

# Disability, death and the responsibility of care

A review of the characteristics and  
circumstances of 211 people with  
disabilities who died in care between  
1991 and 1998 in NSW



Community Services Commission



*Community Services (Complaints, Reviews and Monitoring) Act 1993*

ISBN 0 7347 6236 4

# Disability, death and the responsibility of care

A review of the characteristics and circumstances of 211 people  
with disabilities who died in care between 1991 and 1998 in NSW

**Community Services Commission  
April 2001**

**State Library of New South Wales cataloguing-in publication data.**

New South Wales. Community Services Commission

Disability, death and the responsibility of care/(Community Services Commission)

ISBN 0 7347 6236 4

# Contents

Executive Summary	i
1. Introduction, method and scope	1
1.1 Review project	1
1.2 About the DDRT	1
1.3 Residential services funded under the DSA	1
1.4 Review objectives	2
1.5 Methodology and scope	3
2. Review Group	5
2.1 Where people lived and died	5
2.2 Characteristics	6
2.3 Cultural background	7
2.4 Disability	8
2.5 Dependency levels	11
2.6 Underlying cause of death	12
2.7 Associated health conditions	17
2.8 Coroner contact	21
2.9 Summary of review observations	22
3. Indicated service improvements	24
3.1 Recent initiatives	24
3.2 Access to health services	25
3.3 Health promotion and education	27
3.4 Seizure management	28
3.5 Management of dysphagia and aspiration	29
3.6 Management of asphyxiation and choking	30
3.7 Bathing practices	31
3.8 Prevention of falls – a safe environment	33
3.9 Management of self-harm	34
3.10 Organisational initiatives	35
3.11 Coroner notification	35
3.12 Conclusion	36

Appendix	37
References	42
Glossary	46

## Figures

1	Deaths by gender and age (children and young people)	7
2	Deaths by gender and age (adults)	7
3	Degree of intellectual disability in review group	10
4	Underlying cause of death for review group	14
5	Deaths due to respiratory disease/aspiration in the review group and in the general population	15

## Tables

1	Type and number of disabilities identified in review group	9
2	Known causes of intellectual disability in review group	11
3	Main reported causes of death: review group compared to general population	14
4	Deaths due to external causes in the review group	16
5	Known weight range of 130 deceased	18

## Tables in Appendix

1	Residents in accommodation services in NSW, 1995 - 1998	37
2	Number of review group deaths, 1991 - 1998	37
3	Causes of death and model of accommodation service in the review group	38
4	Age and permanency of care for people under 18 years of age	38
5	Deaths by gender and age	39
6	Comparison of primary disabilities of review group to all people in NSW disability accommodation services in 1998	39
7	Degree of intellectual disability in review group where level of intellectual disability was known	39
8	Underlying cause of death by age	40
9	Selected characteristics and circumstances of people who died of digestive diseases	41
10	Summary of the deceased who drowned in baths or showers	41

# Executive Summary

## Introduction

This Review was undertaken by the Disability Death Review Team (DDRT) to provide an examination of the characteristics and circumstances of 211 people with disabilities who died in care in NSW between 1991 and 1998. The deaths were reported to the Community Services Commission prior to December 1998.

This analysis identifies the demographic, health and other factors associated with deaths in this population. From this data, common characteristics and/or circumstances and any systemic issues related to disability deaths in care are identified and, in addition, a number of individual cases are provided to illustrate key systemic issues.

## Methodology

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

The data on which this Review was based was drawn primarily from client service files, health and medical reports, Coroners' reports and DDRT reports. The Review has also referred to existing research on morbidity and mortality of people with disabilities.

Individual case studies were used in parts of this report (Chapter 3) in order to illustrate key points associated with disability and mortality. Identity changes have been made to maintain the privacy of the deceased and their families. Anonymity has also been provided to the service providers involved at the time of death.

## The review data

The majority of those who died had an intellectual disability with a significant number having a severe to profound level of intellectual disability. The cause of disability was unreported for almost half the group. A considerable number of people also had multiple disabilities.

There was a higher proportion of male deaths and the greatest number of deaths occurred in large residential services.

People aged 25 to 44 years comprised the largest single age grouping of those who died. Children accounted for 15 per cent of the total number of deceased.

The most common cause of death was respiratory disease, followed by diseases of the circulatory system. The proportion of deaths due to drowning, falls and asphyxiation was higher than that reported in the general population.

Underlying health conditions identified in the Review group included nutritional problems, respiratory conditions, epilepsy, dementia, psychiatric conditions and gastrointestinal problems. Feeding and mobility problems were evident in many. A significant number of people in the group required some form of communication assistance.

A higher proportion of deaths due to respiratory disease was reported for people living in large residential centres, compared to people living in other forms of supported accommodation services.

Most other causes of death, including external causes, were similarly represented in both institutional and group home residents, apart from death due to seizures or infection which had a proportionately higher occurrence in group homes. In certain settings, people with disabilities appeared to be at greater risk of death as a result of assault and self-harm.

### Service improvement initiatives

Service improvement initiatives aimed at minimising harm and preventing deaths, as indicated by the data, are outlined in Chapter 3 of this Review.

Initiatives to promote safety and well-being and to reduce the numbers of premature deaths among people with disabilities require a combination of expert input, health screening, monitoring and follow-up. Practical strategies identified include:

- Health screening and reviews;
- Ensuring adequate supervision of vulnerable residents;
- Up to date staff training; and
- Injury prevention programs.

Health screening and review are especially important. Regular health review by health professionals experienced in the area of intellectual disability enables early detection and management of a range of potentially treatable conditions including hypertension, cancer, swallowing and eating disorders, respiratory and cardiovascular disease – conditions seen in the Review group.

In regard to health care and specific causes of death:

- Swallowing and eating difficulties (dysphagia) affected a significant number of people in the Review group. People with these conditions are known to have significantly higher death rates. Adequate supervision, safe mealtime practices, including food modification and correct positioning, are known to reduce the

incidence of choking and asphyxiation for people with swallowing difficulties and recurrent aspiration.

- Epilepsy was a prominent condition amongst those in the Review group. Epilepsy research has demonstrated that a number of practical management strategies, including supervision and safety procedures, as well as regular review of seizure control and anti-convulsants can improve seizure control and provide a safe environment for people with epilepsy.
- Drowning was the largest single external cause of death for those in the Review group, raising clear issues about supervision and safety measures to protect residents in bathing and swimming activities. Identified safety measures for bathroom and swimming activities include: adequate supervision, up to date staff training in first aid and acute seizure management, and use of bathing aids, such as slings and hoists.
- While a relatively small number of people in the Review group died from fall-related injuries, these deaths were significant because of the preventable nature of many falls and the importance of service vigilance in relation to ensuring a safe environment for residents. Preventive measures identified include regular review of supervision needs, mobility assessments and medication reviews.
- Self-harm was identified as a factor contributing to a small number of deaths and a factor impacting on the health of a number of people in the Review group. Minimising the effect of self-harm requires accurate diagnosis and appropriate management of behavioural and psychiatric conditions, including provision of suitable medication and positive behavioural programming.

The Review acknowledges and welcomes a number of service improvement initiatives developed by relevant state government departments since the time of these deaths. These initiatives are set out in section 3.1.

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

# Chapter 1: Introduction, method and scope

## 1.1 Review project

This Review examines characteristics and circumstances of 211 people with disabilities whose deaths in care between 1991 and 1998 in NSW were reported to the Community Services Commission (the Commission). Those who died had been in services provided by either Department of Community Services (DoCS) or non-government services (NGOs). During this period, DoCS had a process in place for notifying deaths of children and adults in the care of the Department to the Commission, but there was no corresponding arrangement for NGOs.<sup>1</sup> Therefore, the Review group does not include every person with a disability who died in care between 1991 and 1998.

## 1.2 About the DDRT

The Disability Death Review Team (DDRT) was established as a function of the Commission in November 1998, by the Minister for Community Services, the Hon Faye Lo Po' MP. The establishment of the Team was in response to considerable community concern about the deaths of people with disabilities in care.<sup>2</sup>

While all disability accommodation services funded under the *NSW Disability Services Act, 1993 (DSA)* are now required to notify the DDRT of residents' deaths, previously there was no reporting requirement for services other than those provided by DoCS. The Team maintains a register of all deaths within its target group and aims to contribute to the prevention of deaths through a focus on systemic issues that may have contributed to the deaths of people with disabilities in care. It is not the DDRT's role to investigate the causes or circumstances of deaths. In NSW, this role is the statutory responsibility of the police and the Coroner.

## 1.3 Residential services funded under the DSA

Primary responsibility for the funding and monitoring of all residential services under the DSA rests with the NSW Ageing and Disability Department (ADD). These residential or supported accommodation services consist of large residential centres, group homes, supported accommodation with part-time support, and facility based respite care services. They include all Department of Community Services' disability residential services and all funded non-government services.

---

<sup>1</sup> Department of Community Services Memorandum SPS-26 *Advice to Community Services Commissioner of Deaths of Children and Adults in the Care of the Department*, 26 October 1994.

<sup>2</sup> Media Releases by the Minister for Community Services, 19 November 1998.

Between 1995 and 1998, the total number of people living in residential and supported accommodation services in NSW was approximately evenly spread between DoCS and NGOs of varying sizes, although there was a gradual increase in NGO resident numbers by the end of 1998 (refer to Appendix, Table 1). Within these services, people with intellectual disabilities represented the largest group of clients (77 per cent of all clients).<sup>3</sup> Data provided by ADD states that, in 1995, 5620 people were living in supported accommodation services increasing to 5856 by 1998, with a growing population in the non-government sector.<sup>4</sup>

The number of people living in long term respite care in 1997 was estimated to be 149, with another 343 people using respite care on a regular basis (CSC, 1998: 8).<sup>5</sup>

In 1995, 545 children under the age of 18 years were living in disability supported accommodation services. This figure had decreased by 29 per cent to 387 in 1998, with ADD reporting at the end of 1998-99, that there were still 170 children and young people living in institutions (ADD, 1999: 14).<sup>6</sup>

Approximately 5,000 people with disabilities are currently living in residential services provided or funded under the *Disability Services Act 1993*, with 2,322 living in large residential centres and 2,360 in group-homes.<sup>7</sup>

#### 1.4 Review objectives

The overall objective of this Review is to provide an analysis of the deaths of 211 people with disabilities in care between 1991 and 1998. This analysis identifies the demographic, health and other factors associated with death in this population. From this data, common characteristics and/or circumstances and any systemic issues related to disability deaths in care are identified and, in addition, a number of individual cases are provided to illustrate key systemic issues.

The Review examines data related to:

- Age;
- Gender;
- Related health issues;

---

<sup>3</sup> ADD Minimum Data Set, 1995-1998 (CSDA MDS Collection) Data Analysis Unit, ADD.

<sup>4</sup> Data collection on the numbers of people in disability accommodation services is only available for the period 1995-98. ADD Minimum Data Set, 1995-1998 (CSDA MDS Collection) Data Analysis Unit, ADD.

<sup>5</sup> The Community Services Commission's *Respite Care – A System in Crisis Report*, 1998, estimated that people in long term respite care occupied four out of five designated respite beds, even though they made up only 14 per cent of total respite users and six per cent of those requiring respite.

<sup>6</sup> ADD Minimum Data Set, 1995-1998 (CSDA MDS Collection) with the last figure taken from ADD's 1998-99 Annual Report. The first two figures are of children living in all disability supported accommodation services, while the figure from ADD's 1998-99 Annual Report refers to children living in large residential centres.

<sup>7</sup> Data Analysis Unit, ADD.

- Type of disability;
- Cause of death and contributing factors;
- Type of accommodation service;
- Length of time a person had been in care; and
- Place of death.

Although not directly linked to factors contributing to death, we will also briefly review those procedures undertaken at the time of death, including the reporting of deaths to the police and/or Coroner. These procedures provide a process of external scrutiny, validation of cause of death and an opportunity to assess compliance of coronial reporting requirements.

The findings of this study will assist with our understanding of deaths currently being reported to the DDRT and the development of systems and practices to improve the quality of care and health outcomes for people with disabilities in care.

## 1.5 Methodology and scope

### 1.5.1 Data sources

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

The data on which this Review is based is drawn primarily from client files, health and medical reports and DDRT reports.<sup>8</sup> The Review has also referred to existing research on morbidity and mortality of people with disabilities.

Core Review documents included:

- Notification of death forms;
- Death certificates; and
- Service reports, including incident reports.

Of the 211 deaths, 147 were also notified to the Coroner. The Review draws additional data on these deaths from:

- Police record of death reports;
- Final post mortem reports (including cause of death);

---

<sup>8</sup> Client files, including health and medical reports, were provided by service providers and copies of client related reports provided by the NSW State Coroner's Office. Additional information about individual deaths was also provided by the NSW Council for Intellectual Disability, NSW Citizen Advocacy, Western Sydney Parents and Friends Association (now the Western Sydney Intellectual Disability Support Group) and People with Disabilities (PWD).

- Witness statements and affidavits; and
- Coronial reports or dispensation of inquest.

Individual case studies are used in parts of this report in order to illustrate key points associated with disability and mortality. Identity changes have been made to maintain the privacy of the deceased and their families. Anonymity is also provided to the service providers involved at the time of death.

An independent consultant provided advice on the project's feasibility and methodology.<sup>9</sup>

### 1.5.2 Data limitations

The nature of the Review is such that it is unable to represent a conclusive assessment of all issues relating to deaths in care over this period.

During the period under review, ADD funded services (NGOs) were not required to notify the deaths of service receivers. The 211 deaths were notified on an ad hoc basis to the Commission by various sources, following the establishment of the Team in 1998. The Review is, therefore, unable to determine the total number of deaths of people with disabilities who died in NGOs between 1991 and 1998.

As the information available to the review was in a non-standardised format, the data presented in the report should not be used to draw generalisations about all people with disabilities living in care, nor about the wider disability population. General population mortality data is referred to where relevant.

The Review should be viewed as a descriptive study of the demographic, health and other factors associated with the deaths of this particular group of people.

---

<sup>9</sup>The Centre for Developmental Disability Studies, University of Sydney provided this consultancy.

## Chapter 2: Review group

The 211 deaths reported below occurred between 30 June 1991 and 31 December 1998 (refer to Appendix, Table 2).

### 2.1 Where people lived and died

The majority of people who died had lived in services on a permanent basis, with less than ten per cent being in respite care at the time of their deaths. However, of those who died in respite care, the majority were children. Less than half the Review group died in hospital settings.

#### 2.1.1 Service provider

From the data available from 1995 to 1998, DoCS and NGOs provided care for approximately the same numbers of people.<sup>11</sup> The lack of obligation on the part of NGOs to report deaths in funded services excludes meaningful comparative analysis of the numbers of reported deaths in DoCS and NGOs (refer to Appendix, Table 1).

#### 2.1.2 Service type

The type of accommodation service was known for all 211 deceased. Three accommodation types were applied.<sup>12</sup>

Within the Review group, 198 people were in permanent care, and of this group 24 per cent (48) had lived in group homes and 76 per cent (150) in institutional settings (either large or mini residential accommodation services). Refer to Appendix, Table 3.

#### 2.1.3 Length of time in care

The time spent in care (known for 130 people) ranged from under one year to 64 years, with 78 people having been in care for 20 years or more.

#### 2.1.4 Permanent care

Of the 211 people who died, 174 adults and 24 children and young people were in permanent care.<sup>13</sup>

---

<sup>11</sup> Of the total 211 deaths, 181 deaths were reported in DoCS' facilities and 30 in NGOs.

<sup>12</sup> Definitions of accommodation types were based on the following:

Large residential centres -	forty or more people;
Mini residential centres -	seven to 39 people; and
Community based group homes -	one to 6 people.

### 2.1.5 Respite care

At the time of death, six per cent (13) had been in either short or long-term respite care. Of this group, seven were under the age of 18 years, including two under the age of ten (refer to Appendix, Table 4). Twelve of the group died in DoCS' respite services, with one person dying in an NGO respite service.<sup>14</sup>

### 2.1.6 Status of care

Guardianship status was known for 176 adults, with 17 people being identified as under guardianship at the time of their deaths. Of the 31 children who died, 22 were described as being in voluntary care arrangements and two were state wards.

### 2.1.7 Place of death

54 per cent (114) died within the service setting and 42 per cent (89) in hospital settings. The other deaths occurred at holiday houses, during ambulance transportation, while visiting family and in the community.

## 2.2 Characteristics

### 2.2.1 Age and gender

During the Review period, slightly more men than women lived in NSW disability accommodation services.<sup>15</sup> In terms of our Review group, more men than women died.

- Of the 211 deceased, 61 per cent (129) were males and 39 per cent (82) were females (refer to Appendix, Table 5).
- The deceased were aged from under one year to 93 years (refer to Figures 1 and 2 and Appendix, Table 5).
- Of the total deceased, 85 per cent (180) were adults and 15 per cent (31) were children under 18 years of age (refer to Figures 1 and 2). Of the children, twelve were under the age of ten years.
- Close to one in five of the deaths were of children and young people under the age of 20 years. During the same period, children under the age of 18 years comprised less than one in ten of the total population in supported accommodation services.<sup>16</sup>

---

<sup>13</sup> Permanency, as a category of care, was determined as being a non-respite placement and principal place of residence.

<sup>14</sup> This generally reflected the distribution of respite services at the time: in 1997, of the 492 people in long-term respite care in NSW, 91 per cent were in DoCS' respite services, of these, 183 were children (CSC, 1999).

<sup>15</sup> In 1995, men comprised 59 per cent of the disability residential population, dropping slightly to 58 per cent in 1998. ADD Minimum Data Set, 1995-1998 (CSDA MDS Collection).

<sup>16</sup> ADD Minimum Data Set, 1995-1998 (CSDA MDS Collection).

- Adults aged 25-44 years comprised the single largest grouping of those who died. Thirty four per cent (72) were in this age group (refer to Figure 2 and Appendix, Table 5)
- Almost 60 per cent of the total deaths were of people aged 44 years and younger (refer Appendix, Table 5).

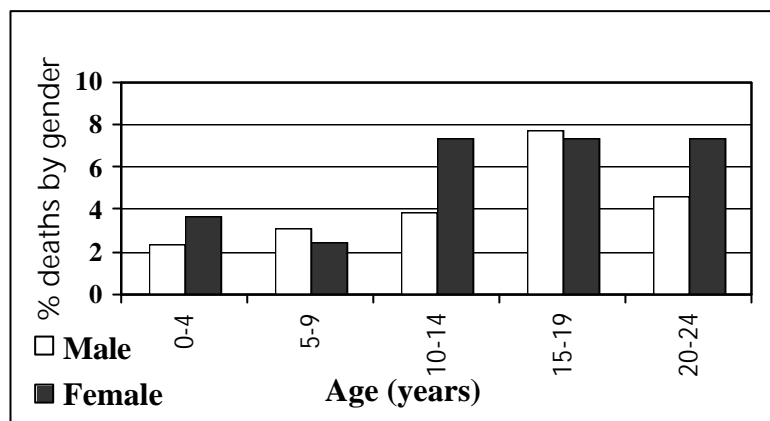


Figure 1: Deaths by gender and age (children and young people)

**Note:** Age groupings for children and young people are shown in five year intervals due to the small number of deaths included in the Review group and to reflect the significantly different stages of development for children and young people (refer to Appendix, Table 5).

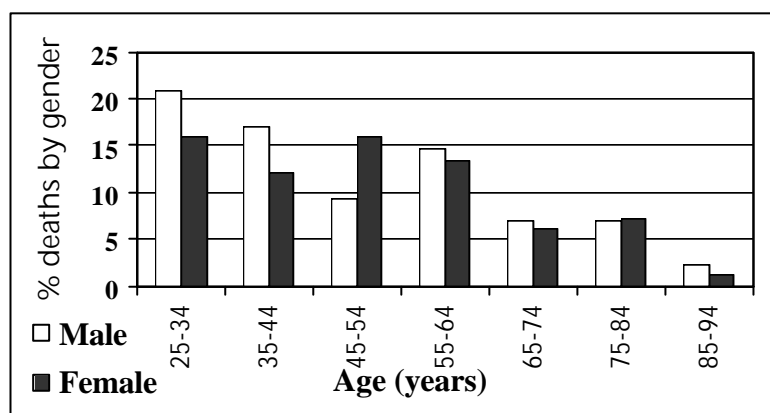


Figure 2: Deaths by gender and age (adults) refer to appendix table 5

## 2.3 Cultural background

There were low numbers of identified Aboriginal (ATSI) and non-English speaking background (NESB) people in the Review group.

### 2.3.1 Aboriginal and Torres Strait Islanders

Four of the deceased were identified as Aboriginal and Torres Strait Islanders (ATSI). In two of the four deaths, the only reference to the person's aboriginality was provided by autopsy reports.<sup>17</sup>

<sup>17</sup> There was no reference provided by other client information in these two cases.

According to ADD, people from ATSI backgrounds are under-represented in the use of services provided for people with disabilities in NSW (ADD, 1995). It is also noted that although a high rate of disability is reported in Aboriginal communities, the reported numbers of people from ATSI backgrounds in disability funded services is low (Yeatman, 1996: 48; AIHW, 1996: 8). Possible factors for the low representation of people from ATSI backgrounds in disability deaths between 1991-98 include:

- The limited access Aboriginal people have to disability supported accommodation services; and
- A lack of identification of ATSI background.

### 2.3.2 People from non-English speaking backgrounds

Of the total group, seven per cent (15) people were identified as being from non-English speaking backgrounds. ADD's 1998 Minimum Data set states that on average, only 2.7 per cent of all disability service users in NSW are people from NESB (even though they make up 23 per cent of all people living in NSW).<sup>18</sup>

## 2.4 Disability

For the people in the Review group known to have an intellectual disability, there were a greater number of people with a severe or profound level of intellectual disability. A substantial number of people also had multiple disabilities.

For the purpose of this Review, disabilities were categorised by way of primary and other disabilities. The primary disability was determined to be the disability or condition causing most difficulty to the person. This information was based on classifications of concepts of cause, impairment and condition developed from the Australian Institute of Health and Welfare's *Studies data guide, data items and definitions* (AIHW, 1999).

Disability categories, including those of intellectual, physical, psychiatric, sensory and neurological disability have been used in this report with the disability classification taken from information provided in service records.

### 2.4.1 Disability data

Intellectual disability was identified as the primary disability in 90 per cent (189) of cases. The other primary disabilities reported were ten with physical disabilities, eight with a neurological disability and four with a psychiatric disability. This, in general, reflected the primary disability types reported for people living in NSW disability accommodation services at the time, apart from the category of physical disability, which had a lower reporting in the Review group (refer to Appendix, Table 6).

---

<sup>18</sup> ADD Minimum Data Set, 1998 (CSDA MDS Collection) and ABS Census, 1996.

For the 211 people reviewed, a total of 463 disabilities were identified (refer to Table 1).<sup>19,20</sup> More than one disability was reported for 78 per cent (164) of the total group, and included conditions such as:

- Physical disability - 45 per cent (84);
- Epilepsy - 47 per cent (99);
- Cerebral palsy - 26 per cent (54);
- Dementia - 6 per cent (12); and
- Mental illness - 11 per cent (24)

Forty nine per cent (44) of the Review group had some identified sensory disability, with 24 people reported as having vision impairment. Two people were reported as having a hearing impairment.

Type of Disability	No. of Cases
Intellectual	192
Physical	84
<i>Cerebral palsy</i>	54
<i>Other physical disabilities<sup>21</sup></i>	30
Psychiatric	24
Neurological	119
<i>Acquired Brain Injury</i>	8
<i>Epilepsy</i>	99
<i>Dementia</i>	12
Sensory	44
<i>Vision Impairment</i>	24
<i>Other sensory impairment</i>	13
<i>Speech impairment</i>	7
Total	463

Table 1: Type and number of disabilities identified in review group

The categories in Table 1 are not exclusive, and may include multiple counts. For example, people with cerebral palsy may also have had an intellectual disability and associated other disabilities, such as scoliosis (18 cases). Twenty eight people with cerebral palsy had spastic quadriplegia.

<sup>19</sup> Information on disabilities other than intellectual disability was not available for 27 people.

<sup>20</sup> Conditions such as cerebral palsy are likely to cause or be associated with other disabilities such as scoliosis and vision impairment, thus increasing the occurrence of multiple disabilities.

<sup>21</sup> Other reported physical disabilities included were associated with conditions such as muscular dystrophy and neuromuscular degenerative disorder.

All people in the group with epilepsy also had an intellectual disability and, in a small number of cases, dementia. All people who had a brain injury also had epilepsy.

#### 2.4.2 Level of intellectual disability

The level of intellectual disability was provided by service records and was largely based on measures such as intellectual assessments (as recorded in client reports).

Intellectual disability was the primary disability for 90 per cent (189) of the Review group. Of the total cases in which intellectual disability was recorded (192), 38 per cent (75) had an unspecified level of intellectual disability.<sup>22</sup>

Of the 110 people where the level of intellectual disability was known, 73 per cent of the deaths were of people with severe to profound levels of intellectual disability (refer to Figure 3 and Appendix, Table 7).

Severe intellectual disability is associated with deficits in mobility, continence and self-feeding and these have been reported to be predictors of early death (Patja, K. Iivanainen, M. et al, 2000; Eyman, R. Grossman, H. et al, 1987). Refer to Appendix, Table 7 for breakdown of level of intellectual disability.

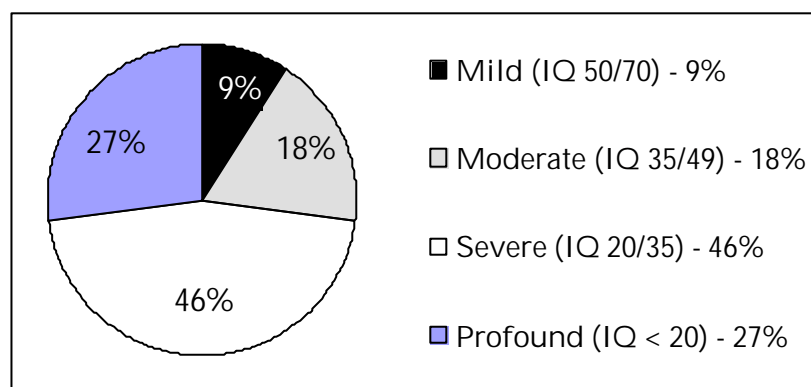


Figure 3: Degree of intellectual disability in review group refer to appendix, table 7

<sup>22</sup> This included seven children under the age of five years who were described as having a 'developmental delay'.

### 2.4.3 Cause of intellectual disability (aetiology)

Table 2 details the cause of intellectual disability, where recorded. In 43 per cent (99) of cases, cause of intellectual disability was not stated.

Aetiology of Intellectual Disability	Total Number
Prenatal	90
Acquired	
- <b>Toxins, infections</b>	11
Genetic	
- <b>Chromosomal</b>	35
- <b>Mendelian<sup>23</sup></b>	20
- <b>Unknown</b>	1
Multiple Anomalies	10
Syndromes	1
Other	12
Perinatal	12
Hypoxia <sup>24</sup>	7
Infection	2
Pre Term	1
Other	2
Postnatal	5
Hypoxia	1
Infection	2
Trauma	2
Not known	5
Not stated	99
Total	211

Table 2: Known causes of intellectual disability in review group

## 2.5 Dependency levels

Certain functional limitations have been identified as mortality risk factors, including immobility, need for feeding assistance and incontinence (Evans, P. Alberman, E. 1990). As identified below feeding and mobility problems were evident for many people in the Review group and a significant number of people in the group required some form of communication assistance.

<sup>23</sup> Mendelian refers to the passing of genetic information from one generation to the next.

<sup>24</sup> Hypoxia refers to oxygen deficiency.

- **Mobility**

Information about mobility was provided for 55 per cent (117) out of the total 211 deceased. Of this group, 17 per cent (20) were independently mobile and 83 per cent (97) were reliant on a wheelchair, mobility aid or other form of assistance.

- **Feeding assistance**

The need for feeding assistance was known for 45 per cent (96) of people. Of these, 16 per cent (15) were reported to be independent at meals, while 84 per cent (81) were identified as requiring mealtime assistance, including food modification or feeding assistance. Of those requiring feeding assistance, 62 per cent (50) had identified swallowing difficulties and, of this group, 46 per cent (23) were enterally fed.<sup>25</sup>

- **Continence**

Bladder and bowel continence was known for 36 per cent (76) of people. Of these, 15 per cent (11) were reported to have no continence difficulties and 86 per cent (65) were reported to be either incontinent of urine, faeces or both.

- **Communication**

The need for communication support was known for 47 per cent (99) of those who died. Of this group, 92 per cent (91) had some form of communication difficulty and eight per cent (8) could communicate without difficulties.

## 2.6 Underlying cause of death

In summary, the data for the group indicated:

- The most common cause of death was respiratory disease followed by diseases of the circulatory system;
- There was a considerably higher proportion of respiratory deaths amongst young people in the Review group compared to that within the general Australian population. In particular, our data identified a high number of pneumonia deaths within this group;
- There was a high number of epilepsy related deaths within the Review group; and
- Twelve per cent of the Review group died of external causes, as compared to six per cent in the general population (ABS, 1998).

---

<sup>25</sup> Enteral feeding requires either a naso-gastric tube or gastrostomy tube. A gastrostomy is a surgical operation that creates an artificial opening into the stomach for the insertion of a feeding tube.

Generally, ascertaining the underlying cause of death in the general population can assist in the identification of death trends and can provide a guide to preventative measures in relation to particular causes of death.

The deaths examined in this Review were categorised according to the Ninth Revision of the World Health Organisation's International Classification of Diseases (ICD-9). ICD is designed to promote international comparability in the collection, processing, classification and presentation of mortality statistics. The Australian Bureau of Statistics (ABS) uses this death classification system, which allows comparison between the causes of death for this Review group and that of the general population.

Determination of underlying cause of death was based on the disease or circumstance that contributed to eventual death.

Underlying cause of death was determined by way of the death certificate or the Coroner's reporting of cause of death. Where possible, for the purpose of this study, we have also referred to other sources such as hospital and police reports and service reports to provide additional information or corroboration of information about the cause of death. Unreliability of 'cause of death', as recorded on death certificates, has been reported in disability and mortality research. The under recording of intellectual disability on death certificates and the under reporting of it as a contributory factor to cause of death is also noted in the literature (Hollins, S. Attard, M. et al 1998 and James, D. Bull, A. 1995). As such, caution is required for interpretation of 'cause of death' as provided by death certificates.

#### 2.6.1 Cause of death in review group compared to general population

Generally, the data concerning cause of death in the Review group was found to be significantly different to that reported for the Australian population (ABS, 1999). Respiratory disease was the most common cause of death for all ages within the Review group but less common in the general population (ABS, 1999).

The following table provides a comparison of cause of death by age grouping in the Review group and the general population (ABS data).

Age	Review group (review data) Number of deaths/main reported causes of death (COD)	General population (ABS data) Main reported causes of death
14 years and under	<b>23 deaths with COD including:</b> <ul style="list-style-type: none"> <li>• Respiratory disease</li> <li>• Complications of congenital heart problems</li> <li>• Complications of hydrocephalus, surgery, epilepsy</li> </ul>	<ul style="list-style-type: none"> <li>• Congenital abnormalities</li> <li>• Perinatal conditions</li> <li>• Sudden Infant Death Syndrome</li> <li>• External causes</li> <li>• Cancer</li> </ul>
15–24 years	<b>28 deaths with COD including:</b> <ul style="list-style-type: none"> <li>• Respiratory disease</li> <li>• External causes</li> <li>• Aspiration</li> </ul>	<ul style="list-style-type: none"> <li>• External causes</li> <li>• Cancer</li> </ul>
25–44 years	<b>72 deaths with COD including:</b> <ul style="list-style-type: none"> <li>• Respiratory disease</li> <li>• External causes</li> <li>• Diseases of the circulatory system</li> </ul>	<ul style="list-style-type: none"> <li>• External causes</li> <li>• Cancer</li> <li>• Diseases of the circulatory system</li> </ul>
45–54 years	<b>25 deaths with COD including:</b> <ul style="list-style-type: none"> <li>• Respiratory disease</li> <li>• Cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Cancer</li> <li>• Diseases of the circulatory system</li> <li>• External causes</li> </ul>
55–64 years	<b>30 deaths with COD including:</b> <ul style="list-style-type: none"> <li>• Respiratory disease</li> <li>• Diseases of the circulatory system</li> <li>• Cancer</li> </ul>	<ul style="list-style-type: none"> <li>• Cancer</li> <li>• Diseases of the circulatory system</li> <li>• Respiratory disease</li> </ul>
Over 65 years	<b>33 deaths with COD including:</b> <ul style="list-style-type: none"> <li>• Respiratory disease</li> <li>• Diseases of the circulatory system</li> </ul>	<ul style="list-style-type: none"> <li>• Diseases of the circulatory system</li> <li>• Cancer</li> </ul>

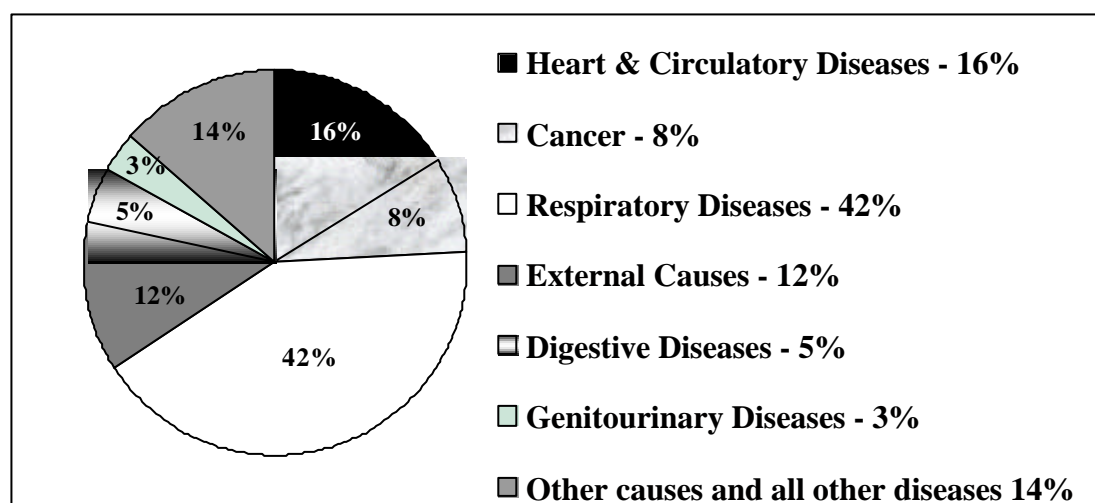
Table 3: Main reported causes of death: review group compared to general population<sup>26</sup>

Figure 4: Underlying cause of death for review group, refer to Appendix table 8

<sup>26</sup> These reported causes of death are ranked in a descending order of frequency.

## 2.6.2 Respiratory deaths

Overall, the most common cause of death was respiratory disease (42 per cent (88) of deaths in the Review group).<sup>27</sup> Pneumonia accounted for 95 per cent (77) of the 88 respiratory deaths. Of these pneumonia deaths, 23 per cent (18) were directly due to aspiration pneumonia – a lung condition caused by aspirating an irritating substance, such as gastric contents into the lungs (Accardo, P. Whitman, B. 1996). In addition to these respiratory deaths, another nine deaths resulted from aspiration pneumonia secondary to epileptic seizures. Asthma and chronic obstructive airways disease (COAD) caused 11 deaths.<sup>28,29</sup>

Factors commonly stated as being associated with pneumonia are age (in particular, the young and elderly), gastro-oesophageal reflux, poor nutritional status, immobility and decreased immunity (Langmore, S. Terpenning, M. et al 1998 and Patja, K. Iivanainen, M. et al 2000).

The Review identified that the main cause of death in young people was from respiratory disease, especially in those with dysphagia and aspiration.

Figure 5 compares the proportion of deaths due to respiratory disease/aspiration in the general population and in the Review Group. In the general population, respiratory disease/aspiration accounts for very few deaths in people under the age of 45 years, but increasing in significance in the older age groups. In contrast, the proportion of deaths due to respiratory disease/aspiration in the Review group is highest in the younger ages, accounting for 69 per cent of all deaths in the 0-14 year age group.

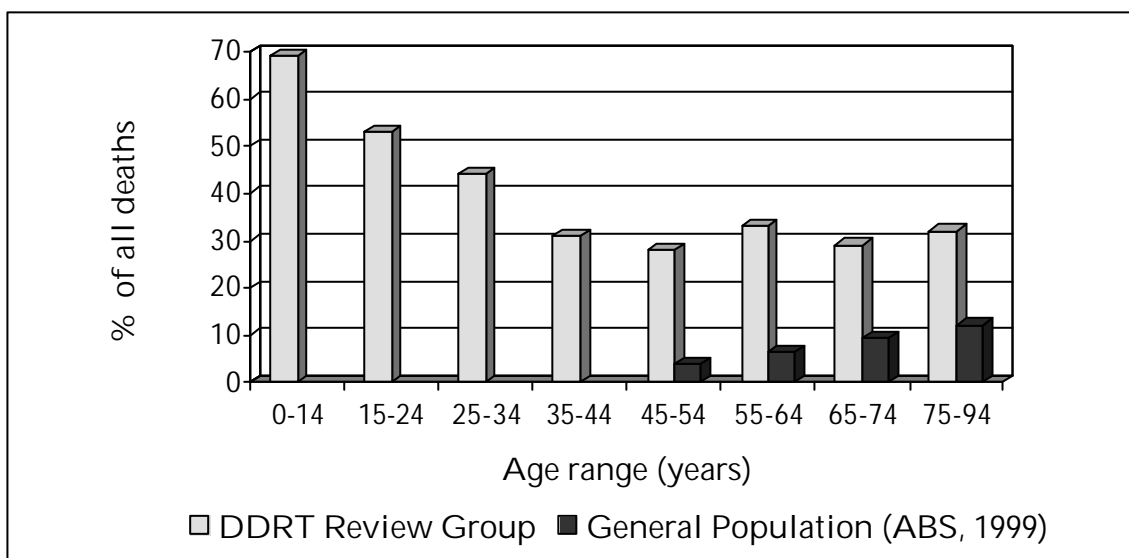


Figure 5: Deaths due to respiratory disease/aspiration in the review group and in the general population

<sup>27</sup> Respiratory conditions included pneumonia, chronic obstructive airways disease and asthma.

<sup>28</sup> Asthma is a reversible airways disease that normally responds to treatment.

<sup>29</sup> COAD is the persistent obstruction of the airways caused by chronic bronchitis or emphysema.

The predominance of respiratory causes of death among those with multiple disabilities is notable. Of the 88 people who died of respiratory diseases, 36 had multiple disabilities with the majority being under 45 years of age.

### 2.6.3 Cancer

Fourteen people died of cancer, seven of the digestive organs, two of the breast and two of the lungs. In addition there were three other deaths due to non-malignant tumours such as angiofibroma of blood vessels. While cancer is a major cause of death for children in the general population, no children in the Review group died of cancer.

### 2.6.4 Digestive diseases

Ten people died from digestive diseases. Of these, three deaths were due to perforated or bleeding ulcers. In seven cases, death occurred 24 hours or less after onset of acute symptoms (refer to Appendix, Table 9).

### 2.6.5 Death caused by external factors

Twelve per cent (26) of all deaths were from external causes, which included falls, burns, drownings and medication toxicity (refer to Table 4). Seven people died as a result of choking due to food or vomit inhalation.

External Cause of Death	Number of deaths
Accidental falls	3
Burns	1
Drownings	6
Medication toxicity	2
Choking <sup>30</sup>	5
Other external causes of death	9
Total	26

Table 4: Deaths due to external causes in the review group

### 2.6.6 Drowning

Drowning was the largest single external cause of death. Six people drowned and water trauma was indirectly implicated in a number of other deaths. Of those who drowned, five died while bathing (refer to Appendix, Table 10). Two people died as a result of being trapped under water.

Drowning was also implicated in the deaths of two men aged 60 and 71 who had wandered from residential centres, fell into water-courses and were unable to get

<sup>30</sup> Choking on food lead directly to the deaths of five people and was classified as an external cause of death.

themselves out. In both matters, the Coroner stated that the cause of deaths were possibly due to drowning and/or hypothermia.

#### 2.6.7 Falls

In the group reviewed, the cause of death for five people was directly related to a fall-injury. These involved:

- complications arising from fractured limbs following falls (two cases); and
- death from a head injury following a fall (three cases).

#### 2.6.8 Deaths caused by self-harm

The Review identified a small number of people whose deaths were associated with self-harm. While these deaths were unexpected, the risk of harm for these individuals was noted on the files.

One of these individuals, who had a history of self-injurious behaviour, was being treated for depression prior to death from self-strangulation. The Coroner could not determine if the person had intended to take their life or had died accidentally.

#### 2.6.9 Service type and cause of death

Within the Review group, there was a proportionately higher occurrence of fatal seizures and deaths due to generalised infections in group homes compared to similar deaths in the larger residential services (refer to Appendix Table 3).

As stated previously, the number of deaths by self-harm and assault was small, with the majority of these deaths occurring in residential settings.

### 2.7 Associated health conditions

The following section focuses on specific health conditions, including underweight, obesity, respiratory disease, digestive disorders, epilepsy, dementia and psychiatric disabilities, as they are evident in the Review group. Importantly, these are areas in which service improvements and preventative strategies can potentially alleviate the impact of such conditions on individuals' health and well being.

#### 2.7.1 Nutritional problems

People with intellectual disabilities have increased nutritional risks, many because of complex medical conditions (von Konnigsmark, 1999). Weight information is a critical component of nutrition management. Weight was recorded for 130 people in the Review group (refer to Table 5). Of these, 55 were underweight, while 14 were overweight or obese.

Weight	Number of deceased	
	N	%
<b>Overweight/obese</b>	<b>14</b>	<b>11</b>
<b>Normal weight</b>	<b>61</b>	<b>47</b>
<b>Underweight</b>	<b>55</b>	<b>42</b>
Total	130	100

Table 5: Known weight range of 130 deceased<sup>31</sup>

### 2.7.2 Underweight

Of the 130 people whose weight was recorded, 42 per cent (55) were underweight at the time of death. This figure is particularly high. For example, the Commission found in a previous study some 15 per cent of people with developmental disabilities in care in NSW were underweight (CSC, 1997).

Of the total Review group, 81 people required feeding assistance and of these, 39 were also underweight. Fifty individuals in the Review group had swallowing difficulties, and 23 of those were underweight, with body mass indices (BMIs) ranging from 10-19 kg/m<sup>2</sup> and reliant on enteral feeding.<sup>32</sup> The underlying health conditions for these 23 individuals included reflux, with or without oesophagitis, asthma and recurrent chest infections. All but two of this group had limited mobility and required assistance with feeding. Of the 23, nine were under the age of 20 years at the time of death.

### 2.7.3 Overweight/obesity

Eleven of the fourteen people who were recorded as being overweight/obese were adults aged from 26-74 years. BMIs for these people ranged from 27 to 53 kg/m<sup>2</sup>. Their health conditions included diabetes, hypertension, heart disease and severe coronary artery disease. Eight of the deaths were directly related to these health conditions.

### 2.7.4 Respiratory conditions

As noted, the most common cause of death in the Review group was respiratory illness including aspiration pneumonia, asthma and COAD. Nine deaths were due to the latter two conditions. People with cerebral palsy (known for 54 people in the

<sup>31</sup> Weights of children were not included.

<sup>32</sup> Body mass index (BMI) is a formula for assessing the weight of an adult in relation to their height. BMI is defined as weight (in kilograms) divided by height (in metres) squared (kg/m<sup>2</sup>). BMI of less than 18 kg/m<sup>2</sup> is considered seriously underweight with associated health risks.

- BMI 18-20 kg/m<sup>2</sup> is considered underweight but not necessarily of concern.
- BMI 20-25 kg/m<sup>2</sup> is considered a healthy weight.
- BMI 25-30 kg/m<sup>2</sup> is considered overweight but not of concern re health issues.
- BMI 30-40 kg/m<sup>2</sup> is classified as obese with health risks.
- BMI over 40 kg/m<sup>2</sup> is considered a serious health risk of "morbid obesity".

BMI measurements may be affected by lack of accuracy in height measurement, particularly for people with cerebral palsy and associated contractures, (Dormans, J. Pellegrino, L. et al, 1998).

Review group) have an increased incidence of primary respiratory disorders, including asthma, COAD and related sleep apnoea (Dormans, J. Pellegrino, L. 1998).<sup>33</sup>

The major contributing conditions identified in the Review group's respiratory deaths included:

- Gastro-oesophageal reflux was reported in 12 cases;<sup>34</sup> and
- Scoliosis with resultant chest wall deformities was reported in 18 cases.

Within the Review group, 50 people were known to have swallowing disorders (dysphagia). Dysphagia is estimated to occur in up to 60 per cent of people with multiple disabilities (DoCS, 1999) with the primary complications being malnutrition and aspiration with resultant chest infections. Aspiration pneumonia is a significant cause of death for people with multiple disabilities. Studies have identified aspiration pneumonia as a cause of death in 20-50 per cent of people with multiple disabilities, with some studies citing a figure of up to 80 per cent of deaths (Langmore, S. Terpenning, M. et al 1998).

### 2.7.5 Epilepsy

Within the Review group, 47 per cent (99) had been diagnosed with epilepsy, and epilepsy was identified as a contributing factor in 26 deaths. Twelve people died shortly after they had experienced a convulsion or following complications arising from a seizure.

Anti-convulsants were implicated in the deaths of nine people with epilepsy. Sub-therapeutic levels, anti-convulsant toxicity and failure to administer medications correctly were issues dealt with by the Coroner.

The mortality of people with epilepsy is reported as being two to three times that of the general population when matched for age and gender (Hauser, W. 1997). There is an increased prevalence of epilepsy in people with intellectual disabilities in the order of 10 to 20 per cent. One study noted that 40 per cent of all institutionalised adults have epilepsy (Pellock, J. Hunt, P. 1996).

While there is an increased death rate for people who have partial seizures, the greatest risk of mortality is for people with generalised seizures, with associated pneumonia being the most common cause of death. People with more severe disabilities are known to face a significantly increased risk of death if their seizures are poorly controlled (Forsgren, L. Edvinsson, S. et al 1996).

---

<sup>33</sup> Sleep apnoea is a condition caused by the structures in the throat blocking the flow of air in and out of the lungs during sleep, resulting in a lack of oxygen and restful sleep. This condition can occur in association with other respiratory conditions.

<sup>34</sup> Gastro-oesophageal reflux disease commonly occurs in people, who are immobile, have scoliosis and/or spastic quadriplegia.

### 2.7.6 Digestive disorders

Details of health history were recorded for eight of the ten people who died of digestive diseases (refer to Appendix, Table 9).<sup>35</sup> Conditions such as chronic constipation, ulcers, hernias or feeding problems were noted.

Chronic constipation is a risk factor for late-presenting intestinal obstruction, which can have deceptively minimal symptoms (Jancar, J. Speller, C. 1994). There is also a relationship between megacolon and paralytic ileus, and the long-term use of psychotropic drugs that have anticholinergic side effects (Fehlow, P. Walther, F. et al 1995).<sup>36</sup>

### 2.7.7 Dementia

Twelve people had dementia. Of this group, seven people had Down syndrome and were aged between 51 and 63 years. All seven had Alzheimer's type dementia combined with epilepsy or dysphagia or were underweight. Individuals with Down syndrome are at risk of premature mortality due to congenital heart disease and the presentation of Alzheimer's disease earlier in life. The risk of death increases for this group after middle age in comparison to the wider disability population (Strauss, D. Eyman, R. 1996).

Five people with dementia who did not have Down syndrome were all older, aged between 72 and 82 years. In this group, the cause of dementia was not stated, although three had Parkinson's disease.

The low numbers of people with dementia in the Review group may be attributed in part to the following:

- Historically, people with disabilities have had shorter life expectancies, and been less likely to develop age-related degenerative conditions, such as dementia;
- Dementia may be under-diagnosed in this population because it is not easily distinguished from pre-existing cognitive impairment, particularly for people with moderate to severe intellectual disability; and
- The numbers of people transferred from disability accommodation services to aged care facilities was not known for the Review period.<sup>37</sup>

---

<sup>35</sup> Digestive disorders include diseases of the oesophagus, stomach and duodenum.

<sup>36</sup> Definitions of terms used here include:

- Paralytic ileus is a condition in which the normal contractile movements of the intestinal wall temporarily stop;
- Megacolon occurs as a result of distension of the large intestine. If left untreated megacolon condition can be fatal; and
- Medications with anticholinergic effects block the normal action of part of the nervous system called the cholinergic nervous system. These effects can cause confusion, blurred vision and constipation.

<sup>37</sup> Two hundred and seventeen people with an intellectual disability under the age of 60 years were reported as living in NSW nursing homes in 1997 (Parliament of NSW Upper House Standing Committee on Social Issues, 1997).

### 2.7.8 Psychiatric disabilities and challenging behaviour

Of those cases where type of disability was recorded, 24 were identified as having a psychiatric disability, categorised as either a primary or other disability. Twelve people with psychiatric disabilities were also reported to have challenging behaviours.

Research suggests a link between psychiatric disorders and traumatic death (Carter, G. Jancar, J. 1984 and Cole, G. Neal, J. et al 1994). The two violent deaths in this Review were of people with psychiatric disabilities.

Challenging behaviours were identified in 44 people, with the records of 17 people indicating a prior history of self-injuring behaviour. Two people died as a result of the ingestion of foreign bodies (pica). Although the prevalence of pica is generally considered to be low in people with intellectual disabilities, it is considered a serious health risk within this population (Jancar, J. Speller, C. 1994 and Decker, C. 1993).

Of the Review group, two adults aged 41 and 45 years and one 14 year old had Prader Willi Syndrome.<sup>38</sup> All three were obese to morbidly obese with associated health conditions (which led to their deaths) and contributing behavioural problems.

## 2.8 Coroner contact

The reporting of the deaths of DoCS' residents to the Coroner is required under s13 (1) (h) of the *NSW Coroners Act 1980*.<sup>39</sup> The reporting of the deaths of residents of non-government services to the police or Coroner is recommended as set out in the *ADD Standards in Action Manual*.<sup>40</sup> The coronial process generally focuses on the immediate circumstances leading up to the death of the person.

Section 12(a) and s13 (1) of the *NSW Coroners Act 1980* requires the reporting of the death of any person to the Coroner, if there is reasonable cause to suspect that the person has died in circumstances including:

- A violent or unnatural death;
- A sudden death the cause of which is unknown; and
- Under suspicious or unusual circumstances.

---

<sup>38</sup> Prader Willi Syndrome is a genetic condition with a number of characteristics including intellectual disability and an insatiable appetite that leads to obesity if not carefully managed.

<sup>39</sup> S13 (1) (h) of the *NSW Coroner's Act 1980* requires a death to be reported to the Coroner if:

*The person died while in, or temporarily absent from, the following establishments:*

*A hospital,*

*A facility within the meaning of the Community Welfare Act 1987,*

*A residential centre for handicapped persons licensed under the NSW Youth and Community Services Act 1973.*

<sup>40</sup> The *Standards in Action Manual* (revised version July 1999) is produced by ADD.

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.<sup>41</sup>

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.<sup>42</sup>

Of the 211 deaths reviewed:

- 75 per cent (158) were reported to the Coroner;
- The majority of notifications made, 93 per cent (147), were of deceased DoCS' residents, with the other seven per cent (eleven) in non-government services;
- Although there was a legal obligation to report the deaths of DoCS' residents to the Coroner, 19 per cent (34) of the total DoCS deaths within the Review group were not reported;<sup>43</sup>
- For the 89 people who died in hospital, 69 per cent (61) of deaths were reported to the Coroner; and
- Thirty-three matters went to inquest with recommendations made in five cases.

For residents of NGOs, whose deaths were not required to be reported to the Coroner under the *NSW Coroners Act 1980*, the number of reported deaths was low and the numbers were even lower if the person died in a hospital setting.

The rate of autopsy for the sample (98 per cent) appeared to be higher than rates recorded elsewhere in Australia.<sup>44</sup>

## 2.9 Summary of review observations

- The majority of those who died had an intellectual disability with a significant number having a severe to profound level of intellectual disability. The cause of disability was unreported for almost half the group. A considerable number of people also had multiple disabilities.
- There was a higher proportion of male deaths and the greatest number of deaths occurred in large residential services.

---

<sup>41</sup> Section 14A, 14B, 14C, *Coroners Act 1980*.

<sup>42</sup> Section 12B, *NSW Coroners Act 1980*.

<sup>43</sup> Over half of this group were deceased DoCS' group home residents (19).

<sup>44</sup> For example, in Victoria, autopsies were conducted in only 53 per cent of matters reported to the Victorian Coroner for the period, July 1990 to December 1997 (Victorian Department of Human Services, 2000).

- People aged 25 to 44 years comprised the largest single age grouping of those who died. Children made up 15 per cent of the total number of deceased.
- The most common cause of death was respiratory disease followed by diseases of the circulatory system. The proportion of deaths due to drowning, falls and asphyxiation was higher than that reported in the general population.
- Underlying health conditions identified in the Review group included nutritional problems, respiratory conditions, epilepsy, dementia, psychiatric conditions and gastrointestinal problems. Feeding and mobility problems were evident in many. A significant number of people in the group required some form of communication assistance.
- A higher proportion of deaths due to respiratory disease were reported for people living in large residential centres (refer to Appendix, Table 3), compared to people living in other forms of supported accommodation services. A proportionately higher occurrence of fatal seizures and deaths due to generalised infections occurred in group-homes.
- Most other causes of death, including external causes, were similarly represented for both institutional and group home residents. In certain settings, people with disabilities appeared to be at greater risk of death as a result of assault and self-harm.

## Chapter 3: Indicated service improvements

Chapter 2 examined the characteristics and circumstances of 211 people who died in care in NSW between 1991 and 1998. The following discussion aims to identify any systemic issues indicated by the Review and consequent considerations for service improvement. The discussion draws on the findings of the Review and issues identified in individual files, medical reports and recommendations made by the Coroner. Case studies, based on the DDRT analysis of the 211 deaths, are used to illustrate issues arising from the Review and to highlight the complexities of health care access and health outcomes for people with disabilities in care.

Given the limitations of the Review data, the following 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' potential issues indicated by the data, which may warrant attention at a systemic level, and to propose possible service improvement initiatives to address the issues.

Areas covered below are:

- Access to health care;
- Health promotion and education;
- Seizure management;
- Management of dysphagia and aspiration;
- Management of asphyxiation and choking;
- Bathing practices;
- Prevention of falls;
- Management of self-harm; and
- Coroner notification.

Suggested reading in conjunction with this paper is *Management Guidelines: People with Developmental and Intellectual Disabilities*, Lennox, N. Diggins, J. (eds), 1999.

### 3.1 Recent initiatives

Since the time of these deaths a number of service improvements have been introduced into the delivery of disability services in NSW. These have been considered in the following proposals and include:

- Establishment of baseline requirements for disability services following the recommendations of the *Performance Audit of Large Residential Centres* (Audit

Office of NSW & Community Services Commission, 1997). These requirements include the minimum practices to protect human and legal rights of residents and address issues such as management of critical incidents, behaviour management and safety (*Standards in Action Ageing and Disability Department, 1998*);

- The establishment of a disability deaths in care register maintained by the DDRT (1998);
- A notification process for all disability deaths in care, including an information package and notification format as per ADD's revised *Standards in Action Manual (1999)*;
- Introduction of the Supported Accommodation Risk Assessment (SARA) tool designed to regularly screen potential risks in supported accommodation services provided by the Department of Community Services (DoCS, 1999);
- The development and implementation of a nutrition risk assessment screening tool by the Department of Community Services (2000);
- The development of a draft 'Health and Well-being' policy by the Department of Community Services which incorporates health guidelines, health care and individual planning and client health care plans (2001); and
- ADD has undertaken a review and developed a proposed framework for the monitoring of funded disability services (2001).

### 3.2 Access to health services

The Review data indicated that many of those who died had multiple disabilities with associated health problems. These health conditions underline the importance of access to primary health care and specialist services for people with disabilities in care.

Certain health problems are more prevalent in people with disabilities but often remain under recognised or under managed, in particular, vision and hearing impairment, unidentified pain or infections, gastrointestinal problems and epilepsy (Lennox, N. Cook, A. et al. 1997, Beange, H. Taplin, J. 1996). Regular health review and screening, with appropriate referral and follow up and health promotion activities are essential components of health care delivery for this population. In conjunction with health review and screening, direct care staff also require information and training regarding the recognition of early non-verbal indicators/symptoms of specific health problems.

#### 3.2.1 Health review, health screening and early detection

Regular health review can provide early detection of a range of potentially treatable conditions including hypertension, cancer, swallowing and eating disorders,

respiratory and cardiovascular disease – conditions seen in the Review group. Regular review also enables preventative health activities such as regular immunisation and education about healthy lifestyles to be carried out.

The circumstances of death of a fourteen-year-old girl with high medical needs highlights the importance of early detection of potentially treatable conditions. Given the range of health problems in the Review group, prevention and early detection of illness is vital.

#### **Resident A**

A 14-year-old girl, Resident A, had a number of alternate placements before being placed in a residential school at four years of age. She had high support needs due to her intellectual disability, hydrocephalus, epilepsy and sensory impairment. As she grew older, school holidays became a problem. Visits to her family home in country NSW became infrequent, and she became a state ward at ten years of age. During the term she remained at school, and went to a large residential service for school holiday care.

Resident A's medical care was provided by a specialist disability/health service when she was at school, but this was not available to her when she was in holiday care.

During her last respite care placement, after ten days of poor health including vomiting, photosensitivity and concerns about a shunt blockage, she was admitted to hospital and died one hour later. The Coroner determined she had died of meningoventriculitis following the blockage of her shunt.<sup>44</sup>

Key issues arising from Resident A's death included:

- The consequences of delays in seeking hospital treatment, following ten days of deteriorating health;
- The adequacy of shunt management, given that she had developed a shunt blockage requiring treatment; and
- The frequency of moves between the school and accommodation service which may have contributed to a disruption of her health care.

For people who are unable to communicate or have limited communication, health screening and review and early detection are especially important, due to the difficulty they may have in identifying or describing symptoms for conditions that may otherwise go unrecognised.

The case of one person, 'Resident B', illustrates the circumstances of a person with severe disabilities and communication impairment whose fatal illness was not diagnosed.

---

<sup>44</sup> Meningoventriculitis – infection in the brain's meninges and ventricles.

## Resident B

Resident B was a 24-year-old woman, who had been in care from six years of age. She had suffered severe brain damage as a four-month-old infant, resulting in a profound intellectual disability and spastic quadriplegia. She was unable to communicate. Resident B had severe scoliosis and was underweight (BMI 15kg/m<sup>2</sup>). She was treated for asthma, recurrent respiratory and ear infections, and chronic constipation.

One morning, Resident B was noticed to be still and unresponsive. Staff began resuscitation without success. Her death had been quick and unexpected.

The autopsy revealed Resident B had multiple gastric ulcers. The Coroner determined the cause of Resident B's death was the perforation of her stomach by three of these ulcers.

Issues arising included:

- Resident B had no diagnosis or treatment of gastric ulcers, although she was treated for a number of other complaints, including chronic constipation.
- Given the condition that caused her death, it is likely that she experienced pain as a result of these ulcers. However, there was no record of discomfort or pain. It was also stated that Resident B had ear infections which would have also been likely to cause her pain; and
- The level of assessment skills, staff training and medical expertise in the assessment of people with severe levels of disabilities, particularly those with communication impairment, was not evident in this case.

### 3.2.2 Disability diagnosis

Within the Review group, there was a significant number of cases where the cause of intellectual disability was unreported, suggesting the need for further genetic assessment and review for people where the cause of the disability is not known. Early knowledge and recognition of the cause of a disability or specific associated disorders is considered essential for the long term management and prevention of associated health problems (Lennox, N. 1999).

Seeking the cause of a disability can be a long-term process and it is recommended that it should continue to be reviewed at regular intervals throughout life (Victorian Medical Committee of Client Mortality, 1997).

### 3.3 Health promotion and education

Within the general community, there is awareness of the risk of danger for vulnerable people, such as children and the frail elderly. Road safety, water safety and drug education are examples of public health and safety campaigns aimed at such groups. People with disabilities have a high risk of death by external cause. In certain settings they may also be at risk of injury and death as a result of assault and

self-injurious behaviour. However, a review of current evidence suggests that people with intellectual disabilities are not accessing mainstream health promotion and health education activities such as fitness, healthy nutrition and injury prevention programs (Durvasula, S. Beange, H. in press). Further, there is little evidence of safety campaigns for people with an intellectual disability, or for disability services providing direct support and accommodation.

Within the Review group, deaths related to underweight and obesity were reported, as well as deaths due to falls and other injuries. The Review data reinforces the need for health and safety promotion and injury prevention programs for people with disabilities in care. A review of health promotion programs has found that programs targeted to specific health conditions can be successfully implemented within this population, if structured appropriately and promoted (Durvasula, S. Beange, H. in press). Such programs should be developed in conjunction with dietetic and disability expertise and be considered an integral part of service delivery within supported living programs.

### 3.4 Seizure management

Epilepsy was a prominent condition amongst those in the Review group. Epilepsy research has demonstrated that a number of practical management strategies can provide a safe environment for people with epilepsy including:

- Supervision for potentially hazardous activities such as swimming, climbing, bathing and cooking;
- Regular medical review of anti-convulsant medications, for the monitoring of efficacy and side-effects;
- First aid training in seizure management and response; and
- Avoidance of seizure triggers (Epilepsy Foundation of Victoria, 2001).

The following case study is based on the circumstances of death of a nine-year old boy who suffocated following an epileptic seizure, and illustrates the importance of issues around supervision and review of individual needs:

## Resident C

Resident C, a nine-year-old boy, had lived in residential care for only two months prior to his death. Although he had been placed in permanent care there was no care order in relation to his placement.<sup>45</sup> Resident C had epilepsy, microcephaly and was described as being hyperactive. He was on anticonvulsant medication (carbamazepine) and stimulant medication at the time of his death.

Sometime after he was put to bed in the evening, staff found Resident C to be not breathing. Following intervention, he was declared deceased by a visiting medical practitioner. His death was reported to the Coroner and a post mortem was conducted. His cause of death was due to asphyxia, caused by an epileptic seizure.

Issues arising included:

- The need for specialist medical review of Resident C's epilepsy management;
- Lack of recording of Resident C's seizures and lack of documentation of his seizure history; and
- Adequacy of staffing levels within the service, particularly night-time staffing levels and adequacy of supervision of Resident C.

### 3.5 Management of dysphagia and aspiration

Swallowing and eating difficulties (dysphagia) affected a significant number of people in the Review group. People with these conditions are known to have significantly higher death rates than people within the general population (Langmore, S. Terpenning, M. et al 1998 and Fryers, Y. 1984). Strategies for the management of dysphagia and aspiration include:

- Regular review by specialist dysphagia services to ensure:
  - Appropriate evaluation of feeding practices including appropriate positioning techniques and seating techniques;
  - Nutritional monitoring of enteral feeding where appropriate; and
  - Management of aspiration.
- Regular weight monitoring and review to ensure appropriate assessment and treatment is undertaken;
- Investigation and management of possible oesophagitis, associated with gastro oesophageal reflux;<sup>46</sup> and
- Regular influenza and pneumococcal immunisation to prevent respiratory infection.

<sup>45</sup> Resident C was in full-time care but was not a state ward.

<sup>46</sup> Oesophagitis is caused by inflammation of the oesophagus. Gastro-oesophageal reflux (GER) refers to the reflux (reverse flow) of gastric acid into the oesophagus. When frequent and prolonged, GER results in inflammation of the mucosa (oesophagitis) and in painful spasms of the oesophageal muscles.

The following case study of the circumstances of death of an underweight man who had oesophagitis and recurrent aspiration due to swallowing and eating difficulties illustrates the importance of regular review and assessment of feeding needs:

#### Resident D

Resident D, a 53-year-old man, had lived in large residential centres since eleven years of age. He had no known relatives and was under guardianship. Resident D was totally dependent with a severe intellectual disability, hemiparesis and kyphosis (angular curvature of the spine). He was receiving treatment for epilepsy, ulcerative oesophagitis and chronic constipation.

During the last ten years of his life, Resident D experienced recurrent aspiration pneumonia. Various techniques were used to address his difficulties including a brief period of gastrostomy feeding five years before his death, followed by a pureed diet with thickened fluid using special posture chair.

He was hospitalised twice for aspiration pneumonia in the last month of his life. He had ten days in hospital with intravenous antibiotics, physical therapies and naso-gastric feeding. Three weeks later, with another bout of aspiration pneumonia, he was returned to hospital for further treatment, where he died.

Issues arising included:

- Assessment of his feeding posture was assessed one month before his death in hospital, however, Resident D was discharged to the service without follow-up;
- The need for specialist medical review of his recurrent aspiration was not identified at his annual medical review, eight weeks before his death. Although he had a history of ulcerative oesophagitis, aspiration and recurrent chest infections, there had been no review of his enteral feeding needs in the six months prior to his death.

### 3.6 Management of asphyxiation and choking

Deaths due to choking on food and asphyxiation were reported in a number of cases in the Review group. The following case is of a woman, known to be at risk of choking, who died after choking on a sausage. The case illustrates the importance of supervision, adequate mealtime preparation and availability of appropriate first aid equipment:

## Resident E

Resident E was a 34-year-old woman, who had lived in large residential services for 25 years. She had a severe level of intellectual disability, epilepsy and challenging behaviours.

Resident E was feeding herself lunch, which consisted of cut-up sausages, thick noodles, cornflake topping and beans. During this meal she was observed to choke.

Attempts to dislodge obstructing food from her throat were not successful and she did not respond to CPR. She was pronounced deceased twenty minutes later.

The autopsy revealed that Resident E had experienced a respiratory obstruction due to the inhalation of a piece of sausage. It was noted on the police report that Resident E had had a previous choking episode three months prior to her death.

Issues arising from included:

- The need for regular review of swallowing and eating abilities for people identified with specific risk factors;
- Adequacy of mealtime supervision and food modification requirements for people with swallowing and eating difficulties; and
- The need for adequate first aid training.

Suggested strategies to avoid choking and asphyxiation include:

- Regular review of diet and mealtime practices to ensure that meals are tailored to individual needs including eating and swallowing abilities; and
- Up-to-date first aid equipment and training.

Further, appropriate mealtime practices and correct positioning are known to reduce the incidence of choking and asphyxiation for people with swallowing difficulties and recurrent aspiration. The need for medical emergency plans, first aid equipment and staff trained in resuscitative techniques are basic requirements in the event of an obstructive emergency (Carter, G. Jancar, J. 1984).

### 3.7 Bathing practices

Drowning was the largest single external cause of death for those in the Review group, raising clear issues about supervision and safety measures to protect residents in bathing activities. Of those who died due to drowning, four men died in baths and one man died in a shower.

The following case study is of a death of a man with epilepsy who drowned in a bath. The case illustrates the importance of supervised bathing for at-risk residents:

## Resident F

Resident F, a 28-year-old man, had lived in a group home with four other people for six years. He had severe intellectual and physical disabilities and epilepsy. While his seizures had been infrequent, he experienced one in the month before his death and, as a result, had his anticonvulsant medication increased.

Resident F was lifted into the bath at a time when there was a high level of activity in the household. One staff member was finishing their shift at 8 pm. The other staff member checked on Resident F twice after the first staff member had left. An hour after Resident F had been put into the bath he was found submerged. The staff member removed him from the bath and with instruction from "000" telephone service gave CPR but could not revive him.

The autopsy confirmed Resident F had drowned, and the Coroner noted his physical disabilities would have made it difficult to keep his head above water to prevent him from drowning. Resident F's medical practitioner stated that Resident F may have fallen asleep in the bath, as he had not had his routine afternoon sleep. The Coroner found inconclusive evidence that Resident F had a seizure in the bath.

Issues arising included:

- Level and type of bathing supervision required;
- Continuity of service during staff changeovers; and
- Ability of staff to administer CPR.

The prevention of drowning and other bathing accidents involves a range of safety measures for bathroom activities. Epilepsy seizure management is also linked to these safety measures. Practical components of safe bathing practices include:

- Regular review of supervision requirements to assess the need and level of supervision required by individuals;
- Up-to-date training in first aid and acute seizure management;
- Use of showers and shower chairs as alternatives to bathing, use of non-slip bathing mats to assist stability in baths and showers, and use of bed-baths for people who are at risk of accidents in baths and showers;
- Avoidance of very hot water (use a thermostat);
- Emergency medical plans including any specific medical requirements for application in the event of a critical incident, and
- Availability of hoists and slings for people who are unable to support themselves in a bath to ensure that they are able to keep their heads above the water level at all times.

### 3.8 Prevention of falls – a safe environment

While a relatively small number of people in the Review group died from fall-related injuries, these deaths are significant at a systemic level because of the preventable nature of falls and the importance of service vigilance in relation to ensuring a safe environment for residents.

The following case, of a woman who died after falling from a shower trolley, illustrates the importance of proactive measures to prevent falls:

#### Resident G

Resident G, a 78-year-old woman, had lived in a large residential centre for many years. She had a moderate level of intellectual disability, diabetes and was limited in her mobility.

Resident G was being bathed on a shower trolley by a staff member and apparently slipped and fell, sustaining injuries including bilateral femoral fractures. She died four days later from complications arising from her injuries.

The matter was not notified to the Coroner.

Issues arising included:

- Whether there had been any recent assessment of Resident G's diabetes and mobility;
- Whether the level and type of bathing supervision in place at the time of Resident G's fall was adequate; and
- Whether there had been an assessment of risk associated with Resident G's bathing routine.

Practical strategies that could assist services in minimising the likelihood of falls include:

- Reviewing supervision needs on a regular basis, to ensure that people at risk of falling are adequately managed;
- Undertaking regular mobility assessments in order to determine any mobility decline and associated risk of falls and ensuring residents have ready access to mobility aids;
- Conducting regular medication reviews to assess adverse affects which may contribute to falls, particularly for individuals using medications which may cause ataxia or dizziness; and
- Undertaking modifications to the physical environment to remove or minimise hazards, such as provision of railings, flat walking surfaces and non-slip flooring; use of bed rails, and substitution of stairs with ramps.

### 3.9 Management of self-harm

Self-harm was identified as a factor contributing to the deaths of two people and a factor impacting on the health of a number of people in the Review group. While representing a small proportion of all deaths, they are significant due to their capacity for prevention.

Self-harm is predominantly linked to behavioural conditions, indicating that management of self-injury should be based in management of the underlying condition and be multi-focused, given that such behaviour is considered to result from more than one influence (Meyer, L. Evans, I. et al 1994).

The following case study is of a person who died from a perforated stomach, caused by massive overeating. The case illustrates the importance of supervision and ongoing review of individual support needs:

#### Resident H

Resident H, a 28-year-old man, had lived in a secured unit within a large residential centre for six years. He had a mild intellectual disability, epilepsy and severe self-injurious behaviour associated with overeating and vomiting. He also had a history of traumatic pancreatitis and peritonitis.

Early one morning Resident H was taken to hospital with abdominal pain and vomiting, where he had surgery to remove three kilograms of undigested food from his stomach. He died while under anaesthetic.

The autopsy stated that Resident H had died from complications arising from a perforated oesophagus and stomach and the Coroner noted that this was due to an abnormal eating disorder.

Issues arising included:

- Adequacy of level and type of supervision required for Resident H;
- Level of staff competencies required for the management of Resident H's self injurious behaviour; and
- No evidence of assessment and review of Resident H's behavioural needs; particularly the management of behaviour associated with his overeating.

Minimising the effect of self-harm requires accurate diagnosis and appropriate management of behavioural and psychiatric conditions, including provision of suitable medication and positive behavioural programming.

### 3.10 Organisational initiatives

Many of the issues raised by the Review indicate the need for measures that address prevention at an organisational level as an essential component of a systemic approach to minimising harm, injury or early death. Key measures should include:

- Training for disability workers in basic health care, first aid, the safe and effective use of medication and nutrition management. Training should encompass areas of specific relevance, such as seizure and choking management.
- Development and monitoring of policies and procedures to regulate and guide practice and performance in key areas, such as accurate record keeping, supervision, management of self-injury and management of epilepsy.
- Commitment to, and provision of, regular case review with specific review of critical incidents.

In addition to internal initiatives, adequate access to allied services is essential. Specialist support, clinical and other services are all necessary components contributing to the reduction of injury and premature death. These include:

- Case management services;
- Medical practitioners, psychologists, behaviour intervention and support teams; and
- Nutritionists, dieticians, occupational therapists, physiotherapists and speech pathologists, programming teams and educators.

### 3.11 Coroner notification

There was a marked inconsistency in the reporting of the deaths of those in the Review group to the Coroner. Deaths in DoCS' services were more likely to be notified to the Coroner than deaths in NGOs. This inconsistency is in part due to an anomaly in the *NSW Coroners Act 1980*, which requires all deaths in DoCS' services to be notified to the police or Coroner, but does not require this in non-government organisations.<sup>47</sup>

---

<sup>47</sup> 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.

This issue clearly needs to be addressed and resolved. 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.

### 3.12 Conclusion

This Review has examined the characteristics and circumstances of 211 people who died in care between 1991 and 1998 where the deaths were reported to the CSC. Aspects of health conditions, disability types, dependency levels and causes of death have been established, with a comparison being made to known causes of death in the general community and reference to morbidity/mortality research of people with disabilities. The Review has also provided an opportunity to consider service improvement initiatives, which may assist in minimising harm and preventing deaths.

Many of the individuals reviewed had lived in residential settings for most of their lives. Research indicates that there are effective interventions that may serve to enhance the quality of life for, and reduce the numbers of premature deaths among, people with disabilities in these settings. Such interventions require a combination of expert input; health screening, monitoring and follow-up; and a strong commitment to organisational and staff development.

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

# Appendix

Note: All percentages have been rounded to whole numbers.

**Table 1: Residents in accommodation services in NSW, 1995 - 1998<sup>48</sup>**

		Service Provider							
		DoCS				NGO			
		1995	1996	1997	1998	1995	1996	1997	1998
Gender	Male	1696	1716	1662	1687	1544	1664	1766	1712
	Female	1078	1103	1067	1069	1206	1349	1333	1361
	Not Known	48	15	1	11	48	18	3	16
Total		2822	2834	2730	2767	2798	3031	3102	3089

**Table 2: Number of review group deaths, 1991 - 1998**

Year of Death	No. of Deceased
1991 - 93	17
1994	33
1995	34
1996	41
1997	40
1998	46
Total	211

<sup>48</sup> CSDA MDS Collection ADD.

**Table 3: Causes of death and model of accommodation service in the review group**

Cause of Death	No. of deaths of people in group homes		No. of deaths of people in LRC and MRC		Total
	N	%	N	%	N
Heart & circulatory diseases	8	17	24	16	32
Cancer	2	4	5	3	7
Respiratory diseases	16	34	83	56	99
External Causes	4	8	10	7	14
Digestive diseases	3	6	6	4	9
Genitourinary diseases	2	4	3	2	5
All other diseases	9	19	8	5	17
Other causes of death	2	4	9	6	11
Unknown	2	4	2	1	4
Total	48	100	150	100	198

**The 13 people who died in respite care are not included in this table**

**Key: LRC = Large Residential Centre      MRC = Mini Residential Centre**

**Table 4: Age and permanency of care for people under 18 years of age**

Type of Care	Age in years															Total
	<1	1	4	5	7	8	9	10	11	12	13	14	15	17		
Permanent	-	-	3	1	1	1	4	1	2	1	2	3	2	3	24	
Respite	1	1	-	-	-	-	-	1	-	-	-	1	3	-	7	
Total	1	1	3	1	1	1	4	2	2	1	2	4	5	3	31	

**Table 5: Deaths by gender and age<sup>49</sup>**

Age (years)	Female		Male		Total		Cumulative percentage of all deaths
	No.	% of all female deaths	No.	% of all male deaths	No.	% of all deaths	
0-4	3	4	3	2	6	2.8	2.8
5-9	2	3	4	3	6	2.8	5.6
10-14	6	7	5	4	11	5.2	10.8
15-19	6	7	10	8	16	7.6	18.4
20-24	6	7	6	5	12	5.7	24.1
25-34	13	16	27	21	40	19.0	43.1
35-44	10	13	22	17	32	15.2	58.3
45-54	13	16	12	9	25	11.9	70.2
55-64	11	13	19	15	30	14.2	84.4
65-74	5	6	9	7	14	6.6	91.0
75-84	6	7	9	7	15	7.1	98.1
85-94	1	1	3	2	4	1.9	100.0
Total	82	100	129	100	211	100%	100.00

**Table 6: Comparison of primary disabilities of review group to all people in NSW disability accommodation services in 1998 (ADD CSDA MDS, 1999)**

Primary Disability Type	All residents of NSW disability accommodation		Review Group	
	No.	%	No.	%
Intellectual	4970	85	189	89
Physical	548	9	10	5
Neurological	193	3	8	4
Other	145	3	4	2
Total	5856	100	211	100

**Table 7: Degree of intellectual disability in review group where level of intellectual disability was known**

Degree of Intellectual Disability <sup>50</sup>	Review Group		Cause of Death		No. by Age (years)
	N	%	Respiratory Diseases	Circulatory Diseases	
Mild (IQ 50/70)	10	9	1	5	3 x 25-34 years
Moderate (IQ 35/49)	20	18	6	4	7 x 75-84 years
Severe (IQ 20/35)	50	46	27	7	10 x 25-34 years (7 due to external causes)
Profound (IQ <20)	30	27	25	2	4 x 10-14 years / 9 x 25-34 years
Total	110	100			

<sup>49</sup> Age groupings for children and young people are shown in five-year intervals.

<sup>50</sup> The seven children with developmental delays have been excluded from this table as the extent of their disability was not determined.

Table 8: Underlying cause of death by age

Cause of Death	Age Range												Total	
	0 - 4	5 - 9	10 - 14	15 - 19	20 - 24	25 - 34	35 - 44	45 - 54	55 - 64	65 - 74	75 - 84	= 85	N	%
Heart & circulatory diseases	-	1	-	1	1	2	8	3	9	3	5	1	34	16
Cancer	-	-	-	-	-	2	3	4	4	2	2	-	17	8
Respiratory diseases	4	3	6	10	5	18	10	12	11	4	3	2	88	42
External causes	-	1	-	2	2	7	5	1	2	2	3	-	26	12
Digestive diseases	-	-	-	-	2	4	2	-	-	1	-	1	10	5
Genitourinary diseases	-	-	-	-	1	2	2	-	2	-	1	-	7	3
Other diseases & death causes, unknown	2	1	5	3	1	5	2	5	2	2	1	-	29	14
Total	6	6	11	16	12	40	32	25	30	14	15	4	211	100

**Table 9: Selected characteristics and circumstances of people who died of digestive diseases**

Age	Sex	Weight	Cause of Death	Other History	Length of Acute Illness	Medications
20	F	U/W (BMI 16)	Perforated stomach due to gastric ulcers	Inoperable hiatus hernia	9 days	Anticonvulsant
20	F	U/W	Paralytic ileus <sup>51</sup>	Gastrostomy feeds, chronic reflux and aspiration	5 days	U/K
24	F	U/W (BMI 16)	Perforated stomach due to gastric ulcers	Chronic constipation, rectal prolapse,	1 hr	No
25	M	U/W	Thrombosis of small bowel	Recurring bowel obstruction	1 month	Anticonvulsant
30	F	U/K	Necrosis with ileum herniated through sigmoid colon	U/K	4 hrs	Antipsychotic
32	M	Healthy	Necrosis with tear in sigmoid colon	Feeding problems, no teeth	15 hrs	U/K
37	F	Healthy	Megacolon and volvulus	Chronic constipation (20 yrs)	2 hrs	No
44	M	Healthy	Acute colitis due to infection	U/K	24 hrs	Anticonvulsants
69	F	U/W	Gastric volvulus	Chronic constipation, Rectal prolapse	3 hrs	Antiparkinsonian (anticholinergic)
85	M	U/W (BMI 16)	Bleeding duodenal ulcer	Heart disease	1 hr	No

Key: U/W = Underweight U/K = Unknown

**Table 10: Summary of the deceased who drowned in baths or showers**

Age	Place of death	Intellectual Disability	Speech	Mobility	Service type
26	Bath	Mild	Complex	Independent	Large Residential Centre
28	Bath	Severe	Limited	Wheelchair	Group Home
29	Bath	Severe	Limited	Walking aid	Group Home
41	Bath	Profound	None	Totally dependent	Group Home
51	Shower	Severe	Limited	Unknown	Mini Residential Centre

<sup>51</sup> Paralytic ileus is a condition in which the normal contractile movements of the intestinal wall temporarily stop.

---

## References

Accardo, P. Whitman, B. 1996 *Dictionary of Developmental Disabilities Terminology* MacLennan & Petty: Sydney.

Ageing and Disability Department, 1995 *Specialist Disability Services, Priorities and Partnerships - 1996 to 1998*, NSW Government: Sydney.

Ageing and Disability Department, *Commonwealth/State Disability Agreement – NSW Minimum Data Set Collection 1995 and 1998 Summary Reports*, NSW Government: Sydney.

Ageing and Disability Department, 1998 (revised 1999) *Standards in Action*, NSW Government: Sydney.

Ageing and Disability Department, 1999 *Annual Report 1998-99*, NSW Government: Sydney.

Audit Office of New South Wales and Community Services Commission, 1997 *Performance Audit Report: Large Residential Centres for People with a Disability in NSW*, NSW Government: Sydney.

Australian Bureau of Statistics (ABS), 1995 *Australian Social Trends*, Commonwealth of Australia: Canberra.

Australian Bureau of Statistics (ABS), 1996 *Census*, Commonwealth of Australia: Canberra.

Australian Bureau of Statistics (ABS), 1998 *Disability, Ageing and Carers: Summary of findings, Australia*, Commonwealth of Australia: Canberra.

Australian Bureau of Statistics (ABS), 1999 *Causes of Death Australia 1998*, Commonwealth of Australia: Canberra.

Australian Institute of Health and Welfare (AIHW), 1996 *The Demand for Disability Support Services in Australia*, Commonwealth of Australia: Canberra.

Australian Institute of Health and Welfare (AIHW), 1999 *Workshop for the development of key disability data elements for inclusion in the National Community Services Data Dictionary*, Commonwealth of Australia: Canberra.

Beange, H. Taplin, J.E. 1996 'Prevalence of intellectual disability in Northern Sydney adults', *Journal of Intellectual Disability Research*, 40:3, 191-7.

- Carter, G. Jancar, J. 1984 'Sudden Deaths in the Mentally Handicapped', *Psychological Medicine*, 14: 691-5.
- Cole, G. Neal, J. W. Fraser, W.I. Cowie, V.A. 1994 'Autopsy Findings in Patients with Mental Handicap', *Journal of Intellectual Disability Research*, 38: 9-26.
- Community Services Commission, 1997 *Report on Nutritional and Mealtime Practices*, NSW Government: Sydney.
- Community Services Commission, 1998 *Respite Care – A System in Crisis*, NSW Government: Sydney.
- Community Services Commission, 2000 Submission to The NSW Parliament's Legislative Council's Standing Committee on Social Issues' *Inquiry into Residential and Support Services for People with a Disability*.
- Decker, C.J. 1993 'Pica in the mentally handicapped: a 15-year surgical perspective', *Canadian Journal of Surgery*, 36 (6): 551-4.
- Department of Community Services Memorandum, 1994 SPS-26 *Advice to Community Services' Commissioner of Deaths of Children and Adults in the Care of the Department*, NSW Government: Sydney.
- Department of Community Services, 1999 *Dysphagia Action Plan*, NSW Government: Sydney.
- Devinsky, O. 1994 *A guide to understanding and living with epilepsy*, F.A. Davis Company: Philadelphia.
- Dormans, J.P. Pellegrino, L. (eds) 1998 *Caring for children with cerebral palsy: a team approach*, Paul H. Brookes Publishing Co: Baltimore, Maryland.
- Durvasula, S. Beange, H. (in press) 'Health Inequalities in People with Intellectual Disability: Strategies for Improvement', *Health Promotion Journal of Australia*.
- Epilepsy Foundation of Victoria, 2001 *Epilepsy Information Sheets*.
- Evans, P.M. Alberman, E. 1990 'Certified cause of death in children and young adults with cerebral palsy', *Archives of Disease in Childhood* 65: 325 – 329.
- Eyman, R.K. Grossman, H.J. Tarjan, G. Miller, C.R. 1987 'Life expectancy and mental retardation. A longitudinal study in a state residential facility', *Monographs of the American Association on Mental Deficiency* (7): 1-73.
- Fehlow, P. Walther, F. Miosge, W. 1995 'An increased incidence of megacolon in psychiatric and neurologic patients', *Nervenarzt* 66(1): 57-9.
- Forsgren, L. Edvinsson, S.O. Nystrom, L. Blomquist, H.K. 1996 'Influence of epilepsy on mortality in mental retardation: An epidemiologic study', *Epilepsia* 37(10): 956 – 63.

- Fryers, Y. 1984 *Mortality and cause of death*, London Academic Press: London.
- Hauser, W.A. 1997 'Mortality in Patients with Epilepsy', *Proceedings of the 22<sup>nd</sup> International Epilepsy Conference, 29 June 1997*, Columbia University: New York.
- 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.
- James, D.S. Bull, A.D. 1995 'Death certification: is correct formulation of cause of death related to seniority or experience?', *Journal of the Royal College of Physicians of London*, 29 (5): 424-8.
- Jancar, J. Speller, C.J. 1994 'Fatal intestinal obstruction in the mentally handicapped', *Journal of Intellectual Disability Research*, 38 (Pt 4): 413 - 422.
- Langmore, S. Terpenning, M. Schork, A. Chen, Y. 1998 'Predictors of Aspiration Pneumonia: How Important is Dysphagia?' *Dysphagia*, 13:69-81.
- Lennox, N.G. Cook, A. Diggins, J. 1997 'Caring for adults with intellectual disabilities', *Modern Medicine*, (3) 79-87.
- Lennox, N.G. Diggins, J. (eds), 1999 *Management Guidelines: People with Developmental and Intellectual Disabilities*, Therapeutic Guidelines Limited: Victoria.
- Maclaine, G.D.H. Macarthur, E.B. Heathcote, C.R. 1992 'A comparison of death certificates and autopsies in the Australian Capital Territory', *Medical Journal of Australia*, 156(7): 462-8.
- Meyer, L. Evans, I. 1994 *Nonaversive Intervention for Behaviour Problems, A Manual for Home and Community*, Paul H Brookes: Baltimore 1994.
- Multicultural Disability Advocacy Association, 2000 *Access of People with a Disability from non-English Speaking Backgrounds*, MDAA: Sydney.
- New South Wales Parliament, Legislative Council's Standing Committee on Social Issues, 1997 *Caring for the Aged*, Standing Committee on Social Issues, Report No. 14, NSW Parliament: Sydney.
- Nielsen, G.P. Björnsson, J. Jonasson, J.G. 1991 'The accuracy of death certificates' *Pathological Anatomy and Histopathology*, 419:143-6.
- Patja, K. Iivanainen, M. Vrsala, 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.
- Peach, H.G. Brumley, D.J. 1998 'Death Certification by Doctors in non-metropolitan Victoria', *Australian Family Physician*, 27(3): 178-82.

Pellock, J. Hunt, P. 1996 'A decade of modern epilepsy therapy in institutionalised mentally retarded patients', *Epilepsy Research*, 25:263-8.

Strauss, D. Eyman, R.K. 1996 'Mortality of people with mental retardation in California with and without Down Syndrome, 1986 - 1991', *American Journal on Mental Retardation*, 100 (6): 643-53.

Strauss, D. Shavelle, R. Baumeister, A. Anderson, T.W. 1998 'Mortality in persons with developmental disabilities after transfer into community care', *American Journal of Mental Retardation*, 102 (6): 569 - 81.

Strauss, D. Shavelle, R. Anderson, J.W. Baumeister, A. 1998 'External causes of death among persons with developmental disability: The effect of residential placement' *American Journal of Epidemiology*, 147 (9): 855 - 62.

von Konigsmark, M. 1999 'An extra D in DD' *Presented at the Australian Society for the Study of Intellectual Disability, 35<sup>th</sup> Annual Conference: Sydney.*

Victorian Department of Human Services, 2000 *Seventh Annual Report of the Medical Committee on Client Mortality (Intellectual Disability) - 1997*, DisAbility Services Division, Victorian Department of Human Services: Melbourne.

Yeatman, A. 1996 *Getting Real - The Final Report of the Review of the Commonwealth/State Disability Agreement*, Commonwealth Government: Canberra.

---

## Glossary

ABS	<b>Australian Bureau of Statistics</b>
ADD	<b>Ageing and Disability Department, NSW</b>
AIHW	<b>Australian Institute of Health and Welfare</b>
ATSI	<b>Aboriginal and Torres Strait Islander</b>
BD&M	<b>NSW Registry of Births, Deaths and Marriages</b>
BMI	<b>Body Mass Index</b>
COAD	<b>Chronic Obstructive Airways Disease</b>
CPR	<b>Cardio-pulmonary Resuscitation</b>
CSC	<b>Community Services Commission</b>
CSDA	<b>Commonwealth State Disability Services Agreement</b>
CSDA MDS	<b>CSDA, Minimum Data Set</b>
DDRT	<b>Disability Death Review Team</b>
DoCS	<b>Department of Community Services, NSW</b>
DSA	<b><i>NSW Disability Services Act 1993</i></b>
ICD	<b>World Health Organisation's International Classification of Diseases</b>
LRC	<b>Large Residential Centre</b>
MRC	<b>Mini Residential Centre</b>
NESB	<b>Non English-speaking background</b>
NGO	<b>Non-Government Organisation</b>
YACS	<b><i>NSW Youth and Community Services Act 1973</i></b>