

## **PART A: BACKGROUND TO THE INQUIRY**

### **1. BACKGROUND TO THE INQUIRY**

During July, August and September of 1996, the Community Services Commission ("the commission") received a number of complaints and reports about the standard of care provided to children and young adults at Cram House (a service operated by the Illawarra Society for Crippled Children). These complaints and concerns came from a number of independent sources, including relatives of residents, advocates of residents and the Community Visitor.

The information provided by these people raised significant questions about the care and treatment of residents, particularly in the areas of:

- medical and health care (including therapy and nutrition);
- behaviour management;
- activities and programs;
- privacy; and
- meeting individual needs.

The information provided also raised issues of:

- conflict between Cram House ("the service") and advocates;
- potential conflict of interest in services being provided by medical practitioners who were also Directors of the Board;
- lack of family involvement in service decision making;
- poor information exchange between the service and families; and
- a general lack of accountability for service provision and the care of the children and young adults.

The Illawarra Society for Crippled Children ("the Society") was notified of the particulars of the various complaints in September 1996, and asked to provide a response. The commission also advised the Department of Community Services and the Ageing and Disability Department of the complaints at this time, and sought information from them to assist in assessing the matters raised. The response from the service (dated October 1996) did not provide sufficient information to satisfy the commission that there was no substance to the complaints, or that other appropriate action was being taken to resolve the issues raised.

The residents of Cram House are primarily children and young adults who have significant physical and intellectual disabilities. The commission was conscious that they are extremely vulnerable to the impact of any poor service

practices which may occur because they are unable to speak up if they are not satisfied with the service, or if they are not having their needs met.

This increases the need for external scrutiny. These circumstances also increase the need for appropriate systems and practices which protect, as far as possible, the rights and safety of residents, and which ensure the early detection and addressing of any problems which may arise.

Additionally, although much of the information raised by complainants and others related primarily to 6 particular residents, the nature of the issues potentially affected all the residents.

For these reasons, the commission decided that the most effective way of addressing the issue was to inquire into the service's policies and practices, and management accountability. This would allow a focus on service provision to all residents, rather than only investigating the particular allegations which had been brought to our attention.

The Inquiry was conducted in accordance with the provisions of s83 (1) (d) and (e) of the *Community Services (Complaints, Appeals and Monitoring) Act 1993*. These sections are attached at Appendix 1.

A number of complaint allegations which raised significant questions of safety and well-being of residents were investigated separately, and are the subject of a separate report. These allegations are listed at Appendix 2.

## **2. CONDUCT AND SCOPE OF INQUIRY**

### **2.1 Terms of Reference**

Terms of Reference developed by the commission for the Inquiry contained 4 objectives. These objectives related to policies and procedures; service delivery to residents; and monitoring and accountability mechanisms, both within and external to the service. Within each objective, there were key areas examined. The full Terms of Reference are attached at Appendix 3.

### **2.2 Methodology**

The Inquiry drew on the methodology developed for the performance audit of large residential centres for people with a disability. This methodology was developed by the Performance Audit Branch of the Audit Office of NSW, in consultation with the Community Services Commission, the Department of Community Services (DOCS) and the Ageing and Disability Department (ADD) in 1996.

### **2.3 Scope of Inquiry**

Information for the Inquiry was collected through the following activities:

- Inspection of Cram House
- Interviews with nursing staff and nursing assistants (4)
- Interview with technical aides (2)
- Interviews with the Director of Nursing (“DON”), Chief Executive Officer, President and 2 other members of the Board
- Discussions with parents (19) and advocates (5) at parent/advocate forums and through telephone and other direct contact
- Discussion with staff (40) through a staff forum, about the scope and process of Inquiry
- Review of service documents
- Review of client files (11)
- Examination of information collected by the commission since July 1996 through complaints, monitoring by the Community Visitor, and a review of a resident under s.11 of the *Community Services (Complaints, Appeals and Monitoring) Act 1993*
- Review of documents provided by ADD and DOCS about their roles and interactions with Cram House
- Discussions with staff of ADD and DOCS.

The ‘on site’ component of the Inquiry was conducted at Cram House from 14 to 17 April 1997 and was undertaken by 3 staff of the commission. Collecting and analysing information regarding external accountability and monitoring was conducted as a separate (and later) component.

## **2.4 Opportunity for Comment on Findings**

Following the completion of the on-site component of the Inquiry in April, the Inquiry team conducted an ‘exit interview’ with management and some Directors of the Society. The purpose of this interview was to advise the service of the preliminary findings of the Inquiry in relation to the adequacy of policies and practices, and to give it an opportunity to provide any further information to the Inquiry.

When the written preliminary report of findings had been prepared, the commission met with the Chairperson and (the then new) Executive Officer in June 1997 to discuss the findings and seek a formal response from the service. The commission also issued the preliminary report to DOCS and ADD. In each case, the commission sought comments regarding the findings of the report, and information or suggestions as to how to address the Inquiry’s findings.

In the intervening period, a number of additional issues came to light, requiring the commission to obtain further information to consider for the Inquiry. We also requested that the Society provide further information to the Inquiry from its Director of Nursing and Medical Practitioner regarding medication practices.

The commission sought the opinion of an independent expert medical practitioner to assist us in assessing the responses to these medication issues,<sup>1</sup> and advice from the NSW Health Care Complaints Commission (HCCC) regarding matters which may warrant referral to them for further action.

The commission sought independent medical advice without disclosing the identity of the service, the medical practitioners or residents involved. Information provided to the HCCC also did not identify any individuals (practitioners or residents).

A draft of our final report containing additional findings and proposed recommendations was distributed to the Society, DOCS and ADD for comment in November 1997.

We have considered comments made by all parties in finalising this report. Where appropriate we have included information provided in responses to the preliminary report, or amended our findings after considering the new information.

The responses from the Society, ADD and DOCS have been considered in formulating the recommendations of this Inquiry. The commission also consulted a number of consumer and advocacy groups before finalising our recommendations. (See Appendix 4 for listing of groups consulted).

We note that the Society has stated that the findings of the Inquiry “are of grave concern to the Board of Directors ... it is obvious that considerable changes are necessary to ensure our service complies with the various legislative requirements. ... The Board undertakes and is willing to comply with any recommendations of the commission emanating from the Inquiry into Cram House , and we are looking at the report as a positive means of improving the services provided.”<sup>2</sup>

The response from the Society is attached in full at Appendix 5. The comments of ADD and DOCS in response to the draft of the final report are also attached (Appendices 6 and 7).

### 3. CONTEXT OF THE INQUIRY

There are a number of instruments and principles which reflect international thinking about the care, treatment and rights of all people, and for people with disabilities and children specifically. These include the Universal Declaration of Human Rights (1984); the United Nations Declaration on the Rights of the Intellectually handicapped (1971); the International Covenant on Civil and Political Rights (1966) and the Convention on the Rights of the Child (1990).

---

<sup>1</sup> Dr Michael Ryan of the Child Protection Unit, New Childrens Hospital, Westmead.

<sup>2</sup> Response to preliminary inquiry report, dated 5.9.97

The Convention on the Rights of the Child requires that:

*State Parties recognise that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child's active participation in the community.*  
(Article 23)

Locally, the key principles, standards and expectations applied in this Inquiry are found in a number of pieces of legislation and their associated instruments. These include the:

- *NSW Disability Services Act 1993*, which requires that services are provided in line with the Objects, Principles and Application of Principles of that Act. These include requirements that services further the integration of people with disabilities into the community, and enable people with disabilities to achieve positive outcomes and their maximum potential as members of the community.
- *Disability Services Standards*, which provide an interpretation of the Principles and Application of Principles and are used by services and ADD to determine whether services are being delivered in accordance with the Principles and Application of Principles.
- *Guardianship Act 1987* which established principles in relation to the rights of people with a disability to exercise freedom of decision making and action, and to express and have their views taken into account in key decisions. The Act also provides a framework for acknowledging the importance of family relationships, the need to encourage self-reliance in persons with disabilities and the need for protection from neglect, abuse and exploitation.
- *Children (Care and Protection) Act 1987* which provides a framework for the protection and safety of children, particularly those in need of care. The Act reinforces the welfare and interests of the child as the paramount considerations and emphasises that children must have opportunities to develop physically, mentally, morally, spiritually and socially in conditions of freedom and dignity. The Act also emphasises the importance of family relationships and the clear preference that wherever possible, children should grow up in the care of their parents.

Recent changes in the provision of substitute care services for children who are unable to live with their families of birth have resulted in progression towards the development of standards in this area as well.

Over the past few years in particular, the issue of appropriate care options for children with a disability has received increasing attention. A recent report

“Families with Young Children with Disabilities and High Support Needs”<sup>3</sup> found that most families interviewed expressed “a strong sense of responsibility and desire to provide family care” and that those families seeking or using alternative care were doing so because it was “necessary for family survival - physically, emotionally or socially.”<sup>4</sup> Llewellyn notes that there is a:

---

<sup>3</sup> Llewellyn, G. et al 1996

<sup>4</sup> Ibid pg 3

*current lack of attention given to the ongoing nature of placement for children with a disability. There is no identified framework for long term planning for these children which ensures their emotional, physical and socio-cultural needs are met....*

*Instead the child with a disability enters the 'disability' system with a focus on their disability rather than their needs as a child and their family needs.<sup>5</sup>*

It has also been proposed that a new standard be included in the Disability Services Standards recognising the particular needs of children with a disability, as follows:

*Each child has the right to be supported in an appropriate family setting, the right to respect for their evolving capacity for independence and the right to any guidance and support they may need.<sup>6</sup>*

#### **4. SERVICE BACKGROUND**

##### **4.1 Service Profile**

Cram House is a residential service operated by the Society in Wollongong, funded through the *NSW Disability Services Act 1993*. There are 26 children and young adults living at Cram House, ranging in age from 2 to 31 years. All residents are described as having "severe intellectual and physical disabilities, requiring extensive personal care".<sup>7</sup> The service is intended for children to the age of 16 years, and the service advises parents that it is their responsibility to arrange for alternative services to enable residents to leave the service when they turn 16.<sup>8</sup> However, the service reports that the lack of appropriate alternative services for young adults with high support needs has meant that many residents have remained well beyond their 16th birthday.

##### **4.2 Physical Accommodation**

Cram House was originally established in 1975 as a nursing home for children. Although some upgrading of the building was undertaken in 1982 to provide for less institutional accommodation, the physical environment is still one of group based care.<sup>9</sup> Sleeping accommodation includes dormitory style rooms for 8 or 4; double bedrooms and some single bedrooms.

---

<sup>5</sup> Ibid pg 5

<sup>6</sup> Proposed by the Ageing and Disability Department's Advisory Committee on Disability Programs, Policy and Planning

<sup>7</sup> Illawarra Society for Crippled Children Annual Report 1995/96

<sup>8</sup> Cram House Admissions Policy brochure (undated)

<sup>9</sup> Annual Report 1995/6

There are two 'living areas'; one which is directly outside the bedrooms in the new part of the building, which is a thoroughfare and accommodates the nursing station.

The other is a large room used for recreation, meals and television. The outdoor recreation area consists of a covered courtyard, with BBQ and a small fenced in yard with a swing and a slippery dip.

### 4.3 Staffing and Management

Direct care staff are made up of Registered Nurses, Enrolled Nurses and Assistants in Nursing. The Director of Nursing (DON) is responsible for "staff performance issues and direct client services.... clinical standards and outcomes, provision of medical support services and developing individual service planing for all clients in Cram House."<sup>10</sup> The DON reports to the Executive Officer. Other staff employed by the Society who are involved with the residents of Cram House include drivers, therapy aides, domestic staff and outdoor staff. The Society also operates a group home for 4 residents, which was not included within the scope of the Inquiry.

The Illawarra Society for Crippled Children is a company governed by a Board of Directors, drawn from the membership. The membership and Board are primarily interested individuals from the local community, with varied backgrounds. The Board has established a House Committee comprising 4 Board members, the Executive Officer and the DON which meets monthly to discuss operational and management issues.

The commission notes that there has been a change of Executive Officer during the course of the Inquiry. At the time of the complaints being lodged with the commission and the Inquiry being conducted, the Executive Officer had held the position for some 15 years. That Executive Officer resigned from the position at the end of April 1997, and the current Executive Officer commenced duties in June 1997. At the 1997 Annual General Meeting, there were also a number of resignations of Directors, and new Directors elected (including some who are parents of current residents).

### 4.4 Funding and Income

The Society currently receives in the order of \$1,050,000 funding per annum for Cram House, from ADD. In addition, charges to residents for accommodation total \$76,000 per annum. The Society also generates income from legacies, fund-raising, donations and investment income, in the realm of \$319,609 per annum.<sup>11</sup>

---

<sup>10</sup> Transition Plan, pg 5

<sup>11</sup> Annual Report 1995/96

The funding agreement between the Society and ADD (and previously the DOCS) is a standard Deed of Funding Agreement Advance of Funds, with standard conditions of funding. These Funding Agreements are general documents, used across a range of programs with different target groups, and program aims and objectives.

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.

## **PART B: EVIDENCE AND SPECIFIC FINDINGS IN RELATION TO OBJECTIVES**

### **1. OBJECTIVE 1 - SERVICE POLICIES AND PROCEDURES**

**To identify whether key policies and procedures to protect the human and legal rights, safety and dignity of consumers are in place, and accessible to direct care staff and consumers, their families and other advocates.**

Under this objective, the Inquiry examined the key areas of policy development; policy coverage and adequacy; accessibility of policies and procedures; and policy implementation.

#### **1.1 Policy Development**

1.1.1 The Inquiry was provided with a document outlining “Philosophy and Objectives” of Cram House, in addition to the following policy documents:

- Meeting individual needs
- Privacy, dignity and confidentiality
- Emergency procedures when on outing
- Participation and integration
- Movement of patients from Cram House (dated February 1996)
- Family relationship policy
- Safety procedures including security, death, emergency procedures, fire safety and disaster plans, and infection control
- Grievance procedure policy
- Human rights and freedom from abuse
- Valued status
- Service management
- Voluntary workers (endorsed by Board of Directors on 28.3.95)
- Citizen Advocacy (endorsed by Board of Directors)

1.1.2 Other than where noted above, policy documents are undated and unendorsed. The Inquiry was informed that most policies have been developed since September 1996, by the DON, and are in draft form only. Nevertheless these are the only guidelines available to staff working with the children and young adults at Cram House.

1.1.3 There is no systematic consultation with consumers, families or advocates in policy development. While some staff stated that parents were “definitely consulted” in the development of policies, this was not confirmed by the parents.

Parents generally reported a high level of satisfaction with service policies, but their level of involvement and understanding of the policies was minimal.

1.1.4 The Board of Directors appears unclear about its role in endorsing and reviewing policy. Board members interviewed during the Inquiry said they “thought” that policies were in place, and expressed confidence in the Executive Officer’s oversight of policy development. However, only two policies (Voluntary Workers and Citizen Advocacy) have been submitted to the Board for endorsement; the rest remain in draft form and have been neither sighted nor endorsed by the Board.

1.1.5 In response to a request from the Inquiry for any policy documents relating to identified practice areas, the service provided a brief outline of current practice in those areas where no policy existed. This included the following areas:

- meeting individual needs
- behaviour intervention and support
- management of critical incidents
- use and provision of medication
- standards of nutrition, hygiene and health care
- access to the community and recreational opportunities
- decision making and choice
- skill development

These explanations of current practice however were developed in response to our request for information. They were not policy or procedure documents which were available to staff.

## 1.2 Policy Coverage and Adequacy

1.2.1 Policy coverage is listed in 1.1 above.

1.2.2 Policies have been developed mainly where there is a requirement under the Disability Services Standards, or to meet an identified need (eg. Citizen Advocacy). Management and staff informed the Inquiry that some procedures do not exist because the service has seen no need for them - eg. there was no perceived need for a procedure for responding to allegations of abuse, as they reported that such allegations were never made.

1.2.3 Policies do not adequately cover key practice areas. Gaps include:

- responding to allegations of abuse
- guardianship issues

- consent
- behaviour intervention and support
- management of critical incidents involving residents
- documentation and record keeping
- meeting individual needs
- use and provision of medication
- standards of nutrition, hygiene and health care
- access to the community and recreational opportunities
- decision making and choice
- skill development

The Transition Plan for the service also identified the development and implementation of policies and procedures as a key step in bringing the service into line with the Standards. In the Transition Plan, the Society stated that it would establish a Policy and Procedures Working Group and forward draft policy statements to DOCS by September 1996 and have policies in place by June 1997. However, this has not occurred.

DOCS, in its response to the preliminary Inquiry report noted that "advice to DOCS was that there was work in progress on the policies and procedures."<sup>12</sup> However, it is apparent that DOCS was not provided with copies of policies as required by the Transition Plan.

- 1.2.4 Policies and procedures are not framed in a manner which promotes accountability - ie. it is difficult to say whether staff have complied with a policy or not, as the policies are too vague. For example the Privacy, Dignity and Confidentiality Policy includes statements such as "Minimise access to the house by others"; "avoid discussing clients personal information without prior consent".
- 1.2.5 Policies are not sufficiently detailed to provide clear procedural guidance for staff, yet they are the only guidelines from which staff operate. The majority of policies and procedures do not identify key responsibilities or authorisations, and some do not provide all necessary information, including any legal obligations.
- 1.2.6 Some existing policies do not promote good practice. For example, the Grievance Procedure Policy requires that complaints be documented in a way which does not ensure confidentiality for complainants (by recording all complaints in the diary kept on the nurses station). This policy also does not allow for situations where a complaint cannot be resolved directly with the DON, and contains out of date information about external complaints mechanisms.

---

<sup>12</sup> DOCS response to preliminary inquiry report, dated 8.8.97

- 1.2.7 If provided to families or advocates, existing policies would not adequately inform them of their rights or of standards of practice to be expected from the service.
- 1.2.8 Information provided to the Inquiry about practices in relation to key areas is not supported by policy information for either staff or families. For example, the Inquiry was told that parents are requested to attend medical appointments with their child but “only a few respond despite phone calls the night before”;<sup>13</sup> yet there are no policies or guidelines which state a parent’s right to choose their child’s medical practitioner, or to be consulted when arranging such interviews.

### **1.3 Policies and Procedures are Accessible**

1.3.1 Most policies are kept in folders at the nursing station which contain policies relating to Standards, plus numerous other instructions, memoranda and staff notices. The folders also contain job descriptions, shift duties lists, and a range of other documents (eg. an instruction about the glass door, and information about enteral feeds). The Citizen Advocacy Policy was found by the Inquiry team on an individual client’s file.

1.3.2 The Inquiry found differing levels of awareness of the content of particular policies amongst staff (ranging from low to reasonable), although there is a high level of staff awareness of the existence of policies and their location.

Certain procedural guidelines (eg. how to lift and change a particular child) are documented (including photographs) and displayed on walls.

1.3.3 The Inquiry was provided with a copy of a memo to “all permanent staff” (undated and unsigned) stating that all staff are to “be aware of the Society’s policies and procedures relating to use of equipment, procedures relating to job description, infection control, O.H.&S., and disability standards”. However, none of the job descriptions reviewed by the Inquiry made any reference to staff requirements to know about or act in accordance with policies and procedures.

1.3.4 Parents are generally not aware of the existence or content of policies, and the service does not routinely advise families or advocates when new policies are developed.

1.3.5 Although both staff and management stated that policies would be provided to people if they asked for them, a number of people reported

---

<sup>13</sup> Document titled “Involvement of families/advocates in decision making and promotion of relationship with families and advocates”

---

to the commission that they had met with resistance from the service in the past when attempting to obtain a copy of the Grievance Policy.

- 1.3.6 Despite the development and implementation of policies being a key component of the approved Transition Plan, copies were not provided to DOCS as required.

DOCS reports that this failure to provide copies of policies occurred despite their repeated requests to the service to do so.<sup>14</sup> There is also no evidence that DOCS included a review of policy development as part of its monitoring role for this service, despite it being an identified need.

## 1.4 Implementation

- 1.4.1 The Inquiry found no evidence of specific training or orientation activities accompanying the introduction of new policies. The service relies on staff meetings as the primary mechanism for discussing new policies with staff. However, staff meetings are poorly attended (attendance ranging from 5 - 20 staff<sup>15</sup>) as staff who are not on duty attend in their own time if they choose. Minutes of the staff meetings do not provide sufficient information to adequately convey policy discussions.

- 1.4.2 There is no system for informing families and advocates of new policies.

### Major findings in relation to adequacy of policy and procedures:

1. Cram House does not have an adequate policy framework to establish expectations and standards of service delivery, or to guide staff in their support of residents. There are insufficient policies even in the key practice areas which have an impact on human and legal rights, and safety of residents.
2. The absence of policies and procedures in these areas means that Cram House is unable to assure that all staff are aware of and comply with any legal and policy obligations which protect the rights of residents, and protect them from abuse or poor treatment.
3. Where policies and procedures exist, the failure of Cram House to provide information about them to consumers, family members and advocates limits their usefulness in promoting accountability.

---

<sup>14</sup> DOCS comments on draft final Inquiry report, 10.12.97

<sup>15</sup> From review of staff meetings book from April 96-April 97. The exception to this was the staff meeting held during the Inquiry, which was attended by 40 staff



## 2. OBJECTIVE 2 - SERVICE DELIVERY TO RESIDENTS

To review the implementation of policies and procedures in key areas to ensure that they are effective in protecting and promoting consumers' human and legal rights, safety and dignity, and comply with government and service policy directions.

Under this objective, the Inquiry examined service practices in 11 key areas important in protecting residents' rights and safety.

### 2.1 Behaviour Intervention

2.1.1 The service does not have clear policies or procedures for responding to residents with challenging behaviour, despite the fact that at least four residents are identified by staff and through file reviews as falling into this category. The behaviours identified in the 'behaviour/fitting chart' include hitting and pushing staff and other residents, scratching and biting self, screaming, and throwing furniture and other objects.

Almost 20% of Staff Accident Report Forms for the past 12 months resulted from behaviour of residents, recording injuries of scratches, bruising and soreness. In another incident, a resident was injured, requiring stitches.

2.1.2 There are no guidelines around prohibited responses to challenging behaviour (although all staff stated that they would not be allowed to strike, hold or shout at a resident), nor are there any guidelines as to the authorisation needed for restricted practices. While the Inquiry found no evidence of restricted practices currently in use, the lack of policy leaves open the prospect of staff responding to behaviour in a way which is potentially unlawful.

2.1.3 The inconsistent documentation of behavioural incidents makes it difficult to identify the extent and seriousness of any challenging behaviour. The service advised the Inquiry that any incidents of behaviour should be logged on the 'behaviour/fitting' chart. However, some injuries reported on Staff Accident Report Forms as resulting from residents' challenging behaviour do not have corresponding entries in the behaviour chart. The way in which information about behaviour incidents is recorded also does not contribute to any analysis of the function or triggers of behaviour.

2.1.4 Only 2 of the 4 residents identified by the Inquiry as having challenging behaviour had documented behaviour management strategies. In one of these cases, the resident has a documented strategy to prevent her from eating clothing (identified as an issue in her ISP under 'financial'),

yet her behaviour chart identifies that she has aggressive behaviour such as throwing furniture around.

Another resident has challenging behaviour such as 'tantrums', general agitation and frequent refusal to eat recorded on his chart, but no strategy for managing these behaviours.

- 2.1.5 The service states that it has attempted to obtain expert assistance for residents with challenging behaviour through the DOCS' Behaviour Management Team.<sup>16</sup> However at least one of these referrals was instigated by a parent, rather than by Cram House.<sup>17</sup> The service reports difficulty and significant delays in accessing behaviour management support through DOCS.

In contrast, DOCS report that the local program team conducted an assessment of one resident's behaviour, but that the recommendations and suggestions were not taken up by Cram House, with the service requesting that the program team actually conduct the program, rather than training the staff of Cram House.<sup>18</sup>

- 2.1.6 Management and staff appear to have no appropriate framework for thinking about challenging behaviour (eg. function, purpose of behaviour, alternatives). For example, the Inquiry was informed that "bad" behaviour is recorded in a "behaviour/fitting" book. The format of these charts is geared to recording the time, description and duration of epileptic seizures, rather than the recording of important information about behavioural incidents (such as preceding events, duration, severity, other people involved, consequences or following events).

One resident labelled as having 'bad' behaviour has a chart titled 'Tantrums' displayed prominently on the wall, which contains the following statement: "(resident) can have a tantrum for no reason eg. doesn't like food on trolley or wants to wear special clothes".

Another resident has cerebral palsy and athetoid movements of his arms, and is described by the service as being able to "control these movements about 80% of the time". Despite this, his behaviour chart includes references to "refused to keep arms on lap", "wouldn't keep arms in" etc. Staff have also labelled his arm movements as "hitting".

- 2.1.7 Staff do not have expertise in behaviour intervention and there is a tendency to label residents who exhibit challenging behaviour as "problems". Despite this lack of expertise, and the identified need for behaviour intervention, the service has not attempted to develop the

---

<sup>16</sup> Referral for one person in 1995 and another in 1997

<sup>17</sup> Letter from Illawarra Programme Team (DOCS) to Cram House dated 25.9.95

<sup>18</sup> DOCS response to preliminary report, dated 8.8.97

skills or competencies of staff in behaviour intervention, even when the opportunity was offered by DOCS.

- 2.1.8 The experiences of the local DOCS programming team are consistent with these findings. The department reports that the program team “identified a number of issues impacting on the particular individual with whom they worked. These included the inappropriateness of the physical environment for this young person, the lack of available resources for program implementation by Cram House, a need for staff training and limitations with the basic routine of Cram House which follows a feeding and basic care scenario.”<sup>19</sup>
- 2.1.9 Behaviour management strategies for individual residents are reportedly discussed at staff meetings, but minutes of these meetings provide inadequate guidance for staff.

### **Major Findings in relation to Behaviour Intervention and Support:**

4. Cram House has not provided the guidelines or training to enable staff to provide appropriate intervention or support to residents with challenging behaviour, even when external specialist support was available. In this regard, the service has failed to take appropriate steps to protect staff or other residents from injuries which may result from resident aggression.

## **2.2 Management of Critical Incidents**

- 2.2.1 The service has a form for recording “accidents and untoward occurrences to residents”. Completed forms are retained by the Executive Officer.

The form states that it is a “Confidential Report, prepared at the request of, and for information of, the Solicitors to the Board of Directors... to enable (them) to give advice in view of anticipated litigation”. However there is no accompanying policy or guidelines to make it clear when the form is to be filled out.

The DON told the Inquiry that the form is only filled out when the “untoward occurrence” results in an injury requiring medical attention. However initial information provided to the Inquiry by the service stated that “all accidents” would be reported to the Sister in Charge and written up on accident forms.

- 2.2.2 The Inquiry was told that both the DON and the Executive Officer review “untoward occurrence” forms, however there is no documented evidence of this.

---

<sup>19</sup> DOCS response to preliminary report, dated 8.8.97

- 2.2.3 There were only two “untoward occurrences” involving residents reported in the period April 1996 to April 1997 - one where a resident required stitches, after being pushed by another resident,<sup>20</sup> and another reporting that that a resident had fallen out of bed and landed on his head.<sup>21</sup>

Neither of these reports included any comments or directions about follow-up action, or strategies for prevention of future similar occurrences. There was also no corresponding entry in the behavioural chart of the incident resulting in the injury to the resident requiring stitches.

In other cases, forms recorded major injuries but with no explanation as to how the injury was sustained. For example an “untoward occurrence” form noted that a resident had fractured her arm, but with no explanation of how it happened.<sup>22</sup> The only reference to this in the resident’s file is a notation that the resident was seen by an orthopaedic surgeon on 10.5.94 regarding a fractured arm.

- 2.2.4 The Inquiry reviewed other documents (eg. client files, diary, House Committee Minutes) and identified a number of other incidents which could be considered “untoward occurrences”, but which were not reported as such.

Examples include:

- confirmed notifications of abuse of a resident by a staff member on 27.9.96 and 6.12.96
- a resident found with his head jammed near the bed rail on 31.1.97
- unexplained bruising on breast and foot, and scratches to buttock on a resident on 12.2.97
- bruising to a resident’s left shoulder following a fall on 16.3.97

The Inquiry could find no evidence of any follow-up in relation to these notations.

- 2.2.5 Staff are not required to consider preventative or remedial action following accidents/incidents, and critical incident information is not collated or reported to the Board, or analysed in any other way.

---

<sup>20</sup> Dated 31.5.96

<sup>21</sup> Dated 22.3.97

<sup>22</sup> “untoward occurrences” form dated 6.5.94

- 2.2.6 Parents reported that they are promptly informed by staff about injuries or accidents involving their children, and that appropriate medical attention is sought whenever necessary.
- 2.2.7 Accidents involving staff are recorded on a "Staff Accident Report Form", regardless of whether medical attention is required. There is provision on this form for both the DON and the Executive Officer to sign, although there is no evidence of any systematic follow up.
- 2.2.8 There were 46 staff accidents reported between April 1996 and April 1997, compared with only two for residents during the same period.
- 2.2.9 There are no documented procedures for responding to or investigating allegations of abuse or mistreatment against staff. The Inquiry was informed that the service believed there was no need for such procedures. However, the Inquiry identified 3 allegations of abuse or mistreatment by staff in 1996, and the early months of 1997, and also found evidence that other allegations and notifications of residents had been made in the past.

The House Committee minutes for 19.6.96 include a report from the Executive Officer that a parent had allegedly been assaulted (hit with a chair) by one of the nursing staff, and that "written reports have been received from both parties". The House Committee recommended that this matter be discussed by the Board, yet there is no mention of it in subsequent Board Meeting Minutes and no evidence of any further action having been taken.

In relation to another incident, written statements were obtained from the staff, following an alleged assault of a resident by a staff member in September and December 1996. However, the DON told the Inquiry that there was no need for further action because "staff wouldn't hit a client". This was despite advice from DOCS to Cram House that the notifications had been confirmed and referred to the Police for investigation. This inability to acknowledge the risk posed by the staff member to the resident is also reflected in a document prepared for a follow-up meeting between Cram House and DOCS in relation to this resident's 'transport arrangements' in January 1997, in which the service maintained that "there is no evidence to prove that these (assaults) happened" and that "(the staff member) is not happy if he is going to be accused of hitting (the resident)."<sup>23</sup>

- 2.2.10 There is little understanding amongst staff of child protection issues, and no documented procedures for responding to alleged abuse of residents who are children.

---

<sup>23</sup> Document inviting parties to a meeting at Cram House on 22.1.97 (3.4.15)

For example, the service did not notify DOCS about alleged abuse of the resident by the staff member in September and December 1996, and the allegations were reported to the House Committee and subsequently to the Board in the context of “transport problems”.

The Inquiry also found a file note (undated, but reportedly some two years old) recording a telephone call from DOCS advising that an allegation had been made that a staff member had assaulted a female resident, resulting in bruising. The service had the resident checked by their Medical Officer (also a Director of the Society at the time) for bruising, advised DOCS that they did not find any evidence of bruising, and informed the staff member allegedly responsible about the notification. There is no evidence of any further action, either by the service or DOCS.

The Executive Officer informed the Inquiry that, in the event of an assault or “severe, unexplained injury” to a resident, she would consult the solicitors on the Board as to what action should be taken.

- 2.2.11 The Inquiry found that over the past 3 years, 6 children and young people have died while in the care of Cram House. These deaths are reported to the Board as “de-registrations” with little other information. The Inquiry notes that in each of the six cases, the death certificates were signed by the General Practitioner (GP) who is regularly used by the service, and who is also a long standing board member. Cram House advised that the deaths of residents are not reported to any external authority such as the Coroner, Police, DOCS or ADD. Wollongong Local Court (which is the local Coroners Court) confirmed that none of these deaths were reported to their office for investigation.<sup>24</sup> It appears that there are no formal requirements for the reporting of deaths of children with disabilities in the care of non-government service providers. (See Section 4.3 for further discussion)

While it may be appropriate for the regular GP to sign death certificates of residents, he has also held a long standing position as a Director of the Society. This, together with the absence of any external reporting (and therefore possible review or monitoring) of deaths of residents, deprives residents, their families and the general public of adequate assurances that all the circumstances surrounding the deaths of children and young people at Cram House are openly and rigorously considered.

---

<sup>24</sup> Letter from Coroner, Wollongong Local Court, dated 11.9.97

**Major findings in relation to management of critical incidents:**

5. Cram House does not have an effective system to respond to, record or monitor critical incidents involving residents.
6. The service has failed to deal appropriately with allegations of abuse of residents, unexplained injuries to residents, or to deal with safety risks posed by repeated injuries or behavioural incidents.
7. There are no preventative measures in place to ensure the safety of residents.
8. The current practice of the regular GP who is also a board member signing death certificates and the absence of any external reporting of deaths provides inadequate accountability regarding the circumstances of each young persons death.

### **2.3 Medication and Consent for Treatment**

- 2.3.1 The service has no policy regarding consent for medical treatment. Information provided to the Inquiry in relation to the use of medication does not refer to consent issues.

Parents are required to sign a general consent form when their child enters Cram House which provides the service with the authority to arrange for “necessary medical attention, including anaesthesia, blood transfusions and/or surgery” as directed by a qualified medical practitioner. The consent form goes on to say that “such measures will only be invoked when time does not permit parents to be consulted beforehand”.<sup>25</sup>

The wording of this form inappropriately places the onus of decision making for medical treatment on the service and its medical practitioner. It fails to make clear that parents retain guardianship responsibility for their children under the age of 16, unless otherwise determined by the Children’s Court, and that there are designated ‘persons responsible’ for providing consent to medical treatment for adults, under the *Guardianship Act 1987*.

---

<sup>25</sup> Illawarra Society for Crippled Children - Cram House Admission/Consent form

2.3.2 The Inquiry found no reference to consent for medical treatment in the files of children reviewed, even where young children are being prescribed drugs which are identified in the *Guardianship Act 1987* as major medical treatment for adults.<sup>26</sup> Examples include a 4 year old prescribed Mogadon over a period of at least 6 months<sup>27</sup>, and an 11 year old prescribed a variety of central nervous system affecting drugs (including Clobazam, Mogadon, Serenace, Valium and Prozac).<sup>28</sup> This is at odds with the wording of the Admission Consent form which imply that parental consent would be obtained except in cases of emergency.

Staff themselves appeared unsure of the requirements for consent to medical treatment, with some reporting that they thought the service posted consent forms to parents, which were then returned and kept on resident's files. Other staff reported that parents would only be contacted in the case of 'drastic' medication changes, but that in most cases decisions about medication are made between the medical officer and the DON. The Inquiry was also informed that attempts were made to obtain parental consent over the telephone, but that such attempts were not always recorded. The service also reported that in some instances parents may be difficult to contact.

In her response to the preliminary findings regarding the absence of documented consent for medical treatment, the DON argued that in all cases cited, parents had been involved in discussions with the relevant medical practitioners, but admitted that the details and information relating to consent for such treatment was "not on our files".<sup>29</sup>

Following the presentation of the preliminary report of this Inquiry, the medical practitioner for Cram House informed the Executive Officer that "informed consent has not been obtained in writing from the parents or guardians of the children for each specific medication but clearly consent has been obtained for the treatment of epilepsy requiring varying and multiple medication regimes by the very fact of their admission to the Illawarra Society for Crippled Children and they have signed normal consent forms for treatment."

In its review of the preliminary report, DOCS noted that "It is doubtful that the signing of a general consent at the time of admission to Cram House is of itself sufficient authority, particularly as that form implies that parents will ordinarily be consulted before the provision of medical treatment."<sup>30</sup>

---

<sup>26</sup> In the Guardianship Regulation 1995

<sup>27</sup> From medication charts: August 1996 - March 1997

<sup>28</sup> From medication charts March-May 1996

<sup>29</sup> Response from DON to EO following preliminary report of Inquiry, dated 6.8.97

<sup>30</sup> Attachment to DOCS response to preliminary Inquiry report, dated 8.8.97

Independent medical opinion obtained by the commission stated that “the Director of Nursing should be aware of the requirements of the *Guardianship Act* in relation to informed consent, and should thus draw to the attention of the medical practitioner his/her responsibility to obtain informed consent.”

- 2.3.3 The Inquiry found that some of the young adults were also receiving medical treatment without the informed consent of their ‘person responsible’.

Of the 10 client files reviewed by the Inquiry, 7 were for residents over the age of 16 years. As adults, any decisions regarding medical and dental treatment are regulated by the *Guardianship Act 1987*, and its associated regulations.

Of these 7 young adults, 6 were receiving medical treatment defined as ‘major’ under the Act, including Depo Provera, anti-anxiety medication, and anti-psychotic medication. Depending on the circumstances, such medical treatments require the written consent of the ‘person responsible’ (usually previous family carer), or where no ‘person responsible’ is available, the consent of the Guardianship Board.

There were only 3 written consents from parents found on file for major medical treatment. These were non-specific in their terms - eg. “agree to hormone therapy”, with no reference to dosages or timeframes for review. In one case, the consent was undated. None of the consents indicated that information had been provided about the need for treatment, possible risks or side-effects of the proposed treatment, or alternative options for treatment.

- 2.3.4 Of the client files reviewed, 5 of the 11 were young women aged over 17 years. 4 of these 5 are currently using either Depo-Provera or the contraceptive pill. Records indicate that the purpose is menstrual suppression, with one consent (provided on Medical Officer’s letterhead for the parent to sign) explicitly stating that “it is to help control her periods so that she may be easier nursed.” (sic).

The use of any treatment for the purpose of eliminating menstruation requires the written consent of the ‘person responsible’ or the Guardianship Board. No consent was found in one of these cases, and in others the consent was non-specific. There is no evidence on the files that alternative approaches to menstrual management were discussed (either within the service or with parents) before resorting to chemical suppression.

- 2.3.5 The Inquiry noted a number of children were prescribed medications listed as being 'not recommended for children' or where the safety and effectiveness of the drug in children is not established.<sup>31</sup> These drugs include Mogadon, Clobazam, Prozac and Serenace. There was insufficient documentation to demonstrate the clinical justification for the use of such drugs in young children or that informed consent to this medical treatment was provided by parents.

Further information provided by the service following the preliminary report indicates that much of this medication has been ceased. The commission sought independent medical opinion on the clinical appropriateness of such medications, given the age and diagnosis of the individual children concerned. This opinion has reported that in some circumstances some of these medications **may** be clinically justified. However, the opinion also noted a number of areas of concern in relation to the levels of some medications, and the need for regular specialist review of such medical treatment. The commission remains concerned at the process and circumstances associated with the use of such medication in these young children.

- 2.3.6 The service has no guidelines for dealing with situations where a child does not have significant family contact, and consent for medical treatment is needed. This is despite the fact that staff and management have identified a number of residents who have little or no contact with their families, and there are references in House Committee minutes to parents who "cannot be found".<sup>32</sup> The Inquiry was informed that a number of residents have families who have no contact with the child, other than to respond to a consent request issued by the service, often "at the last minute".

For example, the House Committee reported to the Board in May 1996 that "(resident's) mother appears to have left her address and cannot be found", and recommended that DOCS or the Guardianship Board be contacted. The Inquiry found no evidence of this recommendation having been acted on. The service reported that the referral had not been necessary because the mother did make contact when needed for a specific consent.

In at least one case, the service has failed to seek needed medical treatment on the basis that parents could not be contacted or were perceived to be disinterested. One resident, who weighed only 5.5 kgs at 10 years of age, was denied any intervention or treatment because her "family are not interested". The service reported that there had

---

<sup>31</sup> See MIMS Annual 1996

<sup>32</sup> See for example May 1996

## **Report of Inquiry into Cram House**

---

been minimal family contact over the 10 years the child had been a resident.

However, neither the commission nor DOCS (in their assessment for care proceedings) could find evidence that the service had attempted to follow-up with the family about this child's condition. Records indicate that there have been concerns about her low weight status since at least 1992, but with no action taken by the service to secure appropriate medical assessment or treatment, or to advise DOCS that she may be in need of care given the lack of contact with her family. When the commission brought this child's situation to the attention of DOCS, care proceedings were initiated, and she was made a ward of the state.

- 2.3.7 Although two residents were prescribed medication apparently for behavioural purposes (Mogadon and Valium PRN for one girl, Tegretol for a young man<sup>33</sup>), there was no link between the use of medication and other behaviour management strategies.
- 2.3.8 The Inquiry did not find consistent evidence of reviews for some medications - eg. neurological reviews for people on anti-epileptic medication.
- 2.3.9 Client files contain inconsistent/contradictory information about clients' medical conditions - eg. one young person's physiotherapy programme states that he has grand mal seizures, but this is not noted elsewhere on his file and the Inquiry found no evidence of him having been prescribed anti-convulsant medication.
- 2.3.10 Medication charts do not show the purpose of prescriptions, whether prescribed on a schedule basis or on a PRN basis. For example, there were no guidelines or indications on the medication chart for one girl about when PRN Valium was to be administered. File review showed that staff used PRN Valium to sedate her for reasons such as "refused to go to bed", "tantrums" and "usual nuisance behaviour". On another medication chart, there is no information to indicate whether Tegretol was prescribed for a young man for epilepsy or aggression.

There appears to be a lack of clarity within the organisation as to respective responsibilities for ensuring appropriate medication systems. The DON is responsible for the services provided within Cram House, which should include overseeing the services provided by any visiting medical practitioner and ensuring that legal and practice requirements are met in relation to medical treatment and any associated instructions. However, in response to the preliminary findings, the DON stated that the matter of insufficient details on medication charts should be "referred to GP's".

---

<sup>33</sup> Medical reports on his file state that there is no evidence of epilepsy, and there are no records of him having seizures on the 'fitting charts'

---

- 2.3.11 The Inquiry found evidence that nursing staff were administering medication on a PRN basis prior to authorisations provided by the medical practitioner. One medication chart showed 3 administrations of medication in April 1996, with doctor's authorisation not being provided until May.
- 2.3.12 The Inquiry found medication records to be poorly maintained. Specific examples of poor practice include administration of medication not being accurately recorded; the medication charts for residents being filed in other residents' files; and medication charts not being filed chronologically.

In the case of one young girl, the Inquiry found instances of PRN valium being administered but not recorded on the medication chart.<sup>34</sup> While the DON has responded that this was "overlooked during a very stressful shift" it had been recorded in 2 other places. Failure to record the use of medication on the medication chart means the medical practitioner cannot accurately monitor the use or effectiveness of the existing medication regime or assess required changes. It can also result in medication being administered in excess of the doctor's authorisation. It must also call into question the effectiveness of any system used to account for medications ordered and used.

---

<sup>34</sup> Diary notes show that PRN Valium was administered to the resident on 1.4.96 and 27.3.96, but with no corresponding recording on the PRN medication chart

**Major findings relating to use and provision of medication:**

9. There is a lack of clarity about consent arrangements for medical treatment for the residents of Cram House. This is of particular concern for those children and young adults who are prescribed central nervous system affecting drugs, or other major medical treatment, and for those children who may not have substantial contact with their families.
10. The failure to obtain appropriate informed consent for medical treatment of the children and young adults potentially constitutes unlawful medical treatment.
11. The practice of administering medication without doctor's authorisation or in excess of authorisation is very poor nursing practice and may also constitute unlawful practice.
12. There is not adequate documentation to demonstrate that the service attempts alternative approaches to deal with behavioural difficulties or menstrual management, prior to medical intervention, or to support any verbal or informal consent arrangements.
13. In some cases, medication is being prescribed and administered in a manner which does not provide sufficient accountability for the purpose and use of the medication. This includes the prescription of medications not recommended for use with children, the failure to accurately record the administration of medication, and the failure to provide information as to the purpose or indications of use of PRN medication.

## **2.4 Nutrition, Hygiene and Health Care**

- 2.4.1 The service employs a cook 7 days per week, and offers residents a 4 week rotating menu. The Inquiry was told that this menu has remained unchanged for the past four years, but that attempts are now being made to introduce new foods. The Inquiry was informed that residents' individual tastes and nutritional needs were taken into account in the provision of meals. Such information is recorded on individual resident care plans under "diet".
- 2.4.2 Cram House has formed an agreement with the Illawarra District Hospital for the services of a dietitian for 1 day per fortnight, to conduct nutritional assessments, review enteral feeding programs, and provide nutritional advice to staff. The contract covers the period December 1996 to December 1997. Given the nutritional vulnerability of the residents of Cram House, this is an important initiative. However, the only evidence of outcomes of this service agreement is a proposal from the dietitian that Cram House receive enteral feeds at cost. There was

no evidence of individual nutritional assessments of those residents identified as being underweight.

2.4.3 A number of residents were identified by staff as being underweight, and document reviews indicate that a number of residents have experienced significant fluctuations in their weight and/or lost weight over time. For example:

- one young man (aged 20) went from 20.6 kg to 26 kg back to 20.5 kg between August '95 and January '97
- a young woman (aged 17) lost 2 kg between August '95 and January '97
- a man (aged 28) lost over 2 kgs from 36.4 kg in October '95 to 33.7 kg in January '97
- a girl (aged 10) weighed only 5.5 kg as at January '97.<sup>35</sup>

The service monitors residents' weight and records this data centrally in a "weight book". However, resident weights are not measured against a target, nor relative to height. Residents who are identified as being vulnerable to being underweight are weighed weekly, however the Inquiry found no evidence of systematic follow up of this information.

2.4.4 The Inquiry reviewed records in relation to two children identified as have eating/swallowing problems. In both cases, their files contained a feeding programme developed by a Speech Pathologist within the last 6 months, although mechanisms for monitoring and reviewing the implementation of these programmes are unclear.

One of the allegations investigated concurrently with the Inquiry was that residents were force fed by staff. The investigation did not find direct evidence of this, but found that there were few safeguards to prevent such an occurrence. There was limited staff training to ensure staff are adequately skilled to feed residents with eating difficulties. Additionally, the service relies extensively on volunteers for all aspects of resident care (including feeding), yet they receive no training.

The investigation also noted that people with significant disabilities, particularly children, face an increased risk of poor nutrition and consequent respiratory diseases. Information provided to the Inquiry by Cram House indicates that for all 6 of the children and young people who have died in the past 3 years, bronchopneumonia was listed as either the primary or secondary cause of death.

---

<sup>35</sup> From review of Weight Book

- 2.4.5 The “behaviour and fitting book” notes frequent refusal on the part of one resident to eat. However, the Inquiry found no evidence of any action taken by the service to address this problem.
- 2.4.6 The premises appear clean, and the Inquiry found a high level of awareness amongst staff of infection control procedures, although there is scant documentation of these.
- 2.4.7 Personal hygiene procedures (eg. toileting, teeth cleaning, nail cutting) are documented in the central policy folder, with additional information where applicable noted on individual resident care plans.
- 2.4.8 The Inquiry was told that residents undergo an annual paediatric review. Unfortunately all paediatric reports by the paediatrician had been removed from client files, reportedly on the paediatrician’s instruction, following complaints alleging a possible conflict of interest in the paediatrician being both a Director of the Society and the paediatrician for the residents. As a result, the Inquiry was unable to ascertain the regularity and content of paediatric reviews for individual residents.
- 2.4.9 A local GP provides the primary day to day medical care for the majority of residents. This person had also been a long standing Director of the Society. The findings of this Inquiry suggest that there is significant scope for a medical practitioner who is a Director to face conflicts between the interests of his patients, his own professional interests, and those of the organisation. Examples include:
- decisions to prescribe medications which may make residents easier to manage (and therefore not straining staffing resources) such as sedatives and medications for menstrual suppression
  - being required to provide death certificates as the medical practitioner for residents, with a resultant reduction in the independence of considering the cause or circumstances of death
  - the potential to exercise undue influence on both staff (as a representative of their employer) and family members (as a representative of the service provider) in decision making about medical care and treatment.

As well, it would be difficult for the Board of Directors to objectively assess or even question the quality of medical care being provided to residents of Cram House because of the medical practitioner’s position within the Society.

The Inquiry found that the Board had not previously considered the possible range of potential conflicts of interest in its arrangement with

this doctor, and had made no attempt to develop safeguards or procedures to deal with such allegations.

The Inquiry was informed that the medical practitioner has now resigned as a Director, and has written to all the parents seeking confirmation that they wish him to continue as the doctor for their children.

All staff and most parents report a high level of satisfaction with the service provided by him, which apparently includes being 'on call' 24 hours a day if needed.

- 2.4.10 One family has explicitly requested that alternative arrangements be made for the medical care of their daughter, following "mutual problems in communication, or lack thereof".<sup>36</sup>

On this client file, the following letter was written by another local doctor to the staff of Cram House: "I am quite happy to write prescriptions and post them to you when needed. All I will need is the name of the drug, the strength and the dosage."<sup>37</sup> The service advised the Inquiry that this arrangement was to compensate for the fact that it was difficult for them to visit this doctor in his surgery when they needed a prescription.

- 2.4.11 Documentation of medical treatment is poor, with the result that the Inquiry was unable to determine whether appropriate follow-up treatment had been provided, as requested in medical assessments. Examples include a recommendation that a resident have an operation to correct rotation of right hip in June 1994 and another needing an audiometric test. There was no information on the files to indicate that these recommended treatments were arranged, nor a documented program for ensuring that such recommendations are reliably followed up.
- 2.4.12 Similarly, although staff state that residents receive regular therapy in accordance with programmes developed by a consultant physiotherapist, the Inquiry was unable to find documented evidence of this.

A "therapy book" is maintained by the Technical Aides, who also provide a monthly written report to the House Committee, however the focus is on equipment (purchase of new, and repairs to existing items such as wheelchairs) and client attendance at external clinics, rather than on regular physiotherapy provided to residents on-site.

---

<sup>36</sup> Confirmed in writing to the doctor 6.10.94, cc to Cram House

<sup>37</sup> Dated 26.6.95

For many of the residents, components of a physiotherapy program relate to appropriate activities, equipment and approaches to daily living, and recommendations about positioning, in addition to more specific 'therapy' routines. It is not clear what responsibility nursing staff have in implementing such program components, and there is no system for ensuring that they are implemented as part of daily practice.

One of the allegations investigated concurrently with the Inquiry was that a particular resident had not received the physiotherapy he required.

In that specific situation, the investigation found that despite the existence of a physiotherapy program for this resident, no physiotherapy was actually provided.

**Major findings in relation to nutrition, hygiene and health care:**

14. While the service has made arrangements for easy access to medical and therapeutic care and attention, the poor documentation of medical treatment and therapy makes it difficult to whether or not all appropriate action is taken.
15. There is an absence of procedures to ensure that the nutritional and therapy needs of residents are being met.
16. The service has failed to address any real or potential conflicts of interest in having a Board member provide the majority of general practitioner services to residents.

**2.5 Access to the Community**

- 2.5.1 A review of the current Outings Book showed 27 outings over a six month period, with some residents having attended significantly more outings than others. The participation rate for outings ranged from one resident who had been on every outing (27) in a six month period, through to 3 residents who had been on none.<sup>38</sup>

Staff informed the Inquiry that children with the least family contact are given priority when deciding who attends outings, but the Outings Book does not support this. For example, 2 residents who have regular contact with their families (including holidays and overnight stays), attended 10 and 11 outings respectively, while 2 children, whom staff identified as having no significant contact with their families, did not attend any outings during this period.

---

<sup>38</sup> Outings Book reviewed covered the period 3.10.96 - 17.4.97.

The DON subsequently stated that the reason these two of the residents have not been on outings is because they “are fed by gastronomy feeds (this takes 2-3 hrs). Outings are in the mornings or after lunch only ... when (they) are not having their feeds they are having physiotherapy.” In relation to the third young person who had not been on any outings, the DON responded “she attends Day Centre four days weekly on Fridays she goes out for a haircut when necessary.”<sup>39</sup> Such a response indicates a poor understanding and commitment to community access and participation for people with disabilities.

---

<sup>39</sup> Response of DON to findings in preliminary report, provided to EO, dated 6.8.97

- 2.5.2 Of the outings recorded in the Outings Book since 1.1.97 (13 in total), 3 consisted of a "bus run", and no purpose or destination was specified for 4 others. The outings comprised groups ranging from 4 to 13 residents.
- 2.5.3 An Activities Officer was employed part-time up until the end of 1996. However, the service advised the Inquiry that funding for this position has not been renewed. Staff and parents reported that, in the absence of an Activities Officer, community activities for the children and young adults cannot be provided because general staffing levels are inadequate.
- 2.5.4 Other access to the community depends on the availability of each individual resident's 'case manager', who may take them shopping for clothes etc. and may also take them home (including for overnight visits). This system is ad hoc, and not necessarily equitable. It is also done in staff's own time, so is not actually part of the service provided by Cram House.
- 2.5.5 Only one young adult has access to a day placement option for 5 days per week. According to the Cram House Statistics Report for January 1997, 10 young adults attend Day Centres 3 or 4 days per week. There are no activities for these residents on the days they remain at home.

The two pre-school aged children are particularly disadvantaged. Both reportedly attended pre-school 3 days per week in 1996, but neither were attending pre-school at the time of the Inquiry teams' visit to Cram House (April 1997).<sup>40</sup> The reasons for this are unclear.

**Major findings in relation to community access:**

17. The extent and quality of community access for most residents of Cram House is extremely poor. It would appear that a few residents almost never leave the centre, while others only leave the facility to attend school.

**2.6 Access to Families and Friends**

2.6.1 The service states that it welcomes and encourages family contact and visits. The Admissions Policy brochure for Cram House states that staff "welcome family members and encourage their participation in the development of service delivery, activities, celebration and fund raising activities." The service cited as evidence of this that it always informs

---

<sup>40</sup> The Inquiry has been advised that both are now attending some form of pre-school placement

parents of specialist medical appointments (asking them to attend); invites family members to ISP meetings; and sends information about special occasions such as Christmas parties and fund-raising functions.

2.6.2 Many families and advocates reported to the Inquiry team that they felt they could visit the service at any time, and were not hindered in any way from doing so. However, the service reports that approximately 50% of families do not live locally and therefore are not able to visit regularly. In addition, a number of families and advocates stated that they did not feel welcome at the service, and the Inquiry notes that there have been specific instances where the service has restricted contact between residents and family members or advocates. (See 2.6.7)

2.6.3 Where families do not live locally or otherwise do not visit or make contact regularly, the service does not facilitate family contact, nor provide regular reports or information to families, other than when consent is required. Staff interviewed during the Inquiry reported that they did not think it appropriate to initiate contact with families in these circumstances, nor provide any feedback or information to families about the activities, progress and development of their child, referring to such a possibility as “social contact”. This is in contrast to the Admissions Policy brochure which states that “regular contact with families is maintained and they are kept informed of child’s activities and progress”.

A number of families commented to the Inquiry about the low level of regular information from the service about their child’s progress and activities, especially in comparison to schools, which were perceived to offer greater opportunities for interaction and feedback.

2.6.4 The provisions on the Admission Consent Form largely remove any decision making from the parents, and give substantial discretion to the service in matters such as medical treatment, activities, participation in publicity campaigns, and overnight stays away from the centre. The only responsibilities remaining with the parents on the Admission Consent form are related to payment of fees and costs of clothing and medical care.

2.6.5 There is an absence of policies and procedures for dealing with residents who may be in need of guardianship due to lack of parental contact. The service does not initiate action where they have a concern about lack of parental involvement. The Inquiry identified up to 7 residents who do not have significant contact with their families.

The service acknowledges that they have limited understanding of child protection issues, or their responsibilities in identifying and

reporting children who may be 'in need of care' in the meaning of the *Children (Care and Protection) Act 1987*.<sup>41</sup>

---

<sup>41</sup> The Director of Nursing advised the Inquiry Team at the exit interview that she had approached local DOCS staff to give a presentation about child protection at a staff meeting

- 2.6.6 Four residents are identified as having advocates. Each of these relationships was initiated by either the Citizen Advocacy Illawarra, or the parents. The service has acknowledged that it has never sought advocacy support, even for those residents who have minimal family contact.
- 2.6.7 The service has in specific instances denied visiting rights to advocates and extended family members, ostensibly on instruction from parents. There is some question as to the appropriateness of this, given that, in at least one case, the resident is an adult and does not appear to have been consulted by the service before his advocate and his grandmother were prevented from visiting.
- 2.6.8 The Inquiry identified a high level of ill-feeling towards advocates amongst staff, management, and parents. The service has tended to be dismissive of advocates' views and complaints, and there is a general lack of understanding of the role of advocates. However, two of the four advocates who attended the parent/advocate forums reported that they have free access to their 'proteges', and are made to feel welcome by staff whenever they drop in.
- 2.6.9 The service has a particularly poor relationship with the local Citizen Advocacy organisation, which the Inquiry observed was related to a poor understanding of the role of advocates and a poor attitude to involvement of external agencies or individuals.

For example, the Executive Officer's report to the House Committee for June 1996 notes: "Illawarra Citizen Advocacy: A problem with (a resident). His mother has indicated she wants him cared for only by staff at Cram House". This is reported to the Board as "further problems with Citizen Advocacy Illawarra", and with the result of the board authorising the Executive Officer to speak to a parent (although not the parent mentioned) about "our concerns regarding ... Advocacy".

Similarly, the Executive Officer reported to the House Committee in August 96 (under an item headed 'Citizen Advocacy') that: "We have had no interference from these people recently, however they have now contacted another child's parents and have permission to provide an advocate for the child". The House Committee recommends "That we have firm rules for any new advocate".

The problematic relationship with Citizen Advocacy is acknowledged by the Board to be an undesirable situation, which is not in residents' best interests. The Inquiry was told that the Board intends to contact the management committee of Illawarra Citizen Advocacy in an attempt to resolve this problem.

- 2.6.10 The service recently introduced a policy on Citizen Advocacy which restricts visiting hours for advocates, and requires parental consent for advocate involvement. This policy does not allow for independent decision making by adult residents, and places different requirements on advocates recruited through Citizen Advocacy compared with any other parties - eg. families, relatives or other friends - who may also 'advocate' for residents.
- 2.6.11 The service perceives the Community Visitor as 'interfering' with service provision, rather than as a positive means of ensuring that residents' voices are heard. The House Committee Minutes of 19.2.97 note that "the upset being caused by the monitoring taking place by the Community Visitor is damaging to staff morale and is an interruption to the efficient delivery of service to our clients".
- 2.6.12 At the time of the Inquiry, there were no parents of residents on the Board of Directors, and the general perception amongst staff and management is that parents are not interested in participating at this level. Although the Board and management state that parents are able to become members of the Society and stand for election to the Board, the organisation does not formally advise all family members and advocates of this.

The Inquiry notes that Board members attended each of the parent forums held to inform parents about their right to nominate for a position on the Board. While this was an encouraging initiative, the message has not been communicated to parents who did not attend the forums. One parent reported that she had written to the Board inquiring about membership in the past, but received no reply.

- 2.6.13 There are no formal mechanisms for general information flow from the service to family members about service issues and developments, nor any mechanisms to enable families to be involved in the development of the service. The service has not provided any opportunities for parents and advocates to meet each other, or work together as a group in representing their interests to the service, nor has the service taken any role in assisting families to access support they may require in dealing with the issue of having a child with a disability.

The Transition Plan strategies (developed in September 1995) include the establishment of a Policies and Procedures Working Group and a Transition Plan Implementation Working Group, both with consumer and staff participation. However, the management of Cram House advised the Inquiry that neither had been established as transition funding had not been provided. DOCS advised that it had established

a working party for the transition plan, which included parents, “but it was not continued by Cram House”<sup>42</sup>

- 2.6.14 There is evidence that attempts by parents to become more involved in decision making or to propose changes were not responded to positively by the service.

The Inquiry notes that at least 2 parents wrote to the Board in April 1996, strongly requesting greater parental involvement in decisions regarding the transition plan.

One of the letters noted that “we as parents should not be denied the opportunity for participation/information or have our children disadvantaged by not securing approved funding for upgraded care.” The letter went on to make specific suggestions regarding greater parental involvement in service decision making.<sup>43</sup>

The other parent wrote to the Board in support of these suggestions, but in the process provided extensive (and potentially valuable) information about service practices which she felt alienated family involvement.<sup>44</sup>

Neither of these letters were listed as correspondence, nor was there any discussion recorded in the Board minutes for April or May 1996. The Inquiry found no evidence that there was any response to these letters or the issues raised.

DOCS has also noted that parents were excluded from key discussions about transition planning, and that members of the Board and management “spoke strongly to suggest that by putting their children into the care of the Society people indicated their inability to be involved in their children’s support” and stated that “parents were not interested”.<sup>45</sup>

DOCS’ awareness of the resistance of the service to include families in decision making about service provision and future directions is reflected in the “Checklist for Processing Transition Plans” completed by the Area Office in November 1995. In this checklist, DOCS noted that “There may need to be continuing support to ensure the planned infrastructure - to enable meaningful consumer/family/ advocate

---

<sup>42</sup> DOCS response to preliminary report, dated 8.8.97

<sup>43</sup> Letter to Chairman, Illawarra Society of Crippled Children, (cc DOCS CPO) from a parent, dated 18.4.96

<sup>44</sup> Letter to Chairperson, (cc DOCS Area Manager) from parent dated 23.4.96

<sup>45</sup> File note provided by DOCS CPO dated 3.4.96

participation in individual and service level decision making - is established and utilised."

DOCS also reported to the commission that its staff had to play a direct role in organising the education sessions and other meetings with parents about the development of the Transition Plan "due to an unwillingness of Cram House to involve families in this process... There was some reluctance expressed by the Board in the value of having parents or advocates involved in this."<sup>46</sup>

- 2.6.15 The Inquiry found evidence that even where structured forums resulted in suggestions from parents, the service failed to respond to issues raised. Parents identified a number of issues they wanted addressed by Cram House during the family consultations held as part of the Transition Planning process (conducted by SPICE Consulting).<sup>47</sup> Not all the issues raised were addressed within the Transition Plan. Those issues which were raised during the family consultations but not included in the Transition Plan related to family involvement in decision making (including staff recruitment) and promoting family contact with each other and the service.

The officer from DOCS involved in the transition planning advised the commission that the service would have received documents from the family consultations, including the list of issues families wished to see addressed.<sup>48</sup>

**Major findings in relation to access to families, advocates and friends:**

18. Although the service states that the involvement of families is welcomed, there are a number of current practices which discourage continued family involvement in the life of the residents of Cram House, and the service has taken no effective initiatives in promoting contact and involvement of families. This failure to involve families in decision making continued even after the transition planning process identified a number of opportunities.
19. The service has a poor attitude towards advocates.
20. The service has failed to ensure legal protection for the children whose families do not have substantial contact.

## 2.7 Privacy, Dignity and Confidentiality

---

<sup>46</sup> Response to preliminary inquiry report, dated 8.8.97

<sup>47</sup> Minutes of family meeting held May 1995

<sup>48</sup> Telephone conversation - CPO Illawarra, 1.9.97

- 2.7.1 The service has made efforts to promote privacy in line with documented policy - eg. by installing curtains around a change table that is located in a public area, and erecting signs to remind people to keep bathroom doors closed. However, the physical environment limits the effectiveness of any such measures.
- 2.7.2 The physical environment is not conducive to privacy - eg. toilets have only curtains (no doors), and no partitions between them; there is a change table located in the living area; eight residents share one room; and bathrooms are located off the main corridor.
- 2.7.3 Staff and management (and parents) display little understanding of the need for confidentiality, particularly around complaints handling. The Inquiry found specific breaches of confidentiality within the service. For example:
- All grievances are recorded in the Diary, which is readily accessible to all staff
  - Parents who were not party to complaints brought to the commission have been told by staff in the service who the complainants are and provided with details of the complaints
  - A parent who was not party to the complaints had obtained the commission's assessment of the complaints (which had not been provided to him by the commission)
  - Parents advised the Inquiry that "certain people" are known to be complainers or "trouble-makers"
  - Members of the Ladies Auxiliary attended a parent/advocate forum conducted as part of the Inquiry, without the consent of the Inquiry team or the parents/advocates concerned
  - Parents who attended the forum reported some of the issues raised by others at the forum, to the staff of the service
- 2.7.4 Client files are appropriately secured in a locked office, and the service does not allow access to client records without parental consent. Staff were consistent in stating that they would not discuss clients' personal details (eg. medical information) without appropriate permission.
- 2.7.5 The Inquiry noted that staff had made positive attempts to provide age appropriate personal possessions and decorations in the sleeping areas.

**Major findings in relation to privacy, dignity and confidentiality:**

21. The service is constrained in its attempts to provide physical privacy due to the limitations of the physical environment, and the number and needs of residents.

22. The service does not protect the privacy and confidentiality of information about residents and their families and advocates, particularly in relation to complaints.

## 2.8 Skills Development

2.8.1 The ISPs reviewed by the Inquiry focus predominantly on daily routine and basic needs, rather than on skills development. For example, a short-term goal identified for one resident is to wear disposable nappies.

Interviews with staff and parents confirmed that ISP goals are kept basic, due to a pervasive belief that clients aren't capable of significant skills development.

2.8.2 The main mechanism for skills development is through various therapy programmes (eg. physiotherapy). Many residents' physiotherapy programmes include activities for development of gross motor and self-care skills, however the Inquiry was unable to find documented evidence of implementation.

2.8.3 Residents under the age of 16 have opportunities for skills development at school, and their achievements are generally documented on file (via school reports). The young adult residents attend external day programs for at least part of the week each, but no alternate skill development programs are provided at Cram House on the days they remain at home.

The two youngest residents had not been attending pre-school from the end of 1996 to mid 1997, and the service did not provide any alternative programs to promote their development.

2.8.4 The Daily Routine provided to the Inquiry by the service is dominated by the activities of bathing, feeding and toileting the children and young adults, as well as domestic type tasks such as emptying nappy bins, stocking cupboards, washing down chairs and tables after meals. Very little of the daily routine is oriented to individual needs of residents other than those associated with their physical care. The result is that some children are left in their chairs or other equipment for several hours while staff are engaged in other duties.

For example, the Daily Routine for Group 2 (which includes the very young pre-school aged residents and those children and young adults who are totally physically dependent) for weekends and holidays reads:

“7.30 am - Teeth cleaning, faces washed etc. Position children until 10.00 am.

10.00 am - Nappy changing and into chairs for lunch, etc.”

None of the Position Descriptions or shift procedures for nursing staff make any reference to supporting the developmental needs of the children and young adults, but reflect a focus on physical care, cleaning and domestic duties. This may be appropriate for hospitals or other settings where stays are temporary, but not for places of permanent residence, particularly for children.

- 2.8.5 “After-school activities” are scheduled between 2.30 and 4.00 pm, Monday to Friday. These include cooking, swimming, videos, and music, as well as visits to McDonalds, Pizza Hut, etc. “Weekend activities” are said to include “free play”, music, videos, and craft. These activity schedules do not allow for age differences between residents (10 of whom are over 18), are not linked to ISPs and assume that all staff and 26 residents participate in the same activity during the scheduled time. However, staff report that most residents require 1:1 assistance to participate in the activities, which the service cannot provide.

The Daily Programme for one resident lists his weekend and holiday activities as consisting of “Positioned on bed” and “Listens to music”.

- 2.8.6 Younger residents have minimal access to age-appropriate toys and equipment. Staff informed the Inquiry that toys and equipment are not made generally available, because certain residents have damaged these items in the past. The two youngest residents, aged 2 and 3, were observed during the Inquiry to spend most of their day lying in front of the television.

### **Major findings in relation to skill development:**

23. Cram House is unable to adequately promote the development of the children and young adults within the service, due to the way the service is structured, the varied duties of nurses and the predominant focus on physical needs. The service is almost totally reliant on schools and day programs to provide for developmental activities.
24. As a result, while most residents spend the majority of their time within the service setting, there are few arrangements for them to have the range of activities needed for their stimulation and development.

## **2.9 ISPs, Case Recording and Documentation**

- 2.9.1 The service has introduced a system of individual service planning for residents, with annual reviews, following assistance provided by DOCS during 1994.<sup>49</sup>

ISPs exist for all residents whose files were reviewed during the Inquiry. ISPs are generally reviewed annually, but tend to remain unchanged (except those which reflect school to post-school transition).

- 2.9.2 There is evidence of family attendance at 7 of the 11 ISPs viewed by the Inquiry. The service has no formal mechanisms to cater for families who cannot actually attend, and it is not clear what assistance or information is provided to families in preparing for an ISP.

The Inquiry found some evidence of advocate attendance at ISP meetings, although this is inconsistent (some advocates have attended, while others have not).

Residents were in attendance at 6 of the 11 ISPs reviewed by the Inquiry. However it is not clear whether they received any assistance or support to actively participate in the ISP process, or have their views and preferences taken into account.

- 2.9.3 'Goals' listed in ISPs are actually programmes - eg. "Residential", "Educational" "Social". ISPs tend to contain statements about the person's current situation, rather than plans for the future (eg. one ISP under "Financial" states only "has her own bank book").

Where specific short- or long-term goals are identified, these tend to be very basic (eg. wear disposable nappies), and are more about changes the service will initiate, than lifestyle issues for residents.

- 2.9.4 ISPs do not clearly identify who is responsible for implementing various aspects of the service plan.

In some instances, the "person responsible" is recorded only as "Cram House". In other cases, families are listed as responsible, even though there is no significant family contact and no evidence of family participation in the ISP process.

- 2.9.5 The Inquiry found little evidence of implementation of ISPs, or of services being tailored to individual needs as identified through the ISP process.

For example, a 'goal' may be for the person to attend outings, without any identification of the person's preferences or interests. There is no

---

<sup>49</sup> DOCS response to preliminary inquiry report, dated 8.8.97

indication that particular outings are arranged in response to ISPs, or that Activities Programmes are developed with individual needs in mind.

- 2.9.6 The service uses ISPs as an opportunity to review and confirm the service provision arrangements for residents rather than a mechanism for identifying a shared developmental goal for residents and developing strategies to work towards these.
- 2.9.7 The service has introduced a system referred to as case management, where each resident is linked up with a staff member who takes responsibility for ensuring clothes shopping is done, and otherwise takes a particular interest in that child (including taking them out during their time off). Despite being called 'case managers', these staff members do not have any particular responsibilities in relation to organising or monitoring ISPs, other than preparing the "Cram House story" which outlines the resident's current situation. Responsibility for organising and following up on ISPs rests with the DON for all 26 residents.

Many families did not refer to the 'case manager' when asked about a key contact person within the service for their child. The majority of parents regarded the DON as the primary contact point for any queries or information.

- 2.9.8 Record keeping by the service is chaotic. Information about an individual resident can be located in several different places, including the 'main' client file, medication charts, Diary, and numerous exercise books including Therapy Book, Outings Book, Behaviour and Fitting chart, and the Weight Book. The Inquiry found no consistent link between these documents. This presents a risk that information will not be recorded because of a lack of easy means to do so, particularly given the demands of direct care and other duties.

The purpose and outcome of some recording is unclear, or not complied with. This significantly limits the capacity for effective monitoring or intervention. For example:

- Although children are weighed regularly, and the Inquiry was informed that children who are identified as having lost weight are referred to the medical practitioner for attention, the documentation system does not allow confirmation that this has occurred.
- Information recorded under "Important Notes" in the client files often consists only of comments such as "quiet day" or "slept well", yet these were reported by the DON as being the most important documentation about individuals. The Inquiry found

inconsistencies between these entries, and notations in other documents such as the diary or behaviour charts.

**Major findings in relation to ISPs and documentation:**

25. The primary benefits of the Individual Service Planning system as used by Cram House is that it offers an opportunity for an annual review of service provision arrangements for all residents, in conjunction with their families. The service is not currently using ISPs as a way of developing their service activities in response to identified individual goals and preferences.
26. Despite the extensive documentation maintained by the service, it does not assist in service accountability and management due to the lack of clarity about the purpose, the use of the different recording requirements and the poor organisation of much of the material.

## **2.10 Safety**

- 2.10.1 The service has documented safety procedures, dealing with death, emergency procedures, fire safety, disaster plans, infection control, accidents and incidents. Copies of these procedures are kept at the nursing station, accessible to all staff.
- 2.10.2 The service advised the Inquiry that they have annual fire inspections, but was unable to provide a copy of the recent inspection report. The Executive Officer was not able to outline the scope of the inspection.

The Inquiry was told that a representative from the NSW Fire Brigade spoke at a staff meeting in May 1996, which was attended by 20 staff. However, the service has not conducted any fire evacuation drills.

- 2.10.3 A review of records indicated that residents occasionally experience injuries or safety risks as a result of the behaviour of other residents, falling or slipping from their beds, or from poor or ill-fitting equipment (including beds and wheelchairs). Cram House does not have an effective process for identifying and responding to such risks.
- 2.10.4 The Inquiry noted a range of unexplained injuries experienced by residents, including bruising and cuts. Injuries are noted in the diary by staff, and sometimes in the Important Notes section of the client files. The Inquiry was advised that where injuries of an unknown origin were noted, the DON would try to establish the cause, generally by talking to staff. However, the service reported that it was not always possible to

establish the cause of an injury, that residents would often incur injuries due to their movements, and that “you just have to trust the staff”.

The Inquiry could find no evidence of follow-up to unexplained bruising and scratches to the breasts and buttocks of a young woman<sup>50</sup>, and no evidence of preventative strategies for recurring bruising to the hands and fingers of another young woman supposedly due to an inappropriate wheelchair, even though the bruising was noted by the advocate to have occurred over a 12 month period.<sup>51</sup>

- 2.10.5 The service is poorly informed about child protection principles and procedures and has no disciplinary procedures in place for dealing with staff whose behaviour or actions are alleged to put residents at risk. This was reported to be due to lack of need, a reliance on placing trust in staff, and a perception that there is limited opportunity for abuse to occur due to supervision practices such as having two staff involved in bathing residents, and volunteers’ hours being restricted to the DON’s shift.

The poor response of the service to a number of allegations of mistreatment, and its failure to acknowledge the child protection and care needs of a number of residents leaves some children and young people at risk.

- 2.10.6 The service has identified and responded to physical security needs of the service. The premises are secured at night by locking the front doors and people visiting after hours are required to ring the doorbell.

The service has increased lighting in the car park area in response to theft of property in the past, both from inside the building and from the car park behind the building and the incidence of people occasionally wandering through the property, which may present a risk to the safety of residents.

- 2.10.7 New staff, volunteers and students are not effectively ‘screened’ prior to appointment. The Inquiry was advised that the service never advertises for nursing staff, but appoints from within the pool of volunteers or casual staff, without any interviewing or other screening process. This is in breach of one of the clauses in the Deed of Funding,<sup>52</sup> and represents poor practice.<sup>53</sup>

---

<sup>50</sup> Noted in diary and Important Notes Feb 97

<sup>51</sup> Bruising to fingers and back of hands noted 9.4.96, 20.5.96, 25.8.96, 20.10.96, 3.11.96, 23.2.97 and 16.3.97

<sup>52</sup> Section 4 Staffing

<sup>53</sup> See “Who Cares? Protecting People in Residential Care” Community Services Commission 1996

Decisions regarding the appointment of nursing staff rests with the DON. The service considers that previous experience as a volunteer or casual staff member is sufficient screening for permanent appointment.

The absence of appropriate advertising, interviewing or other screening for staff appointments appears to be a long standing practice. Although external advertising of staff vacancies is a requirement outlined in the Deed of Funding, there is no mechanism for the funding body to assure itself that funded agencies comply with these conditions. Nevertheless, it appears that DOCS was aware of this issue, as it has reported to the commission that “the CPO spoke to the Executive Officer on the need to screen people and offered support on criminal record checks.”<sup>54</sup>

2.10.8 The service relies heavily on volunteers (including students on placement) to assist staff with the care of residents and other duties. The service has a Voluntary Workers Policy<sup>55</sup> which states that volunteers may be accepted from Skillshare, City Mission or similar groups, schools, TAFE or University work experience, Queens Scout or Guides, Duke of Edinburgh Awards or Community Aid Panels. However, the policy also provides that any individual “for whom a senior staff member is prepared to write a reference” is also able to become a volunteer.

While there are positive aspects to community involvement that can come with the use of volunteers, the current arrangements pose a number of risks for volunteers, residents and the Society.

The service attempts to ensure accountability for volunteers by requiring that volunteers and students on placement always work under direct supervision, and only during the hours the DON is on duty. Volunteers are required to undertake a range of tasks, including feeding of residents, but there are no arrangements for them to be trained prior to commencing such tasks. The scope for volunteers to be involved in direct care to residents includes “cuddling and playing with children”.<sup>56</sup>

The lack of screening for volunteers is of particular concern given that the service appoints permanent staff and casuals directly from their pool of volunteers, with no further screening.

The service also uses people on Community Service Orders, although many parents reported that they were unaware of this. The service reported that people on Community Service Orders do not have any unsupervised contact with residents. However, the Inquiry notes that as

---

<sup>54</sup> DOCS response to preliminary inquiry report, dated 8.8.97

<sup>55</sup> Reviewed by the Board 1995

<sup>56</sup> Voluntary Workers Policy

with other volunteers, there is the potential that people serving Community Service Orders at Cram House may be considered for employment on a permanent capacity, without further screening.

- 2.10.9 The Inquiry was informed by both staff and parents that staff may take children home with them. Other than the Admission Consent Form, the Inquiry found no other policies about allowing children to stay overnight with people other than their families. The service has no mechanisms to ensure the safety of children on such visits, or to outline the responsibilities of staff or others who may take the children home with them. The practice is of particular concern given the lack of screening of staff before they are appointed.

**Major findings in relation to safety:**

27. The service has failed to take the necessary steps to minimise the potential safety risks to residents such as repeated injuries, abuse or mistreatment of residents by staff or other residents. In particular the current arrangements regarding staff recruitment and management, allowing staff and others to take children home with them, and lack of acknowledgment of child protection needs places residents at risk.

## **2.11 Complaints and Concerns**

- 2.11.1 Staff and management told the Inquiry that the service has received very few complaints, and that concerns which have been brought to their attention have been relatively minor (eg. staff have forgotten to put a child's jumper in their school bag).

More serious complaints have been taken up with external bodies, such as the Community Services Commission and DOCS, rather than with the service itself.

- 2.11.2 The service has a grievance procedure which relies largely on verbal handling of complaints by the DON, and presumes that all matters will be sorted out at this level. The grievance policy makes no distinction between responses required for different types of complaints; it does not specify timeframes for resolution of complaints; and does not require that any feedback or response be provided to complainants.
- 2.11.3 Although the grievance policy states that "All grievances will be treated confidentially", the policy requires that complaints be "documented in

the report book and also in the client's file", which are accessible to all staff. It is hard to imagine how complainants' confidentiality can be protected under such a system.

The Inquiry also found evidence that the service fails to protect the confidentiality of complainants in specific cases. (See 2.7.3 for details)

- 2.11.4 Many parents are unaware of the service's grievance procedure, and even those who know it exists, have not seen it. The Inquiry was told that at least one person in the past has asked for a copy of the grievance procedure, and been refused, by both the Executive Officer and a Director.

Parents generally reported that, if they had a problem or a complaint, they would simply "talk to Matron" about it.

- 2.11.5 While many of the parents reported to the Inquiry that they have not had cause to complain about the service provided to their child, the Inquiry also found evidence of previous complaints made either to the service or to other organisations.<sup>57</sup> These complaints raised issues of failure to involve families in decision making (either in relation to their child, or for the service overall), failure to provide for the needs of residents, allegations of mistreatment or abuse, and restricting access to advocates. Other complaints noted by the Inquiry included dissatisfaction with policies of the service relating to payment for certain goods and services. The Inquiry found no evidence of appropriate responses to these complaints by Cram House.

- 2.11.6 Some parents who had experienced problems with the service were not satisfied with the service's response and stated that they had been made to feel unwelcome or uncomfortable by the service staff and management, after questioning aspects of their children's care and treatment. Parents also reported that the continued residence of their child at Cram House was either threatened or made conditional (including pressure to agree to medical treatment) when they raised issues about care and treatment.<sup>58</sup>

While the Inquiry is unable to either discount or substantiate these claims, it remains of concern that parents could be left with such a perception. The Inquiry also notes that it is an offence for a person to take or threaten to take detrimental action against another person because that person makes or proposes to make a complaint, under the

---

<sup>57</sup> Documentation provided by DOCS

<sup>58</sup> Further information regarding these matters is held by the commission in confidence, and is subject to release only on a need to know basis and with the consent of the individuals concerned

*Community Services (Complaints, Appeals and Monitoring) Act 1993* s117. This section of the Act is attached at Appendix 8.

The Inquiry notes that there are a number of factors which would contribute to such a perception by people raising issues. These include the failure of the service to protect the confidentiality of people raising complaints, and the poor attitude of the service to suggested improvements or changes to the status quo. The latter is evidenced by:

- the negative reporting of complaints to the House Committee and Board;
- the dismissal of any allegations as unfounded without an investigative process; eg. allegation of assault by staff on resident, bruising on a young female resident, staff member hitting a mother with chair;
- the lack of policy response from the service when issues are raised eg. complaints about disposable nappy charges and pre-school fees;
- the resentment expressed (to the Inquiry and in documents) towards advocates, Citizen Advocacy and the Community Visitor by staff and management, as well as particular parents who had made complaints or raised issues;
- the negative views expressed by the staff and management about those parents and residents who are perceived to cause difficulties to the service.

2.11.7 The service does not use information gained through complaints to identify service weaknesses, improve service practices, or influence policies. Data about complaints is not collated or analysed in any way, and is not considered as part of a performance information or quality assurance framework.

All reporting of complaints, to both the Board and the House Committee, is anecdotal. A review of the House Committee minutes and Board minutes found the Board failed to deal with or (in some cases) even acknowledge complaints, even where they had potentially serious impact on service quality. An example is a complaint by a parent that a staff member had hit her with a chair (June 1996), reported to the House Committee by the Executive Officer, and noted for the Board's attention. Despite this, the Board minutes for the subsequent meeting show no discussion of this matter, and there is no evidence of any further action towards resolving this parent's complaint.

<b>Major findings in relation to complaints and concerns:</b>
---

28. Although the service has recently introduced a draft grievance procedure, it is inadequate in its content, and has not been provided to parents and advocates.
29. Cram House has not dealt appropriately with complaints and concerns raised by family members or others. Particular problems include the failure to protect the confidentiality of complaints, a negative attitude to complaints and complainants, and a failure to follow-up and either resolve or investigate complaints, even where they involve significant risks to safety, rights or service quality.

**3. OBJECTIVE 3 - MONITORING AND ACCOUNTABILITY MECHANISMS WITHIN THE SERVICE**

**To assess the adequacy of the management and direct staff responsibility and accountability mechanisms for policies and procedures, including responsibility for their initial development, their dissemination, implementation, monitoring and regular review.**

Under this objective, the Inquiry examined the roles and accountabilities of staff and management, the mechanisms for monitoring and reporting performance, quality assurance mechanisms, and strategies for independent review.

**3.1 Roles and Accountabilities of Staff and Management**

3.1.1 The service has no clear mechanisms for development, dissemination, monitoring and review of policies. Responsibility for policy development, dissemination, monitoring and review appears to rest with the DON and the Executive Officer, both of whom acknowledged to the Inquiry that they do not have expertise in these areas.

3.1.2 The roles, responsibilities and accountabilities of the Board, the Executive Officer and Director of Nursing are not clearly defined or documented.

3.1.3 Board membership did not include any parents or advocates of residents (until late 1997), and there are no formal mechanism for families to have input into Board decisions (eg. a parent sub-committee).

As general practice, the Board only advises registered members of the Illawarra Society for Crippled Children about upcoming AGMs and their right to nominate for membership of the Board. The Inquiry does not consider this to be sufficient to ensure that parents and advocates are aware of the opportunities and rights in relation to becoming members of the Society or the Board.

3.1.4 Policies do not specify authorisation requirements for any procedures, although the service states that parental consent is sought for changes to medication and for medical treatment, and that DOCS or schools sometimes also require consent (eg. for referral to a speech therapist).

This was confirmed by parents, although there is little evidence on client files of either written or verbal consents having been obtained from parents in most cases. As previously noted, most files contained only the consent provided in the admissions form, often signed many years ago by parents.

3.1.5 The service uses standard medication charts, which are signed off by Registered Nurses when medication is administered. The service has no documented authorisation/decision making process for the use of PRN medication, and the charts do not provide sufficient information about conditions required before PRN is to be administered. This leaves decision making about use of sedative medications at the discretion of staff on duty, without any guidelines or checking procedures.

3.1.6 Parents are required to sign a general consent form at the time of admission, which gives wide discretion to the Society in making decisions about medical treatment; allowing the children “to accompany any person/s in or away from the Centre at the discretion of the Matron”, including overnight stays; and using the children and young adults in publicity materials, without further reference to parents or guardians. This makes the legality of such consents, and hence subsequent treatment or procedures, doubtful.

There are no further guidelines provided for any of these decisions. For example, staff and parents confirmed that off-duty staff do sometimes take residents home with them, however there are no clear mechanisms for obtaining internal authorisation or parental agreement at the time this occurs. Parents confirmed to the Inquiry that children are taken out of Cram House without their prior knowledge or specific consent.

3.1.7 The service advised that when new people are considering placing their child in Cram House, they are provided with a tour of the facility and verbal information about the service. The service also has a 2 page brochure titled “Cram House Admission Policy”. As previously noted, parents are required to sign an admissions consent form, outlining conditions of stay. No other written information is provided to parents or relatives regarding their rights and responsibilities or the policies and procedures of the service. This lack of information to parents leaves them less able to ensure the service is accountable for its actions, and less able to raise issues with confidence.

3.1.8 Position descriptions for staff give no indication of skills, competencies or knowledge required for each position, and do not define performance indicators. They do not explicitly require staff to work in accordance with relevant policies and procedures, nor provide any framework for staff roles such as rights of residents, or the Principles of the *Disability Services Act 1993*.

The Inquiry was provided with position descriptions for Sister, Nurse/Nurses Aide, and Cleaner. Position descriptions are also highly medically oriented and, as such, give no indication of qualitative requirements or consumer-focused outcomes. Together with the

procedures for nursing shifts, the directions to staff are heavily focused on basic physical care, nursing duties and associated domestic tasks.

- 3.1.9 New staff receive an informal induction from the DON, but are considered to be fully conversant with the responsibilities of their position from their first day, on the basis that they have previously worked as volunteers or casuals.
- 3.1.10 There is no documented disciplinary procedure for staff, nor any system for staff performance appraisal or formal supervision arrangements.

### **3.2 Monitoring and Reporting Performance**

- 3.2.1 The service does not have a formal system in place for monitoring organisational performance, and has not identified key result areas or performance indicators.
- 3.2.2 While there is some monitoring of residents' health status - eg. residents are weighed regularly and have annual medical reviews - this does not consistently trigger appropriate intervention or follow up where specific problems are identified.
- 3.2.3 As previously noted, ISPs generally focus on existing service options and activities, rather than being used to shape the service in response to consumers' needs. Information from ISPs is not used for service development purposes, nor are ISP outcomes considered as performance measures.
- 3.2.4 Information recorded about critical incidents (including staff accidents and injury to residents) and resident behaviour is fragmented and of limited value for monitoring purposes. Such information is not systematically collated or analysed and is therefore not able to trigger appropriate intervention.
- 3.2.5 Complaint information is not consistently recorded, and is not used to help the service identify deficiencies in its practices or policies. Staff and management have a dismissive attitude towards complaints, and do not view them in a positive light.
- 3.2.6 The DON and the Executive Officer report monthly to the House Committee, however the content of their reports is anecdotal, and determined at their discretion. The Board has not established any reporting requirements of the managers.
- 3.2.8 The Annual Report is the only form of reporting to stakeholders provided by the service, but the information provided does not focus

on accounting for the performance of the service to key stakeholders. The Annual Report is readily available at the front desk, for people who visit the service.

### **3.3 Quality Assurance**

3.3.1 Current policies and procedures are inadequate for quality assurance purposes. While there are some documented procedures available for staff (eg. feeding programmes for individual residents; lifting procedures for individual residents), other procedures are poorly documented, with insufficient detail to ensure consistency in implementation.

3.3.2 The service has sought some external input in an attempt to improve service delivery - eg. guest speakers at staff meetings, referral of certain residents to DOCS' behavioural team, and management consultation with professional members of the Board.

However, the service does not identify training needs for individual staff and there is limited opportunity for staff to improve their skills. If staff identify training needs, they have to meet the cost of workshops, seminars etc., and attend in their own time.

3.3.3 In acknowledging the need for additional quality assurance, the Board has been considering the possibility of establishing a sub-committee with responsibility in this area. Details of the purpose, constituency and scope of this sub-committee are yet to be determined.

3.3.4 The service is isolated from information/professional networks, particularly in the areas of disability services, substitute care and child protection. Neither the Board nor management appeared aware of any organisations or initiatives which might assist in quality assurance and service improvement (such as the Mentoring Project). Its only formal links are with the Aged Services' Association and the Nurses' Association.

3.3.5 The service has previously established an Occupational Health and Safety committee, however this appears to have lapsed, despite the continued reported injuries to staff and the resulting absenteeism.

### **3.4 Independent Review**

3.4.1 The service has never initiated an independent review of service quality or practices overall.

- 3.4.2 Limited Independent input has been obtained in some instances from a speech pathologist, and from DOCS' behaviour management team.
- 3.4.3 The lack of independence of the medical practitioners used by the service means that an otherwise good opportunity for external input and assistance has been lost.

**Major findings in relation to accountability of management and staff:**

30. The management systems within Cram House are inadequate for ensuring that quality services are provided, or that policy and legal requirements relating to the care of children with disabilities are complied with.
31. The staff recruitment practices, lack of training for staff, and the lack of information for, and involvement of, families and advocates are major weaknesses in the accountability of the service.

#### 4. OBJECTIVE 4 - EXTERNAL ACCOUNTABILITY AND MONITORING

To assess whether the accountability and monitoring mechanisms of the Ageing and Disability Department (ADD) and the Department of Community Services (DOCS) are adequate to ensure the protection and safety of residents at Cram House and the adequate performance of the service.

Under this objective, the Inquiry examined the roles of ADD as funder of the service and DOCS as the previous funder, and in relation to its child protection responsibilities.

##### 4.1 Funding Relationship and Accountability.

###### *Conditions of Funding*

4.1.1 Funding for services provided at Cram House has been provided by the State government since late 1993, when responsibility for funding of residential services was transferred from the Commonwealth to the State under the Commonwealth State Disability Agreement. From late 1993, until 1995, the funding and monitoring of Cram House was the responsibility of DOCS, through the Community Programmes Officer (CPO). After the establishment ADD in 1995, DOCS continued to undertake service monitoring and funding administration of non-government services, on behalf of ADD until March 1997, when the regional teams of Service Support and Development Officers of ADD took on this role.

4.1.2 The funding for the service (including the 1996/97 year) is provided under a standard Deed of Funding Agreement (including Conditions of Funding). These Funding Agreements are general documents, used across a range of programmes with different target groups and program aims and objectives. The Funding Agreement requires, amongst other things, that funded projects be provided in accordance with legislation, program guidelines, program policies, departmental minimum standards of care and the performance agreement (Schedule F to the Funding Agreement).

There are a number of options within the Funding Agreement to provide for the specific circumstances of the funded project. Schedule A lists the projects for which funding is provided and can also list any 'special conditions' to be imposed on the funding. Schedule F is a Performance Agreement between funded services and DOCS. For services which have an approved Transition Plan, the adopted Plan is

simply attached and forms that Service Description and Outcomes Statement.

This has resulted in Funding Agreements which are fairly general, and fail to outline specific requirements for the service, or expected outcomes for consumers. A recent independent review of the effectiveness of these monitoring arrangements found that “the 1996/97 Agreement does not clearly articulate minimum service requirements for institutions or outcomes to be achieved for residents.”<sup>59</sup> The *Disability Services Act 1993* outlines specific requirements for terms and conditions for the provision of financial assistance (s12). These include the extent to which the service conforms to the principles and application of principles; the outcomes to be achieved for consumers as a result of service provided and performance indicators for measuring outcomes. The review undertaken by the Audit Office and the commission argued that in order to meet these legislative requirements, the “Agreements need to clearly identify the minimum standards for each institution to conform as closely as possible in terms of service standards, service quality and service outcomes to be achieved.”<sup>60</sup>

4.1.3 There appear to be no mechanisms for the funding agency to satisfy itself that the funded service is complying with the conditions of funding, or that the information provided by the service in the funding agreement is accurate. The Inquiry found examples of practices at Cram House which are in breach of the conditions of funding, such as the failure to:

- advertise staff vacancies in newspapers (Clause 4.2)
- ensure regular review and evaluation of the project against stated aims and objectives (Clause 3.4)
- encourage and enable users of the project, their guardians and carers to exercise their rights in negotiating how services are delivered to them, and to access to effective complaints mechanisms without fear of recrimination (Clause 1.4)

In the absence of effective monitoring mechanisms by the funding agency, Cram House was able to continue breaching its funding conditions without any remedial action being taken.

4.1.4 The Funding Agreement outlines a number of reporting requirements of services. These include a “report on the project’s achievements against its stated objectives.” Despite several requests to the

---

<sup>59</sup> Audit Office of NSW and Community Services Commission, “Performance Audit Report: Large Residential Centres for People with a Disability in NSW”, pg 85

<sup>60</sup> As above, pg 87

Wollongong Regional Team of ADD, no such report for Cram House could be located.<sup>61</sup>

- 4.1.5 This year, ADD has introduced a new process for funding approvals, based on an annual self-assessment by services, against the Disability Services Standards. Under this arrangement, services will be required to develop an Action Plan, outlining specific strategies to address outcomes from the Transition Plan not yet achieved, or any new actions needed as a result of self-assessment. While this provides more specific performance requirements of services, its effectiveness will depend largely on the ability of ADD to verify the self-assessments submitted by services, and to negotiate appropriate Action Plans. The Performance Audit Report recommended "ADD establish a program of independent audits ... to enable the Department to verify self-assessments"<sup>62</sup> and noted the important role to be played by the independent assessments every three years against the Disability Services Standards, as required under s15 of the *Disability Services Act 1993*, in enhancing the "validity and reliability of the results of self-assessments".<sup>63</sup>

There is also a need to link the self-assessment clearly to any funding agreement issued by ADD and ensure there are clear processes for sanctions where self-assessments indicate a failure to meet standards or implement their transition plan, or agreed Action Plan.

### *Conformity with the Disability Services Act*

- 4.1.6 DOCS notes that the Board and management of Cram House were resistant to any DOCS involvement in its operations and to the requirements associated with the DSA (particularly transition planning) as early as 1993.<sup>64</sup> It appears that these concerns continued through until 1996, with "local concerns that the Society may not be meeting minimum standards"<sup>65</sup> and "complaints from parents of child residents of a lack of information from and an inability to be involved in the operations of Cram House."<sup>66</sup> A review of the transition plan also shows that the service itself identified a number of minimum standards which it did not meet at the time of formulating the plan. These included minimum standards in the areas of decision making and

---

<sup>61</sup> ADD were also unable to provide copies of Schedule F for the funding of Cram House, nor copies of the original self-assessment against the Disability Services Standards

<sup>62</sup> Recommendation 2.9

<sup>63</sup> Pg 89

<sup>64</sup> DOCS response to preliminary inquiry report

<sup>65</sup> Memorandum from Area Manager Illawarra to Area Manager South West Sydney, undated other than 1996

<sup>66</sup> Letter from DOCS to commission, dated 16.10.96

choice; privacy, dignity and confidentiality; complaints and disputes; family relationships; and the protection of human rights.

The Deed of Funding Agreement states that funded projects are to be provided in accordance with “departmental minimum standards” and Schedule F states that “Minimum Standards (under the Disability Services Standards) to be met by all services funded under the Act.”

However, nothing in the funding agreement stipulates how the funding agency will determine whether such minimum standards are met, or a process of sanctions if a service failed to meet these minimum standards. There is also no evidence that the funding agency initiated any special conditions to the funding or other intervention strategies to address these concerns.

- 4.1.7 Disability services which do not conform to the Objects, Principles and Application of Principles of the *Disability Services Act NSW*, are required to develop and implement a Transition Plan. This Plan then forms the Service Description and Outcomes Statement of the Funding Agreement. Section 4 of Schedule F to the Funding Agreement clearly stipulates that “where a service **does not receive transition funds** to assist in the implementation of the transition plan, the service will need to implement **all aspects** of the plan that **do not require** transition funds in order to conform as closely as possible with the *Disability Services Act*.” (emphasis in original)

The Transition Plan for Cram House identifies costs associated with the varied strategies for conformity, so it is possible to identify those aspects of the Plan which do not require transition funding. However, there is no evidence that the funding agency sought reports from the service on its progress in implementing these components of the Transition Plan, despite a requirement in the Funding Agreement for the service to “self-assess annually against the outcomes and indicators set out in Schedule F of the Deed of Funding Agreement.” 1997 is the first year that ADD has required that services submit a self-assessment of their progress against the transition plan, as part of their continuation of funding arrangements.

DOCS informed the Inquiry that the previous “CEO of Cram House indicated that there was insufficient funding for staff to write policies (although examples of conforming policies and procedures had been provided to the CEO by DCS), to provide staff development or to meet at times suitable to parents in the Working Party.”<sup>67</sup> It is arguable whether specific transition funding is required for such activities. However, the findings of this Inquiry indicate that Cram House had not

---

<sup>67</sup> DOCS response to draft final Inquiry report, 10.12.97

implemented any components of the Transition Plan, even those components which they identified as not requiring transition funding.

### *Policies and Procedures*

4.1.8 The development of policies and procedures was identified as a major need in the transition plan for Cram House. The Outcomes Statement which formed part of the Transition Plan (and therefore part of the funding agreement between the Society and the funding agency) stated that policies and procedures would be in place by the end of 1996.

The Outcomes Statement also stated that copies of policies and procedures would be forwarded to DOCS.

DOCS has noted that it had been “advised that this (policy development) was happening, but there was no evidence of this despite phone calls and visits.”<sup>68</sup> It is not clear why DOCS felt constrained in requesting evidence of policy development, given the details of the Transition Plan and the Conditions of Funding which require that an “organisation will ensure that the projects records and documents are made available for inspection by an authorised representative of the Department” (Clause 5.1.2).

4.1.9 The Inquiry found that even in specific circumstances where there was a need to ensure the existence, appropriateness and implementation of policies to protect residents from abuse, the funding agency took little appropriate action. In two cases, allegations were made about staff physically abusing residents. In one case, while the allegation was not able to be substantiated, DOCS “did suggest that Cram House may need assistance in relation to the appropriateness of their policies (in relation to allegations of abuse by staff) but was advised that these issues were the responsibilities of the Board.”<sup>69</sup>

In the other situation, these allegations (in the form of a child protection notification) were confirmed, and DOCS developed a strategy to ensure that the immediate safety of the child was protected. However, neither DOCS nor ADD followed-up with the service to check if any disciplinary procedures existed or had been initiated.

The failure of DOCS and ADD (as funding agencies) to take steps to ensure the existence of adequate policies within a funded service under such circumstances is concerning. The Conditions of Funding make it clear that departmental representatives have the right to visit a project

---

<sup>68</sup> DOCS response to preliminary inquiry report

<sup>69</sup> Memo from Sue Deliva, Manager Child and Family Services DOCS, to Community Services Commission re Alleged Incident

or inspect records without notice where there is a complaint that a client has been abused or is in danger (Clause 9.3). Even without a specific complaint, as noted above, the Conditions of Funding allow for inspection of project records and documents, which presumably include policies and procedures.

4.1.10 ADD has informed the commission (in its response to the preliminary report) that it is developing a “manual for service providers to assist them to develop their own internal policies and practices... It is expected that the manual will be distributed to service providers before the end of 1997.”<sup>70</sup>

ADD also report that this manual “considers the baseline criteria of the Performance Audit Report...[and] provides a more sophisticated mechanism for monitoring...”<sup>71</sup>

While the commission believes this is an important initiative, and one which will assist Cram House, our findings indicate that the service will require additional assistance to ensure that the manual results in changed service practices. ADD’s response to the preliminary inquiry report indicated that the SSDO would be able to “work with Cram House to develop strategies that should lead to improvements in the management, policies and practices.” However, the commission understands that the regional team in Wollongong consists of 4 people, with responsibility for 250 funded services. On this basis, it seems unlikely that an SSDO will be able to devote the resources required to assist Cram House, given that its current policies and practices are significantly lacking, or effectively monitor the quality of services provided.

### **Major findings in relation to funding relationship and accountability:**

32. Practices at Cram House do not comply with the Conditions of Funding as outlined in the Funding Agreement, nor its attachments (including the approved Transition Plan). Practices also fail to meet the minimum level of the Disability Services Standards.

33. Despite requirements in the Funding Agreement and under the *Disability Services Act 1993*, Cram House did not take the necessary steps to conform as closely as possible to the Objects, Principles and Application of Principles of the DSA.

34. The processes of monitoring compliance with the DSA and the Funding Agreement have failed to identify or address these breaches. In some cases,

---

<sup>70</sup> Response to preliminary inquiry report, dated 18.8.97

<sup>71</sup> ADD response to draft final inquiry report, 5.12.97

such breaches involved risk of abuse to residents, or failure to meet their needs.

35. Current Funding Agreements do not appear to be appropriately structured to provide sufficient accountability for services as required under the *Disability Services Act 1993*.

36. It is unlikely that a self-assessment process alone will provide sufficiently valid information to assure the funding body that services are being provided in accordance with the *Disability Services Act 1993*.

## 4.2 Monitoring Quality and Performance

4.2.1 Information provided to the Inquiry demonstrates that DOCS has access to information from a number of sources which can provide indicators as to the quality of services provided in facilities such as Cram House. Such information can be obtained as a result of the department's functions as a disability service provider and through its responsibilities for child protection. In the past, parents and advocates also contacted DOCS as the funding agency for Cram House, when they had concerns or complaints.

The matters brought to the attention of DOCS in during 1996 and 1997 have included:

- notifications of abuse of residents, by staff (subsequently confirmed)
- notification and subsequent wardship of a severely underweight resident
- complaints from parents about the circumstances or treatment of their children
- copies of letters from parents to the service outlining allegations of abuse, or failure of the service to adequately involve parents in decision making
- reluctance or refusal of the service to address the programming needs of a resident with challenging behaviour

There is no explicit mechanism for such information to be used in considering the continued funding of a service such as Cram House, particularly now that funding and child protection functions are provided by two different departments. DOCS reports that "the Transition Plan was seen as the vehicle for the improvement of the

services at Cram House"<sup>72</sup> and that "department staff have focussed their efforts upon obtaining agreement from the service to comply with the requirements of the *Disability Services Act*."<sup>73</sup> While it is true that most of the concerns brought to the department's attention can be linked in some way to the Standards, the funding agreement is not structured to take into account information which demonstrates breaches of standards or a failure to provide for basic human and legal rights of consumers. Additionally, some of this information indicated breaches of Funding Conditions, particularly around ensuring the rights of consumers and their carers and guardians (Clause 1.4). As discussed in 4.1, the Funding Agreement does not provide for processes or sanctions in the case of suspected or proven breaches of funding conditions, and there is no evidence that the funding agency took action against the service on the basis of information held.

- 4.2.2 Responsibility for processing the Continuation of Funding packages rests with ADD. The Continuation of Funding Package relies heavily on a self-assessment by the service of their policies, and progress against the transition plan. While the process for approving funding includes a step where "SSDO verifies information in (self-assessment) package", it is not clear how rigorous any such verification processes will be. In the recent report "Performance Audit of Large Residential Centres for People with a Disability", the commission and the Auditor-General found that the effectiveness of such an approach to performance monitoring is "limited by the capacity of the SSDOs to verify and judge the performance of institutions, and the absence of independent audit of centre performance."<sup>74</sup>
- 4.2.3 There is no requirement that information held DOCS (such as that listed in 4.2.1) is either provided to, or considered by, ADD in verifying self-assessments or making decisions about renewal of funding. There are records showing that ADD (together with DOCS) has been involved in negotiations with the Society over difficulties in the transition plan since early 1995,<sup>75</sup> and DOCS states that "there have been extensive discussions with ADD about Cram House".<sup>76</sup> Despite such information being available to ADD, there is no evidence that such information resulted in required intervention or special conditions of funding.

In its response to the draft final report, DOCS advised that a meeting was held between DOCS and ADD on 21 October 1997 to discuss

---

<sup>72</sup> DOCS response to preliminary report

<sup>73</sup> Letter from DOCS to commission, dated 16.10.97

<sup>74</sup> Pg 86

<sup>75</sup> Timetable of Contact re Transition Plan, Illawarra Society for Crippled Children - DOCS CPO

<sup>76</sup> DOCS response to preliminary report

“concerns of DOCS re changes required at Cram in regard the care of children in residence. A recommendation for a joint approach to the issues raised was made...” DOCS also advised that they have identified the need for formal links between the two departments.

- 4.2.4 Information from other sources, available to ADD, is also not necessarily used by ADD in considering renewal of funding or the need for any special conditions to the funding agreement. The commission provided the preliminary report of this Inquiry to ADD at a time when Cram House was completing its self-assessment as part of the continuation of funding requirements.

Despite the potential usefulness of the Inquiry findings to the SSDO in assisting verification of any self-assessment provided by Cram House, the report had not been provided to the Regional Team by ADD Central Office.

ADD has established a Service Review and Support Project (in the Disability Services Program) which focuses on assisting the SSDO in working with those funded services with “registered issues of concern.” ADD reports that for these services, the Deed of Funding Agreement will be altered to include an Action Plan which specifies strategies to address the issues raised. Cram House has already been registered as a service of concern, and an Action Plan will be developed.<sup>77</sup>

**Major findings in relation to monitoring quality and performance:**

37. Even in circumstances when specific information was available to DOCS and ADD indicating poor quality services at Cram House, such information was not used in negotiating its continued funding.
38. There are no requirements that information obtained by DOCS (or other agencies) is either provided to, or considered by, ADD in verifying self-assessments or negotiating Funding Agreements.

**4.3 Monitoring Placements and Exits from Service**

*Children Entering Care at Cram House*

- 4.3.1 As noted, the services provided by Cram House do not conform with principles and standards in either the disability services area or

---

<sup>77</sup> ADD response to draft final inquiry report, 5.12.97

substitute care. The DOCS Substitute Care Principles and Objectives state that “no child under 5 years, except as part of a sibling group, will be placed in residential care unless a secure relationship with a parenting figure can be sustained”<sup>78</sup> and that “residential care services **are not to be provided** for children under 5 years, except when a child is part of a sibling group or **exceptional circumstances.**”<sup>79</sup> (emphasis in original).

Despite this, children continue to be admitted to Cram House at a very young age. Examples include a baby aged 9 months, placed in February 1995 and a young child placed in August 1996, aged 3 years. Other children have also entered Cram House as vacancies arise (eg a young girl, aged 7 years, in March 1996).

- 4.3.2 The majority of children are placed at Cram House under a voluntary arrangement between the parents and the Society. In the case of such voluntary placements, neither DOCS nor the Children’s Court may have any involvement at all.

This means that children are placed without any form of gate-keeping (such as an assessment of their needs or the appropriateness of Cram House), and no basis for future monitoring or review as no external agency is involved in the child’s placement at the service.

The only requirement imposed on the service in relation to placement of children into Cram House is the need to have an entry policy in line with the Disability Services Standards. The Standards do not refer to any particular entry policy requirements of services for children.

- 4.3.3 Children placed under such circumstances are denied the processes and safeguards under the *Children (Care and Protection) Act 1987*.

Under section 10(2) of this Act:

“a child residing in a non-government childrens home is in need of care -

(a) if the child has been residing in the home for a period of 12 months or more; and

(b) if there has been no substantial contact during that period between the child and -

(i) any of the child’s parents; or

(ii) any person in whose care the child was immediately before the child began residing at home.”

---

<sup>78</sup> Principle 7 and Objectives following from Principle 7, Substitute care Administrative and Procedural Handbook, Volume 1, 1989

<sup>79</sup> Placement Procedures 3.1.4, Substitute Care Practice and Procedural Manual, Volume 2

As problematic as this section may be (for example in determining “substantial contact”) the greater threshold difficulty for children residing in facilities such as Cram House is that of identifying that they have lived in a non-government home for more than 12 months. There is no systematic mechanism for monitoring voluntary placements into care, which could provide the basis for reviewing such placements once they exceed 12 months. The findings of the inquiry indicate that a number of children (and young adults) residing at Cram House may be in need of care or guardianship.<sup>80</sup>

A recent example highlighting the need for systematic monitoring is the case of a particular young girl who came to the attention of the commission. When assessing the complaints about Cram House, the commission found information which indicated that this young girl had only minimal contact with her family since her placement at Cram House 10 years earlier. When the commission drew this to the attention of DOCS, she was placed in the care of the Director-General and subsequently made a ward of the state until age 18. It is apparent that such information is not automatically available to DOCS, under the current system.

- 4.3.4 Such situations have also led to a lack of clarity about the respective roles and responsibilities of parents and the service in relation to matters of decision making and consent, and poor identification of guardianship needs.
- 4.3.5 The lack of safeguards and appropriate processes in the placement of children into care at Cram House are further illustration of the absence of any link between standards in the disability services area and the principles of substitute care. These and other practices at Cram House also illustrate a serious lack of acknowledgment of the needs and rights of child residents under the *Children (Care and Protection) Act 1987*. None of the accountability mechanisms (funding agreement, disability services standards, DSA) provide a framework to ensure that services provided by Cram House meet the needs of residents related to their childhood status, as well as those arising from their disability.

### ***Deaths of Children and Young People at Cram House***

- 4.3.6 As noted in 2.2.11, deaths of children and young people residing at Cram House are not reported to any external authority, other than registering the death through a Death Certificate.

---

<sup>80</sup> The commission provided this information to DOCS at the time of issuing the preliminary report

Under s 13(1)(h) of the *Coroners Act 1980*, deaths of residents should be reported to the Coroner if they occur in facilities which are either:

- a facility within the meaning of the *Community Welfare Act 1987*
- a residential centre for handicapped persons licensed under the *Youth and Community Services Act 1973*
- a residential child care centre licensed under the *Children (Care and Protection) Act 1987*.

The Coroners Court (Wollongong) advised the commission that it is the responsibility of facility management and the funding agency to ensure that any obligations for reporting are recognised and complied with. The Coroners Court does not keep a listing of facilities which fall under the criteria of s13(1)(h).

Non-government services funded under the DSA are neither licensed nor gazetted, which leaves them outside the jurisdiction of s13(1)(h) of the *Coroners Act 1980*. This would seem to be an anomaly given the policy intent of this section as a way of ensuring that deaths of people in care are open to investigation.

- 4.3.7 Local officers for both DOCS and ADD stated that there were no administrative requirements for deaths in non-government facilities to be reported to the funding body.

In comparison, DOCS requires its own services to report deaths of people with disabilities in care to the Police or the Coroner, as well as to the Director-General and the Community Services Commission.<sup>81</sup> The department also reports all deaths of children in its services to the Child Death Review Team under a Ministerial protocol required by the Child Death Review Team legislation.<sup>82</sup>

ADD has advised that it plans to introduce a policy requirement that funded services must report to it deaths of any service users.

- 4.3.8 Another potential avenue for external monitoring of deaths of children who reside at Cram House is the Child Death Review Team. This

---

<sup>81</sup> DOCS Policies for Working with People with Disabilities - Response to the Death of a Consumer

<sup>82</sup> Advice from Child Death Review Team, 30.10.97

recently established statutory team collects and monitors data on the deaths of all children in NSW. Their initial data is collected through the Registry of Births, Deaths and Marriages, the Office of the State Coroner, and DOCS. As none of the deaths of residents of Cram House are reported to the Coroner, the only information available to the Child Death Review Team will be that provided by the death certificate, providing a medical cause of death.

In the past 12 months, fewer than 20% of certified deaths were identified for further screening. The Review Team data does not currently identify when a child has a disability. Nor is the Team able to identify if the child had been resident in a care facility. Under such circumstances, there is little to trigger a full review by the Child Death Review Team of deaths of children with disabilities in residential facilities such as Cram House, and an extremely limited ability to even monitor trends of such deaths. Even if the Team wished to review the death of a child in a non-government facility, the legislation only provides for them to obtain information from government agencies. Where the death is reported to the Coroner, the Team would be able to obtain information through that avenue. However, where a death certificate has been issued (as in the case of those children who have died at Cram House), the Team is unable to obtain sufficient information even if they were able to identify such a death as warranting further review.<sup>83</sup>

- 4.3.9 This means there is limited possibility for any external review or monitoring of the patterns and circumstances of deaths of residents, or even for the validation of the stated cause of death in individual cases.

**Major findings in relation to monitoring placements and exits from Cram House:**

39. Despite the fact that the services provided through Cram House comply with neither the Disability Services Standards nor the substitute care standards, children continue to be placed there without any external assessment or scrutiny.

40. Current arrangements for voluntary placements of children at Cram House mean that such children are denied the safeguards of the *Children (Care and Protection) Act 1987*, and have left children without appropriate legal guardians.

---

<sup>83</sup> Information provided by Child Death Review Team Annual Report 1995/96, and in telephone discussion with Child Death Review Team, 28.10.97

41. Deaths of children and young people while resident at Cram House are not required to be reported to the Coroner, the police, nor to DOCS or ADD, and there is little likelihood that they will be reviewed in full by the Child Death Review Committee.

42. The absence of any external reporting of deaths, together with the absence of any external monitoring of placements into Cram House, has resulted in a situation where children can be placed inappropriately, remain indefinitely without any review or permanency planning, and even die, without the knowledge or intervention of any authority.

#### 4.4 Child Protection

4.4.1 The findings of this Inquiry highlight the need for rigorous child protection systems for children in care, particularly where staff members are the alleged perpetrators of abuse. The Inquiry found that 2 such incidents had occurred at Cram House over the past few years (see 2.2 and 2.10), and that existing procedures to ensure the safety of residents were inadequate.

One young resident has been the subject of two child protection notifications, following allegations that he was assaulted by a staff member. Both of these notifications were confirmed by the DOCS under their child protection processes, and subsequently referred to the police.

Procedures for Child Protection state that “the staff member identified in the notification should not have access to the child whilst the investigation is being conducted”.<sup>84</sup> However, the department reported that they are not able to enforce this with funded services, but can only encourage services to do so. However, the service has refused to even acknowledge the possibility of the abuse having occurred.

Not surprisingly then, the service took no steps to separate the child from the staff member during the course of the departmental investigation.<sup>85</sup>

The Procedures also require that:

“A report of the outcome of the investigation, ... possible recommendations and advice are to be forwarded to the Licensee of the substitute or residential care service” and that “adequate information must also be provided to the

---

<sup>84</sup> NSW DOCS, 1994

<sup>85</sup> DOCS (in their response to the draft final report, 10.12.97) noted that the young child concerned was taken home by his mother during the initial investigation

person in charge in order that an informed and balanced decision can be made by that person in relation to their employee's continued employment.... It would be appropriate to indicate the seriousness with which the Department views the matter. ... A record of all information provided to the centre must be fully documented and placed on the child's file."<sup>86</sup>

Despite these procedures, no written report was provided to Cram House, although DOCS states a verbal report and explanation was provided in a meeting with Cram House.

As noted elsewhere (2.10), Cram House refused to acknowledge the likelihood of these assaults having occurred, and its response to the notifications and subsequent confirmation demonstrated an unwillingness to implement the necessary safeguards. In the face of such a recalcitrant stance, stronger powers or action may have been required by DOCS to ensure the safety of not only the resident concerned, but all residents.

In another incident a few years ago, DOCS received an allegation that a young woman had been physically abused by a staff member at Cram House. As this person was over 16 years of age at the time, the matter was not dealt with under the provisions of the *Children (Care and Protection) Act 1987*, but instead referred to the Adult Community Team. It appears that when DOCS contacted Cram House in relation to this allegation, the service arranged for a medical examination to be conducted by its own medical practitioner (also a Director on the Board). The service subsequently advised the department that they had found "one small bruise (old)". The department took no further action, after being informed by the DON that the Board and the residents' family had been informed and that "procedures were in place in relation to allegations of abuse by staff."<sup>87</sup>

This process raises numerous concerns, including:

- the department allowing the medical examination to be conducted by the service itself, when the allegation was against one of its own staff
- the acceptance of the reported findings of the medical examination, without any verification

---

<sup>86</sup> DOCS procedures pg 46-47

<sup>87</sup> Information from DOCS, dated 11.7.97

- the seeming acceptance that the report of “one small bruise (old)” was sufficient information to judge that the allegation was unsubstantiated
- the failure to verify the existence of appropriate procedures claimed to be in existence by the service

In their response to the draft final report, DOCS advised that they have referred issues relating to protective intervention for adults with disabilities in care to the Assistant Director-General (Policy and Planning).

### **Major findings in relation to child protection:**

43. There is insufficient provision in current DOCS guidelines to ensure the protection of children from alleged abuse by staff while in the care of a non-government residential service.

44. Action taken by DOCS in response to an allegation of abuse by staff of a young adult resident highlights the absence of an appropriate protective framework for protection of adults with disabilities in care.

## 5. CONCLUDING COMMENTS

The findings of this Inquiry expose a service which has failed its responsibilities to the children and young people with disabilities in its care. Specifically, the service has failed to provide a nurturing environment necessary for children and young people to develop to their potential, or to provide the protective mechanisms needed to ensure their physical and emotional safety. It is a service which has systematically failed to provide for the medical, social, developmental or physical needs of the children in its care, and, both by its actions and inactions, exposes children and young people to unacceptable risks. Many of the practices at Cram House also deprive the children of close and ongoing family involvement, or minimal legal protection in the absence of appropriate parental involvement.

However, the concerns raised by the findings of this Inquiry go beyond the responsibilities of the Society and Cram House. They highlight deficiencies in the systems designed to assure government (and the public) that the care and protection needs of children and young people are being met, wherever they are being cared for.

Many of the findings are illustrative of problems which could be occurring throughout the system, and in many cases, echo findings from other investigations or inquiries. Our recommendations seek to address these issues as well as the problems identified at Cram House to ensure that children and young people with disabilities receive the quality services to which they are entitled, no matter where in the system they are.



Roger West  
**Commissioner for Community Services**

Anita Tang  
**Senior Policy Officer**

Ian Robinson  
**Assistant Manager, Complaints Investigations and Reviews**

8 January 1998

