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A Critical Event at the Grosvenor Centre

Review by the Disability Death Review Team
of DoCS' Internal Review of the Critical Event
at Grosvenor Centre in November 1998

Summary Report

Community Services Commission
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1. Background

During November 1998, Grosvenor Centre - a Department of Community Services' (DoCS) residential facility for children, young people and adults with multiple and complex disabilities - had 12 residents of Unit 2 who became ill and required hospitalisation, eight with respiratory illnesses and another four with unrelated conditions (as was determined by subsequent investigation). Two of these, a teenage boy and a young woman, died some days after their admission to hospital. The Central Sydney Area Health Service's Public Health Unit (PHU) began an investigation, at the request of DoCS, into whether there was a public health problem, such as an outbreak of Legionnaire's disease, at the Centre. DoCS also established its own internal review process to examine the critical event.

The Minister for Community Services and Disability Services, the Hon Faye Lo Po' MP announced the establishment of the Disability Death Review Team (DDRT) within the Community Services Commission on 18 November 1998, with the two Grosvenor deaths the first cases to be referred to the team. The team was established as a function of the Commission, operating pursuant to sections 83 and 84 of the *Community Services (Complaints, Reviews and Monitoring) Act 1993* to enable it to monitor, review and inquire into the delivery of community services and matters affecting children and adults with disabilities who have died while living in residential facilities (both government and non government) in New South Wales. However, given the time involved in establishing a fully functioning team, the Minister agreed that, in relation to the Grosvenor deaths, the DDRT's role would be to review DoCS' review, once complete.

At the end of December 1998, there were two further deaths at Grosvenor, adding to public concern. DoCS determined that these would not be included in the review already commenced but would be subject to separate internal reviews. The Minister also referred these deaths to the DDRT.

DoCS appointed two people to review the Grosvenor critical event, encompassing the first two deaths, and the review commenced in early December. A preliminary Internal Review report was considered by an expert panel convened by DoCS at the end of March 1999 and a copy provided to the DDRT as well. A final copy of the report, along with the report of the expert panel and an action plan indicating DoCS' response to and progress with the review recommendations, was provided to the DDRT on 15 October 1999.

The DDRT's review focuses on the adequacy of DoCS' Internal Review of the critical event in: documenting the circumstances leading up to and surrounding the outbreak of illness and the deaths; identifying any inappropriate actions or practices in relation to these; and highlighting preventative strategies to minimise the likelihood of such an event occurring again.

As well as examining relevant departmental documentation, the DDRT also accessed police reports, the PHU report, visited the Grosvenor Centre and spoke with the Director of Nursing and the relevant Area Manager.¹ However, as the exercise was a “review of a review”, the DDRT did not call for or examine all documentation potentially pertaining to the matter, independently assess service practices, nor interview staff, families and others.

An advance copy of the DDRT’s report was provided to DoCS on 17 November 1999 for comment. Following this, a detailed response and documentation indicating progress with implementation of various recommendations, including those contained in the Internal Review, were provided by DoCS to the DDRT. This information has been incorporated into this report and is referred to where appropriate.

This report does not make any adverse finding in relation to any individual nor call into question the integrity or reputation of any individual.

¹ Departmental documentation examined included the files of the four individuals who died (care plans, medication charts, medical reports, hospital discharge summaries, briefing notes on the deaths and Coroner’s reports where available), Bug Control, Infection Control Advisory Service Report, 11 July 1998, Report on Physical Health of Residents in Unit One and Two, April 1998, the Grosvenor Centre Business Plans for 1998 and 1999, the Peer Review Report, February 1999, and the Review of Management Services at Grosvenor Centre, January 1999.

2. The Four Individuals Who Died

In conducting our review, we also drew on our assessments of the circumstances surrounding the deaths, in November 1998, of Resident A and Resident B. While DoCS' Internal Review did not look at the deaths of the two people who died in December 1998, Resident C and Resident D, we have used information from our assessments of these deaths as well, where we believe it is pertinent to the scope of, and issues arising from, DoCS' review.

Before analysing DoCS' internal review to determine its adequacy, it is useful to look at what we know of the four individuals who died and the circumstances of their deaths.²

Resident A (subject to DoCS Review)

Resident A was a 14-year-old boy who had lived at Grosvenor Centre since the age of three. Resident A had a severe intellectual disability, cerebral palsy, spastic quadriplegia and high support needs. He was underweight at the time of his death, was reliant on gastrostomy feeding and suffered from recurrent respiratory infection.

Resident A was noted to have respiratory distress on 2 November 1998. He was admitted to hospital on 8 November 1998 in acute respiratory distress and died six days later of acute respiratory failure due to pneumonia and asthma. His death was notified to the Coroner by staff of the New Children's Hospital. As well, the Director of Nursing at Grosvenor Centre spoke to the Coroner by telephone about the death of Resident A.

No autopsy was conducted at the request of his parents and the Coroner has dispensed with an inquest.

Key issues around Resident A's care in the 12 months prior to his death have been identified as:

- ongoing access to specialist services including a respiratory medical service;
- treatment provided for his asthma;
- support provided to Resident A's family during his home visits; and
- Resident A's ongoing nutritional and feeding problems.

² These assessments are based on information and reports contained in DoCS' client files, coronial reports and from the Department's Internal Review Report.

Resident B (subject to DoCS Review)

Resident B was a 25-year-old woman who had lived at Grosvenor since the age of four. Resident B had a severe intellectual disability, spastic quadriplegia and high support needs. She was underweight, had recurrent episodes of aspiration, was reliant on gastrostomy feeding, and suffered from asthma, epilepsy and recurrent respiratory infection.

Resident B became ill on 3 November 1998 and was admitted to hospital on 8 November 1998 in acute respiratory distress. She died five days later from aspiration pneumonia. Her death was notified to the Coroner by Royal Prince Alfred Hospital staff. As well, the Director of Nursing at Grosvenor Centre spoke to the Coroner by telephone about the death of Resident B. No autopsy was conducted at the request of her mother and the Coroner has dispensed with an inquest.

Key issues around Resident B's care in the 12 months prior to her death have been identified as:

- follow-up of medical recommendations and therapy needs, including dietician, physiotherapy and speech pathologist services;
- ongoing access to a respiratory physician;
- case management expertise at Grosvenor given the complexity of Resident B's health care needs;
- the need for neurological review; and
- the need for an integrated health care plan.

Resident C (her illness/admission to hospital was covered by the Internal Review's Terms of Reference but not the circumstances of her death.)

Resident C was a 13 year-old girl who had lived at Grosvenor Centre since the age of five. She had spastic quadriplegia and a history of reflux oesophagitis, was seriously underweight, had been reliant on gastrostomy feeding since the age of two and suffered from chronic upper respiratory problems.

Resident C was hospitalised on 13 November 1998 due to a respiratory illness and discharged on 1 December 1998. She was readmitted to hospital on 27 December 1998 and died on 30 December 1998.

Her death was believed to have been caused by general and progressive deterioration as well as possible aspiration. There appears to have been no referral made to the Police or Coroner and no autopsy was conducted. DoCS advises that it believed that the referral to the Coroner had been made by the treating medical practitioner. (This issue is discussed in more detail later in this report)

Key issues about Resident C's care in the 12 months prior to her death have been identified as:

- follow-up of health care referrals, dental treatment and specialists' recommendations;
- support provided to Resident C's family during her last home visit in December 1998;
- record keeping in relation to seizure activity and weight reviews;
- review and update of Resident C's treatment options (documented in 1993); and
- the need for an integrated health care plan.

Resident D (not subject to DoCS Review)

Resident D was aged 18 months at the time of his death. Resident D had complications following his birth and as a result had a developmental delay, skeletal dysplasia, feeding difficulties and epilepsy. He was tube-fed until the age of eight months. Resident D lived with his parents but commenced respite care three days per month at Grosvenor Centre from May 1998 until his death on 30 December 1998.

Resident D died while in respite care at Grosvenor Centre. The Police and Coroner were advised of the death by Grosvenor Centre staff.

The autopsy report notes that there was evidence of aspiration of gastric content. The Coroner made no finding on the cause of death.

DoCS' assessment of Resident D's death found that the alarm in the respite unit was not activated as per Grosvenor Centre's protocol, an ambulance was not called and staff reported difficulty in contacting after-hours support.

Resident D shared some similar circumstances to other Grosvenor residents including:

- high medical support needs;
- feeding difficulties;
- immobility;
- extensive hospitalisation; and
- risk of exposure to infection when in respite care at Grosvenor Centre.

Resident A, Resident B, and Resident C had lived at Grosvenor Centre for most of their lives and died within six weeks of each other. They had in common chronic frail health, complex feeding problems and dysphagia (swallowing difficulties), were underweight and all subject to artificial feeding regimes (gastrostomy tube feeding).³ They also all experienced immobility, incontinence, ongoing need for specialist medical and allied health treatment and long-term institutional care in Unit 2.

Our assessment found that, while Resident A was noted to have acute respiratory distress, he was not admitted to hospital for six days. The Coroner found that his death was caused by pneumonia associated with asthma. There was no file evidence that a respiratory physician assessed or treated him in the previous 12 months. It seems reasonable to conclude that a respiratory physician should have been involved in his ongoing treatment and care, given his medical history.

Resident B also died of respiratory complications but again there was no evidence that a respiratory physician assessed or treated her at Grosvenor. The file indicated that specialist services had been accessed and recommendations to address Resident B's health needs made (for example in relation to dietary/nutritional needs, speech

³ This requires a surgical operation to create an artificial opening into the stomach for the insertion of a feeding tube and then close monitoring of feeds, nutritional growth and management of the stoma.

pathology services relating to swallowing and her recurrent aspiration and sleep disorder). However, it is unclear from the file if these recommendations were pursued, incorporated into ongoing care plans and systematically addressed. There was no file evidence of a review of her epilepsy and anticonvulsant medication, even though apart from one reported seizure in February 1998, she had not had a seizure for many years.

Resident C became ill at the same time as the first two residents and was believed to have died of progressive deterioration and possible aspiration. She too was prone to respiratory infection and required intensive medical monitoring for her condition. She experienced pain and failed to thrive. Our review of her file suggests that, in the areas of pain management, dental treatment and follow up of health care referrals and specialists' recommendations, her care may have been less than optimal.

There were no autopsies conducted for the three permanent residents who died and neither the Police nor the Coroner were advised of the death of Resident C.⁴ Directions for passive treatment plans (such as no intensive treatment, respirator or antibiotic treatment) appeared in place for each of the three residents. Resident A and Resident B had 'not for resuscitation' (NFR) orders when admitted to hospital, according to the Department's Internal Review Report. However, documentation indicating in detail how such decisions were arrived at and on what basis was either not found on the individual files or was scant. This issue is discussed further in section 5.5 of this report.

Although Resident D was a respite client, he shared some similar circumstances to the other three residents. He had high medical and support needs, and his death occurred (along with Resident C) within six weeks of the first two deaths.

It is the DDRT's view that his death, along with that of Resident C, should have been included in the scope of the Department's Internal Review in light of its intended focus on circumstances of death, health and care issues in the preceding 12 months, management of the critical event and broad service delivery issues. All of these factors are equally worth considering and apply in the context of the later deaths. The public interest aspect adds to this view.⁵

⁴ Resident A and Resident B's families requested no autopsies to which the Coroner consented. The Coroner has no record of Resident C's death or any request to waive the autopsy but DoCS advises that the treating doctor had said that he would notify the Coroner and DoCS believed that this had occurred.

⁵ DoCS has responded that Resident C was included in the scope of the Internal Review, as she was one of the residents who became sick during the event. This adds to the view that her death should have been captured by the Internal Review. DoCS has also reported that a separate Internal Review of Resident D's case was commenced but was unable to be finalised because his file was with the Coroner.

3. The Public Health Unit Report

The PHU commenced its investigation immediately after the deaths of Resident A and Resident B, and focused on identifying any consistent patterns amongst those who were ill, whether there were any public health issues, and the need for infection control measures. Its investigation report is therefore an important document and one that was drawn on by the DoCS' internal review.

The PHU identified that 12 residents became ill during November 1998 – 10 of whom were permanent residents of Unit 2 and two of whom attended Unit 2 for respite care. Its report identifies the definition of “cases” to be included in the investigation – being residents who had experienced fever and respiratory symptoms during November 1998. Of the 12 who became ill, eight were identified as “cases” (seven permanent residents; one respite user), while the other four were reported as experiencing unrelated illnesses.

The PHU formed the early hypothesis that it was most likely that a nosocomial (institutionally acquired) viral respiratory tract infection was responsible for the illnesses and that, in the context of the Grosvenor Centre, it had resulted in significant morbidity.⁶

One of the first priorities for the PHU then was to assess whether infection control procedures at Grosvenor were adequate and to ensure that, for those residents who were ill, basic isolation protocols were used to minimise further potential viral transmission. A set of interim recommendations relating to hygiene, cleanliness and infection control was provided to Grosvenor following inspections of Unit 2 and an infection control audit of the entire facility.

From the beginning, the PHU was clear that it was not responsible for investigating the actual deaths (stating that these would be the subject of a coronial inquest), but rather for identifying any ongoing public health issues.

Following its investigation, the PHU reported that, for four of the permanent residents defined as “cases”, serological testing was strongly suggestive of a recent adenovirus infection. Of the remaining three permanent residents defined as “cases”, two did not have all the necessary tests (both had died) and one tested negative for adenovirus. It stated that “hypothetically then, had all cases been fully tested, the association between adenovirus and the recent cluster of illness among permanent residents at Grosvenor could have been stronger”.⁷

It went on to say that “(t)he findings of our investigation have supported our initial hypothesis that a viral respiratory tract infection has exacerbated pre-existing problems in these circumstances” and that, despite identifying many infection

⁶ Investigation of a notification by Grosvenor Residential Centre of an illness cluster amongst residents – CSAHS Public Health Unit, December 1998, p.10.

⁷As above, p.17.

control issues at Grosvenor, it was “unable to conclude that a breach in infection control procedures was directly responsible for the recent illnesses”. The report explains that this was because of the nature of the virus identified and the small sample size involved. The report concludes that it “cannot make any conclusions about the deaths of two Grosvenor residents. Any such conclusions or comments must remain the domain of the Coronial Inquiry”.⁸

The final PHU report makes a number of recommendations aimed at: infection control improvements; developing a staff health program; seeking expert advice on enteral feeding practices; and establishing formal arrangements with medical specialists, particularly for the assessment of respiratory illnesses.

4. The DoCS’ Review (Internal Review Report)

DoCS appointed two people in early December to carry out its Internal Review into the deaths of Resident A and Resident B. The key reviewer was a Director of Nursing at a DoCS large residential facility for children in another Area. The support reviewer was a medical practitioner specialising in disability who had previously worked as a Visiting Medical Officer to Grosvenor and who was a member of a working party reviewing medical services at the Centre.

The Terms of Reference devised were broad, requiring the review to focus on the circumstances of those who became ill and the two residents who died, how their cases were managed, and how the critical event was managed. They also required an examination of the medical care provided over the preceding twelve months, and any health and/or care issues arising from individual plans, for those who became ill and the two who died. As well, the reviewers were to examine the general operations of the Grosvenor Centre, and issues around the health and medical needs of residents generally within such settings.

The reviewers accessed the PHU report, documentation at Grosvenor and the DoCS’ Area Office (including client files and information on previous reviews of Grosvenor), and conducted interviews with Grosvenor management, the general practitioners and dietician providing services to the Centre, and other professionals based at Grosvenor or at the Area Office. A number of tools to assess particular work practices were also used.

The Internal Review report deals with the critical event in Section One and the operations of the Grosvenor Centre in Section Two. It makes only one formal finding – concurring with the PHU report that a viral respiratory tract infection most likely exacerbated pre-existing problems in eight of the cases reported. It adds “(t)he adenovirus infection, which may have been responsible, carries a significant risk of

⁸ As above, p.18.

mortality, and institutional outbreaks are not uncommon. Respiratory disease is the commonest cause of death in persons with severe intellectual disability".⁹

While there is only one formal finding, the report makes a number of conclusions at different points, including:

- no instances of personal errors contributed to the outbreak of illness;¹⁰
- various staff and management should be commended on their interest, support to those residents affected, responses following the deaths and in complying with Departmental policy in relation to client deaths;¹¹ and that
- Grosvenor Centre Management and staff complied with the requirements of departmental policy.¹²

The report also identifies numerous issues arising/issues of concern and makes some 52 recommendations throughout.

The Expert Panel's report records the deliberations of the six member panel in considering the interim Internal Review report and lists some 27 actions arising from these deliberations, which reiterate or expand on issues and recommendations in the Internal Review report.¹³ It concludes that the panel endorsed the methodology used in the internal review and judged the recommendations to be appropriate to the incidents reviewed. Its final recommended action is that an action plan which complements the Area Action Plan be presented to the DoCS executive for endorsement and forwarded to the DDRT.¹⁴

5. The DDRT's Critique of DoCS' Internal Review

5.1 Scope of Internal Review

The scope of the Internal Review was wide ranging, with a strong emphasis on service delivery issues. The two selected reviewers examined a large amount of information and documentation in the course of the Review and in so doing touched on many significant issues.

However, the Terms of Reference did not specifically require an examination of the actions, roles or responsibilities of particular staff before, during or after the critical event and the deaths, and the review does not provide this. Because of this, the conclusions in the Internal Review concerning the conduct of individuals in relation

⁹ Internal Review of Critical Event, Unit Two, Grosvenor Centre, February 1999, p.3.

¹⁰ As above, p.vi.

¹¹As above, p.vi.

¹² As above, p.7.

¹³ The expert panel consisted of two medical practitioners, three departmental representatives and the Chairperson, a senior manager with DoCS. Five other people participated in the meeting, including the reviewers and three departmental representatives.

¹⁴ Report of the Expert Panel Review of the Departmental Investigation of Critical Events at Grosvenor Centre, Department of Community Services, August 1999.

to the critical event are difficult to confirm as the review did not have specific regard to the actions of individual staff and did not provide documented evidence to support such conclusions. Nor did the review provide a comprehensive, chronological overview of the critical event and the two deaths. This is despite the Terms of Reference requiring that the report provide details of the incident “from time of initial sickness until notification of death”.

The focus on the operational aspects of the Grosvenor Centre required by the Terms of Reference was not linked to an examination of the critical event. For example, the reviewers were required to develop a staffing profile and to look at training and supports available, but they were not required to look at which staff were on duty at key stages of the critical event and the support and training that had been provided to them on relevant issues.

The Terms of Reference also required much collation and documentation of information but did not require that this be analysed to test any particular hypotheses, other than to assess compliance with departmental policies and procedures. The seriousness of the matter under review suggests that something more than an audit type approach was needed. The reviewers were also not required to focus on preventative strategies, or to examine the impact of an institutional environment on quality of care and life for children with disabilities.

5.2 Reviewers

In principle, reviews of this nature should be conducted independently of the service. Our assessment of the information provided leads us to the view that while there is no question as to the integrity or professionalism of the reviewers, their selection to undertake the review may not have been totally appropriate. This view is based on the observations that neither was sufficiently independent of DoCS and one was put in the position of reviewing her own work. DoCS has stated that the selection of the reviewers was consistent with its Critical Event and Incident Management procedures and that the reviewers were selected on the basis of relevant experience and expertise. As stated, the integrity and professionalism of the reviewers is not in question. However, because of the seriousness of the matter to be reviewed and the level of public concern and interest in it, DoCS should have been mindful of the need for the greatest possible independence from the outset.

5.3 Methodology and Evidence

Other methodological limitations included: interviews were only conducted with Grosvenor managers and professionals providing services to the Centre, and did not include case managers and other direct carers, families or guardians; the criteria and methodology for reviewing client files and assessing compliance with departmental policy were not given; and some sources of information were not cross-referenced or independently validated but were taken as accurate (e.g. information told to the reviewers during interviews and observations and accepted at face value).

In particular, it is difficult to see how an examination of communication processes with families and advocates during the critical event, and the role of families and/or the Public Guardian in making NFR orders (as required by the Terms of Reference), could be undertaken without these parties being consulted.

The level of documented factual analysis and evidence provided in the Internal Review report is seriously lacking. Significantly, as already highlighted, there is no chronological account presented of the events leading up to the outbreak of illness, the transfers to hospital, the deaths themselves and events afterwards, nor any analysis of the appropriateness of actions or responses. The review does not document the evidence for reaching a number of key conclusions.

In other instances, aspects of the Terms of Reference appear to have been omitted from the Review. For example, despite inclusion in the Terms of Reference, there is no discussion, analysis or documented evidence presented in relation to the medical history of the two residents who died and those who became ill over the preceding 12 months and action taken, nor the identification of health and/or care issues from individual plans. Similarly, communication between DoCS, families and advocates does not appear to have been examined in any detail, the involvement of other agencies is not systematically documented and the impact of hospitalization on those residents who became ill is not looked at.

At times, issues arising are identified suggesting that there could have been problems surrounding the management of the critical event. For example, under "Issues to be considered when Transferring Residents to Hospital" a range of 'issues' or gaps in service provision is listed and then recommendations made to address these. But it is unclear how these impacted on the critical event as the process in question is not documented nor analysed. Similarly, in the absence of a factual analysis of how the critical event was managed, the recommendation that "a process be developed and issued to Areas which describes clearly the steps to be undertaken to manage critical events" gives rise to the question as to whether there may have been inadequacies. It should be noted that DoCS has strongly rejected this view on the basis that there is no evidence that the event was not managed appropriately. However, neither the Internal Review nor DoCS has subsequently presented evidence to indicate how the critical event was managed.

The recommendation that DoCS "issue clear duty of care guidelines for disability services staff to follow where there is a view that parents are making decisions which may be harmful to the welfare of their child" raises serious issues. The review does not contain an analysis of events that supports or logically leads to the inclusion of such a recommendation.

5.4 Infection Control Issues

Another problem concerns the weight given in the Internal Review to the findings of the PHU investigation. While the Internal Review concurs with the main finding of

the PHU investigation that a viral respiratory tract infection was most likely responsible for the outbreak of illness, less weight is given to earlier PHU findings. The PHU's interim observations and recommendations, provided to Grosvenor in November 1998, reported significant infection control issues that needed to be addressed. The main problems identified were poor maintenance of ventolin masks, inadequate hand-washing facilities, and some inappropriate practices in relation to tube feeding. It made 30 recommendations, some of which were noted as urgent, and advised in its December report that these "remain current and should be implemented, if not done already".

The Internal Review notes that the PHU recommendations are similar to those of an earlier infection control review carried out in July 1998 but it does not indicate why these earlier recommendations had not been acted on, nor the status of implementation of the PHU recommendations. Given the seriousness of infection control breaches in an environment like Grosvenor, assessing and reporting on whether the PHU recommendations had been addressed should have been a priority.

Information provided by DoCS in April 1999 suggested that Grosvenor was taking action to address the PHU recommendations. More recent progress reports indicate that most recommendations have been, or are in the process of being, addressed. Although the DDRT is not in a position to determine how effectively the recommendations have been implemented and whether they have brought about the necessary change, a document titled Implementation of Recommendations on Grosvenor Centre (undated but provided to the DDRT in October 1999) states "The independent consultant reviewed Grosvenor again in July 1999 and commended the Centre for having improved compliance with accepted infection control requirements from 40% in 1998 to 77.9% in 1999." While this appears to indicate considerable improvement, the DDRT is of the view that further assistance and review from the PHU would be useful and important to ensure continued progress to full compliance.

5.5 General Care and Health Issues

Because the Internal Review does not include an examination of the medical histories and health care issues for the two residents who died and those who became ill, it does not reach any conclusions in relation to the quality of care provided and the impact of this on residents' physical well-being.

The DDRT's own assessments of the deaths of Resident A and Resident B in November, and the two subsequent deaths in December have highlighted a number of concerns. Despite chronic breathing difficulties, it appears that none of the residents was under the regular supervision of a respiratory specialist. Where specialists were accessed, it is unclear whether recommendations concerning dietary and other needs were followed up. There appeared to be a lack of regular review and recording of weight and epilepsy and no regular review or treatment by a

dietician for Grosvenor residents. Examination of these issues by the Internal Review would have provided useful insights into the quality of health care provided and its implications for the critical event.

Some of these issues of concern were identified in a review of the physical health of residents in Units 1 and 2, undertaken some time prior to the critical event in April 1998.¹⁵ A progress report on the implementation of recommendations from this review, dated 16 August 1999, indicates that while a range of action was being taken at that time, specialist health services including endocrinology, respiratory medicine and ophthalmology services had yet to commence at Grosvenor Centre. The most recent information available, in a document titled "Action Plan arising from Internal Review of Grosvenor" received in November 1999, suggests that these services are still not in place. Although a number of specialist health services have been identified and are in various stages of establishment, there appears to be no coordinated or integrated approach to the delivery of these services at this stage. Regular access to a multidisciplinary assessment service, incorporating therapy, dietetic, medical and social work services should be considered a priority for the delivery of health care to the residents of Grosvenor Centre.

Further, the 1998 review identified significant nutritional and feeding problems in Units 1 and 2 and made a number of recommendations to improve care and practices in these areas. Progress reports suggest that some action to address these problems has been taken. However, the DDRT's assessments of the four individuals who died and the department's Internal Review of the critical event have identified on-going concerns in relation to underweight, nutrition and feeding. DoCS has indicated that the need for more intensive dietician services at Grosvenor (as recommended by the Internal Review) will be considered as part of the Nutrition Pilot Project and that resident assessments and reviews, staff training, etc will be undertaken by the visiting dietician who attends the service once every three months. Given the serious and on-going nature of the problems in these areas, access to a dietician on a quarterly basis and requiring this position to undertake staff training, appears inadequate.

While the Internal Review notes that there is limited access to specialist and allied health services, it does not examine the impact of this on residents. It highlights that quality and coordination of medical care had deteriorated since the resignation of the Career Medical Officer but it does not address why the position had remained vacant for 12 months and why the issue was not addressed earlier. DoCS has stated that the assertion that the medical care had deteriorated may have been the opinion of two of the three General Practitioners interviewed for the Internal Review and one of the Internal Reviewers. However, even if this is the case, a view to the contrary or evidence supporting such has not been put forward and was not raised in the context of the expert panel's deliberations. In fact the Expert Panel recommended that a Career Medical Officer and Registrar position be established for the Inner

¹⁵ Report on Physical Health of Residents Units One and Two, Grosvenor Centre, by Dr Helen Beange, April 1998.

West Area in partnership with Royal Rehabilitation Centre, Sydney. DoCS has indicated in the action plan received by the DDRT in November 1999 that it is pursuing this arrangement and that agreement has been reached with the Royal Rehabilitation Centre, Sydney.

In addressing issues concerning the quality of medical care, the high levels of medical need and associated medical complexities of Grosvenor residents must be considered. It is arguable that the level of medical skill required is at a higher level than that of a Career Medical Officer, and, as such, a specialist physician trained in developmental medicine and/or rehabilitation may be more appropriate. DoCS should give consideration to the appointment of a suitably qualified medical specialist to oversee and coordinate the health care planning of Grosvenor residents.

The Internal Review also highlights the issue of the mix of adults and children and permanent and respite clients in Unit 2. But again, an analysis of this and its impact on those who became ill and/or died, is not given.

Although both residents who died in November had NFR orders on their hospital files, the Internal Review only dealt with this issue generally, rather than in relation to the residents specifically. The review does not document the decision-making processes leading to the orders, the basis on which the decisions were made, family involvement in this, and any implications for the health care and medical intervention provided to the two residents.

File notes accessed by the DDRT indicate that, for one of the hospitalised residents, the Director of Nursing questioned the NFR order, which appeared to have been made by doctors alone, and the order was removed. Yet this incident and the processes involved, are not documented in the Internal Review.

The DDRT's assessments of the deaths have highlighted that, for Resident A, the family appears to have been consulted by hospital staff in relation to the NFR order. Resident B also had an NFR order recorded on her hospital file. This order appears to have been made by hospital staff, in consultation with Resident B's mother during the final hospital admission. For both residents, no advanced planning was evident in relation to these NFR decisions, nor was the decision making process, reasons for decisions, and the extent of family involvement, documented on their Grosvenor client files.

Given the significance of these decisions and the complex issues involved, clear documentation of the process and reasons for decisions is imperative. It also seems reasonable to expect that families, guardians, advocates and service providers should be as fully involved in the decision making process as possible, given their central role in the resident's life. These matters need to be the subject of careful consideration and agreement by DoCS and Department of Health, so that appropriate guidance can be issued to all relevant parties.

5.6 Quality of Life Issues

The Internal Review touches on quality of life issues for residents of Grosvenor but overall, there is very little discussion about the impact of institutional care on the quality of life for children, young people and adults with significant disabilities.

There is a significant body of evidence and opinion that suggesting institutions are not appropriate models of care for people with disabilities, in particular, children. Llewellyn (1996) has identified major limitations for children living in institutions, including:

- Funds directed to services, not consumers;
- Services are fragmented, uncoordinated and highly specialised;
- There is a lack of innovation and flexibility in service delivery approaches and services do not have the capacity to reflect changes in individual needs over time;
- There is a lack of strategic planning to identify emerging need areas resulting in a reactive rather than pro-active service response; and
- Children's residential services meet the identified needs of the disability first rather than the needs of the child.¹⁶

Other studies have highlighted increased rates of mortality for people with disabilities in institutional settings and in settings where there are skilled nursing facilities, with respiratory disease often an associated factor.¹⁷

Certainly these issues appear pertinent to the Grosvenor Centre and some analysis of their impact on the critical event and on the standard of care overall would have added to the quality and depth of the Internal Review.

5.7 Notifications of Deaths to the Coroner

Neither the PHU report nor the Internal Review Report is able to make conclusive findings in relation to cause of death. The PHU was of the view that investigation of the actual deaths would be undertaken by way of coronial inquest.

Resident A died in the New Children's Hospital, Westmead, and Resident B in Royal Prince Alfred Hospital. According to the Internal Review Report, DoCS advised the Coroner's Office on 14 November 1998 of the deaths, and post-mortems were then waived at the request of the parents. The Coroner's Office has stated that it was not made aware that the two deaths were possibly connected, as the notifications were

¹⁶ NSW Ageing and Disability Department *Families with Young Children with Disabilities and High Support Needs*, Llewellyn G, Dunn P, Fante M, Turnbull L and Grace R. April 1996. pp 25-29.

¹⁷ Relevant studies include:

Hollins et al, *Mortality in People with Learning Disability: Risks, Causes and Death Certification Findings in London*, *Developmental Medicine and Child Neurology* 1988, 40: 50-56;

Eyman et al, *Prediction of Mortality in Community and Institutional Settings*, *Journal of Mental Deficiency Research* 32: 203-13; and

Draft Health Project Report by the Centre for Developmental Disability Studies, undated.

made to two separate offices, saying “had the Deputy State Coroner and I known of the possible ‘epidemic’ we would most certainly have ordered full post-mortem examinations”.¹⁸ The Department’s information is that the Director of Nursing contacted the State Coroner on 14 November 1998 to advise him of the death of two residents and the hospitalisation of a number of other residents, before decisions about any autopsies were determined.

Indeed, the Director of Nursing’s file notes, dated 14 November 1998, record that she spoke directly with the State Coroner about the two deaths and the high number of sick residents. However, the Internal Review does not examine this apparent discrepancy. In our view, this is a significant omission. While there is no evidence that DoCS staff did not fulfill their obligations in this regard, there appears to have been a breakdown in other aspects of the reporting process. It would have been useful for the Internal Review to explore this issue in some detail and to make recommendations to ensure improved coordination and communication between those with responsibilities following a death.

In the case of Resident C, the Department’s briefing note of 30 December 1999 indicates that her treating doctor had informed the Coroner of her death and that the Coroner had decided not to proceed with an autopsy. However, the Coroner’s Office has informed the DDRT that it has no record of the death of Resident C, nor of any request to waive the autopsy.

The issue highlights that, within the current system, the potential for a death in a departmental facility not to be reported to the Coroner exists, despite requirements to the contrary. This means that opportunity for external scrutiny, validation of cause of death and consideration of circumstances of death is lost.

The Coroner’s Office has now finalised its action in relation to the November deaths and its inquiry into the death of Resident D, dispensing with an inquest in all cases. The Coroner’s Office advised the DDRT in October 1999 that this decision was informed by the outcomes of the Internal Review and PHU reports.¹⁹

5.8 Internal Review Conclusions

The conclusion of the Internal Review is that the reviewers found no instances of personal errors contributing to the outbreak of illness, and that staff be commended for their efforts in responding to/managing the critical event. Similarly, conclusions were reached that policies and procedures were complied with throughout the critical event.

¹⁸ Letter from NSW Senior Deputy State Coroner to Minister for Community Services, dated 20 November 1998.

¹⁹ Correspondence from the Coroner’s Office to DoCS, dated 21 December 1999 and provided to the DDRT on 19 January 2000, states “...the issues for the Coroner in the above deaths (Residents A, B and D) were competently covered by the report received from your Department. This enabled the Coroner on 1 October 1999 to mark the papers in respect of each death “Inquest dispensed with”.

The DDRT is not in a position to confirm or dispute these findings. The lack of documented analysis provided in the Internal Review raises a question as to what basis of evidence was used to reach such conclusions. The Internal Review's conclusions would have been strengthened if it had systematically collected, presented and documented evidence which then led to more clearly defined findings in critical areas.

5.9 Internal Review Recommendations

The recommendations contained in the Internal Review are wide-ranging and directed at quite fundamental issues, calling into serious question the capacity of institutional environments like Grosvenor to provide the quality of care required by children, young people and adults with significant disabilities who are totally dependent on the care system to meet their daily needs. Evidence of the shortcomings of such environments, and their detrimental effect on the well being and development of children with disabilities, has been mentioned above.

Of particular concern is that numerous other reviews have been undertaken into aspects of the service's operations, with recommendations for service improvements developed (and often repeated) each time, but the required changes do not always appear to take effect expeditiously. As the Internal Review itself notes, it is imperative that the recommendations from all recently conducted reviews and reports be prioritised and amalgamated into one strategic planning document, implemented and reviewed. Questions about timeframes, resourcing, and who specifically has responsibility for implementation of which recommendations also need to be addressed.

While many of the recommendations in the Internal Review appear sensible, the lack of documented evidence provided makes it difficult to know if they are appropriately focused.

5.10 Expert Panel

The Department used, for the first time, the model of an Expert Panel to comment on the Internal Review. While the concept appears to have merit in theory, in this instance its contribution and capacity to add value must be questioned. In general, the Panel concurred with the recommendations of the Internal Review. However, the DDRT considers that it did not sufficiently fulfill its terms of reference in that it appears not to have rigorously examined key aspects of the report, such as the methodology. The process for the panel's deliberation - one three hour meeting, with departmental employees and individuals involved with Grosvenor outnumbering other members - may have mitigated against its input being as thorough and critically objective as it could have been had an alternative approach and membership been adopted.

5.11 Recent information

As already indicated, DoCS has supplied the DDRT with considerable documentation which reports on progress with implementation of recommendations from various reports/reviews concerning Grosvenor. These do suggest that considerable efforts are being made to achieve necessary service improvements. The document "Action Plan Arising from Internal Review of Grosvenor" received by the DDRT in October 1999 reports that a health care plan format and implementation

process have been developed, agreement has been reached to employ a Career Medical Officer, and importantly, clinics in neurology and gastroenterology are now held. According to the plan, credentialling of staff to perform chest physiotherapy and passive stretching has commenced, assessments of residents' mobility and equipment needs continue, a portable suction machine has been purchased and the Centre continues to adopt the Universal Infection Control Precautions Policy and to implement the PHU Universal Infection Control procedures.

However, in some areas progress seems slower. It appears that specialist endocrinology, respiratory medicine, pain management and ophthalmology services have yet to commence. Issues around nutrition and feeding remain concerning despite efforts to improve practice in these areas. Specifically, the need for more intensive dietician services remains unaddressed and there is no indication of a multidisciplinary dysphagia clinic being planned. The separation of respite from permanent care has not yet occurred and the audit of client files to ensure they are maintained in an appropriate manner does not appear to have been done. In some areas, action has been taken (for example a protocol developed or reviews undertaken) but it is not clear as to the impact on the care of residents. Recommendations dealing with systemic issues such as research into, and management plans for, end of life decisions, are reported as "referred to Central Office" but no indication of progress or status is given.

It is therefore vital that appropriate assistance and supports are provided to Grosvenor management and others to ensure that necessary improvements are implemented in a planned and effective way and that these lead to demonstrable positive outcomes for residents. Monitoring, performance measurement, independent scrutiny and reporting on achievements are also needed.

6. DDRT Conclusions

The PHU investigation report concludes that a viral respiratory tract infection was most likely responsible for the outbreak of illness at the Grosvenor Centre during November 1998 and that the adenovirus infection, which may have been responsible, carries a significant risk of mortality.

The DoCS' Internal Review of the critical event does not add to the PHU report, nor to our knowledge, as to how the critical event was managed, the response of staff, or health and care issues for those who became ill and the two individuals who died.

A systematic examination of these factors would have built on the work of the PHU by providing factual and contextual information, some insight into the circumstances of the two individuals who died, and an assessment of the impact on them of the environment in which they lived. This would have added value by identifying, more specifically, issues to be addressed to minimise the risk of mortality and to ensure best practice when such critical events occur.

In the absence of documented evidence in the Internal Review, it is not possible to confirm findings/conclusions as to individual conduct in responding to the critical event, or compliance with the requirements of departmental policy by individuals.

The Internal Review also gives no assurances that the range of infection control issues, identified by the PHU early on in its investigation as significant and in need of urgent attention, were satisfactorily addressed at that time. Given that it is known that the residents of Grosvenor face a high risk of mortality and that the outbreak of such infections is not uncommon in institutional settings, acting on these early recommendations should have occurred immediately and should have been reported on in the Internal Review. Progress reports from the Department indicate that action to address the recommendations continues to be taken and has resulted in improved compliance with infection control requirements. A further review of this by the PHU to independently confirm these reports and to assess whether compliance is at a satisfactory level would be useful.

The DDRT's assessments of the four deaths have highlighted limited access to specialist health and therapy services, lack of adequate follow-up and review where specialist recommendations had been made, and aspects of poor treatment management. The assessments have also highlighted the lack of specialist services readily available to Grosvenor residents in the areas of underweight problems, eating difficulties, aspiration risk, dysphagia and metabolic status. While the three permanent residents who died all had high medical support needs and ongoing respiratory problems, there was no evidence that any of them had integrated health care plans or were 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.

As well, both residents who died in November 1998 had "not for resuscitation" orders when admitted to hospital. While we know that their families were consulted, the extent of this involvement, exactly how the decisions were arrived at, the reasons behind them and their implications for the care of the individuals concerned during the critical event, remain undocumented.

The PHU report, the Internal Review report, other reviews undertaken and the DDRT's assessments of the four deaths provide a strong view that the standard of care and health management at Grosvenor was not adequate at the time of the critical event and the deaths. The DDRT acknowledges that, on the advice of DoCS, improvements have been and continue to be implemented since that time. Of particular significance is the report from DoCS that specialist health clinics are now held. However specialist endocrinology, respiratory medicine and ophthalmology services have yet to commence despite being identified as needed in April 1998. It also appears that action to address nutritional and feeding problems has been insufficient and these remain areas for urgent action.

The Internal Review does not consider in any detail quality of life issues or the impact of the institutional environment on those affected by the critical event. It does identify, or concur with others' identification of, a range of operational and service delivery concerns, including important legal and ethical issues in caring for those with severe disabilities that need to be considered. It makes many seemingly sensible recommendations that are supported by the DDRT. But their very number (overlaid with the actions identified by the expert panel), and the complexity of the matters they attempt to address, raises the issue as to the difficulties in achieving a sufficiently adequate standard of care within the existing environment and service model.

Action plans and progress reports provided by the Department more recently suggest a high level of activity and some important service improvements underway. But it is not possible to determine how these have impacted on the overall standard and quality of care provided to residents and therefore the need for monitoring, independent scrutiny and reporting openly on achievements remains.

Despite the various reviews and investigations undertaken and the involvement of the Coroner, it has not been possible to conclusively establish that the first two deaths were the result of the viral respiratory tract infection, although there are strong indications that this is the case. It has also not been possible to determine if the later deaths were in any way linked to the same infection. Our review has highlighted the need to clarify reporting requirements and the roles of various bodies undertaking investigations or reviews following a death, to reduce confusion and ensure that all relevant aspects are considered and all necessary conclusions are able to be made. Because the potential for a death to go unreported to the Coroner remains, a more rigorous approach to reporting obligations by all parties is needed.

Our review of the Internal Review has also highlighted significant limitations in how the Internal Review was constructed and undertaken and in the use of the expert panel. This reinforces the value of external scrutiny and review of the deaths of people with disabilities in residential care.

7. Recommendations

Our recommendations are focused on: progressing the development of more appropriate models of care as a priority for the residents of Grosvenor; immediate service improvements to ensure quality care and reduce health risks; prioritising and ensuring action on previous recommendations; clarifying reporting and other responsibilities and processes following a death; and providing practice guidance to service providers and health professionals on key ethical and legal issues associated with caring for people with severe disabilities and limited life expectancy.

While the development of new alternative services (Recommendations 7.1 and 7.2) will take time, commitment and action to ensure this happens are needed now. Recommendations concerning service improvements (Recommendations 7.3 – 7.7) in the current environment will apply equally to new service models, once developed for the Grosvenor population. Recommendations 7.8 to 7.12 have a system-wide focus, while Recommendation 7.13 concerns a three tiered monitoring process.

Future Service Models

- 7.1 Ageing & Disability Department (ADD), in conjunction with DoCS, should give urgent priority to the planning and development of new service models for the current residents of the Grosvenor Centre, given the known shortcomings and negative impact of institutional care. This process needs to take account of: the very young age of some residents and their extreme vulnerability; the high medical support needs of residents; the quality and type of care best able to meet individual needs in a more home-like environment and improve quality of life; legislative and policy requirements in relation to children in out-of-home care; and the views and wishes of families and guardians.
- 7.2 This process should involve the development of specialist health and allied services appropriate to the needs of the Grosvenor population; adequate resource allocation; commitment to a detailed and achievable timeframe; and immediate and ongoing consultation with families, guardians and other stakeholders.

Implementation of previous recommendations/service improvement

- 7.3 Within this context, all recommendations from the PHU report, the Internal Review and other reviews undertaken in 1998 should be consolidated into one service improvement plan and reviewed to determine status, feasibility and priority. In our view the more immediate issues to be addressed should include:
- physically separating the provision of respite care from the care of permanent residents, improving the management, provision and

monitoring of the respite care program through the development of necessary processes and systems, and ensuring consumer representation on the Respite Placement Committee;

- establishing, as a matter of urgency, endocrinology, respiratory medicine and ophthalmology services at Grosvenor; and
- undertaking an audit of client files using the Stockton System method, incorporating all clinical information onto individual files and ongoing file maintenance according to Departmental policies.

Health and Nutrition

7.4 DoCS should ensure that the current level of dietetic services provided to Grosvenor is reviewed and significantly enhanced, so that all Grosvenor residents have ongoing access, on an adequate and as needed basis, to appropriate clinical services from a dietician with the necessary expertise.

7.5 As a matter of priority, Grosvenor Centre management, in consultation with the dietician and the DoCS Nutrition Working Party, should establish a policy and practice framework to ensure staff are able to adequately address the nutritional and feeding needs of residents. As part of this, staff training, supervision and support needs in this area should be identified and a comprehensive strategy and resources to address these put in place.

7.6 Grosvenor Centre management should investigate the feasibility of establishing a multi-disciplinary assessment clinic, headed by a specialist medical practitioner with expertise in developmental medicine and/or rehabilitation, given residents' high medical support needs. This clinic should undertake the coordination, referral and follow-up of all specialist medical consultations of Grosvenor residents and provide annual assessments, screenings and reviews.

Infection Control

7.7 The PHU should be requested to revisit Grosvenor as a matter of priority to audit current infection control procedures and practices to assess compliance and to determine whether the recommendations from its investigation of the critical event have been satisfactorily implemented. The PHU should provide Grosvenor with advice and assistance if there continue to be issues of concern. An annual review of Grosvenor infection control procedures should be instituted by the PHU.

Internal Reviews

7.8 DoCS should develop policies and procedures for its internal review processes that are publicly available and that provide guidance on: when an internal review is appropriate; choice of reviewers; ensuring independence;

developing a rigorous and sound methodology based on recognised audit and/or investigative processes; and the use and role of expert panels.

Reporting and Review of Deaths in Care

- 7.9 DoCS should clarify with the Coroner, other relevant bodies (such as hospitals) and its own staff, its responsibility to report all deaths in residential services to the Coroner and the optimal procedure for doing this. DoCS policies should then be amended accordingly and staff educated in this regard, to ensure that the potential for confusion is removed.
- 7.10 DoCS, the PHU and the Coroner should jointly review their communication processes and respective roles in relation to the Grosvenor critical event, with a view to clarifying processes, avoiding confusion and overlap, and ensuring timeliness, the consideration of all relevant aspects and a comprehensive, co-ordinated process of external scrutiny.
- 7.11 The Minister should require that DoCS refer all deaths, including those of children, in its disability accommodation services to the DDRT for assessment in the first instance and that, following such referral, discussions then take place around who will review and how it will be done, with a view to public interest issues, need for independence and required expertise.

Ethical and Legal Issues

- 7.12 In view of the seriousness of the ethical and legal issues raised by the critical event and identified by both the Internal Review and this review, the Minister should request that ADD, in consultation with DoCS and the Department of Health, undertake research, with a view to developing sector-wide policy and practice guidance for service providers and health professionals on:
- decisions-making processes about enteral nutrition procedures including gastrostomies and naso-gastric tube feeding;
 - the provision of palliative care;
 - end of life decisions and 'not for resuscitation' orders;
 - the need for consent to particular treatments and withholding of treatments; and
 - the rights of those with severe disabilities and limited life expectancy.

Such research needs to explore ethical and legal issues, the rights of consumers, decision-making processes, the role of families and guardians, the responsibilities of staff/service providers and the medical profession and accountability issues. Given the range of stakeholders involved and the need for public discussion of the issues, an extensive consultative process should be used.

Monitoring of Recommendations

7.13 The recommendations from this report should be incorporated into the service improvement plan referred to in recommendation 7.3 and a three tiered monitoring strategy established as follows:

- Progress with implementation of the service improvement plan should be monitored on a monthly basis by the Inner West Practice Review Group;
- Progress against the service improvement plan should be reported on a quarterly basis to an identified Senior Manager within DoCS central office. Any critical service delivery issues and events within Grosvenor should also be reported to this senior manager, as such issues or events arise. This position should be responsible for advising on and monitoring action to be taken in relation to Grosvenor, progressing those recommendations with a system wide focus, and keeping other members of the DoCS senior management team informed;
- ADD should take overall responsibility for planning and progressing the development of new service models for residents of Grosvenor (as specified in recommendation 7.1) in a timely and appropriate way. ADD should also monitor the implementation of service improvement initiatives within Grosvenor and the general standard of care provided, in keeping with its monitoring role and responsibilities as the funding body.