Sub 60

family
ADVOCACY
Institute for Family Advocacy & Leadership Development Assoc. Inc.

A New South Wales association concerned with the rights and interests of people who have a developmental disability

RECEIVED
31 JUL 2003
Senate Community Affairs Committee

Secretary
Senate Community Affairs References Committee,
Suite S1 59
Parliament House
Canberra ACT 2600

30 July 2003

Dear Sir/ Madam,

Enclosed please find the submission of Family Advocacy to the Senate Community Affairs References Committee Inquiry into children in institutional care.

We are very happy to meet with the Committee to discuss these issues further.

Yours sincerely,

Belinda Epstein-Frisch

Introduction

Family Advocacy is a state-wide advocacy agency which promotes and protects the rights, needs and interests of children and adults with developmental disability in New South Wales. Its mission is:

> *"to attain positive social roles for people with developmental disability through the development of advocacy by families and through strengthening the role, knowledge and influence of the family."*

The organisation has a priority to undertake advocacy on behalf of children and adults with developmental disability who have very high support needs. It has been a leading voice in calling for:

- a No Admissions Policy for large residential centres;
- the closure of all institutions;
- full proclamation of Children and Young Persons' (Care & Protection) Act, 1998;
- the right of children and young people with disability to be embedded in the family, supported by the community;
- flexible 'do whatever it takes' support for families;
- specialist supports for children with disability to be embedded in mainstream children's services;
- inclusive education for children and young people with disability;
- inclusive lives for people with disability.

Overview of Submission

This submission raises issues associated with children and young people with significant disability who live or have lived in government and non government institutions in NSW. It identifies key public and social policy issues that arise from government reports of neglect and abuse over the past 6 years.

The abuse documented in these reports is not new. It was the establishment of a watchdog body in NSW (the Community Services Commission) that provided the authority to inquire into the lives of vulnerable people who had been locked away. Whilst one of the reports overviewed, (the Performance Audit Report) documents large residential centres for adults, a very significant number of the residents entered these institutional setting as small children and are therefore relevant to the Senate Inquiry.

This submission provides an overview and summary of key findings and recommendations of the following reports:

- Community Services Commission, *Suffer the Children, The Hall for Children Report,* March, 1997.
- The Audit Office & Community Services Commission, *Large Residential Centres for People with a Disability in NSW*, June 1997.
- Community Services Commission, *Cram House – Inquiry into care and treatment of residents*, January 1998.
- Community Services Commission, *A Critical Event at the Grosvenor Centre - Review of the Disability Death Review Team of the Critical Event at the Grosvenor Centre,* January 2000
- Community Services Commission, *Young Deaths – Children with Disabilities in Care. A review of the deaths of eight children and young people at the Mannix Children's Centre*, February 2002.

Family Advocacy has limited resources to address all the terms of reference of the Inquiry in relation to children and young people with disability who are or have been in institutional care throughout Australia.

Family Advocacy thereby urges the Senate Community Affairs References Committee to use its resources to inquire more broadly into the issue of institutional care for children and young people with disability.

Institutional care for people with disability in NSW

Up until relatively recent times, children with disability were routinely given into institutional care at birth or soon after, on the advice of doctors. Large scale institutions were the main model of care for people with intellectual or physical disability and people with a psychiatric illness both in Australia and overseas. Such centres provided whole of life care, from birth to death, for residents.

Since the 1960s, institutional models have been considered unable and unsuitable to meet the needs of people with disability.

In NSW, the main State provision of institutional care was through Fifth Schedule Hospitals which were psychiatric hospitals providing services to people with a psychiatric illness and people with intellectual disability. Provision was opened to the non government sector through the establishment of Special Purpose Nursing Homes by the Commonwealth Government.

Commonwealth responsibility

A significant proportion of the institutions identified in this submission were initiated, funded and monitored by the Commonwealth Government. It was only with the first Commonwealth State Disability Agreement (CSDA) in 1991 that the Special Purpose Nursing Homes were handed over to State Governments, often with totally inadequate funding. They were subsequently funded under the Disability Services Program.

Whilst the reports identified in this submission were written after the first CSDA, they document neglect and abuse that had been going on since the commencement of the institutions. Family Advocacy thereby believes that the children and young people who lived and still live in them fall under the terms of reference of this Inquiry.

Snap shot of people with disability living in large and small institutions

In 1997 the Performance Audit Report[1] provided the following summary of disability residential services in NSW. It recorded:

- Over 1 million persons in NSW have some form of disability.
- Approximately 1825 people live in 17 large government residential centres (defined as having a resident population of 20 or more).
- Approximately 563 people live in 30 large non government residential services.
- Approximately 1055 people live in 219 government group homes.
- Approximately 1260 people live in 286 non government group homes.
- Approximately 201 children under the age of 18 live in large residential centres.

---

[1] The Audit Office & Community Services Commission, *Large Residential Centres for People with a Disability in NSW*, June 1997.

A very significant proportion of people with disability enter institutional care as children.

Family Advocacy believes that all children, young people and adults who have been placed in institutional care experience 'long term social and economic consequences of the neglect and abuse that was a part of their daily lives,[2]; all experience 'human anguish arising from the abuse and neglect they suffered while in care'[3].

Key issues that underpin concerns

1. The children and young people with disability lack the rights and safeguards afforded to children without disability.

- UN Charter on the Rights of the Child (CROC) did not apply to these children and young people.
- The NSW Children & Young Persons' (Care & Protection) Act, 1987 did not apply to these children and young people.
- The institutions in which they lived did not have to comply with the standards required for residential care for children and young people without disability.

2. The services in which the children and young people with disability lived and continue to live make no provision for the unique nature of childhood.

- There is no focus or conscious intent to promote attachment and foster relationships.
- There is no provision to experience the ordinary pleasures of childhood.

3. There is a lack of protection to prevent out-of-home care for children and young people with disability.

- Children and young people with disability lack the safeguards afforded to children and young people without disability.
- Children and young people enter care through voluntary placement without any process of review to determine their best interest.
- Children and young people drift into care and remain in care for their entire lives.

4. There is a lack of safeguards to monitor the children and young people with disability while in care.

- There has been no systems for effective monitoring of the services.

---

[2] Term of Reference 1(b)
[3] Term of Reference 1(d)

- There continues to be no monitoring of the children and young people to determine whether decisions are made in their best interests.
- There is no focus on restoration to the family or on finding an alternate family.

5. Institutions are an inappropriate model of care.

- They are built on a medical model.
- There is no framework of Permanency Planning - the framework used for planning for children and young people without disability in need of out-of-home care.
- There is no focus on attachment or conscious effort to build relationships.
- There is no acknowledgement of the right of the child or young person with disability to grow up in a family.

6. There is an inability to meet the additional needs arising from disability

- The reports document the almost complete absence of specialist medical, allied health & nutritional support.

The remainder of this submission provides an overview and photostat of key sections of the named reports.

Name of report: *Suffer the children: The Hall for Children Report*

Author: **Community Services Commission**

Date of report: **March 1997**

Background

Hall for Children was a 60 bed residential service providing institutional care for children and young people with disability in Hazelbrook in the Blue Mountains of NSW. Its residents were aged from 4 to 31, all having entered as children.

The Hall for Children was initially funded by the Commonwealth as a Special Purpose Nursing Home but came under State responsibility under the CSDA to be funded under the Disability Services Program.

Policy Issues identified in the Report include:

1. Key issues identified on p 4-5
2. Lack of closure of services identified as serious risk to children. The Hall for Children was long recognised as having:
    a. the inability to meet the individual needs of residents;
    b. staffing levels that impinged on the service's ability to provide an adequate standard of care;
    c. substandard physical facilities;
    d. inadequate health care and nutrition.
3. Lack of management, accountability and monitoring of performance, both internally and externally.

5. Summary of findings

The main findings of the inquiry are:

1. **The service presents serious risks to, and cannot ensure the safety of, residents.** Five residents have died while in the care of the Hall since 1994 and these deaths raise issues about the quality of care, lack of supervision and need for monitoring. There is an inadequate approach to identifying risks and preventing accidents so that residents often have unexplained injuries, there are incidents of residents swallowing foreign objects such as rubber gloves and paint clippings, and self injurious behaviour is common. Absconding is a constant problem and time out or containment is still used to manage individuals. Staff must work in an environment that presents considerable risks and they often fear for their own safety. Sexual activity between residents is poorly managed through inappropriate strategies, such as putting all or most young women who are menstruating on the contraceptive pill, unless parents object. The risk and incidence of resident to resident sexual assault is also not identified and dealt with appropriately. These serious safety breaches are the result of consistently poor supervision of residents due to inadequate staffing numbers, and an inability to identify risk factors and develop preventative strategies.

2. **The service does not, and as presently configured, cannot meet the individual needs and goals of residents, nor provide them with the support, services and attention they require.** What assessment process exists is of limited value in ensuring that individual needs are met. Staff have few opportunities to acquaint themselves with information on residents and so have little knowledge of individuals' needs. There is very little individualised care and attention provided, as evidenced by such practices as groups of residents sharing one set of toiletries, women who are menstruating wearing nappies to bed, and haircuts being given in the hallway/alcove. Privacy and dignity cannot be assured in any way, resident involvement in decision making rarely happens, and residents can be forced to leave the service with no notice, planning or preparation. It is unlikely that residents feel valued, respected and wanted in such an environment.

3. **Current staffing arrangements seriously impinge on the service's ability to provide an adequate standard of care.** Staff do not need any qualifications or experience to work at the Hall, no police checks are done on potential employees, very little induction is provided to new workers, there is a high reliance on casuals, a high rate of absenteeism, and a high staff turnover. There is little supervision provided, in-service training must be undertaken in staff's own time and many are stressed and upset by their work environment. Measures to protect residents from abuse by staff and to deal appropriately with these incidents when they occur are inadequate. The ratio of residents to staff makes the work extremely difficult, frustrating and dangerous.

4. **Poor physical conditions are a significant contributory factor to the substandard care provided to residents.** The building is in disrepair, with leaks and other problems occurring during wet weather, some of the verandas have been declared unsafe for use, and there is limited recreation/leisure space for residents. A lack of hot water for some residents' showers is an on-going problem that the service appears unable to fix, some toilets continually have no toilet seats, and there are no light fittings in some bedrooms. These, along with shared and dormitory style bedrooms, beds that are too short, and bathrooms that are shabby

and nothing more than concrete cubicles are some of the obvious problems with the physical environment. The location of the service in an isolated and cold area, some distance from community facilities and activities, also contributes to resident discomfort.

5. **The service is unable to meet the programming and skill development needs of residents, particularly for behaviour management.** Staff do not have the skills to deal with residents with difficult behaviour, containment is often used, and what behaviour management strategies are in place are inadequate, with a seeming reliance on medication. Staff are totally consumed by meeting basic care functions so that opportunities for individual attention and skill development are non existent or extremely limited. As a consequence many residents lose skills and become difficult to manage as a result of their time at the Hall.

6. **Health care and nutrition are inadequate.** Medication controls often fail, the service's approach to gaining consent for medication is poor, and there is a lack of even basic health care skills. The food is sometimes of poor quality and lacking in quantity, the service regularly receives food donations, and certain food preparation practices are inadequate and present health risks. There are no comprehensive procedures in place for ensuring that underweight residents receive supplementary nutrition, there is a high risk of rushed meals so that some residents do not get sufficient food, mealtimes are described by staff as chaotic and there is only limited provision of dietary or nutritional advice to some individuals.

7. **Management, accountability and monitoring of performance, both internally and externally, are seriously deficient.** There are only limited means of supporting and supervising staff and ensuring accountability and effective service delivery at all levels. The service does not encourage staff to raise issues of concern and a climate of fear and intimidation appears to prevail. The board's management and oversight of the service is lacking and does not ensure accountability or the achievement of desired outcomes. Policies and procedures in place are inadequate. There are particular concerns around the contract between Oberlin and Kanowna for the provision of administrative services, including the cost of this arrangement, the conditions attached to it, the lack of evaluation of services provided and the potential conflict of interest. Externally, there is currently no systematic and comprehensive system for monitoring the service to ensure that it meets conditions of funding and identified performance measures. There is also no monitoring of those residents at the Hall who may require wardship or guardianship orders, and no involvement of independent advocates or regular external scrutiny, other than through the Community Visitors.

8. **The provision of services by the Hall for Children is not in accordance with NSW Disability Services Standards, the *Disability Services Act 1993* and international human rights instruments.** The findings of this inquiry demonstrate a wide divergence between service provision at the Hall for Children and the principles and requirements, set out in legal and other instruments, relevant to the rights and care of people with disabilities.

9 **Funding for the Hall has been ad hoc, lacking in rationale and transparency, unconnected to performance measures and apparently simply inadequate.** It has not been possible, within the scope of this inquiry, to verify the Hall's claim that it is underfunded in comparison to other, similar services. This is partly because the inquiry focused on issues of safety and quality of care - and partly because there are no directly comparable services. More work needs to be done in this regard. It is clear, however, that funding decisions have been ad hoc and lacking a rational or equitable basis. There is no transparent funding formula,

Name of report: *Performance Audit Report : Large Residential Centres for People with a Disability in NSW*

Author: **The Audit Office & Community Services Commission**

Date of report: **June 1997**

Background

A performance audit into the provision of residential services for people with an intellectual disability was undertaken by The Audit Office (of NSW) and the Community Services Commission. The audit was suggested by the Commission and requested by the Minister for Community Services following the release of the Lachlan Report, which identified poor practices in the large disability residential centre.

The audit was conducted in seven government institutions and three non government institutions, focusing on policies and practices in ten practice areas considered critical to protecting the legal and human rights, safety and dignity of residents and assessed the policies and practices in institutions against these criteria.

The Report identified:

- limited effectiveness of behaviour management;
- inconsistent management of incidents including injuries and assaults;
- failure to meet legal requirements over administration of medication;
- inadequate monitoring of health information to provide timely and appropriate intervention;
- poor community access;
- lack of privacy through dormitory accommodation, open plan bathrooms, common dining and sitting rooms;
- organisation and structure designed to meet the needs of staff and management not the needs of residents;
- very poor safety record;
- no effective procedure for investigating and managing complaints.

Policy Issues identified in the Report include:

1. Key issues identified on p 4-5
2. Impossibility for large residential centres to ever conform to the NSW Disability Services Act, 1993.
3. Requirement for large residential centres to close.

4. Establishment of interim measures to address deficiencies while residents await closure including:
    - a No Admissions Policy to large residential centres;
    - baseline criteria for the protection of residents;
    - resolution of guardianship issues;
    - an effective system of monitoring.

Executive Summary

The Audit

A performance audit into the provision of residential services for people with an intellectual disability was undertaken by The Audit Office with the Community Services Commission. The audit was suggested by the Commission and requested by the Minister for Community Services following the release of the Lachlan Report (which identified poor practices in a large disability residential centre).

The audit reviewed policies and practices in large government and non-government residential centres to determine if policies and practices protected the human and legal rights, safety and dignity of residents.

The audit was conducted in seven government institutions and three non-government institutions.[1,2] The audit focussed attention on ten practice areas considered critical to protecting the legal and human rights, safety and dignity of residents and assessed the policies and practices in institutions against these criteria. Details of audit criteria are provided in Appendix 6.

Moving from Institutions to the Community

There is broad recognition that institutions are outmoded models of care. Successive state governments have indicated a commitment to closure of large residential centres and their substitution with community based facilities. But the population in these institutions remained more or less the same, providing accommodation for approximately 2,388 people with a disability.

There is now the danger that in these institutions, which are marked for transition to community based facilities, the services and protection will continue to decline due to the lack of attention and funding, thus further aggravating the already poor state of affairs. It is for this reason staff in the centres say *"close us down don't run us down."*

---

[1] The term institution has been used in this context to describe large residential accommodation centres for people with an intellectual disability that were viewed as part of the audit.

[2] These institutions provided services which were not in *conformity* with the Objects, Principles and Applications of Principles of the Disability Services Act 1993 and had not received funding to implement transition plans.

Government Policy

Disability Services Act

The NSW Disability Services Act was introduced in 1993 along with ten Disability Service Standards. These Standards are based on an interpretation of the Objects, Principles and Applications of Principles set out in Schedule 1 of the Act (listed in Appendix 4).

The Disability Services Act 1993 requires disability services, whether funded (non-government services) or provided by the Minister for Community Services, to be provided in *conformity* with the Objects, Principles and the Applications of Principles of the Act. Services which do not *conform* are required to prepare a transition plan of strategies to be employed by the service to achieve *full conformity* and the funding required to fully implement the plan.

Large residential centres by their very nature can never provide services in *full conformity* with the Objects, Principles and Applications of Principles of the Act. Transition plans for institutions focus on the process of transferring people with disabilities from the existing facility to community based settings (that comply with the requirements of the Government's Accommodation Support Policy of no more than six residents per dwelling).[3]

However, none of the residential centres visited by audit had received funding to implement transition plans. While awaiting funding, these centres are required to *conform as closely as possible* with the Act.

Service Standards

The Disability Service Standards provide an interpretation of *conformity* with the Act. Disability services that claimed to be providing services which meet the requirements of the Act were assessed against these Standards and the Objects, Principles and Applications of the Principles of the Act.

---

[3] The NSW Accommodation Support Program states that:
It is recognised that in a small number of cases, there might exist circumstances that require the consideration of service configurations which vary slightly from those stated. In such cases, the Minister will consider these special circumstances before deciding whether or not the proposed accommodation support service is eligible for funding under this program. Such special circumstance will be based on the second of Government's fundamental accommodation goals, that persons with disabilities have the right to choose their own lifestyle, as well as have access to the information necessary to allow informed choice. (Ageing and Disability Department *NSW Accommodation Support Program* 1996 page 5).

In contrast, there is no definition, nor measurable criteria for *conforming as closely as possible* until funding for transition is received. Nor are there any criteria which establish the basic requirements for resident safety and protection from abuse. This means that while the Act and the Standards provide measures for the overall quality of service, there are no measures to determine when a centre is simply unacceptable because it is unsafe.

Operational Policies in Government Centres

Policies guide practices. Government centres use the Department of Community Services *Policies for Working with People with Disabilities,* released in January 1996, as centre policies. These policies represent an important development in establishing guidelines for the provision of services for people living in government centres.

Policies cover critical areas necessary to protect human and legal rights, safety and dignity of residents but are deficient in two areas of interest to this audit, fire safety and the management of critical incidents including resident accidents and injuries.

Audit found significant differences in how government centres had approached and progressed the implementation of these policies and the degree of practice compliance with policy directions. However, there are structural limitations in institutional settings which prevent the successful implementation of all Department of Community Services' policies (and thus prevent institutions achieving *conformity* without reconfiguring the accommodation).

Operational Policies in Non-government Centres

Non-government centres face the same difficulties and limitations as government centres in providing quality services in an institutional setting. However beyond this, none of these centres had developed a set of operational policies which was adequate to protect residents. Some non-government service providers had developed a few policies, but they were deficient in coverage (they did not cover the ten critical practice areas) and, or content (did not provide adequate guidance to staff).

Government and Non-government Centres

In most centres, there were deficiencies in the approach to the implementation of policy; staff were either unaware of the existence and content of policies or had not received training to support the implementation of policy.

Ageing and Disability Department

In 1995, the Government established the Ageing and Disability Department, responsible for policies and programs for people with disabilities. The change separated strategic policy, planning, funding, monitoring and evaluation of disability services from service delivery; all were undertaken at the time by the Department of Community Services.

To date, minimal assistance has been provided by the Ageing and Disability Department to guide both government and non-government centres in the development of policies, particularly in critical practice areas.

Monitoring Service Delivery

Information regarding the performance of large residential centres is not readily available. There are no indicators of service delivery or benchmarks against which large residential centres can be judged.

Centre Based Monitoring

Current systems for monitoring residential centres in terms of accountability and ensuring practices comply with policies and Standards are not effective. Accordingly, there is no assurance that deficiencies would be identified by centre management or those external to the centre with the power to intervene.

Practices in Residential Centres

To compare practices to operational policies, the Disability Service Standards and legal requirements, the audit focussed on practices in the ten critical areas. Findings are outlined in Table 1.

Table 1: Summary of Key Findings in Practice Areas

Practice Issue	Government and Non-government Centres
Behaviour Management	The effectiveness of behaviour management in institutions is limited. Even where management plans are prepared, centres often only achieve behavioural control of residents through medication and containment rather than long term behavioural change.
Management of Incidents Including Injuries and Assaults	Incidents are inconsistently defined, reported, monitored, analysed and are generally not well managed. The largest category of injury to residents is reported to result from resident to resident aggression. The risk factors are poor staff to resident ratios, resident mix, number of residents in the centre, configuration of accommodation, the effectiveness (or existence) of behaviour intervention plans and the centres ability to identify and implement preventative strategies.
Medication Controls and Consent	In government centres, controls over the administration of medication often fail and the legal requirements for gaining consent are often breached. In the non-government centres, medication controls were either non existent or ineffective and the legal requirements for gaining consent for medical treatment were poorly understood and often breached. Across all centres, failure to gain consent for medication, particularly psychotropic, was a problem.
Nutrition, Hygiene and Health Care	All centres had systems for monitoring resident health but recording and monitoring of this information was unreliable and did not assure timely and appropriate intervention. Two non-government centres received donated foods to supplement the menu. Few centres had arrangements for therapy services or nutritional assessments.
Community Access	Community access is still dominated by diversional activities such as group bus rides and group outings with no focus on community integration.
Promoting Access to Family and Friends	In most centres there are no restrictions on visiting hours or formal practices that would prevent family contact and in most cases family contact is supported and promoted by the centre. However, the nature of institutional services mitigates against extended contact.
Privacy and Dignity	Dormitories, open plan bathrooms, common dining and sitting rooms deny residents an acceptable level of privacy. The features of institutional living do not protect and promote dignity.
Individual Service Planning and Skill Development	Most centres are structured to meet management, staff and organisational requirements not the needs of residents. Even when individual plans are prepared, the plans are not always used to provide support to meet the needs of residents. Opportunities for skill development are limited in institutional settings.
Safety	The risk of injury is a major factor affecting resident safety. There is no policy for fire safety procedures in government centres resulting in varied approaches to (and success in) risk reduction. The general response by centres to environmental safety risk facing residents is containment.
Dealing with Complaints and Concerns	Not all centres had established effective procedures for investigating and managing complaints, and families (and residents) were unsure of their rights. Data on complaints is not monitored by Ageing and Disability Department. Families and staff indicated a fear of retribution if they raised concerns or made complaints to service providers.

Assessing Services

Because there was no evaluation methodology for assessing service delivery in large centres, The Audit Office developed criteria and a methodology to test practices in each of the critical areas. This methodology has and will be used by the Community Services Commission and other agencies to conduct evaluations of service delivery.

It was not possible to complete the review of all areas that were included in the original scope of the performance audit. The areas that were not reviewed were staffing levels, competencies and the recruitment of staff to institutions, the management of consumer finances and the audit of service delivery in group homes.

The Audit Office would consider a request to complete the review of the outstanding areas subject to audit commitments and funding.

The Hall for Children

The Hall for Children was one of the centres visited by audit. As a consequence of that review, The Audit Office agreed to the release of working papers prior to the tabling of this report so that the Community Services Commission could complete an Inquiry into that centre. Following that Inquiry, the Minister for Community Services decided to close the centre.

Factors Contributing to Service Delivery

A number of other factors were identified as having an impact on service delivery.

Staffing Issues

Government institutions are a medical model of care and employ only nurses. There is no flexibility to match the mix of staff with the needs of residents. Work arrangements such as shift patterns (and associated costs) have impacted negatively on service delivery and client outcomes.

In non-government centres, recruitment practices can result in inexperienced staff providing residential support to people with an intellectual disability.

Resources

There are no principles to guide resource allocation decisions. The amount of funding an institution receives is based on historical factors not measures such as inputs (eg. needs of residents, salaries, rent, operating overheads), outputs (centre related products) or outcomes (related to the achievement of outcomes).

The effect of this is seen in differing standards of accommodation, staff to resident ratios, access to specialist services, provision of staff training and the provision of day activities.

Physical Condition of Accommodation

The Department of Community Services 1997 property condition audit of its major assets (buildings) identified that large residential centres are in a poor condition and required significant funds (estimated by it to be $22m) to bring them to an acceptable standard. A number of the problems identified relate to resident safety and the basic condition of their accommodation.

This is consistent with audit findings that the physical condition of buildings accommodating residents in large government centres varied from impoverished to acceptable (although still inappropriate).

Respite

People with an intellectual disability can be placed in institutions on a respite or crisis basis.[4] These people, because of their specific needs, can have a detrimental impact on other residents and conflicts can arise.

Advocacy

People with an intellectual disability need access to advocacy support to participate in decision making about the services they receive.

There is significant unmet demand for advocacy services by residents of large centres. The inability of these residents to articulate their feelings, needs and wants without assistance, renders them voiceless and potentially vulnerable consumers.

Guardianship

There are residents in institutions who require the appointment of a guardian to protect their interests. Sometimes the person responsible for making decisions on behalf of the resident has little contact with the resident.

User Pays

Some centres are reluctant to use residents' funds to improve the quality of a resident's life. There appears to be some confusion about which services and goods should be provided by centres and which should be purchased by residents.

Guarantee of Service

It was noted during the course of the audit that a guarantee of continuing care was provided by the Government, through the Minister for Community Services in 1996 to residents of government institutions that were to move to the community. In contrast, residents of non-government institutions did not receive any guarantee of continuing care from the Government.

---

[4] Respite refers to a short term and time limited break for families and caregivers of people with intellectual disabilities, to assist in supporting and maintaining the primary caregiving relationship, whilst providing a positive experience for the person with a disability.

[illegible]

The report indicates that practices in both government and non-government centres fail to protect adequately the human and legal rights, safety and dignity of residents.

Factors contributing to this situation are the absence of minimum criteria for the protection of residents' human and legal rights, safety and dignity, inadequate policies to direct service delivery, the absence of staff training to reinforce practices, low levels of supervision and the absence of effective monitoring systems to trigger a response to service deficiencies.

Even where policies have been developed to guide practices, the nature of institutional care (the environment renders some policies ineffective), inadequate implementation, inadequate monitoring of practices and lack of compliance results in the centre's failure to protect people living there.

Other factors which are more difficult to remedy are those inherent to institutional models of care. These include the whole of life, umbrella approach to the delivery of services, the custodial and impersonal nature of care, the segregation of institutions from the community, the inability of institutions to provide a home-like environment and the inability of institutions adequately to address the physical, emotional, social and skill development needs of residents.

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

Even though community opinion on the movement of people from institutions to community based settings is polarised, the Government's position on providing services for people with an intellectual disability is to provide services necessary for people to achieve their maximum potential.

The Government recognises that people with an intellectual disability can not achieve their maximum potential while they remain in an institution.

It is acknowledged that considerable cost is involved in implementing the recommendations of this audit. The cost involved in moving people from institutions to community based settings is substantial. In the meantime, while people remain in institutions it will be necessary to ensure that they live in a safe environment. This too will involve considerable cost.

The findings of this audit make it clear that the safety of people with an intellectual disability is jeopardised when living in institutions. Service providers and the Government have a legal duty of care to take all reasonable steps to protect these people from foreseeable harm. The failure to do so leaves them exposed to legal actions for damages. For this reason too, it is imperative that the Government act urgently on the recommendations of this report to protect the rights and safety of people with an intellectual disability. In the short term, the immediate safety of people residing in institutions must be addressed and as soon as possible.

It is the mark of a developed and just society that provides care for those who can not care for themselves.

◆

Recommendations

The recommendations of this report, unless otherwise indicated, concern large government and non-government residential centres for people with an intellectual disability providing services which do not *conform* with the Objects, Principles and Applications of Principles of the Disability Services Act 1993 and have not received funding for transition.

The recommendations present both long term changes for large residential centres (awaiting funding for transition) and short term, interim measures to address service deficiencies while awaiting transition.

Transition to *full conformity* for a large residential centre can take from 5 to 7 years to complete as indicated by their transition plans. In order to protect the human and legal rights, safety and dignity of residents during that time, recommendations should be implemented immediately concerning:

- mechanisms to protect people living in institutions including service improvements to reduce the congregate nature of the accommodation and to monitor service quality
- the reduction of service inequities.

The Community Services Commission has indicated that it will follow up and monitor the implementation of recommendations of this report.

Reconfigure Institutions

In regard to transition of large residential centres, it is recommended that:

Funding

1.1 The Government fund the transition of large government and non-government residential centres for people with an intellectual disability to enable services to be provided in *full conformity* with the Objects, Principles and Applications of Principles of the Disability Services Act 1993.

1.2 By way of Regulation to the Disability Services Act 1993, a target date of 7 years from the date of tabling this report be considered for the complete transition of all institutions.

An implementation timetable should be prepared to diminish the effect of uncertainty that currently exists in centres targeted to reconfigure to community based accommodation, and allow centres properly to plan service delivery up to, and following, moving to the community.

Children's Services

1.3 As a priority, the Government consider the movement of children under the age of 18 years currently in institutional care to community based settings that match individual need.

Interim Recommendations for Service Improvement

The following are interim but essential measures to address deficiencies while awaiting transition:

No Admissions Policy

2.1 The Government consider a policy for institutions, to ensure that no more people are placed into these (non-conforming) institutions (government or non-government), even on a respite or crisis basis.

The Ageing and Disability Department should ensure that any persons needing crisis or respite accommodation should be assisted to obtain admission to non-institutional residential centres.

As an immediate safeguard to protect the rights of any person for whom institutional placement is proposed, such decisions should only be made by the Guardianship Board (as an independent substitute decision maker) in the case of adults, and by the Minister for Community Services in the case of children, where it can be demonstrated that such placement is the only available option to meet the person's needs. This decision making authority should not be delegated, and should be provided through legislative amendment if necessary.

Service Standards [illegible]

In regard to protecting the rights, safety and dignity of resident in large residential centres, it is recommended that:

Conforming as Closely as Possible

2.2 The Ageing and Disability Department define the requirements for large residential centres to *conform as closely as possible* to the Objects, Principles and Applications of Principles, pending implementation of transition plans. This definition should:

- include baseline criteria for the protection of residents basic human and legal rights, safety and dignity in the 10 critical practice areas detailed in Appendix 7. Centres must be required to meet this criteria within 12 months
- a staged approach reflecting progressive service improvements each year.

The definition of *conforming as closely as possible* should not be restricted to service enhancements that are cost neutral.

Funding Agreement

2.3 The baseline criteria for resident safety and protection be included in the 1997/98 funding agreements with non-government centres and service contracts with the Department of Community Services. These criteria should be used to judge service delivery and where centres do not meet the baseline criteria within 12 months, funding should be withdrawn.

Progressive service improvements which allow centres to *conform as closely as possible* should be identified by the centre (involving residents and their families) in conjunction with the Ageing and Disability Department and incorporated into annual funding agreements or service contracts.

2.4 Ageing and Disability Department consider the application of the baseline criteria for resident safety and protection to all accommodation services (institutional or community based) through funding agreements.

Protection for Individuals

It is recommended that:

Guardianship

2.5 Service providers identify and refer to the:

- Guardianship Board residents who may need a guardian. Attention should be paid to those residents whose behaviour or medical needs require significant or intrusive treatment, and residents who have no involved family who can act as "person responsible."

- Department of Community Services any children who have not had substantial contact with their parents over the past 12 months.

Community Visitors should monitor individual needs in relation to guardianship, and report to the Community Services Commission where appropriate action has not been taken.

Advocates

2.6 The Ageing and Disability Department ensure that there are sufficient advocacy services to meet the needs of people living in institutions. The provision of additional services should be considered in the context of the NSW Advocacy Development Plan.

Centre Policies

It is recommended that:

Policy Development

2.7 The Ageing and Disability Department:

- provide policy guidance on baseline criteria referred to in 2.2
- assist centres to develop their own policies that reflect the baseline criteria
- review policies developed by centres to ensure they meet baseline criteria.

Policy Gaps

2.8 The Department of Community Services include in its *policies for people with disabilities* practice requirements regarding:

- fire safety
- reporting and investigating critical incidents and injuries involving residents.

Monitoring Service Delivery

It is recommended that:

Ageing and Disability Department

2.9 The Ageing and Disability Department establish:

- baseline criteria for service delivery described in 2.2 to be stipulated in funding agreements with non-government organisations and service contracts with the Department of Community Services
- requirements for information in relation to consumer outcomes and the performance of services against the baseline criteria and progressive service improvements. These requirements should be stipulated in the funding agreements and the service contracts
- a program of independent audits of large residential centres to enable the Department to verify self assessments
- a system for independently reviewing and monitoring the use of psychotropic medication in large residential centres
- a system to enable the Department to monitor complaints about service delivery in large residential centres.

2.10 In relation to the institutions reviewed as part of the audit, the Ageing and Disability Department should monitor the implementation of service improvements to meet the deficiencies identified by audit.

2.11 The Government undertake a review of the effectiveness of service monitoring by the Ageing and Disability Department within 2 years from the date of tabling this report.

2.12 Information on individual centre practices and systemic issues arising from the functions of the Community Services Commission including Community Visitors should be provided to the Ageing and Disability Department. Such information should be used to monitor services and considered in assessing annual funding.

Department of Community Services

2.13 The Department of Community Services establish a system for monitoring services in large government residential centres that consists of :

- regular reporting based on performance indicators that monitor performance against baseline criteria and consumer outcomes stipulated in service contracts with the Ageing and Disability Department
- centralised monitoring of information at the executive level (such as standardised reports and complaints) to allow early identification of systemic problems and service benchmarking.

Residential Centres

2.14 Each residential centre establish a system of monitoring service delivery that consists of:

- collecting and analysing data on practices in critical areas
- regular reporting to key stakeholders on key aspects of service delivery including performance against funding criteria and practices in critical areas
- positions descriptions that clearly indicate to staff responsibility and accountability for the quality of care.

Service Improvements

It is recommended that:

User Pays

2.15 Ageing and Disability Department provide policy guidance which:

- clarifies the goods and services to be provided by the centre within the fee structure
- outlines a process for centres to employ for identifying user pay options
- outlines accountability mechanisms for the use of consumer funds.

Service Improvements

2.16 Large residential centres should implement steps to meet better the needs of individuals, while awaiting implementation of transition plans, such as:

- reducing congregation by limiting the size of resident groupings for activities and promoting alternate accommodation models using existing facilities

- moving day activities off site into the community or arrange for residents to attend community based day activities
- providing greater opportunities for resident skill development through improved training programs and access to facilities to practice skills acquired.

Resident Rights

2.17 Centres should provide printed information to residents, family members, advocates and other representatives which outline the obligations and responsibilities of the centre, and the legal rights and responsibilities of residents and their representatives. This information should include the details of organisations who can provide further assistance.

Improving Equity in Service Delivery

In order to rectify some of the inequities developed over the years, as a consequence of financial assistance to residential centres being determined by historical grant levels without regard to equity or the results of service provision, it is recommended that:

Allocation of Resources

2.18 The Ageing and Disability Department introduce a funding system for non-government centres which allocates funds according to the assessed needs of residents and agreed outcomes to be achieved.

Funding to non-government centres should be reviewed against this model and adjusted accordingly.

Addressing Inequities

2.19 The Department of Community Services should develop a rational approach to the distribution of funds to its government centres.

2.20 The Department should also review the allocation of funding to each large government institution to address inequities in :

- staff to resident ratios
- access to specialist services
- condition of accommodation
- resources available for staff training
- provision of day activities.

Accommodation Standards in Government Centres

2.21 The Government, as a priority, make available sufficient funds to implement recommendations in the Department of Community Services' property condition audit that relate to issues of resident safety and the basic condition of accommodation in large residential facilities.

2.22 In determining priorities for refurbishment of large residential centres, consideration be given to:

- bringing the standard of accommodation for residents to an acceptable level
- decreasing resident groupings to reduce congregation within large residential centres. This includes the size of the groups in shared sleeping arrangements, size of groups using same living facilities (bathrooms, dining areas, sitting rooms).

However, further expenditure should be avoided where it would prolong the existence of institutions as a model of care.

Improving the Effectiveness of Service Delivery

It is recommended that:

2.23 The Department of Community Services examine the opportunities for improving service delivery in large residential centres that would result from:

- changes in staffing arrangements from 8,10 and 12 hour shifts to 8 hour shifts in all centres
- changes in staffing mix (nurses are employed in large government residential centres when employment of residential care workers or assistants would sometimes be appropriate).

Name of report: *Cram House -Inquiry into care and treatment of residents*

Author: **Community Services Commission**

Date of report: **January 1998**

Background

Cram House is a residential facility operated by the Illawarra Society for Crippled Children in Wollongong. In January 1998, there were 26 children and young adults living at Cram aged between 2 and 31 years. The service was intended for children under 16 years but the lack of appropriate alternative services for young people with high support needs, meant that residents stayed on beyond their 16th birthday.

Cram was initially funded by the Commonwealth as a Special Purpose Nursing Home but came under State responsibility under the CSDA to be funded under the Disability Services Program.

Policy Issues identified in the Report include:

1. Key issues identified on p 4-5
2. Lack of policy framework to guide key practice areas which have an impact on human and legal rights and safety of residents.
3. Rights and safety of residents were compromised without triggering an appropriate response from management.(eg management of critical incidents including lack of appropriate response to injuries and allegations of assault and mistreatment).
4. Children and young people unable to have any but their most basic physical needs met.
5. Service management and staff not receptive to external scrutiny and involvement.

Additional accountability requirements for service quality are outlined in the Transition Plan which states the improvements needed in a service to enable it to conform to the Disability Services Standards. At the time of the Inquiry, Cram House had a Transition Plan which had been approved by the Minister for Disability Services for implementation.

5. SUMMARY OF FINDINGS AND CONCLUSIONS

The Inquiry appreciates that staff at Cram House, like those in many similar situations, are doing a very difficult job in the face of increased expectations from government, community and families.

However, good intentions and dedication are not always enough to ensure that children and young adults with significant disabilities are getting what they need to promote their optimal development and quality of life. The Inquiry finds that the service is not currently able to protect the rights and safety of people in its care. The Inquiry also finds that the staff and management of Cram House are operating within a framework which does not sufficiently promote the interests or rights of the residents or their families, or acknowledge the developmental needs of children and their right to family involvement.

The Inquiry made a number of specific findings (see Part B - Evidence and Specific Findings), which has led to the following conclusions:

- **Cram House does not have an adequate policy framework to guide key practice areas which have an impact on human and legal rights, and safety of residents.** The service has made some recent attempts at developing guidelines for staff in line with the Disability Services Standards. However, many of the policies presented to the Inquiry are incomplete, do not provide adequate procedural guidance for staff, and are not framed in a manner which promotes accountability. In addition, some of the policies and procedures are inappropriate and inconsistent with good practice. It does not appear that the service attempted to provide any policy guidance to staff prior to the introduction of the Disability Services Standards.

- **In the absence of clear policies and procedures, the rights and safety of residents can be compromised, without triggering an appropriate response from management.** The absence of policies and procedures reduces the service's capacity to account for the care and support provided, and contributes to the service's failure to provide appropriate care and support to residents.

  The Inquiry found that rights and safety of residents is particularly compromised by the service's poor approach to:

  - the management of critical incidents, including lack of appropriate response to injuries and allegations of assault and mistreatment of residents

  - care and management of residents with challenging behaviour
  - dealing with concerns and complaints raised by families or advocates
  - staff recruitment and training
  - legal requirements for consent for treatment
  - the provision of medical treatment and
  - guardianship of children, and child protection issues

- **The management systems within the Illawarra Society for Crippled Children are poor, resulting in inadequate accountability for the quality of services provided.** The management of staff and service delivery relies almost exclusively on the role and presence of the DON. There are very few explicit guidelines about accountability and decision making, and no mechanisms for formal supervision of staff performance. The Inquiry found little evidence that the Board or previous Executive Officer either established or monitored standards for service policies and practices. There are no management systems to ensure compliance with legal or policy requirements relating to the care and support of residents; or to ensure that staff have the necessary skills and experience to provide quality services. There was limited acknowledgment of the need for quality assurance or service improvements.

- **The children and young adults who live at Cram House are unable to have any but their most basic daily physical needs met, nor are they provided with the individual support and attention they require.** This is due to the number of residents, their high support needs, and the nature of the service. The service has attempted to ensure that individual needs in relation to therapy, and physical needs such as lifting are addressed. However, it has failed to focus on providing services which take into account any future goals or developmental opportunities for residents. The service does not provide activities or assistance to the children and young adults which meet their individual developmental, social or emotional needs, or their personal preferences.

- **Service management and staff do not encourage, and are not receptive to, external scrutiny and involvement.** The service is not open to external input and monitoring, has a poor relationship with the local Citizen Advocacy Program, and perceives the Community Visitor as interfering and unhelpful. Although there is a draft grievance procedure, the service response to complaints and allegations has been inadequate. There are no formal or effective mechanisms for family members or advocates to become involved in the decision making of the service. The Inquiry found a high level of ill-feeling between those families and advocates who had raised issues of concern or who did not accept the current standards offered by Cram House, and those staff and families who were satisfied with the service quality. The service exacerbated this situation by not protecting the confidentiality of some family members or advocates who had made complaints or raised issues.

- **Cram House does not provide for the particular needs of children, including protection, permanency planning, family involvement, and opportunities for development.** The service has failed to establish mechanisms to adequately or effectively promote family involvement in making decisions about the care and treatment provided to children residing at the service. There are some procedures and practices which exclude and degrade parental involvement. The service has also failed to establish effective mechanisms to keep families and others involved in, and informed of, changes within the service. In addition, the service lacks an understanding of child protection processes and principles, and has failed to take adequate steps when children are in need of care or protection due to lack of contact with or support from their families.

- **The current system of funding and external monitoring is insufficient to assure an adequate quality of service.** DOCS and ADD have had information indicating some of the problems arising from the absence of policies and poor practices at Cram House since at least 1993 and 1995 (respectively). However, a lack of systematic monitoring and an absence of rigorous reporting mechanisms have limited its ability to obtain a comprehensive understanding of the situation. Even in circumstances where significant breaches of funding conditions or residents' rights have occurred, there has been a failure to call the service to account.

- **There are some significant gaps in external protective monitoring mechanisms which have left the residents of Cram House vulnerable to undetected abuse or neglect.** There is an absence of any external scrutiny of the situations of children being placed into care at Cram House, the circumstances of children and young people who die while in care at Cram House, and in relation to the potential for staff abuse of residents who are older than 16 years.

6. RECOMMENDATIONS

The findings of this Inquiry and concurrent investigation are serious and wide ranging. As a result, we have made recommendations which are not only directed at the service, but which will also require action by the government, ADD and DOCS.

Our recommendations are aimed at providing appropriate and quality services for the children and young people currently in the care of the Society. These will take some time to implement (if done in a planned way), so we have also identified improvements needed to ensure the immediate safety and well being of residents while the medium term strategies are pursued.

The poor care and lack of response to the needs of children and young people at Cram House reflect weaknesses in the broader system of accountability of funded services for people with disabilities, and gaps in the system which fail to recognise the childhood needs of children with disabilities.

These issues will affect all children and young people in similar circumstances, so we have made a number of recommendations which are about improving the system generally, not just in services provided by the Society.

Information provided by the Illawarra Society for Crippled Children, DOCS and ADD indicate that some progress may have already been made on some of these recommendations. However, for reasons of accountability we believe it is important to list our recommendations in their entirety.

6.1 Recommendations Specific to Services at the Illawarra Society for Crippled Children

Although the focus of the Inquiry and concurrent investigation were on services provided through Cram House, many of the factors which contributed to poor practices here will also affect services provided at other Society facilities. These factors include the poor management and accountability systems of the organisation, the absence of a policy framework, and the poor attitude of the organisation to external scrutiny and involvement. For these reasons, we have included reference to the Bellambi group home where appropriate in the recommendations which follow.

Some of the issues raised in the findings of this Inquiry are still being examined by the commission to determine whether a referral to the HCCC is warranted, and so no recommendations regarding these are made here.

6.1.1 The Government, through the Minister for Disability Services should take the necessary steps to ensure the closure of the Cram House facility, the devolution of the services currently provided and the provision of appropriate alternative community based services for the children and young people who reside there. The alternative services should be developed specifically to meet the individual needs and circumstances of each child and young adult. These services may be provided by the Society, or other organisations, subject to appropriate planning and selection processes.

The planning for the development of alternate services should commence immediately, and be completed within 2 years.

6.1.2 The planning for new services should include strategies to ensure that the services:

(a) reflect the individual physical, social, developmental, educational and permanency planning needs of each child and young person
(b) conform with principles and standards relating both to disability services and substitute care, and reflect the range of options promoted for children in substitute care

(c) maintain or promote access to families, advocates and peers with whom individual children and young persons have relationships, through the location, structure and operational practices of the services

(d) include provision for appropriate preparation for each child and young person's transition to the new environment

(e) take into account the views and preferences of the children and young people, and their families and advocates

6.1.3 In the interim period, ADD should ensure that no further children and young people are placed in Cram House. If necessary, a 'no admissions' clause should be included as a special condition to the Funding Agreement.

Where children and young people are in need of services and might have otherwise been placed in Cram House, ADD and DOCS should ensure that they are assisted to obtain alternative support services which meet their needs, and which are consistent with substitute care principles and the Disability Services Standards.

6.1.4 As an immediate priority, the Society should take the necessary steps to bring its practices (at both Cram House and the Bellambi group home) in line with the baseline criteria for resident safety and protection from abuse, as developed through the Performance Audit of Large Residential Centres conducted by the Audit Office of NSW and the Community Services Commission.

The development of appropriate policies and procedures in the areas of parent/guardian consent, provision of medical treatment, recruitment practices, care and protection legislation and practice, and safety are urgent requirements. The Standards in Action Manual being developed by ADD will provide guidance in these areas. Such policy development must be accompanied by staff training to facilitate improved practices.

6.1.5 ADD should include conditions in its funding agreement with the Society, requiring compliance with the baseline criteria (which are being incorporated in the ADD Standards in Action Manual) within 12 months of this report, as a condition of continuation of funding. Progression towards this compliance should be monitored at 3 monthly intervals. ADD should also provide specific support to the Society, through the regional team or the Service Review and Support Project, to assist their service improvements. Such support may include facilitating links between the Society and appropriate sources of expertise and assistance (eg professionals, peak bodies, other service providers).

6.1.6 The Society should arrange for a review of its current staff roles, responsibilities and structures, and examine alternative staffing structures and models which might more effectively meet the needs of residents within existing resources. Such a review should also examine competencies and position statements which would promote a focus on individual developmental needs, rather than physical care. Any changes to the staffing arrangements should also provide for increased supervision, accountability and training.

6.1.7 The Society should closely examine the current roles and responsibilities of the DON. The Society should determine whether any additional training, supervision, support, counselling or other action in respect of the DON is required in light of the findings of this Inquiry.

6.1.8 The Society should immediately implement strategies to enhance family and advocate involvement in decision making, both at a service level and about support arrangements for individual residents. Such strategies should include (at least) the formation of specific working parties for consultation with families about the planning of new services, and follow up of the issues raised by family members in the course of transition planning and this Inquiry.

6.1.9 ADD should arrange independent support and advice for family members and advocates (of residents at both Cram House and the Bellambi group home) interested in developing their advocacy skills in relation to service involvement and planning, through an appropriate family advocacy or support service. Such an arrangement could also assist family members in participating in the planning for new services.

6.1.10 The Society should ensure that every resident (at both Cram House and the Bellambi group home) undergoes a holistic, multi-disciplinary assessment of their needs, to determine the appropriateness of their current medical treatment, therapy and other programmes. Families and advocates should be involved in these processes. The recommendations from these assessments and reviews should be used immediately to provide the appropriate care and programmes for residents, and should also be considered in planning the new services needed for each individual.

DOCS should continue to assist in making arrangements for such assessments and reviews for child residents and adults for whom they have a case management responsibility. If necessary, ADD and DOCS should assist by providing or referring to the appropriate expertise for such assessments. The progress and outcomes of such assessments are to be monitored by the taskforce referred to in recommendation 6.1.15, and by ADD as part of the Action Plan for Cram House (referred to in recommendation 6.1.14).

6.1.11 If any of the assessments/reviews referred to in the recommendation above, raise questions of actions, care or treatments which indicate breach of legal requirements, or potential harm to the residents, or indicate an unacceptable standard of health care, the taskforce referred to in recommendation 6.1.15 is to ensure that such matters are referred to DOCS as a notification (if child), and/or the HCCC if health.

6.1.12 DOCS (through local Child and Family Services) to complete its review the circumstances of every child residing in Cram House or the Bellambi Group Home, to determine whether any child may be 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.

6.1.13 The Society should review the guardianship needs of all adults residing at Cram House or Bellambi Group Home. Attention should be paid to those residents whose behaviour or medical needs require significant or intrusive treatment, and those who may not have involved family who can act as 'person responsible'. The Society should refer any residents with such needs to the Guardianship Board.

6.1.14 The recommendations above which require action by the Illawarra Society for Crippled Children should be included in the Action Plan to be attached to the Deed of Funding Agreement between the Society and ADD, for 1997/98.

6.1.15 The Minister for Community Services and Disability Services should establish a task force to oversee the implementation of recommendations 6.1.1-6.1.14. Membership of this taskforce should include (but not be limited to):

- ADD (Disability Services Program and regional team);
- DOCS (Child and Family Services, Corrimal);
- Director and Executive Officer of the Society;
- representatives of family members of residents;
- Illawarra Citizen Advocacy;
- Community Visitor;
- Illawarra Disability Trust;
- People With Disabilities (NSW);
- ACROD.

6.2 Recommendations Dealing with Systemic Issues

A number of the recommendations which follow echo those made in other reports into disability services in recent years. The fact that they are restated here reflects the systemic nature of the findings in various inquiries and investigations (such as "Suffer the Children", the "Performance Audit of Large Residential Centres for People with a Disability", and "Who Cares?

Protecting People in Residential Care") and the little progress to date in addressing some of the issues previously identified.

Improvements need to be made to the system, not just the setting. Unless this occurs, we continue to live with the possibility, if not the likelihood, that children with disabilities in other services are being subjected to the same risks and poor care as those at Cram House.

6.2.1 The government should continue its commitment to giving priority for moving children currently in institutional care to community based settings that match their individual needs, in any devolution strategy.

6.2.2 The government should establish a policy to ensure no children are placed into congregate care services which are still in transition. All children requiring out-of-home care should be provided with services consistent with substitute care principles and standards.

6.2.3 The current legislative review of the *Children (Care and Protection) Act 1987* should include the development of an independent mechanism for the monitoring and safeguarding of voluntary placements of children into care. Such a mechanism should include gate-keeping procedures, reporting and reviewing of such placements by an independent body.

6.2.4 ADD should establish as quickly as possible funding and monitoring arrangements which:

- are based on terms and conditions for financial assistance which comply with s12 of the DSA
- require all accommodation services to comply with the baseline criteria for resident safety and protection from abuse
- allow the department to identify and address breaches in the funding agreement
- supplement the self-assessment processes with independent reviews of services at least every 3 years, as required under the DSA

6.2.5 ADD should develop a system to collect and consider information about service quality and performance issues for funded services. Sources of such information would include DOCS, the Community Services Commission and Community Visitors. Information collected from these sources should be used by ADD in verifying self-assessments, evaluating compliance with funding arrangements, and in negotiations for continuation of funding.

6.2.6 In order to immediately address the lack of external reporting and reviewing of deaths of people with disabilities in funded services:

(a) The Minister for Community Services and Disability Services should immediately declare that any premises in which accommodation or respite services are either provided or funded by the Minister (either in whole or in part) under the *Disability Services Act 1993* is to be a facility for the purpose of s4(1)(c)(v) of the *Community Welfare Act 1987*. Such a declaration should be made by order published in the Gazette, as per s3A of the *Community Welfare Act 1987*.

(b) Immediately upon gazettal of the above, ADD should take steps to notify all such services, the medical professions, the Police Service and the State Coroner of these services coming into the jurisdiction of those sections of the *Coroners Act 1980* dealing with reportable deaths, death certificates and inquests. These include sections 12A(1), 12B(1)(g) and 13(1)(d) and (h).

This is only an interim step to addressing the current lack of reviewing of deaths of people with disabilities in care.

6.2.7 As a long term solution, the Minister should negotiate with the Attorney-General to secure an amendment to the *Coroners Act 1980* such that those sections dealing with reportable deaths include facilities providing accommodation or respite services which are designated services under the *Disability Services Act 1993.*

6.2.8 ADD should proceed with its intention to introduce a requirement that deaths of people residing in funded accommodation services are reported to them, as a condition of funding. The specifics of reporting requirements should be determined in consultation with DOCS (to promote consistency), the Community Services Commission and the Child Death Review Team. Where such information relates to the deaths of children, the information should be provided to the Child Death Review Team.

6.2.9 The government should establish an independent, statutory mechanism to review the deaths of people with disabilities. The powers and functions of the Child Death Review Team should be a starting point for the development of such a body. This body should have the capacity and resources to review the circumstances surrounding individual deaths and how they were dealt with, monitor trends and patterns, and identify policy/practice implications and preventative measures.

6.2.10 The Child Death Review Team ("the Team") should include deaths of children in a residential facility (whether they have a disability or not) for reviews by the full Team, regardless of whether a death certificate was issued.

This may require some changes to the data provided to the Team, and their powers to obtain information from non-government agencies.

6.2.11 Any probity unit (or Employment Information Centre) established as a result of the recommendation in the Woods Royal Commission, should be expanded to cover all persons seeking employment in residential care settings.

6.2.12 The other recommendations of the report "Who Cares? Protecting People in Residential Care" should be implemented. In particular ADD should include specific requirements for staff recruitment, selection, appointment and management as part of funding agreements with non-government services and in its agreement with DOCS.

Name of report: *A Critical Event at the Grosvenor Centre - Review of the Disability Death Review Team of the Critical Event at the Grosvenor Centre*

Author: **Community Services Commission**

Date of report: **January 2000**

Background

The Grosvenor Centre is a government institution for children and young people with disability. During November 1998, twelve residents of Unit 2 became ill and required hospitalisation, eight with respiratory illnesses and another four with unrelated conditions. Two of these, a teenage boy and a young woman, died some days after their admission to hospital. In December 1998, there were two further deaths.

Policy Issues identified in the Report include:

1. Key issues identified on p 4-5
2. Limited access to specialist health and therapy services, lack of adequate follow up and review where specialist recommendations had been made and poor treatment management.
3. Lack of specialist services readily available to Grosvenor residents in the areas of underweight problems, eating difficulties, aspiration risk, dysphagia and metabolic status.
4. Lack of integrated health care plans.
5. Significant limitation of internal reviews.

Name of report: *Young Deaths – Children with Disabilities in Care. A review of the deaths of eight children and young people at the Mannix Children's Centre*

Author: **Community Services Commission**

Date of report: **February 2002**

Background

Mannix Children's Centre is an institution for 40 children and young people operated by a non government service provider in Liverpool in Sydney. Between July 1998 and February 2001, the deaths of 8 children and young people from the Mannix Centre were notified to the Disability Death Review Team at the Community Services Commission.

Mannix was initially funded by the Commonwealth as a Special Purpose Nursing Home but came under State responsibility under the CSDA to be funded under the Disability Services Program.

The Review identified significant health issues for the individual children and young people. In addition, it flagged issues warranting attention at the service and systemic level.

Policy Issues identified in the Report include:

1. Key issues identified on p 4-5
2. Lack of policy and service planning to address service standards, practices or factors, which may directly or indirectly contribute to illness, injury and/or premature death for people with disability in care.
3. Lack of provision for adequate support for the medical, health, developmental and physical needs of the children.
4. Inadequate systems designed to ensure a safe and nurturing environment for children and young people with significant disability and medical frailty .

3.8 Summary of deaths

Resident A

Resident A was a 14 year-old boy with severe intellectual disability, spastic quadriplegia, vision and hearing impairments, scoliosis and epilepsy. He was underweight, prone to chest infections, and because of swallowing difficulties, was fed via nasogastric tube. Resident A died in mid 1998.

Shortly before his death, Resident A developed a chest infection and was unable to tolerate his naso-gastric feeds. The local palliative care team was consulted, recommending medication to reduce pain, nausea and vomiting. Despite ongoing chest physiotherapy, postural drainage and nebuliser therapy, he developed bronchopneumonia and died. The death was reported to the police, although there is no record. It was not reported to the Coroner.

Key issues identified in the DDRT review included:

- **nutrition management**; no record of specialist dietary review and no comprehensive feeding management plan on file.
- **access to physiotherapy services;** lack of regular physiotherapy review and no plan or supervision for staff regarding chest care or postural drainage on file.
- **epilepsy medication management;** lack of regular review of epilepsy management, including medications, on file.
- **family contact;** the roles and responsibilities of family and advocate were not clarified. Lack of guidelines for staff for maintaining family contact and responsibilities for decisions concerning treatment and services.
- **file record maintenance;** poor standard of record keeping and file management.

Resident B

Resident B was an eight-year-old boy with a profound intellectual disability, microcephaly, spastic quadriplegia, epilepsy, vision impairment and gastroesophageal reflux (GER).[9] In his six years at Mannix, he was frequently hospitalised for a number of health problems including oesophagitis, pneumonia and feeding difficulties. Resident B died in mid 1998.

Resident B underwent a gastrostomy in 1997 but this did not resolve his feeding problems.[10] A fundoplication was performed.[11] Resident B appeared to be making a satisfactory recovery but he died in hospital, following the procedure. The cause of death was bronchial aspiration, GER, gastroparesis. Resident B's death was not reported to the police or Coroner.

Key issues identified in the DDRT review included:

- **nutrition case management needs;** primary responsibility for Resident B's ongoing nutritional management was left unclear, and the level of nutritional services required was not determined. The recording and monitoring of Resident B's weight was also inadequate.
- **feeding problems;** despite problems with tube-feeding, no gastrostomy management plan was in place.
- **infection control and immunisation;** no immunisation records were kept.
- **end of life treatment plan;** Mannix failed to provide prior advice to the hospital of the family's wishes that their son was not to be actively resuscitated in the event of cardio-respiratory arrest.
- **staffing;** inadequacy of supervision levels, staff training, and lack of access to professional dietary services on site at Mannix.

---

[9] Reflux is a backflow of stomach contents upward into the oesophagus. The lining of the stomach protects the stomach from the effects of its own acid. The oesophagus lacks a similar protective lining. This backflow can also affect the lungs if aspirated.

[10] A gastrostomy is a surgical technique creating an artificial opening into the stomach for the insertion of a feeding tube. The permanent feeding tube (known as PEG) allows for nutrition to be provided by specially prepared commercially available formula, or blended other foods.

[11] A fundoplication is a surgical procedure in which a fold is made in the stomach around the oesophagus. This procedure is undertaken with the aim of reducing oesophageal reflux.

Resident C

Resident C was an 18 year-old man with a severe intellectual disability, spastic quadriplegia, and epilepsy. He also had scoliosis, osteoporosis and in his sixteen years at Mannix, he experienced recurrent respiratory infections. He was fed by nasogastric tube.

At the beginning of 1999, Resident C's health deteriorated and he was given morphine for pain relief by the local palliative care team. His condition continued to deteriorate and he died at Mannix in early 1999. The death was not reported to the police or Coroner.

Key issues identified in the DDRT review included:

- **monitoring of nasogastric feeding and overall nutritional status**; problems with nasogastric feeding but no indication how the service addressed these. Lack of monitoring of weight despite significant weight loss, and no recent dietician assessment.
- **adequacy of medication records**; medication administration and recording was inadequate.
- **end of life treatment and palliative care**; confusing information regarding family members' right to make decisions, and lack of a written palliative care plan, policies, or procedures at Mannix.

Resident D

Resident D was a 14 year-old girl with a severe intellectual disability, spastic quadriplegia, epilepsy and obstructive sleep apnoea. She also had swallowing and long-term feeding difficulties. She required nasogastric feeding in her last months.

Resident D developed congestion in her chest and had difficulty tolerating her nasogastric feed. Soon after a staff member found her with no respiration or heartbeat and she was unable to be resuscitated. Resident D died in early 1999 at Mannix. The cause of death was given as bronchopneumonia. Her death was reported to the police and Coroner.

Key issues identified in the DDRT review included:

- **nutrition and health care;** no timely referral to specialist/dietician for consideration of gastrostomy/other intervention to address dysphagia and feeding problems. Despite chronic respiratory problems, Resident D was not reviewed by a respiratory physician/physiotherapist.
- **legal status;** was unclear due to Resident D's length of time in care and lack of substantial family contact.
- **consent to medical treatment;** lack of consent request follow-up and no alternative treatment proposed when family refused consent.
- **medical certificate of cause of death;** the GP completed the certificate despite not having seen Resident D for nearly three weeks and no recent record of bronchopneumonia on file.
- **emergency/death of a consumer procedures;** procedures for reporting to management/the police/Coroner, informing families and assisting with funeral arrangements were lacking.

Resident E

Resident E was an 18 year-old man with a profound intellectual disability, microcephaly, spastic quadriplegia, epilepsy and visual and hearing impairments. He also had apnoea, scoliosis and recurrent respiratory infections.

In August 1999 he was admitted to hospital with pneumonia by his parents, whom he was visiting for the weekend. His condition initially remained stable but then deteriorated. He died in late 1999 and the hospital issued a death certificate. His death was not reported to the police or Coroner.

Key issues identified in the DDRT review included:

- **nutrition/medical review;** recommendations for urgent consultation with a dietician, speech pathologist and occupational therapist about nutritional status, aspiration and feeding problems, were not implemented.
- **individual planning (IP);** information about health, planning, well being and care was collected separately without identification or link to his overall IP goals. There was no identified case manager.
- **file recording;** poor quality generally and no consent-to-treatment documentation on file.
- **events prior to hospital admission**; it appears the service did not identify Resident E's deteriorating health, failed to seek appropriate medical treatment and sent him to school when ill.
- **end of life treatment and decision making;** no information or family consultation processes were undertaken about treatment options in the case of acute illness or if resuscitation was required.

Resident F

Resident F was a 19 year-old man with a profound intellectual disability, microcephaly, spastic quadriplegia, epilepsy and blindness. He also had severe scoliosis, restrictive lung disease, obstructive sleep apnoea and a history of gastroesophageal reflux (with fundoplication and gastrostomy button insertion in 1993).

Resident F's health had been deteriorating since 1998 and he had episodes of hyperventilation, back-arching spasms and was being treated for pain relief by the local palliative care team. His condition worsened one day and he died in early 2000. The police and Coroner were notified of the death and cause of death was recorded as 'Multiple Developmental Abnormalities.'

Key issues identified in the DDRT review included:

- **medical/nutrition review;** no comprehensive nutritional service was provided for a matter of years. Recommendation for investigation of bacterial infection was not followed up for six months.
- **record keeping;** poor information collection and recording limited the development of pain management strategies and the level of comprehensive overview of Resident F's condition.
- **palliative care;** lack of consultation between Mannix, the palliative care team and the family to discuss treatment or 'end-of-life' decisions and no palliative care plan developed or documented.

Resident G

Resident G was a 15 year-old boy with a profound intellectual disability, spastic quadriplegia, hydrocephalus, epilepsy, and visual and hearing impairments.

Resident G, despite being unwell, was sent to school as usual. He developed a respiratory tract infection, swollen throat, and swallowing difficulties. He was admitted to hospital and given intravenous fluids but continued to deteriorate and died in mid 2000. The cause of death was cardiac arrest, secondary to an electrolyte disturbance, secondary to a chest infection. His death was not reported to the police or Coroner.

Key issues identified in the DDRT review included:

- **recognition of health needs;** delay in Resident G being examined by a GP. Unclear how the decision for him to attend school, despite being unwell, was made.
- **implementation of health recommendations/reviews;** delay in urgently needed speech pathology assessment and blood testing which indicated need for Hepatitis B vaccination. Inconsistent weight/height recording.
- **epilepsy management;** inadequate and inconsistent recording of seizures.
- **legal status;** was unclear due to Resident G's length of time in care and lack of substantial family contact.
- **individual needs;** despite staff raising Resident G's need for larger bed, management failed to take action.

Resident H

Resident H was a 16 year-old girl with a progressive degenerative disease associated with severe intellectual disability, epilepsy and osteoporosis. She also had a hearing impairment, was non-verbal and immobile, and experienced frequent chest infections.

Resident H's health was deteriorating and one night she was given medication for discomfort and pain as needed. Some time later she was found by Mannix staff with no pulse or respiration. Resident H died in early 2001. The cause of death was epilepsy associated with San Filippo 3B syndrome. Her death was notified to the police.

Key issues identified in the DDRT review included:

- **nutrition and medical review;** delay in urgently needed speech pathology and dietetic assessment. Lack of recording of weight/height and diet history.
- **medication management;** lack of information about the ongoing use of anti-psychotic agent.
- **medication administration and recording;** inadequate documentation for the administration of anti-psychotic, epilepsy, and pain management medication.
- **end of life decisions;** were not formally documented or reviewed by Mannix.
- **individual needs;** six-month delay by Mannix in providing a larger bed for Resident H.

4. Findings and emerging themes

Chapter 3 outlined the characteristics and circumstances of the eight children and young people reviewed by the DDRT. The following considers the overall review findings in key areas.

The key observations and themes are considered in two parts. The first identifies significant health issues for the individual children and young people reviewed by the DDRT. The second provides analysis of the service's management and processes around health care, decision making and death reporting.

It should be noted that this report is not a representative analysis of contributory factors in the deaths and subsequent links to service provision or practice. Rather, the intent is to 'flag' issues indicated by the reviews, which warrant attention at a service and systemic level, and to propose possible service improvement initiatives to address these issues.

Specific comment focuses on the following areas:

- **Health issues and management of health care**
  - nutrition management and monitoring;
  - screening, clinical and medical assessment;
  - access to specialist services;
  - immunisation; and
  - infection control measures.

- **Medication management**
  - medication administration and record management; and
  - medication consent and documentation.

- **Palliative care provision**

- **Staffing, decision making and reporting issues**
  - staff competencies;
  - end of life decision making;
  - critical incident handling; and
  - external reporting of deaths.

This section draws on case studies of the eight children and young people and supporting data on health and disability status. Issues arising from individual deaths are used to illustrate and highlight the complexities of health care access and health outcomes for children and young people with disabilities in care.

The discussion aims to identify key practice, service provision and systemic issues indicated by the review and subsequently to identify considerations for service improvement.

Executive Summary

Background

Between July 1998 and February 2001, the deaths of eight children and young people from Mannix Children's Centre at Liverpool were notified to the Disability Death Review Team (DDRT) at the Community Services Commission.[1] Because of the relatively high number of deaths within this service, the DDRT decided to review the circumstances of these children and young people.

Individual death reviews were undertaken in the first half of 2001 in relation to these eight deaths. These reviews examined a number of issues about the provision of services at Mannix, which we considered to have a direct bearing on the health outcomes of individuals, particularly in relation to dysphagia, respiratory infection and underweight.[2]

The service provision areas examined in these reviews included: the management of nutrition, screening and assessment processes; infection control management; staff competencies and the overall management of medication practices.

Information from the individual reviews has informed this systemic group review report and enabled us to:

- identify issues common to the deaths which may be of significance to children and young people with frail health needs accommodated by the service;
- identify practice issues and the factors required to provide adequate supported care and health services to this group of frail young people;
- identify barriers and systemic weaknesses within the service that impacted on the outcomes for these eight individuals; and
- linked to the above, propose relevant service improvement initiatives to ensure adequate service delivery for children and young people with frail health needs.

---

[1] A further two deaths have occurred at Mannix since February 2001.

[2] The most common cause of death for these eight children and young people was respiratory disease, with five deaths resulting from pneumonia.

Context

This systemic Review was conducted by the DDRT under s83 (1) (d) of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* (CRAMA).

This report is based on information, observation and conclusions drawn from the individual reviews. The Review has also referred to existing research on morbidity and mortality of people with disabilities.

The families of the deceased were contacted in October 2001 to advise them of this Review and they were invited to provide comment to the DDRT on the circumstances of their child while in the care of Mannix.

Individual case studies are used throughout this report in order to illustrate key points associated with disability and health care. Identity changes have been made to maintain the privacy of the deceased and their families.

Mannix Children's Centre

The Mannix Children's Centre is operated by The Intellectually and Physically Handicapped Children's Association of NSW (IPHCA), a non-government service provider which is overseen by a board of directors. According to the Ageing and Disability Department's 1999-2000 Annual Report, IPHCA received accommodation support funding of $3,489,905 for the 1999-2000 financial year to operate Mannix and another residential service for children and young people – Whitehall Children's Home at Revesby.

The facility is staffed by registered and enrolled nurses and nurse assistants, with additional professional staff and domestic staff. Medical services are provided by two local medical practices. Many residents are frail and have high medical needs.

The review data

All eight children and young people who died had multiple and complex health problems. The following is a summary of associated health conditions found in the Review group:

- cerebral palsy was the main physical disability reported;
- seven children had swallowing difficulties;
- all of the children and young people had epilepsy;
- all of the children and young people experienced chronic respiratory infections, including aspiration pneumonia; and
- six of the children and young people were underweight and enterally fed.

Key observations of the Review

The key observations and themes are considered in two parts. The first identifies significant health issues for the individual children and young people reviewed by the DDRT. The second provides analysis of Mannix's management and processes around health care, decision making and death reporting.

It should be noted that this report is not a representative analysis of contributory factors in the deaths and subsequent links to service provision or practice. Rather, the intent is to 'flag' issues indicated by the reviews, which warrant attention at a service and systemic level, and to propose possible service improvement initiatives to address these issues.

The Review strongly reinforces the need for ongoing policy development and service planning to address service standards, practices or factors, which may directly or indirectly contribute to illness, injury and/or premature death for people with disability living in care.

Conclusions

The observations and findings made by the DDRT review indicate that Mannix, in many respects, failed to meet its responsibilities to the children and young people who died in its care. Specifically, the service failed to adequately address the medical, health, developmental and physical needs of these eight children.

Aspects of residents' safety, the management and monitoring of nutritional needs and early detection of illness were found to be lacking in a number of the deaths reviewed. There was also evidence of consistent flaws in reporting and documentation processes across the service, from medication management to immunisation records, critical incident handling and reporting of deaths. Specific issues of concern are:

- staff competencies;
- variations in service practice;
- a lack of a considered approach to palliative care;
- the lack of assessment and access to specialist services; and
- less than optimal procedures and practices around infection control and lack of knowledge about relevant legislation and regulatory requirements for infection control.

Also of substantial concern was the failure of the service to actively respond to the identified health and safety needs of residents by obtaining specialist advice. Even where specialist advice was obtained, the service failed to implement the recommendations of relevant experts. Our work also indicates that the service has not responded to concerns about practice issues identified in previous reviews.

Recent proposed action plans and progress reports provided by Mannix, indicate a level of activity is planned and some service improvements are underway. It is not possible at this stage to determine the effect of these on the overall standard and quality of care provided to residents. Mannix must demonstrate the capacity to address the range of issues identified in the Review, and act promptly to do so. The need for Department of Ageing, Disability and Home Care (DADHC) to provide monitoring, independent scrutiny and open reporting will be a high priority for any progress to occur.

The concerns raised in this Review also go beyond the responsibilities of IPHCA. The systems designed to ensure a sufficiently safe and nurturing environment are not in place across the disability service system. The deficiencies identified at Mannix, to some degree, reflect the limitations in the broader system of disability services for children and young people. The issues identified are unlikely to be unique to Mannix, with similar problems having been identified in other services for children and young people with disabilities.[3]

The DDRT Review strongly reinforces the need for government to act on policy development and service planning to address service standards, practices and training and other factors which may, directly or indirectly, contribute to illness, injury and/or premature death for children and young people with a disability living in care.

The DDRT has already made a significant number of recommendations to IPHCA, which will assist the service to improve its care practices.[4] Information provided by IPHCA indicates that some progress may have already been made on some of these recommendations. However, for reasons of accountability, and so the monitoring of this progress can be undertaken, all the recommendations arising from this Review and previous individual reviews are reported below.

As many of the issues identified affect all children and young people in similar circumstances, we have also made a number of recommendations about improving the system generally. These are aimed at the DADHC and NSW Health and Area Health Services. They focus on short and medium term action required to ensure the well-being and safety of residents across the service system. Promotion of compliance with relevant legislation, standards and policies and improving health outcomes for this group is paramount.

---

[3] See Commission reports including *A Critical Event at Grosvenor Centre,* (2000), *Inquiry into Care and Treatment of Residents of Cram House,* (1998), and *Suffer the Children, The Hall for Children Report,* (1997b).

[4] These recommendations are contained in the eight individual confidential reports provided to Mannix, the Minister for Community Services and DADHC.

The Review acknowledges and welcomes a number of service improvement initiatives developed by relevant state government departments since the time of these deaths.

Recommendations

In accordance with the CRAMA legislation, a number of recommendations for service improvement have been made. The following recommendations are informed by the weaknesses identified in the service which we observed to be impacting on the current residents at Mannix.

They consolidate and build on the individual death review recommendations made by the DDRT as provided to the service in August 2001.

1. Recommendations to Mannix Children's Centre, a service of The Intellectually and Physically Handicapped Children's Association (IPHCA)

1.1 Nutrition and health needs

IPHCA should:

1.1.1 conduct comprehensive health reviews of every resident at Mannix, within three months and thereafter maintaining a system of regular reviews. These reviews should include regular medical examination and assessment of immunisation, epilepsy management and nutritional status;

1.1.2 establish and implement a policy and practice framework for a nutrition case management system, which includes adequate supervision and management of the nutritional and feeding needs of all residents;

1.1.3 organise regular and comprehensive screening to identify those at risk of dysphagia and provide timely and appropriate intervention;

1.1.4 establish access to appropriate clinical services (including dieticians, speech pathologists and physiotherapists) on a regular and as-needed basis to assess and review the nutritional and related needs of all residents currently in the service;

1.1.5 develop and implement detailed guidelines for staff on screening and monitoring of nutritional needs and mealtime practices; and

1.1.6 develop and implement guidelines for regular monitoring of resident weight and growth, with the aim of ensuring appropriate intervention where required to improve nutrition. The weight of all consumers should be closely monitored, particularly for those children who are underweight.

1.2 Immunisation

IPHCA should:

1.2.1 urgently review all current residents' immunisation status and establish a system for regular monitoring of this;

1.2.2 develop and implement a policy and practice guideline on immunisation requirements with input of expert advice from a relevant health service; and

1.2.3 implement the development of staff awareness and training program on immunisation requirements.

1.3 Infection control

IPHCA should:

1.3.1 implement hygiene controls to minimise and prevent the rate of cross infection in the service, based on expert advice;

1.3.2 improve its enteral feeding practices, general food preparation, equipment and hand washing practices to comply with NSW Health guidelines; and

1.3.3 improve its feeding equipment cleaning practices to ensure consistency with general infection control policy, contained in *Standards in Action* and health regulatory requirements.

1.4 Medication management systems

IPHCA should:

1.4.1 review its medication management recording system and develop and implement clear policy and procedures based on NSW Health guidelines; and

1.4.2 implement a system of recording medical information in client files in a manner consistent with file management systems and NSW Health guidelines.

1.5 Palliative care

For palliative care to be recognised as a medical or treatment option within this service, a number of strategies are required.

IPHCA should:

1.5.1 with assistance from a PCT identify the palliative care needs of all residents in consultation with parents, guardians and advocates, document all relevant information and provide follow up where necessary or appropriate; and

1.5.2 with assistance from DADHC, examine how best to care for children and young people with profound levels of disabilities and non-progressive neurological conditions and develop an awareness/information program for families and staff on palliative care as a treatment option.

1.6 Staff training needs

IPHCA should:

1.6.1 urgently establish a program to ensure that all staff are adequately trained in nutrition management and monitoring, immunisation, screening assessment tools, medication management and documentation, infection control, critical incident handling and death reporting processes;

1.6.2 ensure that appropriate training on safe feeding techniques is provided to all staff working at Mannix. Such training should include feeding strategies to prevent aspiration and other problems, strategies to feed more effectively, and procedures for dealing with safety risks or incidents; and

1.6.3 provide staff with training to assess swallowing and eating difficulties, such as that developed by DADHC Disability Services.

1.7 End of life decision making

IPHCA should:

1.7.1 develop a framework for end of life decision-making, based on the guidelines issued by NSW Health and ensure that such decision making is appropriately considered on a case by case basis. This process must be supported by clear documentation and written reasons for decision and reviewed within nominated time frames.

1.8 Critical incident reporting

IPHCA should:

1.8.1 establish a policy, procedures and staff training in regard to the handling of critical incidents at Mannix. The system should incorporate a review mechanism to address any outstanding client needs arising from such incidents.

1.9 Death reporting requirements

IPHCA should:

1.9.1 develop a clear policy on, and inform staff of, reporting requirements following the death of a resident. This policy should adhere to the requirements outlined in *Standards in Action*.

2. Recommendations to DADHC in relation to IPHCA

2.1 In light of the seriousness of the issues identified, DADHC should immediately and intensively monitor IPHCA's implementation of the recommendations contained in this report. In the event that IPHCA fails to make substantial progress on the implementation of these recommendations within six months, DADHC should review the continued auspicing of Mannix by IPHCA.

3. Recommendations dealing with systemic issues

From the DDRT work undertaken at Mannix, a number of issues were identified at the broader systemic level of disability service provision. All people with disabilities and high/complex health needs, living in care, face the same risks that these children and young people at Mannix had and there is no reason to believe that the same barriers do not also exist in other services. DADHC has the lead overall responsibility to ensure that residential services caring for children and young people with high medical support needs provide care at an appropriate standard.

DADHC's responsibility is linked to its role as a funder/ monitor, but as the lead agency for disability policy, it also has the responsibility to develop and lead cross-departmental initiatives, reforms and research into the needs of children and young people with disabilities and high/complex health needs.

The DDRT acknowledges and welcomes a number of recent initiatives, as outlined in the report, developed by relevant state government departments since the time of these deaths. Many of the issues identified through the DDRT review require initiative and leadership at a statewide level. The following recommendations are aimed at DADHC, NSW Health and Area Health Services. The DDRT recommends, after having regard to all the issues identified in this report, that DADHC undertake the following:

DADHC should:

3.1 in consultation with key stakeholders, implement a framework for a rigorous monitoring system for service delivery in disability residential services. Such a framework should clarify for all stakeholders, DADHC's role and responsibility to monitor disability services in NSW and detail specific strategies for effective monitoring.

3.2 through its monitoring work and consultation with stakeholders, identify training and professional development needs across the sector and develop a workforce training program across disability and health care needs.

3.3 develop model policies and procedures, and sector education and information initiatives to assist services in improving their policies and practices. Polices and procedures should include minimum requirements for appropriate accountability and review mechanisms.

3.4 ensure the implementation of the DSD *Nutrition Project,* incorporating the *Nutrition In Practice Manual* in order to establish a policy and practice framework to address the nutritional and feeding needs of all people with disabilities living in funded accommodation services.

3.5 in consultation with the NSW Health, institute a service provider awareness program that includes strategies to promote an increased rate of immunisation in disability residential services.

3.6 in conjunction with NSW Health, develop model polices and procedures for infection control, and ensure the development and implementation of infection control plans in all services providing supported accommodation. These plans should include a component of staff education and training and DADHC should monitor the establishment of infection control plans within disability accommodation services.

3.7 in consultation with DoCS and NSW Health, undertake research regarding appropriate palliative care policies and end of life decision making for children and young people with degenerative conditions living in disability residential services, with a view to developing sector-wide palliative care policy and practice guidelines.