

4. Findings and emerging themes

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

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

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

Specific comment focuses on the following areas:

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

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

- **Palliative care provision**

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

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

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

5. Health issues and management of health care

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

- cerebral palsy was the main physical disability reported;
- seven children had dysphagia;
- all of the children and young people had epilepsy;
- all of the children and young people experienced chronic respiratory infections, including aspiration pneumonia;
- six of the children and young people were underweight and enterally fed; and
- four of the children and young people had scoliosis, with resultant chest wall deformities.

Other health issues identified for individuals included restrictive lung disease, gastro-oesophageal reflux, oesophagitis, haematemesis, osteoporosis, tooth decay and sleep apnoea.

This section considers specific aspects of service provision and practices at Mannix, which are considered to have a direct bearing on the health outcomes of residents, particularly in relation to key health issues of dysphagia, respiratory infection and underweight.¹⁸ The service provision areas examined include the management of nutrition, screening and assessment processes, infection control management, staff competencies and the overall management of medication practices.

¹⁸The most common cause of death for these eight children and young people was respiratory disease, with five deaths resulting from pneumonia. Factors commonly stated as being associated with pneumonia are age (in particular, the young and elderly), gastro-oesophageal reflux, poor nutrition status and decreased immunity (Langmore et al 1998, and Patja et al 2000).

5.1 Nutrition management and monitoring

Children with particular disabilities and associated chronic conditions, such as cerebral palsy and spastic quadriplegia, are at an increased risk of developing problems with nutrition and growth. Studies show that children and young people who are undernourished are at increased risk of illness and adverse developmental outcomes (Kessler & Dawson, 1999). Dysphagia is estimated to occur in up to 60 per cent of people with developmental disabilities, increasing the risk of aspirating food or fluids, which can lead to the development of pneumonia or choking. Children with cerebral palsy are known to have an increased risk of dysphagia as a result of difficulty in swallowing and malnutrition (Dorman & Pellegrino, 1998).

Enteral or tube feeding may be indicated if adequate nutrition cannot be supplied orally or if oral feeding is indicated to be unsafe. However, there are increased risks known to be associated with tube feeding practices, including aspiration and for children, an increased risk of gastro-oesophageal reflux (Finucane, Christmas & Travis, 1999) and risk of tube misplacement into the trachea or lungs with the resultant placement of feeds directly into the lungs.

Seven of the eight children and young people reviewed by the DDRT were severely underweight and had significant levels of nutritional depletion, due to dysphagia. Four of the seven children were dependent on tube feeding and gastro-oesophageal reflux was reported in at least three cases. All seven had experienced chronic respiratory infections, including aspiration pneumonia. Respiratory infection was the documented cause of five deaths and was associated with another two deaths of the seven.

The inadequate nutrition management appeared to be a major contributing factor to the overall poor health outcomes for the seven children and young people who were severely underweight and experiencing dysphagia.

Assessment and monitoring of nutritional needs and weight and growth, provision of case coordination and the management of tube feeding to meet the nutritional needs of these individuals are considered below.

5.1.1 Nutrition policies and standards

Policy guidelines governing disability residential services require that nutrition screening and monitoring is carried out appropriately. The *NSW Standards in Action* requires services to ensure that regular nutrition and health risk screening and monitoring is carried out by an appropriate health practitioner.¹⁹

¹⁹ *Standards in Action* Practice Requirement and Guidelines for Services Funded under the Disability Services Act, Department of Ageing, Disability and Home Care, May 1998.

Services must also ensure that special diets are developed for service users who need them, in consultation with a qualified dietician and others as required, and that this information is recorded. These minimum practice requirements must be complied with by services funded by DADHC.

Mannix's '*Nutritional Needs Policy*' covers topics of meal times, maintenance of nutritional status, and swallowing/eating disorders.²⁰ It states that where indicators point to changing nutritional status, the individual should be referred to the Medical Officer for a full assessment.²¹ Where the individual is currently under the supervision of a dietician, the policy directs that a referral to the dietician for review of dietary management should be made.

In relation to weight monitoring, the policy states that all clients in the service are to be weighed, and have their weights recorded, at least once every three months. Children provided with a diet aimed at bringing about a change in body weight are to be weighed fortnightly and have the weight recorded, unless more frequent weighing is required by the dietician, doctor or nurse in charge.²²

The Mannix '*Nutritional Needs Policy*' gives direction about referral processes when indicators point to changing nutritional status. Weight loss, food intake and biochemical indicators are to be monitored for any changes, although mechanisms for identifying consumers who are nutritionally at risk or have deteriorating health are not specified.

While the policy addresses some of the central issues, it has a number of deficits. Particular shortcomings include:

- the policy has no benchmarks for healthy weight range, underweight and overweight;
- it does not specify monitoring frequency and medical intervention requirements for abnormal weight (such as assessment and review of feeding needs or indicators for referral to a nutritional expert);
- there are no practice guidelines in place to assist the service to establish a nutritional early assessment/intervention program; and
- there are no specific guidelines for tube feeding, positioning and seating, screening for swallowing problems or management of choking incidents.

The *Standards in Action* specify the minimum requirements relating to nutrition. It is expected that service providers develop their own practice

²⁰ The *Nutritional Needs Policy* is contained in the Intellectually and Physically Handicapped Children's Association Policy and Procedures Manual, March 1999.

²¹ Nutritional status indicators include low body mass index or recent weight loss, as documented in The Mannix *Nutrition Needs Policy*.

²² The Intellectually and Physically Handicapped Children's Association of NSW Policy and Procedure Manual Volume 1 May 1999.

guidelines. The lack of practice guidelines in the Mannix policy creates the potential for inconsistent and possibly inadequate practice in relation to providing good nutrition to children and young people with complex feeding needs.

5.1.2. Assessment and monitoring of nutritional needs

The DDRT found in the individual reviews that there was a failure to consistently monitor and follow-up individual nutritional needs. This was seen most markedly in the provision of dietetic services. Despite the high level of nutritional needs of residents, the service had not made any arrangement for regular access to dietetic expertise. Instead, nutrition referrals were made to Liverpool Hospital, Sydney Children's Hospital or New Children's Hospital on a case-by-case basis.

In the case of Resident B, an eight-year-old boy, there was no evidence of any comprehensive nutritional service being provided for a number of years. This was despite this child's nutritional needs being of a high order, with ongoing management problems concerning his gastrostomy and frequent hospitalisation and gastro-esophageal reflux disease.

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

There had been no timely referral to a specialist/dietician for consideration of a gastrostomy/other intervention to address Resident D's dysphagia and feeding problems. Despite chronic respiratory problems, Resident D was not reviewed by a respiratory physician/physiotherapist.

Where there had been some monitoring of individuals' nutrition status – for example, when weight was measured and recorded and medical review occurred - this did not consistently lead to appropriate intervention or follow up, as discussed further in section 5.1.4.

Resident F was a nineteen-year -old man. His file provides no evidence of any comprehensive nutritional service being provided for him for a matter of years. He had ongoing management problems concerning his gastrostomy and frequent hospitalisation and gastro-esophageal reflux disease. He was reported to be slowly losing weight.

Although he saw a range of specialists over a period of time, there was no overall case management of his nutritional needs. Twelve months before his death he was seen by an independent nutritionist who recommended that he

be referred for a full dietetic review. This review did not occur. It is not known whether this was because of lack of action by Mannix or the lack of availability of a dietetic service.

Given the chronic nature of the nutritional problems identified in this review group, and the known links between dysphagia and aspiration, regular assessment, monitoring and review should have been rigorously implemented for all residents.

5.1.3. Nutrition case co-ordination/case management responsibilities

At the time of the deaths (mid 1998 through to early 2001) there was neither a case management system in place to deal with nutritional problems nor a system to co-ordinate and monitor critical nutritional indicators. There was no evidence of systematic case conferencing to ensure the provision of appropriate follow-up or to monitor the implementation of necessary interventions. There appears to be no progress on the development of a case coordinating system, apart from a negotiated contract with South Western Sydney Area Health Service for specific nutritional services (see section 5.1.7).

This lack of co-ordination, in our view, led to situations of risk of harm. This was particularly the case for those individuals where weight loss and recurrent swallowing difficulties, combined with respiratory infection and limited food intake, was not acted upon. There are no provisions in the *Standards in Action* or Mannix policies about what is required of a nutrition case coordination or case conferencing system.

In the 12 months prior to his death, two hospitals had been involved in the management of Resident B's medical and nutritional needs, although he appeared to have intermittent dietetic follow up which did not include any specific plan or goals. Dietetic services were more likely to have occurred following a hospital admission, or involve telephone calls to Mannix seeking information on his condition.

Associated with his overall nutritional management, the recording and monitoring of Resident B's weight was not undertaken routinely and no weights were recorded for four months. At this stage, Resident B, an eight-year-old boy, weighed 10 kgs. Two months prior to his death, a dietician requested that he should be weighed fortnightly, however, this did not happen.

Resident B's feeding problems persisted and he continued to experience oesophagitis. It is not known whether having the two dieticians involved, albeit separately, improved Resident B's general nutritional condition, or enabled adequate monitoring of his progress. There was no identified key person at Mannix with the coordinating responsibility of Resident B's nutritional care.

5.1.4 Monitoring of weight and growth

Malnutrition has been reported to affect muscular function, and in children with cerebral palsy, the effects on respiratory muscle function are of great significance. Impairment of respiratory muscle function, combined with oral-motor dysfunction and gastro-intestinal reflux, increase susceptibility to aspiration and recurrent chest infections. This exacerbates weight loss and results in deterioration of nutritional status. The monitoring of growth, and in particular weight becomes a critical component in the overall management of nutrition in this population (Stallings, et al 1993).

Weight and growth records at Mannix were found to be inadequate in six of the eight cases reviewed. There was no evidence of fortnightly weighing of any of the eight children and young people reviewed, even though six of them were nutritionally depleted and required special diets or enteral feeding regimes. In the case of one young boy who had a weight loss of five and a half kilograms in the last two years of his life, the weight records were inconsistently recorded and not cross-referenced to his fluid balance chart, respiratory condition or medication regime. In another matter, a fourteen year old boy who had failed to gain any significant weight in the last two years of life was not identified by the service as being malnourished, even though he only weighed 13 kgs. For another child, who was underweight and tube fed, there were considerable gaps in weight records with no recordings made for an eleven-month period. This was not consistent with Mannix's own policy as set out in section 5.1.1 of this report.

There appears to have been an ad hoc approach to recording of weight and growth, a lack of cross-referencing to relevant clinical data and a failure to analyse weight and growth data in the context of overall nutritional management. Without weight records, no accurate monitoring of overall nutritional needs could take place. It appears that any adjustment to feeding regimes were not adjusted to deal with weight variations, nor was weight loss referred to a dietician in many cases. Close monitoring of weight for all consumers of the service should have been in place, and in particular, for those children where underweight was a major problem.

Accurate and frequent measurement is critical to the diagnosis of growth problems. Although accurate measurement of height and length may be difficult for children with cerebral palsy, alternative methods of measuring growth are available, such as arm span measure, tricep skinfold thickness and use of wheel chair scales (Nickel & Desch, 2000). Assessment of changes in growth percentiles over time is more reliable, with the frequency of measurement determined by the needs of the individual. From the DDRT reviews, there was no evidence of other methods used to measure and monitor the growth rates of the individuals. Mannix has indicated that a ceiling hoist will be purchased, although this has yet to occur.

A dietician specifically requested information from Mannix about a young woman's height and weight, so an accurate determination could be made about her growth. The service did not provide the relevant information. This was despite an earlier nutritional recommendation that this young woman's growth be closely monitored.

5.1.5 Tube feeding practices

Four of the eight children who died were dependent on tube (enteral) feeding regimes in the last twelve to 24 months of life. Enteral tube feeding can be delivered through orogastric, nasogastric (NG), nasojejunal, gastrostomy or jejunostomy, with the most appropriate method for long-term enteral feeding being percutaneous enteral gastrostomy (PEG) (Nicholson, Korman & Richardson, 2000).²³ The feeds in place at Mannix were either nasogastric or PEG and feeding was routinely done at night.

During the period within which these reviews were undertaken, a total of eleven children and young people living at Mannix (including some not reviewed by the DDRT) were dependent on either NG or PEG feeding regimes. A number of the children who died, experienced problems with this feeding. For example:

Resident C was fed by nasogastric tube for almost the last two years of his life. For most of this time there were problems with him tolerating his feed and gaining weight. Despite Resident C having no significant weight gain prior to his death, the service stated that he was not malnourished or underweight at the time of death.

Although Resident C continued to have problems with his nasogastric feeds, he was not assessed for a gastrostomy until his health was too poor to undergo the procedure. It is not known whether this delay was due to a lack of awareness by on the part of Mannix or a delay in being able to access the gastrostomy assessment. He died eleven months later.

Nasogastric feeding regimes were problematic within the review group. Nasogastric feeds appeared to have been used as an alternative or supplement to oral meals, but there were several problems with the nasogastric feeding regime, including:

- two individuals not being able to tolerate the feed volume;

²³ Orogastric is tube feeding through the mouth into the stomach, nasogastric (NG) tube is through the nose and into the stomach, nasojejunal involves a tube being place through the nose into the jejunum via the stomach and duodenum. A gastrostomy is a surgical technique creating an artificial opening into the stomach for the insertion of a feeding tube. The permanent feeding tube (known as PEG) allows for nutrition to be provided by specially prepared commercially available formula, or blended other foods.

- in one case, the nasogastric tube becoming stuck and requiring removal at hospital; and
- in one case, a nasogastric tube being blocked and being coughed up, with the risk that its contents may have been misplaced in the individual's lungs.

In relation to PEG tube feeding, a number of problems occurred for one individual, including:

- frequent incidence of the gastrostomy tube separating from the PEG;
- recurrent blockages of the gastrostomy tube on return from school; and
- gastrostomy feed rates being inadvertently increased.

Mannix staff reported concerns that some individuals could not manage the nasogastric feeds, which were undertaken at night, as they became uncomfortable and could not sleep. No dietician was consulted about the appropriateness of night feeds, or involved in any ongoing supervision of the night feeding regimes.

The following factors appeared to contribute to problems associated with tube feeding practices:

- the service environment including its physical limitations of multi occupancy bedrooms, cramped feeding areas and the lack of separate sinks for cleaning syringes and tubes;²⁴
- the number of enteral feeds (five nasogastric feeds and six PEGs) undertaken at night when less staff were on duty (one registered nurse and two enrolled nurses); and
- a lack of emergency procedures and backup requirements to respond to feeding difficulties.

5.1.6 Developments since completion of reviews

Since the reviews of the eight deaths were completed, Mannix has advised the DDRT that it has developed an enteral feeding policy and training is offered to staff on related topics.²⁵ It is not known if this training has taken place, or whether specialist oversight of night tube feeding practices has been introduced. A ceiling hoist is being installed which will enable residents to be weighed out of their wheelchairs.

²⁴ Sinks are also used for handwashing, as noted in the Report on Physical Health of Residents of Mannix Children's Centre (Beange, 1999).

²⁵ The DDRT was advised of this at a meeting held with Mannix on 15 August 2001.

It is understood that Mannix is currently negotiating a contract with South Western Sydney Area Health Service (SWSAHS) for the services of a dietician and speech pathologist to conduct nutritional assessments, review enteral feeding programs and provide nutritional advice to Mannix staff. The contract covers the period from September 2001 to April 2002.

According to the service, this contract will provide all Mannix residents with a comprehensive nutritional service. However, it does not appear that the contract will contain a specific brief to provide staff training around the requirements of nutritional care, safe eating practices and skill development in the identification and management of dysphagia, all areas of concern identified in the individual reviews undertaken by the DDRT. Nor does the contract appear to address problems identified in the reviews about clinical oversight and supervision of feeding practices, positioning, and supervision of swallowing problems.

While these developments may partly address identified deficits, more will need to be done to ensure residents receive adequate nutritional care.

5.1.7 Further required action for improving nutrition and nutrition management

The capacity of current arrangements with local medical services to provide health care to Mannix residents should be examined. The findings of the individual reviews indicate a lack of case co-ordination and management around nutrition issues, and that the general practitioner could not be relied on to generate consistent dietetic referral and review of individuals or follow through to nutritional services.

The nutritional needs of young people with physical disabilities as identified in the Review group are complex. The lack of assessment and review of nutritional needs were significant issues for all of the eight children and young people. Although Mannix has reported initiatives to improve the situation, the delivery of nutritional services remains a major problem. There is still no dietary advice available on an individual basis to all affected residents. Mealtime practices and enteral feeding regimes are not supervised by an appropriate specialist, nor is there speech pathology consultation for all residents who may require such assessment. Staff training and practice guidelines for the assessment of nutritional problems, particularly those associated with swallowing disorders, have not been developed.

Although SWSAHS is to provide specific nutritional services for a six-month period, there is no obligation on, or stated commitment, by Mannix management to implement any nutritional recommendations that may result. The service's lack of capacity to implement health recommendations was a clear issue in previous contracted reviews undertaken by independent

medical practitioners (refer to section 5.2). The current capacity of Mannix to adequately rectify the issues raised by the reviews requires examination.

In order for Mannix to provide adequate nutritional services to the children and young people in its care, a systematic and consistent approach to meeting the nutritional needs of people with significant disabilities is urgently required. In particular, Mannix must address:

- the development of a policy and practice framework which clarifies Mannix's overall approach to meeting the nutritional and health needs of children and young people with significant disabilities and associated health conditions;
- establishment of mechanisms for monitoring the standard of care in relation to nutrition and feeding, and for ensuring continuous service improvement;
- provision of systematic multidisciplinary assessment of those identified as being at risk;
- regular, systematic access to expert specialised assistance – dietitians, nutritionists and speech pathologists - for individual assessment and treatment, and for staff training in these areas;
- regular and comprehensive screening to identify those at risk of dysphagia and the provision of timely and appropriate intervention;
- establishment of mechanisms for addressing organisational barriers to promoting nutrition and feeding support for people in care. This would include addressing staffing ratios, rosters, provision of relief staff to enable staff training and development;
- provision of detailed guidelines to fully inform staff of practice and procedures in nutrition, including screening, monitoring and mealtime practices;
- staff training in the assessment of swallowing and eating difficulties, such as that developed by DADHC Disability Services Directorate;
- adequate supervision of enteral feeding practices;
- clear processes and guidelines for regular monitoring of resident weight and growth, and examination of reasons for growth failure with the aim of intervention to improve nutrition; and
- establishment of strategies about how to monitor nutritional rehabilitation including quality of life issues. The monitoring of weight, infection rate, use of antibiotics and general well being should be considered as monitoring indicators.

5.1.8 Systemic considerations

Increasing attention is now being given to nutrition-related health issues for people with disabilities (Langmore et al, 1998; Von Konigsmark, 1999). Recent initiatives through DADHC (in DSD),²⁶ and individual disability services include:

- the development of guidelines for nutritionally adequate diets;
- food service plans developed from the 'Food Services Manual' for large residential centres;
- establishment of safe food handling and infection control guidelines;
- tools to identify people who are significantly under and over weight; and
- strategies to better manage health risks associated with swallowing problems and dysphagia.

A number of individual, service and systemic reviews and inquiries by the Commission over the past five years have continued to identify issues of concern about nutrition and swallowing risks facing people with disabilities living in residential care.²⁷ The recommendations arising from these reports have strongly reinforced the need for ongoing policy development and planning to address service standards and practices. Yet, poor nutrition remains a significant problem for children with multiple disabilities living in residential settings.

While DADHC may not be responsible directly for the development of service policy and practice, it does have a responsibility to ensure that disability services have the capacity to equip staff for duty. Although much has been done by DADHC Disability Services Directorate on the nutritional needs of people with disabilities living in government run residential services, the delivery of specialist and multi-disciplinary expertise to non-government disability accommodation services has not occurred to date. DADHC advises that a non-government (NGO) Nutrition Working Party, convened by DADHC, is to be established.²⁸

5.2 Screening, clinical and medical assessments

²⁶ Disability Services Directorate, as part of DADHC provides government run disability accommodation services. It was previously known as Disability Services Directorate, Department of Community Services.

²⁷ The published reports in this area include:

- *Report on Nutritional and Mealtime Practices for People with Developmental Disabilities in Residential Care*, Community Services Commission, 1997;
- *A Critical Event at the Grosvenor Centre*, Community Services Commission, 2000; and
- *Disability, Death and the Responsibility of Care*, Community Services Commission, 2001.

²⁸ Correspondence between DADHC and the Commission, dated 24 September 2001.

The need for clinical review for Mannix residents was identified as outstanding as far back as early 1999. Mannix underwent an independent service review in 1998/99, to evaluate a number of critical practice areas. This independent assessment and subsequent action plan included a recommendation for independent medical and nutritional assessments of all Mannix residents. The then Ageing and Disability Department (ADD) contracted two consultants to undertake the assessments.^{29,30} Four of the eight children who died had undergone nutritional assessments and medical reviews between April and June 1999.³¹

In all four cases, recommendations for dietetic assessment were made, as the individuals were all identified as having dysphagia risk factors. None of the recommendations were implemented for three of the four individuals. In the case of the fourth, follow up of oesophageal reflux disease was delayed for six months and no action was taken on an urgent referral to a dietician. While monitoring of weight and height was requested for three individuals, only one had their growth monitored.³²

Overall, the recommendations arising from the nutrition/medical assessments were either not implemented or not to the degree proposed. In one case, even though the referral for swallowing assessment was considered urgent and review of nutritional needs was outstanding, the referral did not occur. It would appear that the delay or failure to implement these recommendations was partly due to the inability of Mannix to recognise what was required and then to act to ensure that specified treatment was provided.

One of the four children was found to be obviously underweight, with six (out of 14) nutritional risk indicators and seven (out of ten) dysphagia risk factors.³³ The medical assessment found that the child was 'gravely' underweight, experienced recurrent respiratory disease and aspiration and was in urgent need of a nutritional service. Referral to a speech pathologist and to an occupational therapist for aspiration assessment and suitable feeding methods and positioning was also recommended. These recommendations were not implemented, even though the dietetic referral was considered urgent and assessment of his aspiration was outstanding.

²⁹ One consultant was a medical practitioner with expertise in disability medicine and the other was a nutritionist.

³⁰ The Ageing and Disability Department (ADD) is now known as the Department of Ageing, Disability and Home Care (DADHC).

³¹ Of the rest of the group reviewed, three had died prior to the medical and nutrition assessments and a fourth individual was too sick at the time of the assessments to participate.

³² Recommendations for monitoring of growth were made for Residents E, F and G but not implemented. Growth charts were kept in the case of Resident H.

³³ This child had the second highest number of risk factors for the group under review.

Another child underwent a nutritional assessment in August 1999. He was found to have three indicators of nutritional and dysphagia risk and it was recommended that he be urgently referred for a full dietetic review. Again, there was no dietetic referral made.

The service advised the DDRT that there were a number of difficulties in the implementation of the 1999 independent review recommendations, the major one being the lack of availability of specialist services at the time that the assessments were undertaken. No progress had been made on this issue between the time of the assessments and the DDRT Review, and there was no evidence of ADD intervening with the service to ensure that these nutritional issues were acted upon. According to the service, there were no funds provided by the Department for the recommended specialist services highlighted by the assessments. Given that ADD had initiated these assessments in the first place, and its responsibilities of monitoring, the Department should have commenced action to ensure that the assessments were followed up with appropriate treatment.

In the DDRT review of the death of Resident H, it is noted that recommendations from the independent medical and nutritional assessments were not followed up for over twelve months. When a dietetic referral was finally made, requested information concerning weight and growth was not provided to the referred dietician.

This failure to implement health recommendations highlights the difficulties Mannix has in responding adequately to complex health conditions. Notwithstanding Mannix's view that difficulties are primarily systemic in cause and that it has shown a willingness to accept expertise when provided, the reviews indicate an overall lack of capacity to follow through, in an expedient and responsive manner, on issues of major significance for the individuals affected.

5.2.1 Action required

Mannix failed to implement and monitor the health recommendations made following the specialist assessments. The introduction of an individualised health care planning system may provide Mannix with the necessary monitoring framework and response to screening and clinical assessments and recommendations. This system should identify for each resident, which staff member has the responsibility for implementing such plans.

5.2.2 Systemic considerations

There is no evidence of an overall health-monitoring framework that provides guidance on criteria to disability services about screening, health assessments and follow-up. The inclusion of minimum practice requirements around

nutrition and health in *Standards in Action* provide guidance to services about what must be done to ensure the nutritional and health wellbeing of service users. However, there is no explicit guidance and direction around how to interpret and implement screening requirements, or recommendations arising from specialist consultations. DADHC should take a greater policy direction setting and service-monitoring role across the whole of the sector in respect of this issue with the development of policies and guidelines around specific specialist health areas, including that of nutrition. Policies and guidelines should be supported by a service monitoring and review system to ensure that health screening and review is actually implemented at the service level.

5.3 Access to specialist services

Generally, local medical practitioners treated the children and young people, with referrals made to medical specialists as the need arose. The children were accompanied to such appointments by a Mannix staff member, who relayed any relevant information between the specialist and the service.

Specialist neurology, endocrinology, respiratory medicine, pain management and ophthalmology were identified in the individual DDRT reviews as being required on an ongoing basis for the majority of Mannix residents. There are no specialist medical services provided at Mannix Centre, which means that residents are required to travel to services provided through local area health or teaching hospitals and, as demonstrated in the individual death reviews, at times with limited access.

Children and young people in need of specialised treatment are taken to hospital. This arrangement, at times, was problematic, largely because specific specialist services were not always immediately available within the particular hospital setting and, in certain specialties, were not available at the time the treatment was required. For example, pain management only occurred when a child was being palliatively treated and was not generally available to Mannix for treatment of dysphagia, reflux and muscle spasm management.

Resident E had a number of outstanding health conditions requiring urgent attention. Referral to a dietician to review his nutritional status and a speech pathologist for his continuing aspiration, a dental consultation for his tooth decay and a review of pain management for his probable reflux disease had been recommended but did not occur.

There was no evidence that he received these specialist services, even though the dietetic referral was considered urgent and assessment of his aspiration was outstanding. There is no evidence that these referrals were made or that he received appropriate specialist services.

The DDRT reviews highlight the failure of Mannix to ensure that residents were seen by specialists when required. In particular, residents who had problems of underweight, eating difficulties, aspiration risk, dysphagia and metabolic status had difficulty in obtaining regular specialist attention. There was no evidence of documented integrated health care plans for any of the children reviewed and for some, there was no evidence of them being regularly seen by a respiratory physician. These factors, combined with the institutional environment, must be reasonably considered as contributing to vulnerability and a higher susceptibility to illness.³⁴ As stated, Mannix experienced problems with accessing specialist medical service for residents with complex medical conditions. These problems may have been reduced if there had been particular specialist clinics provided on site on a regular basis.

5.3.1 Developments since completion of reviews

In response to the DDRT reviews, Mannix management has advised that improving accessibility to specialised nutritional and respiratory services is a priority for Mannix. Mannix states that a number of barriers exist, including the lack of availability of specific health services and Mannix's own limited financial resources, in being able to provide the necessary improvements and overcoming health system delays.³⁵ Mannix also states that parents and families are generally responsible for determining the health services, including medical treatment, provided for their children, with Mannix providing the transport and escort to such services.

Unless there is some significant change to the current arrangements, it is unlikely that the access problems faced by Mannix residents will change. Although the current contract with SWSAHS may provide much needed resources in this area, further work is required to determine the need for particular specialist health clinics provided on site at Mannix.

5.3.2 Action required for improved access to specialist services

Research indicates that people with disabilities experience poor health outcomes, including increased mortality rates, and increased rates of hospitalisation (Beange, Lennox & Parmenter, 1999). For the Mannix residents reviewed, the provision of adequate health care was a critical factor in its overall care and for some, delays in health services led to serious ill health. As such, Mannix should have initiated the necessary dialogue and developed mechanisms to reduce identified barriers, including representation to DADHC for assistance and enhancements, if necessary. The fact that this did not happen suggests that, although Mannix states that it recognised the need

³⁴ The following research has examined such factors and identified links; Hollins et al, 1988; Eyman et al, 1988; and Draft Health Project Report by the Centre for Developmental Disability Studies.

³⁵ The DDRT was advised of this at a meeting held with Mannix on 15 August 2001.

for assistance and priorities for specialist services, it lacked the capacity to progress required change.

5.3.3 Systemic considerations

Previous work by the DDRT has commented on the lack of access to specialist services for people with disabilities in care.³⁶ It is vital that appropriate assistance and supports are provided to disability services to ensure that necessary improvements are implemented. The review of specialist services although limited to DSP services, currently being undertaken by DADHC should take into account the issues highlighted by this report and in other DDRT reviews.

Access to specialist services for people living in disability accommodation services requires DADHC, as the lead agency for strategic policy, to develop a framework in which promotion of access to mainstream and specialist health services for people living in disability accommodation services is made viable.

5.4 Immunisation

According to National Health and Medical Research Council (NHMRC) guidelines, vaccination against pneumococcal infection is indicated for all people who are immunocompetent and who have chronic debilitating diseases.³⁷ Tetanus and diphtheria vaccinations are recommended for people aged eight years and older. Hepatitis A and B immunisation is recommended for staff and residents of residential facilities. The NHMRC guidelines state that immunisation status for all residents should be checked and inoculation provided where clinically appropriate and not contra indicated. Specific attention should be given to influenza vaccination and hepatitis B/A vaccinations for residents.

There are no immunisation guidelines referred to in the Intellectually and Physically Handicapped Children's Association Policy and Procedures Manual. Within *Standards in Action* guidelines reference is provided to the then DoCS Infectious Diseases Policy Guidelines and Procedures, which has provision on screening and immunisation. However, these guidelines are specific to staff screening and immunisation needs and do not address consumer needs in this area.³⁸

³⁶ *A Critical Event at Grosvenor Centre*, Community Services Centre, February 2000.

³⁷ Australian Immunisation Handbook, NHMRC, 7th Edition, May 2001.

³⁸ *Standards in Action*, Appendix 8, Screening and Immunisation.

There were no immunisation records for seven of the eight individuals reviewed by the DDRT. It is not known if these children were immunised and the information was not recorded, or whether immunisation did not occur.

As part of the overall nutrition/medical review, Resident G's health was reviewed and a series of blood tests were ordered. These tests were undertaken three months later, with the result that a Hepatitis B vaccination was indicated. There is no record on file that Resident G was vaccinated for Hepatitis B.

5.4.1 Improving immunisation rates

The eight individuals who died all had high medical support needs and ongoing respiratory problems. They were at risk of having a higher susceptibility to illness. At the time of these deaths, Mannix had no policy on immunisation services generally and in particular, a lack of guidelines on influenza vaccination. Mannix should urgently consider:

- undertaking assessment of the immunisation status of all current residents and ensuring recommended immunisations are provided;
- instituting a system of regular review of all current residents' immunisation status;
- developing a policy and practice guideline on immunisation requirements with input of expert advice from a relevant health service; and
- implementing the development of staff awareness and training program on immunisation requirements.

5.4.2 Systemic considerations

Improved immunisation compliance is vital to reducing the incidence of vaccine preventable disease among residents of disability residential services. Inadequate or the lack of guidelines for service providers means that there is a risk that services are generally not aware of the importance of immunisation. To improve immunisation rates a number of problems must be overcome. DADHC, in conjunction with NSW Health should institute an awareness program that includes strategies to improve:

- the rate of follow up when primary or booster immunisation are due;
- service providers' level of awareness about the need for immunisation;
- service providers' level of awareness about current clinical information about immunisation;
- service providers' awareness of the extent of mortality and morbidity associated with vaccine preventable disease and the safety of current vaccines;

- co-ordination of service delivery mechanisms so that immunisation levels are increased; and
- awareness of the need for regular review of immunisation status by health providers.³⁹

5.5 Infection control

Within *Standards in Action* reference is provided to the DoCS Infectious Diseases Policy Guidelines and Procedures, which has provision on Universal Infection Control Guidelines.⁴⁰ Infection control measures, in the context of a residential service providing care to people with severe to profound levels of disabilities, should address the range of general hygiene processes, cleanliness and infection control procedures. According to Straube and Thompson (1983) and Porter and Teter (1991), there is a higher risk of infection in the care environments of people who are immuno-compromised, particularly where they have pre-existing respiratory disease or are children with severe levels of disabilities. Hand washing facilities, feeding and food preparation, personal care and equipment cleaning and storage are critical risk points where the transmission of some infectious diseases can be prevented or minimised.

Due to their health status, all eight residents were susceptible to recurrent respiratory infections and the majority were underweight. Infection control was identified in three of the individual reviews as a potential concern in relation to recurrent respiratory infections.⁴¹ Children who are malnourished are known to be at higher risk of infection, particularly for gastrointestinal and respiratory infections. Mannix had a duty of care to take all reasonable steps to contain the risk of infection outbreak as risk factors of incontinence, assistance needed with feeding and immobility, when combined with infection, have been clearly linked to increased risk of premature death (Hollins et al 1998).⁴²

Mannix has stated that there was no specific link between infection outbreak and any deaths and this is acknowledged.⁴³ However, the risk factors identified in the literature and evident in all Mannix residents highlights the need to have in place the very best infection control standards and practices.

³⁹ Promoted by the NHMRC National Immunisation Strategy, Improving Immunisation Rates – Problems and Solutions, April 1993.

⁴⁰ *Standards in Action*, Appendix 8 – DoCS Infectious Diseases Policy Guidelines and Procedures.

⁴¹ These three children experienced recurrent respiratory infections and were underweight. The potential existed for these infections to be aggravated by exposure to cross infection from within the service and the illness of other residents.

⁴² Almost all Mannix residents are incontinent, require feeding assistance and are immobile.

⁴³ The DDRT was advised of this at a meeting held with Mannix on 15 August 2001.

Resident F underwent a medical review, which recommended that he be investigated for *Helicobacter Pylori*.⁴⁴ This did not occur for six months, however when carried out confirmed he was infected with *Helicobacter Pylori*. Resident F was not isolated from other residents. It is not clear from the file why there was such a delay.

It is not known whether any other Mannix residents were assessed at that time for *Helicobacter Pylori*, a transmittable disease known to be common in people who live in institutions (Lennox & Beange, 1999:53). According to Mannix, all residents have now been assessed, and where necessary, treated.

5.5.1 Infection control measures at Mannix

According to the service, disposable gloves, disposable crockery and cutlery are used when residents are identified as being infectious. Soiled items are soaked, disinfected, rinsed, and there is access to a separate washing machine for infection risk items. However, the use of a separate washing machine for contaminated clothing alone is not an adequate means of infection control as this by no means minimises the risk of transmission of nosocomial (institutionally acquired) infection.

Further, the process for assessing risk and identifying infectious residents is not specified in any of the service's policies and procedures. The service has no universal infection control policy, nor any external scrutiny or monitoring of infection control procedures, such as an infection control committee or outside expert advice on infection control processes.

A previous 1999 review of health care at Mannix raised concerns about inadequate infection control measures.⁴⁵ This independent report stated that hand washing facilities for staff were limited and not always clean and that there were no separate facilities for washing syringes and feeding tubes. This report recommended the establishment of an infection control committee to record cross infection and ensure hygiene control. Despite these recommendations, Mannix has not established the committee or provided any specific training for staff on infection control practices. There is no one individual in the service with specific designated responsibility for implementation of infection control procedures who could advise staff on the relevant legislation and regulatory requirements. In discussions held between the DDRT and Mannix management, the service was not aware of what services or resources were available to provide advice and assistance on universal infection control procedures and staff training requirements.⁴⁶

⁴⁴ *Helicobacter Pylori* is a bacterial infection causing chronic gastritis. Once diagnosed it can be controlled or eliminated with antibiotics. If not treated it can cause peptic ulcers and gastric cancer, and is likely to be associated with other ill health.

⁴⁵ Unpublished report on Physical Health of Residents of Mannix Children's Centre, July 1999.

⁴⁶ This meeting was held on 15 August 2001.

5.5.2 Improving infection control

The potential association between environmental factors, other risk factors and disease must be considered in any overall infection control measures. Given the identified risk factors for Mannix residents, who in some instances are immuno-suppressed, the service should seek expert advice on what is required to ensure hygiene control and minimise and prevent the rate of cross infection in this service. In particular, the service should examine its enteral feeding practices, general food preparation, equipment and hand washing practices. Cleaning and disinfection of feeding equipment should be in line with general infection control policy, as referred to in *Standards in Action* and health regulatory requirements.

5.5.3 Systemic considerations

The Commission has identified poor infection control measures as being an issue of major concern for some disability accommodation services.⁴⁷ Infection control practices across the disability service sector should be reviewed with the aim of increasing awareness and improved infection control practices. There is no evidence that DADHC's monitoring of Mannix included any specific infection control measures. DADHC should examine ways by which disability services can improve their compliance of infection control requirements by:

- undertaking an audit of current infection control procedures within disability accommodation services;
- in conjunction with NSW Health, ensuring the development and implementation of infection control plans in all services providing supported accommodation. Infection control plans should include a component of staff education and training; and
- monitoring the ongoing effectiveness of infection control plans within disability accommodation services.

⁴⁷ A Critical Event at the Grosvenor Centre (2000) and *Suffer the Children: The Hall for Children Report* (1997b).

6. Medication Management

6.1 Medication administration and record management

Seven of the eight DDRT reviews identified problems about medication records management. Problems observed in relation to the administration of medication in the individual reviews were, in many cases, associated with poor health care management generally. A number of medication management problems were identified. These included:

- medication not being accurately recorded, inconsistently recorded, or not accurately tracked at the time of administration;
- dosage administered not matching the dosages prescribed in client files;
- immunisation records not kept in some instances, and in others, not kept up to date;
- a lack of medication guidelines to determine what medication data was to be recorded and frequency of records and who was responsible for such records;
- medications not being given on time; and
- treatment records being dispersed throughout different files and folders, making it difficult to maintain an overview of health care.

The DDRT reviews noted poor medication and health record keeping at Mannix, particularly in the areas of seizure activity and weight reviews and reviews of medication and health conditions. Poor documentation of medication has the potential to result in inaccurate, incomplete and inconsistent records and, in some cases at Mannix, led to consequent errors in administration.

In one case, a young person had been treated with Melleril (an antipsychotic medication) for the 13 years that she had been at Mannix.⁴⁸ However, the only record on file to confirm that she was actually receiving Melleril, were medication records for one four week period. This documentation was signed off twice a day, indicating that she was given the medication twice as often as prescribed.

⁴⁸ Information from admission notes to Bambi Nursing Home (the former name for Mannix), dated 11 September 1988, and correspondence from treating doctor to service in 1994, indicate that she was treated long-term with Melleril.

Inadequate records also limited accurate monitoring and effective follow-up and review.

Resident G was a 15 year-old boy with epilepsy. His epilepsy was managed by an epileptologist. On two separate consultations, the epileptologist noted that seizure records in the file were incomplete.

The service's practice for recording seizure frequency was to note details of seizures following their occurrence in the file notes and on a seizure frequency chart. The level and detail of information recorded about seizure activity was limited and inconsistent. There were no details of the length of time during and between seizures, nor any notes about what Resident G had been doing prior to the seizure.

The service's standardised recording system did not have provision for description of pre and post-ictal (seizure) period, duration and specific description of seizure, seizure pattern and action taken. Staff did not accurately and consistently record details of seizure activity.

Information about residents' health care, medication regimes and treatment decisions were not maintained in a central location on client files. Rather, information was found in separate sections of client files, with some data in the nursing notes, and other records on medication administration sheets. In the DDRT's view, this arrangement limited the level of comprehensive overview of health conditions for at least some of the review group. In one client file, the section marked 'seizures' contained fluid balance and weight charts and additional information about weight was dispersed through the whole file.

The level of detail of information recorded by staff was often inconsistent and the information was often not collated or coordinated to provide a comprehensive record of the person's health status and needs. In more than one case, the file records were difficult to follow, both in content and chronology of events. The most reliable notes appeared to be contained in the nursing progress notes, although these notes were not consistent in detail and it was difficult to identify reasons for and instructions about treatment.

Resident C was commenced on morphine and hyoscine two weeks before his death. The medication file entries were difficult to interpret and there were no dated entries for three days, a week before his death.

Somewhat confusingly, medication records also appeared in other sections of his file, namely the nursing notes.

There was no evidence in his file concerning consent to medical treatment or immunisation records.

Reports, such as occupational therapy, physiotherapy and medical treatment were not consistently cross-referenced on file, nor was there always a clear index in which these reports could be found. For seven of the eight children and young people, immunisation records were either not present or, in one case, were not easily accessible. Where individual planning processes were reviewed by the DDRT (in three cases), there was no evidence of what information or reports informed the individual plan.

Record keeping and documentation are critical to managing a child's medical care. Medical treatment in care settings requires close monitoring and recording processes so that information is accurately relayed and because it is more likely that there are many staff and health practitioners involved. Records are also essential to enable medical practitioners to effectively and accurately monitor existing medication regimes and assess required change. Medical and health care history records are needed to inform case planning and decision-making. The quality of information recorded in the client files at Mannix was very poor and inadequate in enabling effective management of the complex care needs of this group of residents, particularly around medication requirements and feeding instructions.

The following example in the case of a 16-year-old young woman highlights a number of these medication management issues.

Resident H's mother was actively involved in her ongoing health care needs and signed a twelve-month medical consent form on behalf of Resident H. This consent was sought for the administration of Epilim, Melleril, Valium and Paracetamol (the last two on a PRN basis).

Even though Resident H had been treated with Melleril for the 13 years that she had been at Mannix, the only record on file to confirm that she was actually receiving Melleril was for a four-week period.

Medication records for the administration of Panadol and Panadeine Forte were not consistently documented in the client file medication charts. Pain management charts were kept only for certain periods. There were also frequent gaps for sign-off by staff at weekends in the records for Epilim administration. Weight charts had significant recording gaps and the accuracy of some weight records was questionable.

6.1.1 Policies and standards

NSW Health (1997) states that it is good practice for staff in residential facilities to keep a record of administration of all medications to residents. While it appears that the service attempted to follow this practice, medication recording compliance was not maintained.

The *Standards in Action* specify minimum requirements relating to details of all medication, use and dosage are documented in the service user's record.⁴⁹ It is expected that service providers develop their own practice guidelines.

Mannix's policy on *Management of Medications* refers to recording instructions but gives no guidelines of what should be recorded and how. There are no specific instructions on medication recording.⁵⁰

While the *Standards in Action* include requirements relating to record keeping, these do not constitute a policy and practice framework for service provision. It is expected that service providers will have developed their own practice guidelines. The lack of practice guidelines in the Mannix policy contributed to the problem of inconsistent and possibly inadequate record keeping including non-compliance with medication management requirements.

6.1.2 Improving medication administration and management

Mannix should determine what is required in its medication management recording system and develop the necessary guidelines. An urgent audit of all client files should be undertaken to ensure compliance with subsequent developed policy requirements. Client files should be maintained in a manner consistent with recognised file management systems.

6.1.3 Systemic considerations

The problems identified through the DDRT reviews indicate a potential need for improvements to medication management records systems in disability residential services. *Standards in Action*, as it currently exists, does not provide explicit guidance and direction for service providers around how to develop or improve such systems. In the case of Mannix, DADHC's monitoring clearly did not go to the level of maintenance of medication records. Disability accommodation services providing services to people with high and/or complex medical needs, would benefit from assistance from DADHC to develop appropriate client data collection systems.

6.2 Medication consent and documentation

6.2.1 Policies and standards

Standards in Action states that agencies should have clear processes for recording consents and authorisations for the administration of medications.

⁴⁹ *Standards in Action*, Standard 10, Managing Medication, Minimum Practice Requirements.

⁵⁰ Mannix's policy on Management of Medication refers to medication management. This policy is contained in the Intellectually and Physically Handicapped Children's Association Policy and Procedures Manual, March 1999.

Mannix's consent policy states that all consents to medical treatment are to be recorded in client files and that a tracking system is required to be put in place by the Manager to ensure that written consent is received for the medication/treatment initiated. It also states that a registered nurse is responsible for obtaining consent after the prescribing doctor or dentist has ensured that the required consent for the substance to be ordered is obtained.⁵¹

In all eight individual reviews, the DDRT observed problems with Mannix's consent to treatment documentation and processes. There was no indication from the information and files reviewed by the DDRT that consent requirements were complied with, nor evidence of a tracking mechanism to ensure that written consent was sought and appropriately recorded.

Overall, the DDRT found that there were no active guidelines in place at the time of these deaths for either consent to treatment processes or staff responsibilities in relation to consent processes. Staff relied on general consent forms signed by parents and client files did not have systems that provide for a written record of consent to treatment.

6.2.2 Consent to treatment and legal status

The DDRT review of the death of a 14 year old girl found that the service had no guidelines for dealing with a situation where a child does not have significant family contact and consent for medical treatment is required. In this case, the service failed to seek urgent medical treatment for six months and, when consent to the treatment was refused by the parent, no alternative treatment was proposed. This highlights the lack of clarity about the respective roles and responsibilities of parents and the service in relation to matters of decision-making and consent, and raises issues of poor identification of guardianship needs.

6.2.3 Improving compliance for medication consent

The lack of compliance with consent to treatment requirements was in part due to a lack of awareness. Mannix should review all current client files and other records for consent to treatment requirements. The service should develop a medical records system in which consents are clearly documented and the authority for consent to treatment is reviewed on a regular basis. If the information provided is out of date, invalid for any reason or wrong, all steps must be taken to rectify the situation. If the child or young person is unable to consent to treatment and there is no legal substitute consent

⁵¹ Mannix's policy on Management of Medication refers to Consent for Medication treatment. This policy is contained in the Intellectually and Physically Handicapped Children's Association Policy and Procedures Manual, March 1999.

provider, such as a 'person responsible' or legal guardian, action should be undertaken as directed by the relevant legislation.⁵²

6.2.4 Systemic considerations

None of these discrepancies in consent records were picked up in DADHC monitoring. There may be a role for DADHC to develop model client data systems in relation to medication consent and documentation. In conjunction with this development, the need for service provider awareness raising and education about the relevant legislative requirements for consent to medical treatment should also be considered by DADHC as the lead agency in disability policy and legislation.

⁵² Consent to medical treatment requirements concerning children under the age of 16 years are found in the *NSW Children and Young Persons (Care and Protection) Act 1998* (to be proclaimed March 2002). Part 5 of the *NSW Guardianship Act 1989* provides the requirements for consent to medical treatment for adults over the age of 16 years.

7. Provision of palliative care services

7.1 What is palliative care for children and young people?

Palliative care for children and young people with life-limiting conditions is an active approach to care, embracing physical, emotional, social and spiritual elements. It focuses on the enhancement of quality of life for the child and support for the family and includes the management of distressing symptoms, provision of respite care and care through death and bereavement.⁵³

There is little in the literature relating specifically to paediatric palliative care. What has been reported, though, is that the needs of dying children are different to those of adults in the same circumstances.

According to an Australian report on paediatric palliative care, children have unique needs in this area: they represent a smaller, more varied population in terms of the range of diagnoses encountered; and the transition from a curative to palliative focus is often less clear (Hyson et al, 2000). Factors contributing to this include:

- children are physiologically and pharmacodynamically different from adults;
- developmental factors which may influence the child's ability to communicate, participate in decision making, and respond to pain;
- medical practitioners often develop long-standing relationships with children and their families and are less likely to want to hand over care to palliative care services; and
- aggressive attempts at cure are more likely in the paediatric setting.

The provision of paediatric palliative care is sometimes restricted by:

- limited discussion and education on the subjects of death and bereavement, particularly of children;
- the palliative care needs of children are often not identified until late into their illness;

⁵³ *A Guide to the Development of Children's Palliative Care Services*. Report of a joint working party of the Association for Children with Life-Threatening or Terminal Conditions and their Families (ACT) and the Royal College of Paediatrics and Child Health, 1997.

- community palliative care services possess valuable skills in symptom control, family support and an emphasis on quality of life, but often lack experience with children;
- research in this area is minimal, resulting in the current evidence base being inadequate for optimal care;
- less understanding of the needs of children with profound levels of disabilities and non-progressive neurological conditions which result in an increased susceptibility to complications and premature death.

7.2 Palliative care policies and standards

There is little specific policy documentation in relation to palliative care for children and young people with disabilities. The *Standards in Action* has no reference to palliative care services or standards required in this area. In general, the guiding principles may be drawn from the NSW Health's *Dying with Dignity Guidelines* (1993) which state that the provision of palliative care should encompass pain control, relief of other symptoms of disease, and the provision of emotional and psychological support in preparation for death. The guidelines also encourage the application of palliative care plans as the means of providing this service.

NSW Health (2001) has recently developed a palliative care framework which is intended to provide guidance for the planning of service delivery and is considered an important step that will promote access to consistent levels of palliative care regardless of where people live. This framework states that palliative care can be provided in a range of settings including the person's home or other community-based environment such as residential aged care and other forms of permanent or semi-permanent residential care.

Mannix has a palliative care policy which states that a palliative care plan should be developed in conjunction with the client, his or her family, guardian or person responsible at the time that a resident is non responsive to available treatment and where death may be imminent.⁵⁴

Although this local policy was in place at the time of the eight deaths, there was little demonstration of palliative care plans being developed or referred to in the dying processes. There was no reference made in any of the individual cases to palliative care guidelines or decision-making processes. The Mannix policy does not specify if any documentation is required for palliative care plans and although the service states that a plan should be

⁵⁴ Mannix's policy on Health and Hygiene refers to palliative care. This policy is contained in the Intellectually and Physically Handicapped Children's Association Policy and Procedures Manual, March 1999.

developed, this was not evident in any of the reviews undertaken by the DDRT.

7.3 Palliative care services at Mannix

As noted earlier, all eight children had multiple medical problems, some with progressive neurological disease and others with deteriorating respiratory disease. Although this was the case, only half the group received some form of palliative care service. In all cases, referral for palliative care was made by the local general practitioner, in consultation with parents and guardians, to a local palliative care team (PCT). Palliative care consultations were undertaken at Mannix.

The DDRT reviews identified that the type and level of palliative care service varied, but included treatment, infection management and provision of physiotherapy. In some of the cases, the need for a referral to palliative care was identified early on, with a local PCT assessing the needs of the child. In these cases, the PCT provided a multi-disciplinary approach and recommended specific action or treatment to be followed up by the service and treating general practitioner.

Early assessment of palliative care needs is particularly important in the ongoing management of pain and medication, of which palliative care teams have specific expertise. Raising issues of palliative care and end-of-life treatment when the processes of death are not imminent is exceedingly difficult but potentially beneficial in the long-term. This early assessment appeared to occur in one case:

In the last two years of life, Resident E received treatment from a palliative care team. The level of this treatment increased as his health deteriorated.

Visits from the palliative care team commenced following Resident E's discharge from hospital. Resident E was placed on a pain management regime of four-hourly oral morphine, with additional 'breakthrough' doses as required. The pain management regime continued, as advised by the GP.

In another case, the PCT was able to arrange for a physiotherapist to attend Mannix Centre to provide the treatment and also give instructions to staff about postural drainage and suctioning.

7.4 Gaps in palliative care services at Mannix

The level of palliative care servicing appeared to be fragmented and inconsistent and referral to palliative care appeared to be ad hoc. For the four individuals who received palliative care, there was no consistency about the recording of palliative care referral, treatment and follow-up. Palliative care plans were not documented. There was no evidence of any case conferencing or records of meetings between the service, the PCT and families to discuss treatment or end of life issues. Recommendations about palliative care were not always actively pursued by Mannix.⁵⁵ For example, in one case the PCT recommended that Mannix should contact Liverpool Hospital and provide any relevant medical information and in particular, to establish any necessary protocol with the hospital in relation to end of life treatment and decisions. There is no indication that this recommendation was implemented.

The DDRT observed little evidence of a systematic approach to determining when and how palliative care decisions should be made. It was found that:

- there were varying levels of consultation with parents about their wishes regarding palliative care treatment and end of life decisions for their children.
- Mannix staff were not always consulted about palliative care or end of life decisions. This, it appears, was partly due to the absence of mechanisms in place to determine the types of care that should be provided and discussed with families and staff. It also led to situations where staff were not clear about what decisions had been taken.
- a parent was concerned that not enough was being done for her son and requested that the service seek an increase of palliative treatment and consult more frequently with the PCT. Although this happened, the parent remained concerned that Mannix staff did not understand the palliative care needs of her son.
- a family was not fully informed about a child's condition and progress and no discussions were held about preferred treatment and agreed treatment options.
- six of the eight individuals experienced pain associated with their disabilities and their health conditions, yet access to pain management services was limited. Pain treatment and advice was provided in only two of these cases and only after referral to the PCT.

According to the service, for some families, palliative care cannot be considered in advance or before a specific need is clearly identified. As such, the service states that it is only able to proceed with a referral when a parent has raised the issue. Such a policy may be limited, as it is unable to provide a framework in which support, planning and guidance can be provided to

⁵⁵ This failure to pursue recommendations for other health needs is commented on in section 5.2.3 *Nutrition management responsibilities*.

assist families with determining appropriate options. Mannix's position is that a hospital referral is sought as a last resort as the service is only able to provide palliative care as a means of treatment for a limited time.⁵⁶

7.5 Developments since completion of reviews

According to Mannix, since the death of one of the eight residents, Mannix staff now have a greater understanding of palliative care issues, although it is acknowledged that there has yet to be specific staff training in this area.⁵⁷ Mannix has one registered nurse with expertise in palliative care who is available to provide informal advice on issues of death and dying. Mannix has indicated further contact will be made with the local PCT for education on palliative care.

Mannix's manager has advised that the service is addressing the need for palliative care plans and related records, but states that this is an ongoing challenge because of its limited resources in this area.⁵⁸ No details have been provided to the DDRT as to what steps are in place to improve the overall management of developing and recording palliative care plans.

7.6 Improving palliative care

The recognition of palliative care needs and subsequent provision of services is difficult, particularly in regard to children with long standing frail health or degenerative conditions. At Mannix, this was compounded by the limitations of access to specialist services. However, even when palliative care advice has been provided, Mannix has not consistently implemented the specialist recommendations. For palliative care to be recognised as a medical or treatment option within this service, a number of strategies are required. These include:

- Mannix should, with assistance from a PCT, identify the palliative care needs of all its residents who have profound levels of disabilities and non-progressive neurological conditions; and
- with assistance from experts in the palliative care field and DADHC, Mannix should examine how to best care for children and young people with a degenerative condition or terminally ill and develop an

⁵⁶ The DDRT was advised of this at a meeting held with Mannix on 15 August 2001.

⁵⁷ The DDRT was advised of this at a meeting held with Mannix on 15 August 2001.

⁵⁸ The DDRT was advised of this at a meeting held with Mannix on 15 August 2001.

awareness/information program for families and staff on palliative care as a treatment option.

7.7 Systemic considerations

According to consultation with a community-based palliative care team, palliative care referrals of children with disabilities are rare. All referrals are reliant on general practitioners identifying the need for such a service and the general practitioner normally is responsible to co-ordinate such services.

Palliative care teams are multi-disciplinary teams providing assessment, review and recommendations. These teams have specific expertise in medication management, pain management, skin integrity and oral care needs of the dying person. Palliative care teams are available to provide clinical training for nursing and care staff.

Action is urgently required by DADHC, with assistance from NSW Health, to develop palliative care guidelines to assist disability services, health providers, families, guardians and advocates to consider palliative care as an option to optimise care of children and young people with degenerative conditions associated with their disabilities. This would allow discussion and education on the subjects of death and bereavement in relation to children and young people. It would also assist in establishing an integrated approach between services, hospitals and the community.

8. Staffing, decision-making and reporting

8.1 Staff competencies

At the time of the eight deaths, the staffing arrangements at Mannix consisted of registered nursing staff (one per shift), enrolled nurses (one or two per shift) and personal care staff. Mannix employment policy does not indicate any particular competency standards (although it has historically employed registered nurses, enrolled nurses and assistants in nursing). There are no industry-wide requirements for pre-service qualifications. According to Mannix management, all direct care staff are provided with training on the job.⁵⁹ The DDRT understands that at the time of the deaths, there was no formal staff training or development program in place. This raises some issues, particularly in regard to ensuring ongoing professional development and providing opportunities to staff to upgrade skills and competencies.

In regard to key areas identified in the DDRT reviews, there was no external training or formal supervision provided by the service in these areas:

- mealtime practices and feeding techniques;
- the management of enteral feeding procedures;
- correct positioning;
- diet preparation; or
- dysphagia screening tool.

There was no professional expertise employed at Mannix (such as a dietician or speech pathologist) to provide on-site training in these techniques. According to the service, nursing staff are informed about feeding practices through advice provided on a case-by-case basis by individual dieticians.

Given the lack of consistent external input to service and staff development, Mannix places itself at risk of isolation from information/professional networks, particularly in the area of disability services, child and family and out-of-home care systems. From DDRT contact, it does not appear that Mannix management has an extensive awareness of, or contact with organisations, initiatives, or training in the health care needs of the group. This appeared to be particularly problematic in areas of nutrition education, palliative care expertise and medication management.

⁵⁹ The DDRT was advised of this at a meeting held with Mannix on 15 August 2001.

8.1.1 Developments since the review

Since the completion of the individual death reviews, Mannix has advised that it has established contact with Disability Services Directorate, DADHC and with assistance from DADHC, is in the process of developing a staff training program across a number of practice areas.⁶⁰

8.1.2 Improving staff competencies

Mannix should urgently review its staff training needs, particularly in the key practice areas identified in this Review. In regard to nutrition, a substantive review of current staff practices in the overall management of nutrition needs should be undertaken with a view to implementing a staff-training program to update nutrition policy and practice. Mannix should ensure as a priority that appropriate training on safe feeding techniques is provided to all staff. Such training should include strategies to prevent aspiration and other problems, strategies to feed more effectively, and procedures for dealing with safety risks or incidents.

In relation to the specific issues of health and medication management, clinical practice training is required in the following areas:

- first aid and critical incident handling;
- safe and effective use of medication, including monitoring and recording of side effects and impacts of medications;
- record keeping and clinical data interpretation; and
- case management and case work practices.

8.1.3 Systemic considerations

At a systemic level, there are no standard competency requirements for staff and caregivers caring for children and young people in residential disability settings in NSW. This means that the skill level of those providing direct care can vary widely, and training arrangements may be ad hoc. Both skill levels and training arrangements are determined at the discretion of the service provider.

There is a potential role for DADHC to initiate a process for determining required competencies for staff in disability services. Competency requirements should be linked to existing requirements for minimum practice standards as set out in *Standards in Action*.

⁶⁰ Mannix advised the DDRT that it was in negotiations with Grosvenor Centre (DADHC) in relation to staff training needs and health care plans at a meeting held with the IPHCA Board of Directors and the Commissioner for Community Services on 23 October 2001.

8.2 End of life decision making

The decision to withhold or withdraw medical treatment was identified in five of the deaths reviewed. For four of these children, 'Not for Resuscitation' (NFR) orders were in place.⁶¹ NSW Health (1993) states that documentation about resuscitation should include

- detailed and unambiguous instructions;
- what treatment is to be commenced or continued;
- what treatment is to be withheld or withdrawn; and
- details of discussion had with patient/advocate about resuscitation.

According to NSW Health (2000), the use of NFR codes in medical records have been widely misunderstood and misinterpreted. The ethical and legal issues associated with these decisions require further inquiry and are beyond the scope of this report. The following therefore relates to the processes around 'end of life' decision making at Mannix.

8.2.1 Processes in place at Mannix

A number of problems were identified with the processes around how 'end of life decisions' were made. The DDRT found in some cases:

- difficulty in accessing/locating documentation relating to the NFR order;
- lack of clarity as to how an NFR order was determined; and
- unclear instructions about what treatment was to be withheld or withdrawn.

In two cases where families had discussed 'end of life' treatment with treating doctors, there was no record kept on the client file documenting decisions and no review of these decisions prior to the child's death. In another two cases, specific NFR instructions which had been in place were not provided to hospitals at the time of admission, even though a palliative care team had recommended that Mannix should provide this to the treating hospitals.

⁶¹ 'Not for resuscitation' (NFR), do not resuscitate (DNR) and cardiopulmonary resuscitation (CPR) are all terms that may be applied to cardiopulmonary resuscitation status and palliative care status.

A 14-year old-boy, Resident A, was seen by the GP as he was not responding to antibiotics and his general condition was deteriorating. Resident A's parents gave written advice to Mannix that they would prefer that their son remain at Mannix (rather than being transferred to hospital) and his treatment be maintained at a conservative level and that he be 'pain free.'

It is not clear if this instruction resulted from a meeting between the parents and the GP as there is no record of any discussion, or why the family had provided written instructions after visiting their son. Resident A died at Mannix ten weeks later.

NSW Health recommends that discussions should be held with families and significant others so that decisions and agreed treatment options are set out in a plan and documented. Discussion should include information regarding prognosis and treatment options and any risk of harm to the patient should be discussed with the family.⁶²

Overall, the DDRT found no evidence of clear and consistent processes by which 'end of life' decisions were made. The decision making process, reasons for decisions, and the extent of family involvement were not documented on individual files. It was also not clear about whose responsibility it was to raise these issues, or how such decisions affected the final care of individuals. In one case, although staff and the child's family had raised the question of an NFR order, there was no follow up undertaken and no NFR order was evident.

At the time of these deaths, Mannix had no guidelines for dealing with a situation where a child did not have significant family contact and consent for medical treatment and decision making was required. In some instances, there was a lack of clarity about the respective roles and responsibilities of parents and the service in relation to matters of decision-making, and poor identification of guardianship needs. This meant that for some residents, there was no advance planning in relation to end of life decisions and treatment.

8.2.2 Improving the processes around end of life decision making

Given the significance of these decisions and the complexity of issues involved in decisions around a child's end of life, Mannix should ensure that end of life decision making is appropriately considered, not only on a case by

⁶² The NSW Health (1993) 'Dying with Dignity' Interim Guidelines on Management, Section 4c state: A management plan should be developed detailing the:

- goals of treatment;
- treatment to be used;
- length of the treatment to be employed; and
- circumstances under which treatment should be foregone.

case basis, but within a framework of clear and consistent procedures, underpinned by clear documentation and written reasons for decision. Any parties that must be involved in end of life decision making should be as fully informed in the decision making process as possible.

8.2.3 Systemic considerations

At a systemic level, these end of life decisions need to be subject to careful consideration and agreement by relevant agencies including the NSW Health, DADHC and the DoCS, so that appropriate guidance can be issued to all involved. The ethical and legal aspects of end of life decisions, in the context of children and young people with disabilities and frail health, requires further research, with a view to developing sector-wide policy and practice guidance for service providers and health professionals.

Service providers should assume a pro-active approach to informing people with disabilities and their families about the legal issues surrounding the responsibility of care, consent, and the impact that decisions about treatment will have on the person with a disability. Documentation of the process of decision making for the individual with the disability will also allow a retrospective view of progress and responses to interventions, which can inform future decisions.

8.3 Critical incident handling

8.3.1 Policies and standards

At the time the first of these deaths occurred (July 1998), the service had no mechanism for recording accidents, critical incidents or events related to resident deaths. However, policies on procedures for client accident or injury and procedures for the death of a client were developed by the service and implemented in March 1999.

Standards In Action require that agencies have in place clear processes for the documentation, reporting, and management of potential or actual incidents.⁶³ Mannix requires that critical incidents and deaths be reported to the residential services' manager and documented in the Unit Report Book. A briefing note is to be completed when the death of a resident occurs. Staff (registered nurses only) are to receive training in relation to death procedures.⁶⁴ However, the policy provides no guidance regarding the requirement of notification of all resident deaths to the DADHC, as outlined in *Standards in Action*.

⁶³ *Standards in Action* Standard 10.6 Management of Abuse, Injury and Neglect.

⁶⁴ The Intellectually and Physically Handicapped Children's Association of NSW Policy and Procedure Manual Volume 1 May 1999.

In the eight deaths reviewed by the DDRT, five occurred after the introduction of the critical incident and death reporting procedures. However, the DDRT could find no specific reference to any critical incident handling process in any of the eight client files. There were no briefing notes, reports on the circumstances of death or any written statements by staff, management or Board of Directors evident on client files. Some information about incidents prior to and including death processes were found on file in nursing notes, treatment and referral forms. This raises the question as to whether the reporting of critical incidents has improved at all, how critical information is disseminated and whether staff have received training in this area.

Mannix's critical incident and death reporting system is not framed in a manner that promotes accountability. Information recorded about critical incidents is not systematically collected or responded to. The policies do not appear to provide opportunity for review of preventative or remedial action following accidents/incidents or analysis of trends, practice patterns or incident review. Although there is a requirement that incident and briefing reports be forwarded to the Executive Officer, the DDRT found no evidence of this occurring.

8.3.2 Improving the handling of critical incidents

Areas for urgent attention by Mannix to improve the handling of critical incidents include:

- review and development of written policies and procedures to guide staff and management's handling of critical incidents
- clarification of the procedures required for responding, reporting and follow up to incidents;
- development of staff and management training to implement policies and procedures; and
- development of a process in which implications arising from critical incidents can be examined for future practice.

8.3.3 Systemic considerations

As a monitoring body, DADHC needs to consider its role in assisting agencies, such as Mannix, to respond to and comply with the practice requirements in reporting and responding to critical incidents so that accountability, review and analysis of trends, practice patterns or incident review can occur within services.

8.4 External reporting of deaths

The reporting of the deaths of residents of disability supported accommodation services to the police or Coroner is recommended by

Standards in Action. In the case of the eight Mannix deaths, this occurred in only three cases.

While the Coroner must be informed of deaths in state care or where deaths are unusual or suspicious, they are not obliged to hold an inquest into all cases, but are guided by the legislation directing those matters where the Coroner must proceed to inquest.^{65,66}

The *NSW Coroners Act 1980* provides that a medical practitioner must not certify the cause of a person's death if it is a death that a coroner should consider as either a death in a state service or under unusual or suspicious circumstances. The medical practitioner must advise the police of the death as soon as practicable.⁶⁷

Of the eight deaths:

Name	Place of death	Medical Certificate of Cause of Death	Reported to police	Reported to Coroner
Resident A	Mannix	Completed	Mannix states that the death was reported to the police, however there is no police report.	No
Resident B	Hospital	Completed	No	No
Resident C	Mannix	Completed	Mannix states that the death was reported to the police, however there is no police report.	No
Resident D	Mannix	Completed	Yes	Yes
Resident E	Hospital	Completed	No	No
Resident F	Mannix	N/A	Yes	Yes
Resident G	Hospital	Completed	No	No
Resident H	Mannix	N/A	Yes	Yes

Death certificates were completed in six cases, three deaths were notified to the police and one autopsy was undertaken. No inquests were held. The DDRT found an inconsistent approach to reporting by Mannix; where in some cases, the police were notified, yet in others, a medical certificate of death was signed and no referral made to the police or coroner. There was no recording

⁶⁵ The *NSW Coroner's Act 1980* under s12B (1)(g), requires the reporting of the deaths of people with a disability in government accommodation and respite facilities within the meaning of the *Community Welfare Act 1987*. Non government accommodation and respite facilities are not licensed under the *Community Welfare Act 1987* and are thus exempt from this requirement.

⁶⁶ Section 14A, 14B, 14C, *Coroners Act 1980*.

⁶⁷ Section 12B, *NSW Coroners Act 1980*.

process available on the client files in which post death procedures could be easily tracked and verified.

Some confusion appeared to exist for the service, about the need to report the death of a resident, with some inconsistency in the reporting of the deaths of the Mannix residents to the police and/or Coroner. It is acknowledged that such inconsistency is likely to be in part due to an anomaly in the *NSW Coroners Act 1980*, which requires all deaths in DoCS' accommodation services to be notified to the police or Coroner, but does not require this of non-government organisations.⁶⁸ However, *Standards in Action* recommends that deaths of residents in non-government services should be reported to the police or Coroner. Within the current system, there is significant potential for a death in a service not to be reported. This restricts capacity for external scrutiny, validation of cause of death and consideration of circumstances of death.

In the case of the death of a 14-year-old girl highlighted below, a death certificate was completed by the local general practitioner, even though the doctor had not medically examined her in the two weeks preceding her death.

Although Resident D had a history of respiratory problems, including aspiration, it was not known what led to Resident D's deteriorating condition in April 1999, nor if or when her bronchopneumonia developed. There was no record of recent bronchopneumonia on her file, no medical examination in the preceding two weeks and a relatively sudden deterioration in Resident D's health. Despite these circumstances, the medical practitioner completed a medical certificate of cause of death, stating bronchopneumonia as the cause of death.

Given these circumstances it would have been more appropriate to defer the completion of the medical certificate of cause of death and refer the matter to the Coroner. It appears that the Coroner's decision not to order a post-mortem was, at least in part, based on the GP's record of cause of death.

8.4.1 Improving death reporting processes

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

8.4.2 Systemic considerations

⁶⁸ Prior to the *NSW Disability Services Act 1993 (DSA)* all funded disability accommodation services, including DoCS and NGO services were licensed under the *NSW Youth and Community Services Act, 1973 (YACS)*. All licensed services were required to notify the deaths of residents to the Coroner.

With the introduction of the DSA, NGO funded services were no longer licensed, and consequently not required to report deaths in care to the Coroner, apart from those that were unexpected, unusual or suspicious. DoCS' services remain 'facilities' within the meaning of YACS and continue to be obliged to report the deaths of residents to the police or Coroner.

A coronial process is the only judicial means of providing external scrutiny and opportunity for consideration of the circumstances, and validation of the cause of death. Yet disability services provided by non-government agencies are not required to report deaths of residents under s12B (1)(g) of the *Coroners Act 1980*, thus reducing the likelihood of coronial scrutiny of such deaths. At a systemic level, this issue clearly needs to be addressed and resolved.

Circumstances of the child or young person

- Age at time of death
- Entry into care
- Disability and level of dependency
- Specific health conditions
- Legal status of child in care

Circumstances of death

- Events immediately prior to death
- Medical treatment prior to death
- Place of death
- Notification of death to families and guardians
- Post death procedures
- Reporting of death to police or Coroner

Nutrition case management

- Access to nutrition assessment and follow-up
- Tube feeding practices
- Screening, clinical and medical assessments
- Monitoring of weight and growth
- Nutrition case co-ordination

Medication management and recording

- File records management
- Consent to treatment processes

Palliative care and end of life decision making

- Palliative care plans
- Processes around end of life decision making

Infection control and immunisation status

**THE INTELLECTUALLY AND PHYSICALLY
HANDICAPPED CHILDREN'S ASSOCIATION of
N.S.W.
BOARD OF DIRECTORS ENDORSED RESPONSE
TO THE MANNIX GROUP REVIEW REPORT .**

**DDRT Review into the deaths of eight residents at the
Mannix Children's Centre - Community Services
Commission.**

The Intellectually & Physically Handicapped Children's Association of NSW Board of Directors (the Board of Directors) expresses deep sorrow with the death of any child or young person in the Mannix Centre. The children and young people in the Mannix Centre have significant intellectual and physical disabilities, most of whom have associated medical conditions that existed at birth or have become increasingly complex during childhood development and lead to frail health.

The Board of Directors will immediately take all necessary positive actions to address the issues raised in the Mannix Group Review Report. These issues will form the basis of a detailed action plan to identify and immediately commence to put in place systems that have been recommended. The Board of Directors will work proactively with the Department of Ageing, Disability and Home Care to develop policies and procedures that currently are not contained within disability service standards or require cooperative arrangements with N.S.W. Health or Area Health Services.

The Board of Directors also believe that a number of factors may also need to be considered, which have not been included within the Mannix Group Review Report. The first of these factors need to be placed in context to the history of the Mannix Centre.

The Mannix Centre (formerly Bambi Nursing Home) was commenced in 1974 for children up to the age of 8 years old. During this time as a Nursing Home, Bambi was funded by the Commonwealth Government under the Nursing Homes Assistance Act. This funding was based on the employment of Registered Nurses, Enrolled Nurses and other trained medical staff to provide medical care and support services to it's residents and was Deficit Funded which meant that all the costs required to run Bambi were fully funded by the Commonwealth every year.

In 1993, the funding responsibility for the Mannix Centre was transferred to the N.S.W. Ageing and Disability Department, under the Commonwealth / State Disability Agreement. The funding then changed to a block funding

arrangement, which means that a set amount was given and was increased through a system of indexation every year to operate the facility.

The amount of funding received by the Mannix Centre for the year ending June 2001 was \$1,990,675, which is \$66,355 per resident per year. During this financial year, the actual cost to operate the Mannix Centre was \$99,083 more than the funding received through the Commonwealth / State Disability Agreement which left a shortfall (or deficit) of \$3,302 per resident in that year.

When the Mannix Centre funding is compared to funding to children or young people with disabilities who reside in group homes and who have similar complex needs, the average funding is in the order of \$98,000 per resident per year. Whilst the Mannix Centre and group homes are required to meet the same Disability Service Standards, the order of difference in funding is greater than \$30,000 per resident per year for group homes.

The level of funding provided to the Mannix Centre impacts on the available staffing for shifts over various periods of the day when all the residents are home. During the morning the ratio of care staff to residents between 6 a.m. and 10 a.m. is 1 carer to 3.3 residents. During the afternoon the ratio of care staff to residents between 3 p.m. and 7 p.m. is 1 carer to 3 residents, but this includes 2 recreation staff that are responsible for activities and community outings for the residents. During the evening the ratio of care staff to residents between 7 p.m. and 9 p.m. is 1 carer to 4.3 residents, which from 9 p.m. until 6 a.m. the next morning reduces to 1 carer to 10 residents.

Carer staffing has been increased in Mannix Centre to reduce carer to resident ratios, but this has steadily increased the deficit to funding received from the Department of Ageing, Disability and Home Care. Whilst increasing carer staffing does not in itself lead to meeting all the recommendations in the Mannix Group Review Report, a review of current staffing would identify that carer ratio improvements over meal times would enable greater levels of support to residents who require intensive feeding and nutritional programs.

Unfortunately the Mannix Group Review Report did not examine any staff to client ratios nor did the report identify the level of funding currently received by the Mannix Centre on a per resident basis.

The Mannix Group Review Report also focuses on the provision of specialist medical services for the children and young people in the Mannix Centre. The Mannix Centre refers individual children and young people to specialist services however the gatekeepers to access such services are the Area Health Services or individual clinics that accept and process referrals. Access to such services has been on the basis of taking the individual to the hospital or clinic for appointment times and dates set by the specialist medical service. The timeframes for such appointments is at the discretion of the hospital or clinic in determining the urgency of need of the individual. The Mannix Centre can

express a desire for a more timely response to a referral, but the final decision for such response has been with the specialist medical service.

In order to expedite the provision of specialist medical services the Mannix Centre has negotiated a contract of service with the South Western Sydney Area Health Service for the provision of a dietician and speech pathologist to provide nutritional assessments, enteral feeding program reviews, nutritional services and staff training. This service commenced in September 2001, is paid for by the Mannix Centre and was a result of negotiations initiated by the Mannix Centre. No assistance has been provided to the Mannix Centre in securing on-site specialist medical services, no guidelines exist for where a dispute arises to timely access to specialist medical services, and no liaison protocols with the Department of Health exist that can be used to negotiate regular medical specialist clinics on-site.

Notwithstanding the barriers that currently exist in accessing specialist services the Mannix Centre will continue to advocate strongly on behalf of the individual residents in care to obtain these specialist medical services on a timely basis.

It is highlighted in the Mannix Group Review Report that a number of systemic issues exist, which lead to inadequate, uncoordinated or in some cases an absence of optimal care practices within the Mannix Centre and the broader disability service system. The report identifies that some of these issues relate to the lack of coordination of policy between different State Government Departments, gaps in legislative requirements and the adequacy of some existing disability standards. Some of these issues include palliative care guidelines, staff competency requirements, end of life decision making policies, coronial notification processes, medication management guidelines, infection control and immunisation protocols.

While it is clear that the aforementioned issues are not unique to the Mannix Centre and that the Department of Ageing, Disability and Home Care have responsibilities in terms of funding, monitoring, policy development and leadership it is nevertheless acknowledged that the current systems of documentation, case management / follow-up and practice audit operating at the Mannix Centre will be reviewed and more efficient systems put into place. To this end the Department of Ageing, Disability and Home Care have recently contracted the services of a part time Clinical Nurse specialist to assist in this review until the Mannix Centre is able to engage a specialist on a more permanent basis.

With respect to the clinical practice issues identified in the Mannix Group Review Report and the acknowledgement that systemic issues exist within the broader disability service system it is felt by the Board of Directors that the Mannix Centre was examined on clinical practice issues for which in some cases there were no policy or guidelines in the disability service system

generally. It is paramount that the Mannix Centre and all service providers in the disability service system have clear and concise clinical and service practice requirements. The Board of Directors believe that any policy, procedure or protocol that is not currently available or has systemic implications regarding adequacy should not be left to the Mannix Centre to interpret and define without due support and direction.

In closing, the Board of Directors would like to reiterate the deep sorrow that is felt by everyone whenever there is the death of a child or young person in care at the Mannix Centre. It is imperative that these deaths are not without meaning and that the opportunity is taken by the Mannix Centre, the Department of Ageing, Disability and Home Care and N.S.W. Area Health Services to learn from the experience (as unpleasant as it may be) and to work cooperatively and in a coordinated manner to develop the necessary frameworks of support which will see people with disabilities provided with the best possible level of care, protection and quality of life.

Yours sincerely,



Robert Kelly
Chairperson
21st January, 2002

Department of Ageing Disability and Home Care

Response to: *DDRT Review into the Deaths of Eight Residents at Mannix Children's Centre*

The *DDRT Review into the Deaths of Eight Residents at Mannix Children's Centre* highlights specific service management and delivery practices on the part of the Intellectually and Physically Handicapped Children's Association of NSW (IPHCA) as well as a range of systemic issues that require consideration and appropriate action across NSW Government agencies. The Department of Ageing, Disability and Home Care (DADHC) recognises the particular vulnerability of children in out-of-home care and is committed to meeting their special needs.

DADHC accepts the recommendations arising from the Review and reaffirms its strongest commitment to ensure their implementation.

The Department's comments in relation to the events at Mannix Children's Centre relate to:

1. its obligation to monitor the service delivery and management practices of IPHCA in ensuring the health and wellbeing of people with a disability in their care;
2. the need for ongoing policy development and service planning, to ensure that planning and implementation of major initiatives relating to large residential facilities address key service system issues, including legislative compliance, standards and policies, with specific attention given to health care requirements for people with a disability who have high medical support needs; and
3. developing/implementing a strategic approach to the devolution of large residential facilities through the creation of an Institutional Reform Coordination Unit in DADHC.

1. Monitoring IPHCA Services

DADHC is working closely with the management and Board of IPHCA to ensure the implementation of recommendations arising from the eight individual death reports. The Department accepts the CSC's recommendation that any lack of substantial progress in this respect will require a review of the organisation's auspicing of the Mannix service.

Actions taken to improve practices in Mannix at the time of the issuing of this final report have included:

- Instigating a corporate governance training program for the IPHCA Board and management to build the capacity of the organisation to act effectively in response to recommendations and implement effective business management strategies to improve the overall delivery practices of the organisation.
- Registered senior nursing staff of the Disability Services Directorate (DSD) of DADHC conducting an audit of service provision, providing Health Care Plan templates and commencing health care plan updates of all residents together with IPHCA staff.
- DSD staff working in collaboration with the local Area Health Service and hospital to access ongoing dietetic and therapy services, and to organise staff training clinics on physical and mobility issues and contemporary health care practices.
- Funding a Clinical Nurse Specialist to work full time at Mannix, assisting in the review of Health Care Plans and monitoring overall service provision improvement in the areas of: nutritional and health needs; immunisation; infection control; and medication management.
- Contracting an Infection Control Advisory Service (ICAS) to audit infection control practices at Mannix. Included in this contract are quarterly reviews by the ICAS on implementation against the audit recommendations; an initial intensive staff training program followed by quarterly refresher training; and an annual reaudit to benchmark improvements in infection control.
- Instigating palliative care planning for those residents at Mannix who have palliative care I needs. The Department does not support palliative care planning for all residents as a matter of course.
- Working with families and advocates to develop plans for relocation of children from the Mannix Centre into more appropriate family and community living options. All plans include Clinical Nurse Specialist supports, both as part of the initial relocation process and in ongoing community based care arrangements. This model of health care, together with liaison and education with the local community and in situ monitoring of health care practices, has proved effective in supporting people with significant disability and related health care needs in community living arrangements.
- Assisting all children in large residential facilities to move to appropriate community based living arrangements. As a result of the planning and education of families and advocates through this process more families are

considering care for their children within the family environment -either in the family home, in share care or foster care arrangements.

2. Systemic Issues Arising from the DDRT Review

DADHC recognises the need for ongoing policy development and service planning that includes service improvement, to ensure the health and well being of people with a disability and the importance of a rigorous monitoring framework. To this end the Department:

- Will be implementing anew Integrated Monitoring System for all funding and service delivery activities in 2002.
- With NSW Health, has agreed to give high priority to collaborative work to develop policies, procedures and sector education to support the provision of services for people with significant disability and health needs.
- Has developed an Industry Workforce Development Strategy to promote industry partnerships, improve access to industry information and resources, identify priority learning and development needed in the industry, and seek to positively influence the quality of the workforce. This initiative is being undertaken together with major industry training bodies and DET and the Commonwealth funded employment sector. Working partnerships have already been developed to inform and support industry learning and development initiatives.
- Is playing a key role in cross-Government initiatives including *NGO Capacity Building* and the *Grants Administration Review* aimed at developing the infrastructure, resources and skill base of non-Government organisations across NSW.
- Is continuing to implement the *DSD Nutrition Project* and is investigating the use of this tool as a policy and practice model for all funded service providers.

3. Institutional Reform

The NSW Government has a policy commitment to devolve all large residential facilities over a period of 12 years. The first phase of this work has begun and includes moving all children currently living in large centres to family-based arrangements in their communities.

The Department has established an Institutional Reform Coordination Unit to progress this work within a strategic framework. The team will also address key policy and system questions arising from the devolution process and other related initiatives.

References

ACT (Association for Children with Life Threatening or Terminal Conditions and their families) & the Royal College of Paediatrics and Child Health. 1997, *A guide to the development of children's palliative care services*. London.

Beange, H., Lennox, N. & Parmenter, T. 1999, Health targets for people with an intellectual disability. *Journal of Intellectual and Developmental Disability*, 24(4), 283-297.

Bowan, I., Duggan, K. & Gerry, M. 1993, *Conflict of rights? Care of the disabled child in hospital*. Paper presented at AWCH National Conference, October 1993, AWCH National Office, Westmead.

Centre for Developmental Disability Studies (CDDS). Undated, Draft health project report. Sydney, New South Wales.

Community Services Commission. 1997a, *Report on nutritional and mealtime practices for people with developmental disabilities in residential care*, NSW Government, Sydney.

Community Services Commission. 1997b, *Suffer the children: The Hall for Children report*, NSW Government, Sydney.

Community Services Commission. 1998, *Inquiry into care and treatment of residents of Cram House*, NSW Government, Sydney.

Community Services Commission. 2000, *A critical event at the Grosvenor Centre*, NSW Government, Sydney.

Community Services Commission. 2001, *Disability, death and the responsibility of care*, NSW Government: Sydney.

Dormans, J.P. & Pellegrino, L. (eds). 1998, *Caring for children with cerebral palsy: A team approach*, Brookes Publishing, Baltimore, Maryland.

Eyman R.K., Grossman, H.J., Tarjan, G. & Miller, C.R. 1988, Prediction of mortality in community and institutional settings. *Journal of Mental Deficiency Research* 32, 203-213.

Finucane, T., Christmas, C. & Travis D. 1999, Tube feeding in patients with advanced dementia. *Journal of American Medical Association*, 282(14),1365-1370.

Hollins, S., Attard, M., von Fraunhofer, N., McGuigan, S. & Sedgwick, P. 1998, Mortality in people with learning disabilities: risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology*, 40, 50-56.

Hyson, J., Sutton, D., Schwarz, R., Devereux, L. & Sawyer, S. 2000, *Paediatric palliative care: towards best practice at the Royal Children's Hospital Melbourne*, Melbourne.

Kessler, D. & Dawson, P., (eds). 1999, *Failure to thrive and paediatric undernutrition: A transdisciplinary approach*. Brookes, Baltimore.

Langmore, S., Terpenning, M., Schork, A. & Chen, Y. 1998, Predictors of aspiration pneumonia: How important is dysphagia? *Dysphagia*, 13, 69-81.

Lennox, N.G. & Diggins, J., (eds). 1999, *Management guidelines: People with developmental and intellectual disabilities*. Therapeutic Guidelines Limited, Victoria.

Lennox, N. & Beange, H. 1999, Adult Healthcare. In *Management guidelines: People with developmental and intellectual disabilities*. Lennox, N. & Diggins, J. (eds), Therapeutic Guidelines Ltd, Victoria.

National Health and Medical Research Council. 1993, *National immunisation strategy: Improving immunisation rates – problems and solutions*. AGPS, Canberra.

National Health and Medical Research Council. 2001, *Australian immunisation handbook*, 7th Ed. AGPS, Canberra.

Nicholson, F., Korman, M. & Richardson, M. 2000, Percutaneous endoscopic gastrostomy: A review of indications, complications and outcome. *Journal of Gastroenterology and Hepatology*, 15(1), 21-25.

Nickel, R. & Desch, L. 2000, *The physician's guide to caring for children with disabilities and chronic conditions*. Brookes, Baltimore.

NSW Ageing and Disability Department. 1996, *Families with young children with disabilities and high support needs*, NSW Government, Sydney.

NSW Department of Ageing, Disability and Home Care. 1998, *Standards in action: Practice requirements and guidelines for services funded under the Disability Services Act*, NSW Government, Sydney.

NSW Ageing and Disability Department. 2000, *Annual Report 1999-2000*, NSW Government, Sydney.

- NSW Health. 1993, *Dying with dignity: Interim guidelines on management*. State Health Publication No. (HPA) 93-33, NSW Government, Sydney.
- NSW Health. 1997, *Guidelines for the handling of medication in community-based health services and residential facilities in New South Wales*. Circular 97/10, NSW Government, Sydney.
- NSW Health. 2000, *Dying with dignity: Revised draft guidelines for clinical decision-making at the end of life*. Discussion Document Part B, NSW Government, Sydney.
- NSW Health. 2001, *Palliative Care Framework*, NSW Government, Sydney.
- Olsen, R. & Maslin-Prothero, P. 2001, Dilemmas in the provision of won-home respite support for parents of young children with complex health care needs: evidence from an evaluation. *Journal of Advanced Nursing*, June, 34(5), 603-610.
- Patja, K., Iivanainen, M., Vesala, H., Oksanen, H. & Ruoppila, I. 2000, Life expectancy of people with intellectual disability: a 35-year follow-up study. *Journal of Intellectual Disability Research*, 44(5), 591-9.
- Porter, J. & Teter, M. 1991, Outbreak of adenoviral infections in a long-term paediatric facility, New Jersey, 1986/87. *Journal of Hospital Infection*, 18(3), 201-10.
- Stallings, V., Charney, E., Davies, J. and Cronk, C. 1993, Nutrition related growth failure of children with quadriplegic cerebral palsy. *Developmental Medicine and Child Neurology*, 28, 729-733.
- Straube, R. & Thompson, M. 1983, Adenovirus type 7b in a children's hospital. *Journal of Infectious Diseases*, 147(5), 814-9.
- The Intellectually and Physically Handicapped Children's Association of NSW. 1999, *Client Services Policy and Procedure Manual Volume 1*.
- von Konigsmark, M. 1999, An extra D in DD. Presented at the Australian Society for the Study of Intellectual Disability, 35th Annual Conference, Sydney.

Acronyms

ADD	Ageing and Disability Department
CPR	Cardiopulmonary resuscitation
CRAMA	<i>Community Services (Complaints, Reviews and Monitoring) Act 1993.</i>
CSC	Community Services Commission
CSDA	Commonwealth State Disability Services Agreement
CV	Community Visitor
DADHC	Department of Ageing, Disability and Home Care
DDRT	Disability Death Review Team
DoCS	Department of Community Services
DNR	Do not resuscitate
DSA	<i>NSW Disability Services Act, 1993</i>
DSD	Disability Services Directorate
DSP	Disability Services Program
GER	Gastroesophageal reflux
IP	Individual Plan
IPHCA	Intellectually and Physically Handicapped Children's Association
MDS	Minimum Data Set
NFR	Not for resuscitation
NGO	Non-Government Organisation
NHMRC	National Health and Medical Research Council
PCT	Palliative Care Team
PEG	Percutaneous endoscopic gastrostomy
PRN	Pro re nata – refers to treatment that is prescribed for use 'as required'
SWSAHS	South Western Sydney Area Health Service
YACS	Youth and Community Services Act 1973