

**Inquiry into Residential and Support Services  
for  
People with Disability**

**Part 2 – Unmet Need**

**Submission from the Community Services Commission**

**February 2000**

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## 1. Introduction

As the principles of the Disability Services Act 1993 (DSA) state, people with disabilities have the same basic rights as other members of Australian society. They also have the rights needed to ensure that their specific needs are met. These include the right to live in and be part of the community, to choose their own lifestyle and realise their individual capacities, to access services that will assist them attain a reasonable quality of life and that are provided in the least restrictive manner, and the right to protection from neglect, abuse and exploitation.

The application of these principles, as spelt out in the DSA, requires that services and programs for people with disabilities must:

- focus on achieving positive outcomes for the individual;
- contribute to ensuring that the conditions of their everyday life are the same as, or as close to, norms and patterns in the general community;
- form part of local co-ordinated service systems and other services generally available to others in the community;
- meet individual needs and goals, including those of people with disabilities who experience additional disadvantage;
- promote maximum physical and social integration with the local community; ensure that no one organisation exercises control over all or most aspects of a person's life and that services are accountable to all stakeholders including consumers;
- provide opportunities for people with disabilities to enjoy lifestyles that are valued by the community and age appropriate;
- enable participation of consumers in decision making, as well as the planning and operation of services;
- ensure access to advocacy support;
- preserve family relationships and cultural and linguistic environments;
- provide avenues for consumers to raise grievances; and
- respect confidentiality and privacy.

Families and others involved in the lives of people with disabilities also need and have the right to expect assistance and support in caring for their loved one, and assurances that, as their circumstances change, their family member will be looked after. As our performance audit report of Large Residential Centres said "it is the mark of a developed and just society that provides care for those who cannot care for themselves" (Audit Office of NSW 1997:x).

The Community Services Commission's aim is to change the culture, quality and reputation of community services in NSW, and to empower the consumers of these services. We focus on those consumers who are most vulnerable and least likely to complain. This gives us a special interest in people with intellectual disabilities, both adults and children, who receive or are eligible to receive services such as supported accommodation, who may be unable to access the services they require, and/or

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whose rights are not being upheld. The problems these consumers can face in accessing community services include being unable to express their views or communicate their needs, lack of awareness of their rights and entitlements, being dependant for their care and well being on others who may have competing interests or needs that are seen as greater, as well as the absence of supportive personal relationships, advocacy and support.

The Commission's role in handling complaints, promoting the rights of people with disabilities and monitoring the delivery of community services gives it considerable insight into the problem of unmet need for people with disabilities and the impact that this has on them and their families. Our functions have also enabled us, over time, to build an understanding of the systemic weaknesses and structural problems that negate attempts to meet unmet need and that must be addressed for real reform to occur.

This submission draws on available research, information from the Ageing and Disability Department (as the funder and monitor of disability services in NSW), the Department of Community Services (as the government, and largest single provider, of disability services in NSW), and the Commission's own work, to highlight how the way in which the disability service system is organised in NSW is seriously flawed. We present evidence and information which shows that the current structure is inefficient and costly, does not provide good outcomes even for those able to access services, fails to meet the needs of a vast number of individuals, causes stress and angst for families, and lacks the capacity (in its current shape) to address unmet need and future demand.

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## 2. The Provision of Services in NSW

For 1998/99, the Community Visitors database identified a total of 4962 people with disabilities in care, 2829 of whom were in DoCS services and 2133 in non-government organisations. Of these, 4380 were adults, with 582 children and young people with disabilities identified as living in these residential facilities. These 4962 individuals were accommodated in 852 services – 393 run by DoCS and 459 run by the non-government sector. The vast majority (approximately 74%) of these services were group homes. 19% were residential units or cottages in congregate care settings.

The 1997 Performance Audit Report of Large Residential Centres for People with Disabilities identified 1825 people living in 17 large government run residential centres, 563 people living in 30 large non-government residential centres and approximately 201 children under the age of 18 in large residential centres (Audit Office of NSW 1997:7). ADD's latest annual report does not provide us with more current figures on the total number of people with disabilities in care and those in large residential centres. However it does indicate that the number of children living in large residential centres had, as of 1998, decreased to 170 (ADD 1999:14). The implications of this are discussed further in section 3.

As well as providing residential care, government and non-government service providers also provide other support services to families and people with disabilities to assist them live independently and/or remain with their families.

ADD's 1998/99 Annual Report indicates that it provided \$138.6 million to non-government organisations and \$194.28 million to DoCS for supported accommodation, \$23.3 million to non government organisations and \$37.1 million to DoCS for community support, and \$60.48 million to non government organisations for community access, respite and other disability services.

Extrapolating from ADD and DoCS' most recent annual reports, it appears that DoCS receives a total of \$406.7 million for disability services, \$231.4 million of which comes from ADD, and the remainder direct from Treasury.

Non government organisations receive a total of \$222.38 million from ADD.

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## 3. The Extent of Unmet Need

### 3.1 Available estimates

A range of information exists and can be collated to present a picture of the level of unmet need for disability services in NSW. However it should be noted that, while a number of attempts to quantify unmet demand have been undertaken at a national level, these have had their limitations and at a state level, less information is available. Therefore available information needs to be interpreted as indicative rather than providing exact numbers.

A 1996 paper prepared for ADD and based primarily on ABS data and other studies found a significant unmet demand for both accommodation and accommodation support by people with disabilities in NSW (Kennedy R, 1996). It reported:

- in relation to the need for accommodation support, it is estimated that the unmet demand in NSW by people with a profound or severe handicap aged between five and 64 years ranges between four-to-eight thousand;
- there is a need for alternative accommodation for around 3,400 people with disabilities who currently live in facilities with more than six people, and do not conform to the *NSW Disability Services Act*;
- there are between two-to-four hundred residents of licensed boarding houses (perhaps more) who may require relocation to accommodation which provides higher levels of support;
- an estimated 900 people aged under 60 years were living under inappropriate conditions in NSW aged care nursing homes in June 1995; and
- in a 1994 survey, an estimated 1,600 people with an intellectual disability were identified as having an urgent or immediate need for community-based accommodation, with others living in respite accommodation on a permanent or semi-permanent basis.

In relation to unmet demand for other disability support services, the study reported that:

- an estimated 4,700 carers in NSW do not access respite services because they are either unavailable or too costly. Over 20,000 carers “don’t know about” or “don’t know enough about” a respite service;
- the low rates of participation in the workforce by people with profound and severe handicap suggest a strong demand for day programs and a need for more supported employment programs. The data also suggests a significant unmet demand for community access services particularly for people with physical, psychiatric and intellectual disabilities;
- there are an estimated 1,100 people with a disability without post-school employment or day programs;

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- it is difficult to quantify or estimate the level of unmet need for children's services and community support services because there are no appropriate data sources;
  - for the 0–4 years age group, the primary areas of unmet need are early intervention, occupational therapy services, speech pathology, and case management services;
  - for the 5–15 years age group the primary areas of unmet need are school-based therapy services, case management, respite, early intervention therapies and behaviour intervention;
  - there is a need for services which are responsive to the individual needs of families with more complex requirements and improved information systems to support families in the process of caring for their child with a disability at home;
  - groups from non-English speaking backgrounds are less likely to report unmet need for help and there is generally a lack of culturally appropriate services; and
  - relatively little is understood about the needs of Aboriginal and Torres Strait Islander people with disabilities, especially those in remote communities.

### **3.2 Information from Commission work**

The Commission has undertaken a range of inquiries, projects and other research that sheds light on the issue of unmet need. Most of it relates to the problems encountered by those already in the system, in residential care, who are unable to access necessary services or are placed in services that are totally inappropriate to their needs. One piece of work undertaken by the Commission in 1996 did however focus, via a survey, on the experiences of those being cared for by their families and who were unable to access services.

#### **The Commission's survey**

138 families responded to the survey, the aim of which was to focus on the problem of unmet need from the perspective of those directly affected. Nearly all respondents (95%) were the parent of the person with a disability and over a half were over the age of 50. In about 80% of cases, the person with the disability lived with the respondent.

The survey was not intended to gain a representative view from families with relatives with a disability across the state.<sup>1</sup> The data obtained is also now quite old. Nevertheless, it presents a graphic picture of the struggle facing many families in trying to get assistance and the devastating impact of not getting a service and of not knowing when any assistance might be available. There is also little to indicate that since the survey was undertaken, the circumstances of people with disabilities and their families in NSW have drastically improved. Key findings from the survey are:

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<sup>1</sup> 275 surveys were distributed to people who had either complained to the Commission about the lack of services or who had contacted the NSW Council on Intellectual Disability on the issue.

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## *Services needed*

- the most commonly cited service need was for accommodation and respite (47 per cent of respondents);
- other identified service needs were peer support and contact, day care, recreation, vocational training and allied health services;
- a number of families already used some disability services such as residential respite care, Post School Options and day programs.

A number of respondents commented that, as their child got older, access to services was reduced or became completely non-existent:

**"...since turning 18 our daughter has received no assistance. Something must be done. You cannot give families respite, assistance in the home, plus school and then when they turn 18 all the help which is given is 22 hours a week Post School Options. As the person with the disability gets older, so do we, the parents. At this crucial time all help is taken away."**

*mother in her fifties caring for her adolescent daughter with a disability*

A number of respondents noted that the lack of options in permanent accommodation support led to people being left in respite services indefinitely. Subsequently, availability of respite for those people still living at home is restricted, placing carers under much strain.

**"Why are people living PERMANENTLY in respite care houses? One such placement affects 20 other families, placing great strains on the family which respite could help to prevent."**

*mother in her forties caring full-time for her son*

**"Due to lack of permanent care, respite beds are being used to accommodate people needing permanent care ... Respite funding was not provided for this purpose."**

*mother in her seventies caring for her adult son with a disability*

The survey results highlighted that in many instances the issue of unmet need is not the result of an absence of services, but due to the inadequacy or inappropriateness of those services which are available. 56 per cent of respondents felt that the services they were receiving were inadequate, with major reasons for this including:

- a lack of resources;
- the low level of services provided;
- the geographical location of services and;
- the types of services available being inappropriate to the needs of the individual.

**"We can use this service (day care), but a 26-year-old playing dominoes is not a good way to be entertained"**

*mother in her fifties caring full-time for her adult daughter*

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**“(Our son’s) day program is very good but he has a very long and expensive trip there and back everyday (almost two hours each way) ... his entire pension is spent to attend.”**

*mother of a disabled man in his twenties*

*Where people go to get help*

- 87 per cent of respondents indicated that they had approached DOCS to request services.
- of those, 17 per cent had been in contact with the department for between 5 and 20 years, while 23 per cent had been in contact with the department for up to 5 years.

14 per cent of respondents who approached DoCS indicated that this contact resulted in services being provided or action taken to obtain and organise services. However, for a greater number, contact with DOCS did not result in obtaining the required services, with responses from the Department including:

- providing general information only (28 per cent);
- assessing the needs of the person with a disability but not providing any services due to a lack of funds (12 per cent);
- referral to another service (6 per cent);
- placing a person on a waiting list, but with no time frame for when the service might become available (5 per cent);
- Having a case conference and being assigned a case worker (3 per cent).

While these figures obviously reflect the sample group (being families who have attempted to obtain services, but with limited success), it is concerning that a further 11 per cent of respondents report getting no response at all from the department.

**“I have contacted the department many times. My son has not seen a case worker for four years.”**

*mother of an adolescent with a disability*

**“What has appalled us is the lack of support at area office level and local level. We are sick of negativism. We need positive support and action. They wring their hands and say why they *can't* help us.”**

*mother caring full-time for her adolescent son with a disability*

Respondents also expressed distress at the fact that DOCS was unable to advise when, or even if, needed services would become available in the future. Less than 10% of those respondents who had approached the department said that they were given a specific time-frame about when a service might be provided.

The survey indicated that 63 per cent of respondents had also approached non-government organisations in an attempt to secure needed services. Of these, only 9 per cent indicated that, as a result of these attempts, the service was provided or

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action was being taken to organise the service. A further 11 per cent reported that their dealing with the non-government organisation had been positive and supportive but had not resulted in any concrete outcomes. Others were placed on a waiting list, or told that services could not be provided due to a lack of resources.

It should be noted that, at the time of the survey, the Ageing and Disability Department was still in the process of being established. This no doubt increased the likelihood that families would turn to DoCS for assistance.

### *Impact on the individual and those caring for them*

The most commonly reported effects for individuals with a disability who could not access needed services were the inability to pursue normal activities, mental and physical deterioration, frustration, boredom, anxiety and stress.

**"[If no accommodation can be found] ... she will retreat further within herself, stay in bed more, get another bed sore and repeat her lack of life chances which is the story of her life"**

*mother aged 69 years who has cared for her daughter with a disability for over 40 years*

The most commonly reported effects for carers were general stress and strain, restrictions on family members participating in normal activities, tensions and breakdowns in relationship between family members, health problems and disadvantage flowing to other siblings.

**"Our four-year-old complains now that we don't have time for him and that is bound to have an effect ... I don't have the time to address his special needs."**

*mother of a blind and disabled son in his early twenties*

**"My eldest son has moved interstate because he has had enough (he's only 17 years of age)"**

*mother of severely disabled sons aged 13 and 15*

A key issue that emerged from the survey was that those who are caring for a person with a disability are very worried and stressed about the future. The respondents indicated that the lack of information and certainty about the types and availability of services that will be provided in the future contributes significantly to the strain of caring for someone with a disability. Family breakdown, fatigue, stress, inability to work, loss of income, and health problems were some of the anticipated problems to be encountered in the future because of lack of services.

**"Having cared for our disabled son for 18 years we need some guarantee that his immediate (i.e. at the end of the year) employment needs will be met and that his long-term accommodation needs will also be met. At this stage we are only living with uncertainty."**

*mother of a young adult son with a disability*

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**“I am frightened to even contemplate the future. I am a fairly healthy individual but if something happens to me ... there is no-one to permanently care for my son”**

*mother in her fifties caring for her adult son with a disability*

## **Recurring issues and concerns from other Commission work**

Many of the respondents to the survey outlined above would probably be envious of those whose family members are already in services. But much of the Commission's inquiry, investigative and review work has highlighted the inadequate circumstances in which many people with disabilities in residential services live. While there have been service improvements efforts made in recent years, there are still issues of serious and ongoing concern.

### *The inadequacies of institutions*

The 1997 performance audit of large residential services found that they systematically failed to protect adequately the human and legal rights, safety and dignity of consumers. Specifically, the audit found poor practice and inadequate service provision in the areas of behaviour management, the management of incidents such as injuries and assaults, medication controls and consents, nutrition, health and hygiene, community access, promoting access to families and friends, privacy and dignity, individual planning and skill development, safety and dealing with complaints and concerns.

The audit uncovered a high level of unmet need and an inadequate standard of care within institutions. While we are aware of attempts in many services to improve standards, we know that, overwhelmingly, individual needs remain unaddressed in such environments and that the devolution of these services, and even service improvements within the existing environment, proceed at a snail's pace. A case in point is the Western Sydney Developmental Disability Service. For a number of years, the Commission has been raising with the department, its serious concerns about this service. Numerous reports and inquiries have been undertaken revealing inadequate service provision, serious safety risks and in some cases, abuse of residents. But despite these reports, various meetings between DoCS and the Commission at a senior level, letters outlining specific concerns, and intensified monitoring by Community Visitors, it appears that little has changed.

A recent report by the Commission's Disability Death Review Team (DDRT) examined a critical event at the DoCS large residential facility the Grosvenor Centre, which involved the deaths of two young people in November 1998. The Grosvenor Centre provides care and respite services for children, young people and adults with significant disabilities and high medical support needs. But it was in this area that the DDRT review found significant deficiencies. Whilst the review acknowledged significant service improvements during 1999, the review highlighted

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limited access to specialist health and therapy services, and lack of follow-up of specialist health recommendations. This was particularly concerning in relation to residents' underweight problems, eating difficulties, aspiration risk, dysphagia and metabolic status (Community Services Commission, 2000).

*Failing to meet the needs of vulnerable children and young people with disabilities*

Of particular concern is the failure to appropriately meet the needs of children with disabilities who cannot live with their families. Our inquiries into the Hall for Children and Cram House revealed the truly dismal circumstances in which residents of these services lived, some of whom were as young as two years of age. They found a failure to provide individual support and attention, a capacity to meet only the most basic of needs, inadequate health care and nutrition, limited opportunities for development and a lack of accountability (Community Services Commission 1997a & 1998a).

They highlighted the inability of institutional environments to meet the emotional and developmental needs of children with disabilities, in a way that is now considered appropriate, and the potential for long term damage. Thankfully, the Hall for Children has now closed and Cram House has recently been targeted for devolution. But according to ADD's 1998/99 annual report there are still 170 children and young people in institutions (ADD, 1999: 14). Our performance report identified 201 children in these facilities, based on a 1995 figure, and we know that DoCS Baringa Centre (51 children) and Hall for Children (40 children, 20 young adults) have closed since then. This suggests that children continue to enter institutions and that progress to relocate them to more appropriate accommodation is minimal and counteracted by their re-entry to the system.

The fact that children end up in institutions raises some fundamental issues about the inadequacies of services and supports currently available. The Commission recently held a forum in collaboration with ACWA and ACROD around these issues where we heard that:

- Children with disabilities with families need a *range* of living options, including but not limited to; in-home support; shared care at home; suitable supported accommodation and specialist foster care;
- Policy makers need to beware that children's rights and need to live with their family should be considered in the context of what supports are realistically available to maintain this and to ensure quality of life for both the family and the child with disability; and
- Supporting children with disabilities at home requires a solid commitment to provide as much support as necessary. Not providing the supports required simply puts us back in the situation we now see where families feel they have no other choice but to have the child live out of home.

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### *Group homes are not the solution*

For some time it has been recognised that the group home model has inherent problems as well as some strengths. While it obviously has some features that are more desirable than those associated with large residential centres, life in a group home can be just as “institutionalised”, rigid and problematic as it is for those in institutions. Problems such as inflexible routines, incompatibility, over or understaffing, limited individual choice, and the risk of assault and abuse (by staff or residents) have been previously reported on by the Commission and others. To date, this model alone has been unable to guarantee the kind of quality service anticipated by the DSA for many consumers.

### *Inadequate provision of allied services and lack of a planned approach*

Information collated by the DDRT in its first year of operation provides valuable insights into the care provided to individuals preceding their deaths and into the service system as a whole.<sup>2</sup> Key issues arising out of reviews and assessments undertaken by the DDRT to date provide a further indication of unmet need for people in supported accommodation, particularly in relation to access to a range of health and other services necessary to ensure wellbeing and optimum development. These include poor management and lack of follow-up of health care, inadequate responses to dysphagia (swallowing difficulties) and underweight concerns, lack of clarity about consent to medical treatment and problems around the support and information provided when a resident is hospitalised (Community Services Commission, 1999b: 36-39).

Our report on nutritional and mealtime practices (Community Services Commission, 1997) found no systematic approach to addressing the nutritional needs of people with significant disabilities, insufficient access to specialist dietitians, inadequate staff training and no regular screening for those at risk of undernourishment. Our monitoring of action taken since indicates that, in terms of improved services for residents, very little has happened. We continue to receive information through Community Visitors and reviews of individuals in care which indicate that the area of nutrition in residential services remains a serious concern.

Community Visitors also provide valuable insights into unmet need within residential services. For 1998/99 the most frequently reported issue of concern for both children and young people and adults with disabilities was the lack or inadequacy of individual planning. As the Community Visitor annual report notes:

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<sup>2</sup> The aim of the DDRT is to contribute to the prevention of deaths of children and adults living in disability accommodation services funded under the Disability Services Act. It does this by receiving, assessing and in some instances reviewing reports of all relevant deaths in care and identifying preventative measures and service improvements.

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*When service staff do not ensure that their support is individually tailored, there is no assurance that the changing needs of residents are identified or addressed, residents have opportunities to learn and develop skills, and residents are able to enjoy challenges and new experiences. (Community Services Commission,1999c:15)*

### *Lack of meaningful activity*

An issue that continues to dominate Community Visitor reports to the Commission is the lack of meaningful activity for residents of many services, particularly those in institutions. Other research confirms this. The Lachlan Inquiry found that off site day placement activities were accessed by only a small number of residents, with most spending the majority of their time at the Lachlan Centre (Community Services Commission, 1998c: 55).

Our 1998 respite report, "Respite Care - A System in Crisis" which surveyed those in long term respite or with a high rate of use of respite, found that only a very small proportion were employed (and where they were it was mostly on site), under half of the survey group were involved in day programs and there was very limited access to programs focusing on skill development (Community Services Commission, 1998b: 39).

Our monitoring of the Hall for Children devolution and of the new auspices for these residents also found that, while most were better off, the lack of meaningful activity was still a problem.

### *The problems associated with the ageing of people with disabilities*

As already noted, advances in medicine and technology have meant that people with disabilities are now living much longer, some into old age. The Commission, through its review and complaint work, is aware of a growing number of circumstances where services decide that they are no longer able to care for the person as they age, regardless of how long they have lived at the service and its importance to them. We have seen instances of individuals being exited, with seemingly very little planning or consultation, to environments that are inappropriate to their needs, that lack the specialist knowledge to care for them, and that fail to provide them with the opportunities they require to lead full and active lives.

This emerging attitude contradicts research which indicates that older people with intellectual disabilities continue to learn and develop into their sixties, are often less dependent and more competent than at other stages of their lives, and can have superior general skills to their younger counterparts (Bigby C, 1999)

### *Contact with the criminal justice system*

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As our submission to the Parliamentary Inquiry into Crime Prevention through Social Support noted, it is estimated that people with intellectual disability are over represented in the NSW prison population by a factor of four. The submission highlights that often experiences in the service system and/or lack of social support can be contributing factors:

*In general, people with intellectual disability have limited access to education and employment, a greater likelihood of being dependent on income support payments and consequent poverty, and may have a history of multiple or inappropriate placements. If these factors are compounded by a lack of family or advocacy support and patterns of challenging or aberrant behaviour, such individuals are at high risk of contact with the criminal justice system.*

*People with intellectual disabilities can also be disadvantaged if they have very limited interactions with society, due to living in institutions over many years. The lack of exposure to broader social norms and patterns of behaviour can result in the development and maintenance of a range of inappropriate behaviours. Those who have lived a large part of their lives in an institution can be unprepared for integration into mainstream society (Community Services Commission, 1999a:12).*

### *The lack of advocacy*

The Commission's work continually highlights the severe shortage of advocacy services in the system, the need for such support, and the difference that it can make to individual lives. Many of the individuals we come into contact with are in desperate need of a person independent of the service system to watch out for them and ensure that their rights are upheld. Often their families are unable or unwilling to take on this role or, in some instances, have conflicting interests. And while many staff provide valuable support and are truly concerned with the individual's best interests, their role in the system can present them with conflicts of interest.

There has been much debate about the type of advocacy support government should provide for people with disabilities. The government's recent decision to fund the Office of Public Guardian to provide advocacy support to residents involved in the transfer of DoCS group homes raises several questions about advocacy provision, particularly around issues of independence, quality of advocacy and the perceived threat to future funding of community based advocacy.

The initiative is an acknowledgement of the value of advocacy and the need for those affected by the transfers to receive support through what could be a very significant process in their lives. However it could be also be indicative of a lessening of government commitment to independent, community based advocacy.

Independent advocacy not only assists individuals in achieving positive outcomes, it also, as is the case in NSW, plays an important role in identifying systemic deficiencies and needed reforms. While this at times can be uncomfortable for

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government, systemic advocacy is an important way of keeping disability issues on the public agenda, raising community awareness of the needs of people with disabilities and giving them a voice and a presence. It is doubtful that many of the significant gains and improvements that occurred over the last decade or so (such as the introduction of the DSA and the establishment of the Community Services Commission), would have happened without the efforts of the advocacy movement.

In NSW, advocacy groups are funded by ADD, the same body that funds service providers and is responsible for overall direction and development of the disability sector. It would be fair to say that relations between ADD and advocacy bodies have always fluctuated, and that relations between government and advocacy bodies are at an all time low. A lack of communication and consultation, secrecy and regular public disagreements seem to be the order of the day. This is unfortunate, as it can only detract from what should be the focus and common purpose of all in the disability sector.

Government funding of advocacy support must include both individual and systemic advocacy, and the need for true independence and the absence of conflicts of interest remain vital. We caution against any temptation to fund government bodies *instead of* community based organisations to provide advocacy.

### *The needs of carers*

The qualitative information from the Commission's 1996 survey presented above highlights the central role played by carers but how they can feel overwhelmed and overlooked, to the point of breakdown. Our survey of consumers in long term respite found that the most frequent reason that they ended up in these inappropriate placements was because of their challenging behaviour and their family's inability to cope with this. However, families continued to experience stress as a result of their loved one being in long term respite, most notably because of the worry caused by the lack of permanent accommodation, increased concern regarding the future well-being of their relative, and frustration experienced at the inadequacy of the system (Community Services Commission 1998b:40).

1993 ABS data indicates that 91.9% of those with disabilities living in households relied on informal assistance from a family member or a friend and that the majority of these did not get any formal assistance. According to a 1996 Commonwealth study, approximately half of these principal carers did not receive any help in their caring role. A particular concern is the number of carers who are ageing and may be unable to continue caring in the same capacity (Yeatman, July 1996:44).

### **3.3 Future demand for services**

Any consideration of unmet need must also look at not only current levels but also demand for services into the future. The study commissioned by ADD cited above also looked at future need for disability support services and reported that data on

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population projections in NSW indicate a trend towards the ageing of the population and an increase in the number of people with a profound or severe handicap, with the rate of increase of both groups being significantly higher than the projected increase in the NSW population as a whole for the same period. Specifically:

- between 1996 and 2011, the total number of people in NSW with a profound or severe handicap is projected to increase by 55,670 people, a 25 per cent increase which is significantly higher than the projected increase in the NSW population as a whole for this period;
- in 1993, there were an estimated 4,900 people aged under 65 years whose carers were aged 65 or over. This group is likely to require support services in the near future, if not currently requiring it;
- Increased life expectancy for people with disabilities means that support services will need to be provided for longer periods of time while higher survival rates for children with disabilities will increase demand for post school options, day programs and accommodation support;<sup>3</sup>
- people who are born with or acquire a disability while young have limited capacity to contribute to costs through means such as user pays schemes; and
- the rate of family breakdown, the greater participation of women in the workforce and more acknowledgement of the rights of people with disabilities may mean an increasing demand for formal, as opposed to informal, support services.

The report notes that:

*The current level of unmet need for accommodation support and other disability support services and the likely substantial growth in demand for support services in future years suggest there are significant resource implications.....It is likely that given the level of unmet and future demand, the strategic distribution of resources will need to be supplemented by additional resources. (Kennedy, 1996:10-11)*

### **3.4 The cost of meeting unmet and future demand**

A separate report commissioned by ADD in 1997 estimated the total recurrent cost of meeting unmet and future demand to 2011 as \$420 million, or an annual increase of 5.67% to the 95/96 NSW budget to 2011 (Gould and Kennedy, 1997).

Cost estimates for unmet demand were calculated in relation to accommodation support, community access, respite, post school options, residents of licensed boarding houses with high support needs, younger people with disabilities in nursing homes and hostels, and transition services (services that must reconfigure or change practices to comply with the DSA). Cost estimates for future demand were provided for accommodation support, community access, respite, community

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<sup>3</sup> While the ADD study did not talk about the higher survival rate of children with disabilities increasing the demand for other services such as specialist therapy, family support services, respite, equipment, etc these are factors that also need to be considered.

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support for adults, children's services, and post school options. For both unmet need and future demand, the highest cost category was accommodation support.

The figure given above was based on minimum estimates and the average cost across different service types at the time. As well, they are not comprehensive in that costs of unmet demand for community support services and children's services were unable to be estimated. It could therefore be argued that it is a very conservative figure that would only go part of the way towards meeting unmet need and future demand.

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## **4. The Government's Response to Unmet Need**

As the above information shows, the level of unmet need in NSW for disability services, while hard to quantify with accuracy, is at a critical level. When estimates of future demand are factored in, it is apparent that the situation is likely to worsen, which can only mean that families' anguish and despair will deepen and the circumstances of those with disabilities who cannot obtain services will deteriorate.

The situation appears to be partly caused by the low level of recurrent spending on welfare services in NSW over a considerable period of time. A recent study by the Australian Institute of Health and Welfare showed that per capita recurrent expenditure on welfare services by the NSW government for 1997/98 was \$177, less than that spent in the Northern Territory (\$221), Victoria (\$205), South Australia (\$202), Western Australia (\$198) and Tasmania (\$186). Only the ACT (\$174) and Queensland (\$108) spent less.

The study also showed that in 1992/93, Queensland and NSW recorded the lowest level of per person recurrent expenditure but that NSW and Queensland had the highest average annual growth rates in expenditure up to 1997/98. For 1998/99, NSW also had the highest proportion of expenditure on aged care and disability services. (Australian Institute of Health and Welfare, 1999: 17-20).

A number of NSW government initiatives in recent years have attempted to better meet the needs of those with disabilities and their families and address some of the unmet demand.

### **4.1 300 places initiative**

In 1995, the government announced its "300 places initiative" which was aimed at providing supported accommodation to people with disabilities with moderate to high support needs, ageing carers and in urgent need of accommodation.

The total funding available for the program was \$50 million, which included recurrent, one-off and capital. The allocation of placements were to be costed at up to \$77,440 per placement (including accommodation, program support and day program) with funding allocated across the then 20 Areas of DoCS based on identified need (using ABS data) and the existing supply of accommodation services. Area placement committees were responsible for identifying consumers who met the criteria for the program and assessing, in conjunction with Area Managers, Expressions of Interest from service providers. Area Placement Committees then made recommendations to Area Managers about who should receive what funding and where they should be placed.

Both the Commission and ADD undertook reviews of the process. Our review involved contacting each of the Area Offices involved and asking either the Area

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Manager or the Community Program Officer (Disability) a standard set of questions about the process. Our findings were that processes for identifying potential consumers and then assessing them varied dramatically across areas with some areas only assessing those people known to them and others casting a much wider net. Interpretation and application of the criteria were also very different from area to area, and all areas with the exception of one indicated that the number of placement packages allocated had been insufficient in view of the numbers identified as being in need. Areas reported that a total of 1216 individuals were identified as in need of supported accommodation and were considered for the packages, but only 290 were allocated.

ADD's review found similar problems with the process and in the program's impact on unmet need. Its 1997 survey identified a shortfall in the number of places allocated relative to consumers who met the criteria, problems meeting the needs and choices of consumers, and initial costings not being able to be sustained over time because of changing needs and inadequate assessments from the outset. ADD also found that the upper level funding for accommodation packages was insufficient for 70% of consumers, and that the average level of expenditure recommended per consumer was 16% higher than that allocated.

The ADD review also found that less than anticipated amounts were allocated to program support and day programs. It points out that this could mean that consumers who received packages were already in day programs and did not require program support or alternatively, that they were just not provided with these services, regardless of whether they needed them or not. The review points out that if this latter assumption is true and if the demand for day programs and program supports is in fact at the same rate as for accommodation services, then the budget to appropriately meet the needs of the same number and type of people whose needs were met by the 300 places initiative would need to be increased by \$4 million (ADD, May 1997).

## **4.2 More recent initiatives**

New funds to address unmet need and initiatives to improve services have been allocated or implemented in recent years. But as this next section shows, in many instances they only address "the tip of the iceberg". There have also been problems with processes for assessing need, allocating funds and costing models of service provision. As such, new resources have not been used as efficiently or fairly as desired.

### **Assistance to 85 individuals**

In 1998/99 ADD allocated new growth recurrent funds of \$14 million which went towards ensuring the continued viability of seventy service providers and permanent accommodation and support packages for people with disabilities in real crisis. According to ADD, factors such as homelessness, abuse, age and frailty of

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carers were considered in allocating the support packages which went to 85 people identified by DoCS as being in the most urgent and critical need of accommodation. While additional funding and allocation of packages can only assist, this initiative has raised concerns:

- if the upper estimate of those in need of supported accommodation is used (8,000), then the 85 individuals who benefited from the recent allocation account for approximately 1% of those with unmet need across the state. If the lower estimate of unmet need is used (4,000) then the packages would have assisted around 2% of those with unmet need;
- how the 85 individuals were identified and their needs assessed remains unknown as unlike the 300 places initiative, there was no consultative or open process used. It is unclear whether the process was fair with all those in need and meeting the identified criteria given the opportunity to apply;
- the assessment processes used to identify the extent of individual need and to cost individual packages is not clear. It is unknown whether need for day programs and other program support were factored in and if they were, whether this was adequate.

### **Boarding house reform**

In October 1998 the government announced a \$66 million package to reform boarding houses over 3 years, \$51 million of which was earmarked for the relocation, to community based accommodation, of 310 residents with high support needs inappropriately placed in boarding houses. Another \$15 million was to raise the quality of health care, personal care and recreational/social habilitation for those residents remaining in boarding houses.

This initiative is to be applauded as it goes along way to meeting the needs of a very vulnerable sector of the population, many of whom have no family or advocate involvement. However it meets the needs of and removes from inappropriate care a group of 310. It does nothing to stop people with high support needs continuing to be inappropriately placed in boarding houses – a scenario that must be expected given the current level of unmet need and estimates of future demand for supported accommodation.

The process used to relocate individuals has also been criticised and ADD has acknowledged that it can be improved on. Anecdotal information provided to the Commission has identified concerns with the lack of a standard assessment tool, limited information provided to the selection panel, and an apparent assumption that all individuals required 24 hour support and group home care. Non government providers involved in the tendering process have also indicated that the level of information provided to them was often insufficient and made it difficult to determine what individuals' real needs were. The funding provided was also lacking in some instances and did not tally with the real needs of the person concerned.

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## Devolution

In October 1998 the Minister committed the government to a 12 year devolution plan. According to ADD's most recent annual report, in March 1999 a special administration unit was established to oversee the implementation of Transition Plans relating to the devolution of institutions and that stage one of the 12 year plan was in the process of being finalised, with children in large residential centres the priority. However, the 1999/2000 budget papers did not identify any funds for devolution and indicated an anticipated decrease in the number of residents in DoCS large residential centres of only 12. Subsequent information from ADD and DoCS is that devolution will occur, in the first instance, within existing operating budgets.

ADD's annual report also claims that since 1995, over \$22 million has been allocated to enable more than 670 individuals to progressively move from government and non government residential services to more appropriate accommodation and support arrangements (ADD, 1999:22). While a breakdown of where these individuals have moved from and where they are now is not given, it is apparent that most of these movements have not happened in recent years. As already indicated, the 1997 performance audit report identifies approximately 2,500 people living in 17 government run and 27 non government institutions, and since then we know only of the closure of the Hall for Children which has resulted in the relocation of approximately 60 children, young people and adults.

The figure of 670 individuals also somewhat contradicts figures reported in ADD's 1997/98 Annual Report. Here, it was stated that over \$22 million from state and commonwealth funding had been committed (with the state government's proportion of around \$10 million to be allocated over time) to assist 489 individuals move from identified government and non-government services. (ADD 1998: 43).

In any event, \$22 million for 670 people means that they have been relocated at an average cost of less than \$33,000 each. Even if some of them have moved back home and only required minimal support, it would be presumed that most would require supported accommodation. This raises questions about where they are now located and the quality of care being provided.

To date, there has been no consultation and no publication of a devolution plan. Key bodies that would expect to be consulted, such as the Community Services Commission, have not been. Recently, what appears to be more concrete information has been made public. This revealed that 83 residents, including 11 children, would be moved out of four institutions by 2003 (Sydney Morning Herald, 8 February 2000). No associated costs and plans beyond this first stage have yet been made public. Whatever these are, it is apparent that the process of devolution will be, in the initial stages, a very slow one as the 83 residents targeted represent only 3% of the population in institutions.

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## Hall for Children

The devolution of the Hall for Children has been a significant step forward in meeting unmet need for a very vulnerable group of consumers who were living in substandard conditions. A questionnaire distributed by the Community Services Commission to parents and other stakeholders affected by the service's closure has shown that most people feel that the outcomes for service users have been positive. Preliminary information from an evaluation being conducted by the Centre for Developmental Disability Studies is that the majority of parents have rated the first three months of their family member being in a new service as "Better than expected" (Community Services Commission, 1999b: 10). Community Visitors who have been monitoring the transition report that the children and young people have adapted well to the change, now have their own rooms and possessions and are much happier and more active (Community Services Commission 1999c: 13).

However, the closure of the Hall for Children (which took over two years) highlights the complexity of the exercise, the need for careful assessment and planning and the importance of involving families, guardians and others from the outset. The CDDS evaluation has also highlighted that a major concern for new auspices has been the lack of information provided about each resident's particular needs, an under-estimation of the costs involved in caring for them and issues around compatibility of residents.

Even with a substantial allocation of resources, careful planning and a dedicated team involved in the process and working closely with families over two years, the task of devolution was still a difficult one. The Hall for Children experience would also seem to indicate that the notion of achieving devolution of other large residential services within existing budgets will be next to impossible to achieve.

## Service improvement strategies

There have been other initiatives implemented by government designed to improve the service system and presumably have an impact on unmet need and/or the poor quality of service provision in some areas. Strategies such as the DoCS Senior Clinical Practitioners, various policy and practice manuals, the DoCS Nutrition Working Party and the ADD support co-ordination project are all genuine attempts at addressing problems and improving the service system. However they are all trying to achieve change within a system that is fundamentally flawed and with only limited additional resources. As such, much of their effort achieves only marginal improvement and often makes very little immediate or obvious difference to the lives of consumers.

For example, the Nutrition Working Group was set up in response to the serious concerns raised by the Commission and others (most notably the Western Sydney Developmental Disability Support Group) work into nutritional and mealtime practices. The Working Group has been overseeing the development of a food services manual to guide staff in the appropriate preparation of food, a risk

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assessment tool, and negotiations on staff training. While these are all worthy activities, they have not as yet lead to any practice improvements, as a recent audit of nutritional practices in DoCS by an independent consultant showed. There is also the concern that such initiatives will be of little value if at the end of the day, there is not greater access for residents to specialist services and resources such as dieticians and speech therapists.

### **A greater focus on early intervention**

There have been numerous indications that government sees the solution to the disability crisis as being, in part, a greater emphasis on early intervention and support to families to assist them care for their children at home. Certainly in comparison to other states, NSW has been seriously lacking in this area and in the provision of family based models of care for children who cannot live at home. Apparently the disability services plan or discussion paper that is in the pipeline proposes a local area co-ordination model to provide responsive, flexible support to families.

While the development of such services is to be commended, three points need to be made:

- Additional resources, rather than a redistribution of existing ones, will be required to make such a system work, meet unmet need and not create further problems;
- Such a scheme will not meet the needs of a great many people with disabilities and their families who are beyond the stage of early intervention and who, because of a lack of appropriate services, are now in crisis; and
- The needs of those children with disabilities and their families who will benefit from early intervention will change over time and eventually they too may be unable to live with their families and will require some form of supported accommodation or community support.

### **4.3 Service planning**

The above information indicates that there is currently no means of measuring with any accuracy the level of demand, supply and unmet need for disability services in NSW. Funding processes described above for the allocation of new resources have all relied on different and very basic methods of determining priorities and costings, and have been shown to be problematic.

Regardless of how new resources are distributed, it is widely acknowledged that the existing distribution of services and resources is inequitable, based on historical precedents, the submission based funding model and other (often unknown) factors. The level of funding provided to individuals and/or services has not generally been based on an assessment of need or the cost of providing adequate support, and the varying amounts provided across the sector lack a rational basis. Some areas have also been identified as having a high number of services, relative to overall

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population figures and those for people with disabilities, while others have no or very few services. Similarly, some individuals have been able to secure a significant amount of funds via an individual support package, while others with seemingly similar needs can end up with no package or can receive a significantly smaller amount. Because the system lacks well developed and transparent systems for the allocation of funds, it can be difficult to determine the rationale for many decisions.

ADD has previously acknowledged its planning and resource allocation limitations and has reported in successive annual reports that it is in the process of developing an improved planning process more focused on the needs and characteristics of people with disabilities instead of planning in relation to particular programs only. However such a model does not seem to have eventuated. While both the 1996/97 and 1997/98 annual reports talk about the development of the population group planning model, with the latter saying it will be introduced in 1998/99 (ADD, 1998: 26), the most recent Annual Report does not mention this initiative in the planning area, instead identifying the employment of six regional planners as the main achievement (ADD, 1999: 17).

Even if ADD were able to develop a planning tool that would more accurately measure supply, demand and unmet need and could take into account local advice and issues, it is unlikely that it would be able to address current inequities. No magic formula is able to resolve what is fundamentally, a case of historical neglect.

#### **4.4 The problem with the approach to date**

The above information clearly indicates that we have a system that is in crisis and that is capable only of reacting to problems once they have occurred, rather than anticipating and preventing them. And even here, we only ever meet a small proportion of need as new funds are generally provided to deal with those at the crisis end. As a result, we are not building the capacity of the system or the community to meet a broader range of needs in flexible, more appropriate ways.

Because families are left to struggle alone until its too late, they cry out for supported accommodation and intensive respite (the hard end of service provision) and want the government to take full responsibility. And because the options available are limited, their relative with a disability enters a service system that is not good at fostering family participation, ensuring connection with the community and providing life enriching experiences for the individual. Family and friends have to be very dedicated and committed to stay involved and advocate on behalf of their relative. And the general feeling is that you're one of the lucky ones if you've got accommodation or access to other services so don't complain!

If the individual is one of the luckier ones, they will be in a service where they get some access to specialist services, participate in some activities in the community, get on okay with their house mates, and still have family and friends involved in their lives. But even in such a "best case" scenario, it would be difficult to describe the

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circumstances of the individual as providing life enriching opportunities and enabling them to reach their capacity.

In the worst case scenario, individuals can be in dangerous or abusive situations, living with a large group of people with whom they have little in common and/or do not get along, spending their time at the facility and enjoying no community participation, getting irregular access to specialist services and having little contact with their family or friends. Yet the provision of such services can be as costly, in many instances, as the “best case” scenario! And all the while, there remains a huge amount of unmet need and queues of people trying to get into this faulty, flawed and damaging system.

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## 5. The Need and Level of Provision of Respite Care

All available information on the extent of unmet need places the need for, and better access to, additional respite services as a priority. Families report that this is a crucial service in assisting them cope with caring. However it is widely acknowledged that the respite system in NSW is in need of dramatic reform.

The Commission's review of the centre based respite system (Community Services Commission, 1998b) reported on a survey of both government and non-government services where there were individuals placed in long term respite. The survey found an undersupply of respite services, inequitable distribution of beds, an estimated 183 children in long term respite and inadequate policy, planning and monitoring systems to ensure effective management and accountability of the system. Most significantly the review identified that, of the 363 respite beds available, 80% were occupied on a long term basis by just 14% of the total population of respite users, and that at least 4,500 people required but could not get a respite service. The report also noted that a significant proportion of respite is provided in conjunction with supported accommodation which contradicts existing government policy and that nearly half of all centre based respite is located in services that do not conform to the DSA.

The Minister for Disability Services accepted the recommendation of the Commission's report that a taskforce of relevant stakeholders be established to further explore the problems of the entire respite system (not just centre based) and devise solutions. While the taskforce has yet to submit its report to the Minister, the final draft notes a range of problems with service delivery including: service fragmentation; lack of a clear policy framework; lack of clarity about the meaning and purpose of respite; inadequate assessment, service planning and carer involvement; lack of quality control; inconsistency in fees charged for respite services; lack of data on respite utilisation; respite services being taken up to meet other needs or gaps in service provision; inflexibility of services; lack of other support services exacerbating the need for respite services; and an inability of respite services to cater to the needs of particular groups such as Aboriginal people, remote area residents and people of NESB background.

The report puts forward a number of recommendations aimed at improving and enhancing the current respite and supported accommodation system, while at the same time reforming the disability sector overall so that a more flexible, responsive service system, with a focus on prevention and appropriate intervention, exists.

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## 6. Issues for Rural and Remote Communities

During 1999, the Commission conducted a number of forums in rural and regional areas.<sup>4</sup> These forums were attended by service providers, consumers and other interested parties and provided substantial information about unmet need across NSW. While much of this is anecdotal, it highlights a number of themes and important issues. Participants at the forums consistently identified a lack of:

- disability services, such as supported accommodation, day programs, supported employment services, recreation services etc;
- respite services for children, young people and adults, across all disability groups;
- specialist support services such as sexuality education, behavioural intervention, therapy services; and
- general community support services, sexual assault counselling, general counselling, mental health services and therapy services, such as physiotherapy, speech therapy, etc.

It was mentioned repeatedly that people with disabilities with behavioural difficulties, dual diagnosis, or complex support needs can have extreme difficulty in accessing any services in rural areas, but particularly respite services.

In many communities, where there are no supported accommodation services or day programs available, people rely heavily on respite services, as often this is the only service option available.

Non-government service providers in rural and remote NSW are often small and poorly resourced. They are more likely to have to cater to people with high support needs and those with low support needs at the same time, and to a broad range of disabilities. They may have to meet the needs of children, young people and adults without necessarily being equipped to do so. Focusing on individual need and ensuring compatibility can be difficult in such an environment. There are also few options for these services to improve performance and quality or develop innovative approaches, as most have relatively low and generally static levels of funding.

Often the community access provided for people with disabilities in these areas has to occur in large groupings because of a lack of availability of specialist transport. The absence of public transport and the high cost of taxi transport, means that many people supported in group homes are fairly isolated and spend the majority of their time at home with support staff. Resident incompatibility exacerbates, and is exacerbated by, this problem.

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<sup>4</sup> Areas visited were Tamworth, Port Macquarie, Wagga Wagga, East Maitland, Woollongong and Dubbo.

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Services in rural and remote areas can also be characterised by poorly trained and poorly paid staff, and less than ideal management practices. In some instances, service managers and the boards they report to have been in place for a number of years and may not have the collective skills required to administer and operate a quality service.

In some areas substantial funding has been provided to services for particular individuals through initiatives such as the 300 places funding. In small communities, inequities in funding across service outlets can be more apparent and can cause resentment.

Even in larger regional centres where there is significant infrastructure and provision of generic services that could be accessed by people with disabilities, this does not always happen. Reasons include the lack of co-ordination between agencies, a lack of case management, and the lack of understanding of the needs of people with disabilities on the part of generic services.

Where the person with a disability has complex medical needs, they often have to be placed hundreds of kilometres away from their families due to the lack of local specialist services. This can make family contact and input into care difficult and can place added strain on families. In places where there is a single disability service provider, people with disabilities and their families can face a range of problems including:

- The person in need of the service may not meet the entry criteria for the service, e.g. because of disability type, perceived support needs;
- The support models offered by the service may not meet the persons support needs, or the family's preferences;
- Where there are difficulties in accessing the service, or problems with the service provided, there are often no alternatives (other than driving hundreds of kilometres; and
- People can be reluctant to complain about the service they receive; and
- Often the disability service provider is located in a large regional centre and supports people whose families live in outlying areas, a considerable distance from the service. Over time, people with disabilities have less and less contact with their families.

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## **7. Aboriginal and NESB Needs**

### **7.1 The needs of Aboriginal people with disabilities**

Aboriginal people with disabilities and their families and communities face particular problems, particularly those in remote areas. From the information available to the Commission, it is apparent that they are vastly under represented in their use of disability services. While it is generally acknowledged that relatively little is known about their needs:

*All of the available evidence suggests that aboriginal access to disability services would be facilitated by having as a first point of contact, a single organisation run by and for Aboriginal people, providing information and referrals, linking services, researching local needs and cultural variables, and representing Aboriginal interests. (Tipper and Dovey, 1991)*

Anecdotal and qualitative information suggests that there is a high rate of disability amongst Aboriginal communities due to congenital factors, poor health, birth trauma, accidents and substance abuse, including petrol sniffing. These can be compounded by cross-cultural issues, lack of understanding by urban professionals, poverty and no appropriate support (Yeatman, 1996:48).

There are also numbers of Aboriginal people currently in institutional care and community-based services, displaced and disconnected from their families and communities. It can be difficult for Aboriginal families to visit their relatives in care because of problems such as distance and lack of understanding of the care system. Often this lack of contact is taken to mean lack of interest. The Commission has seen examples of children placed in institutions where staff are unaware of their Aboriginality and where nothing is done to assist them maintain cultural links.

### **7.2 People from non-English speaking background and disability**

ADD's 1998 Minimum Data set states that on average only 2.7% of all disability service users in NSW are people from NESB, even though they make up 24% of all people living in NSW. It is generally acknowledged the NESB people are less likely to report unmet need for help and that the lack of culturally appropriate services, awareness of services, and whether information is provided in appropriate languages are all contributing factors.

Reviews of people in care undertaken by the Commission have highlighted that, where people of NESB background are able to access services, it can be difficult for them to have their cultural needs recognised and met, and for their families to participate meaningfully in their care. In some instances, families with the added barrier of cultural and/or language differences can "give up" and gradually withdraw from their relative's life.

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## 8. The Security of Funding Arrangements with the Non Government Sector

### Types of funding arrangements

It is important to consider not just whether such arrangements are secure, although this is obviously an issue of primary concern to people with disabilities and their families. It is also necessary to look at the rationale behind and the adequacy of funding arrangements.

Overall information in relation to how ADD's funding processes work is difficult to obtain. Guidelines for them do not appear to exist except in relation to the initiatives described in section 4.2, where new rules and processes have been devised. Much of the information available is anecdotal, based on discussions with service providers.

#### *Block grants*

The majority of funding allocated to the non government sector for supported accommodation services (the service type that receives the greatest proportion of government funding) is by way of block grants to particular service providers to care for an identified number of consumers. However, the allocation is generally based on an historical decision, with increases to cover inflation given but not to meet consumers' changing needs, or indeed changing consumers. A service can receive additional funding by claiming that it can no longer operate within its existing budget. It then applies to ADD for viability funding, undergoes a viability audit, and, depending on the outcome of this, may receive additional funding.

One view is that non-government services can, theoretically, operate with greater flexibility and responsiveness under block grant arrangements, because the funding is not tied to an individual or even a particular outlet. However, most non-government services would argue that the low level of funding received seriously restricts any flexibility and only allows for the most basic of services to be provided. This is also generally cited as the reason for needing to support people in larger groupings rather than allowing for more individualised and innovative models of care.

#### *Individual funding packages*

Individual Funding Packages (IFPs) supposedly allow for a greater focus on the individual's needs and the opportunity to tailor responses and service provision accordingly. Many of the funding initiatives in recent years have involved the allocation of IFPs. However problems with the IFP model are emerging. A common complaint is that the IFP was inadequate in the first place to meet the individual's real needs. The reality is that most non-government services simply group

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consumers with IFPs together or accommodate them in an existing service so that the opportunity to tailor a service is lost.

Another problem is that most IFPs go to those with the highest or most complex support needs but many non-government services are not well placed to deal with these consumers, often lacking the expertise and necessary specialist infrastructure. Funds allocated for specialist support through the IFP process can end up being spent on expensive consultants or on other needs. Either way, non-government services do not develop the expertise or specialist services in these critical areas, available money is not spent effectively and consumers do not benefit fully.

Regardless of whether funding is through a block grant or IFP process, there are real problems with how such arrangements are arrived at and monitored by ADD. Problems include the ongoing inability of ADD to measure and cost individual need, the inability of services to apply for additional funds as consumers' needs change over time or to upgrade service quality, and the fact that funding agreements and monitoring arrangements do not assess or require outcomes for particular individuals.

Overall, there is a lack of transparency and clarity about funding processes, which must impact on ADD's ability to monitor outcomes and ensure quality care for individuals.

### **Security of funding arrangements**

A concern expressed by many parents, guardians and others in the disability sector is that non government services do not provide the same degree of security as do government services and that, for residents with complex or high support needs and/or challenging behaviour, this presents real risks. Certainly the evidence heard for part one of this Inquiry demonstrated the strong desire for certainty and stability in accommodation services for people with disabilities and their families and the perception that government, more so than the non government sector, is able to offer this.

As stated in our earlier submission, the Commission is aware of a small number of cases where non-government organisations have made a decision that a particular resident can no longer remain in a service and this has caused considerable angst. We are also aware of a growing problem (discussed previously), whereby ageing residents with disabilities are being exited to nursing homes that are not able to appropriately meet their needs. It should be noted that this problem is not confined to non-government services and that there appears to be a lack of ability to monitor such occurrences and protect the rights of the individuals involved.

The inadequacy of funding provided to the non-government sector has already been mentioned. There are also concerns with how funding is linked to performance and

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particular outcomes, and the effectiveness of funding agreements. As our submission to the Law Reform Commission's review of the DSA stated:

- Performance agreements used by DoCS and ADD have not provided an adequate basis for imposing duties on service providers;
- Powers of the funding body to take action where there are concerns about service quality are not satisfactory;
- Service providers have failed to fully comply with their funding agreements without the funding body acting promptly to correct such deficiencies; and
- Valuable information about service quality is not collected or used by the funding body (NSW Law Reform Commission July 1999: 107).

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## **9. The Desirability of a Continuing Role for Government in Direct Service Provision**

In principle, the Commission's view is that neither government nor non-government services are automatically better at meeting the needs of people with disabilities. Provided the service is effectively managed, able to meet the individual's needs, appropriately resourced to do so and then monitored, it should not matter whether the service is being provided by a government or non-government provider.

In reality however, there are differences. As already indicated, within the current system government services are often better resourced with greater access to specialist support, trained staff and other expertise. They are also often more likely to be able to cater to the needs of those with high support needs or who are difficult to care for, and to be able to provide a service in remote areas. For the government to discontinue its role in direct service provision, there would need to be substantial reform of the current system to better resource and enable the non government sector to provide the services required, and to demonstrate to consumers and their families that this was the case. Even with such reform, government could only ease out gradually and once it was clear that this would not reduce the level of service available nor contribute to further unmet need, and that appropriate safeguards would still exist.

The Commission's view is that caution needs to be exercised in applying competition policy and competitive tendering models to areas as complex and as fraught as disability services. The effectiveness of such models and their impact on the lives of people with disabilities need to be tested over time and carefully evaluated, rather than enthusiastically embraced and applied across the board before such information is available.

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## 10. The Adequacy of Administrative Arrangements between DoCS and ADD

The performance audit in 1997 found that there were no formal arrangements between ADD and DoCS for the delivery of government services and the monitoring of service delivery, although contractual arrangements between the two departments for the delivery of services were being negotiated at that time.

After numerous requests, the Community Services Commission obtained, in August 1999, a copy of the funding agreement supposedly in place between ADD and DoCS. However it is unsigned and undated so its exact status remains unclear. The document states:

*Both parties will use their best endeavours to ensure that the activities undertaken by both will be undertaken in a way that enhances co-operation and lessens duplication of effort. Each party acknowledges that neither party has the necessary clarity of data or sophistication of monitoring to enable the full articulation of the funder provider relationship at this time. Each party affirms its intention to work co-operatively and where appropriate collaboratively from their respective role to achieve mutually agreed reporting and monitoring mechanisms over the period of this agreement.*

The document indicates that the agreement is an interim one, which will be in place until there is sufficient reliable data available regarding demand and level and cost of service provision, or until 30 June 1999, whichever is sooner. On this basis, the agreement must have expired on 30 June 1999, perhaps before it was signed! Regardless, it gives an indication of the inadequacy of the arrangement between DoCS and ADD and the open acknowledgement that ADD will not be monitoring DoCS in any rigorous, objective manner, nor requiring from it reporting against defined performance measures. Given the level of funding received by DoCS for disability services, this lack of accountability is worrying, both for those needing disability services and for the general, tax paying community.

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## 11. The Status of Implementation of The Disability Services Act

The recent review of the DSA by the NSW Law Reform Commission found strong sector-wide support for the Act and 'adamant' views that its provisions should not be weakened in any way (NSW Law Reform Commission 1999:12). This show of support, from service providers and consumers alike gives government a solid platform on which to pursue the objects of the DSA. However, the Commission is concerned that a commitment to the DSA, its provisions and the government responsibilities it entails, does not feature strongly in government or bureaucratic rhetoric and that it is at risk of becoming invisible.

The Law Reform Commission's review notes that, even though the three year time limit whereby services had to reach conformity with the Act has lapsed, 30% of non government services and 86% of DoCS services still do not conform. Our 1997 audit report recommended that "conforming as closely as possible needed to be clearly defined and criteria to measure it developed". While ADD has developed the standards in action manual, this does not adequately define "conforming as closely as possible" or how this should be achieved by services. And, as already highlighted, monitoring in relation to it is grossly inadequate.

But by far the biggest problem with assisting services to achieve conformity has been the lack of funding to enable them to do so. This situation makes a mockery of the DSA and places the Minister for Disability Services in the difficult position of not being able to fulfil her duties under the Act.

The Law Reform Commission has recommended that the transition process to assist services to meet the objects, principles and application of principles should continue but that the Minister should be required to prepare a plan indicating how and when transition services will be funded to achieve conformity, and that a new independent mechanism, DisQAC, comprising representatives of consumers and the service industry, be established to oversee and monitor transition and quality assurance processes and to certify disability services as conforming to the DSA.

While establishing a new body to take on this role may not seem a viable option to government, it should be given consideration. Such independent quality assurance mechanisms exist in a range of industries, including areas of the community services and health sector and have been proven to be an efficient and effective means of raising standards and the quality of service provision over time. The involvement of service providers and consumer representatives in the development and ongoing operation of such a scheme can also work to ensure its acceptance and success. In view of the failure of ADD to develop and apply a systematic monitoring regime across government and non government services and the lack of confidence this has engendered in the sector, such a proposal warrants serious consideration.

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A fundamental problem highlighted by the Law Reform Commission review is that, while the DSA itself is highly regarded and seen as an appropriate framework for the provision of disability services in NSW, the disability standards themselves are seen as flawed and unable to provide a means of ensuring that services conform with the Act. The standards are regarded by many as not adequately reflecting the full set of principles and application of principles as set out in the DSA. In other instances, it has been suggested that they reflect principles that are not contained in the Act and that there is an overemphasis on services' responsibilities to conform with particular processes, rather than achieving actual outcomes for consumers.

As well as monitoring already funded services to ensure conformity with the Act, the Minister has a duty to provide new funding only to those services that demonstrate compliance or the ability to comply. This presumably requires a rigorous assessment process before funding can be allocated. As indicated in our previous submission to this Inquiry, the current Expression of Interest process being used by ADD in relation to the transfer of group homes relies on self reported information from the applicant to determine conformity. As well, the information package for applicants does not outline measurable and specific criteria to be met to demonstrate conformity. We have suggested to ADD that the development of any EOI process needs to obtain a proper balance between flexibility and ensuring the government is able to meet it's legal responsibilities.

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## 12. The Way Forward

This submission paints a grim picture of the level of unmet need for disability services in NSW and the inability of the current system to deliver high quality, timely, appropriate and flexible services and support to people with disabilities and their families equitably and fairly.

Worse, the structure of the system and the way in which services are delivered have isolated many people with disabilities and alienated them from their communities, families and other supports. Their lives and everyday experiences do not reflect those valued by society nor community norms. Most shocking of all is the cost and inefficiency of keeping the current system afloat, and to date the lack of any long term plan or framework within which policy, resource allocation and decision making occurs.

Our submission highlights how the current state of play is causing undue stress and anxiety for consumers, carers and their families, negating the effectiveness of initiatives to address unmet need, and fuelling a climate of mistrust, lack of openness and a loss of common purpose.

But the Commission is firmly of the view that the situation is salvageable and that it must be salvaged, to honour stated commitments to uphold and protect the rights of people with disabilities and to fulfil our obligations as a just society. The current economic buoyancy is further reason for tackling the problem head-on, and for embarking on a reform process.

We need to engage the sector in rebuilding a system that supports people with intellectual disabilities to live enriching and fulfilling lives as independently as possible. Such a system needs to nurture and build on existing supportive relationships, by providing services that complement and enhance these and that are responsive to individual circumstance and need. We need to recognise the important role that advocacy and less formal support networks play in making the individual feel wanted, included and listened to. We need to provide flexible support and accommodation options that allow for the expression of individuality and choice of lifestyle, instead of the “one size fits all” approach. And we need to develop the capacity of the system so that it can grow over time, respond to changing needs, and become innovative and resourceful.

The strategies to achieve this reform should include:

- Re-engaging and building bridges between families, carers, advocates, service providers, bureaucrats and government so that there is a sense of trust and common purpose;
- A commitment to long term and planned investment in the disability services sector to rectify past neglect and meet emerging demands;

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- A commitment to retaining, implementing and strengthening the Disability Services Act 1993;
  - The development of a funding model that recognises government responsibility to finance disability services (as it does health and education services) and that plans for and links growth funds to population projections and estimates of unmet need and future demand;
  - The development of a state-wide disability plan in consultation with stakeholders that clearly shows Government's recognition of the current crisis, commitment to resolving it and specific strategies by which this will be achieved;
  - A recognition that improvements to the system cannot be achieved only by reconfiguring or reallocating existing resources, but that a substantial injection of growth funds is and will continue to be required as well as strategies to use resources efficiently and effectively;
  - Greater transparency and accountability in terms of how funds are allocated and spent, the basis on which decisions are made, and outcomes achieved for people with disabilities, for DoCS and ADD;
  - An urgent clarification of the future role of DoCS as a service provider, and community access to specialist services currently within DoCS;
  - Developing a plan to speed up relocation of children living in institutions as a priority, and ensuring that adequate resources are provided to enable devolution of all institutions to happen in the best way possible with the best results achieved for consumers and their families;
  - Increased availability of supported accommodation and respite service options to provide assistance to those in crisis and/or in need, through models that promote individuality, choice, community norms and can cater to changing needs;
  - Development of a broader, more flexible range of support options with a focus on early intervention, intensive family support where appropriate, local support and innovation;
  - Demonstrating a commitment to maintaining and developing independent advocacy;
  - Skilling up and building capacity within ADD and other central agencies to ensure first class strategic planning, policy development, program management and innovation in the disability area;
  - Skilling up, investing and building capacity in the service provision sector to foster the development of competent and committed managers and direct care staff who are able to structure a service around an individual's needs and whose focus is on maximising the consumer's opportunities; and
  - Consideration of the establishment of an independent quality assurance mechanism with industry and consumer representation to ensure conformity with the DSA.

Disability services must be reconfigured on the basis of a new "shared care" model - one that recognises the roles of government, families, carers, consumers and the community in the shared care of people with disabilities and respective responsibilities. Governments cannot meet the high demands alone. Nor is that what is required.

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Yet the balance of responsibility is currently unfairly distributed, with people with disabilities the ultimate losers, and the well being of their carers further declining.

The disability service system is neither a short term nor crisis care system, yet it operates as if it were. The time for a well planned, appropriately resourced, efficient, quality care system with the rights and aspirations of people with disabilities at its centre is long overdue.

The responsibility for caring for people with disabilities is a whole-of-society issue and requires genuine dialogue and renewed commitment. Government however must lead and facilitate that dialogue, and demonstrate a whole hearted commitment to dealing with the fundamental issues and problems that continue to be raised.

Above all we need to respect and value people with disabilities and afford them the quality of service, support and opportunity to which they are entitled as valued members of our society.

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