Health and Community Services
COMPLAINTS COMMISSION

INVESTIGATION REPORT

Investigation into complaint by
North Australian Aboriginal Justice Agency
about the care provided to
Ms N by
Department of Health and Community Services, the Public Guardian and Council.

27 June 2013

1. EXECUTIVE SUMMARY

In 2007 the HCSCC commenced an investigation into the standard of care provided to Ms N, a woman from Arnhem Land. Ms N had an intellectual disability, a physical disability and epilepsy. She lived in a remote NT community and was the subject of Adult Guardianship Orders, under which Adult Guardians and the Public Guardian were appointed to make decisions on her behalf.

Over a period of two decades, Ms N was under the care of the Department of Health and Community Services who provided and funded disability services, the local Council who provided support and respite services, and the local health clinic. At various times she also received a range of other services including from hospitals and mental health providers.

Despite the number of players involved in Ms N's care, the investigation has shown that there were significant shortcomings in the management of her care; ongoing concerns about her safety and well-being that were not addressed; deficiencies in support systems; and other issues of serious concern surrounding provision of everyday care to Ms N. All of these shortcomings were well known to the service providers from at least 1993 up until her death in 2006.

The investigation has concluded that service providers failed to meet the requirements of the NT Disability Service Standards in their delivery of services to Ms N. Systemic failings were identified in relation to individual planning of services; coordination and communication between service

providers and guardians; adequacy of safeguards; and level of service provided.

The Council did not deliver services in line with the relevant service agreements or individual plans for Ms N. It did not maintain records or communicate adequately with other relevant parties.

The DHCS failed to adequately monitor service providers that it contracted and funded to ensure they delivered services to Ms N at an appropriate standard. It failed to forward plan for Ms N or to visit regularly to monitor her well-being.

The Office of the Public Guardian failed to make decisions and effectively advocate to secure for Ms N delivery of consistent service at an acceptable standard. It failed to communicate adequately with Adult Guardians and service providers, and to report issues of suspected abuse to police.

The Health Clinic failed to report suspected abuse to police, and to communicate adequately with Guardians or the DHCS concerning Ms N's health, care and circumstances.

It appears that there were no consequences for any of these organisations for their failures.

Noting the length of time that has passed since Ms N's death, the Commissioner acknowledges that circumstances may have changed with respect to the delivery of care services to persons with disabilities in remote

communities. However in light of the systemic failures identified in this investigation over two decades, a real and significant potential risk to a cohort of our most vulnerable community members cannot be excluded based on simple assurances of change.

Recommendation

As a result, it is recommended that a comprehensive and independent inquiry be undertaken to determine whether care provided to people with disabilities in remote communities has improved since Ms N's death in 2006, or whether their safety, well-being and dignity remains at serious risk as a result of the same systemic failures that had such a tragic impact on Ms N's life.

2. AUTHORITY

1. By letter dated 26 October 2006, the North Australian Aboriginal Justice Agency ("NAAJA") made a complaint about services provided to Ms N and requested that the Health and Community Services Complaints Commission conduct an investigation into her care. Enquiries were made with the then Department of Health and Community Services ("DHCS") and in March 2007 the Health and Community Services Complaints Commissioner determined to investigate the complaint ("the Investigation").

Section 48 (1) of the *Health and Community Services Complaints Act* ("the Act") provides:

> *The Commissioner may, as he or she thinks fit, investigate*
> *(a) any matter referred under section 20 (1) or 21 (1);*
> *(b) a complaint that the Commissioner has decided to investigate under section 27; or*
> *(c) an issue or question arising from a complaint or a group of complaints if it appears to the Commissioner*
> *(i) to be a significant issue of public health or safety or public interest; or*
> *(ii) to be a significant question as to the practice and procedures of a provider.*

2. This investigation was carried out pursuant to section 48(1)(c)(i) and (ii) of the Act - the complaint raised significant issues of a public health or safety or public interest; and raises significant questions as to the practice and procedures of a provider.

The investigation was to consider whether:

- the standard of care and treatment provided to Ms N was reasonable in the circumstances and in accordance with legislation and/or service standards,
- the communication and care-coordination between all parties was reasonable in the circumstances, and
- there were systemic issues that needed review.

3. PROGRESS OF THE INVESTIGATION

3. The Investigation was commenced in 2007, however due to the Commissioner's limited resources, the finalisation of the Investigation and Report became significantly delayed. On 22 July 2010 the then Commissioner authorised Ms Raelene Webb QC, assisted by Ms Elizabeth Armitage, to complete the Investigation pursuant to section 50(1) of the Act. The Investigation was progressed following the appointment of the current Commissioner in September 2010.

4. In January 2012 comments were sought from relevant parties on factual aspects of the report only. Following further investigation a complete draft of the report was circulated for comment to respondent organisations in December 2012. Responses were received from the Department of Health and Office of the Public Guardian and further consultation with NAAJA occurred between April and May 2013. The final report on the Investigation was provided to parties on 27 June 2013.

5. The Commissioner acknowledges the significant delay in finalising this Investigation and on behalf of the HCSCC apologises to the parties

concerned for the time taken to review the circumstances leading up to Ms N's death.

6. During the course of the Investigation records were obtained from DHCS, the Office of the Public Guardian, NAAJA, the relevant Health Clinic, Gove District Hospital and Royal Darwin Hospital. Although requested, no records were received from the relevant Community Centre (Aged and Respite Service)(the "Respite Centre") or Council (the "Council") as the Commission was advised that the relevant computer and paper work had been discarded. No information was received in response to a Notice to Produce.

7. Interviews were conducted with staff from DHCS, the Health Clinic, the Respite Centre, NAAJA, and the Office of the Public Guardian.

8. This version of the report has been amended prior to publication in an effort to protect the identity of Ms N.

9. The background of events that follows is as comprehensive as the information available to the Investigator allows.

4. BACKGROUND

10. Ms N was born on 3 May 1973 and lived most of her life in an Aboriginal Community in Arnhem Land. Ms N had an intellectual and physical disability and also suffered from epilepsy. Ms N's seizures commenced when she was 5 months old and significant developmental delay was identified at 4 years of age. In 2001 an MRI scan revealed that Ms N had

mesial sclerosis, a brain lesion, which was the likely cause of her epilepsy and intellectual disability.

11. Ms N died on 15 October 2006. The cause of death was recorded as leukaemia and ischaemic stroke of the left cerebral artery. It is not suggested that the circumstances outlined in this report were direct causes of her death.

12. Ms N's older brother suffered from chronic schizophrenia and Ms N's mother suffered from a chronic medical condition. There were therefore competing and concurrent demands on Ms N's extended family to provide care to a number of family members.

13. In her adult life and up until her hospitalisation in mid-August 2006, Ms N mainly lived at her stepfather's house or with other relatives in her community.

14. Throughout most of her adult life Ms N was the subject of Guardianship Orders pursuant to Adult Guardianship Act. Ms N was first placed under a Guardianship Order on 15 February 1994. The Orders were reviewed and varied from time to time as the legislation or her circumstances required.

15. At the time of her death, Ms N was subject to a Guardianship Order which commenced on 16 June 2004 and was due for review in June 2006. The Guardianship Order appointed family members as joint Adult Guardians. It gave authority to the joint Adult Guardians and the Public

Guardian to make decisions concerning Ms N's health care, accommodation and day to day care. The Public Guardian also had authority to manage the finances and estate of Ms N.

16. The Public Guardian was required to notify all "interested parties" as to the existence and terms of a Guardianship Order. On 7 January 2005 letters were sent to the Adult Guardians, the Health Centre, the Health Clinic, the Aged and Disability Services Manager DHCS, and Gove District and Royal Darwin Hospitals, informing them of, and enclosing copies of, the Guardianship Order. Accordingly, the existence and scope of the Guardianship Orders was well known.

5. HISTORY OF CARE

1993

17. In November 1993 Ms N was admitted into Gove District Hospital as a form of crisis intervention due to lack of respite support for her family. A Community Nurse requested an assessment and review of Ms N's current social situation. The Community Nurse's report was later forwarded for consideration by the Local Court in Ms N's first Adult Guardianship hearing. This report contains the following observations, which remained relevant throughout the history of Ms N's care:

"Lack of respite facilities available for (Ms N) has meant that the family have had little support in caring for (Ms N).

Over recent years the relationship between (Ms N) and her family has led to the situation where (Ms N) is now being abused physically on a regular basis.

The Community Health Centre report they have treated (Ms N) for burns when boiling water was thrown over her, and cuts requiring stitches from fights with family and being bashed with sticks or clubs….

Community and family members do not feel equipped to manage (Ms N) when she exhibits manipulative or aggressive behaviours.

The family are finding it more difficult to care for (Ms N). Both her parents are aging and her mother now suffers from chronic physical illness.
Attempts to care for (Ms N) at the family outstation have not been successful...

Care by relatives is inconsistent as the person who shows the most responsibility …has many responsibilities working in the community council…

I have had some discussion with (…) at the Office of Adult Guardianship. I think it is important that he is involved as it appears that the environment that (Ms N) now lives in as it stands must be breaching basic human rights and this is the concern of the Adult Guardian.

Support facilities in (…) Arnhem for people suffering mental impairment is practically zero. On paper there is an (…) Arnhem Adult Assessment team but this consists of one very overworked occupational therapist who already has an overloaded caseload.

Community programs have not been successful….(Ms N) requires assistance with the basic cares, hygiene, food and clothing. At this point in time no one in

(her community) is willing to take on this level of care and her immediate family are becoming too old.

…due to bed shortages and staffing, respite generally is not possible.

Staff are not capable of managing (Ms N) at GDH (Gove District Hospital) as no one is trained in behavioural management…

There are no practical supports available in (her community) other than the Community Health staff.

I do not think for reasons of basic human dignity that it is appropriate to ignore this particular case or continue to shuffle responsibility from one department to another because of the degree of difficulty in providing support."

18. In December 1993 staff at Gove District Hospital complained that they were unable to manage Ms N's behaviour. Staff who were not trained in behavioural management, had difficulty managing Ms N's challenging behaviours which included physical violence and sexual disinhibition. Accordingly, Ms N was transferred to the psychiatric unit (Cowdy Ward) of Royal Darwin Hospital for respite care and assessment. On admission into Royal Darwin Hospital her physical condition was considered poor and her behaviour was considered difficult to control.

1994

19. A temporary Guardianship order was obtained on 15 January 1994.

20. Whilst at Cowdy, Ms N was not diagnosed with any mental illness, so she was returned to the community on 18 January 1994.

21. On 27 January 1994, shortly after her return to her community, Ms N was re-admitted into Gove District Hospital with uncontrolled seizures. It was apparent to hospital staff that upon her return to the community Ms N's care had been neglected. She had not received her anti- convulsant medication, her hygiene was poor, and she was reportedly discovered by family members naked behind the community store with several men nearby. Family members reported that they were concerned that she had been sexually assaulted.

22. Ms N was again transferred from Gove District Hospital to Cowdy Ward due to her challenging behaviours and Gove District Hospital did not have the power to restrain her. An application to have her detained under the Mental Health Act was declined as she was not assessed as suffering from a mental illness.

23. Ms N spent approximately 7 weeks in Cowdy Ward.

24. In a letter dated 14 February 1994 prepared for the Guardianship hearing, a Senior Psychiatrist reported that "without a court order, the care we can offer is little better than no care at all".

25. In a report dated 14 February 1994 prepared for the Guardianship hearing, the District Medical Officer (DMO) noted that whilst in Cowdy Ward, Ms N:

(i) Repeatedly absconded - on one occasion she was struck by a car and on another she was found in a stranger's house, and

(ii) Was frequently violent with patients and staff.

The DMO concluded that it was not appropriate for Ms N to remain at Cowdy Ward as she was not suffering from a mental illness. However, no alternative care could be identified for Ms N.

26. A treating Psychologist prepared a Psychological Report dated 13 February 1994 for the Guardianship hearing. The Psychologist reported that "at a recent meeting her family indicated they felt they could no longer cope with her". He noted that while there was obvious concern for Ms N, the family lacked the adequate skills or resources to match their concern. The Psychologist records that the recent respite was precipitated by Ms N being found naked in proximity with a number of men. The situation resulted in a curse being put on the family home so the family lived in a tent while negotiating for the curse to be removed.

27. The Psychologist records that whilst in Cowdy Ward Ms N punched and kicked staff, disturbed fellow patients, and absconded. Her behaviour was considered to be "highly challenging". He noted that although "Cowdy Ward was not a rehabilitation centre for individuals from a different cultural background with multiple, although obscure disabilities, (it) established a program which constructively engaged Ms N to a greater degree than had been achieved in her home community".

28. The Psychologist concluded that Ms N had a significant intellectual disability which was most obvious in the area of social intelligence and

that this left her confused and frustrated. He thought that Ms N was consistently under-challenged in what she was capable of. Her behavioural issues resulted from a lack of stimulating and challenging activities.

29. The Psychologist considered that Ms N was "at risk as well as being a danger to others" but noted that there was no-one in her community or Darwin who was able to exercise a restraining influence on her risk behaviours without resorting to physical restraint.

30. The Psychologist made the following further observations concerning Ms N's circumstances:

> *"Without specialist input family support is ad hoc and takes place within the context of a variety of community problems such as substance abuse, domestic violence etc. Often individuals were left under-challenged, vulnerable to abuse with escalating social and psychological problems which, in turn, contribute to the larger community problems. At regular crisis points attempts to engage outside services generally flounder because of existing services not having the legislative brief nor the expertise to deal with the problems. This is the context of (Ms N)'s current referral to the Adult Guardian."*

31. Following the appointment of the Public Guardian on 15 February 1994, the OPG focussed on finding suitable accommodation for Ms N. As there were no existing services available to take Ms N, DHCS negotiated with Anglicare to provide a house and carers in Darwin for a period of 6

months. It was intended that Ms N would return to the community at the end of the contract. The 6 month contract was provided at a cost of $77,000.

32. In April 1994 the OPG obtained an opinion from a lawyer from the Solicitor for the Northern Territory, as to the OPG's duty of care to Ms N, especially concerning her "absconding". The OPG considered that Ms N's absconding placed her at risk. The OPG was advised that its duty of care was to "*take reasonable steps to ensure (Ms N)'s safety by deciding for her where and with whom she should live…The continuing duty as to what to do when she leaves depends on the Public Guardian's assessment of the risk factors (neglect, abuse or exploitation) weighed against the positive factors (development of skills and assistance to become capable of making reasonable judgements for herself).*"

33. The opinion also touched on a guardian's decision making processes and duties. The opinion noted that the:

> *"….intention of the (Adult Guardianship) Act therefore seems to be that a guardian appointed for the narrow purpose of assisting a person to make decisions relevant to daily living…(is) to have regard to the wishes of the person as well as their protection".*
>
> *"…it is necessary to recognise that the law required the Public Guardian (as it requires any reasonable person) to consider what the relevant issues area and make decisions based on the facts. There is no duty at law to be 'right' basically because in most cases there is no 'right answer'".*

> *"A guardian is appointed to make daily living judgments for a person who is unable to make such decisions due to an intellectual disability. The focus of the guardian's duty is therefore on decision making.*
>
> *In determining the scope of the guardians powers under the legislation the guardian has to assess the mental capacity of the person…..In this case, (Ms N) apparently has the mental capacity of a 12-13 year old. It is therefore not appropriate to treat her as if she were a 4 or 5 year old."*

34. The opinion highlighted the complexity of decision making for Ms N. It noted there were *"serious competing considerations" and "pros and cons in every way you may proceed. At the end of the day you (the Public Guardian) need to adequately weigh all those risks and benefits to make a decision."*

35. The opinion noted that Ms N's behaviours required the full time attention of one Guardianship Officer leaving only one other Guardianship Officer to deal with the remaining 46 OPG clients. It was noted that "this situation is clearly unacceptable based on the resources available to the OPG at the moment."

36. A Delegate of the Public Guardian prepared a report dated 31 August 1994 for a Guardianship Order review. The Delegate noted that from the commencement of Ms N's placement, Anglicare experienced problems. Ms N exhibited aggressive outbursts and sexual disinhibition, she left her residence and consumed alcohol. Attempts to persuade Ms N to return to her flat were met with aggressive or self-injurious behaviours. Over time it was noted that Ms N became more cooperative and her

health improved, however, the challenges presented by her behaviour did not cease. The Delegate concluded that Ms N was at risk if she remained in Darwin because it was impossible to prevent her from leaving her flat.

37. Throughout her placement with Anglicare, Ms N maintained contact with her family and persisted in expressing a desire to return to her community. Arrangements were made for that to occur in September 1994. It was agreed that Ms N would live with and receive care from family members who were also her Adult Guardians. Ms N's family members indicated they were willing to protect Ms N from sexual and physical abuse. It was planned that respite would be provided for Ms N in Darwin every 3 months. (However, the Investigation did not identify any evidence that this occurred.)

1995

38. In September 1995 Ms N was admitted into Royal Darwin Hospital for skin grafts following burns to her hand from a camp fire; it is not known if this occurred through neglect or deliberate act. On 4 October 1995, the Director of Nursing reported that Ms N was aggressive to staff, refused to eat or drink, and had to be restrained and heavily sedated to prevent her removing bandages. Urgent assistance with her care was requested from Rural Mental Health Services.

39. On 2 October 1995 the Senior Adult Guardianship Officer provided a report to DHCS. The report was prepared while Ms N was still hospitalised. The Adult Guardianship Officer raised concerns about Ms

N's future care and return to her community. The Adult Guardianship Officer:

(i) Requested that DHCS investigate the circumstances of Ms N's burns as it was thought that they may not have been accidental.

(ii) Expressed her concern that Ms N was at risk from abuse and sexual exploitation as the "community guardians were not doing their job".

(iii) Noted that respite in Darwin was not successful because Ms N was at risk through continuous "absconding" and requested that other options for respite be considered; and

(iv) Requested that a case manager be appointed to, inter alia, develop a plan of management and respite for Ms N.

The response to this report is not known.

1996

40. DHCS Mental Health Services documented a day visit to Ms N in her community on 21 February 1996. The visit was requested by the OPG. The visiting doctor, whose name could not be identified from the records, reported that Ms N's home was unhygienic, overcrowded and without adequate bedding. The doctor was unable to identify anyone who was providing supervision to Ms N and noted she was receiving minimal assistance. When invited to comment on the history as set out in this report, DHCS noted that, whilst the living conditions experienced by Ms N were poor, they were not unusual and similar conditions were typical of many homes in the community at that time.

1997

41. DHCS internal memoranda document the following:

(i) 26 June 1997 from a report entitled: "Findings to date from assessment by Disability Resource Unit at (Ms N's community), 23-27/6/97" prepared by (…) Manager, Disability Resource Unit.

"(Ms N)'s hygiene and self- care needs cannot be met..
(Ms N) is the victim of physical assault..
(Ms N) is essentially homeless…
She sleeps in the street with dogs..
She is reported to be having seizures..
(Ms N) does not have regular meals..
(Ms N) is not having regular showers..
She is usually dirty and dishevelled..
It is believed she is being sexually exploited..
(Ms N) is at extreme risk.."

(ii) 30 July 1997- in support of a Pilot Project for a community based Aged and Disability Program, the Senior Management Behaviour Training Officer, reported to the General Manager Arnhem District as follows (extracts):

Rationale

"Care for (Ms N) as outlined in the Challenging Behaviours Support Unit assessment, 1994, is not being provided. (Ms N) is essentially homeless, and there are immediate grave concerns for her health and safety. (Ms N) is under a Guardianship Order. The obligations of that order for her care are not being met.

Owing to the lack of adequate support in (her community), (Ms N)'s circumstances frequently reach crisis stage. She has been evacuated to GDH four times in the last 6 months.

If services are not provided to (Ms N's community) so as to be able to meet (Ms N)'s needs more adequately, the likely scenario is repeated evacuations and the deterioration of (Ms N)'s condition so that she will require permanent placement in supported accommodation."

Memo

"Following DRU's (Disability Resource Unit's) visit to (Ms N's community) in June, it was evident the community could no longer support (Ms N) through the use of informal support systems ie. Family, clinic and other community based generic services. The respite service was overwhelmed by the prospect of providing services to Ms N without skilled support.

On (Ms N)'s return to (her community) following a week of crisis respite, DRU in conjunction with concerned community members developed an interim support plan. The plan was developed as a stop gap measure until such time as the formal supports required by (Ms N), identified by DRU in the draft proposal, were implemented.

The interim support plan is no longer effective. It was identified early in the development of the interim support plan that the degree of support provided by those involved was unlikely to be sustained for any significant period due to the challenges one is confronted with in providing support to (Ms N). This is why

an Aged Disability Community Worker was identified as the only community based solution likely to achieve any durable outcomes to what has been a longstanding duty of care issue.

The community Council President ..described the situation as 'very bad' and that 'everybody is very angry that nothing has happened'…community tolerance of the situation is again at crisis point. The Council has received numerous complaints regarding (Ms N)'s well-being. Given the expense and associated risks of absconding further respite in Darwin is inappropriate and addresses only the symptoms as opposed to the cause of the problem.

It is important that we prioritise implementation of the pilot project or seek supported accommodation elsewhere. It is the consensus of DRU staff and the community members involved with (Ms N) that she is again at risk and likely to require crisis evacuation.."

42. It is noted that the Disability Resource Unit was a Darwin based service which was not funded to provide outreach services to communities.

43. On 11 August 1997 the Adult Guardianship Officer documented an urgent meeting between the OPG and members of the DRU. The Adult Guardianship Officer noted:

"The situation for (Ms N) has worsened and a crisis point has been reached – her health and welfare continue to be at risk and the (…) community is fast getting to the point of saying ENOUGH and are intolerant of the perceived lack of action on the part of Territory Health Services. The President has complained strongly that nothing has been done for (Ms N).

…I cannot stress enough the importance of the need for immediate action in providing the support that (Ms N) requires. I must also advise that the Public Guardian may be viewed as negligent if the perceived inaction continues."

44. The DRU acted on the "Pilot Project". The Pilot Project directly acknowledged that "the family and community carers were unable to meet Ms N's needs because of overwhelming additional demands on them, lack of appropriate training, and insufficient professional support." By employing a trained Aged and Disability Support Worker for Ms N's community it was intended to develop models of support for aged people and people with disability who lived in remote communities. It was envisaged that the Pilot Project would be developed in stages. Stages 1 and 2 were to focus on the development and implementation of an individual support plan for Ms N, her care coordination and support for her respite services. The Pilot Project further identified 31 residents who met the criteria as "frail and aged" in Ms N's community and who required care. It was envisaged that stage 3 of the Pilot Project would focus on the needs of up to three other individuals. Although the Pilot Project was to be reviewed, the results of any review were not provided to the Investigation.

1999-2003

45. Thereafter care continued to be provided to Ms N by the Respite Centre and the Health Clinic (the "Health Clinic"). From 1999 through to 2003 records from DHCS indicate that the care provided was detailed in a "support program" and was paid for by "challenging behaviour

funding". Although detailed information concerning this period was not provided, DHCS reports describe the care as having "degrees of success". In its response to the draft report, the OPG advised that during this period, due to regular visits from the case manager and funding to the Council, Ms N's care was considered relatively stable.

2003

46. In 2003 Ms N's circumstances again deteriorated. DHCS progress notes reveal that over a period of 6 months there were increasing incidents of Ms N not receiving her medication. Her health suffered and she was evacuated to Gove District Hospital.

47. During mid-2003 the Health Clinic progress notes documented the following interventions:

    (i) On 25 May Ms N was picked up at the school. She was unwashed, and experiencing a seizure because she had not received her medication; and

    (ii) In June 2003 phone calls were made to DHCS to report that Ms N was not getting looked after, no-one was getting paid to look after her, she was "unkept (sic)" and "humbugging".

    The OPG advised that there were not alerted to either of these events by the Health Clinic.

48. Gove District Hospital medical records document admissions into Gove District Hospital during 2003 on:

    (i) 23 - 28 April for respite care. At that time, it was recorded that she had scabies and head lice. (DHCS reported that scabies and

head-lice are often associated with poor housing and overcrowding, and are seen in hospital admissions from remote communities.) The OPG was notified of this admission by the Health Clinic and informed that respite workers "had not been around".

(ii) 4 - 9 August for "neglect" and possible non-compliance with anti-convulsant medications. The records document "nits++" and a fungal infection in both legs. Hospital progress notes refer to Ms N as a "very neglected woman". The notes record "No-one takes responsibility or accountability for her. Went for 6 days without medication and only recommenced because Health Clinic harassed family after Ms N brought to the Health Clinic after fitting episode. Gets washed approximately every 2 weeks." On 6 August 2003 the OPG was notified of this admission by the hospital. In response to the notification, the OPG contacted the officer from Northern Territory Disability Services, and were reassured that the "Respite Centre is more organised", "there were new nurses in the Health Clinic" and medications were being supervised by a respite worker.

49. The OPG advised that in June 2003 an officer from Northern Territory Disability Services and a local doctor alerted them that Council was not paying the respite workers. Both the officer from Northern Territory Disability Services and the local doctor told the OPG they had raised the matter with the Council and the officer from Disability Services further advised that she intended to visit Ms N's community on 9 and 10 July 2003.

50. In August 2003 an officer from Northern Territory Disability Services prepared an "Individual Lifestyle Overview" as part of an "Individual Community Support Package Funding Application". The officer reported that the lack of a consistent carer and staff changes at the Respite Centre and the Health Clinic were possibly causing the breakdown in Ms N's care.

The 2003 Lifestyle Plan

51. The DHCS Case Manager was based in Arnhem Land and she travelled by road or light aircraft to Ms N's community and other remote communities which she served. She was employed as a Case Manager for the community by the Arnhem Aged and Disability Services team from August 2003 – August 2006.

52. The DHCS Case Manager was interviewed as part of the Investigation. She described her role as Case Manager in the following terms: "I was required to travel to different communities to liaise with health clinics, councils, respite services, to co-ordinate the care needs of the client, to determine the best care needs…Whatever the issues with any of the clients be they aged or disabled, I was the main point of contact."

53. In August 2003, in response to problems identified with Ms N's care, the DHCS Case Manager developed an "Individual Lifestyle Options Plan" (the "Lifestyle Plan") to identify RN's care needs.

54. The Lifestyle Plan developed by the DHCS Case Manager remained in force until Ms N's death and was to be subject to review.

55. The Lifestyle Plan identified Ms N as having:

    (i) Moderate intellectual disability.

    (ii) A physical disability.

    (iii) Challenging behaviours including self-mutilation, hitting people, throwing rocks, and verbal abuse; and

    (iv) Epilepsy.

56. The Lifestyle Plan identified the following services as necessary to meet Ms N's care needs:

    (i) 9 hours of support each week, being one hour each Monday – Friday and two hours each Saturday and Sunday.

    (ii) The employment of "regular" people to give medication each evening Monday to Friday, and each morning and afternoon on Saturday and Sunday.

    (iii) The provision of a meal each evening or afternoon when the "regular" person attended with Ms N's medication; and

    (iv) A roster of care "to ensure it happens".

57. A goal of the Lifestyle Plan was to ensure that the services provided would "assist Ms N to live in a non-institutionalised setting".

58. The Lifestyle Plan acknowledged that "regular liaison by the DHCS Local Area Coordinator, the Respite Centre and the Guardianship Board" would be required, and to this end monthly meetings were to

occur "to ensure her health as well as her physical well-being is being looked after".

59. DHCS were to pay the Council $13,200 per annum to fund the identified services for Ms N. Grant funding in the sum of $19,319.30 per annum was also paid to Council for the Respite Service to provide services to young people with a disability in the community.

Service Agreement Between DHCS and Council 2004 - 2006

60. As noted above, the Council received block and individual funding from DHCS to provide services in the community to DHCS clients. The Council agreed to provide services for Ms N pursuant to an agreement in force between 1 January 2004 and 30 June 2006 (the 'Service Agreement'). Schedule 2 to the Service Agreement outlined the services to be provided to Ms N and identified a performance measure for each service. It is apparent that Schedule 2 was intended to ensure that the care identified as necessary in the Lifestyle Plan was actually delivered to Ms N. Schedule 2 provided as follows:

Service	Performance Measure
Provision of personal care, hygiene, feeding, washing/laundry, to (Ms N) for 5 hours per week 40 weeks per year.	(Ms N) will maintain her health and hygiene and is fed each day.
Financial training to (Ms N) for 2 hours per week for 40 weeks of the year.	(Ms N) will develop and gain skills to enable her to shop at the weekly store.
Day respite service to be provided to (Ms N) at the Respite Centre.	(Ms N)'s social skills will develop and her health will be maintained through medication, monitoring and feeding.

61. The Service agreement and supporting Service Plan further required that:

    (i) The services be delivered in accordance with the NT Disability Standards and the Disability Services Act.

    (ii) Council was to provide half yearly performance reports for clients of individual funding, addressing the performance measures, to the Local Area Coordinator DHCS for Arnhem (the "LAC").

    (iii) Council would initiate regular progress meetings with the LAC, or when significant changes affected service arrangements.

    (iv) Council was to participate with DHCS in reviewing the Services to determine if it was meeting its contractual obligations. DHCS was to give 28 days notice to Council of a Service Review and could request written reports from Council; and

    (v) Council was to work in consultation with DHCS to review their service against the Disability Standards over the period of the agreement.

62. The NT Disability Standards are specified in the Northern Territory Home and Community Care Personal Care Guidelines of September 2004 (the "Personal Care Guidelines").

63. The Personal Care Guidelines applied to Council and DHCS and were intended to ensure that personal care service providers and their staff

applied and maintained appropriate standards of service. The Personal Care Guidelines also expected that care providers and staff were aware of their responsibilities in providing personal care to people with disabilities (Guideline 3). The Guidelines were designed to ensure, inter alia, that "clients receive quality personal care that best meets their needs" (Guideline 2.2).

64. Personal care is defined to include daily self-care tasks such as bathing, dressing, hair care and grooming, toileting, mobility, eating, and self-medication (Guideline 5). Many of the services identified as required by Ms N fell within the definition of personal care and the Personal Care Guidelines applied to the provision of those services.

65. Guideline 16 specifies the minimum level of training expected of Personal Carers.

66. Guideline 11 requires service providers to ensure, inter alia, that:
    (i) Staff availability is sufficient to meet the needs of clients.
    (ii) Staff are appropriately trained; and
    (iii) There is an accountable system of assessment, referral training, and supervision.

67. As to compliance with the Service Agreement and Lifestyle Plan, the Clinical Nurse Manager of the Health Clinic, told the Investigation:

> *'Her care here is atrocious, there's only so much that we can do. She's seriously neglected, she's not being fed, she's not being washed, she doesn't have clean clothes on, she doesn't get her tablets.. Nobody*

would take her because she was so much trouble and we were told blankly at the end (by Gove District Hospital) don't ask us again because we will not take her…she is just too hard. It was so sad watching this poor woman being neglected and abused that way she was but nobody would help, nobody would do anything. It would have been reported many times in the 5 years before she passed away. We would have teleconferences with respite, with (the Adult Guardianship Officer).. The family would come in and say how caring they were…and I would be sitting there and thinking that's not true…they just didn't want the responsibility of her.''

68. However, in its response to the draft report, the OPG countered that it instigated the case meetings held on 20 April 2004 and 27 January 2005 and received assurances that problems would be rectified. The OPG further claimed that the Health Clinic had failed to maintain contact with the OPG and failed to report issues and concerns relating to Ms N.

69. In an interview with the Respite Centre Manager, it was apparent that:

    (i) The Manager had none of the formal personal care qualifications and nor did any of the staff at the Respite Centre.

    (ii) She was not aware of any reporting requirements concerning the delivery of services.

    (iii) She demonstrated a limited understanding of Ms N's Lifestyle Plan. She said "I'd go round to see if she wanted to come out for the day, buy her smokes, get her food, you know take her places if need be, take her out just to, you know, get her out of the house, those sorts of things. That was my understanding of

what I was supposed to do." The Respite Centre Manager expected Ms N's family to provide significant care even in areas specifically provided for in the Lifestyle Plan. The Respite Centre Manager conceded: "I probably shouldn't have let the family take so much responsibility. Not that it was all put onto them. But I don't think I really should have let them take that much responsibility."; and

(iv) There were inadequate procedures in place when the Respite Centre Manager took leave. The Manager said: "(another officer) knew what was supposed to happen...He had the care plans so he just made sure they were done on a daily basis." However, considering cultural and gender issues, a male carer should not have provided personal care to Ms N (Guideline 13).

70. The Investigation revealed that neither the Respite Centre staff nor other paid carers took regular responsibility for Ms N's medication. Although the Lifestyle Plan provided for daily contact and was designed to ensure the daily provision of Ms N's medication and a meal, it appears there was an expectation and over-reliance on family members to meet her needs, even though it was repeatedly identified that family members were failing to provide for Ms N.

71. DHCS acknowledged that the Respite Centre was often managed by "whoever was the wife of the current builder, plumber, council staff, and so on". The Respite Centre Manager advised that none of the workers

had any formal qualifications and only received "on the job" ad hoc training.

72. The Investigation found no evidence that regular progress meetings or other formal meetings took place between Council and the DHCS Local Area Coordinator as required by the Service Agreement. However, DHCS did inform the Investigation that it was common practice for DHCS Aged and Disability Team members to visit the council and Respite Centres when they visited the community.

73. Although it was planned that a member of the DHCS Arnhem Team would visit each community every six weeks, travel records inspected in the Investigation reveal that community visits to Ms N's community were in fact much less frequent. Records provided to the Investigation indicate visits to the community on: 12 December 2005; 13 March 2006 (13 weeks between visits); 22 May 2006 (10 weeks between visits) and 10 August 2006 (12 weeks between visits). DHCS advised this was likely due to staffing shortages and recruitment difficulties.

74. Although there were reporting requirements against performance measures in the Service Agreement, there was no evidence that these were complied with. The Respite Centre Manager was not aware of the reporting requirements. It appears they were not enforced by DHCS.

75. Although the Service Agreement permitted DHCS to review contractual compliance with service delivery, there is no evidence that any such review ever took place. Further there is no evidence that DHCS ever

reviewed the delivery of service to ensure compliance with the Disability Standards.

Care in 2003 - 2005

76. Following the development of the Lifestyle Plan and the Service Agreement, problems with the delivery of care to Ms N continued.

77. The OPG provided records which documented the following interventions:

    (i) In November 2003 Ms N was fitting having not had her medication for a few days.

    (ii) On 1 December 2003 an officer from the Council phoned the OPG to advise Ms N had pulled a knife on the shop manager's wife.

    (iii) On 6 February 2004 an officer from Northern Territory Disability Services called the OPG to inform them that one of the joint Adult Guardians had taken Ms N to the Health Clinic the day before because she could not move. The OPG called the clinic and were told that Ms N had been assessed, she was "v.weak", "not eating properly", "?meds". The Health Clinic said they would monitor Ms N and the OPG would be called if her condition deteriorated. A report of a doctor for the OPG dated 27 May 2004 provided further information. The doctor noted that the Health Clinic was very worried about Ms N but that Gove District Hospital refused to admit her. Ms N was commenced on antibiotics. She worsened and a week later

could not stand. Gove District Hospital again "did not want her" so Ms N was evacuated to Darwin.

(iv) On 19 February 2004 the joint Adult Guardian called and told the OPG Ms N had gone to Darwin. The OPG called the Health Clinic and a registered nurse advised Ms N had been sent to Royal Darwin Hospital (RDH) with possible pelvic inflammatory disease and dehydration. The OPG kept in contact with staff at RDH for updates.

(v) On 29 March 2004 the joint Adult Guardian reported to the Adult Guardianship Officer that there were family arguments about Ms N who was still sleeping outside.

(vi) On 2 April 2004 the Health Clinic contacted the OPG to advise that Ms N had begun cutting her arms, that the joint Adult Guardians were not involved, and there was uncertainty as to whether she was taking her medication. It was agreed that a teleconference was needed. On 6 April the OPG spoke to the officer from Disability Services about arranging one.

(vii) On 20 April 2004 a teleconference was held. The Adult Guardianship Officer, the registered nurse, the officer from Disability Services, the joint Adult Guardian, an officer from the Council and other family members attended. It was agreed "needs more support++ discussion about how this can work".

(viii) On 12 May 2004 a woman called the OPG to advise she was the new Respite Centre Coordinator.

(ix) On 27 May 2004 a Registered Nurse at the Clinic provided a report for an upcoming Guardianship Review which did not raise any concerns about Ms N's care.

(x) On 7 December 2004 the OPG called an officer from the Council as the joint Adult Guardian had advised the OPG that Ms N owed some money to the store. The officer advised that Ms N had been going to the store, demanding food and threatening staff. She advised Ms N was given food and the OPG noted "?who is eating the food". The Council officer also advised that she had left the Council and another woman who had been involved in care had left the Respite Centre. (She gave the name of the woman she believed was managing the Respite Centre).

(xi) On 16 December 2004, the store manager rang the OPG to complain about Ms N demanding food, threatening staff and bringing knives. The Manager reported that (joint Adult Guardian) was not around and sister "takes food".

78. The Health Clinic records and OPG records, include the following entries & information:

(i) On 30 December 2004 Ms N presented to the Health Clinic hungry, dirty and with a chest infection, it is recorded "Will look into someone else caring for Ms N. (…) to have carers money stopped".

(ii) On 12 January 2005 Ms N presented to the Health Clinic too weak to stand and it was noted she had been without medication for two weeks. She had worms, was dirty, and required fluids and food.

(iii) On 14 January 2005 Ms N presented and the clinic file note is recorded as follows: "Brought to clinic, respite workers claim

she has maggots in her vagina (obs) still spitting out tablets and food unable to walk. Passing faeces and urine. Not vomiting, abdo soft and relaxed. PV clean and healthy swabs taken. Respite manager says she will do things for herself when she is there but not when workers help her. So behavioural issues. Has been told she will need to go to a hostel in Darwin if unable to do anything for herself. Review Monday."

(iv) On 27 January 2005 a second teleconference was instigated by the OPG following a call from the Respite Centre, in which concerns were expressed about Ms N including "house in a terrible state", "all her clothes are taken", "(Ms N) v. neglected", "clinic concerned". The OPG records indicate that in the teleconference the Registered Nurse at the Clinic reported that Ms N's "health (was) reasonable, hygiene poor, needs four weeks out for respite". Possible abuse was raised, "?(sister) hitting her". The Health Clinic records note that arising from the teleconference it was decided that Ms N should receive "respite as soon as possible, (DHCS Case Manager) to arrange- in interim- care plan being developed". (It is not known if respite was provided and no changes were identified as having been made to the Lifestyle Plan.)

(v) Within one week of that conference, on 1 February 2005, the Respite Manager brought Ms N to the clinic after she was found lying down by the road with blood on her head. Ms N reported that she had been sexually assaulted by three men. No injury was noted at the Health Clinic. Ms N agreed to move

to (a family member's) house for her safety. The Health Clinic records indicate a staff member was to "ring (the DHCS Case Manager) and her Guardian to advise of assault". Records confirm that the assault was reported to (the DHCS Case Manager) who in turn notified the Adult Guardianship Officer. In response to the notification the Adult Guardianship Officer rang the Health Clinic and spoke to the Registered Nurse. The OPG file notes record that the Registered Nurse reported that Ms N had been examined and swabs had been taken, and that she had been moved to another house until respite could be arranged. The Registered Nurse reassured the Adult Guardianship Officer that Ms N "will be okay there" and advised against reporting the matter to the police as it would "only make matters worse" for Ms N due to "payback". The Registered Nurse did not notify the police. In her Investigation interview, the Registered Nurse at the Clinic explained that should the allegation have become known, there was no way of protecting Ms N from reprisals which she believed would inevitably follow. There were no police stationed at the community at that time.

(vi) On 3 March 2005 a family member brought Ms N to the clinic. The family member had been ill. She complained that neither family members nor the Respite Centre were assisting with Ms N's care. Ms N had not been out of bed for 2 days. Ms N had a fever associated with either a vaginal or urinary tract infection. She was commenced on a three day course of medication, Gentamicin, but only received one dose.

(vii) On 15 March 2005 Ms N was collected because her course of Gentamicin had not been completed. She received doses on 15 and 16 March, but there is no record of her having the required third dose.

(viii) On 25 March 2005 Ms N presented with a small infected graze following a fall. She was smelly and needed a shower.

(ix) On 7 April 2005 Ms N presented feeling dizzy.

(x) On 15 April 2005 Ms N presented to the Health Clinic with flu symptoms and a small graze on her face. According to OPG records, on the same day, a worker from the Respite Centre called the OPG with concerns about Ms N reporting that the family had a big fight about her and she was not walking again.

The woman advised she had spoken to the joint Adult Guardians, had moved Ms N from her step-fathers house, and had arranged for respite at the Missionaries of Charity facility in Katherine.

(xi) On 2 May 2005 the Respite worker contacted the OPG and provided further information about the respite arrangements.

(xii) On 6 May the OPG recorded phoning the Health Clinic to request that a copy of Ms N's medical records be sent to Katherine where Ms N was receiving respite.

(xiii) On 16 May 2005 the OPG recorded contacting the Missionaries of Charity to enquire about Ms N. The OPG was advised that the Respite worker had taken Ms N back to her community as she required too much support and the Sisters considered she needed full nursing care. No alternative respite care could be

found so the worker was forced to take Ms N back to her community. The Adult Guardianship Officer attempted to contact the worker and requested by fax that she make urgent contact. The Adult Guardianship Officer rang the DHCS Case Manager and requested urgent respite. The DHCS Case Manager advised she would visit the community the following day.

(xiv) In response to the Adult Guardianship Officer's fax, the respite worker contacted the OPG on 17 May 2005. She agreed that urgent respite was needed and was aware that the DHCS Case Manager was visiting.

(xv) On 23 May 2005 the respite worker phoned the OPG to advise that the DHCS Case Manager was looking for further respite options.

(xvi) On 25 May 2005 Ms N presented to the Health Clinic with a small cut above her right eyebrow. She said she had been pushed.

(xvii) On 26 May 2005 a new carer attended the clinic and was given information about Ms N's medications, what to do if she had a seizure, when to bring her to clinic, and she was told to "keep an eye out for any danger from abuse".

(xviii) On 1 June 2005, the respite worker advised the OPG that Ms N was now spending all day at the Respite Centre as there were problems with her evening medication.

(xix) On 20 June 2005 the respite worker contacted the OPG about financial arrangements and to advise that she was leaving the

community. She recommended someone as her replacement at the Respite Centre.

(xx) On 21 July 2005 Ms N was brought into the Health Clinic with pains, reportedly having had a seizure four nights previously.

(xxi) On 28 July 2005 the new Respite Centre Co-ordinator commenced administering Ms N's medications as her family had not been giving them to her.

(xxii) On 25 August 2005 the Health Clinic records note that the Respite Co-ordinator "has been dispensing Ms N's tablets (even on weekends!)". (The surprise reflected by the exclamation mark in the notes is significant, given that the Lifestyle Plan purportedly provided for 4 hours of paid weekend assistance to ensure Ms N received her medication and meals on weekends.)

(xxiii) On 7 December 2005 Ms N had a seizure in the street.

79. The OPG complained that it was not fully informed of the health and care issues concerning Ms N during this period. According to OPG records, when the OPG contacted the Health Clinic to request a report for an upcoming Guardianship review, the Registered Nurse advised there were "no issues with (Ms N)- has only been to clinic once with minor cuts – seems to be well supported by (the Respite Centre Manager) at the Respite Centre". Further, on 2 December 2005 the Adult Guardianship Officer called the DHCS Case Manager for an update about Ms N. The Adult Guardianship Officer maintained notes of the call as follows:

> *Mostly being cared for by (…)- they are doing a good job – however (Ms N) still choosing to go back to (Stepfather) sometimes – …*

coordinator at Respite Centre – make sure (Ms N) has b/fast, shower and medications at centre each day – some problems if (the Respite Centre Manager) away. Mobility ok. Continence – refuses pads – has a mattress protector at (…)'s but if at (Stepfather)'s wets the mattress. (Adult Guardian)'s husband is sick – spending her time caring for him – (Adult Guardian) not around. Clinic review medical needs regularly – …. $ going ok – (the Respite Centre Manager) collects cheque – buys food – have had meetings with the store – (the DHCS Case Manager) wrote to them saying (Ms N) not to have any book up (will send copy of letter)".

80. The OPG also reported that it was not advised of the new Respite Centre Coordinator's name until 20 December 2005.

81. It is apparent from the Health Clinic records and records maintained by the OPG that in spite of the Lifestyle Plan and Service Agreement, Ms N was not receiving sufficient care and was often suffering from neglect. It appears her neglect was not always reported to the OPG. However, it seems that her situation improved somewhat with the appointment of a new carer in May 2005 and the commencement of the new Respite Centre Co-ordinator in July.

82. It is noted that in 2005 renewed funding in the amount of $25,600 for the provision of services identified in the Lifestyle Plan was requested. Funding in the sum of $15,000 was approved. DHCS told the Investigation that this apparent shortfall might be explained by Ms N receiving services that were block, rather than individually, funded.

2006

83. On 13 March 2006 the DHCS Case Manager visited the community and saw Ms N.

84. On 18 May 2006 the DHCS Case Manager completed an "Assessment of Individual Needs Report" and recorded that:

    (i) Ms N lived with her stepfather and received only minimal and sporadic family care. Respite workers often found her sleeping on a hard floor or soiled mattress with minimal clothing, even though mattresses, liners (to prevent soiling) and linen had been provided to the family. The house was very unhygienic. More appropriate accommodation was available at an Aunt's house but Ms N chose to live at her stepfather's.

    (ii) Ms N received daily respite care at the Respite Centre "most days" which included help with her personal hygiene, clean clothes, medication and meals. Ms N was increasingly incontinent but refused continence aids. She was reliant on the Respite Centre or the Health Clinic car for mobility and attendance at the Respite Centre.

    (iii) Ms N attended and enjoyed fishing excursions, drives and trips to the barge landing.

    (iv) Respite external to Ms N's community was found not to be a viable option because it placed Ms N at a high risk of harm.

    (v) On a number of occasions when respite workers were away, Ms N did not receive her medication, and became ill to the point of not being able to walk. She also experienced seizures.

(vi) Dealing with Ms N's challenging behaviours consumed significant staff time and resources and caused "burn out" and a high turnover of staff at the Respite Centre.

(vii) The problems surrounding Ms N's care were longstanding, and were not likely to be resolved unless a reliable and willing carer was located and agreed upon by the family and the community.

85. In her report the DHCS Case Manager concluded that Ms N had very high care needs. Ms N's family had been burnt out by her challenging behaviours and were not very keen to assist (or in the case of some Aunts, were unable to assist) in her day to day care. Respite Centre workers were tired and reluctant to care for Ms N as there was conflict with her family. The report noted that support to the Respite Centre was required; however it failed to specify what additional support would (or should) be provided to the Respite Centre. No funding application was identified as having been made for additional support. No alteration in the care plans was identified to accommodate the provision of additional personal care to deal with Ms N's incontinence. It is not known on what basis it was reported that Ms N was enjoying excursions. There is no evidence that any excursions had occurred for some time, a matter confirmed by the DHCS Case Manager's later visit to the community in August 2006 (see below).

86. The OPG advised that they were not provided a copy of the "Assessment of Individual Needs" report and, when they rang the Respite Centre

Manager on 19 May 2006, were reassured when told that things were "mostly going well".

87. It is clear that Ms N was not consistently getting the care specified in the Lifestyle Plan and that her Case Manager and DHCS were aware of this.

The Guardianship Order Review of June 2006

88. In preparation for a Guardianship Order review, reports were prepared for presentation to the court. The Registered Nurse at the Clinic prepared an unsigned report dated 24 May 2006. According to OPG records, this report was neither provided to the Court nor the OPG. The unsigned report contained the following information:

    (i) Ms N is on the respite program and can attend for showers, meals etc but she does not always choose to.

    (ii) Her health status is reasonable for someone with physical and mental disabilities living in a remote community.

    (iii) She has learned that self-harm will get her what she requires in the shop.

    (iv) Her family take very little care of her and will exploit her if possible. There have been incidences when we believe sexual abuse has occurred but have been unable to prove it.

    (v) She needs to stay under the care of the Guardianship or she will be completely exploited by her family.

    Although it is not certain who saw this report at the time it was made, references to failures to attend to daily hygiene, self-harm, exploitation and sexual abuse ought to have raised alarm bells. There is no evidence of any immediate further inquiry from DHCS.

89. The DHCS Case Manager provided a report for the Court dated 29 May 2006, following a visit to Ms N's community on 22 May 2006. The report was provided by way of a pro-forma document which required comment on a number of issues and included the following (extracted):

> **Current health status / issues:** *(Ms N)'s health is in relatively good status*
>
> **Relevant health history since (date):** /
>
> **Ability to initiate self-care:** *(Ms N) would not shower or change her clothing without assistance. (Ms N) will not take her medication.*
>
> **Next of kin:** *Stepfather…, little involvement in care.*
>
> **Visitors:** *(Ms N) is well supported by the Health Clinic and Respite Centre. (…) Aged and Disability also assess needs/ changes to care plan as required and provide support to the community services at (her community).*

90. The DHCS Case Manager's report did not mention the problems of Respite staff "burn-out" or that there was inadequate care provided when Respite staff took leave. It did not mention Ms N's unhygienic living conditions and her increasing incontinence.

91. A Medical Practitioner provided a medical report dated 10 June 2006. The report records Ms N's medical history and medication. Under the heading "Functional Assessment" it is reported that:

    (i) Ms N manages daily living with the support she receives at present.

    (ii) Her family plays a minimal role in her support.

(iii) Ms N is offered support in (her community) through the respite program where she has assistance with showering, meals and shopping, as well as receiving her medications.

The report concludes that consequently her health status has been reasonable and her epilepsy control much improved since mid-2005. "It is my opinion, shared by the staff who work with her on a daily basis, that it is in Ms N's best interest for Adult Guardianship and local support structure continue as they are at present."

92. Although the doctor visited Ms N's community on 30 May 2006, he did not see Ms N as she could not be located. The doctor's report was prepared from records and on the verbal reports of others. On reading the report, it is not readily apparent that there was no consultation between the doctor and Ms N. The OPG advised that they were not aware that the doctor had not seen Ms N. However, DHCS advised that there was some correspondence associated with his report which revealed that the report was not based on a personal assessment.

93. The Health Clinic Progress Notes record that on 3 June 2006 clinic staff were called out to provide medication to Ms N and on 6 June 2006 Ms N experienced a seizure in the street. This information was not conveyed to the Delegate of Public Guardian during an OPG initiated phone call with the clinic on 8 June 2006 and did not form part of the information available at the Guardianship Order review.

94. OPG records indicate that on 14 and 15 June 2006 the OPG attempted to contact the Respite Centre Manager by phone and by fax. On 14 June

2006 the OPG also rang the Health Clinic to arrange an escort for Ms N to attend her Guardianship Review. The Health Clinic advised that there was "sorry business at present – everything closed – neither (Adult Guardians) in town, therefore no escorts".

NAAJA's visit to Ms N's community

95. In preparation for the Guardianship Order review, a lawyer from NAAJA visited Ms N on 22 June 2006.

96. The NAAJA lawyer visited Ms N's house which she found to be dirty, decrepit and in disrepair. Ms N was found lying on a soiled mattress, unresponsive, immobile and dirty. Ms N's stepfather and her sister complained to the NAAJA lawyer that the Respite Centre was not providing sufficient care, Ms N was not being washed, and there was a problem with her medication. They complained that her stepfather was having to "toilet" Ms N which was culturally "not right".

97. The NAAJA lawyer was concerned that Ms N appeared very unwell and arranged for her to be seen at the Health Clinic. Clinic staff told the lawyer that Ms N was:

    (i) Quite immobile as she had been in bed for over a week.
    (ii) In a soiled nappy that had not been changed for at least several days.
    (iii) Unresponsive; and
    (iv) Unable to stand.

    The Health Clinic records confirm these observations.

98. The Registered Nurse at the Clinic also told the NAAJA lawyer that:

(i) Ms N was self-harming.

(ii) Ms N was smoking a lot of "gunga" and that this was the reason for her going to her stepfather's house.

(iii) She was concerned Ms N had been sexually assaulted but this could not be confirmed because the clinic had no sexual assault kits. Furthermore, if there was a complaint Ms N would be forced to leave the community.

(iv) The Adult Guardians living in the community did not have much involvement with Ms N.

(v) There was a high turnover of carers; and

(vi) There were more than 7 adults and many children living in the house.

99. During her visit the NAAJA lawyer also spoke to the Respite Centre Manager who:

(i) Informed her that members of Ms N's family "humbugged" Ms N for money, stole money from her, ran up her account at the shop, and ate her food.

(ii) Expressed concerns about sexual activity.

(iii) Complained that the Adult Guardians living in the community had no involvement; and

(iv) Said she had been on leave but that Ms N's care would improve now that she had returned.

100. The NAAJA lawyer was unable to speak to either of the Adult Guardians who normally lived in the community and it appears that they were not in Ms N's community when she visited.

101. It was obvious to the lawyer that Ms N was not receiving adequate care and was living in very poor conditions. Her observations appeared to be at odds with the reports prepared for the Guardianship Order review (referred to above). In effect the lawyer was concerned that the reports prepared for the Guardianship Review were inaccurate and potentially misleading.

102. On 27 June 2006 the NAAJA lawyer telephoned OPG and informed the Adult Guardianship Officer of her concerns. The Adult Guardianship Officer took notes of the conversation. The Adult Guardianship Officer records that her told her that:

    (i) Ms N was in a "bad state". She had been in bed for 7 days with no medication, clothes, or nappy change. She was unsteady on her feet and not communicating.

    (ii) The Health Clinic nurse checked her over and no problems were identified.

    (iii) There seems to be a conflict between the family and the Respite Centre.

    (iv) The Respite Centre Manager had returned from leave.

    (v) An OPG visit was suggested.

103. In response to the suggested OPG visit, the Adult Guardianship Officer advised that she informed the lawyer that it was the Case Manager's

responsibility to coordinate Ms N's services and that a family and community meeting usually improved the situation. The NAAJA lawyer and the Adult Guardianship Officer agreed that it might benefit Ms N if the Adult Guardianship review were held in her community as this might provide an opportunity to increase family involvement. The Adult Guardianship Officer agreed to attend a hearing in Ns N's community and planned to combine this with a family and service provider meeting. The lawyer agreed to follow up the possibility of the hearing occurring in Ms N's community.

104. The DHCS's Aged and Disability Team met on 30 June 2006. The meeting's minute's record that the DHCS Case Manager's planned monthly visit to Ms N's community was to be delayed due to staff shortages.

105. On 7 July 2006 the Adult Guardianship Officer emailed the DHCS Case Manager and informed her of NAAJA's concerns. The Adult Guardianship Officer suggested the DHCS Case Manager visit Ms N's community and suggested that the Guardianship Review be used as an opportunity to arrange a meeting.

106. On 10 July 2006 the DHCS Case Manager phoned the Adult Guardianship Officer presumably in response to the 7 July 2006 email. The DHCS Case Manager informed the Adult Guardianship Officer that there had been a problem while the Respite Centre Manager was away which was compounded because there were no female respite workers during that time. The DHCS Case Manager said there was "++ grog and

gunga" at her stepfather's and said that she would be visiting the community "next week". In fact, the DHCS Case Manager did not visit until 8 August 2006.

107. The NAAJA lawyer phoned the Adult Guardianship Officer on 10 July 2006 to let her know that the Council had agreed to make rooms available to the Guardianship Review and the Adult Guardianship Officer updated the lawyer on her conversation with the DHCS Case Manager.

108. The OPG faxed the Respite Centre Manager on 12 July 2006 and asked her to call to discuss the upcoming Guardianship Review.

109. In its response to the draft report, the OPG advised that as the Health Clinic had identified no health problems on 27 June 2006, there was no indication of a health risk to Ms N. Further, they were reassured by the return of the Respite Centre Manager that issues of personal care would be addressed.

Arnhem Aged and Disability Service Trip 8 – 10 August 2006

110. The DHCS Case Manager and her replacement visited on 8 – 10 August 2006. According to their Service Trip Report they observed that "there was limited day respite and service provision available", "there did not appear to be any centre based and day respite activities", and "high needs clients' hygiene was unsatisfactory".

111. Issues concerning Ms N were identified and discussed including: the level of care being received, her living situation (overcrowded and no

domestic help), her declining mobility, the lack of day activities, her increasing incontinence and lack of assisted toileting which left her frequently soiled, her lice infestation which caused severe sores and scratching, and Health Clinic staff reports of possible sexual abuse. It was "agreed" that Ms N was to attend the Respite Centre daily for a shower and health workers were to be allocated daily to care for her. However, the Investigation notes that the Lifestyle Plan had been in place since 2003, further "agreement" as to the provision of services specified in the Plan was obsolete, what was required was delivery.

112. On 11 August 2006 the Arnhem Aged and Disability Team meeting minutes note that Ms N was no longer mobile, and was very dirty with a head-lice infestation. Emergency respite was discussed.

113. The results of this visit were not reported to the OPG until 1 September 2006. The Adult Guardianship Officer made a note of the conversation she had with the new DHCS Case Manager. The new DHCS Case Manager told the Adult Guardianship Officer that she was concerned about Ms N's "maggots and lice++ - poor mobility – asked what could be done – (response from) (the DHCS Case Manager) – nothing. The Adult Guardianship Officer responded "explained to (DHCS Case Manager) that AGO also very concerned – apparent neglect over some time – AGO not advised of seriousness of situation – not impressed".

Ms N's hospitalisation

114. In phone calls between the Adult Guardianship Officer and the Respite Centre Manager on 28 and 31 August 2006, the Respite Centre Manager told the Adult Guardianship Officer that Ms N was last seen walking on either Wednesday 9 or Thursday 10 August 2006. The weekend that followed was a long weekend. The Respite Centre Manager reported to the Adult Guardianship Officer that the "boys" checked on Ms N on Tuesday 15 August and the Manager visited her on Wednesday 16 August 2006. During the visit the Respite Centre Manager reported to the Adult Guardianship Officer that family members had told her that Ms N had not eaten for 3 days. The Respite Centre Manager reported that she took Ms N to the Health Clinic.

115. The clinic records for 16 August 2006 document that Ms N was weak and suffering from bed sores and pneumonia. She was evacuated from her community by air and admitted to Gove District Hospital.

116. Further, the clinic records document that the Registered Nurse at the Clinic phoned the Adult Guardianship Officer and said that she "went to the house – disgusting state" and that she was concerned that Ms N was so ill she may have died.

117. However, in its response to the draft report, the OPG advised that there was no contact from the Health Clinic on 16 August 2006. Gove District Hospital notified the OPG of Ms N's hospitalisation on 17 August 2006.

118. According to the OPG, the Health Clinic did not make contact until 21 August 2006 at which time the Registered Nurse "apologised for not advising PG of air evac to GDH – was planning to have a family meeting today and then remembered AGO involved". The Registered Nurse advised that Gove District Hospital wanted to send Ms N home or to a nursing home in Darwin.

119. On 21 August 2006 the Adult Guardianship Officer spoke to the Manager Arnhem Aged and Disability Team, and gave instructions that Ms N was not to be returned to her community until more was known about her physical status, and an assessment was made as to the risks associated with her continuing to live with her step-father. The Adult Guardianship Officer also requested a copy of the assessment of Ms N's current needs but this was not provided.

120. On 24 August 2006 the Respite Centre Manager contacted the OPG and apologised for not advising the OPG of Ms N's hospitalisation. The Respite Centre Manager reported her concerns that Ms N was "greatly at risk at (her stepfather)'s house - ?subject to abuse- certainly neglect.." The Respite Centre Manager also reported that the new DHCS Case Manager had said the OPG could not refuse to let Ms N return to her community (an apparent reference to the Adult Guardianship Officer's instructions).

121. On 24 August 2006 Ms N was transferred from Gove District Hospital to Royal Darwin Hospital with right hemiparesis (weakness on the right side of the body) and aspiration pneumonia. She was uncommunicative and could not move independently.

122. On 28 August 2006 a CT scan revealed that Ms N had suffered a stroke (left temporal frontal infarction). She was also suffering from aspirated pneumonia, and had a 7-10 cm pressure sore on her hip which was necrotic.

123. In its response to the draft report, the OPG advised that the Adult Guardianship Officer had expressed her concerns to officers from NT Disability Services on 11 September 2006 and on 19 September 2006 that she had not been kept informed of care and health issues raised by the Respite Centre, Health Clinic or Case Manager. The OPG advised that the Adult Guardianship Officer "requested a review of (Ms N)'s care, support and case management during the previous 6 months due to her concerns about possible neglect and system failure".

124. On 11 October 2006 Ms N's blood tests revealed she might be suffering from acute leukaemia. However definitive investigations were not performed because they would have caused undue pain and distress and because Ms N was not a candidate for treatment. Onset of the disease was noted as "uncertain but more than 9 weeks".

125. Ms N died on 15 October 2006. The cause of death was recorded as leukaemia and ischaemic stroke of the left cerebral artery.

6. RESPONSES TO THE DRAFT REPORT

OPG

126. As noted earlier, drafts of this report were circulated for comment and response in January and December 2012. A detailed response was received from the OPG on 1 February 2013.

127. The OPG response identified what it considered to be factual errors in the draft report based on records maintained by the OPG. The final report was amended to include the OPG's evidence of events. Where there were inconsistencies between agencies or accounts, the competing versions were reported without preference.

128. The OPG provided further information about its activities concerning Ms N which have also been incorporated into the history of Ms N's care. The OPG submitted that it had adequately fulfilled its decision making and advocacy roles in respect of Ms N according to the information and options available at the time decisions were made.

129. As to the information available to the OPG, the OPG:

(i) Expected paid service providers to advise of any concerns or issues relating to Ms N.

(ii) Complained that it was not kept fully informed of issues and concerns relating to Ms N in spite of correspondence with service providers clearly advising of the guardianship orders. Service providers, including the Health Clinic, were sent copies

of the Adult Guardianship Orders on 21 August 2002 and 7 January 2005. The notifications included the following information "If any issues arise that require the involvement or consent of the Guardians please contact (joint Guardians) and call an Adult Guardianship Officer on (xxx) during business hours or telephone pager (number) after hours". The Health Clinic file also contained an information sheet that included the following information "under Guardianship (see notes and letters) Delegate of the Public Guardian ph: (xxx) after hours page (xxx)… Adult Guardianship (xxx)".

(iii) Advised that if calls to the OPG were unanswered there was a message service and a paging service for urgent matters. Records maintained by the OPG show that neither the Health Clinic nor the Respite Centre ever used the paging service.

(iv) Complained that there was no regular liaison between DHCS, the Respite Centre and the OPG. The OPG pointed out that the only two meetings held were instigated by the OPG; and

(v) Noted that although the Adult Guardianship Officer visited Ms N's community in 2003, there was no travel budget to enable regular visits. Accordingly, the Adult Guardianship Officer necessarily relied on the reports of others about Ms N as the basis for her decisions.

130. As to the care options available to Ms N, the OPG advised:

(i) That the OPG did not create or monitor services. The OPG agreed to plans developed by DHCS and expected them to be

implemented. DHCS were responsible for monitoring the provision of services it provided or contractually funded.

(ii) The only potential alternative option to care in the community was care in Darwin, and in Darwin Ms N's history of absconding placed her at high risk.

(iii) Of the two choices available (care in Darwin or the community), care in the community was the better option; and

(iv) Care in the community worked when services were delivered in accordance with agreed plans.

131. As to its decisions, the OPG said they:

(i) Were made based on the options identified by DHCS and other service providers.

(ii) Were made based on the opinions and information available to the OPG as provided by service providers and the Adult Guardians.

(iii) Were made jointly with the Adult Guardians.

(iv) Took into account Ms N's wishes, and the views of family and community members, and

(v) Were made in accordance with the requirement that decisions be made in the least restrictive manner.

132. As to the role of the Adult Guardians, the OPG provided the following information:

(i) Adult Guardians are appointed for cultural and family reasons to enable family to participate as joint decision makers with the Public Guardian.

(ii) When Guardianship Orders are reviewed, the Adult Guardians are asked if they are willing and able to continue in their role and, if not, other family or community members are identified. Over the years Ms N's Adult Guardians were changed according to their willingness and capacity.

(iii) An Adult Guardian does not need to be in the community in order to carry out their functions, they only need to be available and accessible.

(iv) An Adult Guardian may have competing roles and responsibilities which means they might not always be available to carry out their guardianship responsibilities.

(v) The OPG was satisfied through discussion with the Adult Guardians and their participation in two case conferences, that the Adult Guardians understood their roles. However, there was no budget for the formal training of Adult Guardians.

Department of Health

133. The Department of Health provided a response to the draft report on 21 January 2013.

134. The Department emphasised the complexities surrounding Ms N's case and admitted it was *"one of the most complex the Department has managed"* but contended that changes had been made since 2006 which would now ensure that *"structural systems (are) in place to oversight the care provided on behalf of the Department"*.

135. The Department highlighted some of the significant changes made to disability service delivery since 2006 and in particular identified the following matters:

(i) The philosophical framework in which services are provided has changed. In Ms N's time the wishes of the client were considered to be paramount. The current approach considers and values the desires of clients and their families, but also considers duty of care and risk.

(ii) In 2006 the Northern Territory Government commissioned KPMG to conduct a review of disability services in the Northern Territory (The Review). Recommendations were implemented which included *"service improvement activities both internal and external to the Department and the enshrining of operational standards providing guidance to clinicians about assessment and case management activities"*.

(iii) In 2007, Dr Howard Bath made recommendations about managing risk for clients with high, complex and challenging needs and the role of the Department in providing a case management approach even if services were outsourced (The Bath Report). The Department advised that risks associated with care are now assessed and considered *"through a structured risk assessment process"*.

136. The Department submitted:

> *The Review and the Bath report and the subsequent launch of the Aged and Disability Program (A&DP) Practice Manual in October 2009 has resulted in a more robust approach to assessing, managing*

and internal reporting of clients presenting with a high risk of harm to themselves or others…There now exist complex case management positions that offer a higher level of expertise and focus on planning and intervention for clients presenting with challenging and complex needs. This approach to disability practice provides very clear guidelines for case managers developing responses for high risk clients when balancing the very complex issues of duty of care and dignity of risk. There are many examples of practice today where the recommendations and decisions are made in an integrated, shared care approach, including Adult Guardians, A&DP Case managers and other relevant stakeholders.

On the ground this has resulted in the development of a specialised disability support worker workforce that provides direct care and support for clients deemed to pose a high level of risk. This approach provides intensive, focussed and closely monitored therapeutic programs aimed at producing positive client outcomes."

137. The Department acknowledged that in 2006 performance measures for service providers were not clearly defined and there were limited requirements concerning quality or standards, but submitted:

"Current agreements identify performance measures associated with funded service outputs and organisations are required to develop and maintain procedures addressing risk management, incident management and reporting, medication and training for all staff. Work continues to ensure these requirements are supported by strong contact management by the Department."

138. The Department further advised that:

> *"As a step towards accreditation of disability services the Department has funded the National Disability Service to develop and implement a quality framework for disability services in the Northern Territory. Service reviews are undertaken during the life of the agreement as part of this framework."*

7. CONCLUSIONS

Standard of Care

139. It is clear from this Investigation that the shortcomings in the management of Ms N's care; concerns about her safety and well-being; deficiencies in support systems; and other issues of serious concern surrounding provision of everyday care to Ms N were well known to service providers since at least 1993.

140. An assessment requested in 1993 and later used in Guardianship proceedings in 1994, raised concern about lack of respite facilities, absence of support for carers, Ms N's vulnerability to and experience of physical abuse, general lack of specialist support for people with mental impairment, shortcomings in day-to-day care in her community and an overall absence of options for securing Ms N's wellbeing. At the 1994 Guardianship hearing, one report, noting Ms N's significant intellectual disability, lamented the fact that individuals in Ms N's circumstances were often left "under-challenged", not being given the opportunity to find out what she was capable of. While the Department noted that the absence of stimulating activity was widespread in communities and not solely an issue related to disability, for Ms N the absence of stimulating and challenging activities was identified as a crucial element that contributed to challenging behaviours, escalating problems and in turn impacting on community attitudes and problems relating to Ms N. Aside from short periods of time in which improved care and outcomes were seen, all of these issues remained current at the time of Ms N's death

some thirteen years later. None of the issues or concerns had been addressed in any meaningful or sustainable way. To varying degrees and in varying ways, all services involved in Ms N's care and daily life failed to protect her, to ensure her safety, and to promote her wellbeing, her dignity and her place in the community.

Northern Territory Disability Service Standards

141. The Northern Territory Disability Service Standards apply to all services for people with disabilities provided and / or funded by Territory Health Services. They applied to DHCS, the Council, the Respite Centre, the Health Clinic, and the hospitals accessed by Ms N. They were the standards the OPG was entitled to expect Ms N's service providers adhered to, and for which the Public Guardian ought to have more effectively advocated.

142. The Disability Service Standards are founded on five underlying principles, namely that:

    (i) the human rights of people with disabilities be recognized.

    (ii) all people with disabilities have an optimum quality of life- 'a life not just an existence'.

    (iii) all people with disabilities have meaningful choices about how their needs are met and how they are involved in the ongoing development, delivery and evaluation or services they receive.

    (iv) all people to disabilities have the right to services that meet their individual needs in a timely and culturally appropriate manner.

(v) all services to consumers be accountable to their consumers, families of consumers, support workers and funding bodies.

143. The Disability Service Standards list eight standards which are designed to ensure services provided to consumers are consistent with the Principles and Objectives of the *Disability Services Act*. While all the Standards are relevant to Ms N's care, particular reference is made to:

(i) Standard 2.1: which provides that each consumer will receive services that take account of their individual needs.

(ii) Standard 5.1: which provides that each consumer will be protected from abuse and exploitation.

(iii) Standard 5.6: which provides that each consumer who cannot make fully informed decisions will have a substitute decision maker.

(iv) Standard 7.3: which provides that agencies will provide appropriate training to workers; and

(v) Standard 8.2: which provides that agencies will implement procedures to maintain the accountability of its governing body.

144. It is readily apparent that the service providers failed to meet the Disability Service Standards in relation to the delivery of services to Ms N. Further, DHCS failed in its responsibility to monitor the service providers that it contracted and funded, to ensure they delivered services at an appropriate standard. Although the Public Guardian was faced with limited care options and relied on DHCS for their delivery, it also failed Ms N. It failed to make decisions or effectively advocate to

secure the delivery of consistent service at an acceptable standard. It appears that there were no consequences for any of these organisations for this failure.

DHCS and the Aged and Disability Service

145. DHCS's role in relation to Ms N's care and wellbeing was to provide case management for Ms N and to fund other services to look after other aspects of Ms N's needs. According to one officer who held the role, case management included liaison with the variety of service providers, coordination of care, and being the "main point of contact" for issues with any clients of the service. In relation to the funding role, best practice would assume oversight and accountability of funded services to be crucial.

146. Provision of case management to Ms N appears to have been patchy at best. There were periods when care had "degrees of success" (1999-2003), and times when the case manager was involved in establishing Lifestyle Plans with clear aims, identifying necessary supports and support levels. However these highlights are overshadowed by the ongoing circumstances of Ms N's life.

147. Although DHCS planned staff visits to Ms N's community every 6 weeks, such regular visits rarely eventuated. Available records demonstrate 12 and 13 week gaps between visits in 2006. Given Ms N's fragile existence, DHCS visits were too infrequent to ensure carers were supported and to ensure Ms N was receiving adequate care.

148. When staff did visit Ms N in her community, notes of her circumstances consistently identified the same types of issues and concerns documented back in 1993, although formal reporting over time did not always objectively reflect Ms N's poor condition and circumstances.

149. The understatement of Ms N's circumstances is evidence that the DHCS became immune, or at best inured, to the reality of Ms N's life and viewed the situation as intractable.

150. There is no other reasonable explanation for the fact that no action was taken at times when there were genuine concerns that Ms N was:

- sexually abused;
- physically unsafe;
- living in circumstances which were unhygienic;
- not being fed;
- financially exploited; and
- so physically unwell she could not be roused.

151. Efforts to find solutions or improve Ms N's circumstances were piecemeal, not followed through on, and as a result their effectiveness was very limited.

152. In addition to failures in direct service delivery, whether the result of staffing levels, resources or other factors, the DHCS failed to adequately oversight the provision of funded services to Ms N.

153. Lifestyle Plans, along with applicable Disability Standards and personal care guidelines, were incorporated into a Service Agreement with the Council in 2004-2006. The Service Agreement set out service level requirements, and contained inbuilt oversights such as performance reporting, progress meetings and formal reviews. There is no evidence that any of these safeguards were utilised on a regular basis, nor is there evidence the regular liaison between DHCS, Respite Centre and the Public Guardian identified as a requirement of the Lifestyle Plan occurred.

154. Further, DHCS failed to initiate any review of the services being delivered when crisis points were reached which should have alerted DHCS to significant failings in the delivery of services to Ms N. DHCS did nothing to ensure change or improvement in the delivery of services to Ms N.

155. The only review of the Service Plan occurred at its completion in May 2006. The OPG was not consulted during this review and no significant changes were made to the plan despite identified burnout of Respite Centre staff and family members involved in Ms N's care. The replacement plan was not provided to the OPG and did nothing to improve the quality or level of service provided to Ms N, or the quality or level of support provided to carers. By failing to act, DHCS accepted the risks to Ms N and did nothing to mitigate them.

156. In response to this Investigation DHCS reported that some of the concerns about Ms N's care were attributable to the generally poor

standard of housing, overcrowding, cleanliness and hygiene in remote communities. However, Ms N was a person with multiple conditions contributing to severe disability. As such, she was an extremely vulnerable client of DHCS. DHCS was required to provide, and in its role as funder ensure provision of, care in accordance with the Disability Service Standards.

157. If the level of services required could not be delivered in the community, if Ms N's basic human rights could not be protected in the community, it was incumbent on DHCS to provide the services in another way, and if necessary, at another location. However, DHCS failed to identify or provide any alternative care arrangements.

158. The standard of service provided to Ms N by DHCS was not reasonable nor in accordance with relevant legislation and service standards.

The Council and Respite Centre

159. Despite being served with a Notice to Provide Information or Produce Documents, no records were produced to the Investigation by the Council or the Respite Centre.

160. There is no evidence that the Council were aware of or delivered services that complied with the Disability Service Standards or the Personal Care Guidelines they were required to comply with as recipients of DHCS funding.

161. As noted above, there is no evidence that the Council complied with the reporting, review and notification requirements under the 2004-2006 Service Agreement with DHCS. In particular there is no evidence that regular (as opposed to ad hoc) meetings with DHCS occurred, or that 6 monthly performance reports were provided. There is no evidence that the Council advised DHCS of any significant changes in Ms N's care despite the fluctuations in her wellbeing and ongoing concerns.

162. As the people responsible for the delivery of services to Ms N on behalf of the Council, staff of the Respite Centre should have been aware of their roles and responsibilities under the Service Agreement. There is no evidence that the Council met or in any other way conveyed this information to Respite Centre staff, nor is there evidence that the Council took any other steps to ensure services were delivered to Ms N in accordance with the contractual requirements or the Disability Service Standards.

163. The Health Clinic notes and other medical records demonstrate the regular and recurrent failure of the Respite Centre and paid carers to deliver services in accordance with Ms N's Lifestyle Plans and the Service Agreement. In particular the history demonstrates that Ms N regularly failed to receive her medications, was often hungry, suffered from a complete lack of hygiene, was severely neglected, and at extreme risk.

164. Despite the staff shortages, lack of training and qualifications, and evidence of staff "burn out" there were individuals at the Respite Centre

who endeavoured to provide care to Ms N to the best of their abilities. These staff, and ultimately Ms N, were let down by the absence of support, inadequate training, lack of information about service obligations and responsibilities, and staffing shortages.

165. Due (at least in part) to inadequate staffing, the Respite Centre was unable ensure the delivery of culturally appropriate care.

166. The standard of service provided to Ms N by the Council through the Respite Centre was not reasonable and failed to comply with relevant legislative and service standards.

Office of the Public Guardian

167. Guardians are substitute decision makers who are required by the *Adult Guardianship Act* to make decisions which are in a person's best interests, in the least restrictive manner, and which, where possible, take into account the person's wishes. Guardians can make decisions about a person's health care, accommodation, and day to day care but are not case managers and are not responsible for providing care.

168. Section 20 of the *Adult Guardianship Act* requires a Guardian to act in the best interests of a person and to as far as possible, protect the represented person from neglect, abuse or exploitation.

169. Section 23 (4) of the *Adult Guardianship Act* requires the Executive Officer to provide to the Court such information and reports as it considers necessary for a review.

170. Ms N was subject to Guardianship orders from 15 February 1994 until her death in October 2006. From 16 June 2004 Ms N's joint Adult Guardians and the Public Guardian were authorised to make decisions about where and with whom Ms N was to live, Ms N's health care and Ms N's day to day care. The Public Guardian was also appointed to manage Ms N's finances and estate.

171. In order to make decisions about Ms N's care it was necessary for the Public Guardian to receive reliable information and be contactable. Although the Adult Guardianship Officer said that an officer from the OPG was contactable 24 hours a day, both the Respite and Clinic Staff in Ms N's community told the Investigation the Adult Guardianship Officer was difficult to contact.

172. The Health Clinic staff and other carers told the Investigation that Ms N's circumstances and neglect was reported to OPG many times but that the OPG failed to act on these reports.

173. Concomitantly, the Adult Guardianship Officer complained that she did not receive sufficient information about Ms N's care and living conditions, even though the service providers were well informed of OPG involvement. The Adult Guardianship Officer said she was not told when Ms N was suffering from neglect or abuse. The OPG records support the Adult Guardianship Officer's assertion that she was often not informed or only belatedly informed about health and care issues.

174. It does appear that over time, front line carers developed fatigue about reporting matters of concern to the OPG because of their perception that phones went unanswered; and, perhaps more importantly, because of their perception that the OPG lacked the capacity to effect sustained change or improvement in Ms N's circumstances.

175. It appears that the OPG mistakenly believed that its interventions on Ms N's behalf were effective. The OPG trusted that planned for services would be delivered at an appropriate standard (in spite of the evidence of repeated failings) but did not have the capacity to objectively or reliably verify whether or not services were in fact delivered.

176. Concerning her role, the Adult Guardianship Officer, told the Investigation:

> *"You are given some choices and you decide between options. The Guardians are not responsible for providing day to day care, for providing care or case management…*
>
> *(Ms N) was able to say what she wanted…The Act requires that we, where possible, take into account the person's wishes…She was saying I want to stay at (her community) and (that) is my home, and that was very clear..*
>
> *(Ms N) voted with her feet…there had been times over the years when we trialled her coming to town for respite and it was horrific, absolutely horrific…She was more at risk in town…The best place for her to be was in (her community) and to remain there, and then it was up to the Department to put in place services to support her to live there and to monitor those services…*

The role of the Guardian is really as decision makers. So if there aren't decisions to be made we might not see clients for some months…We rely on whoever's providing the service to them to let us know if there's a problem."

177. Although the OPG was not responsible for providing care, the Guardians, including the delegate of the Public Guardian, were required to make decisions about accommodation, health care, and day to day care which were in the best interests of Ms N. Ms N's expressed wish to remain in her community, shared by her family, was not an overriding consideration. Nor were the views or opinions of the service providers. The simple fact is that the care provided in her community repeatedly failed, resulting in dire health and safety consequences for Ms N. The delegate of the Public Guardian ought to have reconsidered the balance and given greater weight to securing appropriate and consistent care for Ms N. Concomitantly, DHCS ought to have identified or developed better, safer, and more reliable care options for Ms N.

178. As noted above a Guardian is required, as far as possible, to protect a protected person from abuse or exploitation. The delegate of the Public Guardian was aware or ought to have been aware that on and from 1993 Ms N was allegedly subjected to physical abuse at the hands of frustrated family members resulting in physical harm requiring hospitalisation. Further from January 2004 the OPG was aware or ought to have been aware that Ms N was likely the victim of sexual assault in her community. The Adult Guardianship Officer articulated these concerns in reports to DHCS on 2 October 1995 and again on 11 August

1997. The Adult Guardianship Officer was advised of a likely sexual assault by 3 men on 1 February 2005. On 24 May 2006 the Registered Nurse at the Clinic drafted a report for the Guardianship review referring to concerns about self-harm, exploitation and sexual abuse. It is not clear why this report was not finalised, considered, or acted upon. There is no evidence before the Investigation that the Adult Guardianship Officer reported the suspected sexual assault to the police for investigation. In spite of concerns about the lack of a police presence in the community and pay-back, a police investigation of this most serious allegation of possible sexual assault ought to have occurred. Ms N's safety could have been protected by providing care away from her community. The OPG did not make choices that resulted in Ms N being removed from the community but instead made choices that left her vulnerable and unprotected.

179. Ms N's guardians, including the Public Guardian, had a duty of care to act carefully and reasonably in fulfilling their functions and duties, and to advocate for and make decisions that were in Ms N's best interests. The evidence of continued neglect and harm suffered by Ms N revealed by this Investigation demonstrates that the OPG was not kept fully informed of Ms N's condition and circumstances. This contributed to the Guardians failing to adequately and appropriately exercise the decision making powers conferred on them under the *Adult Guardianship Act*.

Inadequacy of Resources in Ms N's community

180. The Investigation revealed that all services in the community accessed by Ms N, including the Health Clinic and Respite Centre, were inadequately

resourced and staff lacked training to deal with her high care needs and challenging behaviours. The community was not serviced by a police station so there was no immediate police protection for Ms N when she was assaulted.

Communication and Care Coordination

181. Communication among the service providers, and between service providers and the OPG, was inadequate, ad hoc, and broke down over time. The Investigation found that this was a crucial ingredient to the compromising of Ms N's care and well-being during her adult years.

182. Evidence of this break down is most striking when there were opportunities for the identification of risk, as well as for improvement of service and service coordination, for Ms N and these opportunities were not reported to relevant stakeholders and missed.

183. As referred to above, one clear opportunity for improvement was the development of the Lifestyle Plan in 2003. The plan was an attempt to put Ms N at the centre of service planning. It identified the challenges associated with her care as well as the level of care required to meet her needs. The Plan was to be put into place through the requirements of the Service Agreement between DHCS and the Council. It noted that "regular liaison by the DHCS Local Area Coordinator, the Respite Centre and the Guardianship Board" would be required to ensure its success, and to this end monthly meetings were to occur "to ensure her health as well as her physical well-being is being looked after". There was no evidence provided to the Investigation that any such meetings ever took

place. As noted above, there is no evidence that the implementation of the plan was a success.

184. There was inadequate communication between the OPG and the Adult Guardians. The Public Guardian depended in part on the Adult Guardians to report concerns to her and did not take sufficient responsibility for proactively maintaining regular contact with the Adult Guardians. At times this information path broke down when the Adult Guardians were not in the community for extended periods and when they could not carry out their responsibilities because of competing family and cultural demands. Officers from OPG raised concerns about whether various Adult Guardians were fulfilling their responsibilities as far back as 1995; concerns were again raised in 1996, 1997 and 2006 and the Adult Guardians were replaced from time to time according to their stated willingness and ability. It is not clear what support the Adult Guardians had in the performance of their roles or whether they fully understood the extent of their decision making responsibilities. None of the Adult Guardians received any formal training concerning their responsibilities, as the OPG was not funded to provide any such training.

185. Over time, carers on the ground reported that they found it difficult to contact the OPG and felt they was not sufficiently responsive to their concerns when contact was made. The OPG did not appear to make proactive enquires about Ms N unless and until concerns were reported to her, or unless there was a pending review. The Delegate of the Public Guardian in turn complained that she felt she was not kept well informed about Ms N's circumstances but maintained that

communication by phone was always available. Ad hoc avenues of communication adopted by the parties appeared to break down over time.

186. There were no visits after 2003 by the OPG to Ms N's community as they did not have a travel budget. Visits by DHCS to the community were infrequent, regularly cancelled or postponed. As with the OPG, DHCS officers relied on information provided to them by third parties. The infrequency of visits by DHCS inevitably led to reduced oversight of services delivered in Ms N's community.

187. There is no doubt that Ms N's situation was a difficult one that presented challenges for all service organisations as well as her family and broader community. Although the OPG was able to achieve some short term improvements in care delivery when it instigated case conferences in April 2004 and January 2005, improvements were not sustained over time. Other opportunities for pulling together to discuss and generate ideas to address the serious issues of concern relating to Ms N's care and general wellbeing were inevitably missed due in large part to a breakdown of communication between all involved in her care.

8. SYSTEMIC ISSUES OF CONCERN

188. The Investigation revealed consistent and repeated shortcomings with respect the care, protection and well-being of Ms N over at least two decades. The failings can be attributed to all service providers and agencies who dealt with her. The problems with her care are well documented, and were aired via reports in recurrent Guardianship court proceedings. However, nothing sustainable was done. Extrapolation to a conclusion of systemic failure is inescapable.

189. Critical matters of systemic concern in respect of Department of Health and Community Services include:

(i) Its failure to ensure there was any compliance at any level with its Service Agreement with the Council, in particular the failure to:

a. Ensure the Council reported against its performance measures.
b. Conduct a review of the service to ensure compliance with obligations and Disability Standards; and
c. Participate in regular progress meetings.

(ii) Its failure to ensure compliance with the Lifestyle Plan, in particular its failure to:

a. Ensure services were delivered to Ms N as specified in the plan at a standard consistent with the Disability Service Standards.
b. Ensure there was regular liaison by DHCS LAC, the Respite Centre and the Guardianship Board (sic).

c. Participate in monthly meetings with health clinic staff and respite services.
d. Ensure that the contracted service provider was adequately staffed; and
e. Ensure that the contracted service provider employed appropriately trained staff (or provided the necessary training).

(iii) Inadequate staffing and over-work of the Aged and Disability Service such that staff could not regularly visit the community or oversight Ms N's care.

(iv) Its failure to identify any appropriate and regular respite service outside of Ms N's community.

(v) Its failure to identify or provide any alternatives to the care contemplated in Ms N's community.

(vi) Its failure to communicate adequately with the Public Guardian; and

(vii) Its failure to forward plan for Ms N.

190. Critical matters in respect of systemic failings by the Council and the Respite Centre include their failure to:

(i) Deliver services as required by the Service Agreement and Lifestyle Plan.

(ii) Deliver services that complied with the Disability Service Standards (including as to level of staffing and training).

(iii) Comply with the reporting, meeting, and liaison provisions of the Service Agreement and Lifestyle Plans.

(iv) Maintain any records about the delivery of services to Ms N; and

(v) Communicate adequately with the Public Guardian.

191. Critical matters in respect of syetemic failings of the Health Clinic include their failure to:

(i) Report matters of suspected abuse to the police; and

(ii) Communicate adequately with the OPG and DHCS concerning Ms N's health, care and circumstances.

192. Critical matters in respect of systemic failings of the Office of the Public Guardian include their failure to:

(i) Communicate adequately with and take responsibility for communication with the Adult Guardians and service providers.

(ii) Report matters of suspected abuse to the police; and

(iii) Consistently advocate and make decisions in Ms N's best interests.

9. RECOMMENDED ACTION ARISING FROM THE INVESTIGATION

193. It is acknowledged that, given the length of time since Ms N's death and the delay in the completion of this investigation, circumstances may have changed with respect to the delivery of care services to persons with disabilities in remote communities. The Department submits that following two earlier reviews, recommendations have been implemented

which ensure that complex clients are proactively case managed, risks are assessed, services are delivered and standards are maintained.

194. However, in light of the systemic failings identified by this Investigation over two decades, a real and significant potential risk to a cohort of our most vulnerable community members cannot be excluded based on reassurances of change and further investigation is essential.

195. A comprehensive and independent inquiry must be undertaken to determine whether care provided to people with disabilities in remote communities has improved since Ms N's death in 2006, or whether their safety, well-being and dignity remain at serious risk as a result of the same systemic failures that had such a tragic impact on Ms N's life.

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10. NATURAL JUSTICE

Section 67 of the *Health and Community services Complaints Act* states:

> *67. Adverse comments in reports*
> *(1) The Commissioner must not make any comment adverse to a person in a report under this Part unless –*
> *(a) the person has been given a reasonable opportunity to be heard in the matter; and*
> *(b) the person's explanation (if any) is fairly set out in the report.*

196. All parties to this investigation, namely the North Australian Justice Agency, the Department of Health, Office of the Public Guardian and the Shire that has replaced the relevant Council were provided with the draft report on two occasions. On the first occasion, in January 2012, comments were sought on the factual aspects of the report only. In December 2012 comments were sought from DoH, OPG and the Shire on the draft conclusions and recommendations. Further consultation with NAAJA occurred between April and May 2013.

197. Comments in response to the draft report have been considered and included in the final report where necessary to provide correction, address difference of view, or add further detail.

198. The names of the people directly involved in the provision of services to Ms N have been removed where any adverse comment has been made or may be implied. This has been done in light of the conclusions that it was a failure of the various systems, rather than any one individual that were the main issue in this investigation.

199. Ms N's family were consulted prior to the finalisation of the report and requested that Ms N's name not be used for cultural reasons. The family were not provided with a draft of the report and have not provided direct comment on its content.

Lisa Coffey
COMMISSIONER
27 June 2013