CHAPTER 5

CHILDREN AND YOUNG PEOPLE WITH DISABILITIES IN CARE

> Children and young people with disabilities have historically entered the out-of-home care system for different reasons than other children. Professionals, parents and the Australian community believed that the disability specific needs of a child made that child unlike other children and so needed to receive different care to most other children. Families were not expected to 'bear the burden' of raising a child with a disability…children with disabilities were…segregated from the wider community.[1]

Introduction

5.1 Evidence has illustrated that many systems in Australia for the care and protection of children and young people with disabilities in various settings including out-of-home care, are often not working. Among issues raised are those relating to abuse in care, lack of foster care options particularly for high-needs children with disabilities, lack of support for families to ensure that they can keep their children at home and inadequacies in certain aspects of the law for the care and protection for children and young people with disabilities.

Children and young people with disabilities

Types of disability

5.2 As defined under s.4 of the *Disability Discrimination Act 1992* (Cth), 'disability' includes intellectual, psychiatric, physical, sensory, neurological and learning disabilities as well as physical disfigurement and the presence in the body of disease-causing organisms, such as HIV/AIDS.[2] In 1998, there were approximately 3 905 600 children aged 0-14 years living in Australia, of whom 296 400 (or 7.6 per cent of children aged 0-14 years) had a disability. Of the 296 400 children with a disability aged 0-14 years, 252 800 experienced specific restrictions. Of these, 206 300 experienced activity restrictions (ie, in the areas of self care, mobility or communication) and 175 200 experienced schooling restrictions. The level of core activity restriction experienced by a child provides a broad understanding of the level of support that they reportedly need in the known above activities. In 1998, there were

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[1] *Submission* 77, p.3 (Disability Council of NSW), quoting Community Services Commission, *Inquiry into the practice and provision of substitute care in NSW – new directions: from substitute to support care*, NSW Government, Sydney, 2000, pp.47-48.

[2] This definition is similar to that in the *Anti-Discrimination Act 1977* (NSW). However, it is broader than that in other Acts in Australia, including that in the *Disability Services Act 1993* (NSW) – New South Wales Law Reform Commission, *Review of the Disability Services Act 1993 (NSW)*, Report 91, July 1999, pp.75-77.

an estimated 144 300 children aged 0-14 years (or 3.7 per cent of children in this age group) with a severe or profound core activity restriction (severe disability). There were: 76 500 children aged 0-14 years (2.0 per cent of children of this age) with a profound level of core activity restriction, meaning that they were unable to do, or always needed help with, one or more core activity; 67 800 children in this age group (1.7 per cent of children of this age) with a severe level of core activity restriction, meaning that they sometimes needed help with a core activity task, or had difficulty understanding or being understood by family or friends, or could communicate more easily using sign language or other non-spoken forms of communication; 20 000 children in this age group (0.5 per cent of children of this age) with a moderate level of core activity restriction meaning they did not need assistance but had difficulty performing a core activity; and 42 000 children in this age group (1.1 per cent of children of this age) with a mild level of core activity restriction, broadly meaning they had no difficulty performing a core activity but used aids or equipment because of a disability. In addition, 175 200 children aged 0-14 years had a schooling or employment restriction. Of these, 128 700 also had a mild, moderate, severe or profound core activity restriction, while 46 500 had a schooling restriction only.[3]

5.3 Some children have a need for intensive medical and therapeutic support or continuous care. Others may have long-term behavioural patterns that can include a range of actions such as regular violence to themselves or others, chewing or breaking furniture and house fittings, screeching or being noisy at all hours, ingesting inedibles, smearing faeces, or absconding.[4]

Accommodation options

5.4 Historically, children with a range of disabilities were often accommodated in institutions specifically for the disabled which had been set up in the nineteenth century 'to protect society from the "feeble minded"'.[5] The first Australian institutions for disabled children were established including institutes for 'deaf and dumb' children in Victoria and New South Wales where parents were required to sign over complete control to their management committees. Similar institutions for children with disabilities were established in other Australian States in the late nineteenth century.[6] Therefore, during much of the 20th century Australian children with disabilities were provided with 'whole of life' services, usually in large, segregated institutional

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[3] Australian Institute of Health and Welfare (AIHW), *Children with disabilities in Australia*, 2004, pp.14-15, [AIHW Cat. No. DIS 38].

[4] Bain KJ, 'Children with severe disabilities: options for residential care: is living under the same roof necessary for a nurturing family relationship?', *Medical Journal of Australia* 1998, 169, pp.598-600.

[5] *Submission* 173, p.15 (Victorian Government), quoting Ozanne, Rigby, Forbes, Glennen, Gordon & Fyffe, *Reframing opportunities for people with intellectual disability,* University of Melbourne School of Social Work, 1999, p.173.

[6] Mellor EJ, *Stepping stones: the development of early childhood services in Australia*, Harcourt Brace Jovanovich, London, 1990, pp.27-28.

settings.[7] A number of organisations have noted that in earlier times, families of children with disabilities were very often encouraged to place their children in care:

> …removal was traditionally viewed as the best option for parents and families who needed to be spared the burden of raising a child with a disability. Parents and families who ignored this view were expected to take full responsibility for their children with very little government support.[8]

5.5 The 1960s saw significant criticism directed towards traditional institutions. Influences were also at work with the application of human rights principles to mental health, and intellectual and physical disability, and various theories were applied to the possibilities of creating more independent lifestyles for people with intellectual and physical disabilities.[9] However, despite Bowlby's attachment theory about the importance of nurturing relationships for healthy child development that accompanied deinstitutionalisation in mainstream child protection services in the 1960s and 1970s, for children with disabilities this did not occur until the 1990s.[10]

5.6 Throughout the 1970s-1980s other factors diminished the need to have large institutions including better Commonwealth government financial assistance that allowed people, especially mothers, to keep their children rather than relinquish them to an institution. As Centacare-Sydney noted:

> Much research was being undertaken with regard to child development and the increasing body of knowledge was clearly stating that children were not best cared for in institutionalised settings, rather in a family environment or within small group homes.[11]

5.7 Deinstitutionalisation entailed a shift in service delivery from large-scale institutions to smaller, community-based settings, originating with the activities of United States and Scandinavian human rights advocates in the 1950s and 1960s. Gaining momentum in Australia in the 1980s and 1990s for people with disabilities, its proponents compared the negative aspects of large institutions with the potential benefits of community homes, including the opportunities for independence and an improved quality of life. The idea of moving people from large institutions to smaller home-based or community care was attractive to governments because the latter option was more cost effective.[12]

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[7] ACROD, 'Children with disability', *Fact Sheet*, May 2004, p.1.

[8] *Submission* 165, p.8 (People With Disability Australia Inc), quoting reports from the Community Services Commission, Family Advocacy and Leadership Development, and Amicus Brief to the Community Services Appeals Tribunal.

[9] AIHW, 'Deinstitutionalisation: the move towards community-based care', *Australia's Welfare 2001*, Canberra, 2001, p.99.

[10] *Submission* 77, p.4 (Disability Council of NSW).

[11] *Submission* 82, p.3 (Centacare-Sydney).

[12] AIHW 2001, pp.97-103.

5.8 For mental health issues it was accepted that some institutional services would continue to be required, partly for the management of acute episodes, and for some on a continuing basis. As such, a policy emphasis was placed on opening psychiatric wards within or in association with acute care hospitals, rather than continuing large-scale stand-alone psychiatric hospitals.[13]

5.9 In Victoria for example, until the 1980s the major form of long-term placement for children with disabilities were large residential institutions. Some children were placed in smaller congregate care situations of 20-50 residents, under the former Commonwealth nursing home program. The early 1980s saw the introduction of the Community Residential Units, small group houses with rostered staff, managed by community-based parent committees. State institutions were gradually closed and institutional care for children with intellectual disabilities was phased out by the early 1990s. After the handover of the former nursing homes from the Commonwealth to the States, the Commonwealth financially supported State initiatives to redevelop some of the large facilities. When large institutions closed options for children may have included a return to birth families with a support package, a family placement or a small group residential placement.[14]

Permanency planning

5.10 Over the last 15 years or so, professional and government opinion has changed regarding children with severe disabilities and high-support needs. In the late 1980s, 'permanency planning' ideas gained professional favour in child welfare. In the context of children with severe disabilities, permanency planning favours that they live with a family, preferably their birth family or an adoptive or foster family and is based on the view that a long-term, day-to-day relationship between the child and at least one continuous caregiver is necessary. It arose from the concern that children in foster care drift, with a loss of contact with natural parents and negative emotional and social consequences for the child as placements break down and foster agency staff move. Specific aims of permanency planning include: the provision of financial and other support to birth families to enable the child to stay at home, at least until legal adulthood; the pursuit of permanent reunification with the natural families for children who have previously been relinquished or placed in institutions; and adoption or long-term placement with a foster family, preferably on an 'open' basis so that birth parents can continue with an informal parenting role where parents have requested an out-of-home placement.[15]

5.11 Variations exist across Australia regarding accommodation for children and young people with disabilities who are unable to remain at home. Some jurisdictions'

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[13] AIHW 2001, p.102.

[14] Gordon Meg, 'Family care of children with an intellectual disability', in *Reframing opportunities for people with an intellectual disability*, A report funded by the Myer Foundation undertaken by School of Social Work, University of Melbourne, 1999, pp.225-226.

[15] Bain 1998, pp.598-600.

government departments may prefer 'specialised' foster care while others opt for the use of group and large institutions yet others may focus on in-home support, respite houses or residential units attached to hospitals.[16] Anecdotal evidence about the placement preferences under the Family Options program in Victoria, suggests that practices vary from region to region.[17]

5.12 Underpinning contemporary permanency planning ideas has been the philosophy of *inclusion*. This principle subscribes to the notion that everyone, including people with disabilities, can participate in mainstream community life, and is best supported through the family which is ideally placed to provide the child with a sense of identity and practical and emotional support. Many ideas are put forward to support permanency placements including programs to assist parenting roles. It is also recognised that issues surrounding all family members need to be addressed, particularly given the lack of congruence at times between the needs of the child with a disability and the needs of other family members. For permanency planning to work, wide-ranging flexible supports, tailored to the individual family needs, should be available.[18]

5.13 Certainly the strains on families who have a child or children with disabilities are well documented, and it is obvious that the availability of good supports for such families is important. Many families with a child with disabilities experience a loss of income as a result of the mother's or both parents' reduced paid employment. Often a mother's chance to study or make future plans for employment can be seriously curtailed. Mothers of children with disabilities are more likely to be unemployed, in part-time employment and on lower salaries than mothers of non-disabled children of the same age. The above issues are important in considerations of a family's total function. If a child with a disability is to remain at home, families of children with disabilities need to have at minimum, the degree of financial security and opportunity of other families.[19] Many high-needs children with disabilities and their families require significant attention and assistance and living expenses for them can be particularly high, irrespective of where they live.[20]

5.14 While research has compared the effects of various types of child rearing and placements for children, little research has been conducted for family placement of children with disabilities. One study of different care models showed both positive and negative results associated with each. Little research is available on the impact of the combination of good quality, small residential care with frequent, positive contact with the child's birth family.[21] Comprehensive family support programs have been

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[16] Bain 1998, pp.598-600.

[17] Gordon 1999, p.226.

[18] Gordon 1999, pp.198, 202-204.

[19] Gordon 1999, pp.203-205.

[20] Bain 1998, pp.598-600.

[21] Gordon 1999, p.199.

successful in substantially reducing out-of-home placements and keeping children with disabilities in the family home. While it is unclear if family support programs reduce family stress, they may increase a family's coping capacity.[22]

Numbers of children and young people with disabilities

5.15 It can be difficult to determine the number of children and young people in Australia with disabilities. A study in 1993 estimated that 63 500 Australian children aged 5-14 years had a severe or profound handicap (that is, they always or sometimes need personal assistance or supervision with activities of daily living).[23]

5.16 As noted earlier, in 1998 in Australia, about 296 400 children aged 0-14 years, were estimated to have a disability.[24] Almost twice as many boys as girls had a disability (192 800 or 9.6 per cent of boys compared to 103 600 or 5.4 per cent girls). This sex difference also applies when considering the pattern for children with a severe disability (97 400 or 4.9 per cent of boys compared to 47 000 or 2.5 per cent of girls). Of the 296 400 children aged 0-14 years with a disability, 144 100 children (or 3.7 per cent of the population aged 0-14 years) were estimated to have a physical/diverse disability, either as a main disabling condition or an associated disabling condition.[25]

5.17 The Disability Council of NSW cited figures from the Community Services Commission (CSC) from May 2001 of 310 children and young people with disabilities living in residential care, but acknowledged that this did not include children living in non-disability specific residential facilities. The Council also noted that national figures are hard to obtain stating that 'Australia wide, a little over 4 000 children lived in residential services or corrective institutions, but the number of these children who have disabilities is not identified'. The Council advised:

> …the number of children with disabilities in disability services institutions, psychiatric institutions, hospitals, boarding schools, long-term respite placements or other forms of 'temporary care' arrangements is not known. It has been unfortunate that with deinstitutionalisation and the use of alternate congregate care options it has become more difficult to identify and monitor children and young people with disabilities in out-of-home arrangements.[26]

5.18 The Victorian Government quoted a 2001 survey showing one disabled child living in congregate care and 142 disabled children and young people in shared supported accommodation on the snapshot day, ranging in age from under five years

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[22] Gordon 1999, p.211.

[23] Bain 1998, pp.598-600.

[24] AIHW 2004, p.14.

[25] AIHW 2004, pp.xii-xiii.

[26] *Submission* 77, p.5 (Disability Council of NSW).

to 18 years. The same survey showed that there were also 82 children in out-of-home care supported by the Family Options program.[27]

5.19 Mr French from PWD spoke of numbers of children with disability who are in the nation's care and protection system:

> …something like 40 per cent of children and young people in the care and protection system in Australia are also children and young people with disabilities. They grow up and eventually leave care…they are very poorly supported, generally speaking.[28]

5.20 Figures from a Commonwealth State Territory Disability Agreement (CSTDA) data collection have shown that on a snapshot day, around 8 000 children aged 0-14 years have been assisted under the CSTDA.[29]

5.21 Little is known about the rate of Aboriginal and Torres Strait Islander children's disabilities for a number of reasons including that indigenous people are not identified in the Australian Bureau of Statistics 1998 Survey of Disability. A 1989 study by Bower et al noted some significant differences in some particular congenital malformations between indigenous and non-indigenous infants in Western Australia, 1980-1987, including that Aboriginal infants were more likely to have microcephaly, than non-indigenous babies. The prevalence of disability among Aboriginal children aged 4-17 years in Western Australian was investigated in 2001-2002 by the Telethon Institute for Child Health Research. Its findings included that:

- 8.1 per cent did not have 'normal' vision in both eyes. This rate fell from 11.3 per cent in the Perth metropolitan area to 3.1 per cent in areas of 'extreme' relative isolation;
- 6.8 per cent did not have 'normal' hearing in both ears. Of these children, 49 per cent were deaf or partially unable to hear in one ear and 24 per cent were deaf or partially unable to hear in both ears;
- 9.8 per cent had trouble saying certain sounds. Among children aged 4-11 years, this difficulty was more pronounced in boys (16.5 per cent) than girls (9.9 per cent); and
- 8.5 per cent had a speech impairment which prevented other people readily understanding them when they spoke.[30]

5.22 Given Australia's trend from institutional care towards in-home care including with their families, in 1998, almost all children aged 0-14 years with disabilities lived in a household. Less than one per cent lived in care accommodation.[31]

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[27] *Submission* 173, p.16 (Victorian Government); as this submission notes, many older adults with disabilities have spent at least part of their childhood in institutions.

[28] *Committee Hansard* 4.2.04, p.77 (People With Disability Australia Inc).

[29] AIHW 2004, p.42.

[30] AIHW 2004, pp.29-30.

Legislative and government framework – for children and young people with disabilities

5.23 The Commonwealth and State and Territory governments have enacted legislation to protect the rights and interests of people with disabilities. The Commonwealth State Disability Agreement (CSDA) was established in 1991. Nowadays as the Commonwealth State Territory Disability Agreement (CSTDA), it provides a framework within which the Commonwealth and jurisdictions aim to protect the interests of people with a disability and is supported by a range of Commonwealth and State and Territory disability legislative provisions. The United Nations Convention on the Rights of the Child (UN Convention) also applies to children and young people with disabilities. Some of these provisions are discussed below.

Anti discrimination legislation

5.24 Disability anti-discrimination legislation has been in place in most Australian States and Territories since at least 1977, to address discrimination against people with disabilities.[32] In NSW, the *Anti-Discrimination Act 1977* (NSW) prohibits among other things, discrimination on the ground of disability in the provision of goods and services (whether for payment or not). Other States and Territories have similar legislation. The Human Rights and Equal Opportunity Commission (HREOC), administers various pieces of Commonwealth legislation including the *Disability Discrimination Act 1992* which contains anti-discrimination provisions.[33]

CSTDA and associated legislation and policies

5.25 The Australian, State and Territory governments fund government and non-government provided services for people with a disability. Funding regimes and service delivery regimes vary across jurisdictions. The CSTDA between the Australian, State and Territory governments defines their roles and responsibilities in providing specialist disability services to people with a disability. The CSTDA's purposes include: providing a national framework to underpin specialist disability services across Australia, and outlining a means for measuring and publicising the progress of governments towards achieving this national framework; outlining the respective and collective roles and responsibilities of governments in the planning, policy setting and management of specialist disability services and providing accountability mechanisms regarding government funding for services.[34]

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31 AIHW 2004, p.xiii.

32 Yeatman A, *Getting real: the final report of the review of the Commonwealth-State Disability Agreement*, AGPS, Canberra, 1996, p.1.

33 New South Wales Law Reform Commission 1999, pp.53-55.

34 Productivity Commission, *Report on Government Services 2005, Volume 2: Health, Community Services, Housing*, Canberra, 2005, pp.13.4-13.5.

5.26 Under the CSTDA, the Australian Government has responsibility for the planning, policy setting and management of specialised employment services. The State and Territory governments have similar responsibilities for services such as accommodation, respite and other support services. As such, each jurisdiction has entered into bilateral agreements with the Australian Government which identify ways by which both levels of government can work together to address issues of local concern.[35] The Commonwealth provides funding to the States and Territories to assist them with their responsibilities as required under the Agreement.[36]

5.27 Prior to the transfer of Commonwealth-funded services to the States which accompanied the introduction of the CSDA, services for people with a disability were administered by the Commonwealth under the *Disability Services Act 1986* (Cth). Before the Agreement took effect, the Commonwealth required all States and Territories to enact disability services legislation to complement the Commonwealth *Disability Services Act*. The *Disability Services Act 1993* (NSW) represents the complementary legislation in New South Wales; other jurisdictions have similar legislation. As with comparable Acts in other jurisdictions, the NSW *Disability Services Act* contains objects, principles and applications of principles that people with disabilities have the same basic human rights as other members of the community. Among the Act's objects are principles to assist people with a disability to integrate into the community, achieve increased independence and access employment.[37]

5.28 Examples of Commonwealth and State and Territory departments which deal specifically with issues that affect people with disabilities, including children and young people are: the Commonwealth Department of Family and Community Services; Disability Services Queensland; the Western Australian Disability Services Commission; the Department of Ageing, Disability and Home Care, NSW; and the Department of Health and Community Services in the Northern Territory.

United Nations Convention on the Rights of the Child

5.29 The United Nations Convention on the Rights of the Child, provides an international framework for the treatment of children and young people with disabilities. Included in its principles are the following:

5.30 Article 23.1 of the Convention provides that children with a disability should:

> enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.

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[35] Department of Family and Community Services (FaCS), 'Commonwealth State Territory Disability Agreement', *Factsheet*, 30 July 2004 – www.facs.gov.au

[36] Australian Institute of Health and Welfare (AIHW), 'Disability and disability services', *Australia's Welfare 2003*, Canberra, 2003, p.358.

[37] New South Wales Law Reform Commission 1999, pp.8-9, 17.

5.31 Article 23.2 recognises the right of a child with a disability to special care, and shall encourage and ensure the extension of appropriate assistance to the child and those responsible for his or her care. Under Article 23.3 such assistance should be designed to:

> ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

5.32 People With Disability Australia (PWD) has pointed out that the UN Convention has not been wholly incorporated into domestic law in Australia.[38]

State and territory disability departments' programs

5.33 The following information provides some examples of the role of government departments and their programs for children with disabilities.

5.34 State and Territory Acts are administered by relevant government agencies. In NSW under the DSA, services to people with a disability, including those delivered by non-government agencies, have been administered and funded by the Department of Ageing, Disability and Home Care. The department has funded services that include accommodation support such as large residential services, hostels, group homes and alternative placements and community supports related to early intervention, independent living and transition from school to adult community living.[39]

5.35 In Victoria, the first Disability-funded family placement programs, Shared Family Care and the IDS Permanent Care Initiative, were established in 1987-88 and were subsequently expanded. Provided through the State's generic foster care and permanent care programs, these programs represent a compromise between a generic and a specialist model of service. In 1995-1996, the Family Options program, for children with disabilities and high daily support needs was established, funded through the 100 Places initiatives supplemented by CSDA funds. Placements have been accessed through the Department of Human Services' regional offices.[40]

5.36 The Queensland Government submitted details of its long-term reform policies and responses for children with a disability and complex and high-support needs, to help children remain with their families. Through Disability Services Queensland's Family Support Program, it supports over 480 families with a child with a disability who has complex and high-support needs. Included in the Queensland Government's key responses are:

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[38] *Submission* 165, p.22 (People with Disability Australia Inc).

[39] New South Wales Law Reform Commission 1999, pp.10-11.

[40] Gordon 1999, p.226.

- a research paper commissioned by Disability Services Queensland in 1996 to investigate best practice in supporting families long term as a preventative measure to placing children with a disability into State care;
- the introduction of the Family Support Program in July 1999 to support families including with discretionary funding, to continue to care for a child with a disability with high and complex support needs (where they might otherwise be relinquished into the care of the State department); and
- the development of a Quality framework in 1999 and an ongoing commitment to best practice within all its services to children and adults with a disability, both direct and funded. A key commitment in the Future Directions for Disability Services 2003-2007 has been the provision of a further $83 million over four years to improve services to children and adults with a disability.[41]

5.37 The Queensland Commissioner for Children and Young People assists children and young people who have a disability, including via advocacy, and monitoring and reviewing laws, policies and practices, particularly for children and young people in institutional care. Under the Commission's Community Visitor Program, 24 community visitors State wide visit children in out-of-home facilities such as youth detention centres and authorised mental health services.[42]

Issues raised in the inquiry

5.38 As noted in various reports including *Forgotten Australians*, institutional care for children has been very unsatisfactory. A number of submissions were critical of the treatment and care received by many children with disabilities in institutions:

> Institutional settings [are]…the site of almost unbelievable levels of abuse and neglect of children and young people with disability. Apart from this, institutional care by its very nature is utterly incapable of meeting the emotional and developmental needs of children and young people.[43]
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> Children…have experienced unsafe, improper and unlawful treatment in these institutions. They have experienced long-term social and economic consequences as a result of the neglect and abuse that has been part of their everyday lives, and they certainly continue to experience human anguish resulting from that neglect in care.[44]

5.39 Evidence cited many examples of inadequacies with institutions and associated situations for the placement of children and young people with disabilities including:

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[41] *Submission* 125, pp.7-8 (Queensland Government).

[42] *Submission* 72, pp.1-2 (Queensland Commission for Children and Young People).

[43] *Submission* 165, p.1 (People With Disability Australia Inc).

[44] *Committee Hansard* 4.2.04, p.74 (Family Advocacy).

- many institutions for children and young people with disabilities have served as 'attractive' places where people who prey on vulnerable children can do so;[45]
- despite moves to smaller community settings, many children with disabilities continue to live for long periods in congregate care environments such as group homes, psychiatric facilities, and juvenile justice detention centres, and hospitals, where they are likely to be abused and taken advantage of;[46]
- children with non-acute illnesses are often not viewed by authorities as requiring a mental health service and therefore not assisted to successfully live with their families or helped to stem their illnesses, often resulting in self-harming behaviour;
- the system is often unable to effectively treat and assist children with a dual diagnosis such as an intellectual disability and a mental illness;
- children with acute illness are often placed in adult units where they can be at risk of harm and not given appropriate care;
- a lack of after-care options and services exists to the point where government departments often place children and young people with challenging behaviour in inappropriate institutions such as juvenile justice centres which do not have the capacity to meet the child's needs;
- there are difficulties in recruiting suitably-qualified staff to care for children and young people with disabilities, attributable to reasons that include a preference of some carers not to work in disability areas;
- there is a lack of degree courses or other training programs that would equip staff with skills to work in this area;[47]
- problems are occurring for children living at home because of a lack of specialist services including speech pathology and respite and school-based therapy. This often results in family breakdown, dysfunction and crisis, with the only option for children becoming the out-of-home care system.[48]

5.40 Groups such as PWD presented evidence to show that children with disabilities from an indigenous background have a greater potential for disadvantage and vulnerability than other children and are over represented in all welfare statistics.[49]

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[45] *Submission* 77, p.7 (Disability Council of NSW).

[46] *Submission* 77, pp.4-5 (Disability Council of NSW); *Submission* 165, p.14 (People With Disability Australia Inc).

[47] *Submission* 165, p.16 (People With Disability Australia Inc); *Committee Hansard* 4.2.04, pp.58-59 (CREATE Foundation); *Submission* 77, p.12 (Disability Council of NSW); *Committee Hansard* 4.2.04, pp.83-84 (People With Disability Australia Inc).

[48] *Submission* 165, pp.11-12 (People With Disability Australia Inc).

[49] *Submission* 165, p.20 (People With Disability Australia Inc).

Standards and laws in practice

5.41 Governments and families have a wide array of responsibilities towards children with disabilities. The legal framework in which policies operate include those relating to monitoring a child's living arrangements, legal guardianship issues for a child in out-of-home care and situations where parents relinquish guardianship. For instance, the Australian legal system offers an option (appropriate in some instances), of voluntary relinquishments of guardianship by parent/s to a third party through the Family Court's processes and legal framework.[50]

5.42 Many services which allocate government funds to service providers for programs require a compliance with standards. The Disability Services Commission of Western Australia cited guidelines which apply to respite support programs funded through Western Australia's Local Area Coordination Program, including those for monitoring and supervision, mandatory reporting of suspected abuse and neglect and liaison with that State's Department for Community Development. The WA Disability Services Commission's care and protection policies apply to its staff and include reporting mechanisms for allegations or concerns about a child with a disability, interagency protocols regarding child protection and a wide range of other standards and policies including those for privacy, complaints and disputes, consumer protection from abuse, neglect and exploitation and police clearances for agency staff, volunteers and board members.[51] Comparable agencies in other jurisdictions have similar standards and requirements.

5.43 The Committee was advised of inadequacies in Australia's laws to protect children and young people with disabilities, ranging from an inherent bias against people with disabilities to more tangible aspects that laws are being ignored or not enforced. An underlying area of concern is that people with a disability often find it difficult to access competent legal advice and advocacy because of the lack of specialist expertise in the disability area and the prohibitive costs of lawyers' fees.[52]

5.44 It was argued that children and young people with disabilities experience extra disadvantages within the Australian legal system. For instance, often they are simply not believed when they allege abuse, or, the incident may not be treated seriously. As the Australian Law Reform Commission noted:

> …children with disabilities may be particularly disadvantaged within the legal system, including an inability to communicate, susceptibility to manipulation (particularly in the context of questioning and investigations)

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[50] Gordon 1999, pp.228, 230.

[51] *Submission* 84, pp.4-6 (Disability Services Commission WA).

[52] *Submission* 165, p.25 (People With Disability Australia Inc).

> and barriers to participation based on stereotypes of their abilities to participate.[53]

5.45 In describing the outcome after an 11-year-old Down Syndrome girl had been sexually abused by a man, one group of experienced carers wrote to the Committee:

> Needless to say, no-one is ever arrested or charged when the victim is disabled.[54]

5.46 Some organisations emphasised that the standards that apply to children and young people with disabilities in institutional care have been developed for adults, not children:

> …so staff who work there may work to the standards or try to run their service to the standards, but those standards do not take into account the particular emotional and developmental needs of children and young people…those services cannot cater to the needs of children and young people.[55]
>
> Standards have not been developed with children and young people with a disability in mind and they are often seen as mini adults with deficits, rather than as children who have some additional needs.[56]

5.47 Evidence also suggested that often discrimination against people with disabilities occurs, 'in a covert and insidious way':

> A sort of Clayton's discrimination…I refer particularly to state-based legislation: privacy legislation, occupational health and safety legislation, workers' compensation, funding formulae for education of difficult and disabled school children etc…imbedded in many types of legislation are latent discriminatory features which make the care of children in institutions difficult and giving rise to circumstances which are not in their best interests.[57]

5.48 A 1999 NSW Law Reform Commission review of the NSW *Disability Services Act 1993* found inadequacies in the Act's coverage. The review noted that while children under the age of 18 years were living in large residential centres in that State and the department funded services and supports for children with a disability, the Act contained no specific provisions about children nor did its principles and application of principles specifically mention children. The Commission noted:

> They do not address the issue of the participation of children and their parents as consumers of services. There are no special standards for

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[53] Australian Law Reform Commission (ALRC), *Seen and heard: priority for children in the legal process*, Report No. 84, Human Rights and Equal Opportunity Commission, 1997, p.109.

[54] *Submission* 220, p.2.

[55] *Committee Hansard* 4.2.04, p.85 (People With Disability Australia Inc).

[56] *Committee Hansard* 4.2.04, p.85 (Family Advocacy).

[57] *Submission* 502, p.7.

> organisations that provide accommodation or other support for children with a disability.[58]

5.49 Evidence has noted that in NSW 'anybody can put up a shingle and call themselves a disability service provider' and that standards and policies are not applied as such because of no systematic independent way of accrediting agencies against those standards.[59] The Disability Services Commission of Western Australia noted that the WA *Disabilities Services Act 1993* does not provide specifically for the establishment or licensing of any government or non-government institutions, or foster practices to provide care and/or education for children.[60]

5.50 While acknowledging shortcomings in Australia's mainstream child protection system, some organisations considered that its best interests for children approach is better than what the disability service system offers. They emphasised that under the relevant legislation there is no monitoring of the 'best interests' of the child or focus on restoring the children to a family or alternate family, and no framework of permanency planning.[61] Family Advocacy explained the lack of legislative protection for children with disabilities placed voluntarily in NSW institutions rather than via the State's care and protection system:

> There are two pathways into care. There is the court-ordered care that leads children and young people into the child protection system. Whilst the safeguards for young people in out-of-home care through the child protection system are less than adequate, children with disability do not get the same levels of protection.[62]

5.51 Family Advocacy noted that under the NSW *Children and Young Persons (Care and Protection) Act 1998*, review and monitoring processes apply to children and young people in out-of-home care who are under a children's court, care and protection order under s.150 of the Act. Arrangements for children in voluntary out-of-home care for extended periods are outlined in ss.155 and 156, though these sections have not been proclaimed. While children in out-of-home care via a court order have the legislative protection of the Children's Guardian, those placed 'voluntarily' do not have such safeguards, resulting in situations where children may be experiencing protracted, unplanned periods in care without any legislative review safeguards. Many children with disabilities have been in institutions long term, where their needs are not met and parental contact has been severed. These children have no 'child specific' authority to assume guardianship, exercise parental responsibility or focus on their best interests. In other words, because disability services are not

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[58] New South Wales Law Reform Commission 1999, p.120.

[59] *Committee Hansard* 4.2.04, p.84 (People With Disability Australia Inc).

[60] *Submission* 84, p.3 (Disability Services Commission WA).

[61] *Committee Hansard* 4.2.04, p.75 (Family Advocacy); *Submission* 165, p.8 (People With Disability Australia Inc).

[62] *Committee Hansard* 4.2.04, p.75 (Family Advocacy).

included in the definition of 'designated agencies' under s.139 of the Act, such agencies are not required to be accredited by the Children's Guardian or comply with government standards and accreditation standards and processes.[63]

5.52 The Committee was further advised that some provisions and standards of the NSW *Disability Services Act 1993* are not being met, including that:

> in New South Wales a number of disability service families have been found not to meet even minimum legislative requirements of the *Disability Services Act 1993* and some operate outside this legislation
>
> a large number of abuse in care cases occur particularly regarding physical and sexual assault and these constitute breaches of criminal law
>
> policies, standards and guidelines to assist services comply with legislation, such as Disability Service Standards, are not being met, or they are being contravened.[64]

5.53 In addition, comments were received that many programs for children in NSW under the State's care and protection legislation, do not benefit children and young people with disabilities:

> There are some specific after-care programs that have been developed, for example in New South Wales under our new *Children and Young Persons (Care and Protection) Act 1998* but, by and large, they address the general population of children and young people and do not address the specific issues that confront young people with developmental disability, intellectual disability for example, or perhaps mental health conditions when they are leaving care.[65]

5.54 Of further concern is the lack of adherence to the law regarding the placement of indigenous children with disabilities as noted by PWD:

> a review of 850 transition plans as required by the DSA for indigenous people with disabilities has shown no plans to address the issue of restoring Aboriginal children with a disability to their families or to find a suitable permanent placement with their extended family or the community.[66]

5.55 Various submissions detailed instances of abuse of children and young people with disabilities in various settings. The parents of a young person with disabilities who had been the subject of serious sexual abuse in a care facility, expressed concern that the Queensland Commissioner for Children and Young People is powerless to do

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[63] *Submission* 60 (Family Advocacy, pp.1-2 additional information).

[64] *Submission* 165, p.21 (People With Disability Australia Inc).

[65] *Committee Hansard* 4.2.04, p.77 (People With Disability Australia Inc).

[66] *Submission* 165, p.21 (People With Disability Australia Inc).

anything and that it 'would appear' that Disability Services Queensland (DSQ) is in a similarly powerless position.[67]

5.56 However, there appears to be little or no formally-reported evidence of any abuse of children with disabilities in care, as the following excerpts show:

> The Department of Community Services (DoCS) has a statutory responsibility for responding to reports of child abuse in NSW and the Ombudsman is responsible for overseeing investigations of child abuse against employees of designated agencies, which includes employees of disability services institutions. There is little evidence that reports of abuse in institutions, by staff or other residents are received and/or acted upon by DoCS;[68]
>
> of 125 mandatory reports reviewed dating back to 1999 in Western Australia, there was no evidence of service provider involvement in unsafe, improper or unlawful care or treatment or of any occurrences of serious breach of any relevant statutory obligation to children under the age of 13 years in care.[69]

Problems with deinstitutionalisation

5.57 It has been noted that deinstitutionalisation in itself does not necessarily guarantee better care or quality of life for children with disabilities. Some of its desired aims such as more independence and life choices have not always come to fruition, for reasons that include:

- despite being in the community, group homes do not mean greater participation in community activities, better quality care or necessarily that individuals have their needs met or are protected from abuse and neglect; an incompatibility of residents often leads to injury, aggression, hostility, threats, intimidation and fear;[70]
- often children and young people with a disability are being abused in community settings;[71]
- the monitoring of residents' activities processes and support systems that are necessary to enable deinstitutionalisation to work effectively, are not necessarily occurring. Various studies have shown that group homes are not

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[67] *Confidential Submission* 91, p.13.

[68] *Submission* 77, p.9 (Disability Council of NSW).

[69] *Submission* 84, p.4 (Disability Services Commission WA).

[70] *Submission* 165, p.10 (People With Disability Australia Inc), quoting Audit Office of NSW, Performance Audit Report: Ageing and Disability Department, *Group homes for people with disabilities in NSW*, 2000, p.30.

[71] *Submission* 165, p.20 (People With Disability Australia Inc).

suitable for many people and that family environments are the most apt for children and young people with disabilities;[72]

- children and young people with disabilities are being placed in homes where many residents have complex and high support needs. This has created mini institutions and not enabled people with a disability to move into a better quality of life as members of the community.[73]

Family care (permanency planning) versus institutional care

5.58 Proponents of permanency planning maintain that a child needs to live virtually full time with one family, to gain emotional security and personal identity. However, co-parenting can work well and there are examples of successful long-term stable arrangements among a range of networks, as often demonstrated in today's world of blended families. Residential schools are common in the United Kingdom and in some parts of the United States, with close family involvement, or regular residential services for people with disabilities.

5.59 Some evidence, while noting the closure of many large institutions occurred 'with good reason', also reminded of the importance of considering the impact of the deinstitutionalisation on the person and families. A view was put by a parent of a severely-intellectually disabled child that contemporary ideology which promotes 'that the best place for children with a disability is with their family, supported by services from within the local community to meet their particular needs', rings as hollow as any populist slogan. This parent advised that:

> Because of the almost non-existent support to families of children with difficult behaviour or disabilities…the 'inclusionist' ideology has led to many families becoming institutionalised. It has increased the new 'mini-institution' the family home. Of great concern is that these 'mini-institutions', these families, are invisible to the policymakers and ideologues. Their isolation and loneliness is not factored into policy because they neither have the time nor the energy to agitate and be heard…this holds true for most families who have the difficult task of not only meeting the challenges of life in the modern world, paying the mortgage, meeting expectations/commitments of work and relationships as well as raising children and the special challenges presented by this unique task. Add to this the difficulty of a child with difficulties either medical problems, behaviour problems or a disability and the task of keeping a family in tact seems almost impossible. Is it any wonder these families are endangered.[74]

5.60 The operation of special schools can provide a successful model of care. A number of Sydney parents highly recommended the ethos and practical programs of

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[72] *Committee Hansard* 4.2.04, p.77 (People With Disability Australia Inc).

[73] *Committee Hansard* 4.2.04, p.77 (Family Advocacy).

[74] *Submission* 502, p.7.

Anglicare's Kingsdene Special School, for children who are severely to profoundly intellectually disabled, many of whom cannot speak and have physical disabilities and challenging behaviour. Comprised of group homes and hostels and catering for 25 children aged 10-18 years, the school is jointly funded by the NSW Government, State Disability, the Commonwealth Education Department, Anglicare and parents' contributions. It combines residential living with a typical school setting and operates Monday-Friday during school terms. Children return home for weekends, school holidays and when sick or ill.

5.61 The mother of 13-year-old, Nicholas, who has the 'developmental age of a two-year-old', physically-disabling epilepsy, many autistic tendencies and at times, 'challenging and destructive' behaviour wrote about Kingsdene. She considers the school to be 'a centre of excellence' which 'should be imitated and emulated', describing it as a place where children learn to live life to the best of their ability with their peers and have their potential maximised.[75]

5.62 Nicholas' mother noted that it meets individual needs in an unrestricted fashion so that the needs of children with autistic tendencies who are often affected badly by changed routines can be best met. The school has a diverse physical environment to cater for the needs of varying degrees of disability, 'very well trained' carers and a curriculum providing wide-ranging educational and social activities. The school's ethos is based on ideas about being self-contained while also sharing its facilities to prepare the children for what occurs in the wider community, carried out in a way that can reduce or at least not trigger, the anxieties which can set off a child's aggressive behaviour. Because of the school's emphasis on self care and being aware of appropriate behaviour towards peers and other people, the children are taken into the community where they shop at the local supermarkets and attend restaurants or clubs. In other words, such interactions become a learning process about what happens in the wider community and in their families. As Nicholas' mother noted:

> Since my son commenced at Kingsdene, he is so much happier, he loves going to school, he is with his friends and he is with people who help him control his aggressive behaviour. He is provided with a rigidly structured environment where he knows exactly what is going to happen next and which helps him cope with the world.
>
> He is learning self-control and living within the framework of rules and that consideration of others must be part of his experience. He is happier, more settled and is much better behaved. He is learning life skills, to make a sandwich, a tuna mornay for lunch, pizza, to make a milkshake. He is learning to shop for the ingredients to make these lunches. Bearing in mind all these activities must be supervised for his safety and the safety of others, he is nonetheless learning to live.[76]

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[75] *Submission* 502, pp.1-3.

[76] *Submission* 502, pp.1-3.

5.63 The mother of 12-year-old Charley, who has Angelman Syndrome wrote that her son has the 'intellect of an eight-month old baby' and that he has positive experiences at Kingsdene. She described the facility's lifestyle including its consistent routines, stable 'mini' community that provides a stepping stone for children to learn to cope with spontaneity and a small integrated physical environment where staff can share good or bad days with each other. Charley's mother emphasised the facility's worth in assisting families:

> Parents get a chance to have a normal life during the week. Parents get a chance to spend time with their other kids, taking them to ballet, rugby or swimming, helping them with homework without feeling guilty because they are not attending to the routine they have been given for their disabled child (toileting routine, exercise, etc).[77]

5.64 The school's attributes include a heated swimming pool and play equipment and purpose-built environment to increase the freedom of movement and safety for children who would be restricted in a normal school. Charley's mother emphasised its capacity to help the children create strong friendships among themselves:

> Real, two-way, level friendships. Friendships developed with the 'normal' community are very important but – let's be honest – are unequal and patronising at this severe level of intellectual disability. (You ask any parent what it feels like to see their child greeted by peers with screams of delight and open arms – you just can't beat it).[78]

After-care options and assistance

5.65 Evidence shows a distinct lack of permanency planning and support for children with disabilities when they are discharged from institutions to birth or alternative families. It was said that changes in NSW legislation for children and young people with disabilities that accompanied the introduction of the modern guardianship legislation have resulted in detrimental effects for such children. The Committee was advised that in some cases that occurred because many people who were discharged from guardianship did not fit within certain provisions of the modern guardianship law and as such, were discharged into the general community without support. PWD explained that the effects of children with disability being given no support or assistance with life skills often becomes apparent later in their lives, particularly when they have children and are not equipped to care for their children:

> Where you see this typically is in children's courts where you see parents with intellectual disabilities, who have often spent their entire lives in an institutional setting, struggling to support their children. Mum and dad might both have an intellectual disability and people assume that they are struggling to care for their children because of their intellectual disability. Often the real reason is that they had no parental model that has taught them how to parent children and the support services that they need to be

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[77] *Submission* 503, p.2.

[78] *Submission* 503, p.2.

> effective parents are not available. A parallel can be drawn there with many Aboriginal families who struggle for the same sorts of reasons.[79]

5.66 Other views posited related to Commonwealth programs such as the Supported Accommodation Assistance Program (SAAP).[80] PWD described the program's policies and practices of excluding children because of their disability or stipulating conditions which children with a disability cannot comply, as 'unlawful' under the Commonwealth *Disability Discrimination Act 1992* and State anti-discrimination laws. SAAP has been cited as an area where young people with a disability seek assistance but which does not always meet their needs.[81] SAAP operates in a way that excludes children and young people with a disability from the supports. Such exclusion occurs for a range of reasons including:

- the inability of SAAP workers to deal with the challenging behaviour of many children with a disability which results from previous abuse and neglect. Often, SAAP services call the police to deal with such behaviour, increasing the children's involvement in the juvenile justice system. This is counterproductive given that sector's emphasis on punishment and rehabilitation rather than assessment, intervention and support services;
- because many children with disability in SAAP are not identified as having a disability when they enter the program their specific support needs are not necessarily addressed;
- there is a lack of interagency cooperation that could assist a person with a disability including practice agreements between SAAP and other services;[82]
- no monitoring of children and young people in SAAP occurs because they are not considered to have been in institutional care and it is often unclear whom has responsibility for such children, including in relation to medical treatment.[83]

Measures to support deinstitutionalisation and permanency planning

5.67 In recent years there has been increased awareness of the need for a mix of services to assist people with disabilities. Choices could include group homes, home-based support services and individualised funding packages and cluster housing that could involve various people such as families.

5.68 The Committee is aware of a need for the continued development of community specialised and generic disability services so that intensive family

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[79] *Committee Hansard* 4.2.04, p.78 (People With Disability Australia Inc).

[80] SAAP provides transitional supported accommodation and associated services to help people who are homeless or at risk of homelessness.

[81] *Submission* 165, pp.17, 21 (People With Disability Australia Inc).

[82] *Submission* 165, pp.15-17 (People With Disability Australia Inc).

[83] *Submission* 77, pp.13-14 (Disability Council of NSW).

supports are adequately funded. As well, there is a need to consider what is best for the child and the effects for families of having a child or children with a disability. PWD noted that to a large extent, early intervention can assist in ensuring that a child or young person with a disability does not need to be placed in out-of-home care, an event which is usually accompanied by a crisis which often leaves parents unable to cope and does not necessarily result in a good outcome for the child or the family.[84] A variety of early intervention measures are required including those to ensure that children's educational or development needs can be met within their communities. A number of organisations noted the need for collaborative approaches:

> When we are talking about a primary support system we are talking about the development of family support services that would provide emotional and practical support to families, and the development of clinical services that a family can draw on. In the case that you talk about that means specialised behaviour intervention and support services that can teach families behaviour management skills so that they know how to teach a child who is not able to verbalise other ways to communicate so the frustration does not result in the child lashing out at siblings, perhaps teachers at school or perhaps mum and dad, and a whole range of other components that would be essential to be able to keep kids in families.[85]
>
> The children and families service system must be able to respond to the needs of all children, whether they are from culturally linguistically diverse backgrounds, Aboriginal and Torres Strait Islander backgrounds, or if a child in the family has a disability.[86]

5.69 The Disability Council of NSW emphasised a need for changes to child protection practices so that family preservation becomes the preferred model. It was noted that this would require training for child protection workers including to identify ways to assist parents who find it difficult to care for the child.[87] The Committee noted the positive aspects of a range of practical assistance measures. PWD cited the findings of the NSW Law Reform Commission about a range of basic assistance measures for families with children with disabilities:

> The greatest emphasis should be placed on giving the family the support that it needs to care for the child at home. This is really about very practical interventions like domestic assistance – someone to help with a bit of the housework from time to time. Often the child will generate more washing than other children might…Having some attendant support around mealtimes is often very helpful because the child might take additional time to eat and so forth. Home modifications are often a critical issue. If a child has cerebral palsy or some other significant physical disabilities, young families, especially those in our large cities where housing is a very large

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[84] *Committee Hansard* 4.2.04, p.81 (People With Disability Australia Inc).

[85] *Committee Hansard* 4.2.04, p.81 (People With Disability Australia Inc).

[86] *Submission* 77, p.15 (Disability Council of NSW).

[87] *Submission* 77, p.16 (Disability Council of NSW).

> cost, would benefit from government intervention that would allow them to modify their homes. Then mum would not have to carry a 50-kilo child upstairs and wreck her back.[88]

5.70 Family Advocacy cited an example of institutional care for children with disabilities that works well with permanency planning and support:

> In Queensland, in the early 1990s, there was an institution called Xavier children's nursing home…which housed 54 children and young people with disability who were medically frail and had very high support needs. A policy decision was taken to close that institution on the premise that children belong in families. Under that premise, every one of those children and young people was either returned to their birth family or placed in alternative families who were properly supported, as the birth family was properly supported. There was an assumption that they were children first, a belief that it could work and supports were built up to make it work.
>
> Unfortunately, our experience in New South Wales has not been nearly so positive because there is not a framework of permanency that says, 'Children belong in families and we need to plan for them in a lifelong way'. There is not a system that supports and believes that it can be possible. Therefore, group homes become the mechanism that is developed. But we do have experience even here in Australia that shows it being done successfully, even for children with the highest support needs.[89]

Non-government and government assistance measures

5.71 A number of submissions and evidence cited a range of programs for children with disabilities. For example, the Disability Council of NSW advised that programs such as Family Options, Victoria; Options Coordination, South Australia; and, Melanie's Program in NSW, demonstrate that children with complex medical needs or challenging behaviour can grow up in a family, provided that the right support is available.[90] Catholic Welfare Australia cited Melanie's Program, Sydney, where long-term foster care is provided for children aged 0-12 years who have moderate to severe physical and/or intellectual disabilities.[91]

5.72 Western Australia's Mofflyn described its Family Care Program that provides placements in families for children with severe and/or multiple disabilities in group houses. The program includes assessments of origin families and foster families to ensure positive matching of children, support to assist children as they grow and their needs change and measures to assist origin families cope with their sense of loss and grief and case management including advocacy for carers and children. Mofflyn cited its high success rate for placements, the commitment of carers, positive feedback to

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[88] *Committee Hansard* 4.2.04, p.79 (People With Disability Australia Inc).

[89] *Committee Hansard* 4.2.04, p.78 (Family Advocacy).

[90] *Submission* 77, p.15 (Disability Council of NSW).

[91] *Submission* 71, p.19 (Catholic Welfare Australia).

families and best practice standards about the management of cases and family numbers as indications of the program's positive aspects.[92]

5.73 Family Advocacy pointed to the local support coordination system for disability services which is operating in some Australian States:

> …it builds from the person in the community and it builds their informal networks of support and uses resources in a much more tailored way. Each…individual or family really has a significant control over the ways in which the resources that are targeted for them are used…reviews, including by the Productivity Commission…have shown them to be significant value for money.[93]

5.74 In Western Australia, the Disability Services Commission funds consumers for supports through the Commission's Local Area Coordination program, where supports are individually tailored around specific needs of families and a family member with a disability. Based on voluntary engagements between the family, the person with a disability and its services, the program aims to support families and complement family strengths. The Commission funds and assists with organising a range of in-home or out-of-home options for families where children have a disability, and the options that have been funded include foster care, host family, co-residency models and a limited number of group home situations.[94]

5.75 In Victoria, some children with disabilities needing out-of-home care are placed through mainstream foster care or permanent care programs, and additional support can be provided to caregivers. Many are placed through the specialist Family Options Program, which provides higher levels of support to specifically recruited specialist foster carers.[95]

5.76 In noting its Family Support Program for families with children with disabilities, the Queensland Government cited a 2002 program evaluation which found that many families had developed the capacity to continue with the long-term care of their child in ways which met the needs of the family and the child, thus creating a preventative rather than a crisis intervention approach.[96]

5.77 The advocacy group, PWD, auspices the National Disability Services Abuse and Neglect Hotline, funded by the Commonwealth Department of Family and Community Services. It is an Australia-wide hotline for reporting abuse and neglect of people with disability, including those children who use Commonwealth, State or

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[92] *Submission* 160, p.11 (Mofflyn).

[93] *Committee Hansard* 4.2.04, p.80 (Family Advocacy).

[94] *Submission* 84, pp.2-3 (Disability Services Commission WA).

[95] *Submission* 173, p.16 (Victorian Government).

[96] *Submission* 125, p.8 (Queensland Government).

Territory funded disability services. As noted later in the chapter, the hotline receives information about a wide range of abuse of people with disabilities.[97]

Funding and income supports for children with disabilities

5.78 Under the CSTDA, all Australian governments co-operate to fund and provide disability support services. The third CSTDA covers the five-year period, 2002-2007. While in 2000-2002, governments provided an extra $519 million in response to the unmet need for services, the need for additional resources for early intervention services for children (including aids, equipment and therapy) and for families to have a break from constant caring, remains urgent.[98]

5.79 The Queensland Government submitted that under the Family Support Program for children with disabilities, 2002-2003 funding was $10.2 million and its 2003-2004 Budget provided significant extra funding over four years to support additional families with children with a disability to maintain their family unit.[99]

5.80 Families may receive the non-means tested Carer Allowance (Child) if they look after a child with a disability or severe medical condition. Centrelink uses the Child Disability Assessment Tool to assess medical eligibility for the Allowance by measuring the child's functional ability. A list of severe disabilities and chronic medical conditions allows fast-track entry to the Allowance for children with more severe conditions. Families are eligible to receive the more generous Carer Payment if they provide constant care in their home for one or more children under the age of 16 years with a profound disability or medical condition, and meet the income and assets tests.[100]

Need for apology to children and young people with disabilities

5.81 A number of organisations emphasised the need for an apology to children and adults with disability who have been abused and/or neglected in institutions. PWD suggested that such groups be consulted about any acknowledgment or apology. The organisation considered that such a gesture would only be meaningful if accompanied by a commitment to genuine and immediate deinstitutionalisation in conjunction with intensive family support and family-based programs as well as collaborative interagency services including health, police, education and housing. PWD emphasised that people with disabilities need to be included in any consideration of reparation measures to people who have been in care and should be afforded the same access to opportunities as other people.[101] The Disability Council of NSW saw the

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[97] *Submission* 165, p.5 (People With Disability Australia Inc).

[98] ACROD, 'Children with a disability', *Factsheet*, May 2004, p.2.

[99] *Submission* 125, p.7 (Queensland Government).

[100] ACROD, 'Children with a disability', *Factsheet*, May 2004, p.2.

[101] *Submission* 165, p.24 (People With Disability Australia Inc).

need for an acknowledgment, apology, financial compensation, as well as services such as education, training, counselling and other support as recommended in the Forde Inquiry in Queensland.[102] Issues surrounding the giving of apologies and linking them with positive actions and the provision of services were discussed in chapter 5 of *Forgotten Australians*.[103] A number of churches and agencies have commenced issuing apologies or statements of regret with plans of action to be taken. These are noted in chapter 1 of this report.

Initiatives suggested by organisations

5.82 The Committee received many suggestions on ways to improve the lives of children and young people with disabilities in care, and their families, including evidence which called for the Commonwealth Government to consider overseas initiatives for introduction in Australia. PWD cited the Canadian government's draft national plan of action for children and young people that attempts to achieve this.[104]

5.83 Other recommendations included:

- the appointment by all States and Territories of independent children's commissioners whose functions would include monitoring compliance with the United Nations Convention on the Rights of the Child;[105]
- an incorporation of the Convention's principles into legislation such as the NSW *Disability Services Act 1993;*[106]
- more active Commonwealth involvement in developing social policy and legal and political consciousness of children and young people with disability as children and young people first, and the implementation of national legislation in line with the Convention;[107]
- the appointment of a national children's commissioner to meet Australia's national obligations under the Convention for children with disabilities.[108]

Vulnerability of children and young people with disabilities

5.84 Children and young people with disabilities are vulnerable to all forms of abuse. They are the most likely group in society to be institutionalised yet they are often placed in venues which are the least able to protect them. The abuse of people with disabilities is characteristically invisible and underreported. People with

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[102] *Submission* 77, p.17 (Disability Council of NSW).

[103] *Forgotten Australians* 2004, pp.197-198.

[104] *Committee Hansard* 4.2.04, p.76 (People With Disability Australia Inc).

[105] *Submission* 165, p.25 (People With Disability Australia Inc).

[106] *Submission* 77, pp.18-19 (Disability Council of NSW).

[107] *Committee Hansard* 4.2.04, p.76 (People With Disability Australia Inc).

[108] *Submission* 165, p.25 (People With Disability Australia Inc).

disability generally do not have their complaints taken seriously or have the capacity to bring them to public attention where they might be able to secure help or justice to redress any problems of abuse or neglect. Often an individual's impairment may result in an inability to understand what is occurring and to know who to approach for help. Compounding these factors is that any reporting of abuse against care givers can be difficult given a person's dependence on care givers for their basic needs.[109]

5.85 PWD quoted studies, reports and inquiries from various countries and institutions which identify some aspects of the vulnerability of this group of people:

> abuse and neglect is perpetrated by care workers, including those who prey on vulnerable children
>
> abuse and neglect is sanctioned by inappropriate formal or informal policies and guidelines, such as behaviour management strategies that rely on physical punishment and restraint, timeout and medication
>
> abuse and neglect is a result of the design of the institutional system, which relies on isolated environments, untrained or inadequately trained staff, lack of monitoring or accountability of both staff and the institution and lack of attention to the medical, health, nutritional, developmental and privacy needs of children.[110]

5.86 The Disability Council of NSW argued that emotional abuse from abusive and neglectful environments leaves children growing up without any consistent carers to nurture and affirm their relationships, resulting in them having no power about decisions or choices and being more vulnerable to abuse and 'powerless' in asserting their needs and wishes.[111]

5.87 PWD noted that the Aboriginal Child Placement Principle outlines an order of preference for the placement of Aboriginal children who cannot live with their families so that placements should be within the child's extended family, community or failing that, with other Aboriginal people. PWD advised that despite national recognition of the Principle, it appears to have only limited application and services often fail to provide the necessary support for Aboriginal children with disability to remain in their own communities.[112]

Examples of abuse in care

5.88 The Committee received substantial evidence about abuse of children and young people with disability in out-of-home care, including details of a Community Services Commission (CSC) report of physical and sexual abuse, in institutions for

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[109] *Submission* 165, pp.22,25 (People With Disability Australia Inc).

[110] *Submission* 165, p.10 (People With Disability Australia Inc).

[111] *Submission* 77, p.8 (Disability Council of NSW).

[112] *Submission* 165, p.20 (People With Disability Australia Inc).

children with disability where children could be unsafe and in extreme cases, children died. The CSC noted the behavioural management strategies of some institutions:

> …[in] 1997, Community Visitors noted that the incident report file for a four-year-old resident recorded eight incidences of 'time out' being used for 'naughty or non-compliant' behaviour over a ten-week period. Using what amounts to solitary confinement on such a young child to control behaviour that most four-year-olds exhibit is a serious infringement of human rights.[113]

5.89 Categories of abuse reported to the National Disability Services Abuse and Neglect Hotline have been wide ranging and related to various places such as immigration detention centres, hospitals and mental health facilities and juvenile justice facilities. Cases of abuse have included physical, sexual, psychological, legal and civil, as well as financial abuse.[114] Family Advocacy noted that in NSW, a number of independent, quasi-judicial reports show that in the last few years in some institutions, children 'have starved almost to death and that some of them have died':

> That has occurred because the staff ratios and the staff training have not permitted those children to eat sufficient nutrition to be able to survive.[115]

5.90 A specific example of abuse in care relates to an institution in New Zealand conducted by an Australian group, the St John of God Order:

> Campbell attended from 1966 to 1974…I was increasingly concerned at how withdrawn he became over these years. Also of concern was the dishevelled and grubby state both he and his clothes were at term holidays…He was always very reluctant to return after the holidays and I would literally carry him into the plane and do up the seat belt and walk out leaving him screaming. We weren't allowed to take him back by car from Central Otago where we lived. In hindsight I see that rule as an attempt to keep us at arms length. Never in eight years did one Brother speak longer than two minutes with me and when we took him back after 5 years of him having left Marylands they just didn't want to know him or us which I felt strange at the time!...In late January 1995 I mentioned to Campbell that a certain Br Bernard McGrath was in jail. 'What for?' asked Campbell. I told him for sexual abuse 'did he ever touch you', pause then he replied 'I don't think so'. Eight weeks later he hung himself dressed in 'female clothing' which sexual abuse advisers assure me is indicative of having been abused.[116]

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[113] *Submission* 77, p.7 (Disability Council of NSW), citing Community Services Commission (CSC), *Suffer the children: the Hall for children report*, NSW Government, Sydney, 1997, pp.4-7.

[114] *Submission* 165, p.5 (People With Disability Australia Inc).

[115] *Committee Hansard* 4.2.04, p.83 (Family Advocacy).

[116] *Submission* 288, p.1.

5.91 The Committee notes a recent decision in the Downing Centre Magistrates Court in Sydney to extradite to New Zealand a priest and brother from the Order to face child sex charges arising from allegations of abuse perpetrated during the 1960s and 1970s at the Marylands school in Christchurch which cared for many boys with an intellectual or learning disability. The men were tracked down in Australia after Christchurch authorities began collating complaints from alleged victims in 2002 thereby sparking a full-scale investigation.[117]

5.92 The Order of St John of God has also been the subject of many reports of abuse of children in their institutions in Australia. The Order's homes in Cheltenham and Lilydale, Victoria, were cited as places of substantial abuse of boys with some form of intellectual disability including Down Syndrome, as Broken Rites noted:

> We have received many stories from the former residents of the Cheltenham Home about the operations of a ring of paedophiles who were Brothers in the Order. Allegations have also been made about one or two of the male employees at the home being paedophiles. A second group of callers to Broken Rites have been the parents and relatives of intellectually disabled men who were in residential 'care' at Yarraview. They too were making complaints and allegations about the activities of paedophiles taking place in the eighties. Again the alleged offenders were Brothers in the Order.[118]

5.93 As mentioned, people including children and young people with certain types of disabilities, are often unable to communicate or report any instances of abuse towards them, to anyone who may be able to help them. The Committee received concerning evidence about the abuse of a young Down Syndrome person in a Queensland care facility where he had been placed by his ageing parents, with the financial assistance of a Queensland Government grant. Initially, the young man was very happy and settled in well. His parents had chosen the facility for a number of reasons including that it was small and was able to provide the specialised communication program which had been successful for him.[119]

5.94 Some months after, however, the young person returned home with discernible behavioural changes including being very subdued, withdrawn and lacking his communication and independence skills. He also had substantial health concerns such as infectious sores, gingivitis, psoriasis, problems with his central nervous system and a hearing impairment from being hit across his ear over a long period. He was subsequently diagnosed with Post Traumatic Stress Disorder. His parents found that their son had not only been sexually abused by two alleged paedophiles, one of whom was a volunteer from interstate, but had also been cruelly treated including via regular, inappropriate manipulation to his mouth, tongue and jaw as part of the volunteer's technique to teach him to speak.

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[117] AAP, 'Catholic priest and brother to be extradited to NZ', 14.2.05.

[118] *Submission* 79, p.8 (Broken Rites [Australia] Collective Inc).

[119] *Confidential Submission*, pp.1-2.

5.95 The young man refused to return to the facility. He was so afraid of sleeping alone that he slept on his parents' bedroom floor for seven months, only returning to his bedroom when in the company of his dog. Among the legacies of his time in the facility are a fear, with one exception, of male carers and a refusal to go anywhere near large crowded centres or even to his 'beloved library', for fear of reprisals from the men who abused him and also had threatened harm to his parents.[120]

5.96 Apart from the obvious concerns about paedophiles in the care facility, the young man's parents have highlighted other problems such as the employment of inexperienced people, increased numbers of inmates and a marked decline in attention, and the attempted manipulation of them by management. They also expressed reservations about the government department including its seeming inability to control the use of the funds which it allocated to the facility and its acceptance of the young man's signature on a form, despite that he is not really equipped to sign, particularly concerning given that it related to the expenditure of large sums of government money. They also stated that the care facility had previously been the subject of complaints to the government department including by another child about the same carer, who, it was claimed, 'was now employed by Disability Services Queensland' and that those previous complaints had not been acted upon.[121]

5.97 The Queensland Government provided information on another matter relating to abuse. It advised of investigations in 1993 by the former Criminal Justice Commission into allegations of abuse and neglect of clients in the Basil Stafford Centre, a government-run accommodation and care institution for intellectually disabled people, including children. The investigation uncovered evidence of serious wrongdoing. In March 1995, the Honourable DG Stewart recommended its closure. At the time of the Stewart Inquiry, 17 residents at the centre were children aged under 16 years. The Queensland Government advised that Mr Stewart's recommendations were reviewed first in 2000 and again in 2001; findings did not uncover allegations of maltreatment of children in the centre.[122]

5.98 The Queensland Government also noted investigations into management and service delivery practices of the Cootharinga Society which provides disability services such as accommodation to children and adults. The Government advised that an examination of the services found them to be of a high standard, with no evidence of abuse or neglect of children cared for by the society.[123]

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[120] *Confidential Submission*, pp.1-2, 5.

[121] *Confidential Submission*, pp.8-12.

[122] *Submission* 125, p.6 (Queensland Government).

[123] *Submission* 125, p.7 (Queensland Government).

Conclusion

5.99 There is substantial unmet need for children with disabilities including for those living at home with their families. It can be hard to obtain national figures on the numbers or other information on children and young people with disabilities in out-of-home care, for various reasons including that any material on disability issues tends to be about adults. In can also be difficult to gain a clear picture of the differing responsibilities in the provision of disability services between the Commonwealth and State and Territory governments. A point made by the Western Australian welfare agency, Mofflyn, perhaps best describes this situation:

> There are many services offered to children with disabilities; they tend to be very *ad hoc* and it is difficult to know which agencies are offering which services at any one time.[124]

5.100 The Committee agrees with the view that the lack of services for families with children with disabilities is an abuse in itself especially since such groups have greater needs than the rest of the community for counselling, support with housing, financial management, connections to other services and respite care.[125]

5.101 Further, families and individuals with a child with severe disability face many problems including personal and financial stress, a limited social life, reduced time and energy for other family members, reduced career opportunities, extra demands of school holidays, physical and emotional tiredness and feelings of low esteem.[126] If ever there is a sector in the community that needs assistance it is people, including children and young people with disabilities. However, at times, the system seems stacked against them and they seem to be often overlooked by policymakers. The Disability Council of NSW suggested that it is possible that because of notions developed over time that parents do not need to 'bear the burden' of raising a child with a disability, such children are being overlooked in public policy and community debates.[127] As well, PWD highlighted the difficulties for the disability sector which is competing for resources with other needy areas requiring government assistance.[128]

5.102 The Committee has considered many suggestions put forward on ways to improve the lives of children and young with disabilities and their families and has identified some specific areas of need. These are discussed below.

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[124] *Submission* 160, p.11 (Mofflyn).

[125] *Submission* 160, p.12 (Mofflyn).

[126] Bain 1998, 169, pp.598-600.

[127] *Submission* 77, p.3 (Disability Council of NSW).

[128] *Committee Hansard* 4.2.04, p.81 (People With Disability Australia Inc).

Need for family support and assistance

5.103 There is a need to explore options that could work for families to ensure that they can keep their children, whether that be on a full or part-time basis, perhaps with the assistance of an appropriate small institution. For families, any decision to place their children with disabilities in care is simply a 'no-choice' one, made only after a great deal of personal pain and anguish. Many families do not have any family support; often they have other children to care for; their homes are not set up to care for children with disabilities, and, in many service areas, support is lacking. Realistically, the term 'voluntary' is a misnomer.

5.104 Assistance for families to keep their children at home if they wish is vital. Evidence has served as a reminder of many possibilities or combinations of options which could suit a number of family circumstances. Assistance options might include shared care arrangements such as a mix of houseparents and natural families, combined with support for parents and families to have contact with their children if they wish. Obviously, smaller residential care environments with small numbers of children and young people would be preferred, especially if that allowed for a consistency of adult carers and easy access to a child's or young person's parents and extended family.

5.105 While a family may be happy to have their children at home, the care required is stressful, demanding, labour-intensive, constant, costly, tiring and mostly unacknowledged. A 1993 United States study found that families who placed their child in a residential facility were more likely to continue a high level of contact with their child than did previous generations. Tangible benefits for other family members occurred when the child with disabilities was placed elsewhere, including being able to access better employment and educational opportunities.[129]

5.106 Some parents may want to use group homes with rostered staff particularly if they provide long-term security, have trained staff and allow birth parents influence over decisions about the child's welfare. Rostered staff carers can resist 'burnout' and often develop a familiarity and attachment to the child, even when it is not strongly returned. A successful situation of 'permanency' might be achieved if the child lives in such a home with ongoing contact with their birth family on important issues for the child such as educational and medical matters. However, studies have shown that developmental opportunities claimed for special foster care are unlikely to be realised for children at the lower levels of intellectual functioning.[130]

5.107 Among key issues for permanency planning success are that culturally appropriate services should be provided and that children live with a family most of the time. As mentioned, the use of residential services especially those that provide individualised attention to the child's social-emotional and cognitive development,

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[129] Bain 1998, pp.598-600.

[130] Bain 1998, pp.598-600.

may be just as good as other options such as alternative family care. Certainly, the success of Anglicare's Kingsdene School has demonstrated this theory, and may well be a model worth emulating across Australia.

5.108 There is a need for diversity in the provision of out-of-home care for children and young people with disabilities. Many children and young people can have their needs met by staying with their families, along with support and assistance measures. For some children with high needs, a level of care is required that can only be met by residential care staffed by highly-trained professionals and in that sense there may need to be more in-house care, provided it is properly staffed and staff are monitored. Therefore, a continuum of options and various forms of respite care will be required.

Consideration of legislative and policy issues

5.109 Legislative protection for children in out-of-home and residential care is especially pertinent to children with disabilities as they are more likely than other children to live in voluntary care. The Committee considers that all legislation relating to children and young people with disabilities needs to take account of factors such as the rights of children with disabilities, services required, culture and identity issues, especially for Aboriginal and Torres Strait Islander children and those from non-English-speaking backgrounds and the special needs of children and young people with disability to ensure access to services such as education, health, rehabilitation, transition to employment and opportunities for social integration and individual development. Simply, children and young people with a disability must have the same basic human and legal rights as other children and young people in Australian society.

5.110 The Committee agrees with recommendations put forward that legislative coverage for children with disabilities should apply to care facilities and services where children with a disability reside as well as to advocates and advocacy services.

5.111 In that context also, PWD has noted a need for improvements in aspects of the standards, laws and government policy processes relating to the needs of children and young people with disabilities, including those relating to having: better systems of enforcement regarding complaints and investigative powers; the development of effective cross-government and inter-agency responses to the abuse and neglect of children; research on Aboriginal and Torres Strait Islander children with disability; a comprehensive framework of independent individual and systemic advocacy for children and young people; better education of judiciary and legal profession to ensure consistent understanding and commitment to meeting the needs of children with disability.[131]

5.112 There may well be a need for better collaboration among policymakers conversant with the needs of children with disabilities and Australia's law-making processes, in the day-to-day oversight and administration of the law and for the

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[131] *Submission* 165, p.25 (People With Disability Australia Inc).

assistance of legal practitioners with knowledge of disability issues and a familiarity with the wide-ranging problems for children with disabilities. It may be that training is required to ensure that lawyers and members of the judiciary are more cognisant of the everyday lives of children and young people with a disability and the impact of aspects of legislation and common law decisions on children's lives.

5.113 A review of policies and practices as well as research into the laws, legal framework, practices of the legal profession and judiciary and teaching and courses of university law schools, as they relate to children and young people with disabilities, would be worthwhile. It would be useful to ascertain how the barriers to accessing legal assistance might be broken down for such groups and become better understood for children and young people with disabilities and their families. Such reviews could be conducted in conjunction with other areas of social policy and disciplines.

Deinstitutionalisation assistance

5.114 It is imperative that whatever form deinstitutionalisation take, that the necessary supports are in place to ensure its processes can work. In that sense, policymakers would need to consider ways to make deinstitutionalisation work with the necessary supports for young people in group homes and community settings. Obviously, such situations will require professional staff to ensure that residents of community homes are properly cared for with regular meals, monitoring of activities and in administering medicines and treatment. For children with disabilities, who cannot live with their birth families, it is important that policies be directed to assisting with placements with family environments that recognise childhood needs and where possible, maintain shared care with birth families.

Recommendation 10

5.115 That the State and Territory Governments consider the information in this report and use as a base on which to assist in providing more flexibility in accommodating and caring for children with disabilities, particularly where families can have their children at home. Such considerations would include an examination of a mix of living arrangements such as institutional care combined with options for children to return to families at particular times; week-day residential schools; and other options including various combinations of living at home with families, residential and respite care and foster care, along with a mix of carers and support. Where required, options could include the use of high-level residential care facilities and highly-trained professional staff and with an emphasis on ensuring that where necessary, the quality of care and actions of the staff are monitored.

Recommendation 11

5.116 That State and Territory Governments enlist the expertise of policymakers in disability and other areas of social policy when formulating laws for children and young people with disabilities, so that legislative provisions take account of the special needs of children and young people with disabilities and

are broad ranging in their application, including in relation to residential facilities and services for children with a disability as well as to the actions of advocates and advocacy services.

Recommendation 12

5.117 That the Commonwealth, State and Territory Governments examine ways to break down the barriers to legal assistance for children and young people with disabilities and their families; make the law more easily understood for such groups; and harness the expertise of practitioners in social policy and other disciplines to formulate laws to better serve all people with disabilities.

Recommendation 13

5.118 That the Australian and/or State Law Reform Commissions conduct research among legal practitioners to ascertain their knowledge and expertise in areas of disability and the law. The outcome of such research would highlight the need to introduce measures to educate lawyers so that they are better able to advise clients about laws affecting the lives of people with a disability, particularly in explaining the impact of certain legislative provisions and common law decisions for children and young people with disabilities. Such investigation might also include examining ways to encourage legal practitioners to offer *pro bono* services to children and young people with disabilities, who cannot afford legal fees.

Recommendation 14

5.119 That, where applicable, all jurisdictions amend their *Disability Services Acts* to ensure that terms relating to people with a disability, specifically include children and young persons, as well as adults. This may require additions to legislation to include principles and applications for children and young people with a disability.

Recommendation 15

5.120 That the Commonwealth Government encourage the New South Wales Government to take note of the evidence presented to this inquiry and proclaim ss.155 and 156 of the *Children and Young Persons' (Care & Protection) Act 1998*, so that all children with disabilities in care, including those who have been voluntarily placed, have broad-ranging legislative protection and monitoring of their care.