

COMMUNITY SERVICES COMMISSION



Changing the face of community services

Submission to

Committee on Children and Young People

Inquiry into prescription and use of drugs and medications in children and young people

This submission focuses on issues particular to children and young people living in out-of-home care for reasons of care and protection or living in residential care services for people with a disability.

September 2001

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Executive Summary

This submission focuses on two particular groups of children and young people – those with a disability living in specialist disability accommodation services, and those who are placed in out-of-home care for care and protection reasons. These children and young people face some specific risks and difficulties associated with the use of prescription medication due to their circumstances and characteristics.

The submission draws on information gathered by the Community Services Commission through its various functions, and highlights the range of risks associated with the prescription, administration and management of medication and drugs for children and young people in care settings.

There are various elements of decision making around the use of prescription medications that can be problematic, including obtaining appropriate medical authorisation and ensuring thorough review and monitoring of medical conditions and the effect of prescribed medications. We have noted problems relating to obtaining consent for medical treatment, either due to an absence of policies and procedures or simply poor service practices. In other cases, the unclear legal status of children and young people, particularly those in voluntary care, creates problems in obtaining consent.

The circumstances of being in care poses some particular challenges in ensuring proper administration of prescription medication. Children and young people are unable to manage their own medication, and some care settings involve staff on shifts or changes of caregivers over time. Under these circumstances, accurate record keeping and documentation and clear arrangements for transferring information about medication between caregivers is critical to ensuring appropriate administration of medication. Our work indicates that in some services there are problems with the standard and consistency of documentation about medication and health issues; poor arrangements for the transfer of information about medication; and problems with the actual administration of prescription medication to children and young people.

Some children and young people in care settings have behaviours or physical needs that may result in the use of medication for management, rather than treatment, purposes. Examples include the use of psychotropic / sedative medications to suppress challenging behaviour, and the use of long-acting injectable medications to suppress menstruation in young women with disabilities.

Some of problems surrounding the use of prescription medication for children and young people in care settings are linked to systemic or service-wide issues in the disability services or out-of-home care system. We believe that these systemic issues

need to be addressed in order to promote more appropriate use of prescription medications for children and young people in care. Considerable improvements are required in the arrangements for overall health care management for children and young people in care settings, including the issue of access to specialist medical assessments and treatment. We have previously recommended specific strategies for promoting co-ordination of services needed to promote effective health care management. We also identify some opportunities for improving the accountability and monitoring of medication use and medical treatment of children and young people in care settings. The lack of continuity of care for children and young people, particularly those in the out-of-home care system, creates particular challenges in health care and medication management, as does the absence of any standard competency requirement for caregivers responsible for children and young people in care settings. Our submission suggests a number of areas where greater policy and practice guidance, and options for promoting the development of staff competencies are needed.

1. The Community Services Commission

1.1 Community Services Commission's functions

The Community Services Commission (the Commission) is an independent statutory authority established under the *Community Services (Complaints, Reviews and Monitoring) Act 1993 (CRAMA)*. The CRAMA provides the Commission with a range of functions aimed at promoting the rights of consumers of community services, including:

- to review the situation of a person in care (S11);
- to receive, resolve or investigate complaints in relation to unreasonable conduct of a community service provider (S12 & S23);
- to inquire into matters affecting service providers and persons receiving, or eligible to receive, community services (S83);
- to co-ordinate a state-wide Community Visitors scheme which monitors accommodation services, including those provided to people with disabilities and children in care (S9); and
- to co-ordinate the Disability Death Review Team (DDRT) who monitor, review and inquire into the deaths of people with disabilities in residential centre. The DDRT was established in 1998.

The Commission's services are for consumers who are receiving or who are eligible to receive community services provided by the NSW Departments of Community Services (DoCS), Ageing, Disability and Home Care (ADHC), and any other non-government services receiving funding from the Minister for Disability Services, Ageing and Community Services. The Commission's target group therefore covers children and young people in need of care and protection and placed in out-of-home care; and children and young people with disabilities who are provided residential services through government and non-government organisations. These consumers can be especially vulnerable because of their age, capacity or personal circumstances.

1.2 The Commission's interest in the inquiry

We are particularly concerned about two groups of children and young people – those placed in out-of-home care for care and protection reasons; and children and young people with a disability who are not living with their parents.

The views expressed in this submission have been developed following analysis of information held by the Commission relating to the provision of services to children

and young people. This includes information from published and unpublished investigations and inquiries, as well as unpublished work from other functions including reviews of children in care; reviews of the deaths of children with disabilities in disability accommodation services; complaints data; and reports from Community Visitors (see Appendix 1 for more details).

The Commission's work highlights the range of risks associated with the prescription, administration and management of medication and drugs, and, by association, concerns about overall health care for children and young people in care. The aim of our submission is to inform the Parliamentary Committee for Children and Young People of the impact of these issues on this specific group of children whose characteristics and circumstances increase their vulnerability to problems associated with the use of prescription medication.

2. Context

2.1 Out-of-home care for children and young people in need of care and protection

2.1.1 What is out-of-home care

Out-of-home care is the residential care and control of a child or young person who is not living with their family of origin. Out-of-home care services are provided directly by the government, through the Department of Community Services, as well as by non-government agencies. Out-of-home care placements include foster care and residential care providing short and long term services, and are an integral part of the system providing care and protection for children who are unable to remain with their own families for reasons of abuse or neglect.

At 30 June 2000 8,517 children aged between 0 and 17 years old were in care in NSW. Of these children 2,145 were of Aboriginal or Torres Strait Islander background. Just over a third of all children were in care on a long-term basis (Department of Community Services Annual Report 1999-2000). Eight per cent of wards were recorded as having a disability (DoCS ISCD 2000 in Community Services Commission 2000a, pp.60).

The vast majority of children and young people are placed in family type arrangements, with 40.2 per cent with extended family or kin, 31.4 per cent in foster care, and a further 10.8 per cent with non-related family. A smaller proportion of children and young people (4.3 percent) are placed in non-family settings including supported accommodation, residential care and family group homes (Department of Community Services 2000a).

2.1.2 Why this group requires special consideration in the context of this inquiry.

The Commission's Inquiry into Substitute Care, conducted in 2000, found that the substitute care system is characterised by systemic and service delivery problems, too often leaving children and young people vulnerable in a poorly performing system of support and care. Our Inquiry noted that previous studies have found that the health and wellbeing of children and young people in care is affected by systemic and practice problems (Community Services Commission, 2000b).

The current system in NSW struggles to provide many children and young people with appropriate placements that can address their needs. Many children and young people in care experience multiple placements and caregivers, several school

enrolments, placements outside their own communities, poor liaison between the various adults and agencies charged with their care, loss of contact with friends and family. This lack of stability often means that knowledge about the child's medical needs and mental health is lost along the way, making it difficult to manage their physical and emotional health needs. Significant health conditions may be missed or at best noted and diagnosed but not treated, and poor case planning means that health care needs, along with other needs, are not adequately monitored or reviewed (Clare, 2001; Cashmore, et. al. 1994; Community Services Commission, 2000b).

2.1.3 Relevant legislation and standards

Currently policy and practice in out-of-home care is governed by the *Children (Care and Protection) Act 1987* that clearly states that the safety, welfare and well-being of children and young people is paramount. Service provision is guided by the Department of Community Services *NSW Standards for Substitute Care Services* (1998) and the recently revised *Keeping Kids Safe* DoCS Child and Family Handbook.

Imminent changes to out-of-home care are expected early next year (2002) with the proclamation of relevant sections to out-of-home care under the new *Children and Young Persons (Care and Protection) Act 1998*. Under the new legislation, the Office of the Children's Guardian (Children's Guardian) will review all case plans of children under guardianship orders and be responsible for accreditation of out-of-home care services.

2.2 Residential services for children and young people with a disability

2.2.1 What is residential care

Most families care for their child with a disability at home. However, for a variety of reasons alternative care may be required for some children with disabilities. For those children who live away from their families, the specialist disability service system is heavily focused on residential care options, rather than family-like settings.

There are currently 310 children and young people living in disability services in NSW funded or provided by the Department of Ageing, Disability and Home Care. Over 50 of these children and young people are living in large residential settings that accommodate adults with disabilities as well as children.¹ The remainder of the children and young people with disabilities live in group homes or hostels, sometimes accommodating both children and adults.²

¹ In 1999 the government announced its commitment to the devolution of disability residential care services with the devolution of children's services having priority. All children will be moved by 2004.

² Data provided by Department of Ageing, Disability and Home Care, June 2001

2.2.2 Why this group requires special consideration in the context of this inquiry.

Research indicates that people with disabilities experience poor health outcomes, including increased mortality rates, and increased rates of hospitalisation (Beange, Lennox and Parmenter, 1999). People with disabilities face specific health management issues, often involving the use of prescription medication. The Commission has previously noted that certain functional limitations experienced by people with high support needs are risk factors for premature death (2001). It has also been noted that people with developmental disabilities have been over-prescribed psychotropic medications, resulting in serious side-effects, and that there is a need for a rational approach to the use of psychotropic medications for people with developmental disabilities (Einfeld, 1990). People with intellectual disabilities are often subject to polypharmacy practices (the prescription of multiple medications), requiring rigorous monitoring and review. It has been noted that a particular risk faced by people with disabilities is that medications are 'often prescribed at the behest of caregivers', heightening the need for careful monitoring of the effectiveness of medications and any side-effects (Beange, Lennox and Parmenter, 1999).

The Commission's work has found that children with disabilities can be placed in environments that fail to adequately meet their developmental needs (Community Services Commission, 1997; 1998a; 1998b). Poor service practices within care settings can exacerbate existing health risks for children and young people with disabilities.

2.2.3 Relevant legislation and standards

Disability services are governed by the *NSW Disability Services Act 1993 (DSA 1993)*. The NSW Disability Service Standards interpret the 'Principles' and 'Application of the Principles' contained in the *DSA 1993*. The *Standards in Action: practice requirements and guidelines for services funded under the DSA 1993* provide guidelines for service providers. However, there are no specific provisions in the *DSA* or the service standards that relate to the needs of children and young people with disabilities.

Parts of the *Children and Young Persons (Care and Protection) Act 1998* deal with the provision of out-of-home care services, and will cover residential disability services accommodating children, when proclaimed.

3. Decisions about medication

Many children and young people in care, and people with disabilities living in residential care, have multiple and complex health issues and/or challenging behaviour issues that result in the use of medication. The *Children and Young Persons (Care and Protection) Act 1998* requires that all decisions and actions must have the safety, welfare and well-being of the child or young person as the paramount consideration.³ This includes any decisions relating to medical treatment, including the use of medication.

The Commission holds particular concerns about the decision-making processes for medical treatment of children and young people in care settings. For the general population, decisions about medical treatment involve considering the recommendation of a medical practitioner, and the provision of consent.⁴ However, children and young people in care settings may have limited input into decisions about medical treatment, and rely on adult caregivers or guardians to make appropriate decisions regarding their medical treatment.

Consent for medical treatment is an important safeguard, and should only be provided on behalf of children and young people in care settings where the substitute decision maker can be satisfied that the proposed medical treatment is in the best interests of the particular child or young person. For some children with disabilities in long term residential care, their unclear legal status can complicate the issue of consent to medication.

3.1 Medical authorisation

Policy guidelines governing disability residential services and children and young people in out-of-home care require that no medication can be given without a prescription from a medical practitioner. The only exemptions are for a limited range of some 'over the counter' / non-prescription medicines such as mild analgesics; and non-restricted topical agents (Department of Community Services 2000b; Ageing and Disability Department, 1998).

These guidelines are intended to ensure that an appropriately qualified person authorises and oversees the use of particular medications for individuals. However, the provision of a prescription by a medical practitioner is insufficient in itself to ensure appropriate or transparent decisions about the use of medication for

³ s9(1).

⁴ Informed consent means that a person is entitled to be informed of the advantages and disadvantages of what they are being asked to consent to, and possible alternatives.

individual children and young people. The Commission's observations suggest that there is still substantial risk that medications are prescribed for individual children and young people without adequate assessment and clinical justification. Our observations are based on issues raised in complaints, and in our inquiries into particular service providers. For example, one inquiry into a large residential service for children and young adults with disabilities, found that a number of children were prescribed medication listed as being '*not recommended for children*' or where the safety and effectiveness of the drug in children is not established. The medications involved included Mogadon, Clobazam, Prozac and Serenace. There was insufficient documentation to demonstrate the clinical justification for the use of such drugs in young children. A medical opinion provided to the Commission on this matter expressed concerns about the levels of some of the medications, and stressed the need for regular specialist review of such medical treatment (Community Services Commission, 1998a).

In some cases known to the Commission, children and young people have been administered prescription medication without documented authorisation from a medical practitioner. In one residential service for children and adults with disabilities, we found only half the medication charts examined had been authorised by the medical practitioner (Community Services Commission, 2001a, unpublished). In another service for children and adults with disabilities, we found evidence of medications being administered prior to obtaining authorisation from the medical practitioner (Community Services Commission, 1998a). This appears to be a particular risk in relation to *prn* medication prescribed to manage behaviour.⁵

The Commission has observed that some residential services for people with disabilities and out-of-home care services for children and young people rely on the services of only one medical practitioner or specialist for all their clients. Particularly in residential services, it is not unusual for the service provider to arrange a 'visiting medical service' where one medical practitioner regularly attends the service to deal with the health care needs of all residents. In other services, there may be a preferred medical provider, either an individual practitioner or a medical centre that all clients use. While this is generally to ensure convenient access to medical care, such arrangements can also reduce the independence, transparency and rigour of medical treatment decisions, including prescribing medication.

3.2 Consent policies and practices

The *Children and Young Persons (Care and Protection) Act 1998* outlines the consent requirements for medical treatment classified as 'ordinary' (non-surgical and surgical), 'emergency' and 'special'. An authorised caregiver may consent 'ordinary medical treatment'. Special medical treatment (as defined in the Act or in

⁵ *prn* – pro re nata – refers to medications prescribed for use 'as required' rather than according to a predetermined administration schedule

regulations) requires consent from the Guardianship Tribunal, except under certain circumstances. In relation to the use of prescribed medication, the current definition of 'special medical treatment' only covers the administration of long-acting injectable hormonal substances for the purpose of contraception or menstrual management.⁶ There is scope for further types of medical treatment to be defined as 'special' by regulation.⁷

The *Guardianship Act 1987* provides a framework for substitute decision making about medical treatments for adults with disabilities who are unable to provide their own consent. Under this Act, medical treatments are identified in a hierarchy, with different consent requirements for each category, in recognition of the different risks and levels of intrusiveness of different medical treatments.

Children and young people in care would benefit from a clear framework for consent that recognises some of the key medication issues canvassed in this submission. Allocating the responsibility of consent to major treatments to a party who must act in the best interests of the individual is an important safeguard. Medical treatments should be given in association with professional assessment, regular reviews and where appropriate behaviour intervention plans.

Our inquiries into a number of residential services for children and young people with disabilities found a lack of clear guidance to staff about the requirements for consent to medical treatment. In the Commission's view, this lack of guidance contributes to poor consent practices, with medications being prescribed for, and administered to, children and young people without proper written consent for each medication from parents or those with legal responsibility for the individual. Community Visitors have also reported concerns about the absence of documented consents for medical treatment, including the use of prescribed medication.

The mother of a 16-year-old young woman living in a disability accommodation service signed a medical consent form on behalf of her daughter. This consent was sought for the administration of Epilim, Melleril, Valium and Paracetamol (the last two on a *prn* basis). This consent was considered to be valid for twelve months. This arrangement allowed the service to administer, without further consultation with the mother, a range of medications including at least one psychotropic medication for behavioural management, over an extended period and without review.

In some services, medical practitioners and staff relied on a general consent form signed by parents at the time of admitting the child to the residential service,

⁶ S175.

⁷ The draft regulations for the Children and Young Persons (Care and Protection) Act 1998 propose that the use of psychotropic medications for the purpose of managing behaviour be considered 'special medical treatment', but these regulations are yet to be confirmed

sometimes years earlier (*Cram House Inquiry*, 1998a; *Suffer the Children - Hall for Children*, 1997). General consent forms are non-specific in their terms, provide no reference to dosages or timeframes for review. General consent allows a service to administer prescribed medications without requiring staff to obtain written consent from parents for changes in medication. General consents fail to make clear that parents retain guardianship responsibility for their children under the age of 16, unless otherwise determined by the Children's Court (Community Services Commission, 1998a).

3.3 Unclear legal status

Children in voluntary care, including children with disabilities, are particularly at risk of having medical treatment decisions made without consent from an adult who can legally and appropriately make decisions on their behalf. Reasons for this are that in some cases, their legal status is unclear, or caregivers are unaware of the requirements for consent where a child is in voluntary care.

Many children and young people placed voluntarily in disability accommodation services have neither DoCS nor the Children's Court involved in their placement. These children and young people can be extremely vulnerable if they have little or no contact with their parents, but have not been subject to a Court order that reallocates guardianship. There are no mechanisms to ensure their needs are assessed or to monitor the appropriateness of the placement. Often this leaves children and young people with no external scrutiny of their placement and no basis for future monitoring or review. All children and young people residing in non-government accommodation services for 12 months or more should be reviewed to determine whether they are in need of care under s10 of the *Children (Care and Protection) Act 1987*, and to take appropriate action if any child is so identified. However, in practice this is rarely applied (Community Services Commission, 2000a, pp.60).

If the service provider does not have clear guidelines for responding to residents whose legal status is unclear, they cannot ensure that appropriate consent is provided for medication or other medical treatment. The absence of an authorised legal guardian may mean that children and young people are being medicated without appropriate consent, or that they are not being provided with appropriate medical treatment, as highlighted in the example below.

A young girl with multiple disabilities had lived in a disability service for over 10 years, with minimal family contact. Service records indicate that there had been concerns about the child's low weight (5.5kgs at 10 years of age) for at least 6 years. However, neither the service nor the medical practitioner took any action to secure appropriate medical assessment or treatment, on the basis that the parents could not be contacted or were perceived to be disinterested. The service had also

not advised DoCS that the child may be in need of care given the lack of contact with her family.

3.4 Monitoring and review of medication

Inadequate arrangements for the monitoring and review of medication are a particular factor that contributes to the risk of inappropriate use of prescription medication. Our work has highlighted the difficulties in accounting for decisions about changing or continuing prescribed medication regimes in the absence of documented medication reviews. Common problems include poor records about observed side-effects of medication or about the incidence of seizures or behaviour patterns even when medication is prescribed specifically to manage these, and a reliance by medical practitioners on verbal reports from staff and caregivers in reviewing medication regimes.

A young woman with multiple disabilities, who had been living in care for most of her life, had been prescribed Melleril (a psychotropic medication) for many years, although it was not clear why there was continuing use of this medication. According to her client file, she had undergone only one psychiatric review during the 13 years she had been in care and this was because of increasing spasms and possible side effects of the continuing use of Melleril.

In some cases, it is not even possible to ascertain that reviews of medication are conducted at appropriate intervals. This appears to be more of a problem where the required review involves specialists, such as neurologists or psychiatrists. In other cases, where specialists have been involved in determining the medical treatment of children and young people in care settings, it has been difficult to establish whether the specialist advice has been implemented.

4. Administration of medication by non-parental caregivers

Some children and young people in care settings have medical conditions requiring the use of one or more types of prescription medication, sometimes several times a day. The safe and effective use of prescription medication relies on correct administration, accurate record keeping, close monitoring of the effect of medication and regular reviews of medications. The relevant policies of both DoCS and ADHC state that the administration of medicines must be carried out according to the instructions on the pharmacist's label or manufacturers instructions on the container and that records are kept of the use of all medications (Department of Community Services 2000b; ADD, 1998). However, our observations are that prescribed medications are not consistently being administered in the way in which they are prescribed or in a manner that provides sufficient safeguards for consumers. Staff in care settings may be subject to competing priorities and heavy workloads, leading to practices that place the health of residents at risk.

4.1 Administration practices in residential care

Various inquiries, reviews of children with disabilities who have died in care, and reports from Community Visitors have contributed to the Commission's concerns about poor administration practices in residential care settings for children and young people, including those for children and young people with disabilities. Information from these functions suggests a range of poor administration practices by some non-parental caregivers including:

- medications not being given on time;
- the wrong medication being given to residents;
- dosages administered not matching the dosages prescribed in residents file;
- incidents where residents refused medication and therefore missed scheduled dosages;
- medications administered in food, with the risk that it will be eaten by someone else;
- medications being administered prior to any authorisation by a medical practitioner;
- immunisation medications not being kept up to date;
- using other residents to assist with the administration of medication; and
- medication not being stored safely.

Family members of children and young people with disabilities in residential care have also expressed concerns about how medication is administered. In a survey of parents of one residential service, respondents who identified concerns associated with the use of medication raised issues about administration practices, inadequate monitoring of medication, inadequate information to parents about medication, and the lack of staff training in medication issues. One parent said '*the current method of medication dispensing and recording is not proof against confusion or wrong application*' (Community Visitor, 1999, unpublished).

Family members associated with another residential service for children and adults with disabilities told the Commission that the service failed to administer their relative's medication at the prescribed times. The service's response to the family's queries about this was that it was 'convenient' for workers to administer medication to residents all at the same time (Community Services Commission, unpublished 2001a).

4.2 Documentation and record keeping

Poor documentation of medication may result in inaccurate, incomplete or inconsistent records and may contribute to consequent errors in administration. Inadequate records may also impede accurate monitoring and effective follow-up and review. The minimum practice requirements for recording of medication and reviews of medication are outlined in the two Departments' practice guidelines *Standards in Action* (Ageing and Disability Department, 1998) and *Keeping Kids Safe* (Department of Community Services, 2000b).

The Commission's work has raised concerns about poor documentation and record keeping practices. Our inquiries into residential care for people with disabilities, reports from Community Visitors to residential institutions for children and young people in care and DDRT reviews indicate poor documentation practices are occurring in some services. The type of poor practices we have found in medication records include:

- medication not being accurately recorded or logged at the time of administration;
- variations in the type and detail of information recorded about medication;
- medication charts not showing the purpose of prescribed medications;
- administration of *prn* 'over the counter' and *prn* prescribed medications (e.g. Valium) being poorly recorded;
- authorisations and guidelines for medication from the resident's doctor not being documented on file;
- medication charts for residents being filed in other residents files;
- medication charts not being filed chronologically;

- treatment records being dispersed throughout different files and folders, making it difficult to maintain an overview of health care; and
- not all residents having a proper history of childhood immunisation.

In one residential service for people with disabilities, the information about prescribed medication (name and dosage) that was recorded in the resident's personal file, was substantially different to the information recorded in this person's medication chart. We also noted that many records held by this service were undated and sometimes illegible.

Poor record keeping about the administration of medication poses particular risks where there has been a problem, such as when a dosage of medication is missed or incomplete, or where a person is given the wrong medication. If information about medication errors is not recorded, it is less likely that the errors will be brought to the attention of the appropriate manager or medical officer to determine if further follow-up is required.

A child with a disability who lived in a large residential service went through a period of refusing part of his medication (Epilim). Staff did not consistently record when only part of his medication was taken. From his file review there were no records of his drug levels having been tested during this period thus it is not known whether the missed doses of medication led to increased seizures.

The risks associated with poor record keeping about medication are increased when service providers file information about behaviour, health needs and medication of individuals in various places. We have observed that in some disability residential settings, information is recorded in the resident's personal file, resident's medication file, day book and group home diary. The level of detail of information recorded by staff often lacks consistency, and the information is not collated or co-ordinated to provide a comprehensive record of the persons health status and needs. Various DDRT reviews and other work focused on residential services for children and young people with disabilities have highlighted this problem (Community Services Commission: 2000d; and 20001, unpublished). The DDRT in particular, have noted poor record keeping about seizure activity and weight reviews, and poor records about reviews of medication and health conditions, as illustrated in the example below.

A young girl living in a residential service for children with disabilities had poorly controlled epilepsy requiring her to be regularly reviewed by a neurologist. The child died in late December 1998. A review of the care and circumstances prior to her death observed that it was difficult to assess the extent of her epilepsy and how the service monitored her condition, due to poor record keeping. For example, the last notation on her 'Seizure Chart' was in December 1997, yet the

medical officer noted in November 1997, that nursing staff reported that the girl had daily seizures, but this was often unrecorded.

Medical practitioners require accurate and comprehensive records of the administration of medications in order to effectively monitor the use or effectiveness of the existing medication regime or assess required changes. Poor documentation and record-keeping about medication and related health and behavioral issues jeopardises the effectiveness of any medical treatment, and the capacity for accurate and considered decision making about the use of medication.

4.3 Transferring information between caregivers

Documentation and record keeping are particularly important for children and young people who move between settings, whether on a permanent basis or for regular short-term stays in other places. These situations include children and young people going home or to respite settings for short stays, transfer of medication from care settings to school each day, and where children and young people change placements.

Appropriate arrangements for transferring information about medication regimes, and the medication itself, is essential to ensuring that medication is administered appropriately. The quality of information exchange between the parents, staff and young people, and the level of support provided to the child's family during home visit stays, are critical to ensure a person's health care needs are being met.

The DDRT has noted that inappropriate preparation and information transfer about medication and the health of residents may occur prior to short-term visits and transfers, as illustrated in the following example.

One service organised a temporary transfer for some of the children with disabilities to a different group home within the organisation. The documentation sent with the children included information about each child. In relation to medication, the information sheet only directed the new caregivers to administer medication from two different dosette boxes, morning and evening. Medication charts were not provided for the duration of the temporary transfer, which means that no records of medication administration would have been kept for the time the children stayed at the alternate placement.

Similar issues can arise relating to exchange of information about medication and health care between residential centres and schools.

Greg was sent to school when unwell, with the school expressing concern about his deteriorating health. He returned to school the following day. He continued to deteriorate and was admitted to hospital. He died one week later. Greg's mother queried the service

about why her son had been sent to school when he was obviously unwell. There is no evidence that a written information system existed between the service and the school, although at times, embedded in the nursing notes, specific care instructions were provided for Greg's home visits and schooling.

Where children and young people change care placements, poor record keeping and inadequate transition planning arrangements can result in disruptions to health care arrangements, including the administration of medication. This problem has been noted in reviews of children and young people in care, and by Community Visitors. In some cases, it means that current caregivers have no information about why children and young people have been prescribed certain medications. Results of poorly managed moves in care include loss of knowledge about health status and needs, and sudden changes in medication regimes, as the example below illustrates.

Sally is a young girl in state care with high support needs relating to her behaviour and mental health and is prescribed psychotropic medication. Various health professionals were involved in her care, providing assessments and reviews, and participating in case conferences. However, when the service she was living in closed, she was moved to a crisis placement where it appears that the new caregivers did not maintain her medication schedule. The health professionals involved in Sally's care were not consulted or involved in the planning for her move from one service to another, and there appears to have been no transition planning around her medical needs. The lapse in administering her medication resulted in Sally's emotional state deteriorating, followed by an admission to the hospital.

While stable placements are more likely to result in continuous health care, record keeping and documentation are critical to safeguard against a child's medical history and medical treatments being forgotten and thus not appropriately monitored and reviewed. Medical and health care history should also be recorded for the purposes of case planning and life story work.

5. Use of drugs and medication for management purposes

Some children and young people (including those with a disability) may have behaviours or physical needs that may result in the use of medication for management rather than treatment purposes. This includes children and young people who behave in ways that are self-harming, harmful to others or to property. Other examples include the use of medication to suppress or manage menstruation in young women, particularly those with disabilities.

Where children and young people are in care settings there is a risk that decisions about using prescription medication can be influenced by the interests or needs of the caregiver, which might be different to the interests of the individual. We have observed examples of such situations through our complaints handling and inquiries, as well as reports from Community Visitors.

In some cases, the inappropriate environments in which children and young people are placed can exacerbate their challenging behaviour. Management strategies other than medication can be thwarted because of poor client to staff ratios or the lack of adequately trained and experienced staff. Safeguards are needed to ensure that alternative options to medication for management purposes have been considered, that medication decisions are reasonable and in the best interests of the individual child or young person, and that medication is part of an overall management plan for the child or young person.

5.1 Challenging behaviour

5.1.1 Psychotropic / sedative medications and children and young people with disabilities

The use of psychotropic/sedative medications for the purpose of reducing challenging behaviour, particularly in the absence of a psychiatric diagnosis, constitutes chemical restraint. Medication for dealing with challenging behaviour may be prescribed on a *prn* basis or scheduled basis, and involves the use of drugs that affect the central nervous system. The risks associated with the use of chemical restraint include:

- the wide discretion available to caregivers to determine when to administer *prn* medication;
- use of medications that are contra-indicated for children;
- reliance on medication in lieu of other behaviour management strategies;

- side-effects of some psychotropic and sedative medications; and
- the impact of different medications interacting with each other.

The issues associated with the use of psychotropic medication on children and young people have been recognised in guidelines issued by both the Department of Community Services and the Department of Aging Disability and Home Care. *Keeping Kids Safe* states it is important to consider possible alternatives or seek further professional advice rather than use medication as a form of restraint, and that psychotropic medication should only be used after a comprehensive specialist assessment.

The Ageing and Disability Department's *The Positive Approach to Challenging Behaviour: Policy and Guidelines* addresses the use of psychotropic medication in the context of providing disability services. The *Guidelines* state that while any medical practitioner can legally prescribe psychotropic medication, it is advisable to consult a practitioner with expertise and experience in intellectual disability and psychiatry. The *Guidelines* also require that regular review should be undertaken of the effect of medication on target symptoms (Ageing and Disability Department, 1997, pp.88-89).⁸

Reports from Community Visitors and observations from reviews have noted situations where prescription medications have been used to make children and young people easier to manage, including restraining challenging behaviour, particularly through excessive or inappropriate use of *prn* medication. Examples include Community Visitors reporting that file notes refer to *prn* medication being used to 'calm' residents down or to ensure the young person was 'good on outings'. In one of our inquiries into a residential service for children with disabilities, we found that children had been prescribed psychotropic and sedative medication, including Mogadon and Valium, for behavioural purposes. Records showed that staff used *prn* Valium to sedate a child for reasons such as 'refused to go to bed', 'tantrums' and 'unusual nuisance behaviour'. This service did not have any policies or guidelines governing the use of psychotropic / sedative medication for managing challenging behaviour. Our inquiry also found that staff had no expertise in behaviour intervention (Community Services Commission, 1998a).

In another example, there was reported conflict between a caregiver and a school when the school wanted a child's medication dosage increased so the child's behaviour would be easier to manage.

Where psychotropic/sedative medication is being prescribed for the purposes of managing challenging behaviour, it should only be used as part of a broader behaviour management plan detailed in a child or young person's individual case plan. Reviews of people in care, inquiries, and reports from the Community Visitors have shown that medication is often the only strategy for the management of

⁸ ADD's *Standards in Action* do not specifically address psychotropic medication.

challenging (including offending) and self injurious behaviour in residential care. The following example illustrates the failure of the system to address the causes of challenging behaviour, and a reliance on the use of medication.

Joe is a 13 year-old boy with an intellectual disability who was a victim of sexual assault and exhibits sexually inappropriate behaviours. Joe was placed with two other adolescent males with intellectual disabilities who also have challenging behaviours, including aggressive outbursts and sexually inappropriate and offending behaviour. All three were prescribed psychotropic and other medications, including Melleril. The staff in the house were unable to implement any effective behaviour management plans for the boys due to their lack of expertise, and none of the boys were being provided with appropriate interventions.

The lack of rigorous monitoring and review of the use of psychotropic/sedative medications to suppress challenging behaviour can result in ongoing use of medication without adequate clinical justification, or careful consideration of the balance between the need for the medication and side-effects and interactions with other medications. Monitoring and review of medication is particularly important for those children and young people who are prescribed multiple medications. We have found situations where children and young people have been prescribed psychotropic / sedative medication as a short-term measure or during a crisis and because their behaviour settles down the medication is continued, in some cases into their adulthood. Long term use of some forms of medication or the impact of polypharmacy can lead to irreversible side-effects, as illustrated in the example below.

A young boy with a disability and significant challenging behaviour was prescribed multiple medications, including Prozac and Serenace, in an attempt to manage his self-injurious behaviours. During a medical review, a doctor recommended that the use of Serenace be tapered off due to its contribution to restlessness, appetite stimulation and the development of tardive dyskinesia in the longer term. At the time of our review a few years later, this had not occurred and medication remained the primary way of managing this child's self-injurious behaviours.

5.1.2 Children and young people with Attention Deficit and/or Hyperactivity Disorder

Our work has found a significant number of children and young people in care are diagnosed with Attention Deficit Disorder (ADD) and/or Attention Deficit and Hyperactivity Disorder (ADHD). In our survey of files of state wards who had had contact with the juvenile justice system, we found just over one third had been diagnosed as having ADD or conduct disorder (Community Services Commission,

1999a). In a group review of 17 children and young people formerly living in a large residential care service for children in substitute care, we observed that approximately one third were receiving medication prescribed and reviewed by a paediatrician or psychiatrist for ADD or ADHD (Community Services Commission, 1999c, pp.47-51).

In our consultations about issues for children and young people who were at risk of contact with the juvenile justice system, concerns were raised about the extent to which these children were receiving appropriate medication and medical supervision for their ADD or ADHD. Children and young people with ADD or ADHD may find themselves in a 'no-win' situation, where their challenging behaviour may contribute to placement disruption, with resultant difficulties in maintaining continuity of medication regimes. The Commission has found that multiple placements were common among a group of young people in care with Attention Deficit Disorder (Community Services Commission, 1999a). Changes in caregivers and doctors means loss of continuity of care and diffused responsibility for a child's medication and management.

Recent research shows that a large number of children diagnosed with and receiving medication for this condition in NSW are not being adequately monitored, in terms of their changing needs and the possibility of over medication (Community Services Commission, 1999a, pp.28-29). If this is a problem for children living with their parents, then it is likely to be a problem for children in care who may receive inconsistent care and are not subject to regular medical check-ups.

5.2 Menstrual management

Young women with disabilities who are menstruating may present management difficulties for caregivers. In a few instances, the Commission has found young women with disabilities being prescribed contraceptive medication for the purposes of managing or eliminating menstruation. This is a particular concern where alternative options for managing menstruation issues have not been considered, or where there is no valid consent for this treatment. Our inquiry into a residential service for children and young people with disabilities found a number of young women were prescribed Depo-Provera (a long acting injectable menstrual suppressant) or the contraceptive pill. There was no evidence that alternative approaches to menstrual management were discussed within the service or with parents before resorting to chemical suppression. In one case, the records for one young woman stated *'it is to help control her periods so that she may be easier to nurse'*. (Community Services Commission, 1998a). In another situation, a Community Visitor reported that a 12 year-old girl in a residential service was prescribed Depo-Provera after only one menstruation.

6. Use of alcohol and tobacco by children and young people in care

Many children and young people in out-of-home care are grappling with personal histories of family breakdown, neglect and abuse. When in care, some children and young people are further harmed by multiple placements, long stays in institutional settings, disrupted relationships and low family contact. Some young people have told the Commission they get '*really pissed off or angry*' and they participate in unsafe practices such as smoking cigarettes, drinking alcohol, taking amphetamines, heroin, marijuana, sniffing aerosol and lighter fluid. Some young people in care whose situations we have reviewed had developed significant problems with drug and alcohol dependency resulting in hospital admissions, and in a one case, death from an overdose (Community Services Commission, 1999a, 1999b and 1999c).

Young people in care who have contact with the juvenile justice system are particularly likely to be using alcohol or other drugs. A study conducted for the Department of Juvenile Justice showed that approximately one quarter of a sample of 279 young people detained in juvenile justice centers perceived themselves as suffering from a current alcohol or other drug problem. Of the young people in the sample, 90 per cent reported having tried alcohol, tobacco, cannabis and pain relievers; 33 per cent had tried amphetamines; and nineteen per cent had tried heroin (Zibert, Hando and Howard, in Community Services Commission 1999a, pp.27).

Young people in care can also experience difficulties in accessing appropriate services to address their use of drugs and alcohol. Problems include poor assessments and identification of substance abuse issues, and poor casework practices. During the Commission's inquiry into substitute care, we were told that there is a critical lack of inpatient detoxification services for young people, and of drug and alcohol rehabilitation services, particularly in regional areas. Service providers also expressed frustration at the time consuming and ineffective processes for negotiating with drug and alcohol services on behalf of children and young people in care (Community Services Commission, 2000b). Additionally, there is a need for effective interagency work between DoCS, juvenile justice, health and education for those young people in care who abuse drugs and alcohol to ensure a consistent and comprehensive approach to service provision and case planning.

Addressing substance abuse by young people in care is complicated when young people are reluctant or not ready to seek treatment or counselling. The Commission has seen that even when a quit smoking programs are run in residential services, uptake was low (Community Services Commission, 1999b and 1999c).

7. Systemic issues

This section identifies and describes some of the systemic issues emerging from the information available to the Commission about poor or inappropriate medication practices. These observations are drawn from the body of work referred to in previous sections, including inquiries, reviews, complaints and Community Visitor reports. The issues described here are those that warrant attention at a systemic or service-wide level in order to promote more appropriate use of prescription drugs and medication for children and young people in care settings.

7.1 Poor health care management

The problems observed in relation to the use of medication are, in many cases, associated with poor health care management generally. This includes arrangements for overall health management, and access to specialist medical care.

Despite the complex or high health needs of some children and young people in care settings, and the evidence that children and young people in care (including those with disabilities) have poor health outcomes, health care is still not receiving sufficient priority for this group. Indicators of an absence of a structured focus on health care needs for children and young people in care settings include:

- the failure of case plans for children and young people to include health issues;
- failure of service providers to obtain specialist assessments or reviews; and
- problems in co-ordinating health care arrangements (Community Services Commission 1998a; 1999c; and 2000d).

Although it is well documented that children with high support needs are at risk of being poorly nourished and chronically underweight, the adequacy of health care management for this group remains a major concern.

Problems in managing the health care of children and young people in care settings are exacerbated by problems in accessing specialist assessments and support. Numerous Commission reports have noted difficulties experienced by service providers and case workers in ensuring the provision of specialist health services for children and young people in care settings. Our reviews of children with disabilities who have died in care indicate that this appears to be a problem even where the children and young people involved have complex health needs associated with severe levels of disability, and even where they are residing in congregate care settings staffed by nurses. In some instances, recommendations arising from one off

medical reviews have not been implemented, even when these have required urgent attention.

7.2 Lack of continuity in care

Managing the health care needs of children and young people in care settings is challenged by lack of continuity in care arrangements. Continuity in health care can be threatened when children and young people move between placements, or when there is a change in caregivers or health care arrangements within residential settings. The poor documentation and record keeping evident in some care settings substantially exacerbates this risk.

Our work has confirmed that continuity of medical care and counselling services is a significant problem for children and young people who change placements frequently (Community Services Commission, 1999c). Results of disrupted care arrangements include poor monitoring and review of medication and other health issues, loss of knowledge about medical treatment and history, and even failure to administer prescribed medications. We also know that children and young people experiencing multiple placements include those who have intensive support needs, including behavioural difficulties, conduct disorder and mental health issues (Community Services Commission 1999c and 2000c). This group of children and young people are particularly in need of comprehensive health care management to ensure appropriate treatment for their needs.

Foster carers have also reported that some children and young people are placed with them without adequate information about their needs and history, including issues of health care and medication.⁹

7.3 Caregiver training and expertise

In NSW, there are no standard competency requirements for staff and caregivers looking after children and young people in care settings. This means that the skill levels of those providing direct care can vary widely, and training arrangements are ad hoc. Both required skill levels and training arrangements are determined at the discretion of the service provider. We have observed that many residential care workers were untrained or undertrained and inexperienced (Community Services Commission, 1996).

In relation to the use of prescription medication in children and young people in care settings, we are concerned about three particular areas of expertise:

- management of health needs and medical conditions;

⁹ Commission discussions with foster carers 2001, and representations from foster care representatives.

- behaviour intervention; and
- requirements for consent to medical treatment.

This is consistent with a recent review of group homes for people with disabilities that found critical gaps in the training and skills of staff, including in areas such as first aid, behaviour intervention and specialised support (Audit Office of NSW, 2000).

In some of our work, we have noted that even in care settings for children and young people with disabilities, staff may not be provided with basic first aid training, or training in epilepsy management. In such circumstances, there is substantial risk that staff may not be able to detect, or respond appropriately to, critical incidents such as seizures or choking, and subsequent drowning and asphyxiation (Community Services Commission, 2001; 2000d; and 1997). In the specific area of nutrition management of children with disabilities, the lack of training and supervision in feeding techniques, physical positioning and management of swallowing difficulties continues to be a major concern, placing children and young people with disabilities at serious risk of harm.

Lack of training also means that staff may not be able to adequately follow-through on medical treatment regimes, or to monitor the administration and side-effects of prescribed medications.

The lack of adequate training of staff to deal with challenging behaviours of children and young people is an issue we have raised repeatedly as a result of individual reviews, group reviews, investigations and policy work. We recently surveyed providers of out-of-home care and supported accommodation for children and young people and found that 11.4 per cent of respondents provided no training in behaviour intervention for staff or caregivers. The remainder of services reported providing some form of training in general behaviour intervention, but 36 per cent of those who allowed the use of restraint did not provide specific training in the use of restraint (Community Services Commission, 2001c).

The findings from a number of inquiries into services for children and young people with disabilities consistently highlight problems related to the lack of knowledge amongst staff about consent requirements for the use of prescription medication (Community Services Commission 1998a, 1997, 2001a unpublished).

8. The Way Forward

Over the past few years, the Commission has made numerous recommendations to the Department of Community Services and the Department of Ageing, Disability and Home Care that identify directions for developing better systems to promote the health and wellbeing of children and young people in care settings.

At present, there are several processes of reform and policy development that provide opportunities for improving the management of health care, including the use of prescription medication, for children and young people in care settings. These include the new legislative framework for children and young people in care, and its accompanying regulatory and policy guidelines, and the establishment of a Children's Guardian. In the disability area, the current devolution of large residential centres gives priority to moving children and young people with disabilities from institutions into community based placements. The Department of Ageing, Disability and Home Care has also recently moved to address core issues relating to the health and well-being of people with disabilities, through the development of action plans on nutrition and death, and the drafting of a policy on health and wellbeing.

In this section, we summarise some of the key directions for addressing the problems described in our submission.

8.1 Co-ordination and responsibilities

The need for interagency co-ordination and clearly articulated responsibilities and links between services for children and young people in care settings has been identified in various Commission reports (1999a, 1999c, 2000b, and 2000d). Children and young people who are most at risk of inappropriate use of prescription medications and substance abuse are amongst those most in need of a range of co-ordinated services.

Some of the key specialist supports needed in meeting the health care needs of children and young people in care settings include:

- adolescent mental health services;
- mental health services for children and young people with cognitive disabilities;
- drug and alcohol services;
- treatment services for children and young people with Attention Deficit Disorder or Attention Deficit Hyperactivity disorder;

- behavioural assessment and intervention services;
- physiotherapists;
- dental services;
- speech therapists and dieticians in relation to nutritional and feeding practices, particularly for children and young people with severe disabilities; and
- neurologists.

Some specific proposals for improving the co-ordination of services to improve health care management and outcomes for children and young people in care include:

- The development of an integrated framework that defines respective roles and responsibilities for supporting children and young people in substitute care, using the *Interagency Guidelines for Child Protection Intervention* as the model for a whole of government approach (Community Services Commission, 2000b). An overarching framework should also deal with enhancing the capacity, availability and accessibility of preventative health programs for children and young people in care settings.
- The development of inter-departmental agreements for the provision of, and access to, support and other services (Community Services Commission, 1999a). These agreements or guidelines should address access to specialist health services such as child and adolescent mental health, adolescent drug and alcohol services and behaviour intervention support.
- The release and implementation of the policy framework on children and young people with disabilities that is being developed by the Department of Ageing, Disability and Home Care. We are hopeful that the establishment of a policy framework for children with disabilities will address issues of access to health and other specialist services needed to promote appropriate health care management.
- The establishment of multi-disciplinary assessment clinics for children and young people with disabilities and high medical support needs, to provide expert health assessments, screening and reviews. Specialist clinics could play a key role in the co-ordination, referral and follow-up of specialist medical input for those in need of close health care management (Community Services Commission, 2000d).
- The establishment of a cross-agency program for children and young people in care who have challenging behaviours, incorporating services from the Departments of Health, Housing, and Education and Training to provide an

integrated range of supports addressing therapeutic as well as care needs (Community Services Commission, 1999a and 1999c).

8.2 Accountability and monitoring

The problems we have observed with the use and management of prescription medications for children and young people in care settings highlights the need for vigilant monitoring and effective accountability mechanisms. We believe the system of safeguards should include those focused on individual children and young people, as well as those that focus on practices and responsibilities of service providers.

There are a number of new safeguards for individual children and young people in care settings, based on provisions in the *Children and Young Persons (Care and Protection) Act 1998*. We believe that a number of these provisions, if developed and implemented appropriately, could significantly improve the accountability and monitoring of medical treatment.

Some specific proposals for improving accountability and monitoring include:

- Incorporating health care management issues in the review of out-of-home care placements to be conducted by the Children's Guardian and designated agencies, as defined by the *Children and Young People (Care and Protection) Act 1998*.
- Incorporating a review of standards and processes for health care and medication management in the accreditation process for agencies providing out-of-home care.
- Clarifying consent requirements for the use of special medical treatment and certain classes or uses of prescription medication, under regulations to the *Children and Young Person (Care and Protection) Act 1998*.¹⁰
- The introduction of clear guidelines by the Children's Guardian about the exercise of parental responsibility, including consent for some types of medical treatment, for children and young people in care.

8.3 Promoting good practice

8.3.1 Policy and practice guidance

¹⁰ The draft regulations for the *Children and Young Persons (Care and Protection) Act 1998* propose that the use of psychotropic medications for the purpose of managing behaviour be considered 'special medical treatment', but these regulations are yet to be confirmed.

Our work suggests that there are a number of key areas where clear policy and practice guidance for service providers is needed to better protect children and young people from the risks associated with the use of prescription medication. Common themes have emerged from reviewing the deaths of people with disabilities, inquiries into particular service providers, and our policy research, indicating some core areas where greater policy and practice guidance is required.

Specific areas requiring the development of policy and practice guidance include:

- A centralised policy framework to promote the use of appropriate behaviour intervention strategies for children and young people in out-of-home care settings, and to reduce the use of inappropriate or unnecessarily intrusive forms of behaviour management, including the use of psychotropic drugs and medications (Community Services Commission, 2001c).¹¹
- Mechanisms to regulate and guide practices within disability accommodation services in key areas such as record-keeping about medication and health care, management of epilepsy, and the management of self-harming behaviours (Community Services Commission, 2001).
- Improving the focus on identifying and addressing health issues as part of case management to ensure that children and young people in care receive comprehensive and continuous health care management, including comprehensive periodic reviews of prescription medications.
- Guidance to services about identifying children whose legal status needs to be resolved, and about appropriate arrangements for consenting to the use of prescription medications and other medical treatment.

8.3.2 Workforce development

The problems we have observed about staff competencies in relation to the management of medication and health care are indicative of a systemic need for workforce development. As noted in Section 7, the absence of any standard competency requirements for people providing direct support to children and young people in care settings means that there can be considerable variation in the skills of staff and caregivers.

In order to address workforce development issues, the Commission has previously proposed:

- Consideration of pre-entry training and accreditation for those seeking to work in residential settings, using models already established in other industries (Community Services Commission, 1996).

¹¹ Although the *Keeping Kids Safe Handbook* provides some guidance relating to the use of psychotropic medication, there are no specified processes for ensuring compliance with the guidelines.

- an enhanced commitment to training and development to attract and retain quality workers and caregivers for children and young people with high support needs in the out-of-home care system (Community Services Commission, 2000b).

In relation to the specific issues of health and medication management, our work indicates that direct caregivers require training in the following areas:

- behaviour intervention;
- first aid;
- safe and effective use of medication, including monitoring and recording of side-effects and impacts of medications;
- accurate record keeping; and
- case management and casework practices.

9. Conclusion

Children and young people in care settings, including those with disabilities, comprise a highly vulnerable sub-set of the population of children and young people. Although they may experience some of the same problems as other children and young people with the use of prescription medication, they are also subject to additional risks and difficulties due to their circumstances and characteristics.

The issues associated with the use of prescription medication are compounded for some children and young people in care settings because they have more complex health needs, associated with a disability, conduct disorder, or experience of personal trauma. The circumstance of being in a care setting also contributes to the risks of poor medication and health care management, where the care is disrupted or where non-parental caregivers are insufficiently trained or supervised to manage medication regimes. Issues around decision making for medical treatment, including consent and medical authorisation, are also more complicated for children and young people in care settings, than for those whose total care rests with their parents.

Many of the problems we have observed in relation to the use and management of prescription medication for children and young people in care settings are indicative of broader problems in health care management for this group. While some of the problems we have identified in this submission could be addressed through specific changes to practices around the prescription, administration and management of medication, substantial change in the health outcomes for children and young people in care settings will require broader systemic and service-wide improvements.

Glossary

ADD	Ageing and Disability Department, NSW.
ADHC	Department of Ageing, Disability and Home Care, NSW. Previously known as ADD.
CRAMA	<i>Community Services (Complaints, Reviews and Monitoring) Act 1993, NSW.</i>
Disability Services	Large institutional, group homes, hostels and mini residential centres provide residential accommodation to children and young people with disabilities (often they accommodate adults as well) and operate under the <i>DSA 1993</i> .
DoCS	Department of Community Services, NSW.
DSA	<i>Disability Services Act 1993, NSW.</i>
LAC	Looking After Children (case work management tool).
Out-of-home care	Out-of-home care is care provided for a child or young person away from their usual home and by a person who is not their parent or relative. They operate under the <i>Children and Young Persons (Care and Protection) Act 1998</i> . Care provided in situations such as boarding schools and hospitals is not considered as out-of-home care (oohc).
<i>prn</i>	pro re nata - refers to medication that is prescribed for use 'as required' rather than according to a predetermined administration schedule

Bibliography

Ageing and Disability Department 1997 *The Positive Approach to Challenging Behaviour: Policy and Guidelines*, Sydney.

Ageing and Disability Department NSW 1998 *Standards in Action: practice requirements and guidelines for services funded under the Disability Services Act*, Sydney.

Audit Office of NSW 2000 *Group homes for people with disabilities in NSW*, Sydney.

Beange, H., Lennox, N. and Parmenter, T. 1991 'Health targets for people with an intellectual disability' in *Journal of Intellectual and Developmental Disability*, 24(4) pp.283-297.

Cashmore, J., Dolby, R and Brennan, D. 1994 *Systems Abuse Problems and Solutions*. A report of the NSW Child Protection Council. Publication now available at the Commission for Children and Young People, Sydney.

Clare, B. 2001 'Managing the Care Journey: meeting the health needs of children in out-of-home care' in *Children Australia* 26(1).

Community Services Commission 2001 *Disability, death and responsibility of care: a review of the characteristics and circumstances of 211 people with disabilities who died in care between 1991 and 1998 in NSW*, Sydney.

Community Services Commission (2001c) *Choices and Challenges: behaviour intervention and use of restraint in care and supported accommodation services for children and young people*, Sydney.

Community Services Commission (2000a) *Substitute Care in NSW: forwards, backwards, standing still... A Discussion Paper*, Sydney.

Community Services Commission (2000b) *Substitute Care in NSW: new directions – from substitute to supported care. Final Inquiry Report*, Sydney.

Community Services Commission (2000c) *Service Closure Inquiry*, Sydney.

Community Services Commission (2000d) *Critical Event at Grosvenor*, Sydney.

Community Services Commission (2000e) *Inquiry into Substitute Care Practice in a Regional Community Services Centre*, Sydney.

Community Services Commission (2000f) *Community Visitors Annual Report 1999-2000*.

Community Services Commission (1999a) *Just Solutions – state wards and juvenile justice*, Sydney.

Community Services Commission (1999b) *Ormond Investigation Report*, Sydney.

Community Services Commission (1999c) *Group Review- Experiences and progress of 17 young people in substitute care*, Sydney.

Community Services Commission (1999d) *Inquiry into Crime Prevention through Social Support – submission to the Standing Committee on Law and Justice*, Sydney.

Community Services Commission (1998a) *Cram House Inquiry, a service of the Illawarra Society for Crippled Children*, Sydney.

Community Services Commission (1998b) *Respite Care: a system in crisis*, Sydney.

Community Services Commission 1997 *Suffer the Children - Inquiry into The Hall for Children*, Sydney.

Community Services Commission 1996 *Who Cares? Protecting People in Residential Care*, Sydney.

Department of Community Services, NSW (2000a) *Annual Report 1999-2000*.

Department of Community Services, NSW (2000b) *Keeping Kids Safe DoCS Child and Family Handbook*, Sydney.

Department of Community Services, NSW 1998 *NSW Standards for Substitute Care Service*, Sydney

Einfeld, S. 1990 'Guidelines for the use of psychotropic medication in individuals with developmental disabilities' in *Australian and New Zealand Journal of Developmental Disabilities* 16(1) pp.71-73

Guardianship Board 1994 *What is the Guardianship Board? A guide*. Training and Information Branch, Guardianship Board, Sydney.

Guardianship Board (1994b) *Behaviour Management and People with an Intellectual Disability – the role of the Guardianship*. 1994 updated version. Training and Information Branch, Guardianship Board, Sydney.

Law Reform Commission 1999 *Review of the Disability Services Act 1993 (NSW) Report No. 91* NSW Law Reform Commission

Appendix 1: Unpublished Work

- one inquiry into residential services for children and adults with a disability (unpublished 2001a);
- one investigation into residential services for children and adults with a disability (unpublished 1999);
- fourteen reviews of children in care (including children with disabilities) since 1994;
- fourteen reviews conducted by the Disability Death Review Team (DDRT) since 1998;
- complaints data on the issue of medication since 1997;
- results of a survey of parents who have a child with a disability living at a non-government residential service for children, young people and adults with a disability (Community Visitor, 1999); and
- Community Visitors data since 1998.