The AIHW noted that there are significant discrepancies between the reported unmet expenditure in several jurisdictions, including NSW, and the increase in funding shown in the data on total expenditure provided by the Productivity Commission (see Table 4). The reported reason for discrepancies in NSW figures was that the creation of DADHC involved the merging of three different financial systems to bring all disability expenditure under the auspice of one agency, and the fact that the DADHC accounts were not audited at the time of publication: AIHW 2002, p.35.

Table 4: Expenditure on CSTDA services by Commonwealth, State and Territory Governments, 1995-96 to 2001-01, actual and adjusted for 2001 prices ($'000)

	1995-96	1995-96 adjusted $2001	1996-97	1996-97 adjusted $2001	1997-98	1997-98 adjusted $2001	1998-99	1998-99 adjusted $2001	1999-00	1999-00 adjusted $2001	2000-01
New South Wales	395,397	442,845	470,995	522,804	508,535	564,474	591,060	644,255	660,750	700,395	731,966
Victoria	427,671	478,992	466,892	518,250	506,060	561,727	559,565	609,926	613,292	650,090	705,674
Queensland	158,529	177,552	168,770	187,335	199,409	221,341	217,824	237,428	246,621	261,418	268,016
Western Australia	129,990	145,589	147,224	163,419	170,450	189,200	176,055	191,900	187,253	198,488	204,010
South Australia	127,466	142,762	131,586	146,060	143,586	159,380	153,237	167,028	163,360	173,162	170,298
Tasmania	53,469	59,885	59,054	65,550	59,237	65,753	57,936	63,150	59,948	63,545	63,242
Australian Capital Territory	18,200	20,384	21,894	24,302	22,118	24,551	23,882	26,031	28,940	30,676	30,904
Northern Territory	10,413	11,663	9,715	10,784	13,384	14,856	12,666	13,806	14,034	14,876	17,877
Commonwealth	224,183	251,085	231,782	257,278	246,903	274,062	274,688	299,410	276,113	292,680	289,493

Source: AIHW 2002, (using Productivity Commission data), Table 3.2; Australian Bureau of Statistics, Cost Price Index, All groups, weighted average of 8 capital cities, *6401.0 June 1996 to June 2001*

Note: Commonwealth funds to State and Territories are shown within the State and Territory totals

Case Study - Unmet Need

In May 2000, the Committee met six families who had adult children with disability who were in urgent need of accommodation. One mother opened the meeting by graphically describing a recent assault on her by her adult son. At this time, few had caseworkers, only some were able to access respite and they all lacked any kind of constant reliable support from any service provider. Some of them had been waiting for support for over 10 years: submissions for funding had been prepared but not acted upon, and in some cases had been lost in the regional office of DoCS.

Many of the families were struggling with issues related to ageing. As parents and their child grew older, families found their problems were exacerbated but felt that access to services was reduced. This was particularly true for families of people with challenging behaviours – instead of being provided with more support they were told that programs would not accept their children..

The families were in despair at the long delays in getting accommodation and support. None of them felt that there was any prospect that they would ever obtain permanent accommodation.

When we met with the families again in December 2001, none had obtained permanent accommodation. For one family, the situation had become so unmanageable that they had left their child blocking a respite bed. However, 4 of the families were having their needs assessed through the SAS and two had been included in the *197 Program*. The families were now slightly optimistic. While little practical change had taken place, there was a now a hope that they might achieve a permanent solution some time in the future. For one family, progress had been made towards their daughter's move into a group home and they expressed a cautious optimism that those arrangements would stand.

By May 2002, two years after our initial meeting, three out of the six families had made substantial progress. Still, only one family had had their son move out of the family home into an arrangement that they were happy with, while another had begun the transition process. Another family was waiting for funding to be allocated so that planning for accommodation could begin.

Four months later, in late September 2002, the son or daughter of three of the families had successfully moved into permanent accommodation and the families very pleased with the solution. Of the remaining three, one had made considerable progress and their son was preparing for the move.

For the remaining families, there was little practical change. Their support plans under the SAS had been approved but no progress had been made. Reasons given to them for the delay included that they would have to wait until other people with compatible needs were found to move into a group home together, or that further accommodation would not be allocated until all vacancies within the existing system were filled.

One of these families includes the person who was assaulted in May 2000. According to their advocate, their son's behaviours have escalated to the point where his parents are unable to have a conversation in the house without risking a violent reaction. When the parents need to talk, they do so quietly in their garage. According to their departmental caseworker, who is also now their SAS support planner, the son's challenging behaviours are a result of his frustrated desire to move out of home.

Chapter 9 Systems for service delivery

> … it is how programs are delivered as much as *what* programs are delivered that impact on consumer outcomes.[103]

Examination of progress in the three priority areas identified in *A Matter of Priority* suggests that some underlying structural issues have limited the capacity of the Department of Ageing, Disability and Home Care to deliver new services. Funding has been provided for new services but there have been delays in getting those services to people who need them. The establishment of effective infrastructure and management systems within the Department to deliver outcomes for individuals is thus an important reform priority. This chapter proposes a necessary first step in achieving change through the expansion of the Service Access System (SAS) into a general intake and support coordination system.

General intake and support coordination system

9.1 In *A Matter of Priority* we observed that the role of the then ADD was changing from policy development, funding and monitoring at arms length to active management of an expanding accommodation support system and individual case management. DADHC's role in actively managing the transition of people into new services and the reform of existing services means that it now has a direct responsibility for individual service delivery. The incorporation of the disability services arm of DoCS and the Home Care Service into the new Department confirms this transition.

9.2 By this we do not mean that DADHC should necessarily be a direct provider of all day-to-day services such as supported accommodation or respite. However, DADHC has a responsibility to manage individual requests for support and to ensure that appropriate services are available to provide that support. This responsibility lies with DADHC regardless of whether direct services come from government or non-government providers. The effectiveness of the Department as a whole is measured largely in terms of its ability to ensure the individuals who need support receive effective and timely services.

9.3 The structure and resources of the Department should reflect this service delivery role. A consistent message arising out of submissions, evidence and consultations is that people need an easily identifiable point to obtain information about disability and support options, assistance in accessing generic services and clearly defined procedures for accessing specialist services.

9.4 The Department has also acknowledged the need for such a system which is:

> … a bit like the system that they have in aged care where there is a place you can go to to access that system, have your needs assessed for it, and that provides a

---

[103] The Nucleus Group, *Final Report: Review of current response to meeting service needs of people with a disability and the effectiveness of strategies to support families*, June 2002, www.nucleusgroup.com.au

> good database for that system … there is not actually such an opportunity within the disability system.[104]

9.5 The Committee considers that DADHC should expand the Service Access System into an effective broad-based intake and support coordination system that provides a clearly defined point to enable people with disability and their carers to register a range of support needs. The system should have the capacity to plan proactively for the needs of people with disability and to provide strategic assistance to individuals to prevent an escalation of support needs.

9.6 The system should form the basis for management of and planning for the specialist disability service system as well as allocation of funding for key program areas such as respite, supported accommodation and day programs. It should operate as a point of access and service management across both the government and non-government sectors. The system should also provide a formal point of contact and referral with other service systems, particularly health, community services and education, to enable them to share relevant information about the support needs of individuals and develop joint support options for people with complex needs.

9.7 The system should be broad enough to encompass minor requests for information, requests for preventative supports like respite and requests for more intensive forms of support, with an ability to respond to crisis, and should also provide a point of contact for people who wish to register future needs as well as individuals already within the service system who wish to change their support arrangements. From the outset, it should have the capacity to manage requests from under-represented groups such as people with physical disability and acquired brain injury and people from NESB.

Possible models

9.8 Many witnesses, including representatives of DADHC,[105] have suggested that intake processes for disability services should operate in a similar way to Aged Care Assessment Teams (ACATs). ACATs provide a system where people can have their needs assessed by members of a multi-disciplinary team who are based in regional offices. The teams then put together a package of suitable supports drawing on local services. ACATs are acknowledged as providing an effective point of entry to the service system but do not always provide ongoing support or case management after assessment.

9.9 Considerable support has been expressed for the Local Area Coordination (LAC) model that operates in Western Australia. LAC was initially developed to meet the challenges of supporting people in rural and remote areas but now operates across Western Australia. It focuses on individualised and flexible coordination of support strategies for individuals with an emphasis on family support and community building. Coordinators work locally with people with disability, families and community groups to develop support options and also to build the capacity of local organisations to support people with disability. LAC also

---

[104] Griew evidence, 9 May 2002

[105] Griew evidence, 9 May 2002

provides a point of entry to the specialist disability service system.[106] Evaluation has shown that, in addition to meeting the needs of individuals more effectively than conventional services, LAC is extremely cost effective.[107]

9.10 Some elements of a local intake and service coordination system already exist in New South Wales. Community Support Teams located in regional offices of DADHC provide a range of services including assessment, therapy, case management, behavioural intervention and drop-in support for people with disability who live independently in the community. While demand for these services is high, a recognised strength of Community Support Teams is their capacity to provide interdisciplinary support of people with disability.

9.11 A Local Support Coordination program has also been established in several regional areas of New South Wales and is being expanded. As with the Western Australian LAC model, coordinators work with people with disability and their carers to identify informal and formal support services in their local community.[108] Capacity building within non-government organisations is also undertaken by Service Support and Development Officers.

9.12 The Department's Early Childhood Intervention Coordination Program (ECICP) is extremely well regarded. The ECICP aims to coordinate support for children with disability. The Program seeks to facilitate early identification of children who need support, provide information about support options and link people to local services. The program includes a state-wide information and referral service and is overseen by a structure of State, Area and Local Committees. The program initially supported children aged 0 to 6 but is being extended to children aged 0 to 12. We note that the approach taken by the ECICP is more generally applicable across the lifespan of people with disability.

9.13 Further development and integration of these models is required as part of the establishment of a general intake and support coordination system that operates systemically across the State.

9.14 We do not propose a detailed model for a service intake and support coordination system. However, we consider that it should operate as more than just a system for intake and assessment for existing specialist disability services. While there is an urgent need to develop an effective intake system for existing services, we consider that the system should also provide the basis for a more flexible, individualised and cost effective system. A system that operates simply as a point of entry to current models would be a significant advance but will not ensure that the disability service system is sustainable over the longer term.

---

[106] The Nucleus Group, op cit, p. 39

[107] For example, analysis of 1998 Productivity Commission data undertaken by the Nucleus Group indicated that average annual support costs for a group of 56 people deemed to be in critical need of support were $26,464 compared to $60,000 in conventional disability services: Nucleus Group, op cit, p. 81

[108] Department of Ageing, Disability and Home Care, Annual Report 2000-2001, *A New Beginning*, June 2002, p. 12

9.15 Recent research undertaken for national disability administrators by the Nucleus Group supports consistent evidence to this inquiry that the only way to manage growing demand for disability services is to develop a service structure that provides proactive and integrated support for people with disability. The Nucleus Group found that an approach that combines service coordination, support for families and support for independent living is more cost effective and produces better outcomes for individuals than current service structures.[109]

9.16 A comprehensive, state-wide system of support coordination is a necessary aspect of the system that is currently missing. The new system should have the capacity to draw a range of services and support networks together into a support package for individuals. Support coordination underpins a proactive approach to people with disability – ensuring that appropriate levels of support are provided as early as possible to prevent crisis – and takes a long-term coordination role – recognising that as people's needs change over time, their support arrangements should vary to reflect this change. This approach is also recognised as being particularly appropriate to rural and remote areas.

9.17 Support coordination encompasses the existing role of case managers within DADHC but differs significantly in that the role involves actual authority to make decisions about service access and funding allocations. Support coordination also has a broader focus than traditional case management. Whereas traditional case management concentrates on access to formal disability services, support coordination focuses on enhancing both informal and formal supports and requires a more flexible approach and a more diverse range of skills. Effectively used, support coordination facilitates the skills and independence of people with disability and moves away from a support model based on the perceived deficits of people with disability and their need for 'care'.

9.18 In addition to providing a clear point of entry to formal services, the system should therefore operate as the first layer of support within a broader disability service system. We consider that it should include the following elements:

- A clearly defined local point of contact to register needs
- A strong emphasis on local decision-making
- An interdisciplinary approach to assessment and support
- Clearly defined and consistent procedures and guidelines to determine eligibility for service access, supported by effective business systems and a client database
- The capacity to respond quickly to requests for support that prevent an escalation of needs
- An ability to build individualised support around the needs and choices of individuals drawing on informal networks, generic services and specialist disability services

---

[109] The Nucleus Group, op cit, p. 9

- The flexibility to respond rapidly to changes in support needs and transition between stages of life

- The capacity to provide continuing coordination and support to people with disability and their carers

- The ability to respond to cultural and linguistic diversity and the specific cultural needs of groups such as Aboriginal and Torres Strait Islander people.

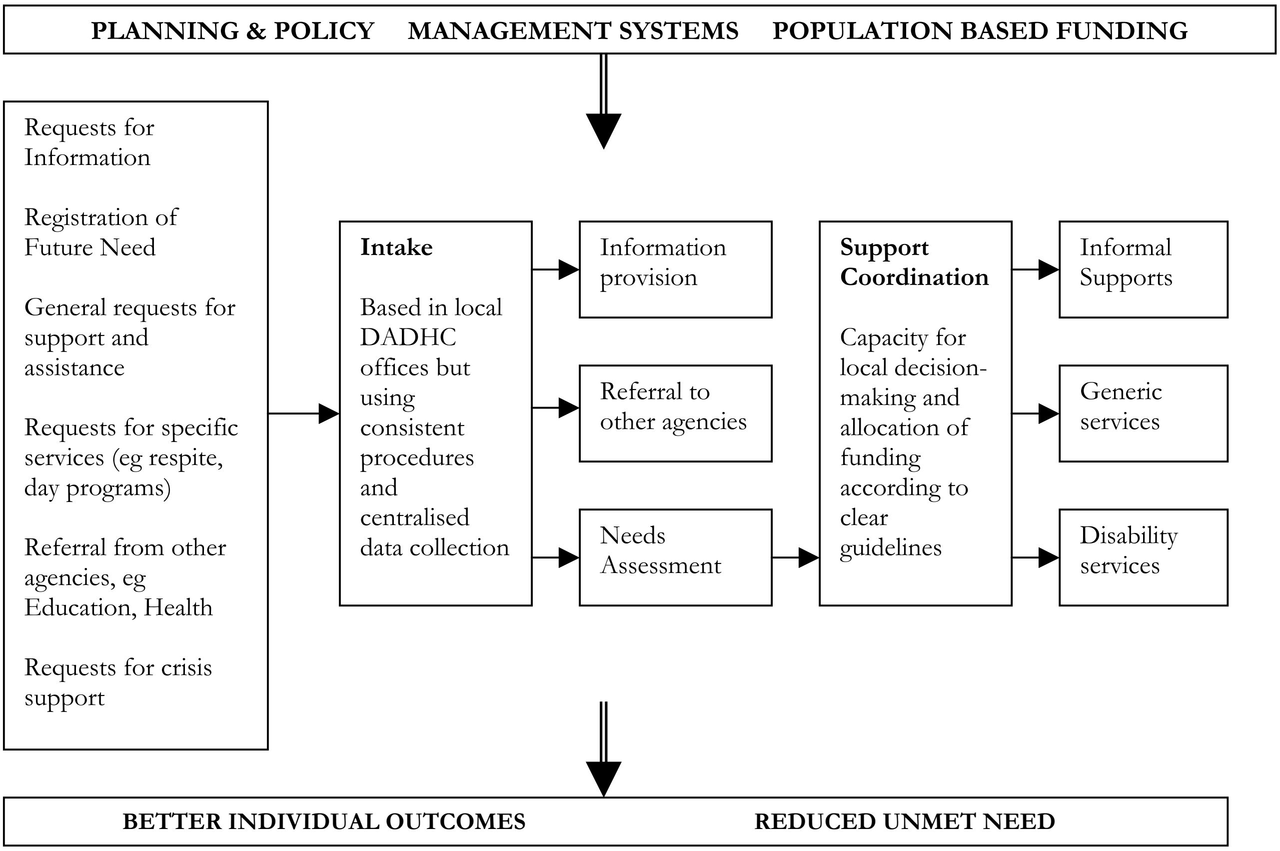
9.19 There may be some concern that the new system will create the unrealistic expectation that every request for support will be met immediately. We do not consider this to be the case. Eligibility criteria will have to be developed for access to various levels of support and requests will need to be prioritised. The proposed model provides both a rational process to manage requests for existing services and a way to match supply of new services to demand. The system is necessary to ensure that growth funding for disability services is used effectively to address unmet need.

9.20 Importantly, the system recognises that prevention and early support is significantly more cost effective than current models of support. The development of a comprehensive system of support coordination that builds on existing support networks, emphasises prevention and is proactive in providing the support arrangements can make significant inroads into unmet need. This approach is therefore far more cost effective than attempting to address unmet need through the current service structure.

9.21 Effective intake and support coordination also ensures that the risk of service provision is not transferred to people with disability and their families or to individual workers. We argue throughout this report that the service system should meet individual needs and empower people with disability and their families to make real choices about their support arrangements. Within this approach, DADHC has a responsibility to ensure that people with disability and their families receive sufficient support to manage their support arrangements properly. People with disability and their families cannot be expected as a matter of course to procure and manage services or assume responsibility for worker entitlements.

9.22 Figure 1 contains a schematic representation of how the system might operate:

Figure 1: General intake and support coordination system



Implementation

9.23 The successful development of a general intake and support coordination system presents a significant opportunity for DADHC to build a new relationship with the sector and to overcome persistent criticism of past performance. The Committee believes that successful implementation will have a significant effect on departmental morale, relationships with non-government services providers and the broader disability sector.

9.24 Establishment of a general intake system will pose a significant administrative task for the Department but is a necessary step in the reorientation of its business towards service delivery. Experience with the SAS has shown that initial demand is likely to be high. Effective processes backed up by sufficient staff resources need to be in place prior to its commencement. To avoid the problems associated with rapid reform we consider that the establishment of the general intake system should happen through a staged process, either by progressively incorporating different programs into the system or by rolling out the system region by region. It may also be necessary to establish different pilot models in different regions during the establishment phase.

Regional operation

9.25 Whereas the SAS originally operated centrally, the new system should operate regionally, with an emphasis on local decision-making. The Department has started to move in this direction. According to the Director General, the incorporation of the former DoCS Disability Services and the Home Care Service of NSW will provide a state-wide infrastructure to support this new regional approach:

> The inclusion in the new department of a comprehensive state-wide infrastructure is also allowing us to reconfigure our business to a regional service delivery focus. This allows responsive decisions to be made locally for clients, their families and for funded organisations.
>
> We are also now in a position to be able to design a coordinated intake system that provides coherent pathways for clients and their families and to provide services in small and remote communities where non-government providers do not operate.[110]

One of the first steps towards this regional approach has been the transfer of the operation of the SAS from head office to regional offices. As part of its recent Strategic Directions statement, the Department has also outlined a new regional structure for service delivery.[111]

9.26 The Committee supports these moves. Regional coordination of service delivery by DADHC provides genuine opportunities to speed up and simplify the provision of assistance to people with disability and their families. Regional service delivery will also assist the Department to plan for local needs and support the development of a local service infrastructure.

9.27 We note that incorporation of the former DoCS Disability Services into the new Department is not yet complete. Many DADHC staff remain in DoCS offices and continue to use DoCS systems. Establishment of a clear departmental identity at a regional level will be an important step in establishing a regionally based intake system within DADHC. We consider that a clear process and timeframe should be established for the formal separation of DADHC from DoCS.

Promoting flexibility

9.28 A longstanding criticism of the existing system is that it provides little flexibility to people who already receive some level of support. The system operates on a presumption that people who are in some type of service, even an inappropriate one, have their needs met. It is very difficult to negotiate access to additional support for people whose needs have increased, or who have been incorrectly assessed as having lower support needs:

9.29 It also creates an incentive to maximise the level of funding initially provided and a disincentive for people to move into less intensive support arrangements. People therefore

---

[110] Allison evidence, 9 May 2002

[111] Department of Ageing, Disability and Home Care, *Strategic Directions*, www.dadhc.nsw.gov.au/strategicdirections.htm

become locked into the types of service and funding arrangements that existed when they entered the service system.

> Because of the current system's lack of focus on individual needs and the abilities of individuals, there is an increasing cost for support of those people. There is no incentive for services to assist people to reach their full potential because staffing will always remain at the same level.
>
> Any steps to decrease staffing means that funding is taken away – never to be returned when the person's needs change.[112]

9.30 The intake and service coordination system needs to accommodate requests from people who wish to change their support arrangements. Examples include younger people who have been forced to live in nursing homes, people living in large centres, or a person living in a group home who wishes to move to semi-independent living.

9.31 Similarly, there are predictable changes in support needs as people go through transitions during life stages. For example, completing school will be a significant transition for a young adult with disability. People require additional support during these transitions and a failure to provide appropriate support can result in crisis and rapid escalation of support needs. The system therefore needs to provide continuing case management support and coordination for people with disability to address changing needs.

Information and business systems

9.32 During this inquiry, concerns have been raised about the quality of record keeping within both the former DoCS and ADD. Requests for assistance and information about client needs were at times mislaid or not properly followed up. Applications for crisis funding for individuals have been lost. Prior to the establishment of the SAS, a standard approach and format for lodging requests for support did not exist. A proper system to track requests for support, individual funding and case management decisions is still to be developed. This significantly impedes DADHC's overall capacity to manage and plan for disability services.

9.33 The general intake system and support coordination system will need to be supported by robust information systems and procedures. Systems should be established that operate consistently across the State, ensure that decisions about service access are made in accordance with clearly defined guidelines, record and support case management service access and funding decisions, enable the central tracking of requests for assistance and facilitate state-wide data collection. Decision making processes must be transparent and have clearly defined avenues for review and appeal that are accessible to people with disability.

9.34 A proper vacancy management system should also be incorporated into the core operations of the general intake system. Proper management and tracking of vacancies as they arise in

---

[112] Van Dam T., Wunsch A. and Hugill P., *Proposal to the Minister for Disability Services: Recommended Structures for the Provision of Accommodation Support Services to People with a Disability in New South Wales*, Disability Safeguards Coalition, December 1998

disability services is necessary to ensure that services are effectively used. Our previous report highlighted an Audit Office finding that there is an urgent need to develop a system to manage vacancies across both the government and non-government services.[113] We acknowledge that there are some cases where vacancies should not be filled, for example in large residential centres or in services where financial viability is an issue. Similarly, people should not be required to fill vacancies in services that do not meet their needs.

Consolidation of programs and policy

9.35 At present, there are multiple programs within DADHC for people with disability. For example, in relation to accommodation these include the boarding house reform program, the *197 Program*, the SAS and the group homes project. This can have an effect on the Department's ability to deliver solutions. During evidence, the Director General commented that the existence of multiple programs,

> has in a sense created its own problems and complexities in dealing with all these various different buckets of money and having to account separately for them as opposed to having some broader systemic guides to which we are working.[114]

9.36 We consider that consolidation of existing programs into a single framework for service provision will assist the Department to streamline processes for delivering accommodation and related supports. While some specific projects, such as devolution, should be managed separately, the creation of a service intake and support system should be accompanied by reform to consolidate the existing range of programs and services offered by DADHC.

9.37 This consolidation must be supported by the development of clear and consistent policy guidelines to determine eligibility for service, procedures to access services and what types of service are acceptable. In particular there is a need to develop a clear accommodation policy. The following comment from the Community Service Commissioner reflects comments made by individual service providers, the Disability Council and peak groups:

> [T]here is no guidance for service providers … The sector - both the service providers and the consumers - need guidance as to what will be acceptable, together with the support that is necessary as part of the service development. We need a very comprehensive accommodation policy. I understand that once you commit to anything there will be critics of it, but the absence creates problems.[115]

Consultation and information provision

9.38 The disability service system in New South Wales has been characterised by a lack of information about how the system operates, what new initiatives are taking place, what

---

[113] *A Matter of Priority*, p. 41; Performance Audit Report, *Ageing and Disability Department: Group homes for people with disabilities in NSW,* Audit Office of New South Wales, 2000, p.72

[114] Allison evidence, 9 May 2002

[115] Fitzgerald evidence, 17 April 2002; see also Riddley evidence, 17 April 2002; Sweeney evidence, 17 April 2002

types of service are available and how services can be accessed. Our consultations have shown that lack of accessible information about service options is one of the greatest sources of frustration for people with disability and their carers. As part of the implementation process, a comprehensive communication strategy should be developed to ensure that the community is aware of the existence and the scope of the new system. This strategy should take into account the communication needs of people with disability, including people from diverse cultural backgrounds and those living in rural and remote areas.

9.39 While the Committee believes that the process of establishing a general intake and service coordination system should commence immediately, we note that it is important to ensure that stakeholders are properly engaged in the implementation process. The involvement in the design of a general intake system of people with disability, service providers and advocates, many of whom have had considerable experience with the existing SAS, will help ensure that workable reform is achieved. We therefore consider that an implementation group with representation from key stakeholders should be formed to assist with the design and implementation of the system.

9.40 It is particularly important that meaningful consultation with people with disability occurs. They will be the users of the system and they should have a significant role in its design. Similarly, the consultation process should engage with people from culturally and linguistically diverse backgrounds and with people living in rural and remote areas to ensure that there is broad and representative input into the implementation process.

Resourcing the new system

9.41 The system must be supported by appropriate resources from the outset. A difficulty experienced by DADHC with the management of recent initiatives has been that new funding for service growth or reform has not included a sufficient component for administration. The Department has therefore not been able to establish an effective infrastructure to manage new initiatives and their implementation has been unsatisfactory. In a situation of significant unmet need these difficulties rapidly create dissatisfaction.

9.42 While existing regional staff in the operational parts of DADHC could form the core of the system, additional resources will be required. Operational staff of DADHC already have high workloads and have limited capacity to take on additional work. For example, limited access to DoCS caseworkers, or to HACC assessment services, was consistently raised as a major concern during our consultations. Recent feedback from advocacy groups following the transfer of the SAS to the regions already suggests that the high workloads of case managers in regional offices are contributing to continued delay in finalising support arrangements. The new system will also require staff to work in new and more flexible ways and they will need appropriate training and support for their new role.

9.43 An effective intake and coordination process will be fundamental to the operations of DADHC. The intake, assessment, referral, support coordination, case management and funding tasks associated with the system must be supported by adequate staffing. Concerns about the need for sufficient resources within the Department to manage new initiatives and reforms were raised in our previous report. We remain concerned that unless sufficient additional staff are provided to operate a general intake system, the problems previously experienced with implementation will be replicated. There is a responsibility within Treasury to ensure that DADHC receives the funding necessary to establish an intake and support coordination system that works.

9.44 In this context we note that approximately 10 percent of disability service expenditure in Western Australia is directed to service intake and coordination.[116] We consider that the additional resources invested in the system will be offset over time through reduced expenditure on intensive forms of support and crisis interventions. By providing a rational basis to the management of specialist disability services the system will also promote a more efficient service structure.

Recommendation 31

The Department of Ageing, Disability and Home Care should establish a general intake and support coordination system for people with disability. The functions of the system should include:

- Receipt of requests for support and assistance
- Assessment and prioritisation of requests
- Referral and information provision
- Support coordination
- Case management
- Vacancy management.

The general intake system should provide a point of contact with other human service systems such as health, education, community services and aged care.

Recommendation 32

The Department of Ageing, Disability and Home Care should develop a comprehensive communication strategy to ensure that the community is aware of the existence and the scope of the new general intake and support coordination system. This strategy should take into account the communication needs of people with disability including people from diverse cultural and linguistic backgrounds and people in rural and remote areas.

Recommendation 33

The Department of Ageing, Disability and Home Care should establish an implementation group with representation from key stakeholders, and in particular people with disability, to assist with the design and implementation of the general intake and support coordination system.

---

[116] The Nucleus Group, op cit, p. 80

Recommendation 34

Additional funding should be provided to the Department of Ageing, Disability and Home Care to support the implementation of a general intake and support coordination system. In particular resources are necessary to support:

- The development of information and business systems to support the system
- Additional staffing to support the intake process and support coordination roles
- The formal separation of regional offices from the Department of Community Services.

Recommendation 35

The Department of Ageing, Disability and Home Care should ensure that clear and transparent policy and decision-making guidelines are developed to support the operation of the system and that an accessible system for review and appeal is established.

Chapter 10 Direct service delivery by DADHC

Throughout this inquiry there has been considerable debate over the role of government as a direct service provider for people with disability. The group homes project generated uncertainty about the future role of government and this uncertainty has not yet been resolved. Our terms of reference ask the Committee to address the future of government as a direct service provider[117] and we note that resolution of this question is necessary to achieve greater clarity within the disability service system. Incorporation of the former DoCS Disability Services and the Home Care Service into the same agency that controls funding and access to services means that the role of the Department as a direct service provider, and the relationship between the funding, service access and direct service aspects of the Department, must be clarified as soon as possible.

Target groups for existing DADHC services

10.1 Evidence to this inquiry about direct service delivery by government has focussed on those aspects of DADHC that were formerly DoCS Disability Services. We received relatively little evidence about the Home Care Service.[118] Our comments therefore focus on the supported accommodation services, Community Support Teams and ancillary supports such as therapy that were previously part of DoCS.

10.2 DADHC is the largest provider of accommodation and related supports to people with disability in New South Wales. According to the most recent figures, 1,395 people live in large residential centres and 1,261 live in group homes operated by DADHC.[119] DADHC also operates respite services and day programs. Support for people living in informal care arrangements or semi-independently in the community is also provided through the Department's Community Support Teams.

Focus on intellectual disability

10.3 The stated target group for accommodation services provided by DoCS Disability Services was people with medium to high support needs whose primary disability was intellectual.[120] This reflects the historical transfer of responsibility for accommodation of people with intellectual disability from NSW Health to the Department of Community Services. To date, this focus has been retained within DADHC accommodation services.

10.4 A number of witnesses have questioned whether it is appropriate for the direct service delivery arm of DADHC to support only people who have an intellectual disability, given

---

[117] Paragraph 3(f)

[118] We note that DADHC has now commenced a restructure which will see the Home Care Service and the former DoCS Disability Services combined into a new Operations Directorate: Department of Ageing Disability and Home Care, *Fast Facts*, edition 9, 13 September 2002, p. 2

[119] Correspondence from Ms Janet Milligan, DADHC, October 2002

[120] Group Homes Proposal, p.95

that the Department as a whole is responsible for all people with disability. One consequence of this focus is that long-term support for people with high needs but who do not have an intellectual disability is provided inappropriately within the aged care sector.[121] It has been argued that it is anomalous that these groups are excluded from the largest provider of supported accommodation, which is also the service provider of last resort.

Restriction to people with medium to high support needs

10.5 In our first report, we noted a range of concerns about restricting government service provision to people with higher needs. These include:

- Supporting a group of clients who all have moderate to high support needs within a community setting can lead to excessive staff workloads and a volatile client mix within some homes
- Focus on a narrow client group is likely to result in a reduction in corporate knowledge within DADHC.

10.6 It is nevertheless appropriate that people with higher needs be supported within the government system. As the largest provider, DADHC has the funding base and infrastructure to support people with higher needs.

Service provider of last resort

10.7 Another issue is whether DADHC should be a service provider of last resort, supporting clients whose needs cannot be met within non-government services. Taken to its logical conclusion, this would see DADHC as a residual service provider that supports only those people with the most complex needs.

10.8 The Committee believes that DADHC clearly has a role directly supporting people who cannot receive support elsewhere. Government has a responsibility to directly support people where other services do not exist or are not appropriate. This does not, however, mean that DADHC should only operate as a provider of last resort.

Current residents of accommodation services

10.9 People with a range of support needs currently live in or receive community support from DADHC services. This places a significant constraint on the ability of the Department to change its focus. A shift to service provision for people with higher needs would require people to transfer out of DADHC accommodation services. Experience has shown that the transfer of people who are already in a service into non-government services would be a resource intensive process and would need to be undertaken voluntarily. As the group homes project demonstrated, the imposition of a transfer process can be counter-productive and may in fact entrench existing arrangements.

---

[121] See Chapters 5 to 7 for further discussion of younger people in nursing homes

10.10 The Committee understands that there is no further proposal to transfer existing residents of DADHC group homes to non-government services. As a matter of principle, we consider that existing residents of DADHC services should not be forced to participate in any compulsory transfer processes.

10.11 This does not mean that innovation, change and flexibility should not be promoted for existing residents of DADHC services. People who wish to change their support arrangements, perhaps by moving to another provider, should have the opportunity to seek changes. Like other providers, DADHC needs to foster support arrangements that reflect people's individual choices and needs rather that the requirements of service providers. The general intake and support coordination system proposed in the previous chapter will provide an appropriate framework for this to occur.

Therapy and allied support services

10.12 The therapy, allied health, behavioural and other specialist supports offered by DADHC are a vital source of support for people with disability. These services assist people with disability to communicate, eat, move about and to manage their behaviour. They are a critical component of early intervention programs for children with disability and are necessary to enhance and maintain the quality of life of many adults. Consultations have shown that demand for these services greatly outstrips supply.[122]

10.13 A key concern reported to us has been that criteria for access to these services appear to be inconsistently applied across the different DADHC regions. A common perception was that residents of DADHC accommodation services received priority over other people to access these supports. In addition, evidence to this inquiry as well as the Committee's early intervention inquiry has suggested that some regions of DADHC view the therapy needs of people who do not have an intellectual disability as being outside their area of responsibility.

10.14 There is a need to clarify the role of the clinical and associated supports offered by DADHC and to develop a consistent, equitable approach to access to these supports. The allied health and behavioural services provided by DADHC require a significant level of specialist expertise that usually cannot be accessed through other means. As part of this process, there is a need to enter into clear protocols with NSW Health to take responsibility for therapy and to ensure that people do not 'fall between the gaps' and miss out on therapy because they do not meet either department's eligibility criteria.

New areas of activity

10.15 Our consultations have indicated that there is a need to develop better forms of community-based support for the following groups:

- People who need assistance with behaviour management

---

[122] As stated in Chapter 4, this undersupply is especially critical in rural and remote areas

- People with complex medical needs
- Children with disability who have high support needs
- People who have dual diagnosis
- People who come into contact with the criminal justice system.

10.16 The Committee received very little evidence about what role DADHC should have in providing new models of support to address service gaps. While we consider that the non-government sector has a role in developing supports in these areas, we note that it is difficult for non-government organisations to provide support in areas where there is a high level of risk. These may include people with significant medical needs or people who, without appropriate support, are at significant risk of breaking the law. With the devolution of large residential centres, DADHC will also have access to a significant pool of medical expertise that can contribute to the development of new ways of supporting people with high medical needs within the community. We believe that DADHC has a role to develop and deliver new support models for people with high needs who are not well served by existing services.

Defining roles

10.17 The Committee is not in a position to fully define the role of government as a direct service provider. The role of DADHC needs to be determined through a strategic assessment of what the Department's current strengths as a service provider are, where its core responsibilities lie and how it can best contribute to the development of the disability service system in a climate of reform and growth.

10.18 This assessment needs to take into account the relationship between DADHC and the non-government sector as well as the needs of non-government service providers. For example, it could be appropriate for DADHC to continue to specialise in supporting people with intellectual disability provided that appropriate community-based support, and funding, is available within the non-government sector for other groups of people. The direct service provision role of DADHC cannot be properly determined without addressing issues relating to the sustainability of the non-government sector. The role of government as a direct provider therefore needs to be determined as part of the industry development planning process referred to in the next chapter.

10.19 It is important, however, that the process of clarifying the direct service provision role of DADHC commence. The following recommendation outlines the principles that must inform any decision about the role of the government as a direct provider.

Recommendation 36

The Government should clarify its role as a direct provider of services to people with disability with reference to the following principles:

- Existing clients of the Department of Ageing, Disability and Home Care services should be able to remain with the government provider if they choose to do so
- The government provider should not exclude people who would otherwise be within their target group but who do not have an intellectual disability
- The government provider should provide community-based support options for people with high or complex support needs, risky behaviours or offending behaviours
- The government provider should support people with disability who are unable to find alternative supports, including people in rural and remote areas who cannot access other services
- Guidelines for access to therapy, behavioural and other allied supports provided by the Department of Ageing, Disability and Home Care should be developed to ensure that access to these services is provided on an equitable basis to people with disability.

Conclusion

10.20 The incorporation of funding, service access and direct service delivery responsibilities in one organisation carries the inherent risk of conflict of interest. We therefore believe that there should be clear structural separation between the service provider and intake and support coordination system responsibilities of DADHC. The general intake and support coordination system will operate as an intake point for both government and non-government services and therefore needs to operate transparently and consistently across the disability system. Decisions about service access and funding need within a region need to be separated from decisions about management of DADHC services in that region.

10.21 There may also be benefits in establishing a clear separation between the clinical support services such as therapy provided by DADHC and the Department's accommodation and respite services. These clinical services will support the intake, assessment and support coordination role of DADHC and it may be appropriate to separate their management from management of accommodation.

Recommendation 37

Specific steps should be taken to ensure that there is a clear structural separation between the general intake and support coordination and the service delivery operations of the Department of Ageing, Disability and Home Care. Consideration should be given to separating the management of clinical services, including therapy and behavioural intervention, from the supported accommodation and respite services provided by the Department.

Chapter 11 Supporting non-government providers

Non-government organisations (NGOs) have always been an important part of the disability service system in New South Wales. Much of the service growth in recent years has taken place in the non-government sector and there is likely to be continued reliance on NGOs to provide further growth. This chapter considers issues that have been raised about the sector's role during the inquiry. These include the adequacy of current funding arrangements for NGOs, their relationship with DADHC, the use of the expression of interest process to allocate funding and the need for an industry development plan. The Committee notes that if the non-government sector is to continue to contribute to the desired outcomes for people with disability then it is important to ensure that the sector is sustainable, highly skilled, accountable and actively engaged with government in shaping the policy framework in which it operates.

The role of the non-government sector

11.1 Non-government organisations have been supporting people with disability in New South Wales since the 19th Century. Systemic government funding for NGOs was first introduced by the Commonwealth in 1972 following the passage of the Handicapped Person's Assistance Act.[123] Direct responsibility to fund accommodation and day programs provided by NGOs was transferred to the States in 1991 under the first Commonwealth State Disability Agreement (CSDA).

11.2 The majority of NGOs have the status of charities and funded services predominantly operate on a not-for-profit basis. These organisations range in size from national charities to small local organisations that are embedded within particular communities.

11.3 These organisations operate in parallel with DADHC services but support a wider range of clients. Non-government services support people with low, medium and high support needs and the sector is not restricted to people with intellectual disability. For instance, specific services exist within the non-government sector for people with physical disability and with acquired brain injury.

11.4 Despite this broader potential client base, there is considerable overlap between the actual client base of non-government and DADHC accommodation services. As with DADHC services, the majority of people living in non-government services have support needs arising out of intellectual disability and live in either group home or congregate accommodation.

11.5 Some of the benefits that NGOs, particularly smaller organisations, bring to the disability sector include their potential to work more flexibly than government agencies, their connection to their local community and their capacity to support particular communities. According to NCOSS:

> [T]here are many strengths that non-government organisations bring as service providers. In particular, they allow for decisions about individual people and their

---

[123] Submission 239, ACROD

> services to be made closer to the ground and closer to the client, which tends to mean better quality decisions. It means better responsiveness, more flexibility, quicker responses and greater capacity for innovation. The other things that non-government providers bring are greater opportunities for community participation and participation of clients' families and other community members in the management of services and in decisions. A particular strength is around cultural appropriateness, particularly for Aboriginal and Torres Strait Islander communities and for some non-English speaking background communities where there may be a history of poor trust of government agencies.[124]

11.6 This level of responsiveness is not always apparent in non-government providers, however, and we understand that the Community Services Commission views a number of non-government services as services of concern. It has also been suggested that some of the larger non-government providers are relatively inflexible and have limited capacity for innovation.

Funding

11.7 While government funding is a significant source of income, most NGOs are not funded for the full cost of services they provide. The balance comes from fundraising or commercial activities undertaken by the organisation. Service providers and the peak industry body, ACROD, have consistently highlighted the inconsistency between the way that NGOs and DADHC services are funded. Despite providing broadly similar services to a broadly similar clientele, DADHC services are fully funded by the government whereas NGOs are required to generate income to cover a proportion of their costs.

11.8 This difference can be traced back to the origin of government funding which was at first intended to supplement the income-generating activities of relatively self-sufficient organisations. Funding was provided in the form of block grants to help an organisation to support a given number of individuals. In many cases, the level of funding given to organisations under block grants has not been reviewed and, when adjusted for inflation, is based on what an organisation received before the transfer of direct funding responsibility to the States under the first CSDA.

11.9 Over the past decade, the accountability requirements of government and the expectations of service users that they will receive quality community-based service have grown considerably. At the same time, the capacity of NGOs to raise funds from sources such as charity or supported employment enterprises has diminished. This has been accompanied by increasing recognition that people with disability should not have to rely on charitable handouts in order to achieve a decent quality of life. As a result, services have had limited capacity to maintain or improve the support that they give to their clients, or to meet legislative requirements, but have been under increasing pressure to do so. Services have reported that additional funding can be difficult to obtain and is usually only provided when the viability of an organisation is at stake.

11.10 The conceptual basis on which funding has been provided has also shifted over time. With the implementation of legislation to govern funding, and the establishment of the CSDA,

---

[124] Kirkland evidence, 17 April 2002

government has taken on a more formal role in the disability service system. NGOs are now funded to provide services that are defined by government, so there is a perception that NGOs provide services on behalf of government. Previously, funding was provided to assist NGOs to achieve their own organisational objectives or mission.

Individual funding packages

11.11 Since 1996, there has been a move towards individualised funding, through creation of packages that are designed to meet the full support costs for each person. Individual packages have been seen as a positive step because, at least theoretically, they link funding to a person's actual need and provide a more realistic level of funding. Individual packages also recognise that the beneficiary of funding should be the service user, not the service provider. On a per capita basis, individual packages tend to involve higher amounts of funding than the older block grants.

11.12 Despite these positives, individual packages have been criticised by both advocates and service providers. Advocates have told the Committee that individual funding has not yet achieved the objective of empowering service users to take control of their funding and exercise choice about who provides their support. Residents of accommodation services face considerable difficulty negotiating change to their support arrangements and, due to an under-supply of services, often cannot find alternative services if they are dissatisfied with their current provider. Funding is provided to services rather than to individuals to purchase services.

11.13 Service providers report dissatisfaction with the added administrative and compliance costs that the packages place on organisations. Their most significant concern has been that individual packages have not provided sufficient infrastructure funding for organisations. NGOs that have received growth funding to support new clients have had difficulty meeting the added costs that service growth has placed on their organisations.[125]

11.14 Common to both groups has been a concern that in practice individualised funding packages are inflexible, making it difficult to tailor a package to a person's needs and very difficult to renegotiate where support needs increase.

11.15 A significant issue is that individual packages have increased the level of inequity within disability services. Packages have been provided only to new clients of funded services, or to people who have moved into community-based accommodation through devolution of large residential centres. Systemic action has not yet been undertaken to review the level of funding to other service users provided through block grants. As a result, people who are funded through block grants tend to receive less support overall than people on individual packages.

---

[125] ACROD evidence, 10 September 2001

Developing a new funding model for non-government providers

11.16 We acknowledge that the issues surrounding funding of NGOs are complex. However, NGOs have a clearly recognised and growing role in delivering the outcomes desired by government for people with disability in New South Wales.

11.17 This means that:

- Funding should be sufficient to ensure that NGOs are sustainable over the longer term – consideration should be given to funding the full cost of service delivery
- Funding should be provided on an equitable basis that reflects the current actual needs of each individual rather than historical grants to services
- Methods of quantifying funding should be flexible enough to accommodate changes in support needs and clear processes should be developed to allow renegotiation where needs change
- The role of DADHC in directly supporting the infrastructure needs of NGOs needs to be clearly defined.

11.18 Considerable work will be required to address the historical funding inequities that relate to non-government providers. For organisations that provide congregate care, funding reform is already taking place through the devolution project.[126]

11.19 Beyond this, the Committee considers that a comprehensive review of funding for NGOs should be undertaken. The outcome of this review should be to ensure that a consistent approach is taken to the funding of all non-government services in New South Wales. In particular, funding for clients of services funded by block grants should be consistent with the allocation of growth funding for new clients.

11.20 As part of the review, a sound funding model should be developed for non-government services. This model should take into account the need for greater flexibility in the way that funding is used for people with disability. Critics of individual funding have not suggested that there should be a reversion to block grants, however they have identified a clear need to develop a model that properly addresses the needs of both the individual and the service provider. We are aware that substantial work on costing models has recently been undertaken in Victoria and a comprehensive funding reform project is currently underway in Queensland. Similar work to develop a new funding model is required in New South Wales.

11.21 The development of a consistent and equitable funding base for all non-government services is a necessary step in reforming the disability services sector in New South Wales so as to achieve better outcomes for people with disability. Consistent funding, linked to measurable outcomes, will reduce the current fragmentation of the sector and provide a basis for long-term planning to meet the needs of people with disability. The funding

---

[126] Issues regarding the scope and pace of devolution are discussed in Chapter 8

model should also identify and address the additional costs of service delivery for people in rural and remote areas.

Recommendation 38

The Department of Ageing, Disability and Home Care should, in consultation with service users, advocates and representatives of non-government services, develop a new funding model for non-government services so as to:

- Provide an equitable and consistent cost base for service delivery
- Support the autonomy of service users and their ability to exercise choice about their living arrangements
- Promote the long-term sustainability of non-government organisations
- Provide a basis for greater flexibility in the use of funding to support people with disability.

The new funding model should identify the additional cost of service delivery in rural and remote areas so as to provide a basis for additional funding for these areas.

Recommendation 39

The Department of Ageing, Disability and Home Care should undertake a review of existing funding to non-government service providers to ensure that all clients of non-government disability services are funded in a consistent manner.

Staffing and infrastructure

11.22 Non-government providers face a number of structural difficulties that limit the capacity of the sector to deliver quality services to an increasing number of clients. These include a limited ability to attract, train and keep skilled staff, a shortage of infrastructure support and limited access to specialist management expertise. Some of these difficulties arise out of the charitable origins of non-government services and include a high reliance on voluntary managements and staff who were willing to work for limited pay, rather than professional staff and management. They point to a need for DADHC to provide strategic support to the sector that builds its capacity to contribute effectively to quality outcomes for people with disability.

Staff training and workforce issues

11.23 Workforce issues pose particular problems for the NGOs. There is a shortage of skilled staff who are available to work within disability services, particularly over the longer term. Staff turnover is high and services frequently have to rely on casual and untrained staff to support clients. A contributing factor is that award rates of pay within the non-government sector have been lower than those within DADHC for some time and there are limited opportunities for career progression within many organisations. Despite these difficulties, the staff of NGOs often display great commitment to the people with whom they work and a desire to improve their skills.

11.24 During consultations, service providers indicated that access to staff training on an ongoing basis is necessary to overcome problems related to the skills base of their workforce. The services indicated that there are three major barriers to obtaining a sufficient level of training:

- Appropriate training may not be available, particularly in regional and remote areas
- Services do not have the capacity to pay staff to attend training
- Services are not funded to provide relief for staff who are absent at training courses.

In addition to a need for training associated with direct support, our consultations suggested a need for training about management, corporate governance and finance. Again, this need was more pronounced in regional areas.

11.25 The quality of service provided to people with disability depends fundamentally on the skills and attitudes of staff. The need for resources to provide appropriate staff training is raised consistently in the research[127] and has been a longstanding concern within the non-government sector.[128]

11.26 Issues related to training and accreditation of staff in NGOs were considered in our first report. In that report, the Committee recognised that there is a need for government to ensure that adequate resources are made available to services to provide staff training. We also recommended that specific guidelines be developed regarding skill development and accreditation programs and the level of funding to be provided to support staff development.

11.27 There have been some positive developments since the report. As part of its capacity building strategy, DADHC has provided funding to several organisations to develop and deliver training to disability service providers. Some services are also developing training packages that they provide on a fee for service basis to other organisations.

11.28 The next step is for DADHC to develop a comprehensive strategy to address the training needs of the non-government sector as a whole. In common with other areas of the human services, it is likely that staff turnover will continue to be high and the training strategy should take this into account. Training and development is part of the recurrent activity of all service providers and this needs to be properly reflected in their funding base. Services also need to be able to provide an environment that encourages and rewards skill development in order to attract and motivate staff. This strategy should be developed as part of the industry development plan recommended at the end of this chapter.

---

[127] AIHW 2002, op cit, Nucleus Group 2002, op cit, Victoria Department of Human Services, State Disability Plan 2002

[128] Submission 239, ACROD

SACS Award increase

11.29 In November 2001 the New South Wales Industrial Commission granted significant increases under the Social and Community Services (SACS) Award.[129] Hourly pay increases of 11.6 percent were granted under the new Award and a 38 hour week was introduced.[130] The new Award also rewards skills development by providing for progression to higher pay rates for people with recognised qualifications.

11.30 The award resulted in a substantial cost increase for the NGO sector and caused financial viability concerns for many services. The New South Wales Government initially agreed to meet the State's share of the cost of the award increase and sought supplementation from the Commonwealth for its share. The Commonwealth has failed to contribute to the cost of the new award.[131] To ensure that services are not disadvantaged by the increase in pay rates the State has now agreed to meet the full costs of the new SACS Award and to contribute to the cost of grade movements.[132] We consider that this contribution will help to address staffing difficulties in the sector.

Infrastructure and management

11.31 Access to appropriate infrastructure support is a particular issue for smaller organisations. Small organisations can be particularly effective in providing flexible support and are especially important in rural areas. However they may have difficulty funding infrastructure, such as information technology, premises, equipment and vehicles or accessing specialist management expertise. The infrastructure difficulties faced by smaller providers are linked to an increasing tendency to fund larger organisations to provide support to people with disability.

11.32 ACROD have warned that the benefits of flexibility and diversity within the sector will be lost if there is a shift to larger organisations. This view was echoed by a number of peak groups, who suggested that as organisations grow larger, they tend to become bureaucratic, inflexible, less cost effective and less community-based.

11.33 The Committee acknowledges that from the perspective of government it may be easier to work with a smaller number of large NGOs rather than a diverse range of organisations of different size. However, we are concerned that an increasing reliance on larger organisations would reduce the capacity for innovation and flexibility in disability services. We are particularly concerned that a focus on larger services would limit the ability of NGOs to develop community-based solutions for regional and remote areas and services that meet the cultural needs of specific groups. In this context we note that recognised

---

[129] Industrial Relations Commission of New South Wales, Social and Community Services Employees (State) Award, Matter No IRC 5544 of 1998, 16 November 2001

[130] Australian Services Union, *Campaign News*, 16 November 2001

[131] The Commonwealth State Territory Disability Agreement is discussed further in Chapter 12

[132] Department of Ageing, Disability and Home Care, *Fast Fact*, edition nine, 13 September 2002

examples of best practice often occur within small to medium sized organisations, such as Hornsby Challenge.

Expression of interest process

11.34 Significant concerns about the expression of interest (EOI) process were raised in our first report.[133] Dissatisfaction with the use of EOIs has been persistently raised by advocacy groups and service providers. According to ACROD, the EOI process transfers the risks associated with service delivery from government to the service provider and favours larger organisations that have the capacity to absorb such risks. Participation in EOI processes has also been resource intensive for services with the result that many services have not participated. For example, the Supported Accommodation EOI process undertaken in late 2000 identified 69 services out of a possible 250 as being eligible to support new clients.[134] A view put to the Committee following the EOI was that a number of the services identified as being eligible were not well equipped to provide community-based support for people with disability, while some effective organisations were not identified.

11.35 Participants also highlighted the contradiction between the current funding approach for NGOs which does not meet the full costs of service delivery and the requirement that services participate in EOIs:

> We think there is a contradiction at the moment in that we are told that government agencies have moved to a purchasing model of services as opposed to the traditional funding model. Our argument will be that the logical extension of a purchasing model is that you pay for what you buy. That is not the case, so we see a logical contradiction between the Government saying that it is purchasing services but not contributing the full costs of those services.[135]

11.36 The fundamental concern is that the EOI process, which is premised on competition, is not suited to the sector:

> I believe that the disability sector can only operate if we worked together, all of us. An expression of interest process pits one organisation against another and, generally in an effort to drive down costs, corners are cut.[136]

11.37 In a climate of high demand and limited capacity, the competitive purchasing model does not work. While central agencies such as Treasury often impose competitive tendering principles on human services agencies like DADHC, the evidence to the inquiry has shown that the EOI model has been counterproductive in the disability services area. The extensive use of EOIs has fractured relationships between the government and service providers and generated concern within the broader disability community. The Committee

---

[133] *The Group Homes Proposal*, p. 99

[134] Submission 239, ACROD

[135] Kikland evidence, 17 April 2002

[136] Riddley evidence, 17 April 2002

therefore considers that EOI process should be reviewed and a new approach to procurement of services should be developed.

Recommendation 40

The Department of Ageing, Disability and Home Care should review the use of expressions of interest to purchase services and develop a new approach to service procurement.

Relationship with the sector

11.38 Concerns about the EOI process are part of a more general concern about the way the relationship between NGOs and government has changed over time. According to a number of participants, the increasing reliance on NGOs to deliver outcomes for government has not been supported by active engagement with the sector in the development of these initiatives:

> I am sure the issue of difficulty in roll-outs of new funding and new initiatives has been discussed at some length. We think that one of the reasons for that is that major initiatives are often announced with an unrealistic time frame, without their having been any dialogue with the non-government sector before that announcement.
>
> That has meant that in reality the department then becomes engaged in a process of consultation. That has not always led to a situation that there is full support for an initiative or for a particular approach. That has then held up implementation; reforms are not fully implemented; money is not fully expended. What could in fact be well-supported initiatives simply are not implemented fully. That could be overcome by a strong, well-articulated approach to engage in non-government organisations in the development of initiatives.[137]

11.39 According to ACROD, there is a need for the Department to develop a more collaborative approach in service delivery which recognises that:

> … the non-government service provider sector is an equal partner in all aspects of the development of the disability service sector. This partnership should recognise and value the expertise and specialist knowledge that resides in the sector.[138]

11.40 The Committee agrees that better engagement with the non-government sector will support better service delivery planning and outcomes for people with disability. This engagement should commence with the development of the industry plan referred to in the next section.

---

[137] Kirkland evidence, 17 April 2002

[138] ACROD evidence, Tabled Document, 10 September 2001

Industry development plan

11.41 The issues outlined in this chapter facing non-government services are complex. They will take time and a joint commitment to resolve. In mid-2000, the Audit Office noted the need for an industry plan, as did the Commissioner for Community Services earlier this year.[139] We agree that the way forward for the sector is to create a comprehensive industry development plan. Victoria has recently committed itself to the development of an industry plan for the non-government sector and we believe this approach should be replicated in New South Wales.

Recommendation 41

The Department of Ageing, Disability and Home Care, in consultation with relevant stakeholders, should prepare an industry development plan for non-government service providers. The plan should address:

- The need for funding reform referred to in Recommendation 38
- The need for a new approach to procurement referred to in Recommendation 40
- Ways to support the infrastructure needs of smaller organisations and the need to maintain a mix of large, medium and small organisations within the sector
- Ways to support services in regional, rural and remote areas
- Strategies to address the needs of people who are under-represented within the service system, including people with physical disability and acquired brain injury and people from culturally and linguistically diverse communities
- The role of the Department of Ageing, Disability and Home Care in supporting the non-government sector
- The relationship between the intake, support coordination and direct service delivery roles of the Department of Ageing, Disability and Home Care and non-government service providers.

---

[139] Fitzgerald evidence, 17 April 2002

Recommendation 42

As part of the industry plan referred to in Recommendation 41, the Department of Ageing, Disability and Home Care should develop an agreed strategy to address the training needs of non-government organisations. The strategy should ensure that:

- Services have the capacity to provide ongoing training and development for staff as part of their core business
- Adequate training can be accessed in rural and remote areas
- Services are able to obtain appropriate management training
- Funding to support the costs of training is incorporated into the funding base of non-government providers.

Chapter 12 Other systemic issues

As the previous chapters have noted, DADHC is increasingly held responsible for the individual outcomes for people who enter the disability service system. The capacity of DADHC to deliver these outcomes is linked to systemic issues that need to be resolved. These include enhancing a whole of government commitment to services for people with disability, resolving longstanding issues with the Commonwealth State Territory Disability Agreement and developing a monitoring framework that focuses on outcomes for people rather than service outputs.

Monitoring and quality assurance

12.1 Service quality underpins outcomes for people with disability. Effective monitoring systems are necessary to ensure that the service system delivers what it is intended to achieve and does so efficiently. The importance of monitoring is recognised in section 15 of the Disability Services Act (DSA) which requires the Minister to ensure that funded services are reviewed every three years to measure the extent to which desired outcomes for service users have been achieved.

12.2 The current service monitoring framework comprises several components. All funded services are required to complete an annual self-assessment form provided by the Department. In addition, Service Support and Development Officers (SSDOs) visit non-government services to review their procedures and to develop service capacity. Where issues of concern are identified, the Service Review and Support program will investigate and ensure that services develop an action plan to address any problems and monitor the service to ensure that outcomes specified in the action plans are achieved. External review is provided through the Community Visitors program, coordinated by the Community Services Commission, and the Commission's complaint and investigation functions.

12.3 We have had consistent evidence that current systems for service monitoring and quality assurance are insufficient to ensure quality outcomes for all service users. Some of the concerns raised about these monitoring systems include:

- Self-assessment systems are not rigorous enough to ensure that service providers fulfil their obligations to provide high quality service

- Information collected through monitoring processes is not acted on by the Department for service development or systemic planning

- SSDO numbers were too few to enable them to visit services frequently enough to monitor them adequately. Some service providers also suggested that there was a potential conflict between the SSDO monitoring role, which could result in sanctions being imposed on a service, and their support and development role for services experiencing difficulty

- Monitoring requirements for the government provider are less rigorous than those for NGOs

- Monitoring systems focus on organisational policies and procedures rather than outcomes for service users
- Key services including respite and semi-independent living are not subject to the Community Visitor Scheme, which is limited to government-funded services that provide full-time supported accommodation
- Community Visitor hours and remuneration are not sufficient to ensure appropriate coverage of service users.

12.4 Similar issues around disability service monitoring have been raised in recent reports by the Law Reform Commission and the Audit Office. In 1999, the Law Reform Commission (LRC) found that monitoring processes within the then ADD did not have the confidence of the disability sector. Accordingly the LRC recommended a new model based around the establishment of an independent Disability Services Quality Assurance Council to administer quality assurance processes and to monitor service quality. Key features of the proposed model included consumer involvement and peer review in assessing quality and the introduction of a system of certification for services based on the quality of service offered.[140] Similar concerns were again raised by the Audit Office in its performance audit of group homes.[141] Overall, the Audit Office found that the former ADD

> Has little capacity to evaluate both the performance of service providers and the effectiveness of the overall disability program.[142]

12.5 In response to such concerns, DADHC has indicated that a new service monitoring framework will commence in 2003. This system is currently being developed and details are therefore not yet available.

12.6 In our view, effective monitoring and quality assurance systems are not an 'add on' to the direct service delivery role but an integral part of an efficient and effective service system. Service monitoring underpins the rights of people with disability and provides essential information to support the policy, funding and industry development roles of the Department. Monitoring systems should be rigorous and applied consistently across the government and non-government sectors. The requirement in the DSA that regular service monitoring be undertaken is intended to safeguard individual rights and to ensure that services achieve and maintain compliance with the Act.

12.7 An appropriate monitoring framework is particularly important to ensure that accountability is maintained within the service system as it becomes more flexible and less centralised. In other parts of this report we note that the development of a disability service system that is sustainable over the longer term will require a shift away from a relatively narrow range of fixed service types towards localised flexible decision-making.

---

[140] New South Wales Law Reform Commission, Report 91, *Review of the Disability Services Act 1993 (NSW)*, July 1999, Chapter 7

[141] Audit Office of New South Wales, Performance Audit Report, *Ageing and Disability Department: Group homes for people with disabilities in NSW*, June 2000

[142] Ibid, p. 73

We acknowledge that this presents challenges for current notions of accountability, which tend to measure a limited range of outputs and place an emphasis on cost effectiveness. However, a properly designed monitoring framework that measures outcomes for individuals and for the system as a whole will enhance accountability and efficiency.

12.8 DADHC's new monitoring framework should therefore be designed around measurement of client outcomes and in particular client satisfaction. The monitoring role of the Department complements the service access and coordination role outlined in Chapter 9 and should be resourced accordingly. Many of the concerns about the current monitoring system stem from lack of resources.[143] Resources for monitoring should therefore be proportionate to the size of the service system and growth funding needs to take into account the need for service monitoring.

Community Visitors

12.9 Community Visitors are the element of the current system that is most explicitly focussed on client outcomes. Their role includes monitoring, advocacy and local resolution of minor complaints.[144] They are a necessary part of the disability service system at both a systemic and individual level. The Committee shares the concerns expressed by others about the declining frequency of visits and declining rates of pay for Community Visitors. We are also concerned that the independent qualitative review offered by Community Visitors does not extend to respite services and semi-independent living arrangements programs.

12.10 Recent amendments to the legislation governing the Community Visitor Scheme[145] have extended its jurisdiction to licensed boarding houses. This will close a significant gap in current monitoring arrangements. The Committee understands that additional resources will be provided to support this extended jurisdiction and that it will commence following the transfer of the Community Services Commission to the Office of the Ombudsman.

12.11 To address the decline in frequency of visits to other disability services, the Committee considers that appropriate funding methodology should be developed to ensure that the number of visitable hours is linked to the number of clients in visitable services. Remuneration for Community Visitors should also be automatically adjusted to reflect wage increases for public sector employees.

12.12 As part of its broader reconsideration of service monitoring, DADHC should also determine whether the coverage of the Community Visitor Scheme should be extended to other accommodation support services such as respite and semi-independent living services. The LRC recommended against extending the coverage of the Community Visitor Scheme to services that do not provide full-time support on the basis that visitor schemes in other jurisdictions are restricted to services that provide full-time residential support.[146]

---

[143] Ibid, p. 44

[144] New South Wales Law Reform Commission, *Review of the Community Services (Complaints, Appeals and Monitoring) Act 1993 (NSW)*, Report 90, July 1993

[145] *Community Services Legislation Amendment Act 2002*

[146] LRC, Report 90, p. 162

12.13 The Committee considers, however, that alternatives to the traditional 'all or nothing' approach to accommodation support will become increasingly important within the disability service system. We have already emphasised the importance of regular high quality respite that builds skills and enhances independence. Given the importance of ensuring that proper evaluation of outcomes for users of these services takes place, we consider that there could be value in either extending the Community Visitor Scheme to a broader range of service types or developing a similar client-focussed monitoring scheme for these services.

External monitoring

12.14 An important issue is whether monitoring should be undertaken internally by DADHC or by an external body as suggested by the LRC. A number of witnesses have commented that lines of accountability have become blurred through the amalgamation of the former ADD with the largest service provider bodies. They have also stressed that external monitoring promotes transparency. At the same time, internal monitoring provides valuable performance information that, properly used, can feed into departmental policy and planning. We therefore recommend that consideration be given to whether some or all aspects of service monitoring should be undertaken by an external body as recommended by the Law Reform Commission.

Recommendation 43

The new Department of Ageing, Disability and Home Care service-monitoring system should be designed around the measurement of client outcomes and client satisfaction.

- Performance indicators should be developed that reflect the Principles and Applications of Principles of the *Disability Services Act 1993* and measure qualitative outcomes for individuals rather than narrowly conceived service outputs
- Monitoring processes should ensure that service user views and satisfaction are actively canvassed as part of routine service monitoring
- Monitoring processes should be consistent across government and non-government service providers
- Specific steps should be taken to ensure that there is a clear structural separation between the monitoring, service access and service delivery operations of DADHC
- To promote transparency, consideration should be given to whether some or all aspects of service monitoring should be undertaken by an external body as recommended by the Law Reform Commission
- Systems should be developed to ensure that information collected through monitoring activities is acted upon at an individual level and is also used systemically as part of the planning, policy and industry development responsibilities of the Department
- Resources for monitoring should be adequate and linked to the level of funding provided for direct service delivery.

Recommendation 44

Funding methodology for Community Visitors should be developed that links the number of visitable hours to the number of clients of visitable services. Remuneration for Community Visitors should automatically be adjusted to reflect wage increases for public sector employees.

Recommendation 45

Consideration should be given to either extending the coverage of the Community Visitor Scheme to respite, semi-independent living and other accommodation support services funded by the Department of Ageing, Disability and Home Care or developing a similar client-focussed monitoring scheme for these services.

Whole of government commitment

12.15 It is neither possible nor desirable to meet all the needs of people with disability through the specialist disability service system. Access to a broad range of services shared with the wider community should be available as a matter of course and is necessary to expand the opportunities available to people with disability. As a representative of the Disability Council explained:

> To be able to talk to the Department of Fair Trading is just as important for some people as wanting to talk to DADHC. This process has the potential to have really major outcomes in changing the way government provides services to people with disabilities. We are members of the community and we do not always have to go to DADHC, because all of our problems are not disability specialist service based.
>
> … I see it as part of DADHC's role as the lead agency in disability to provide disability specific services but also to look at mainstream generalist issues that are as important to people with disabilities as they are to other sectors of the community.[147]

12.16 Appropriate support to enable people with disability to access basic services such as transport and education helps to embed them within the community. Within government, DADHC has a leadership role in ensuring that people with disability can access government services and in developing a whole of government approach to meeting their needs.

NSW Government Disability Policy Framework

12.17 Within New South Wales, the main driver for a whole of government approach to people with disability is the NSW Government Disability Policy Framework, which was released in November 1998.

12.18 Our consultations have shown that the Framework has the support of the sector:

> It is a great leap forward. It attempts to do what has never been attempted before, which is to get all the government departments to actually recognise that they are there to serve the whole community, not just [those] that do not have a disability. [148]

12.19 The Committee considers that the promotion of whole of government responsibility for people with disability through the Framework has been an important achievement. The Framework gives content to the requirement in section 9 of the Disability Services Act that departments prepare and implement a plan that furthers the principles and applications of principles of the Act. As the Law Reform Commission notes:

> The effect of section 9 is to extend the principles and applications of principles to most government bodies, and to *all* services provided by those bodies, whether or not they are provided specifically for people with a disability.[149]

---

[147] Druett evidence, 17 April 2002

[148] Moxam evidence, 4 July 2001

[149] New South Wales Law Reform Commission, Report 91, *Review of the Disability Services Act 1993 (NSW)*, July 1999, p. 52

The Framework provides detailed guidance to government agencies about how to meet this statutory obligation.

12.20 The Framework is now some years old and we are aware of concerns about its effect. A number of witnesses suggested that the Framework has not always led to practical change. Concerns were also raised in evidence that the reporting requirements of the Framework may be reduced in response to criticism from some agencies that they are too onerous.[150]

12.21 We believe that it is important to maintain a whole of government approach to disability. It is therefore necessary to ensure that a process remains in place to facilitate compliance with section 9 of the Disability Services Act. In view of concerns about its effect and proposed changes to its operation, the Committee considers that it is appropriate to review the Disability Policy Framework.

12.22 In 1999, the Law Reform Commission made a number of recommendations aimed at strengthening section 9 of the Act. These included broadening the scope of section 9 to include all government agencies and local government authorities, strengthening the integration of disability plans into corporate planning and enhancing the accountability mechanisms by requiring:

- Government agencies to include a report on their progress in implementing their section 9 plan in their annual report
- ADD (now DADHC) to report progress on the implementation of other agencies' plans in its annual report
- The Minister to report annually to Parliament on progress that government agencies have made in implementing their section 9 plans.[151]

12.23 The directions suggested by the Law Reform Commission have the potential to bolster the commitment of agencies to ensure that their services comply with the principles and applications of principles in the Disability Services Act. Immediate consideration should therefore be given to implementing the Commission's recommendations.

---

[150] Druett evidence, 17 April 2002

[151] New South Wales Law Reform Commission, Report 91, *Review of the Disability Services Act 1993 (NSW)*, July 1999, Recommendations 13, 14 & 15

Recommendation 46

The Government should review the NSW Disability Policy Framework as a means of achieving a whole of government approach to policy and service delivery for people with disability. In particular the review should consider:

- The extent of progress in achieving the objectives outlined in the Framework
- Whether the Framework is effective in addressing service gaps for people with disability
- Whether the current reporting and accountability requirements of the framework are an appropriate means to achieve compliance with section 9 of the *Disability Services Act 1993*.

Recommendation 47

In order to enhance the whole of government commitment to support people with disability, immediate consideration should be given to implementing Recommendations 13, 14 and 15 of the New South Wales Law Reform Commission, Report 91, *Review of the Disability Services Act 1993 (NSW).*

Addressing specific service gaps

12.24 While the Framework underpins a cross-government approach to support for people with disability, there are some agencies that have significant responsibilities in this regard. Throughout this report we have commented on service gaps that exist for people with disability who have needs that extend beyond departmental boundaries. The structure of government departments tends to compartmentalise the needs of individuals, and there is a reluctance to take on responsibility to support people with disability who have needs that fall within the responsibility of more than one department. Consequently, service provision is poor in areas where departmental responsibilities overlap. Similarly, as people move through life transitions, they move between different systems such as childcare and education. Support is required to manage these transitions, along with effective systems to promote information sharing between agencies. Table 5 outlines some of the more significant service gaps arising out of departmental overlap that were raised during the inquiry:

Table 5: Significant service gaps

Service Gap	Departments with overlapping responsibility
People with high medical needs	DADHC, NSW Health
Therapy	DADHC, NSW Health
Children with disability	DADHC, DoCS, DET
Parents with disability	DADHC, DoCS
People with dual diagnosis	DADHC, NSW Health

12.25 There is a need to clarify departmental responsibilities at their program boundaries and to ensure seamless service delivery for people whose support needs extend beyond a single department. Clear policy and protocols need to be developed between relevant departments to ensure that a continuum of service is provided across departments and that responsibility to coordinate and fund service is clearly delineated. We therefore consider that DADHC should establish formal Memoranda of Understanding with relevant departments, particularly NSW Health and DoCS, to clarify respective roles and responsibilities for service provision to people with disability.

Recommendation 48

The Department of Ageing, Disability and Home Care should develop formal Memoranda of Understanding with all relevant departments, including NSW Health and the Department of Community Services, to clarify their responsibilities to support people with disability and ensure that there is a continuum of service across program boundaries.

Commonwealth State Territory Disability Agreement

12.26 The Commonwealth has a significant responsibility within the disability service system to fund some types of service directly and also to fund State Government disability service programs. Under the Commonwealth State Territory Disability Agreement (CSTDA, formerly known as the Commonwealth State Disability Agreement or CSDA), the Commonwealth is responsible for the funding, planning and management of employment services and it shares responsibility with States and Territories for advocacy services. States and Territories are directly responsible under the CSTDA for all other specialist disability services, including accommodation support, respite and day programs.[152] While States and Territories are directly responsible for the administration of these areas, the Commonwealth contributes approximately 20 percent of the funding for Statebased programs. This contribution arises from the fact that prior to the CSTDA, the Commonwealth funded non-government service providers directly.

12.27 All jurisdictions in Australia are facing similar challenges relating to unmet need and the growing complexity of demand to those faced in New South Wales. The CSTDA is intended to clarify the respective roles of States and the Commonwealth in this area and to provide a national framework for provision of specialist disability services.[153] The present CSTDA is due to expire at the end of November and is currently being re-negotiated.

12.28 Participants in the inquiry have raised concerns about the outcomes of the CSTDA. A key difficulty is that joint responsibility for disability services tends to promote cost shifting between levels of government. For example, some supported employment services told the Committee that funding restrictions and policies that are intended to make supported employment services operate on a commercial basis affect their viability and their capacity

---

[152] AIHW 2002, p. 2

[153] Ibid.

to employ people with high support needs. Cutbacks to employment services then place pressure on state-based day programs and accommodation providers. This is a particular concern in rural and regional areas where opportunities for commercial enterprise are limited. We have already outlined the problem of cost shifting in both directions between the aged care and disability service systems, and the effect that this has for younger people in nursing homes as well as people with disability who are ageing.

12.29 An emerging concern is the apparent reluctance of the Commonwealth to contribute significant amounts of growth funding for disability services or to contribute to cost increases within state-based programs. Figures published by the Australian Institute of Health and Welfare demonstrate that the majority of recurrent growth funding in the past few years has been provided by the States, with the largest contribution to growth funding made by New South Wales.[154] Recent Commonwealth offers of growth funding have been very limited[155] and the indexation figure used by the Commonwealth to account for cost increases in existing funding has not been sufficient to meet actual cost increases faced by disability service providers.[156] For example, research undertaken earlier this year by the Social Policy Research Centre shows that an increase of 8.35 percent in Commonwealth funding will be required to meet cost increases in existing services in the 12 months leading up to July 2003.[157]

12.30 In part, this is a consequence of unresolved issues arising out of the initial CSDA in 1991. Funding transfers from the Commonwealth have never been sufficient to meet the costs of service delivery in organisations that transferred from the Commonwealth to the States, or to support their transition into services that conform with the Disability Services Act. State Treasury departments have consequently been reluctant to meet the shortfalls. These difficulties have contributed to protracted disputes each time the agreement is due for renegotiation.

12.31 In New South Wales these difficulties contributed to the dispute over responsibility to meet the full cost of the recent SACS Award increase for employees of non-government services. Initially, New South Wales agreed to meet part of the cost to service providers of the new award, and sought a contribution from the Commonwealth to meet cost increases in services that were previously funded by the Commonwealth. The Commonwealth has not done so and New South Wales has now met the full cost of the new SACS Award.[158] The cost will inevitably reduce the funds that are available to support the service growth

---

[154] AIHW 2002, Chapter 3

[155] For the current financial year, the Commonwealth has offered $15 million in growth funding by comparison to $110 million from States and Territories: Hon Sheila McHale, MLA, Minster for Disability Services, Western Australia, *Commonwealth State Territory Disability Agreement: Bulletin No 7*, October 2002

[156] Social Policy Research Centre, *Methods to address requirements for changes in funding disability services brought about by external change*, April 2002

[157] Ibid.

[158] Department of Ageing, Disability and Home Care, *Fast Facts*, Edition 9, 13 September 2002

and departmental reforms that are necessary to ensure that an effective and sustainable disability service system is developed.

12.32 The CSTDA underpins the disability service system in New South Wales. To have an effective and equitable system it is essential that workable and cooperative funding arrangements exist between the two tiers of government. From the perspective of people with disability, advocates and service providers, arguments about which level of government is responsible to provide additional funding appear to be little more than evasion of responsibility by both levels of government.

12.33 Given that a decade has passed since the initial CSDA, there is a clear need to reach a final settlement about the responsibility to fund accommodation services that transferred to the States at that time. As part of this process, the Commonwealth needs to significantly increase recurrent funding provided to the States under the CSTDA. It is also necessary to develop an approach that links overall levels of funding to identified need, and which reduces the level of disputation between governments about their responsibility to provide additional funding for unmet demand.

12.34 It is also important to clarify issues around daytime activity. People with disability that we spoke to during regional consultations indicated an overwhelming preference for employment over non-work related day programs. They were particularly concerned about the contraction of supported employment programs and the resultant loss of opportunities for financial independence and participation in the community. The Committee notes that access to employment is critically important for all members of the community and considers that significant additional funding for supported employment services is required.[159]

Recommendation 49

As part of the negotiation for the forthcoming Commonwealth State Territory Disability Agreement, the Government should:

- Seek additional funding from the Commonwealth as a matter of urgency both to address unmet need and to accommodate cost increases in disability services
- Seek to develop an approach to funding under the CSTDA that links growth funding from the Commonwealth to identified unmet need
- Specifically seek additional funding for supported employment programs.

Recommendation 50

In negotiating the forthcoming Commonwealth State Territory Disability Agreement, the Government should seek to ensure that the new agreement provides greater clarity about the respective roles of the States and the Commonwealth to fund specific programs and services and to fund increases in the cost of providing services.

---

[159] Daytime activity is discussed further in Chapter 13

Chapter 13 Supporting children, families and independence

Evidence throughout this inquiry has highlighted the current crisis orientation of the disability service system. Families and advocates have widely reported that they are unable to access supports until they reach crisis point, and programs such as the Service Access System have reinforced a perception that 'creating' a crisis will produce a response. A key transition to be made in order for disability services to function equitably and effectively is to develop a system that is focused on prevention, early intervention and planned life transitions. The balance of investment needs to shift from crisis-driven high-cost services to preventative supports that maintain independence and inclusion of people with disability within family and community. While this transition must occur throughout the disability system, to date it has taken hold most strongly in children's services, where the benefits of maintaining children within the family unit have provided significant momentum for change. The establishment of a general intake and support coordination system recommended in Chapter 9 is a key element in any preventative focus. This chapter explores a range of early intervention initiatives that together will contribute to a comprehensive prevention system in disability services.

An emphasis on prevention and early intervention

13.1 Preventative services enable people with disability to maintain their existing living arrangements, often with their families or partners. They protect people with disability and their families from moving into crisis and then requiring intensive and at times inappropriate forms of disability support. Through an emphasis on building people's skills and independence rather than just providing 'care', preventative supports also limit negative outcomes in other areas of people's lives, for example family breakdown, carer ill-health or injury, and entry into the criminal justice system.

13.2 By forestalling the escalation of need and promoting independence and inclusion, preventative services deliver positive outcomes for people with disability and their family while also making good economic sense. As the Committee has noted in relation to its Early Intervention into Learning Difficulties and Child Protection Inquiries,[160] governments are increasingly looking to early intervention and prevention across the range of human services as a means of averting high-cost services and tempering ever-increasing demand. However, in order to achieve these long-term goals, preventative approaches require significant investment and careful planning. Early intervention does not just mean early in life. It can also mean intervening early in a transition point in a person's life, such as transition to and from school or from home to independent living.

13.3 Within the New South Wales disability system, a key prevention program is DADHC's Early Childhood Intervention and Coordination Program (ECICP), which brings together health, therapy, education and support services to work with children with disability aged 0-6 and their families. The Department is now expanding its early childhood intervention

---

[160] Standing Committee on Social Issues, Report 26, *Prevention: Interim Report on Child Protection Services*, October 2002, Standing Committee on Social Issues, Report 27, *Early Child Development: A Co-ordinated Approach*, *First Report on Early Intervention for Children with Learning Difficulties*, October 2002

programs to provide support for children with disability aged 6-18 years and their families.[161] Another key program is Local Support Coordination (LSC), which supports a person with disability and their family to access local informal support systems. Both these programs are highly regarded although currently limited in scope, with early intervention services presently not going beyond school age and LSC having only 8 coordinators at present, although this number will soon expand by 13.[162]

13.4 A preventative approach also underpins the government's increased investment in respite services and the growing recognition in policy of the role of families and carers in supporting people with disability. Nevertheless, the Committee observes that a preventative framework that is cast beyond children and which is built systematically into the disability system is yet to be developed. The recent creation of the Prevention and Early Intervention Unit within the Department's Policy and Planning Directorate signals commitment to a preventative approach, and we encourage the Department to continue the task of constructing an effective and comprehensive system of prevention.

13.5 At the same time, we note the ongoing need for a sound system of 'traditional' disability supports such as supported accommodation and day programs, including intensive supports for those people who will continue to need these types of programs. DADHC needs to strike and sustain the right balance between prevention and support.

Principles

13.6 The following principles, reflected in evidence to the inquiry and in research, are in our view essential to an effective system that supports children and families and promotes long-term independence:

- *Adequate funding:* effective intervention is not only a matter of intention and policy, but also requires an appropriate investment of resources. Treasury must ensure that prevention initiatives are sufficiently resourced

- *A long-term approach:* by their very nature, the outcomes of prevention programs emerge in the longer term and thus require both a sustained commitment and an appropriate performance monitoring framework

- *A broad target base:* effective and equitable prevention strategies are aimed not just at people with high needs, but with lower needs as well. At present DADHC's focus is increasingly on those with complex needs, to the long-term detriment of other groups

- *An empowering approach:* a proper system of preventative supports promotes community inclusion, autonomy and choice for people with disability.

---

[161] DADHC, Annual Report 2000-2001, p.12

[162] The Hon Faye Lo Po', MP, Budget Estimates Answers to Questions on Notice, 25 June 2002, p. 41

- *An holistic framework:* prevention supports see the person with disability and their family in their broader context, also recognising their non-disability related needs
- *A relationships focus:* effective prevention is aimed at supporting quality relationships between people with disability, their family, broader social networks and the community, and
- *A whole of life approach:* people with disability and their families require preventative supports over their lifetime and especially through key transitions such as school entry, movement from school to employment or other day activities, and movement from day activities to retirement.

Support for children

13.7 As noted above, support for younger children is the area where the preventative approach has taken greatest hold in disability services. This has been informed by the recognition that children have the right to live in families, and that by providing appropriate services as early as possible in a child's life, we will maximise their abilities and independence over their lifetime. As the Director General has told the Committee:

> Our policy objectives with children are fairly clear, and that is to provide the services needed to keep children with their families. There would be a strong view in the Department that children with a disability are children first and foremost, and as with other children in the community, they have the right to be raised in the context of their family, along with the supports those families need in order for that to happen. So there is a very deliberate intent to improve our level of family support services, which includes respite, which includes behaviour intervention and support services and a range of other therapy services that families might require.[163]

13.8 Given the widespread unmet need for therapy services, behaviour intervention and support that have been documented throughout this inquiry, the Committee welcomes this commitment. There is a need for both significant investment in these services and the development of strategies to address structural issues around supply, such as the difficulty attracting therapists to non-metropolitan areas.

13.9 At present, the specialist disability service system does not cater well for the needs of children with disability or their families, and this has been acknowledged by DADHC. The new directions taken by DADHC need to be supported by significant reform to ensure that appropriate levels of support are provided to children with disability and their families.

---

[163] Allison evidence, 9 May 2002

Holistic family support

13.10 The primary emphasis of support services for children with disability should be to develop approaches that support children within their family.[164] Programs are required that emphasise the development of children with disability and build the capacity of their family to support their child in the home. A clear message from our consultations was that families and children needed more timely and flexible support, but that the current service system did not allow this. The effectiveness and efficiency of support provided was constrained by rigid program guidelines that focussed on specific outputs, such as the number of hours of Home Care per week, rather than the actual desires of families and children.

13.11 At present, DADHC does fund on a limited basis specific family support services which operationalise many of the principles of early intervention. These intensive family supports are generally provided within a case management framework, primarily through non-government agencies, and offer packages of services including support, coordination, counselling and advice.[165] We consider that this approach should be expanded upon as part of the creation of the general intake and support coordination system.

13.12 Looking across the broad continuum of services that seek to support families, including holistic models, respite and behaviour intervention, a recent literature review prepared by The Nucleus Group for the Victorian Government provides a summary of the effective features of family support. The Committee believes that DADHC should consider these features in developing its system of family supports:

- Close and ongoing contact between a family and coordinator, who works directly with the whole family
- Early intervention, with services provided as soon as possible after the first indication that the child may have a disability
- Family self-management through participation in decision making and appropriate control of services
- Provision of information to families, about the nature and implications of their child's disability as well as about support options and the disability service system
- Transition support for families over the periods of movement between life stages, when resilience can be most tested
- Services and strategies to assist families with management and prevention of challenging behaviour

---

[164] New South Wales Law Reform Commission, *Review of the Disability Services Act 1993 (NSW)*, Report 91, July 1999, Chapter 8; French evidence, 9 February 2000

[165] The Nucleus Group, *Review of Current Responses to Meeting Service Needs of People with a Disability and the Effectiveness of Strategies to Support Families*, Final Report, June 2002

- Flexible short-term care, with respite provided as part of an integrated package of support for families
- Care plans which focus both on the needs of person with disability and their family unit.[166]

Recommendation 51

The Department of Ageing, Disability and Home Care should develop an appropriately resourced model of holistic support to provide planned and responsive support to children with disability and their families, which includes the following elements:

- The development of care plans for children with disability within their family unit
- Support coordination that focuses on the needs of the whole family
- Access to appropriately resourced early intervention services
- Behaviour management support
- Planned access to additional support during key life transitions
- Provision of flexible short-term care for the children.

Out-of-home care

13.13 There is also an urgent need to develop a better approach to support for children with disability who are unable to live at home with their family. In its review of substitute care, the Community Services Commission outlined significant issues that need to be addressed to ensure that children with disability in out-of-home care are supported effectively. One of the most significant concerns is that the level of support and care provided to children differs according to whether they live in specialist disability services administered by DADHC or in substitute care services administered by DoCS. According to the Commission:

> The two systems fail to inter-relate and coordinate, even where there may be overlapping concerns … Neither care system is able to adequately identify and meet the needs and best interests of the child or young person. The disability services system is adult focussed and services are predominantly delivered within a medical model. The child or young person's disability renders them unlike other children or young people and tends to become the primary focus … In the substitute care system, a lack of adequate assessment processes can often result in

---

[166] The Nucleus Group, op cit, p. 95-96

> the child or young person's disability and related needs failing to be identified and/or addressed.[167]

13.14 There is considerable overlap in the responsibilities of DoCS and DADHC to support children with disability. For example, the *Children and Young Persons (Care and Protection) Act 1998* (CYPCP Act) places substantial obligations on DoCS to support families and children with disability where there is a risk that the family will no longer be able to continue to support the child.[168] At the same time, many children live in disability services funded by DADHC. The Committee considers that a consistent approach to support for children with disability needs to be developed jointly by both departments.

13.15 In general, there is support for greater use of substitute care services, rather than specialist disability services, to support children with disability.[169] The Committee notes that there is significant unrealised potential in models such as shared care, intensive family support, foster care, professional foster care and the provision of family-like environments for children for whom a family placement is not possible. The Department has indicated that it now intends to work closely with the child and family welfare sector to find better ways to support children with disability in out-of-home care.[170]

13.16 The legislative basis for support to children with disability should also be addressed. The Law Reform Commission recommended that the Disability Services Act be amended to include a specific part for children and young people with disability and the recommendation has received support from within the sector. The unproclaimed powers and role of the Children's Guardian outlined in the CYPCP Act will also provide significant safeguards for children with disability who live in out-of-home care. In the context of the Committee's Child Protection inquiry, disability groups have therefore argued that proclamation of the relevant sections of the CYPCP Act is necessary to support a better system of out-of-home care for children with disability.[171]

13.17 The Committee supports the view of the Law Reform Commission that the Disability Services Act should be amended to include a part for children and young people with disability. At present, the Act does not specifically refer to the needs of children and young people. This contributes to the current lack of appropriate services for children with disability.

13.18 The question of proclamation of the relevant sections of the CYPCP Act is central to our other inquiry into Child Protection Services which is due to report in December 2002. While we believe that there are substantial arguments in favour of proclamation, we intend

---

[167] Community Services Commission, *Inquiry into the practice and provision of Substitute Care in NSW: New Directions – From Substitute to Supported Care*, Final Inquiry Report, November 2000, p.48

[168] See for example, Section 21 relating to requests for assistance

[169] Community Services Commission, 1998, op cit, p.55

[170] Allison evidence, 9 May 2002

[171] Submission 29, Northcott Society, to the Inquiry Into Child Protection Services

to take further evidence from the Director General of DoCS on this issue before recommending a specific timetable for proclamation be developed.

Recommendation 52

The Department of Ageing, Disability and Home Care and the Department of Community Services should jointly develop an agreed and consistent approach to the funding and support of children with disability in out-of-home care.

Recommendation 53

The Government should amend the *Disability Services Act 1993* to include a part for children and young people with disability in accordance with recommendations 30, 31, 32, 34, and 35 of the New South Wales Law Reform Commission's review of the *Disability Services Act 1993 (NSW).*

Respite services

13.19 Respite services have long been the mainstay of preventative disability services, and in the Committee's view, must continue to play a central role in any prevention framework. While the term 'respite' implies that caring is a negative experience, the periodic support offered by flexible and high quality respite services can provide equal benefits both to people with disability and their carers.

13.20 The Committee notes the need for a range of truly flexible respite options, which respond to the preferences of the person with disability and their family, including centre-based supports, and which emphasise a respite outcome or effect.[172] As the Committee was told in relation to children:

> When you are looking at other support services like respite, then you look at what does this family or this person in this situation need in terms of the respite effect. Now, at some stage of people's lives, for example, young children who have young siblings, the best kind of respite might be home help so that mum has quality time to spend with the children. Later on it might form the basis of a support service where someone can take the young person off for social activities, or enable them to play a sport or whatever. Later on in life as a young adult living at home, they might then go on a holiday or be able to spend time doing other things away from their family.[173]

13.21 The Committee endorses the growing investment in the respite system as a key plank of an early intervention framework. We note, however, that while an emphasis on respite is necessary over the short to medium-term to build preventative capacity within the disability service system, this should not divert attention from developing the range of other

---

[172] See Chapter 8 for further discussion of respite services

[173] Seares evidence, 9 February 2000

elements that will make up an effective preventative system, including carer and family support.

Carer support

13.22 Supports that are specifically targeted at individual carers are an essential element of a preventative framework for disability services. In *A Matter of Priority*, the Committee noted the impact of unmet need for accommodation upon the carers of people with disability. Impacts included relationship breakdown, interruption to life plans, injury, withdrawal of care, financial difficulties and social isolation. All of these effects are borne out in research, which has shown that in comparison with non-carers, carers are more likely to experience poor physical and mental health, isolation, lower levels of employment, and reduced income in the short and longer term.[174] Significantly, the emotional impact of caring has been shown to be greater among parent carers than any other group.[175] As the Committee was told during a community consultation:

> [H]ere in Tamworth we see on a monthly basis families that are teetering on the edge of crisis all the time. They will get a couple of hours of assistance to get them out of this crisis but within a couple of weeks they will be back in crisis again. Now it is those families where the kids will end up in an institution unless we start to keep families on a fairly even keel.[176]

13.23 Supports such as counselling, support groups and training, along with workplace reforms that enable carers to maintain their employment, are important means of sustaining carer resilience over time. While the New South Wales Government has made a significant investment in these kinds of supports through the jointly managed DADHC and NSW Health Care for Carers Program, this initiative is not yet fully implemented,[177] and the recurrent funding base of $5.1 million per annum perhaps does not reflect the true level of carer need. We consider that the implementation of this initiative should be completed. There is also a need to evaluate the outcomes of the Program to determine whether it is an effective strategy and whether it is sufficiently resourced.

Recommendation 54

The Department of Ageing, Disability and Home Care and NSW Health should complete the implementation of the Care for Carers Program. The outcomes of the Care for Carers Program should be evaluated to determine whether it is an effective program and whether it is sufficiently resourced.

---

[174] Schofield H., Bloch S., Herrman H., Murphy B., Nankervis J. and Singh B., *Family Caregivers: Disability, Illness and Ageing*, Allen and Unwin, 1998

[175] Schofield et al, cited in Submission 205, Carers NSW

[176] Service provider, community consultation, Tamworth, 19 July 2000

[177] Hon Faye Lo Po', MP evidence, General Purpose Standing Committee No. 2, 25 June 2002

Emerging demands, changing aspirations

13.24 A range of other efforts are required to develop a truly preventative system for children. Of key importance is developing an approach to disability that promotes inclusion and participation in mainstream services wherever possible:

> I have a great belief that if we educate our children with disability alongside their able-bodied peers, we have an opportunity to provide not only much more positive outcomes for children with disability but we are influencing the way the coming generation, people without disability, think and view the world and view people with varying ability levels … It is a great benefit to all children to be educated together. Children with disability who are educated with their peers then become much more a part of the community. They form friendships. Families form links with each other and friendships and that placement in the community is the beginning of support services that then become important later on in life and helps to decrease the level of need for support that a person requires later on in life. They have these informal support systems that we all develop that are very important in achieving independence.[178]

13.25 As the generation of children with disabilities who have access to early intervention strategies grows older, they and their families are developing new expectations that pose new challenges and opportunities for the disability system. These emerging aspirations and demands reflect a shift in society's constructions of disability:

> Families that are asking for the regular class at the local school are not asking for a group house respite for a week of holiday at Christmas time for the child, but are asking for support for the child to go to Brownies or Scouts or to join the local swim class like every other child in their family does.[179]

13.26 The aspirations of families for children with disability mean that current models are not necessarily what they want for their children's present or future. They will not be looking towards a group home or traditionally conceived day program when their child has completed high school:

> [T]here are many families that want something different to those traditional service structures. I have three children and my middle daughter has an intellectual disability. I do not want her to live in a group home and work in sheltered workshops when she is an adult.[180]

13.27 Underlying this approach is the need to ensure that the focus of specialist disability services shifts from the provision of care through a separate service network to providing the support necessary to ensure that people with disability can access the same services and opportunities experienced by the broader population. Provided that proper supports are in place early to facilitate independence, community-based networks and skill development,

---

[178] Seares evidence, 9 February 2000, p.26

[179] Sweeney evidence, 10 September 2001, p. 21

[180] Ibid.

these new expectations will reduce the reliance on specialist disability services as the sole source of support for people with disability.

Support for independent living

13.28 While a family-based approach is essential to supporting children, the Committee also notes that just as other children leave home when they become adults, so should people with disability have the opportunity to realise their independence at an appropriate age. In doing so, they will require a range of housing and support options including semi-independent living and supported accommodation. It is important that the government does not have an expectation that families will care for a person throughout their lives.

13.29 There is a growing research base to demonstrate that people with disability can be supported to live quite independently in the community.[181] During our consultations the Committee had the opportunity to meet with clients and staff of two Community Support Teams that were part of the former DoCS Disability Services. A number of these people had lived previously in institutions and then within group homes but had chosen to move into more independent arrangements with drop-in support from professional staff. Others had moved directly into semi-independent living arrangements from the family home. Within the non-government sector, Hornsby Challenge is well recognised for having enabled people to move from group homes into more individualised support arrangements.

13.30 These types of support arrangement are highly regarded and can provide a good basis for people with disability to exercise greater choice and autonomy about their lifestyle. A key feature of these arrangements is that they deliver better outcomes for clients for the same or less funding than conventional models such as group homes. With the establishment of a general intake and support coordination system, the Committee considers that there is considerable scope to provide greater support for independent living arrangements.

13.31 We have identified three aspects of the service system that require further action to promote independence and inclusion for people with disability: provision of meaningful daytime activity, support for people with lower support needs and support for parents with disability.

Meaningful daytime activity

13.32 A common theme during consultations was that when a person with disability leaves school, they and their family lose access to a valuable support network. They also face a lack of meaningful daytime activity that can rapidly lead to poor self-esteem, frustration, the emergence of challenging behaviours and crisis. Access to supported employment or day programs was therefore raised as a significant area of unmet need in submissions, evidence and hearings.

---

[181] Stancliffe R., 'A matched comparison of outcomes and costs of group homes and semi-independent living', *Journal of Intellectual Disability Research*, 44, 2000; Van Dam T. and McGill C., 'Beyond Group Homes', *Interaction*, 8(3), 1995

13.33 According to the Australian Institute of Health and Welfare, there are currently 5,400 people nationally who have unmet need for employment support and 8,200 people who report unmet need for non-employment related community access, or day programs. These figures equate to roughly 1,800 and 2,730 people respectively for New South Wales.[182] We note that these estimates are based on current Commonwealth eligibility criteria for access to supported employment services,[183] rather than an actual assessment of people's capacity or desire to work. Different eligibility criteria could therefore result in a higher number of people needing access to supported employment programs and a correspondingly lower number requiring access to community participation. It is therefore more accurate to state that there are approximately 4,530 people in New South Wales who report unmet need for meaningful daytime activity.

13.34 Meaningful daytime activity enhances the independence, community participation and integration of people with disability and contributes to their wellbeing. In speaking to people with disability and advocates, the following key points emerged in relation to daytime activity:

- People with disability overwhelmingly prefer employment to day programs
- Continuity of funding for day programs must be ensured to provide certainty for people with disability, their families or service provider
- Non-employment related day programs should be flexible and emphasise inclusion in the community. Rather than provision of activities in an isolated setting, day programs should facilitate access to mainstream activities such as further education and training through TAFE.

13.35 Paid employment affords both a valued social role as well as an income, enabling people to exercise choice in many aspects of their lives. There is substantial unmet need for supported employment programs that both utilise people's skills and provide opportunities for further development. The disability service system should reflect the preferences of people with disability and ensure that opportunities for employment are promoted as the first priority. In Chapter 12 we noted that this is an area where the Commonwealth could do more to fulfil its responsibilities.

13.36 At the State level, evidence to the inquiry has been characterised by high levels of uncertainty about the ATLAS Program for school leavers. For those who are unable to participate in employment and training programs, the Committee stresses the need for a system that provides meaningful day activities for all those who wish to participate in them.

13.37 There is an inextricable link between supported employment and day programs. We therefore consider that the State and Commonwealth should develop a joint and cooperative approach to meeting unmet need for meaningful daytime activity. The approach should be based on the principles outlined in the recommendation below.

---

[182] AIHW 2000, p xxii

[183] Ibid.

Recommendation 55

The State and Commonwealth Governments should develop a joint and cooperative approach to meeting unmet need for meaningful daytime activity. This approach should be based on the following principles:

- Growth funding from both the Commonwealth and the State will be required to address unmet need for meaningful daytime activity
- The primary emphasis should be on supporting people with disability to access employment
- People with disability who are not able to access supported employment services should have guaranteed and continuing access to day programs.

Support for people with lower needs

13.38 In the current situation of high unmet need, resources tend to be directed to people with the highest support needs. People with lower support needs are a lower priority for access to disability services and often miss out. As a consequence, people with lower needs can be left unsupported and at risk of crisis. Appropriate support for this group can significantly enhance their independence and quality of life.

13.39 Lack of support for people with lower needs is also very costly. Numerous studies have shown that the types of support required by people with lower needs are not expensive and the lack of effective support for people with lower needs creates significant additional costs to government.[184] These costs are most apparent in the significant over-representation of people with disability in the criminal justice system and the child protection system. For example, the annual cost of 'permanent accommodation' in gaol ranges between $44,040 and $73,020, in addition to which there are court costs.[185] Significant police time is also associated with unproductive follow up for people with lower needs:

> [P]olice may spend ten hours with a person while they unsuccessfully seek assistance from human services, and this situation may repeat itself "again" and "again".[186]

13.40 In keeping with research on this topic, our consultations showed that people with lower needs require support in the following areas:

---

[184] New South Wales Law Reform Commission, Report 80, *People with Intellectual Disability and the Criminal Justice System*, 1996; Standing Committee on Law and Justice, *First Report of the Inquiry into Crime Prevention Through Social Support*, NSW Legislative Council, December 1999; Simpson J., Martin M. and Green J., *The Framework Report: Appropriate Community Services in NSW for Offenders with Intellectual Disabilities and those at Risk of Offending*, Law and Justice Foundation of New South Wales, July 2001

[185] Framework Report 2001, p. 4

[186] Ibid.

- Ongoing support coordination to ensure that they are linked to necessary generic services such as health and education and have a consistent point of access to further advice, support and referral
- Continuing personal assistance with essential tasks such as budgeting
- Access to an advocate
- Access to affordable transport options and appropriate housing.

13.41 The needs of people who are at risk of offending were considered in an independent research report, *The Framework Report*,[187] which was released last year. While that that report was focussed on the criminal justice system, many of the report's findings and recommendations are more generally relevant to people with lower support needs. The Committee supports the recommendations of *The Framework Report* and notes that they are consistent with the directions outlined in this report.

13.42 DADHC has a responsibility to ensure that people with lower needs are supported appropriately. Creation of a general intake and support system will be a critical first step to ensuring that effective support is provided to this group. Similarly, an enhanced commitment to whole of government support is important and it is necessary to strengthen and review the Disability Policy Framework as recommended in Chapter 12. In addition we consider that specific and quarantined additional funding is required to develop capacity to support people with lower needs. Growth funding to date has been directed towards people with higher needs and unmet need for this group remains high, it would be inappropriate to divert this funding to other areas. Additional investment in support for people with lower needs will enhance the preventative capacity of the disability service system and lead to lower overall cost across government.

Recommendation 56

Additional recurrent funding should be provided to the Department of Ageing, Disability and Home Care to ensure that the Disability Service Program has sufficient capacity to support people with lower needs.

Parents with disability

13.43 The ability to exercise control over fertility and the decision to have a child is a fundamental right for all people. The recognition of the rights of people with disability to become parents is a reflection of their greater independence.

13.44 Parents with disability face particular challenges in obtaining sufficient support for their parenting role. Parents with intellectual disability in particular face discriminatory assumptions and attitudes about their ability to properly raise children and a lack of specific services to assist them with their parenting role. The results of this lack of support are very

---

[187] *The Framework Report,* 2001

disturbing. Evidence to our child protection inquiry shows that parents with intellectual disability are more likely to come into contact with the child protection system than other parents, are more likely to have a child removed early in life and are more likely to have more than one child removed.[188]

13.45 For example, data collected by the Family Support Services Association suggests that 17 percent of families seen by family support services include a parent with a cognitive disability. These families were more likely to have a child removed and made a State ward (18 percent compared to 4 percent of other families who have been seen by a family support service). It is estimated that 1 in 6 children in out-of-home care have a parent who has a disability.[189]

13.46 On the other hand, research demonstrates that outcomes for most children who are placed in out-of-home care are often significantly worse then for other children. When appropriate support is provided to parents with intellectual disability, the outcomes for their children do not differ significantly from others.[190]

13.47 In policy terms, parents with intellectual disability are currently viewed as risk factors within the child protection system, rather than as people with specific and identifiable support needs. This focus on risk and child protection intervention acts as a disincentive to parents with intellectual disability to seek assistance because the act of seeking assistance carries a risk that their child will be removed.

13.48 Parenting issues are virtually invisible within the disability service system. In 1998, this Committee noted that:

> [T]he rhetoric of disability service provision omits any mention of people with disability as parents, and there are no facilities or services which can accommodate parents with intellectual disability and their children.[191]

13.49 In terms of service delivery little has changed over the past four years. There is presently only one specific support program for parents with intellectual disability, the Parent Access Program that commenced in 1991. The Program provides state-wide support, training and

---

[188] Submission 237, Parent Access Program, Inquiry into Child Protection Services; Submission 158, Dr David McConnell, Inquiry into Child Protection Services; Llewellyn, McConnell, Rogers and Spencer evidence, 5 November 2002, Inquiry into Child Protection Services

[189] Submission 237, Parent Access Program, Inquiry into Child Protection Services

[190] Tymchuck A. and Leldman M., 'Parents with mental retardation and their children: review of research relevant to professional practice', *Canadian Psychology/Psychologie Canadienne*, 32(3), 1990, pp. 485-496; Heighway S., *Helping Parents Parent: A Practical Guide for Supporting Families by Parents with Cognitive Limitations*, Madison Winsconsin Council on Developmental Disabilities, 1992; Llewellyn G., McConnell D., Bye R., *Parents with Intellectual Disability: Support and Services Required by Parents with Intellectual Disability*, Report to the Disability Services Sub-Committee, October 1995; Booth T. and Booth W., 'Supported parenting for people with learning difficulties: lessons from Wisconsin', *Representing Children*, 9(2), 1996, pp. 99-107, cited in Submission 237, Parent Access Program, Inquiry into Child Protection Services

[191] Standing Committee on Social Issues, *Working for Children: Communities Supporting Families*, Inquiry into Parent Education and Support Programs, NSW Legislative Council, September 1998, p.204

resources for workers in family support services. While this service is well regarded, it is under-resourced. The service receives $45,000 in recurrent funding which is sufficient to employ one specialist worker for two days per week. Apart from CPI adjustments, the service has not received a funding increase since 1994.[192]

13.50 The evidence to the Committee and research on the needs of parents with disability points to a need for a broad based approach to support for parents with intellectual disability. There is a need for generic parenting programs to become more inclusive and accessible to parents with disability and also a need for more intensive and specialist models. Given the high representation of parents with disability in the child protection system, there is also a need to reassess the practices of child protection workers in DoCS and to ensure that they receive proper training about the support needs of parents with disability.

13.51 We consider that a more effective approach to support for parents with intellectual disability will require the following:

- Strategies to promote inclusion of people with disability within mainstream parenting and family programs
- The development and provision of specific educational resources and programs to provide parenting education and support for parents with disability
- The provision of additional in-home support through the Home Care program to assist parents with disability with the many practical issues associated with parenting
- The development and funding of more intensive support options, including intensive in-home support and residential support options for parents with disability. There is a particular need to develop residential models for parents who have limited parenting experience, mothers who are experiencing domestic violence or families that experience extreme social isolation or economic hardship.[193]

13.52 We note that support for parents with disability is a cross-agency responsibility. DADHC has a leadership role in supporting people with disability. DoCS has direct funding responsibility for Family Support Services and the *Families First* strategy coordinated through the Cabinet Office also funds parent support programs. While DADHC has a leadership role, we consider that a joint approach to program design and funding for support for parents with disability is required.

13.53 The Committee notes that a significant body of research around the needs of parents with disability now exists. For example, the former ADD funded the development and evaluation of an intensive home based education program for parents with disability called the *Home Learning Program*. The efficacy of that program has now been demonstrated.[194]

---

[192] Submission 237, Parent Access Program, Inquiry into Child Protection Services

[193] Ibid.

[194] Ageing and Disability Department, Llewellyn G., McConnell D. and Honey A, *Healthy and Safe: NSW Parent-Child Health and Wellbeing Research and Development Project*, Family Support Services Project, School of Occupation and Leisure Sciences, University of Sydney, May 2001

There is a need to build upon this research base and develop a more comprehensive approach to support for parents with disability. As with other areas, we note that preventative expenditure of this sort will reduce expenditure in other areas. For example the costs of child protection intervention are significant, in terms of DoCS caseworker time, costs associated with the operation of the Children's Court, recurrent foster carer payments and other costs associated with supporting State wards.

Recommendation 57

The Department of Ageing, Disability and Home Care should in consultation with the Department of Community Services, the Cabinet Office and other relevant agencies develop and fund a support strategy for parents with disability. The strategy should include the following elements:

- The development and provision of training for Department of Community Services child protection caseworkers on ways to support parents with disability and their children
- Provision of additional funding to the Parent Access Program to enable it to operate on a full-time basis
- Development of service access guidelines to ensure that parents with disability receive priority access to Home Care services and support
- State-wide implementation of the Home Learning Program as a support model for parents with disability
- The establishment of a residential supported accommodation service to provide short, medium and long-term support for parents with disability.

Conclusion

13.54 The major focus of this chapter has been on supports for children or younger people with disability and their families. These are areas that particularly warrant a preventative approach, but we consider that the same approach is necessary throughout the disability system.

13.55 Effective support for children and families requires a long-term view that accepts that outcomes are only likely to emerge over time. In deciding the level of investment that it is willing to make in early intervention and prevention services for people with disability and their families, the Committee urges the Government to consider outcomes broader than those related to disability, and more particularly, the costs to the community that are associated with family breakdown, health crisis and entry into the criminal justice system. A lack of appropriate and early supports for people with disability in effect shifts longer-term costs onto other pages of the State budget.

Chapter 14 Supporting innovation and research

This report has focussed on access to services by people with a range of special needs, the development of systems for delivering additional disability services, and a way forward for the new Department. One aspect of this way forward concerns an issue raised by several organisations during this inquiry: the need to invest in the development of innovative service and funding models that respond more effectively to current needs and emerging preferences. This chapter explores how innovation can be encouraged in disability services in New South Wales.

The need for innovation

14.1 A major focus of DADHC's work has been managing demand for crisis support in an environment of significant unmet need. In this crisis-driven climate it is very difficult to develop and pilot new ideas and models that may better meet the needs and preferences of people with disability, their families and carers or offer solutions for the problem of unmet demand.

14.2 The Committee was told that rather than being valued and nurtured, innovation is currently stifled within disability service systems in Australia:

> What is happening in New South Wales, is very similar to what I am seeing in other jurisdictions … the struggle to try and keep up with unmet need and crisis related stuff is, in a sense, impeding any further evolution of the solutions that we need to find. I think it is also really concerning that, despite the fact that over the last decade or two we have had very broad legislation which offers a lot of promise, policies which offer a lot of promise, by and large what we are continuing to deliver are quite standardised solutions, and what we are finding, of course, is that solutions, which in the accommodation area are group homes, are not going very far to meet the overall parameters and the problems and issues that people are facing.[195]

14.3 According to ACROD, this climate is partially a legacy of the Commonwealth State Disability Agreements which fundamentally changed the relationship between government and the non-government sector and led to the establishment of a funding system focussed on narrowly defined service types – respite, accommodation, day programs and so on – rather than on outcomes for people. Prior to that there was a greater emphasis on identifying needs, developing services to address them and a desire to try new ways of doing things.

> Whereas the dialogue had essentially been the organisation saying to the Department, "We've developed a new service model which should deliver outcome X to group Y. Can you provide funding?" the paradigm shifted and saw the bureaucracy saying, "We need more day/accommodation/respite services. Can you provide them within our understanding of the model?"[196]

---

[195] Cross evidence, 19 October 2001

[196] Submission 339, ACROD, p.5

14.4 Correspondingly, ACROD argues that a return in government to a focus on outcomes for people with disability, rather than on funding and administrative programs, will lay the foundation for a flexible, evolving and effective service system.

14.5 We acknowledge that DADHC is currently, and properly, focussed on resolving difficulties within the existing service structure. Service growth in the immediate future is likely to take place using existing models. However a capacity for innovation needs to be established early. The Department needs to actively commit itself to innovation, making it part of its core business, and taking a leadership role within the sector.

> It is up to the government to go from the narrow definition of what is possible, to lead the way to innovation … We have to help people to see some different ways. We have to establish some proactive strategies that will link that innovation ultimately to general service delivery. We have to allow the people who are thinking about innovation to work together and share ideas … Ultimately those kinds of innovations need to feed back into general service development and general policy.[197]

14.6 This capacity should support the potential for greater flexibility and responsiveness offered by the general intake and support coordination system.

14.7 One area where innovation is particularly desirable is accommodation support. Over the course of the inquiry, the Committee has witnessed widespread frustration with the 'six pack' model of group homes. There is no doubt they are an effective alternative to institutional living and a useful model for government in that they allow both a standardised approach to service delivery and predictability of costing.

14.8 There is, however, a clear view that group homes should be only one element of an evolving continuum of accommodation options and life experiences for people with disability. Other models have existed for some time,[198] but on a limited basis and with little opportunity to feed into mainstream service development and investment. Well-established examples of alternative household types include co-tenancy arrangements and semi-independent living.[199]

14.9 Taking this a step further, as the government looks towards family and community to take a greater role in supporting people with disability, current constructions of the service system which dichotomise funders, service providers, people with disabilities and families are becoming increasingly outdated and constraining. New approaches are also required for emerging groups such as people with brain injury and those with high medical support needs. The needs of people from diverse cultural backgrounds as well as people in rural and remote areas also require innovative and flexible responses. In all instances, there is a

---

[197] Epstein-Frisch evidence, 10 September 2001

[198] Van Dam and Cameron, 1998, cited in Coalition Against Segregated Living, 2000, *Challenging Institutions: Community Living for People with Ongoing Needs*, Action for More Independence and Dignity in Accommodation (AMIDA)

[199] See Community Services Commission, *Living arrangements: A guide to supported accommodation for people with disabilities*, October 2001 for further discussion of support models

need not just for new service models, but also for innovative approaches to funding, based on a partnership approach.

Innovative models

14.10 With respect to the growing involvement of families and communities in supporting people with disability, the Committee heard in evidence from Family Advocacy that in keeping with their new expectations of the service system, some families are seeking a more flexible approach to funding services that will make use of the capacity of families and communities to develop solutions to meet children's needs. Several models which transfer both funding and control to people with disabilities and families, and which make use of informal supports offered by families and others, were cited:

- Family governed flexible supports in Massachusetts, which allow families to substantially define and prioritise their own needs through an overseeing committee elected by families. A host organisation typically provides the auspice

- Homes West, a non-profit organisation made up of ten families which seeks funding for and provides accommodation support to adults with a disability. This commenced as a project auspiced and supported by the Queensland Government's Community Resource Unit

- Self management of funds, operating in Western Australia and Queensland, where government funding is provided directly to people with disability and their family through the Local Area Coordination process

- Microboards in British Columbia, which decide on and procure the most appropriate mix of services for a person after funds are provided for an individual.

14.11 There is strong argument to trial approaches that involve self-management of funds. In the previous chapter we referred to research undertaken for national disability administrators that underscores the importance of promoting independent living for people with disability as a way of achieving better outcomes. A suggested direction was to provide 'increased autonomy and power in the hands of beneficiaries and informal caregivers through mechanisms such as cash payments or vouchers'.[200]

14.12 The basis for a more flexible approach to funding exists within the *Disability Services Act 1993*, which provides that financial assistance can be approved to individuals, their family or carer, to eligible organisations for provision of service, and to individuals or eligible organisations for research and development. We acknowledge that moving away from standardised programs poses significant challenges for government. Government funding programs tend to be structured around the delivery of specified outputs, or 'units' of service, for set costs to a specific clientele. Part of the role of government is to ensure that limited funds are directed equitably to those in greatest need. Programs are therefore developed to address specific needs and have specific eligibility criteria. From this

---

[200] The Nucleus Group, op cit, p. 105

perspective, flexible support models raise questions about accountability, equity, quality and cost effectiveness.

14.13 We believe that greater flexibility, including self-management of funds, can achieve better outcomes for people with disability without compromising accountability requirements. This can be achieved through the development of rigorous quality assurance and monitoring systems that focus on individual outcomes as recommended in Chapter 12.

14.14 Similarly, workplace issues such as employment relationships as they affect both the person with disability and the employee should be taken into account. We consider that this should be addressed through proper planning during the project development stage.

Managing innovation

14.15 In the initial phase, the funding and management of innovative projects should be quarantined from the current emphasis on crisis support and reducing unmet need. A unit responsible for innovation, with specific funding for projects and evaluation, should be established within DADHC. The unit should test and evaluate new models for support and funding, including models that involve substantial self-management of funds by people with disability and their family. To ensure high-level commitment to innovation, the unit should be accountable directly to the Department's Executive. Procedures should be developed to ensure that the outcomes of evaluation are assessed, disseminated and incorporated into the operational policy and programs of the Department. The work of the innovation unit should also support the overall development of the sector. Details of projects that are funded and outcomes of evaluation should therefore be made public as a matter of course.

14.16 We consider that the establishment of this unit should be part of a wider commitment to innovation and research within disability services. The existence of the unit should not restrict the ability of regional support coordination staff to fund innovative and flexible local support arrangements, but should supplement their development. We would therefore expect that the innovation unit would work closely with regional staff in relation to specific projects that occur within particular regions.

14.17 The Committee notes that there are many experts in the disability sector whose knowledge would be invaluable in promoting innovation in DADHC service development and provision. The expertise of these people would assist the proposed innovation unit in looking at the full range of service models in operation internationally and in understanding the inter-relationship of service provision of different types at different stages of life of a person with disability. In addition, the understanding of the outcomes and methods of evaluation that are appropriate could be enhanced by these experts. We therefore recommend that an Expert Advisory Panel on Innovation should be appointed to assist the Department in this regard.

Recommendation 58

The Department of Ageing, Disability and Home Care should establish an innovation unit with quarantined funding to develop and pilot innovative support and funding models, including models that involve substantial self-management of funds, for people with disability.

- The unit should be directly accountable to the Department's Executive
- Procedures should be established to ensure that the outcomes of evaluation are assessed, disseminated and where appropriate, incorporated into the operational policy and programs of the Department
- Details of projects that are funded and the outcomes of evaluation should be made public
- An Expert Advisory Panel on Innovation should be appointed to assist the Department in this regard.

14.18 There is a need within the sector to develop greater understanding of new approaches to support for people with disability, to ensure that international best practice is understood and disseminated within New South Wales and to develop leadership within the sector. At present DADHC funds some research, much of which is related to specific Departmental projects or initiatives. For example, the Department commissioned an independent evaluation of the devolution of the Hall for Children and has funded reviews of specific program areas such as therapy for school aged children. Often the results of such research are not published, meaning that they do not contribute to knowledge within the field or inform future practice. An enhanced commitment to open research and evaluation needs to be developed within DADHC to ensure that the corporate knowledge base both within the Department and the sector more broadly continues to expand.

14.19 We consider that DADHC should develop and fund a clear research and study agenda to build knowledge and leadership within disability services. This could be achieved by developing:

- A program of annual disability research grants
- An annual scholarship program, open to staff of government and non-government services, to support further study.

Recommendation 59

The Department of Ageing, Disability and Home Care should establish a clear and transparent research agenda to foster innovation, best practice and leadership within disability services. The research agenda should include:

- A program of annual disability research grants
- An annual scholarship program to support further study by staff of government and non-government services.

Chapter 15 Planning

> What we would like to see come from this inquiry … would be an acknowledgement that the whole disability area requires long-term planning. … We would like an acknowledgement that perhaps we need to start from scratch and not keep putting the bandaids on.[201]

The need for planning goes to the heart of this inquiry. Many important gains have been achieved for people with disability over the past decade, and recent initiatives such as the creation of the SAS have shown a willingness to address some of the sector's key concerns. DADHC and its predecessor, ADD, have also engaged in a range of planning processes, commencing with the establishment of the Accommodation Working Group in 1996. However, the outcomes of these processes in terms of planning for service delivery and strategic direction for the sector are unclear. DADHC has yet to properly demonstrate to people with disability, advocates and service providers that it has a coherent and effective policy and planning framework for disability services in New South Wales.

Developing a State Plan for Disability Services

15.1 The last comprehensive plan for disability services was published in 1996.[202] Our previous two reports have highlighted the urgent need for a comprehensive disability services plan for New South Wales, as have other reviews.[203] Throughout the inquiry, witnesses have stressed the need for proper planning and policy to guide service development, delivery and reform in New South Wales. Clear and transparent planning is essential to build the cooperative relationships upon which the system relies.

Planning must be open

15.2 We are aware that considerable planning for service delivery is undertaken within DADHC. For example, the population group planning process has been used for some years to attempt to spread resources more equitably across the different regions. Regional planning processes based on local consultation have also been undertaken to enable the Department to identify service needs and priorities in each region.

---

[201] Riddley evidence, 17 April 2002

[202] Ageing and Disability Department, *1996 Plans for Disability and Home Care Services*

[203] New South Wales Law Reform Commission, Report 91, *Review of the Disability Services Act 1993 (NSW)*, July 1999. Audit Office of New South Wales, Performance Audit Report, *Ageing and Disability Department: Group homes for people with disabilities in NSW*, June 2000. Fitzgerald evidence, 17 April 2002

15.3 In most cases, the outcomes of these planning processes have not been made public. Participants in this inquiry have consistently criticised the apparent reluctance of the Department to publish planning documents. Absence of public planning has led to concerns about a lack of transparency within government regarding disability policy and a perception that effective planning does not take place. Witnesses and participants in our regional consultations reported a feeling that they have been consulted but not listened to. Many people described a feeling of 'consultation fatigue' resulting from attending too many meetings that have not led to any firm action.

15.4 The ability of the disability service system to deliver better services depends on effective engagement with stakeholders, which in turn depends on open planning processes.

Planning must be comprehensive

15.5 Disability plans are a feature of most other States. Victoria has recently undertaken a comprehensive consultation process leading up to the development of a 10 year strategic State disability plan and a three year implementation plan for specialist disability services.[204] Importantly, the Victorian plan includes performance indicators that identify how their success in implementing the plan will be measured.

15.6 We consider that a comprehensive plan for disability services in New South Wales is necessary in order to:

- Ensure that people with disability and other stakeholders have an opportunity for input into the way that the service system operates
- Build confidence amongst stakeholders that the disability service system is effective and capable of delivering what it is intended to deliver
- Identify the desired outcomes that the disability service system should achieve for people with disability, the strategies that will be used to achieve these outcomes, and how success in achieving these outcomes will be measured
- Identify what types of services are available to support people with disability and how that can be accessed
- Establish priorities for action and reform over the short, medium and long term
- Clarify the roles and expectations of the various stakeholders in achieving these outcomes
- Properly define the role and responsibilities of government in achieving outcomes for people with disability

---

[204] Further information and copies of the Victorian State Disability Plan and the Implementation Plan can be obtained from the Victorian Department of Human Services website at **www.dhs.vic.gov.au/disability**

- Establish a clear process for achieving the full implementation of the *Disability Services Act 1993*.

15.7 Underlying all of these planning issues is the need to develop a proper funding base for the disability service system that is linked to identifiable and predictable demand.

15.8 While we have focussed largely on the responsibilities of government in this inquiry, we note that there is an increasing emphasis in human service systems internationally on partnerships between governments, communities, non-government organisations and individuals to identify and achieve outcomes. We consider that a collaborative approach based on genuinely shared responsibility is essential to build a system of supports for people with disability that is sustainable over the longer term. However, government as a funder has a very significant responsibility for achieving outcomes and this responsibility needs to be clearly defined.

15.9 The long-term vision for people with disability in this report is spelled out in the Objects, Principles and Applications of Principles in the Disability Services Act. In 1998, the Law Reform Commission found that there was considerable support for these aspects of the Act and submissions to this inquiry have endorsed that view. In this and past reports we have noted that the Act has not been fully implemented. As part of the long-term planning process there is a need to outline a process for achieving the full implementation of the Disability Services Act.

15.10 Evidence to this inquiry has indicated that equal opportunity to participate in community life is an important objective for many people with disability. Better access to generic services is essential to achieving inclusion in the community. Services should acknowledge and respond to the rights of people with disability as citizens and valued members of the community. There is a need for a whole of life and whole of person approach to support in order to avoid the crises that arise as a result of service gaps and discontinuities. There is also a need for greater flexibility so that services match the needs and lifestyle choices of individuals and then adapt as these needs and choices change. Within the broader approach, there is a need for an effective and accessible system of specialist disability services.

15.11 We consider that the disability plan must be determined in consultation with people with disability. While conscious of the problem of 'consultation fatigue', it is not appropriate to establish long-term directions for disability services without opportunities for input and comment from stakeholders.

Recommendation 60

The Government should, in consultation with relevant stakeholders, develop a State Disability Plan for New South Wales. The Plan should identify the long-term vision for people with disability and identify the outcomes that both generic and specialist disability services should achieve for people with disability in New South Wales. The plan should also outline a process for achieving the complete implementation of the *Disability Services Act 1993*.

Planning for specialist disability services

15.12 At a more immediate level there is a need to develop a proper framework and forward plan for the delivery of specialist disability services. This involves identifying:

- The type and mix of services that will be provided to support people with disability
- The level of demand for these services and the level of supply required to meet this demand
- Pathways for access to services and systems to determine eligibility for services
- Policy for service development and service provision
- What the roles of the various participants in delivering these services should be, and in particular the government and non-government roles
- Points at which disability services intersect with other service systems, such as health, education and aged care, with inter-departmental agreements or protocols to ensure that service gaps do not exist
- How the system will be administered and funded
- Arrangements for quality assurance, monitoring and review
- Performance indicators to evaluate the effectiveness of the system as a whole.

15.13 The recommendations in other chapters of this report are directed towards achieving a better disability service system and are intended to feed into various aspects of the forward planning process. These recommendations outline some of the central components of a forward plan for disability services including:

- Systems for intake and support coordination that promote a proactive and preventative approach to support
- The need for an industry plan for the non-government sector
- The need for an equity strategy to address the needs of under-represented groups and people who are not properly supported within current models.

15.14 Four specific areas which need to be addressed within the broader planning process include funding, workforce support and development, evaluation of systemic performance and consultation.

Funding

15.15 History has shown that planning for disability service provision will not achieve a great deal unless it is supported by a realistic funding strategy. There are a range of data sources that enable a broad estimate of need, and likely growth in need, to be developed. These include the population-based estimates developed by the AIHW, information within the SAS and information within the education and health systems about emerging needs. It is beyond dispute that considerable unmet need for disability services exists and further growth funding is required.

15.16 While better information about the exact nature of needs is needed to refine planning and funding processes over time, sufficient information is now in place to establish funding benchmarks that are linked to need. As part of the planning process, population-based funding benchmarks should be established for disability services. The disability service system needs demand-based targets for service growth that are supported by sufficient funding.[205]

Workforce issues

15.17 The quality of support provided to people with disability depends fundamentally on the quality of staff within the sector. A highly skilled and professional workforce is required to ensure that people with disability achieve good outcomes, are valued and are safe from exploitation. While we have specifically identified the development needs of workers in non-government services as requiring specific attention in Chapter 12, we note that workforce issues are integral to the overall planning process for disability services.

15.18 This report has foreshadowed the need to develop more flexible and individual ways of working. It is important to ensure that proper safeguards for both service users and workers within a more flexible environment. For staff, a commitment to work more flexibly should not mean that they lose employee entitlements and their working conditions must be reasonable. In planning for a more individualised approach to service delivery, adequate organisational and industrial safeguards will be required to ensure that people with disability obtain unhindered and real benefit, flexibility and empowerment from these support arrangements. In particular, care must be taken to ensure that legal responsibility for any breach of an Award, or State or Commonwealth laws is not shifted from the funding body to a person with disability or their family.

Systemic performance

15.19 In Chapter 12 we discuss the need to develop a service monitoring framework that measures outcomes for individuals. Linked to this is a need to develop performance indicators that measure the overall performance of the disability service system. Systemic outcome measures, similar to those included in the Victorian State Disability Plan, are needed to assess the effectiveness of the current service structure in delivering outcomes for people with disability and to provide guidance about future reform. These performance indicators should be made public and performance against them should be openly evaluated and reported upon.

---

[205] Funding for disability services on a per capita basis across Australia is outlined in Table 2 in Chapter 8

15.20 While the development of specific indicators is a matter for the Department, we note that the performance information that is regularly reported upon includes the areas covered in this and earlier reports. This includes information about progress in the devolution of large residential centres, the allocation of additional supported accommodation and details about supply and demand for respite services.

Consultation

15.21 Throughout this report, and in previous reports, we have highlighted the need for effective consultation and engagement with stakeholders in the development and implementation of new initiatives. Effective consultation enables the Department to draw on the knowledge and experience of participants within the disability sector, and can garner support within the sector to drive reform initiatives.

15.22 Planning is a continuous process that requires constant consultation and refinement to take into account changing circumstances and the evaluation of past initiatives. There is a need to ensure that review and consultation mechanisms are built into the planning framework to ensure that planning is responsive to and meets the needs of the sector. The primary stakeholders within any service planning process are the service users. Consultation processes should therefore ensure that people with disability are active participants in service planning.

15.23 We do not consider that broad-based consultation is required in relation to every initiative or every aspect of planning for disability service provision. The Community Services Commission has noted that in addition to the broad-based consultative role undertaken by the Disability Council the Department needs to develop strategically focussed consultation processes to guide specific initiatives:

> If we are talking about an industry development arrangement, it may well be appropriate to have a targeted working party established with sector representatives for a period of time and with limited terms of reference to work together to look at what that means.
>
> If we are talking about an alternative delivery system, it is extremely important that there be active consultation. Active consultation means also transparency and access to full information.[206]

15.24 Consultation will not always achieve consensus, since the disability community is too diverse to ensure complete agreement on many issues, however open and strategic engagement with the sector is necessary to develop shared responsibility for initiatives and to ensure that areas of difference are identified and minimised.

---

[206] Fitzgerald evidence, 17 April 2002

Recommendation 61

In consultation with people with disability and other relevant stakeholders, the Department of Ageing, Disability and Home Care should develop and publish a comprehensive forward plan for specialist disability services. The plan should address:

- The type and mix of services that will be provided to support people with disability
- The level of demand for these services and the level of supply required to meet this demand
- Pathways for access to services and eligibility criteria for services
- Policy for service development and service provision
- What the role of the various participants in delivering these services should be, in particular what the respective roles of the government and non-government sectors should be
- Points at which disability services intersect with other service systems, such as health, education and aged care, and protocols to ensure that service gaps do not exist
- Workforce development for disability services
- How the system will be administered and funded
- Population-based funding benchmarks for disability services
- Arrangements for quality assurance, monitoring and review
- Performance indicators to evaluate the effectiveness of the system as a whole.

Chapter 16 Conclusion: Making It Happen

This report has outlined a broad range of reforms that are required to build a more equitable and effective system of supports for people with disability in New South Wales. We believe that the implementation of these recommendations will contribute to the development of a robust and responsive disability service system and will make genuine inroads into the persistent problem of unmet need.

This inquiry is about people

16.1 More than our other reports, this report has focussed on systems and structures. While there is limited discussion about people in this report, this inquiry has been all about people's lives. It is about the people with disability whom we have met as well as their carers, witnesses to the inquiry, and the many people who attended consultations and made a submission to the inquiry.

16.2 Support for people with disability is about creating an inclusive society where people with disability have the same rights and opportunities as other people; where they are valued members of the community; where dignity and quality of life is a valued objective for government and the community; where they exercise choice and control over their lives and where they are secure. We recognise that people with disability are disabled more by the inability of the community to provide the support that they need than by their actual disability. We hope that this report will help people to obtain those supports so they can participate more fully in the community.

16.3 The Committee is aware of the dynamic nature of the task of achieving inclusion. Creating opportunities for participation will generate still more opportunities. For example, by participating in the life of their community, people with disability will achieve greater visibility in our society. The more visible they are, the more inclusion they will achieve over time, and the more 'enabled' they will become. This in turn will create both challenges and opportunities for government as the expectations of people with disability and their families evolve.

16.4 Within government, there is a need to plan more effectively for the needs of people with disability, to ensure that new services are made available to meet needs and that commitment to people with disability becomes ingrained in the actions of all departments. We must recognise that the environment in which people with disability live is changing, as are their hopes and aspirations. People with disability are living longer and it is now less appropriate than ever to keep people in a segregated support system that concentrates on their disability and limits their access to a broad range of experiences. Younger people with disability and their families are also developing new expectations and needs and we must respond accordingly.

16.5 Underlying many of our recommendations is the *Disability Services Act 1993*. The Act is a visionary piece of legislation that provides a basis for a disability service system that promotes the rights of people with disability and seeks to ensure their inclusion and participation within the community. We acknowledge through this report and our earlier reports that the Act has not yet been fully implemented. Services still exist that do not conform to the requirements of the legislation that underpin disability services in this State. The acceptance of our recommendations will help to achieve fuller implementation of the Act. We also note the important contribution of other review bodies, including the Community Services Commission, the Law Reform Commission and the Audit Office, towards the implementation of the Act and towards reform of disability services more generally.

Moving forward

16.6 Given the broad scope of our recommendations, we consider that their implementation may need to take place in several stages.

Stage 1 – Delivering current commitments

16.7 Action is required to ensure that existing commitments are delivered. Persuasive evidence has been presented to the inquiry that an immediate priority is to ensure that the existing service structure operates effectively and provides certainty for service users and providers alike. DADHC has had difficulty increasing the supply of permanent accommodation, providing support to people in crisis through the SAS and progressing the devolution of large residential centres. The recommendations in Chapter 8 are intended to address these issues.

Stage 2 – Building a system for service access and delivery

16.8 Enabling people to access support through a workable, planned and equitable process should be part of the routine business of DADHC. The establishment of a properly resourced general intake and support coordination system, recommended in Chapter 9, is essential to ensure that this can take place. We have emphasised the importance of both intake and support coordination because the disability support system will never be able to operate effectively without each of these features. At the same time, the disability system needs to become more equitable; the recommendations of Chapters 2 to 7 are necessary to ensure that the disability service system is accessible to all who need support.

16.9 A proper basis for service growth also needs to be established to support people as they move through the intake process and into services. This involves a clearly defined strategy to increase the capacity of the disability service system and a demand-based funding model.

Stage 3 – Shifting the balance of investment from crisis to prevention

16.10 There is substantial agreement that over time the balance of investment in disability services needs to shift away from crisis-driven high cost services to preventative supports. A proper system of preventative supports promotes community inclusion, autonomy and choice for people with disability. These supports prevent people with disability or their carers from moving into crisis and requiring intensive and often inappropriate forms of support. Preventative supports also have an emphasis on building people's skills and experience rather than just providing 'care'.

Funding

16.11 Funding remains a central concern for disability services. While this report has emphasised that we need to find more effective ways to use funds to support people with disability, we note that a progressive increase in funding for disability services over the longer term is necessary to address unmet need. It is therefore critically important that Treasury establish a proper population-based approach to funding for disability services that links levels of funding to actual need. As part of this it is essential to resolve the longstanding difficulties arising out of the CSTDA, and to ensure that the Commonwealth contribute effectively to the quality of life of people with disability across Australia.

Appendix 1

Submissions Received

No	Author
1	The Cabinet Office, Mr Roger Wilkins, Director General
2	Confidential Submission
3	Western Sydney Intellectual Disability Support Group Inc, Ms Lisa Stelc, Executive Officer
4	Tamworth & District Respite & Advocacy Group *in conjunction with* Statewide Disability & Advocacy Coalition, Mrs Marie Cowling, Honorary Coordinator
5	Manly Warringah Families and Friends of People with Disabilities, Ms Christine Agius
6	Multicultural Disability Advocacy Association of NSW Incorporated, Ms Barbel Winter, Executive Director
7	People with Disabilities (NSW) Inc, Mr Phillip French, Executive Officer
8	Disability Council of NSW, Ms Leonie Manns, Chairperson
9	Ms Rhonda M Hodges
10	Community Services Commission, Ms Edwina Pickering, Community Visitor Coordinator
11	Inner-West Group Homes Parents and Friends Association, Mr John Eager, President, & Ms Darleen Fawl, Secretary
12	Community Services Commission, Mr Robert Fitzgerald, Commissioner
13	Mid North Coast Area Disability, S J Rooth, Chairperson
14	Action for Citizens with Disabilities Ltd, Ms Ruth Robinson, Executive Officer
15	Westmead Hospital and Community Health Services, Mr Robert Moen, Social Worker & Team Leader FAACT Team
16	Dare to Care, Ms Christine Regan, Chairperson
17	Public Service Association, Ms Janet Good, General Secretary
18	Statewide Disability Coalition (NSW), Mr Jim Laird, Chairperson
19	Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc, Ms Judy Ellis, Director
20	Far North Coast Disability Action Team, Mr Tom Gorman, Committee Member
21	Jewish Community Services, Ms Freda Hilson, Manager Disability Services
22	Intellectual Disability Rights Services Inc, Ms Melissa Bellanta, Solicitor
23	ACROD NSW Division, National Industry Association for Disability Services, Mr Graham Catt, Executive Officer
24	New Horizons Enterprises Limited, Mr Stephen Kinkead, Executive Manager
25	Autism Association of NSW, Ms Imelda Dodds, Executive Director
26	Uniting Church in Australia, NSW Synod, Ms Lindy Kerr, Disability Education & Services Officer
27	Disability Advocacy Service Hunter (DASH) Inc, Mr Mark Grierson, Co-ordinator

28	Hunter Intellectual Disabilities Advocates, Ms Yiota Rae, Spokesperson
29	The Samaritans Foundation, Mr Cec Shevels, Director
30	The Housing Connection (NSW) Inc, Ms Anne Louise Hickey, Manager
31	Life Activities Inc, Ms Lyn Dowling, Social Worker
32	Catholic Women's League, Warialda Branch, Mrs A Jones, Secretary
33	Council of Social Service of NSW (NCOSS), Mr Gary Moore, Director
34	The NSW Council for Intellectual Disability, Ms Helena O'Connell, Executive Officer
35	The Disability Safeguards Coalition
36	Baringa Parents and Friends Association, Mr C R Peters, President
37	Stockton Hospital Welfare Association Inc, Ms Lorna Morris, Secretary
38	Confidential Submission
39	Confidential Submission
40	Access Community Education Services (ACES), Ms Beth Sawilejskij, Co-ordinator
41	Blue Mountains Disabilities Forum Inc, Mrs Marilyn Dibbs, Secretary
42	St Anthony's and St Joseph's Centre of Care, Mr Kevin Howard, Chief Executive Officer
43	Confidential Submission
44	Confidential Submission
45	Ms Maria Pappalardo
46	Mrs Dorothy Harrington, OAM & Mr Frederick Harrington
47	Confidential Submission
48	P J Collins
49	Mrs D Sammut
50	Ms Lorraine Yudaeff
51	Ms Marie Heaney
52	D E & M I Allen
53	Mr Ian Firth
54	Mr Garry Hancock
55	Mr A R Williams
56	Ms Yiota Rae
57	Mrs Dorothy Knight
58	no name – address supplied
59	Mrs L S Blyth
60	Lee Francis
61	Mr Tom O'Keeffe & Ms Deirdre O'Keeffe
62	Mr David Baker

63	Mr Terry Fawl
64	Confidential Submission
65	Mr A Holey & Mrs B Holey
66	Mrs Darleen Fawl
67	Miss M W Bowles
68	Checkpoint, Ms Maxine Brem, Convenor
69	Mrs Stephanie Robinson
70	Ms Maree Walz
71	Ms Darrell Evans
72	Mr Laurence See
73	Ms Pamela Morris
74	Confidential Submission
75	Mrs Betsy Hilton
76	Mrs Eva Nagy
77	E de Heer & Sheila de Heer
78	Nardy House Committee, Ms Denise Redmond and Ms Betsy Hilston, Secretary
79	Ms Meryl Harding & Mr Ian Harding
80	Mr Keith Manning
81	Mr Peter Hutten
82	Mr Eric Walters
83	Lower Hunter Temporary Care Inc., Ms Fiona Smith, President
84	Confidential Submission
85	Mr John Collins & Mrs Shirley Collins
86	Ms Helen Pitcher
87	Mrs E Studholme
88	B & P Hammett
89	Mr Francis Baker & Mrs Janet Baker on behalf of Mr Matthew Baker
90	R E & P Walsh
91	Mr John Eager & Ms Janet Eager
92	Confidential Submission
93	Ms Margaret Gorman
94	Mr Mark Gorman
95	S P O'Brien
96	Bonnie Johnson
97	Mrs Kerry Stratton
98	Confidential Submission
99	Confidential Submission

100	Mrs Wanda Osborn
101	Mr James Condren
102	Mrs M Booth
103	Mrs A Eshman
104	Ms Melissa Athinson
105	Ms Jennie Adam
106	Ms Gaye Essex
107	G Baddock
108	Mr Ian Dunlop & Ms R Dunlop
109	Ms Anne Elysee
110	Mr Christopher Peters & Ms Jayne Peters
111	Mrs Marie T Clair
112	Ms Deborah Maher
113	P H & L L Driscoll
114	Confidential Submission
115	Ms Christine Smith & Mr Scott Smith
116	Ms Thelma Morris & Mr Bert Morris
117	Ms M Brem
118	Ms Dora Perdikaris
119	M Leousis
120	Mr Paul Jones & Ms Anne Jones
121	Ms Jenny Coughlan
122	Ms Barbara Spode
123	Confidential Submission
124	Mr Trevor Carter & Ms Mary Lou Carter
125	Mr Trevor McLennan & Ms Veronica McLennan
126	Ms Yvonne Snow
127	Ms Beverly Buckridge
128	Ms Monica Johnson
129	Mr Mohan Das & Mrs Barbara Das
130	Ms Pascale Carratt
131	Mrs Evelyn Shoesmith
132	Mr Bert Redding & Ms Kath Redding
133	Ms Rhonda Brettschneider
134	Ms Maria Heaton
135	Ms Jeanette Moss, AM
136	W G & C R Packman

137	Hunter Region Disabled Lobby Group, Ms Melina Middleton, Co-ordinator
138	Drs K & R Frank
139	Ms Margaret Shepherd
140	Mr John Collins & Ms Shirley Collins
141	P & D McDonald
142	Ms Shirley Martin & Mr Gregory Martin
143	Confidential Submission
144	Ms Marcia McLennan
145	Ms Joan Marr
146	Mrs R Chapman, Mrs D Woodhill, Mrs T Dyson, Mrs M Dearn
147	Kirinari Community Services, Mr Gary Roberts, Chief Executive Officer
148	Allenby & Marjorie Bolte
149	Mr Richard Radcliffe Walton
150	Confidential Submission
151	Armidale Pathways Committee, Ms Mary Devine, Armidale Community Care Coordinator
152	Ms Pamela Pearse
153	Families First Macarthur Parent Support Group, Ms Karyn Ingram, Vice-President
154	NSW Nurses Association Stockton Centre Branch, Mr Andrew Batcheldor, Branch Secretary
155	Access Plus Spanning Identities Inc, Ms Annie Parkinson, President
156	Armidale Disabilities Interagency, Ms Jan Roads, Chairperson
157	J F Brett
158	Mr John M Mowbray
159	Macarthur HACC Forum, Ms Linda Margrie, Macarthur HACC Development Worker
160	Mr Paul Race & Ms Lorraine Race
161	Macarthur Disability Network, Ms Julie Deane, Chairperson
162	Interchange Bega-Eden Respite Care Inc., Pat Jones, Co-ordinator
163	Ms Moya Smith
164	Mr Tom Kenny
165	Rights Forum, Ms Kim Walker, Community Educator
166	The Association of Childrens Welfare Agencies Inc., Mr Nigel Spence, Chief Executive Officer
167	New England Early Childhood Intervention Co-Ordination Committee, Ms Jane Rudd, Chairperson
168	Caring Together Ipswich, Mr Stephen Attwood
169	Ms Jennifer Conden

170	Mrs Frances Lanteri
171	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
172	Uniting Church in Australia (NSW Synod), Ms Lindy Kerr, Disability Education and Services Officer
173	The Spastic Centre of New South Wales, Mr Richard Spencer, Chief Executive Officer
174	Ms Kim Walker
175	Mr Sydney Fernandes
176	Mrs Josie Bugeja
177	Jewish Community Services, Ms Freda Hilson, Manager Disability Services
178	Mrs Mary Cheney
179	Mrs J M Symonds
180	Lee Frances
181	Ms Deborah S Maher
182	Mr Robert Campbell & Ms Elizabeth Campbell
183	Chris Marsh
184	Confidential Submission
185	Ms Rosa Bartolo
186	Ms Barbara Satherley
187	The Disability Safeguards Coalition, Ms Belinda Epstein-Frisch
188	Ms Moya Clarke
189	Mrs Enid Darling
190	Lesley Freedman
191	Mrs Avelyn Gogos
192	Confidential Submission
193	Mrs Marie Clair
194	Hunter Consumer Unit, Ms Karen O'Hara, Consumer Liaison Co-ordinator
195	Mrs Dorothy Harrington, OAM
196	Mr Alan Kennedy
197	Mr Bert Morris & Mrs Thelma Morris
198	Mr Michael Hanretty
199	Mr Ian Leneham
200	Stockton Hospital Welfare Association Inc, Mrs Lorna Morris, Honorary Secretary
201	Parkes Post School Options, Ms Janet O'Donoghue, Co-ordinator
202	Confidential Submission
203	Inner-West Group Homes Parents and Friends Association, Ms Darleen Fawl

204	Mrs Margaret Chadwick
205	Carers NSW Inc, Ms Joan Hughes, Executive Director
206	Mr E Kearney
207	Action for Citizens with Disabilities Ltd, Ms Ruth Robinson, Executive Officer
208	Interchange Respite Care (NSW) Incorporated, Ms Jacqueline Parmenter, Executive Officer
209	Confidential Submission
210	Ms Margaret Shepherd, Ms Denise Shepherd, Ms Christine Smith
211	Hunter Mental Health Service, Ms Tina Smith, Co-Ordinator, Hunter Mental Health Supported Accommodation Project
212	Mr Ian Dunlop
213	Lachlan Centre Parents and Friends Forum, Ms Annette Guterres
214	Citizen Advocacy Western Sydney Incorporated, Ms Annette Jones
215	Mr Ken Benson & Mrs Jan Benson
216	The Lorna Hodgkinson Sunshine Home, Mr Jim McMenamin, Chief Executive
217	Professor Lindsay Gething, Director, Nursing Research Centre for Adaptation in Health and Illness, Faculty of Nursing, The University of Sydney
218	Community Services Commission, Ms Christine Carter, Community Visitor
219	The Australian Quadriplegic Association Ltd, Mr Mark Relf, Acting Chief Executive
220	Ms Dorothy McNamara
221	Ms Jennifer Lane
222	Mrs E P Norris
223	R.E.D. Inc., Mr Allan Ellis, President
224	Mr Allan Ellis & Ms Fran Ellis
225	The Cabinet Office, Mr Roger B Wilkins, Director General
226	Community Services Commission, Ms Joanna Quilty, Manager, Service Monitoring and Policy
227	Council of Social Service of NSW (NCOSS), Mr Gary Moore, Director
228	Statewide Disability Coalition Inc. (NSW), Mr Jim Laird, Chairperson
229	Physical Disability Council of New South Wales, Mr John Moxon, President
230	Western Sydney Intellectual Disability Support Group
231	Mid North Coast Area Disability Committee, Mr S J Rooth
232	Disability Network – Hunter Inc., Ms Valerie Shevels, President
233	Mr Bernard Fitzpatrick & Mrs Rhonda Fitzpatrick
234	Confidential Submission
235	Confidential Submission
236	Office of the Public Guardian, Mr John Le Breton, Director
237	Mrs Josephine Bugeja

238	Brain Injury Association of NSW Inc., Mr Kevin Marron, Executive Officer
239	ACROD NSW Division, National Industry Association for Disability Services, Mr Graham Catt, Executive Officer
240	Multicultural Disability Advocacy Association of NSW Incorporated, Ms Barbel Winter, Executive Director
241	Deaf Blind Association (NSW), Janne Bidenko
242	Ms Heidi Roland
243	Public Service Association of New South Wales, Ms Janet Good, General Secretary
244	Intellectual Disability Rights Service Inc, Ms Paula Rix, Co-ordinator
245	SPICE Consulting, Ms Deborah Fullwood, Principal Consultant
246	Mr John Jacobsen
247	Ms Beverley O'Reilly
248	Mrs Gloria Banks
249	Ms Elizabeth Plant
250	Ms Barbara Spode
251	Far North Coast Disability Action Team, Ms Faye Druett, Committee Member
252	Action For Citizens With Disabilities, Ms Ruth Robinson, Executive Officer
253	Mrs Joan Marr
254	Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc, Ms Judy Ellis, Director
255	The NSW Council for Intellectual Disability, Ms Helena O'Connell, Executive Officer
256	HunterPlus, Ms Kay Meehan, General Manager
257	Sutherland Shire Carer Support Project, Ms Sue Roach on behalf of the Parent's Working Party for Permanent Accommodation
258	Ms Sandra Milling
259	Jemalong Retirement Village, Mr A J Reichelt, Chief Executive Officer
260	Bob Freda & Scott Drinkwater
261	Mr & Mrs A Jones
262	Ms Annette Jones
263	Mrs E P Norris on behalf of the Norris family
264	Mr John Shearer
265	Trundle Central School, R T Kingwill, Principal
266	Mercy Centre Lavington Limited, Sr Patricia Weekes, Chief Executive Officer
267	Mrs Helen Byrne
268	Mrs Dawn Henderson
269	Ms Rosemary Symon
270	Lachlan Centre Parents and Friends Forum, Ms Annette Guterres

271	Ms Judith Kleeman
272	Hastings Foundation Limited, Mr Peter Merrotsy
273	Ms Karen Denny
274	Mrs Marlene Horn
275	Disability Advocacy Service Hunter (DASH) Inc, Mr Mark Grierson, Co-ordinator
276	Ms Irene Glassop
277	Mrs Lorraine Spieler
278	Parkes Shire Council, Mr Brian Matthews, Director of Corporate Services
279	Greenacres Association, Mr Neil Preston, Chief Executive Officer
280	Mr John Bilboe & Mrs Margaret Bilboe
281	Greenacres Association, Mr Neil Preston, Chief Executive Officer
282	Ms Enid Darling
283	Mr Ken Gibbon
284	Disability Assistance for Shoalhaven Inc., Mr George Mackenzie, President
285	Life Activities Inc, Ms Kay Tierney, Chief Executive Officer
286	Mr Ches Penfold
287	Mr Noel Morris & Mrs Lorna Morris
288	Ms Dianne Beatty
289	Confidential Submission
290	Central West Brain Injury Action Group Inc., Ms E Sewell, Secretary
291	Mr Ian Dunlop & Ms R Dunlop
292	Mr Roy Duffy
293	D J & E F C Graham
294	Ms Michelle Tang
295	Mrs Ann Melbourne
296	Confidential Submission
297	Mr Carl Ferguson
298	Mrs Claire Symonds
299	N.E.T. Kirkland Research and Education on the Holistic Approach to Schizophrenia, Ms Odette Nightsky
300	Stockton Hospital Welfare Association Inc, Ms Lorna Morris, Secretary
301	Confidential Submission
302	Confidential Submission
303	Mrs Rochelle Jang
304	Caringa Support Services, Ms Vicki deVaurno, Services Administrator
305	Mrs Margaret Gorman
306	Ms Jan Bowan

307	Kerry Pascoe
308	Confidential Submission
309	Muscular Dystrophy Association of NSW, Mr Martin Laverty, Chief Executive Officer
310	Mrs Dorothy Johnston
311	Ms Therese Mackay
312	The Northcott Society, Mr Glenn Gardner, Chief Executive Officer and Professor T K F Taylor, Chairman
313	Miss M Bowles
314	Mr Robert Godfrey
315	Ms Janet M Hadson
316	Confidential Submission

Appendix 2

Witnesses at Hearings

4 July 2001	
Mr John Moxam	President Physical Disability Council of NSW
4 July 2001	
Mr Douglas Herd	Executive Officer Physical Disability Council of NSW
4 July 2001	
Ms Barbel Winter	Executive Director Multicultural Disability Advocacy Association of NSW
4 July 2001	
Ms Helena O'Connell	Executive Officer NSW Council for Intellectual Disability
4 July 2001	
Mr Phillip French	Executive Officer People With Disabilities (NSW) Inc
4 July 2001	
Ms Christine Regan	Senior Policy Officer Council of Social Service of New South Wales
4 July 2001	
Ms Belinda Epstein-Frisch	Convenor Disability Safeguards Coalition
4 July 2001	
Ms Marianne Hammerton	Director, Purchasing and Planning Department of Ageing, Disability & Home Care
4 July 2001	
Ms Janett Milligan	Director, Strategic Policy, Planning and Funding Directorate Department of Ageing, Disability & Home Care
10 September 2001	
Mr Trevor Davis	Executive Officer ACROD NSW
10 September 2001	
Ms Robin Way	Chair, Accommodation Subcommittee ACROD NSW
10 September 2001	
Ms Catherine Dickson	Divisional Manager Disability Services Australia

10 September 2001	
Ms Megan Sweeny	Advocate Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc.
10 September 2001	
Mr Alexander Purvis	Advocate Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc.
10 September 2001	
Ms Judith Ellis	Advocate Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc.
10 September 2001	
Ms Belinda Epstein-Frisch	Advocate Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc.
24 September 2001	
Mr Paul Vevers	Acting Executive Director, Policy and Strategy Directorate Department of Housing
24 September 2001	
Ms Lynn Ready	Manager, Metropolitan Team Office of Community Housing, Department of Housing
24 September 2001	
Mr Stephen Alchin	Executive Director, Transport Masterplanning and Infrastructure Department of Transport
24 September 2001	
Mr James Holgate	General Manager, Taxi and Hire Car Bureau Department of Transport
24 September 2001	
Mr Peter Murray	Acting Director, Rural and Regional Strategy Department of Transport
24 September 2001	
Ms Kirsten Berg	Acting Manager, Model Integration and Industry Reform Department of Transport
24 September 2001	
Mr John Robinson	Acting Manager, Funding Contracts and Compliance Department of Transport
24 September 2001	
Mr Ray Furfaro	Manager, Station Projects Group State Rail Authority

24 September 2001	
Ms Margaret Brazel	Project Director, Strategic Issues State Rail Authority
24 September 2001	
Ms Margaret Stack	Project Manager, Disability Access State Rail Authority
19 October 2001	
Ms Anne Cross	Director, Strategic Development Community Resource Unit Inc, Queensland
19 October 2001	
Ms Judy Ellis	Advocate Family Advocacy: Institute for Family Advocacy & Leadership Development Association Inc
19 October 2001	
Mr Kevin Marron	Executive Officer Brain Injury Association of NSW Inc
19 October 2001	
Ms Margaret Wilson	Vice President Brain Injury Association of NSW Inc
12 December 2001	
Ms Anne Whaite	Chairperson Western Sydney Intellectual Disability Support Group
12 December 2001	
Ms Anne Elysee	Member Western Sydney Intellectual Disability Support Group
12 December 2001	
Ms Jane Thompson	Member Western Sydney Intellectual Disability Support Group
12 December 2001	
Ms Bridget Ramsey	Member Western Sydney Intellectual Disability Support Group
17 April 2002	
Mr Robert Fitzgerald	Commissioner Community Services Commission
17 April 2002	
Ms Anita Tang	Manager, Policy and Community Education Unit Community Services Commission
17 April 2002	
Ms Jo Ridley	Chief Executive Officer Greystanes Children's Home

17 April 2002	
Mr Alan Kirkland	Director Council of Social Service of New South Wales
17 April 2002	
Ms Christine Regan	Senior Policy Officer Council of Social Service of New South Wales
17 April 2002	
Ms Faye Druet	Acting Chair Disability Council of New South Wales
17 April 2002	
Ms Megan Sweeney	Member Disability Council of New South Wales
17 April 2002	
Mr Kevin Byrne	Executive Officer Disability Council of New South Wales
9 May 2002	
Ms Margaret Allison	Director General Department of Ageing, Disability and Home Care
9 May 2002	
Mr Robert Griew	Executive Director, Strategic Policy and Planning Department of Ageing, Disability and Home Care

Appendix 3

Community Consultations

20 March 2000	**Dubbo Community Consultation** Dubbo Civic Centre, Dubbo
21 March 2000	**Parkes Community Consultation** Coachman Hotel Motel, Parkes
23 March 2000	**Albury Community Consultation** Albury Commercial Club, Albury
11 May 2000	**Wollongong Community Consultation** Cram House, Wollongong
04 July 2000	**Newcastle Community Consultation** Newcastle Workers Club, Newcastle
10 July 2000	**Broken Hill Community Consultation** Post School Options/ATLAS Centre, Broken Hill
19 July 2000	**Tamworth Community Consultation** Coledale Community Centre, Coledale
22 August 2000	**Ballina Community Consultation** Ballina RSL Club, Ballina

Appendix 4

Summary of Recommendations

from *The Group Homes Proposal*,
Inquiry into Residential and Support Services for People with Disability

Summary of Recommendations from *The Group Homes Proposal*

Recommendation 1

That any savings achieved in the Department of Community Services disability services program through increased efficiencies should, as a general principle, be redirected to the Ageing and Disability Department for re-investment in disability service delivery. Savings achieved through efficiency measures should not be returned to Consolidated Revenue.

Recommendation 2

That, in order to ensure that clients have a genuine choice of service provider, the Department of Community Services be required to submit an expression of interest for the existing service in each case.

Recommendation 3

That the expression of interest process should apply to complete households unless consultation processes clearly indicate that residents of a house do not wish to remain together. In such cases, those who wish to remain together should be able to do so. Where residents of a service choose to move to the non-government sector, contractual arrangements with service providers should ensure that people are able to remain within their existing residential grouping as long as they choose to do so.

Recommendation 4

That the Ageing and Disability Department review the decision to seek expressions of interest for Community Accommodation Support Teams operated by the Department of Community Services.

Recommendation 5

That if, after reconsideration, it is decided to seek expressions of interest for Community Accommodation Support Teams, the expression of interest process should ensure that clients of the services are able to exercise genuine choice of service provider. This choice should include the clear option of remaining with the Department of Community Services.

Recommendation 6

That, in the case of homes which include one or two residents with moderate or high support needs, the Ageing and Disability Department ensure that negotiations involved in the expression of interest process are independently facilitated and conducted with genuine input from residents, parents and advocates.

Recommendation 7

That people who decide to transfer to a non-government service provider be given a guarantee that they will receive the same level of access to case-work, clinical and allied health services that they currently receive within the Department of Community Services. Funding agreements should ensure that non-government service providers are fully resourced to provide these services. The funding agreement should contain sufficient flexibility to provide additional funding for increased access to these services in cases where a person requires increased support.

Recommendation 8

That the expression of interest process be structured in a way that enables non-government providers to negotiate with the Department of Community Services to ensure clients have continuing access to case-work, clinical and allied health services currently provided by the Department.

Recommendation 9

That the Ageing and Disability Department ensure that funding for training and accreditation is an integral component of the Expression of Interest process for the current group homes initiative.

Recommendation 10

That specific guidelines be established setting out the required levels of skill for staff in non-government organisations , skill development and accreditation programmes, and the level of funding to be provided by the Government to support staff development and accreditation.

Recommendation 11

That the Ageing and Disability Department fully supplement award increases for non-government sector employees to ensure that workers are adequately paid, and that trained staff with necessary skills are attracted to, and remain in, the sector to provide quality care.

Recommendation 12

That the Ageing and Disability Department ensure that the expression of interest process undertaken for the current proposal evaluates the infrastructure of non-government organisations and that the evaluation takes into account the specific infrastructure needs of organisations that submit expressions of interest.

Recommendation 13

That the Ageing and Disability Department investigate the infrastructure of small organisations, with an aim to develop funding strategies to meet future infrastructure needs to enable small organisations to support additional clients.

Recommendation 14

That the expression of interest process be structured to ensure that its principal object is to achieve quality of service, measured in terms of improved outcomes for people who participate.

Recommendation 15

That each expressions of interest Selection Panel convened as part of the group homes initiative be structured in a way that facilitates participation of people with disability in decision-making through the inclusion of effective representation of stakeholders. In particular, the Selection Panels should include residents of services and relatives or advocates of residents.

Recommendation 16

That expression of interest Selection Panels be structured in such a way as to ensure that residents, in conjunction with their guardians and advocates, exercise effective choice about which service provider is chosen following the expression of interest process.

Recommendation 17

That the terms of reference for the Independent Probity Auditor engaged by the Ageing and Disability Department to oversee the expression of interest process include the requirement that:

- the Selection Panel for each service includes key stakeholders.
- the primary issue in selection of a future provider is quality of service, measured in terms of improved outcomes for individuals who participate in the process.
- the process has ensured adequate client support and effective consultation.

Recommendation 18

That a communication strategy be developed and implemented as a matter of urgency to ensure that residents have a clear understanding of the expression of interest process. The communication strategy should ensure that residents understand that they will have the genuine option of remaining within the Department of Community Services.

Recommendation 19

That an appeals and complaints mechanism in relation to the expression of interest process be established which is readily accessible to residents and carers who participate.

Recommendation 20

That the Ageing and Disability Department ensure that the assessment of clients' support needs takes into account any relevant information in addition to that provided by the proposed Service Needs Assessment Profile and Vermont tools. The assessment process should be finalised after consultation with clients, families, advocacy groups and staff.

Recommendation 21

That consultation with individual clients and their guardians or advocates take place as part of the assessment process.

Recommendation 22

That no assessments take place without the consent of the client, or where the client is not able to give consent, the consent of the person who exercises consent on their behalf.

Recommendation 23

That the Ageing and Disability Department develop and publish an evaluation strategy in consultation with key stakeholders, including people with disability, relatives and guardians and representative organisations.

Recommendation 24

That the evaluation referred to in Recommendation 23 take place over a period of time sufficient to enable judgements to be made about long-term outcomes for people from the 41 identified services who choose to transfer to the non-government sector.

Recommendation 25

That no further expressions of interest be sought for the operation of Department of Community Services group homes until thorough evaluation of the expression of interest process for the 41 identified services, and its outcomes, has taken place.

Recommendation 26

That in the event of increased involvement of non-government providers in service delivery, additional resources should be made available to the Ageing and Disability Department to ensure adequate monitoring of these services.

Recommendation 27

That the Ageing and Disability Department ensure that interpreter services are made available on departmental information hotlines. Advice on accessing the hotlines should be provided in community languages.

Recommendation 28

That the Minister establish and maintain a consultation framework for the disability sector to ensure that stakeholders are consulted about future significant policy decisions involving people with a disability.

Recommendation 29

That the Department of Community Services and the Ageing and Disability Department have regard to the need to improve public confidence in their ability to provide comprehensive services to people with disability and the Departments jointly develop a strategy to achieve this objective.

Recommendation 30

That the Ageing and Disability Department ensure that the views of residents are actively sought as part of the expression of interest process in ways that genuinely demonstrate an interest in the point of view of residents.

Recommendation 31

That in developing consultation strategies for people with disability as part of the current group homes initiative, the Ageing and Disability Department give careful consideration to the recommendations of the Report, 'Consultation with residents and clients of identified services' contained in Appendix 4 of this Report.

Recommendation 32

That an effective communication protocol be devised to ensure that residents are kept fully informed of the decisions made about future accommodation services.

Recommendation 33

That the Ageing and Disability Department and the Department of Community Services ensure that staff are provided with timely information and assistance so they may fully support residents and ensure a smooth transition process for residents who wish to transfer to the non-government sector.

Recommendation 34

That the Ageing and Disability Department ensure that all clients who do not have advocates are provided with independent advocacy support as part of the expression of interest process and that adequate funding for advocacy support be provided.

Recommendation 35

That the consultation framework referred to in recommendation 28 specifically include formal mechanisms for the participation of people with disability.

Recommendation 36

That the funding agreements for people who transfer as part of the group homes initiative should include clearly stated arrangements to meet changing support needs.

Recommendation 37

That the Ageing and Disability Department ensure that the expression of interest process for the current group homes initiative accounts for full funding for non-government service providers.

Recommendation 38

That the Government provide residents who choose to transfer to the non-government sector as part of the group homes initiative with an unconditional life-time guarantee of service.

Recommendation 39

That, as part of the guarantee referred to in Recommendation 38, the Government guarantee immediate placement in an alternative service providing an equivalent level of care in the event that a resident's placement breaks down.

Recommendation 40

That the Ageing and Disability Department ensure that the particular needs and requirements of residents and families from rural areas are considered in the expression of interest process for the 41 identified services.

Recommendation 41

That the Ageing and Disability Department ensure that residents residing in metropolitan services, but whose family members are located in rural and regional areas, are provided where necessary with independent advocacy and support during the current expression of interest process.

Recommendation 42

That the present role of the Department of Community Services as a provider to people with a broad range of support needs be maintained. Disability services provided by the Department of Community Services should not be restricted to people with medium to high support needs, or people who cannot be provided for in the non-government sector.

Appendix 5

Summary of Recommendations

from *A Matter of Priority*, Report on Disability Services, Second Report

Summary of Recommendations from *A Matter of Priority*

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.

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.

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.

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 development of the planning process.

Recommendation 7

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

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

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.

Recommendation 25

As part of the planning process referred to in Recommendation 23, funding should be identified now to enable 80 percent 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.

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.

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.

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.

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.

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.

Recommendation 32

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

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.