

STATE CORONER'S COURT OF NEW SOUTH WALES

Inquest:

Inquest into the death of AA

Hearing dates:

30 September, 1,2,3, 4 October 2013

Date of findings:

26 September 2014

Place of findings:

Newcastle

Findings of:

Deputy State Coroner E. Truscott

Catchwords:

Childhood Obesity, Obstructive Sleep Apnoea, Medical Neglect

Care and Protection

File number:

2012/3007

Representation:

Counsel Assisting: Mr I Bourke instructed by Crown Solicitors

Office (Mr A Mykkeltvedt)

YY and ZZ (parents): Mr R Cavanagh instructed by Mr J.

Herrington of Legal Aid Commission NSW

Hunter New England Local Health District: Mr P Rooney

instructed by Ms Henry of Curwood's Solicitors

Department of Family and Community Services: Mr D. Shridhar

instructed by N Hali of Legal Services (FACS)

NSW Department of Education and Training: Ms D. Ward

instructed by Ms Sandra Butler of Legal Services NSW

Department Education and Training

Drs Tang and Gulliver: Mr Hewson instructed by Avant Law

NPO made under s105 of Children and Young Person Care and Protection Act. Name of children not to be used and any identifying features , school, suburb not to be published.

Findings:

AA died on 29 September 2010 at the John Hunter Hospital from hypoxic brain injury occasioned in a cardio-respiratory arrest due to complications of morbid obesity which, contrary to medical advice, was not addressed by his parents.

Recommendations:

- 1. Consideration be given to the establishment of a Weight Management Unit within the JHCH for the treatment of children with eating disorders including serious obesity.
- 2. That sections 7 and 10 of the Ministry of Health Policy regarding Neglect and Responses to Neglect be amended so that child protection issues are properly identified and responded to.
- 3. Consideration be given to the establishment of a formalised and administratively supported Child Protection Unit at the John Hunter Hospital.
- 4. That the D-G Ministry of Health and the D-G Family & Community Services give consideration to entering into an arrangement under s27A(2) of the Children and Young Persons (Care and Protection) Act 1998 so that a formalised system involving Alternative Reporting Arrangements can be introduced to the JHH, JHCH and RNC ("The Hospital")

That if such an arrangement is made:-

- (a) the D-G Ministry of Health designate persons or a class of persons who are members of the Child Protection Team at the Hospital as "assessment officers" for the purposes of 27A(3) and (6);
- (b) the Child Protection Team at the hospital be structured, funded, and administered to carry out the functions under \$27A;
- (c) the CPT be identified as a "Unit" capable of employing seconded Child protection officers in the employ of Community Services;
- (d) the CPT have its own office space so that clinicians, medical staff, members of the public and other agencies identify the place where the Unit exists;

- (e) that Policy Procedure and Guidelines be developed in line with CPT carrying out the reporting duties under s27A;
- (f) that Director Health liaises with Director Communities, Hunter to develop mutually acceptable procedures for the introduction and evaluation and improvement of a system of alternative reporting by the Hospital.

E. Truspott

26

September 2014

DEPUTY STATE LORONER

Reasons for Decision

Introduction

- AA died at the John Hunter Hospital in Newcastle shortly after he was taken off life support on 29 September 2010. Twelve days prior, AA had suffered a catastrophic cardiorespiratory arrest and though he was resuscitated he had suffered major brain injury from which he could not recover. He was 10 years old. The circumstances leading up to the fatal injury are the subject of this Inquest.
- I have conducted the Inquest pursuant to sections 22 and 24(b) of the Coroners Act 2009 ("the Act"). Under those sections of the Act, a Senior Coroner may hold an Inquest into the death of a child who had within 3 years of his death been subject to report/s under Part 2 of Chapter 3 of the Children and Young Persons (Care and Protection) Act 1998.
- Section 23 of the Children and Young Persons (Care and Protection) Act 1998 sets out 7 situations where a child may be "at risk of significant harm".
 - (a) the child's or young person's basic physical or psychological needs are not being met or are at risk of not being met,
 - (b) the parents or other caregivers have not arranged and are unable or unwilling to arrange for the child or young person to receive necessary medical care,
 - (b1) in the case of a child or young person who is required to attend school in accordance with the <u>Education Act 1990</u> -the parents or other caregivers have not arranged and are unable or unwilling to arrange for the child or young person to receive an education in accordance with that Act,
 - (c) the child or young person has been, or is at risk of being, physically or sexually abused or ill-treated,
 - (d) the child or young person is living in a household where there have been incidents of domestic violence and, as a consequence, the child or young person is at risk of serious physical or psychological harm,
 - (e) a parent or other caregiver has behaved in such a way towards the child or young person that the child or young person has suffered or is at risk of suffering serious psychological harm,
 - (f) the child was the subject of a pre-natal report under section 25 and the birth mother of the child did not engage successfully with support services to eliminate, or minimise to the lowest level reasonably practical, the risk factors that gave rise to the report.

Note: Physical or sexual abuse may include an assault and can exist despite the fact that consent has been given.

- Reports that AA was at risk of harm in 2009 and risk of significant harm in 2010 were made to the Director General of the then Department of Community Services consistent with (a) (b) and (e).
- At the commencement of the inquest, I granted leave to appear to the NSW Department of Health, Department of Education and Training and the Department of Family and Community Services (previously known as Department of Community Services), all of which had some involvement with AA and his family. (Throughout these findings I will refer to the Department of Family and Community Services as Community Services or "CS"). I have been assisted by Reports from the NSW Ombudsman and the NSW Child Death Review Team. I have also received other evidence in relation to the child and his family.
- The Inquest has involved issues of childhood obesity and its serious medical consequences particularly on the child's respiration and heart. The evidence has also involved the issue of medical neglect and the delivery of health and support services to AA and his family.
- Unfortunately, I received limited evidence about AA's parents and the factors impacting on them affecting their ability to meet AA's medical needs. AA's parents refused to give a statement to the police and have refused to give evidence in this Inquest, preferring that their 21-year-old daughter do so. Accordingly, in assessing these matters I was limited to referring to file notes made by health care providers when the parents presented for opiate replacement therapy and, in the case of AA's mother, the Stimulant Treatment Programme and the John Hunter Hospital in relation to her medical care and AA's medical care respectively.
- There has also been some limited evidence about the parents through the Department of Education and Training records and Community Services' Records. It would have been preferable to have heard the parents' perspective to understand the factors underpinning their apparent difficulties in meeting AA's medical needs.

Changes have been made since AA's death so that there is a better exchange of information and resources between the services of health, community and education. These changes have come about partly in connection with an Ombudsman's Inquiry and a Review by the Child Death Review Team relating to AA's death, and partly as a result of the development of the NSW State Government Child Protection Policy "Keep Them Safe", which commenced in January 2010. That policy was implemented as a consequence of the Wood Inquiry into Child Protection. There have also been changes at the hospital, primarily with policy relating to childhood obesity, medical neglect and the Child Protection Team. Finally, I have received evidence about how some of the changes will be improved with the allocation of resources to assist children in need of medical care and protection.

Background

- AA was the youngest of 6 children of ZZ and YY. Though the parents lived in separate homes for much of AA's childhood, they lived close to each other and both parents played a role in caring for him. Prior to AA's death, he and his mother were living at his father's house with his teenage brother and sister. An older sister lived elsewhere with her baby and the two elder brothers were living outside Newcastle. Both parents have a history of illicit drug use and both have been on the methadone programme for over a decade.
- The family had been the subject of numerous reports to Community Services over the years and the older children, when young, were in the care their paternal grandmother for a time. In about 2003, YY had been diagnosed with Borderline Personality Disorder and commenced medication. However, she continued to struggle with amphetamine use which became a significant problem; ultimately causing her much ill-health requiring to be hospitalised on occasion for endocarditis.
- By the time AA was born all the children had returned to live with their parents. Reports regarding the family continued to be made to Community Services. However, little, if any intervention by Community Services' occurred.
- 13 The father's house is a 3 5 minute walk to the local primary school, which AA attended from 2006 until his death. AA had a reasonably high level of absenteeism in kindergarten and year one. From 2008 onwards, the absenteeism escalated consistent with his ill

health. Despite AA's absenteeism, school staff did not have concerns about YY and ZZ's care of AA because on the occasions he did go to school he appeared to be much loved, well presented and well behaved and he tried his best.

In May 2008, when he was nearly 8 years old, AA was admitted to the Intensive Care Unit (ICU) at John Hunter Children's Hospital (JHCH), suffering respiratory distress. He was diagnosed with Morbid Obesity and Obstructive Sleep Apnoea. The doctors told the parents that AA would need to use a ventilation system when sleeping, and he needed to lose weight by adjusting his diet and increasing his exercise levels. He was required to attend regular appointments to review him but he attended only a few. He was readmitted into the ICU about one year later in mid June 2009, after his health had deteriorated. In July 2009 a doctor described AA's sleep apnoea and morbid obesity as being at a "medical emergency intervention stage". Unfortunately, by the end of that year he had ceased having contact with the hospital and continued to gain weight. He attended rarely and when he did he had much difficulty in staying awake and breathing properly. Ultimately, in September 2010 he was taken to hospital after losing consciousness at home. He stopped breathing on the way to the hospital and never regained consciousness.

Initial Diagnosis

- On the evening of 6 May 2008 the mother took the then 7 year old AA to her General Practitioner Dr Lindsay Marsh who referred him to the Emergency Department at John Hunter Hospital. AA was admitted into ICU and after 5 days was transferred to a ward at the John Hunter Children's Hospital (which is part of the same campus).
- This was the first time AA had seen Dr Marsh. AA only saw him on one other occasion on 17 July 2009 so it cannot properly be said that Dr Marsh was his treating General Practitioner. There are no records of either of the parents taking him to see any other doctor.
- During the May 2008 admission Dr Jodi Hilton and Dr Tanya Gulliver became involved in AA's medical care and treatment. Both Dr Gulliver and Dr Hilton are specialists in Paediatric Respiratory and Sleep medicine at the John Hunter Children's Hospital. They are part of a team together with Dr Whitehead and Dr Mattes. In her evidence, Dr Hilton explained that when AA presented to the hospital his family gave a history of symptoms

consistent with obstructive sleep apnoea, which had never been investigated. Whilst in the Emergency Department AA was observed to have recurrent apnoeas and was diagnosed with tonsillitis. He was admitted to ICU to support his airway and to treat his tonsillitis with IV steroids and antibiotics.

- Dr Hilton explains "apnoea" as a pause or cessation of breathing and obstructive apnoea as where something is physically obstructing the upper airway. In children the primary cause of obstruction is enlarged tonsils and/or adenoids. In adults the primary cause is related to obesity. AA had both enlarged tonsils and morbid obesity (his BMI at the time of that admission was 30 (normal range about 14 to 20), weight 50kgs and height 130cm). Dr Hilton explains "common features of obstructive sleep apnoea are habitual snoring, pauses in breathing overnight and disturbed sleep. The sequelae include excessive daytime somnolence (falling asleep), behavioural changes in children and difficulty with concentration and learning and can have long term complications of hypertension and cardiac disease. Another symptom can be early morning headaches, which AA did describe, relating to rising carbon dioxide levels. Oxygen levels are affected during the obstructive episodes due to lack of respiration."
- Whilst in ICU, AA was fitted with a CPAP machine that provides a "continuous positive airway pressure" delivered through a nasal mask worn when sleeping. On 12 May AA was transferred to the Paediatric Sleep Unit for a sleep study which confirmed severe obstructive sleep apnoea. AA tolerated 7cm of pressure via a nasal mask on CPAP with "almost complete resolution of obstructive sleep apnoea".
- On 12 May 2008 the Paediatric Endocrine team also reviewed AA and he had tests for high lipid and thyroid function. As a result of those tests, the team were of the view that AA's obesity was due to excessive oral intake and inadequate energy output eating too much while exercising too little. An appointment was made for AA to attend an oral glucose test on 5 June 2008. He was also to return for a repeat sleep study in 6-8 weeks. On 12 May 2008, AA's mother was educated about the need for her son to use the CPAP and how to use it. On 13 May 2008 both parents were educated about the CPAP. There are no notes about what it was they were told but at the least it was the need for AA to wear the mask overnight while sleeping and how to operate the machine.

It is questionable whether at that point of time either parent understood properly the seriousness of the risk that AA's weight and apnoea posed to his health. Though the evidence is that they were handed pamphlets about the CPAP machine and were advised that AA needed to lose weight, Dr Hilton remarks in her statement that neither parent thought that AA was overweight let alone obese, and saw no problem with his weight. Dr Hilton wrote that the mother "could not seem to comprehend that AA's obesity was a health risk and contributing to the problem that AA currently had". Dr Hilton remarks in relation to the father "I got the impression he didn't really understand what was going on, despite numerous attempts at explaining to him AA's health issues. The doctors, nurses, dieticians and social workers repeatedly provided education and voiced our concerns to both AA's mother and father".

Outpatient Treatment

- AA was discharged from John Hunter Children's Hospital on 13 May 2008. Prior to his discharge, an outpatient plan was prepared. The outpatient plan involved him attending the dietician and weight management group. He also needed to attend hospital for an Oral Glucose Test to determine whether he was suffering from diabetes. The appointment was scheduled for 5 June 2008. AA's parents were also to make an appointment to consult with Dr Walker, an Ear Nose and Throat specialist about AA having surgery to remove his tonsils and adenoids to assist his breathing. He also needed to have a respiratory team sleep study review on 26 June 2008.
- On 22 May 2008 a registered nurse working at the hospital made a follow-up phone call to AA's parents. Her notes say she was told that AA was using the CPAP mask without problems and the parents said that there was a marked difference and improvement in AA's sleep quality and energy levels.
- The reassurance that things were going well for AA is not borne out by the school absentee records. After AA's discharge from hospital, there were 40 days remaining of the school term. AA was predominantly absent from school. Between 22 May and 26 June 2008 he attended 3 full days and 6 partial days some for as little as 5 minutes before he would go to sick bay and the school would telephone his mother to come and pick him up.

- AA underwent a sleep review on 26 June 2008. It would seem that his absence from school on that day was due to his attendance for a medical appointment but this wasn't conveyed to or recorded by the school other than being "sick". The evidence suggests that when AA's mother collected him from the school sick bay, she would indicate that he needed to go home to be put on the CPAP machine. Otherwise, the school was completely unaware of what medical treatment AA required or was receiving.
- The opportunity to use AA's school attendance as a potential marker for his wellbeing was not identified by the hospital. Had the hospital been advised that AA was still largely absent from school the question as to whether this was due to an inadequate improvement to his sleep quality and energy levels could have been investigated rather than relying on the parents' reports.
- The night before the oral glucose test scheduled for 5 June 2008, the hospital telephoned YY and confirmed that AA would need to fast from midnight and arrive in the morning. However, AA did not arrive for the test, nor was any message received about his failure to attend. The hospital rang the parents who advised that they didn't get to hospital because they had car trouble. Another appointment for the Oral Glucose Test was made for 13 August 2008. AA was supposed to also attend a dietician on 5 June 2008 but according to YY they were too sick to attend and despite the staff encouraging YY to rebook she did not.
- The mother did take AA to the Paediatric outpatient sleep review on 26 June 2008. She told Dr Gulliver that AA didn't like to use the CPAP machine because of the cold air. He was then provided with a humidifier, which makes the air warmer and moister. AA and YY were shown how to use it.
- Dr Gulliver inquired about Dr Walker's advice and when she was told they hadn't made an appointment she gave the mother another referral. Despite having been counselled in May about the importance for AA to reduce his weight, AA had actually gained about 5 kg in the 7 weeks since his discharge from hospital. Given AA's weight gain, the missed blood glucose test and the lack of follow up with Dr Walker, Dr Gulliver was concerned that the parents had failed to implement the treatment plan. However, she did not consider referring AA to a paediatric social worker or consider whether he was at risk of

harm through medical neglect and therefore should be referred to the Community Services Helpline.

- On 12 August 2008 AA and YY attended for an overnight sleep study, which indicated that his oxygen saturation was only 56% (it had been 81% in his first sleep study in May), so his CPAP pressure was increased with some resolution of symptoms. This also indicates that if AA had been using the CPAP he would have been receiving little benefit from is consistent with his continued school absenteeism.
- AA was supposed to have had an oral glucose test the morning of 13 August 2008 (following the overnight sleep study). The test required AA to fast from 10 pm the previous night. A doctor was supposed to attend to place the cannula at 8 am but was delayed due to a medical emergency elsewhere in the hospital. By 10 am, the doctor had still not attended and the discharged AA saying that it was cruel to starve a child. The hospital notes say that it was the mother and not the child who was distressed about the fact that he was required to fast for longer than planned.
- During AA's hospitalisations it was noted by staff that the mother and sometimes the father would feed AA high calorie non nutritious food such as cordial, chips and chocolates, even during times when AA was resting or attempting to sleep with the CPAP mask on. Though staff asked AA's parents to not do this, this advice was usually ignored. there was no real attempt to assess whether AA's weight gain, the parent's inappropriate feeding of him, his lack of attendance upon Dr Walker, and missed appointments were representative of medical neglect.
- Another sleep study and review with Dr Whitehead was booked for 21 August 2008 but AA did not attend. Another appointment was made with Dr Hilton for 22 September 2008. That appointment was not kept either. There was no reason recorded for non-attendance. It was important for AA to have these reviews not only to make sure he was tolerating and using the CPAP but also to make sure it was on the correct pressure. There was also a need to monitor his weight, as that was such a significant factor to his apnoea. By this stage there should have been a picture presenting itself that AA's medical needs were being neglected but there were still no reports or referrals to a paediatric social worker or Community Services.

- AA did attend an appointment to undergo a sleep study on 20 November 2008. It had been over 3 months since his last sleep study and review. Both parents attended and they reported that AA was regularly falling asleep at inappropriate times and was not consistently wearing the CPAP mask. They also stated that he was missing a lot of school because he was falling asleep. He had not seen the dietician and again the mother refused to allow him AA to have the oral glucose test. AA had gained a further 4 kilograms and his BMI had increased to 32. The parents had still not taken AA to see Dr Walker so Dr Hilton made another referral, (the third).
- Six months had passed since his May 2008 discharge without improvement. In fact, AA's condition had deteriorated in some respects; he had gained more weight and was missing more school. Again, there was no referral to a social work paediatrician or Community Services.
- Unbeknown to the medical staff involved in AA's care, the mother was struggling with amphetamine use throughout this time. The Newcastle Pharmacology clinic's records dated 25 September 2008 indicate that she continued to use drugs despite clear awareness of the risk to her health. The records also show that when YY attended in July 2008 she informed them that her son was recently admitted to JHH, had sleep apnoea and was then receiving CPAP treatment there is no mention of his obesity. There was no dialogue between the clinic and JHH despite both being members of Hunter New England Area Health Service.
- Dr Hilton said in her statement and in her evidence, that she formed the opinion that AA was not using his CPAP adequately. If he had been doing so, he would have been more active and sleeping better. Another sleep study appointment was made for 3 February 2009. AA did not attend that appointment either. When the hospital staff rang YY to determine why they hadn't attended she told them it was "none of their business". Another appointment was made for 9 March 2009. That appointment was not attended either. The mother was using amphetamines throughout this time as evidenced by the records held at the Newcastle Pharmacology clinic. On 5 March 2009, it was recorded that YY claimed to have stopped "using" a couple of weeks prior then last "used" a week or so earlier, there were dramas with the family and she was looking after a

granddaughter. The clinician noted a weeping lesion on YY's left forearm, consistent with being a drug related infection site.

Dr Gulliver says in her statement that there was a multi-disciplinary team meeting with the family in early 2009 where it was impressed upon them that AA's condition was life threatening. I consider it likely that this was an error in her memory as there are no records and no indications at all that there was any such meeting, indeed the family failed to attend on 3 February 2009. It may be that Dr Gulliver is referring to a meeting with the Child Protection Team to decide whether to make a report to Community Services that AA was at risk of harm.

On 31 March 2009, following consultation with the hospital's child protection team, Dr Gulliver made a notification to Community Services that AA was at risk of harm for failure to attend for medical treatment. I return to this notification later, but suffice to say that a social worker from Community Services telephone the mother and without inquiring into what was happening for them to miss the appointment, made another appointment for AA to attend the non-invasive ventilation clinic on 7 May 2009. This was one of two annual clinics run by the paediatric outpatients. Dr Gulliver was advised to report AA again to the Helpline if he didn't attend that appointment.

AA did attend on 7 May 2009. It had been nearly 6 months since he attended for the sleep study. The CPAP was serviced. Dr Whitehead reviewed AA and found that he had gained a further 10 kilograms. He now weighed nearly 68 kg and his height was 137.6cm. AA had gained approximately 18 kilograms in the 12 months since his first admission. This weight gain was vastly disproportionate to his height gain of 7.6cm. Dr Whitehead says that the parents told him that AA was wearing the CPAP mask and that he was bright during the day and did not nap during the day. This is not borne out by the school absentee records (2009 Term one, AA was absent 13 days, in term 2 he was absent 34 days) or the teachers' statements that he would fall asleep in class. It is also not consistent with the amount of weight he had put on.

The parents had still not made an appointment with Ear Nose and Throat specialist Dr Walker though they had told Dr Whitehead that AA had had two bouts of tonsillitis.

There appear to be no Medicare records for these bouts of illness, suggesting that AA

wasn't taken to a doctor for treatment and did not receive antibiotics. On 7 May 2009, Dr Whitehead referred AA to the dietician and made another referral to Dr Walker.

- Deirdre Burgess, a dietician met with AA and his mother on that day. Her statement says she observed that AA had a skin disorder called Acanthosis Nigricans described as dark marks at the back of his neck and underneath his armpits. This condition may be attributable to insulin resistance, a side effect of being overweight. There are notes about a referral to a heart specialist but no indication that one was actually made.
- Ms Burgess noted that AA and his parents were keen for him to lose weight and YY told her that he was playing soccer and trained once per week and played once per week. Ms Burgess asked YY about AA's food intake. Ms Burgess's notes describe large amounts of take-away food, high fat foods, and high sugar drinks chicken nuggets, sausages, hotdogs, pies etc. Ms Burgess also noted that AA would eat 2 cups of pasta or rice at dinner a large serving for an 8 year old. Ms Burgess provided a meal plan after working out with YY snack foods, meal sizes and appropriate drinks.
- It would appear that during the last 12 months, AA's parents had not been able to effect any changes to AA's intake though AA's participation in soccer was an increase in his energy output. The there is a statement from the soccer coach remarking that after a game AA's father would buy him a meat pie and a coca cola.
- Another dietician appointment was made for 28 May 2009. AA did not attend that appointment. AA was staying with his father at that time because the mother was admitted to JHC on 15 May as she was suffering from endocarditis due to amphetamine use. In her statement, Ms Burgess says that a lot of patients cancel appointments or do not attend because weight loss is so difficult. She remarked that higher staffing levels would mean that a higher level of support could be given to families. It would make sense that a person would not want to attend a weigh in if they had either failed to lose weight or indeed had put weight on since their last attendance. However, I do not know if this is the reason AA was not taken to the appointment.
- The level of the mother's drug use was reported by her to a doctor as being very significant. She said she was using amphetamines at a rate of \$100 per day and had been for about a year. She remained a patient for 6 weeks. A psychiatric review by Dr Davies

at the end of June sets out that though YY had awareness as to the potentially fatal consequences of continuing to use and despite really wanting to stop she had little confidence in her ability to do so. She was referred to the Stimulant Treatment Programme, which she commenced in July. It is difficult not to draw the conclusion that her powerlessness or inability to change her drug use was no different to the inability to change AA's diet and exercise.

- On 7 May 2009 another sleep study with AA was booked for 22 June 2009. The father took AA to that sleep study, during which it was noted that he did not tolerate the CPAP and sat up fighting against it and pulling off his mask. The mask pressure was changed and he appeared to tolerate it at a pressure of 12 cm of water. Again this indicates that AA was probably not using the machine as he didn't like it. Again this is consistent with the school absentee records. Another sleep study was booked for 23 July 2009. AA had still not seen Dr Walker so another referral was made- this was the 4th in the 12 months.
- On 27 June 2009 AA was admitted to hospital. He had a cough and shortness of breath, and required immediate CPAP support due to central cyanosis and chest pain associated with severe respiratory distress. He was diagnosed with a respiratory viral infection. His oxygen saturation was 82%. He remained on oxygen and CPAP in hospital for 4 days.
- At the time of AA's admission, his mother was still an inpatient. She was discharged on 2 days later. The reason for YY's hospitalisation was not recorded on AA's file so the implications of her drug use and her own medical condition and any impact on her being able to meet AA's medical needs was not subject to inquiry by AA's treating doctors. As the parents had still not made an appointment to see Dr Walker the hospital arranged an appointment on 1 July 2009. Dr Walker agreed to AA's surgery to remove his tonsils and adenoids. Dr Walker notes indicate that the parents were afraid AA would die during the surgery. Dr Walker reassured them and referred them to Dr Farrell, an anaesthetist.
- Also during that admission, a Dietician met with AA and YY on the ward. YY insisted that AA was not a big eater. She also denied having been given a meal plan on 7 May 2009 and refuted the suggestion that there had been appointments they hadn't attended. YY was upset saying she felt she was being judged by the hospital. She also indicated that she thought AA's weight was a problem only in that it "may" be linked to his

breathing. She was given (another meal plan) and she agreed to follow it for a month and see if AA lost weight. AA was discharged on 1 July 2009.

- The next day the parents attended a joint meeting with AA's healthcare team, dietician and physiotherapist. Doctors Hilton and Gulliver were in attendance at this meeting. The parents agreed to take AA to appointments including a monthly respiratory team meeting so his breathing could be monitored. There are few notes about what was said to the parents about AA's medical condition but it is recorded that his condition was at a medical emergency intervention stage.
- I am confident that this was conveyed to AA's parents and they understood the seriousness of his condition. This conclusion is supported by the evidence contained in the statement from "K", who was friend of YY's, "I remember that YY told me maybe 12 or 18 months before he passed away that the doctors at the hospital had told her point blank that if AA didn't lose weight that he was going to die. That was when they got him into playing soccer to try and lose weight. (June 2009). AA's parents knew that AA's problems were weight related but it was like they didn't know what to do about it. Even though they had doctors telling them what to do, it just didn't seem to sink in...but they didn't do anything about it. They just continued on the way they did..."
- Furthermore, YY and ZZ's elder daughter, in her statement to the police, said on occasion she had heard her parents say to AA when insisting that he wear his CPAP mask that it was a matter of life and death. That certainly has the ring of truth however she resiled from having said that to the police explaining that her parents would never say that to a child. I think that she told the police the truth when she made her statement but did not wish to say anything she perceived as adverse about her parents when she was in the witness box.
- At the meeting on the 2 July, a paediatric social worker attended the meeting, but was not involved in any follow up. This case never involved the Child Protection Team at the hospital despite the earlier referral to the CS Helpline and the recurring difficulties with treating AA and poor outcomes since his May 2008 admission.

- On 2 July, a number of further appointments were booked for AA: Weekly physiotherapy appointments were made from 9 July 2009 AA attended 3 of these -, 29 July, 5 August and 4 September. AA was to have a sleep study review on 23 July 2009 and appointments with the dietician were booked for 23 July, 20 August, 24 September, and 22 October 2009. AA attended the dietician 3 times- his last attendance was 24 September 2009. He attended the sleep study and dietician on 23 July. He was supposed to attend the sleep unit again on 10 September but did not.
- AA had attended Dr Marsh on 17 July 2009 presenting with complaints of sleep apnoea, morbid obesity and a sore right knee. AA's parents told Dr Marsh that AA was playing soccer and riding a scooter. They were adamant he was not eating too much. Dr Marsh referred him back to see Dr Gulliver for assessment. The mother took AA to see Dr Gulliver on 23 July. She wrote to Dr Marsh on 27 July 2009 indicating that AA had started exercising and that she planned to regularly monitor AA and follow up in a month's time. AA did not attend Dr Marsh again nor did he attend Dr Gulliver again missing the appointment on 10 September. Despite Dr Gulliver's plan to monitor AA monthly no further appointments were made or kept for the sleep review.
- AA and his parents did meet with Dr Farrell, the anaesthetist on 21 August 2009 and again with Dr Walker on 17 September 2009 to discuss the risks associated with the contemplated surgery to remove AA's tonsils and adenoids. Dr Walker says that the parents were still concerned about the risks to AA if he had surgery and he advised them to talk to Dr Whitehead (JHH respiratory team leader) about the benefits of AA undergoing the surgery. AA did not attend an appointment with Dr Whitehead in the Non Invasive Ventilation Clinic on 22 April 2010. That appointment was to involve a review of AA's condition and the servicing of his CPAP machine.
- The parents had apparently decided not to proceed with the surgery but did not wish to discuss this with Dr Whitehead or any other physician. Though the surgery would not have cured AA's condition, it would have alleviated the obstruction to his breathing, lessening the risk to him if he experienced an apnoeic episode, for example, when the mask fell off during the night.

- ZZ had agreed to take AA for the oral glucose test on 27 August 2009. When AA did not attend, the staff rang YY who said she was not aware of the appointment, so another appointment for 3 September was made. On that day, YY telephoned and cancelled the booking, saying AA was sick. Another appointment was made for 1 October 2009. Again he did not attend, again the hospital rang his mother and again she said they couldn't attend, this time because the father was very sick and had to go to hospital.
- I doubt whether this was true as unbeknown to the hospital the parents had relapsed into heroin use as evidenced by the parents' pharmacotherapy records. On 21 August 2009 the father disclosed that he had been injecting almost daily. On 12 October 2009 he reports using heroin once since 21 September 2009; he looked well and didn't say he had been sick. On 9 November 2009 he reported that he was continuing to use. I note that the mother attended the clinic and received her methadone on 1 October 2009 so there should not have been anything stopping her from taking her son to the glucose test. It seems obvious that she still did not want AA to have the test.
- On 1 October, the hospital made a notification to Community Services that AA was at risk of harm due to the unattended appointment and that they had made another appointment for the test to be conducted on 5 November 2009. Again AA did not attend. This time a report wasn't made to Community Services. There was no follow up by the hospital to see what had become of AA and no consideration was given to reporting again to the CS Helpline that he was a child at risk of harm due to medical neglect.
- The last contact AA had with the hospital prior to his final admission in September 2010 was on 24 September 2009 when he and the mother attended Emily O'Connor.
- Ms O'Conner met with AA and YY on 27 June 2009 while AA was hospitalised and again on 2 July 2009, when the intensive monitoring plan was put in place. They also met on 23 July and 24 September 2009 as scheduled (having missed the August appointment). Ms O'Connor says that AA's weight increased from 64.4kgs on 2 July to 67.3kgs on 23 July and on 24 September 2009 he recorded the same weight of 67.3k. At the 23 July meeting YY said that they were going for walks but she had been unable to implement the food plan given on 2 July 2009, saying that it was difficult to maintain a

routine for food, and as an example they had had McDonalds before that day's appointment, stating she was unable to deny AA that.

- Ms O'Connor said in her statement that she thought the number of food changes overwhelmed YY so she tried to get YY to focus on small changes such as stopping buying sugary drinks. At the appointment on 24 September 2009, YY indicated that AA's food intake appeared to be the same as previously and that she had been unable to make any changes. They planned on meeting on the same day as the oral glucose test on 1 October 2009. AA did not attend then or any date after.
- AA did not have any medical intervention for his weight management and OSA over the following 12 months. His weight escalated to 80 kg. The evidence overwhelmingly indicates that adherence to any meal plan was extremely short lived and AA's diet and underactivity continued through that year. Given the failure to attend appointments on all fronts sleep study, oral glucose test, dietician, physiotherapy, not having the CPAP machine serviced the last 12 months of AA's life was a period where his medical condition was left untreated and unmanaged by his parents.
- That is not to say that they did not care about it nor care for him. There is ample evidence that both parents loved AA very much and were dedicated to AA and sought to meet his needs on many levels. In fact, in her statement "K" indicates that whatever AA wanted, his parents gave him. But the one thing that AA really needed help with could just not be delivered and not only did AA suffer from morbid obesity and obstructive sleep apnoea he also suffered from medical neglect.
- Ultimately, though the parents were told that AA's weight and obstructive sleep apnoea were life-threatening, I consider it unlikely that they ever thought his death would be as imminent as it was. I think they probably just got used to AA being constantly drowsy and "falling asleep". YY and ZZ had parented other boys who were also very overweight as youngsters and apparently as they got older they slimmed down. However, there is no evidence to suggest that those sons also had sleep apnoea or stopped breathing during the day so that they couldn't go to school or had to be sent home after being there for 5 minutes because they couldn't stay awake. Though the doctors impressed upon the parents that AA was in a life and death situation and though the parents were able to convey that to their friends, it was as if they didn't or couldn't really believe it. To the

extent that they did comprehend the severity of the situation, it appeared that making the necessary changes was, for them, impossible.

The Extent and Role of Parental Drug Use in Context of AA not having his medical needs met

- The hospital notes indicate that the paediatricians, dieticians, physiotherapists were trying to engage the parents. There is no indication however that the clinicians had any idea that the lack of engagement may be due to drug use, which had been a problem for the parents since AA's diagnosis (and, in YY's case, pre-existing). Newcastle Pharmacology Records relating to YY indicate that on 10 July 2008 YY was well and not using drugs. She reported that her son had been recently admitted to JHH and diagnosed with sleep apnoea and given a CPAP machine. In September 2008 the records indicate she was using amphetamines fortnightly, which was continuing as at December 2008.
- On 5 March 2009 YY reported that she had stopped using a fortnight prior but had used a week ago and a weeping lesion was noted on her left forearm as an injection site. On 7 July 2009 YY attended the Newcastle Stimulant Treatment clinic requesting to enrol with the Stimulant Treatment Programme, where she would receive prescribed dexamphetamine and counselling. During the assessment interview she received a number of calls, 3 of which were from AA who was according to YY at home unwell due to sleep apnoea. YY reported that she used "amphetamines to give her more energy to do simple things like make the bed" and that when didn't use she "has no energy and wouldn't even get out of her PJs".
- YY identified amphetamine speed/Ice as the drug she used, and said she used it daily, by Intravenous injection, at a cost of \$50-100 for 3-4 points, last used 8 weeks ago, had been using daily for about a year. She reported that she had no other problem with other drugs except heroin, which she hadn't used for 4 years and had been on methadone for 9 years. She reported she had experienced drug-induced psychosis from using "speed and ice".
- YY continued to use amphetamines after her discharge from hospital and referral to the STP. On 14 July 2009 she reported she had used only once and on 28 July 2009 she reported that she had not used since but that prior to going on the programme her pattern of use had been to receive her methadone dose and then go to her dealers each day.

- YY didn't attend the STP clinic on 4 August 2009, ringing to cancel but refused to wait for another appointment to be made. The clinic staff left 3 messages for her over the ensuing 2 days asking her to contact the programme to make an appointment. On 17 August she reported to her methadone providers that she was using \$300 heroin a day. On 18 August, she reported to STP that she was using heroin, 1-1½ points per day, and injecting 2-3 times, and that she and her partner were using. She had her methadone increased 5 days prior and it was increased again on that day. She was stressed about one son who was in prison and her 9 year old who has poor health and weight problems. YY said that she and AA had moved into ZZ's house a month earlier because of an argument she had with her eldest son and his partner but planned to move back to her house when they moved out.
- On 21 August 2009 the father's methadone dose was increased at his request because he said he had been injecting heroin almost daily and was keen to quit illicit drug use. His dosage was again increased from 31 August 2009 because he was still using, but less frequently. On 21 September 2009 he reported that he injected heroin ordered by his girlfriend and that he only used because he was in the company of other injectors.
- YY's records indicate that she attended the STP because they had withdrawn treatment due to not attending appointments. The notes for that day are concerning. YY said she had used heroin 3 times before she missed her appointment on 8 September 2009 and again the previous week with her partner and friend. She said that on 18 September (the day after the parent's appointment with Dr Walker) they all had severe adverse reactions—"vomiting, severe headaches and disorientation" and that she thought they were going to die. AA and his friend were present and "helped look after them". She said it had frightened her, admitted it was wrong for the children to experience that and she would never do it again. YY and AA were still living at ZZ's house. The mother said there were a number of matters causing her stress: she had to visit one son in gaol, she had one son at the police station and her daughter tried to strangle herself when she was challenged over her Internet access. AA needed to have his tonsils removed but JHH staff said he had gained "20 kilos in 3 weeks" so she was concerned that he would not survive the operation.

On 12 October 2009 the father reported that he had only used once (in the last fortnight) and was still committed to not using. On 27 October the mother attended STP and said that she has had the longest drug free period she has had for 12 years. She attributed that to her "changed attitude", her motivation was to be there for AA, that she can't change the past but can change the future. She said she hadn't used heroin for 5 weeks. However, on 9 November ZZ reported to the methadone clinic that he was continuing to use because he is bored and does it for fun.

The downfall of the closely monitored multidisciplinary team's care plan for AA coincided with the parent's heroin use and YY's continued amphetamine use. Though both reported stopping heroin use after the incident on 18 September 2009 and attended the dietician on 24 September 2009, YY was unable to stop amphetamine use despite being on the STP programme. Her own physical health also began to deteriorate.

How AA's ill health and need for really intensive help impacted on the mother's attempts to address her drug use is difficult to tease out. It probably became a vicious cycle. The diet intervention was completely abandoned within several weeks of it being supposedly implemented after AA's discharge on 1 July 2009. There had been no earlier dietary intervention- indeed when YY met with the dieticians in June 2009, she denied ever having been given a menu plan and in 2008 there had been no engagement with dieticians.

The implementation of the healthcare plan for AA in July 2009 co-incided with the parents relapse into heroin use after apparently many years of abstinence. They had been told that their son was at a medical emergency stage, they had been told that he was a high risk patient for surgery; they knew the surgery was not going to be lifesaving nor curative but that it that would assist AA's ventilation. This was a very big decision for them and given that YY could not even bear the process of AA having to fast for the Oral Glucose Test, her experience of putting AA at risk or even having the surgery was contrary to her feelings of protection towards him. She didn't feel that the hospital staff understood her position though it appears that both Dr Walker and Dr Farreli were highly reassuring about their ability to keep AA alive.

- Having made the decision that AA would not have the surgery, it appears that the parents were unable to return to see Dr Whitehead or any-one else at the Paediatric Respiratory and Sleep Medicine because the mother feared she would be judged and not supported in their decision for AA not to have surgery.
- It seems unlikely that there ever was a regime of home cooked meals and family routine preceding the health care plan despite the testimony of the elder daughter where she sought to paint a picture of the mother providing portion controlled meals of meat and vegetables to AA each night.
- YY's amphetamine use and AA's obesity are inconsistent with a picture of healthy eating. Asking the mother to implement a meal plan and take away AA's junk food was asking the impossible. She probably experienced those changes as causing deprivation and suffering to her son. Exercise was not part of the parent's lifestyle and they had no structure to implement it for AA. I am sure that they understood the dire situation AA was in but because they were unable to deal with it and implement the changes he needed, the only comfort they had was telling themselves that AA would grow out of his obesity as had their elder two sons.
- The parents' inability to deprive AA and make him, in their eyes, suffer and the knowledge that his life was in their hands probably contributed to their collapse into heroin use and then for the mother, amphetamine which would have added the dimension of chaotic distraction from that stress but in itself causing more stress. It is unavoidable to conclude that the parents, particularly the mother, were poor at even attending to their own health needs let alone their son's.
- The only information from healthcare services about AA after October 2009 until his final admission in September 2010 is what is contained in the health material relating to YY and to a lesser extent, ZZ. On 10 November 2009 YY was reporting to STP that she was breathless and couldn't smoke or talk and walk at the same time. AA was sick off school. This was the day he was supposed to attend the sleep clinic. YY had a distended abdomen and was advised to see a doctor as soon as possible. She still hadn't seen a doctor by 17 November when she still reported as unwell, breathless and having a sore throat. YY cancelled her STP appointment on 8 December 2009, but attended her

methadone provider on 18 December 2009 and indicated to them that she had used both heroin and methamphetamines the previous week.

By 21 December 2009, the father said he was no longer using. The mother continued to use amphetamine. She was hospitalised again from 21 to 26 March 2010 as an injection site on her arm had become inflamed and infected. Though the hospital wanted to treat her with intravenous antibiotics she was not compliant and kept leaving the hospital so she was prescribed oral antibiotics, the script for which she left at the hospital upon her leaving.

On 22 April 2010, AA did not attend a scheduled ventilation clinic appointment. YY attended her Pharmacology clinic appointment that day. She was non-compliant with the oral antibiotic medication prescribed in March and her infection continued. She was readmitted to JHH on 6 May 2010 with chest pain. At that time she reported having last used drugs 2 weeks previously, which is consistent with her having used drugs around the time when AA was due to attend his appointment at the ventilation clinic. YY was diagnosed with having septic emboli in her lung and a septic knee (which required an arthroscopic wash out under anaesthetic). She also had infection in her foot from an injection site. She was in hospital for 4 weeks on intravenous antibiotics.

YY was discharged on 9 June 2010 and attended STP on 16 June 2010, where she reported having injected "Ice" within a week of her discharge and that she was stressed about one son who was on curfew with the police checking all hours of the night and AA struggling with his breathing mask at night. She said AA was very clingy as he was scared that she would die. She was living with AA back at her house (methadone clinic records of 21 June 2010).

On 15 July 2010 YY attended STP and reported she was staying at the father's house because he was very sick but refusing to see a doctor. She said she was finding it hard to give AA the attention he deserves. The next appointment at STP on 3 August 2010 was cancelled. On 20 August 2010 the methadone report indicates that she had used methamphetamine twice about a week apart. She said that she used in a context of "presently living in an environment with drugs" while her house was being repaired as it caught alight when her eldest son was filling a mower with petrol in the lounge-room and

his friend was smoking a cigarette. After the fire, she and AA moved in with ZZ. There are no further records at STP until after AA's final admission to JHH.

The School as a Protective Factor for a Child Suffering from an Untreated Medical Condition

- The school records also indicate a history of absenteeism, which escalates as AA's ill health, and weight gain escalates. Though the school had extremely minimal engagement with the family, when Community Services telephoned the school after receiving a risk of harm report in 2009, the deputy principal remarked that the family were well engaged with the school.
- This information provided a false reassurance to Community Services. AA was not neglected in the sense some children are. His parents came to pick him up when the school called them which was often. AA was well dressed and well presented; he was well behaved and tried hard. AA was loved and adored by his parents and their dedication to him such as picking him up when called, actually may have masked their failure to provide for AA's medical needs.
- The school records indicate that AA's absences escalated consistently with his ill health. The school year has about 190 teaching days, each of the 4 terms being divided into 4 blocks generally each of 10 weeks. Ms Shepherd was the school principal from 2007. She made two statements and gave evidence. In Kindergarten (2006) 44 absences are noted. In Ms Shepherd's first statement, she identified that in year one (2007) AA was absent 68 days (of which 25 were in term 2 (April-July). In her second statement she says he was absent 66 days and 17 partial days, most of which were recorded as "unjustified". She says that when AA was in year two (2008) his health problems really became apparent to the school. He was absent 93 whole days and 25 partial days. She says that they believed there was a medical explanation and hoped things would improve with the help of his doctor. On 7 August 2008 the classroom teacher Ms Anderson spoke with AA's mother suggesting that she obtain a medical certificate to explain AA's absences. This was never provided nor was it ever followed up.
- 91 The school referred AA to the Home School Liaison Officer David Thompson on II November 2008. The referral form indicates that the school intervention included

"several phone calls, teacher's discussions with family, child has been ill—related to breathing-sleeping issues. Medical intervention has occurred we believe". There is no record in the school records of any medical intervention and indeed the last appointment since the diagnosis in May 2008 was 12 August for the sleep study, which was followed by AA's failure to have the Oral Glucose Test on 13 August, and failure to attend two consecutive appointments at the respiratory clinic.

92 On 17 November 2008, Mr Thompson attended ZZ's house to explain why home liaison was involved. ZZ (after becoming somewhat hostile) showed Mr Thompson "some sort of breathing device". Mr Thompson visited again on 2 December 2008, and on 7 December 2008, when ZZ told him that AA's attendance should improve in the New Year because he was going to have surgery to remove his adenoids over the Christmas holidays. After this, Mr Thompson and the School Deputy Principal decided to wait and see how AA attended in early 2009. Given that AA had not yet (despite earlier referrals) consulted with the ENT surgeon (Dr Walker), it appears that there contrary to ZZ's assertion to Mr Thompson, there was no plan in place for AA to have surgery over the Christmas holidays. The consultations with the surgeon and anaesthetist did not occur until September 2009 (after numerous referrals) following which, the parents indicated they would not proceed with surgery. There appears to have been little attempt by the school to confirm what the medical issues were, whether they were in fact preventing school attendance, whether medical attention would improve attendance, and whether AA and his family needed support to access medical treatment, to improve school attendance.

In year three (2009), AA's absenteeism increased such that he failed to attend school on 101 whole days and 11 partial days. Ms Shepherd says early in the year she gave medical care plan forms to AA's mother to complete and made an appointment for 3 February 2009 to discuss AA's Health Care Plan. Neither the forms nor the meeting were attended. Despite the increase in absenteeism no further referral was made to the Home Liaison Officer. Indeed, Ms Shepherd said in her evidence that she did not make any inquiry as to whether AA had had surgery over the 2008/2009 holidays. There was no engagement or attempts to engage with AA's parents after the missed appointment on 3 February 2009. Ms Shepherd did say that the following year, on 15 March 2010 she saw AA's mother at the front office and she grabbed her and asked her to fill out an "Emergency and Health Care Plan" right away at the office counter.

The Plan identifies that YY described AA's medical condition as "Sleep Apnoea and Nalipson" which I take to mean narcolepsy – a condition he didn't have but suggests that YY was indicating that he sleept like he did have it. The medications are described as "C Mask every time he sleeps". The Plan asks if the child is Asthmatic which is circled "Yes". The Plan says "In consultation with student, parent/caregiver, medical practitioner and relevant health care professionals, record an action plan for each health care identified. Include description of procedure, and the agreed process and for managing these procedures in the school context. Attach additional information from parent/caregiver or doctor to this plan".

Clearly those words indicate that to complete the Plan, serious consideration and medical consultation was required. The document is divided into 3 columns "Risk" "Strategy" and "Who?" An extremely rudimentary completion of the document was filed as follows: "Risk: Falling asleep (even standing up) and stopping breathing. Strategy: If he falls asleep at school, splash water on his face, go for a walk. If this does not work, ring YY. If in sick bay, let him sleep till YY arrives. Who? Ring mum immediately if water or walk does not work." There was no consideration as to whether a doctor ought to be consulted nor does it seem there was any consideration about whether splashing a child's face with water or going for a walk was an appropriate medical strategy to deal with a child who might stop breathing.

Out of a total of about 145 days, in AA's final 3 terms at the school in 2010, AA was marked absent 103 days and 21 partial days. Again, throughout these 3 terms, there was no attempt by the school to inquire with the family as to AA's medical needs and there was no further referral to Home Liaison. Ms Shepherd did say that when YY came to pick AA up on the partial days YY would remark how she needed to get him home to put him on the machine. It appears the school accepted that AA had a medical condition preventing his attendance at school but they did not identify if the medical condition was being treated so that AA could improve his attendance at school.

Our government and community identify our children's schools as places of safety and protection, particularly for a child who may be at risk of harm in the home. Schools are a place outside the child's home where a child's well-being can be assessed and protected. This did not occur for AA. The school correctly considered AA's parents as being very

loving and dedicated to him. However they were not managing his medical condition and their drug use was impacting on their ability to do so. The school was completely unaware of the parental drug use or what was happening for AA at home – though I am sure the parents were very adept at disguising their drug use.

AA's long term and worsening absenteeism continued without the school making any attempt to assist AA and his family after November 2008. The evidence suggests that AA was not alone at this school as being a student with marked absenteeism. AA's class teacher from July 2010 until his death, Ms Thompson summarises it aptly: "I never felt the need to make any reports to Department of Community Services... his absences were explainable. His food was fine. His cleanliness and appearance were fine. When I spoke to his mother she was very interested in his school work and getting him through".

AA's teachers were aware that AA had sleep apnoea from 2008. In particular one of his teachers in 2008, Ms Fair, was aware that "with sleep apnoea the body retains CO2 which causes the sufferer to pass out rather than fall asleep". She said "At different times I spoke to AA's mum and his dad and they would talk to me about AA still falling asleep. I tried to explain to her that he wasn't actually falling asleep. I tried to explain to her that he was passing out. I don't think she really understood the physiological mechanisms of his disorder. Another thing that AA's mum told me at one stage (in 2008) she had problems trying to keep AA's CPAP mask on at night. He didn't like wearing it because it was uncomfortable." The teachers instigated a regime whereby AA would have a class buddy who would inform the teacher that AA had "fallen asleep" and they would wake him and walk him to expel the CO2 and/or take him to sick bay for his parents to pick him up. That regime continued throughout the remainder of his schooling.

The statement of AA's last teacher (Ms Thompson) refers to the mother telling her that AA had had a seizure and she had taken him to the doctor. YY had said the seizure was different to AA falling asleep. Ms Picton, the school administrator says that the last time AA attended sick bay, the father attended to take him home and she heard AA tell his father that he hadn't been sleeping but that he was sick that he had "taken a turn, felt funny".

There is no evidence of AA being taken to a doctor in the months before his collapse other than presenting at the Mater hospital in two days in August 2010 with conjunctivitis. The Medicare records indicate that the last Doctor AA ever attended was Dr Whitehead on 17 September 2009. The hospital records do not indicate what school AA attended and no inquiry was made as to his attendance to see whether he was well.

Health Services' Child Protection Systems

102 I have been assisted by the Report to the Ombudsman dated 9 May 2011 prepared by Professor Vimpani Senior Paediatrician JHCH Child Protection Team, in conjunction with Ms Susan Heyman (District manager of Violence Prevention and Care) and Dr Keith Howard (Children, Young People and Families Health Network within Hunter New England Local Health District). That report seeks to answer a number of questions particularly in relation to the adequacy of the clinicians' actions and responsibilities towards reporting AA as a child at risk of harm.

I agree with the conclusions that, in this case there was a lack of co-ordination of AA's medical care and there were a number of missed opportunities where that could have occurred. There were occasions where additional reports to Community Services could have been made and on the two occasions when they were made there was a lack of follow up.

I have heard evidence from Dr Hilton and Dr Gulliver. It appears that they were not aware if Community Services was involved with the family or not as a result of the reports made to the Helpline in March 2009 and October 2009. They both indicated in their evidence that they were not aware of how Community Services operates in terms of procedures with investigating reports or any interagency engagement. In 2008 and 2009 the hospital's Child Protection Team had an arrangement where there would be a Monday meeting where treating doctors could discuss a case with the social worker and other doctors involved in child protection. This was an informal arrangement which did not involve case allocation or management. As a result of Professor Vimpani's review there is now such a system in place and as at October 2013 there had been a very recent implementation of new policy guidelines in relation to responding to child medical neglect.

When AA first presented to JHH in May 2008 the treating physicians queried whether AA was a child at risk of harm and they requested a paediatric social work assessment. David McNamara, Director of Paediatric Social Work has provided a statement and has given evidence. Mr McNamara attended the meeting where AA's case was discussed. It is not possible to determine what was decided at the meeting. However, given that there was no mandatory reporter made to CS Helpline, it is fair to conclude, that it was determined that there were no reasonable grounds to suspect that AA was at risk of harm. As Mr McNamara said in his statement: "it was early days in AA's admission, a few things needed to happen to assess the situation, a paediatrician needed to assess his obesity, needed to have a dietician assessment, and there was a need to see the response to the medical and dietician assessment to determine if parents' behaviour was putting AA at risk of harm."

AA's obesity was in itself probably insufficient to give a medical clinician reasonable grounds to suspect that he was a child at risk of harm though the parents' behaviour was such that it was a case that required ongoing assessment. However, when AA was discharged, there was no re-referral to the paediatric social work team or liaison from the social work to the respiratory team, so no such re-assessment occurred.

It did not take long for the missed appointments to accumulate, and for AA's weight to increase to the point where the "wait and see approach" should have been again assessed and consideration about whether a report to CS Helpline should be made. There was no system for review or reassessment and there was no clear understanding about how the paediatric social workers could assist the treating doctors in securing AA's medical care. There was inadequate note taking and record keeping which compounded with the fact that there was no one person co-ordinating AA's care from a child protection position meant that there was a lack of continuity of care and management of his medical neglect.

The Hospital did not have a system in place whereby a Child Protection Caseworker could open a file for AA and co-ordinate and liaise with Community Services, the treating doctors and other clinicians such as weight management, dietician, physiotherapists, the family and the school. This approach would have ensured continuity of information, care, progress, and interagency engagement. Such a system would mean that those

responsible for AA's care would have an overall picture including the parents continued failure to make an appointment with Dr Walker, failures to attend the appointments with the respiratory team, the dieticians and the physiotherapist.

When AA was attending the JHH the treating doctors believed that the only means of helping AA was to reporting him to the Community Services Helpline. They had no understanding about what that process involved in terms of whether CS would provide casework so that AA's medical needs would be met. Unbeknown to AA's treating doctors, they were not the only health service providers reporting to CS. Despite repeated reports to the Helpline there was also a lack of understanding by CS about the significance of the reports being made and the level of risk of harm AA. There was also a lack of resources to allocate a case worker in any event.

Health workers as Mandatory Reports and Community Services' Processes

- Section 27 of the Children and Young Persons (Care and Protection) Act 1998 sets out the circumstances where a person who works in health care, welfare, education, children's services, residential services or law enforcement is required to report a child at risk to the Director General of Family and Community Services. Prior to 24 January 2010 the law stated "it is the duty of the person to report, as soon as practicable, to the Director General....the child....they have reasonable grounds to suspect....is at risk of harm". Since 24 January 2010, the relevant threshold is now a child who is at 'risk of significant harm'. The change of definition would have had no bearing in relation to AA as he was clearly at risk of significant harm the reports were made.
- Typically, a child being admitted to hospital with unexplained injuries or a child with complaint of being sexually or physically abused would give a health service provider reasonable cause to suspect that the child is at risk of significant harm. So would a child presenting with an advanced untreated medical condition.
- This inquest has not specifically examined the question of whether a child suffering morbid obesity and a related medical condition such as Obstructive Sleep Apnoea is per se a child at risk of significant harm. Dr Hilton said that in her opinion she would have reasonable cause to suspect that the child is at risk of significant harm where the parents

are educated about the child's condition but do not address it. The defining feature for that risk of harm is medical neglect rather than the obesity or sleep apnoea itself.

- Consideration does need to be given as to whether childhood morbid obesity (regardless of current or expected associated medical conditions) is an eating disorder just as the condition of childhood anorexia nervosa is considered an eating disorder. If obesity is an eating disorder, morbid obesity might be regarded as a serious eating disorder. It involves not only physiological concerns such as cardiac failure, but also psychiatric and/or sociological factors, for which treatment is highly complex (not restricted to just nutrition). It may require inpatient treatment and a high level of engagement with the family.
- In May 2008 when AA first presented to John Hunter Hospital, he was 7 years old. His presentation with Obstructive Sleep Disorder and morbid obesity at such a young age placed him in a very special category. There were concerns about the parents' accepting that he was in fact overweight let alone understanding that his health was at risk because his sleep apnoea placed strain on his heart.
- In December 2008 Dr Hilton wrote to the paediatric dietician Ms McRory, to Dr Marsh (who she believed to be AA's G.P) and to Dr Walker advising of the problems associated with the parents' lack of engagement in AA's treatment. A report to CS was supposed to have been made at the time when they failed to attend the last glucose test appointment but due to the file being misplaced there was no report to CS. Appointments for AA to attend both the dietician and the sleep unit were made for 3 February 2009. AA failed to attend both appointments. Another appointment was made for 9 March 2009. He did not attend that appointment either. Unbeknown to the paediatricians, there were also other factors in AA's life, which placed him as a child at risk of harm. Those factors were the parents' drug use and YY's consequent ill health.
- Though Dr Gulliver had consulted with the paediatric social worker, and AA was apparently discussed at the Monday Child Protection Review Meeting before the March 2009 report was made, there is no clear indication as to what follow up was done by the hospital social worker. It was determined that Dr Gulliver should report her concerns as a specialist physician so that CS would understand the significance of the risk to AA. The

Report was recorded by Community Services in these terms (as taken from CS's Assessment):

Caller met AA in May of last year having an episode of acute sleep apnoea. Caller reports that AA is morbidly obese and hasn't returned to attend his appointments since November 2008. In the callers professional opinion AA needs to attend these appointments as he could have severe consequences of right heart failure if he is not adequately ventilated. Caller reports that this form of severe obstructive sleep apposea is rare and is one of the most severe forms she has ever seen. AA's mother seems compliant with attempts in August to provide AA with sleep therapy as they were trying to adjust his ventilation to the optimal levels. Staff at the hospital has tried to contact AA's mother multiple times by phone and have spoken to her twice in regards to attending appointments and no reason has been given for non-attendance. Caller reports that in her opinion AA and his mother may feel victimised in regards to suggestions that AA should lose weight and caller feels that hospital staff and AA and his mother have guite different views of what AA's needs are in relation to his weight. The caller reports immediate concerns for AA's safety as he is diagnosed with severe sleep appoca needs to be treated by attending regular appointments at the hospital in order to adequately ventilate AA otherwise in caller's professional opinion AA could have a right heart failure.

- After Dr Gulliver spoke with the Helpline, the report was assessed on intake by CS. That assessment included looking at earlier reports to CS about the family and it is written in the assessment: There is a likelihood that this Risk of Harm will continue for AA is increased, as previous reports relate to mother's inability to parent due to drug use this could result in AA not attending necessary medical care. However, it is unknown whether or not AA's mother may have sought another Paediatrician to provide this care for her son.
- The case was referred from the CS Helpline to the Community Service Centre (CSC) at Mayfield for further assessment within 72 hours (a level 2 response). The next date recorded is 7 April when a caseworker called YY twice but the call went through to message bank. This occurred again on 15 April but there was successful contact on 16 April 2009, two weeks after Dr Gulliver's report.
- YY told the caseworker that there was a family emergency on 9 March 2009 and she rang the hospital to cancel the appointment. She stated that when she did so, the person she

spoke to was abusive and unable to re-schedule the appointment. She said she was happy to take AA to the hospital but did not want to speak to the person who abused her. The caseworker said that she would make an appointment for her and call her back. The caseworker then telephoned Dr Gulliver who told her that the appointment could be scheduled for 7 May 2009. The caseworker asked Dr Gulliver to report back to CS if they did not attend. The case worker then telephoned the mother and told her she needed to go to the appointment and that if she did not attend CS would be in contact with her. The mother responded "I love my son and I want him to be well, of course I will attend".

Surprisingly, the hospital did not know the school AA attended at the time of the report. The CS caseworker had to telephone 5 schools before identifying the right school. In late April 2009, the school's Deputy Principal told CS said that AA presents well, always clean, tidy and always had lunch that he is obese and has a number of health issues and when he is in sick bay he can be struggling for breath. He said the mother appeared to be caring and loving towards her son and she was engaged with the school in regard to AA's ongoing health and learning difficulties. He failed to report that AA in fact was rarely at school, that his absenteeism was so significant that the Home Liaison Officer has spoken with the father in November who claimed AA was going to have surgery over the Christmas holidays so would be able to attend school again. The Deputy Principal failed to tell the CS caseworker he and the Home Liaison did not follow AA's continued absenteeism and did not know if AA had the surgery or not.

On 7 May 2009 AA's notification was discussed at a CS Peer Review. This was the same day AA was had the appointment to attend the hospital. The review sheet stated that the computer system did not set out the previous CS intervention had been required given that AA was last reported as at risk of harm in June 2006. The assessment sheet says that the paper file was yet to be viewed. The sheet noted that Dr Gulliver reported that AA was at immediate risk of harm as his mother failed to provide follow up medical attention and Dr Gulliver said that AA was at risk of death from heart failure if appropriate treatment was not provided. It set out some risk factors known from a history of reports dating back to 1991.

- Under the heading "Analysis" it said that it was unknown whether AA's natural mother was still abusing drugs or taking part in the methadone clinic. Further investigation was said to be warranted in order to ascertain AA's safety and to ensure that he received medical attention. The follow up call making the hospital appointment and the telephone discussion with the school's deputy principal was noted. Despite determining that further investigation was warranted and despite not waiting to see if AA attended the hospital that day, the outcome of the peer review meeting was to close the case "due to competing priorities". This term essentially means that there was no caseworker available to take the case due to the workload at the Mayfield CSC. It appears that Dr Gulliver was informed that there would be no allocation of AA's file. However, Dr Gulliver says she did not know what had happened as a result of her report to the Helpline.
- The Allocation Review Meeting of 7 May 2009 contains a summary of 21 cases including AA's case. This document sets out the reasons for outcomes of each matter at the meeting. The summary downplayed the risk of harm reported by Dr Gulliver suggestive of an attempt to minimise concern about why the case was closed. The synopsis of the case in the table says "Report in regards to child being overweight with sleep apnoea. Mother appears caring and interested in helping child"...matter is not able to be allocated over other high risk matters within unit, matter to be closed due to current competing priorities". The summary excluded Dr Gulliver's opinion that AA was at risk of death from heart failure if appropriate treatment was not provided.
- When the mother was admitted to hospital on 15 May 2009 due to drug related illness, a notification was made to CS that AA was at risk of harm. The report observed that YY was on the methadone programme and using \$100 day on drugs over the last few months. It appears that the notifier was a staff member from JHH but was not familiar with AA as they called the pharmacy where YY received her methadone and inquired about AA and was told he was "overweight" but could not provide any further details. It was reported that AA was staying with his father. The assessment sheet from the Helpline indicates that the last report was 31 March 2009 and related to "medical treatment not provided; risk of physical harm (<72hrs). Reports of child needing sleep therapy however not attending... Child also having weight issues". There was also a reference to 2 earlier reports, one in June 2006 where a report of AA witnessing domestic violence was made

and one in July 2003 wherein YY was said to have been using drugs, failing to supply food for the children, and threatening serious self-harm.

This report was also sent to Mayfield CSC for an assessment to be conducted within hours. On 20 May, CS rang the hospital to see when the mother would be discharged. They were told that it was not within the immediate future and the child was staying with his father. The hospital was asked to notify CS when the mother was discharged. CS phoned AA's school. The school's principal advised that AA had very poor attendance and had not been at school from 11-15 May or 18th May but did go on 20th with his father for an Aboriginal "fun day".

The notification was assessed at a peer review meeting. Under "analysis" the document reads: "There has been extensive history with little Department intervention. Past reports indicate an environment of severe ongoing neglect for all children in the family, including a lack of food, housing and medical attention. The natural mother's significant drug use has been ongoing and persistent for decades with little to no respite and has now caused serious damage to her heart. Little is currently known about AA's current circumstances other than his own significant health issues that appear to be mismanaged by his parents. Little is known about the ability of his natural father to be a protective ally for his son at present... A full risk of harm assessment is needed to undertake (sic) AA's current needs, with a focus on the capacity of his natural parents to meet these needs".

The outcome of the peer review reads: "Follow up completed and indicates that child is in the care of his natural father. While school attendance does not appear to be occurring at a satisfactory level, he is attending sometimes and his natural father had attended at the school with regard to participation in an Aboriginal cultural day." The case was closed on 1 June 2009. The reason was "competing priorities" that is, there was no-one at the Mayfield CSC who could take on any more cases.

The next report to CS was on 22 September 2009. Again it was referred to Mayfield CSC for a level 2 response within 72 hours. This report related to risk of harm to not only AA but his 13 year old siblings, who it was reported both had severe behaviour problems. AA's brother was reported to have trashed his father's house and was going to court, the parents were on the methadone programme and were using heroin intermittently and the

previous week while AA was at home they were vomiting with headaches and blacked out and AA thought they were going to die. It was reported that there were concerns for AA both from the siblings' behaviour and the parents' drug use. The report also stated that AA's parents needed help with his sibling's behaviour and that the mother was on the stimulant programme and hadn't used amphetamines for 5 weeks. Finally, it stated that AA was morbidly obese and under the care of a paediatrician at John Hunter Hospital. Part of the analysis includes the following statement: "It is possible that AA's physical condition and the twins behavioural issues are linked to parental drug abuse as it appears the parents may place their drug use above the needs of the children". The earlier 2009 report details were also described in the assessment. This report did not even make it to the peer review process for reasons I do not know.

The next report to CS was 1 October 2009 when AA didn't attend the Oral Glucose Test 129 for the third consecutive time. The CS team member's analysis of the report identifies the issues: "AA 9 is considered to be at significant risk of physical harm on the basis of his medical needs not addressed by parents. AA is stated to be morbidly obese and has severe sleep apnoea. His parents neglect AA's medical condition by repeatedly refusing to bring him to hospital for scheduled medical tests. Other concerns relate to drug abuse by both parents; neglect DV issues; behaviour issues for older siblings. This matter is referred to Mayfield CSC for assessment and to ensure that AA attends necessary medical tests". This was another level 2 referral but with an initial assessment of Risk of Harm as High. It also referred to the previous notifications and said there were no open plans as they were closed without being allocated to a case worker. On 9 October 2009 a caseworker telephoned the ward clerk who said that an appointment had been made (by the hospital) for AA to attend for the oral glucose test on 5 November. The case was then closed again without peer review and without seeing if the parents attended. There is some suggestion that the hospital would contact CS if there were a failure to attend but I have been unable to identify the file note from the hospital or CS's records to confirm this.

130 The last report relevant to AA was made in March 2010 when the mother was again hospitalised. This was a non-risk of harm report to indicate that the mother was still using drugs; her teenage children were verbally abusing her in front of AA. It also indicated that she had discharged herself against medical advice. A further report was not made

when the mother was re-admitted to hospital due to non-compliance of her own medical needs.

Child Death Review Report/Recommendations

131 Community Services through the Child Death Review process has interviewed staff and investigated why it was that AA's case was not allocated to a caseworker despite the significant risk of harm that was found to exist even on a basic assessment. That review engaged in a reconstruction of events to identify the thinking and practice of staff. The Child Death Review Report was finalised in June 2011.

The review identified 4 main features relevant to why CS did not become involved:

- a) the risks to AA were not adequately understood;
- b) that the intersection of medical needs with neglect were not understood;
- (c) the effective management required a joint child protection and health service intervention;
- (d) the high workloads, competing priorities, poor interagency collaboration and inexperienced staff in key roles.

I agree with all those findings.

- One of the cited reasons for CS staff not adequately understanding the risks associated with medical neglect was the fact that though the hospital had been experiencing difficulty engaging the parents from the outset, there were only 2 reports made to CS. This, it was said, may have allowed staff to think the health risks faced by AA weren't so serious. Another reason suggests that there was an inconsistent relationship between Health Services and CS resulting in the success of interagency collaboration being largely dependent on which particular staff member from health was involved.
- Though Dr Gulliver consulted with the JHCH Child Protection Team before making the report, she was the health service provider who made the report. She had no relationship with CS and did not know what to expect from them. CS in turn did not appreciate that the fact that the report was made by a paediatric specialist was a report that should be taken very seriously. This raises not only the issue of interagency engagement but also the issue of intra-agency engagement.

Changes to Reporting to Community Services and Interagency Responsibilities

- In 2008 there was a Special Commission of Inquiry into Child Protection in NSW headed by Justice James Wood. In 2009 the recommendations of that Inquiry started being implemented and the reforms were largely in place by the end of 2010 under the initiative called: "Keep them Safe: A Shared approach to Child Wellbeing". One of the cornerstones of the Inquiry's findings was that all agencies education, health, police, communities, government and non-government should take responsibility for children involved with their service with the aim to provide appropriate support to families earlier and, in turn, prevent the need for statutory child protection intervention arising.
- Some of the key measures implemented from 24 January 2010, included changing the statutory threshold of notifications of a child suspected of being "at risk of harm" to being "significant risk of harm" so that CS were able to use their finite resources to respond to higher risk cases.
- 136 Computerised Structured Decision Making (SDM) tools were created so that Reports to the CS Helpline were better assessed for risks and levels of response, and so that information gathering and safety and risk assessments could be consistent and improved.
- 137 An On-line Mandatory Reporters Guide was introduced so that reports, which do meet the threshold, contain appropriate and thoughtful information so that the notifier to the Community Services properly communicates the concerns and risks to the child.
- 138 Child Well Being Units for health, education and police were created to provide advice and referral for matters which did not meet the statutory threshold. Those Units also receive reports of matters falling below the threshold called "contacts" and keep information, which can also be accessed by CS and shared between the agencies. Both mandatory and non-mandatory reports, which do not meet the threshold, can be given to the Units for information keeping and advice. The Units can provide advice; refer matters to other services and non-government agencies.
- On 3 November 2009, legislation was enacted introducing Chapter 16A to the Children and Young Persons (Care and Protection) Act 1998. That provision authorises and requires agencies to provide and receive information relevant to the provision of services

to children and young people relating to their safety, welfare or well-being and requires those agencies to take reasonable steps to co-ordinate the provision of those services with other such agencies. Under s245E "prescribed bodies are, in order to effectively meet their responsibilities in relation to the safety, welfare or well-being of children and young persons, required to take reasonable steps to co-ordinate decision-making and the delivery of services regarding children and young persons". S245B defines a prescribed body as that contained in the definition of s248 (6) — it includes police, school, public health organisation and private health facility. So, for the purposes of this matter, the Local Area Health District, John Hunter Hospital is a body charged with the responsibility.

- In December 2010 Community Services' Intake Guidelines were replaced by the Triage and Assessment of Risk of Serious Harm and non-Risk of Serious Harm events at CSCs Practice Guidelines. The specific differences between the old and new guidelines is involves a report being received at the Helpline, an assessment to determine if the risk passes the threshold of significant risk of harm and then with the collection of information and analysis to assess the risk itself and give it a response level as the aim of the triage process is to support the use of the resources in a CSC by targeting intervention to children who are the highest risk of significant harm. (iny emphasis) (Practice Guidelines July 2011 pg. 3).
- I have received evidence from Ms Flynn, the Director Community Services Hunter Region and I have been greatly assisted by her explanations about those initiatives and the positive impact they have had on child protection reports to CS. I can see how those reforms have vastly improved the quality of reports being made to CS.
- The tool for mandatory reporters to determine the level of risk to a child assists the user by taking them through a series of questions requiring them to think about the child's situation and needs and assists the user to describe and communicate the same. After having responded to these questions the user is guided to a conclusion as to whether a report is required or not. If a report is required, the guide will direct the user to make such a report to the CS Helpline. A copy of that advice and what was written in the process of completing the guide can be printed out and placed on a child's file.

- If upon completion of the Mandatory Reporters Guide, it is determined that a report is not required to be made to CS but the guide determines that the user should contact the Child Wellbeing Unit, it will tell the user to do so; again this advice can be printed out and kept on a file.
- Even without using the MRG, a reporter can contact the Child Wellbeing Unit and speak to an operator for the purpose of reporting a risk of harm matter (which falls below significant risk), seek further information in relation to their own or another agency reports, and seek advice which may include referrals to other agencies or organisations other than CS who can provide the child with assistance.
- When CS receives a report that a child is at risk of significant harm, the CS can access all the information given to the relevant Child Wellbeing Unit. The CS can access it across the agencies to properly assess and process the report. This system improves not only the identification of children at risk of significant harm, but also improves record keeping, inter-agency communication and engagement and access of resources for children who may be at risk of harm below the threshold. In this way, it frees up CS from having to assess and respond to reports that would otherwise not fall in the category for which their services are necessary.

Shared Approach and Interagency Responsibility

- The shared approach to child wellbeing has been specifically relevant in this Inquest. The Child Death Review recommended collaboration between Health and CS to identify how instances of severe and entrenched medical neglect can be jointly addressed between the agencies and to consider whether similar such discussions should occur in other regions. There was also a recommendation that policy makers discuss the range of options for increasing understanding of morbid childhood obesity and other rarely encountered child protection issues.
- I commend those recommendations and I have heard evidence as to the work and collaboration that has occurred and continues in the region. In August 2011, the Community Services Child Protection Policy (Unit) and Child Deaths and Critical Reports Unit (CDCR) attended the Directors' Child and Family Forum which are held bi-

- monthly. This led to agreement for a joint discussion between the 3 regional agencies: Community services, NSW Health and Department of Education and Community.
- 148 This multi-agency meeting occurred in April 2012, and identified a number of actions that needed to be taken so that high risk cases could be handled more effectively in the future. These actions included the following:
 - Health to establish criteria to define severity of medical neglect which corresponds to the CS Levels of Response;
 - That there was a need for Health to communicate information in relation to whether a child's condition has deteriorated to an extent that its continuation may lead to a threat to life where this is being contributed to by the neglect of their medical needs by the parent or carer;
 - there was a need for CS and Education staff to enhance their ability to ask questions of health to ascertain same;
 - there was a need for training in using the MRG and CWU and screening and
 response priority tools (SCRPT) & SARA) to identify high risk medical neglect
 cases, for assistance and training how to communicate urgency clearly to
 Helpline, develop key contact points for high risk medical neglect cases in the
 agencies and circulate, maintain ongoing training in/between agencies;
 - Health staff/specialist teams having concerns about the delivery of appropriate medical care to high risk patients to discuss with the local (hospital) Child Protection Team and improve interagency case discussions at point of case closure.
- The "case closure" discussions refer to the proposal that CS notify Health or Education by letter that a case is closed. This is intended, in cases where the agency staff believe a risk of significant harm remains, to permit the agency to contact the CS Centre to request an Interagency Case Discussion. Where it involves the closure of a high risk medical neglect case then CS initiates an ICD. Finally, a CSC is to keep a high-risk medical neglect case open beyond 28 days with Director Children and Family approval, where the need for ongoing monitoring of attendance at medical appointments is identified.

- In September 2013 another multi-agency meeting was held. That meeting resulted in plans for an education package about medical negligence, the use of mandatory reporting guide, the use of screening tools and reporting to the Helpline. At the time of the Inquest it was intended that a workshop would be run in November 2013, for 30 key personnel across the agencies, to pilot the package with the expectation that it would be rolled out across the region and perhaps the State.
- If the Child Death Review sought to acknowledge that the changes in place since 24 January 2010 have come some way in addressing unsustainably high workloads for the CSCs. From the evidence I have heard in this Inquest about the workload in the Newcastle area generally and Mayfield specifically the workload is still unsustainably high. The evidence is that though the changes to the statutory threshold halved the number of reports to CS, 70% of cases are responded to and only about 28% are in fact allocated to a caseworker who would then carry out a safety assessment and risk of harm assessment.

Would AA have been allocated a caseworker under the Keep them Safe Initiative?

- The Child Death Review recommended that CS carry out a test to see what would happen to AA's case now under the new system. AA's case was de-identified and with guidelines was referred to 4 CSCs. The case was then considered along with other contemporary cases at the management weekly allocation meeting. Three of the 4 CSC chose not to reveal to the management team that there was a test case contained in the cases to be considered to increase the opportunity for genuine discussion.
- The outcome of the test was that all 4 CSCs identified that AA was at risk of serious harm (not just harm and not just significant harm) factors taken into account included his age, health issues, known child protection history, including neglect. One CSC determined that further information was required from DEC. All 4 CSC discussed the imminent nature of the risk to AA. Though 2 CS's were confused about the medical terms used in the reports it was agreed that they communicated a serious risk to AA's life heart failure in particular being compelling. Two of the CS's focused on medical neglect rather than the medical condition itself and all 4 determined that regardless of the complexity of the

medical terms and diagnoses the role of CS is to assess how this translates in terms of risk to children in the context of medical neglect – as one Manager of Client Services said "we don't need to be the experts about the consequences but if the parent is not addressing the health issue, that is the risk".

Though all 4 CSs determined that the case should be allocated to a caseworker, only 1 CSC was in a position to allocate the file. The remaining 3 did not have a case-worker to allocate the report to but determined to carry the case over to the next week to see if resources were available. Due to the carry over none considered the use of an ICD (because it is only when a case cannot be allocated and is closed that an ICD can be considered).

There are always going to be competing priorities in any CSC - at any given time there will never be enough caseworkers for all matters assessed as requiring allocation. The ability to keep cases open for up to 28 days (or longer with Director's approval) or initiate an ICD where a case is going to be closed is obviously an improvement. However, the table of cases at the 7 May 2009 meeting indicates that not one of the matters were able to be allocated but there were a number of cases which were to be returned to a future allocation meeting after further investigations or information gathering was completed so that the concept of possible capacity at a later time existed under the old system as well but to a lesser extent.

The interagency reviews and training which have been carried out since 2012 and are planned for the future should assist to ensure that each agency provides reliable information to the others so that an accurate picture is able to be seen by those who are trying to protect children. The Structured Decision Making tools now in place (Mandatory Reporters Guide, Community Services' Helpline Screening and Priority tools and Community Services' CSC's safety and risk management tools) all assist people to critically identify, articulate and determine child protection issues, needs and responses and courses of action to be taken. Those tools improve the capacity of CS to respond to child protection reports. I note that the "Schools In" initiative for the Education Department being trialled in the Hunter will also improve assessment and service delivery for the interagency engagement.

- The 25% case allocation rate from the test sites is consistent with the average 25-28% allocation rate Ms Flynn suggested applies to Hunter Region CSCs. Despite the changes in the system the ratio of allocation now is no different to the rate when reports were made for AA.
- Allocation is just the end of the first stage or beginning of the next. The allocation would be so the caseworker could undertake a full safety and risk assessment and determine what the parents needed to do so that the child could remain safely with them. Given the difficulties that AA's parents were experiencing and the need to resolve the factors contributing to AA's weight gain to then address losing weight would require a process of family engagement and casework. In AA's case it would require such a great deal of complex work and time, it is difficult to contemplate how much additional load the caseworker could carry. I note that there is a Family Referral Service in Newcastle, which is available to provide co-ordination of case management and support for families where the case does not meet the statutory threshold or is not being allocated. I don't think that such a service would meet AA's needs. It is not possible to say with confidence that AA's case would be allocated to a CS caseworker as it would ultimately depend now as it did then, on capacity.
- CS is currently engaged in a substantial review of Community Services' Neglect Policy and Practice Guidelines, which was last reviewed in 2006. I have perused the "old policy" and note that whilst the old Intake Assessment guidelines may have been more incident based than the now applicable triage and assessment process, the applicable policy on neglect strongly and clearly warns the child protection practitioner of the difficulties in assessing neglect and to not rely on incident based assessments because of the very nature of neglect being "omission". In cases of neglect, the incident is not going to be there. It also describes the need to look at factors associated with neglect first on the list is parental substance abuse. The research indicates that intervention in these types of cases has a limited success rate because changes are generally short-lived. A case such as AA's could not be allocated in a risk management resource limited framework.
- I agree with the Child Death Review suggestion that the risks to AA could not have been effectively managed without joint child protection and health service intervention. What

that joint intervention could or would have been is unknown especially as at the time of the first report in 2009, CS and the other agencies did not share the relationship that now exists since implementation of the Keeping them Safe system.

- Ms Braye, Manager Client services Mayfield, said that they have had a few formal 161 interagency case discussions but often the interagency collaboration happens informally as well. Ms Braye sought to emphasise, in her evidence, that the way the agencies interact is very different now than it was previously. She said "one of the things that the Wood Commission recommended was that child protection was a community responsibility and we needed to have a partnership approach and...many, if not all of the agencies that we work with, do have that view, so we approach it ourselves as a partnership and we talk to them quite openly about the fact that we think the matter might be very concerning but we can't allocate, we share information. Even if we don't call agencies together...because we are operating under Chapter 16A, as are all the other services, we can give information more freely than we used to be able to, so we can talk...and provide information...and perhaps ask them to monitor...there's more opportunities for communication and information sharing". That is a very different practise and culture to that of pre-2010 and certainly indicates for the Hunter region at least there seems to be a successful outcome from those recommendations.
- Since September 2013 CS is now operating as 15 distinct Family and Community Services in line with the Local Health Districts. This division is aimed at allowing CS to work closer with families and ostensibly enables more effective communication and collaboration between the agencies.
- Even under the current system and resources of CS, a report such as AA's case would not necessarily be allocated to a caseworker. Statistically his case would have a 30% chance of allocation. That is a simple reality of a finitely resourced government department managing infinite community based child and protection needs. The consequence of this is that agencies such a Health Department, in this case JHH, really needs to step up and provide services where previously they weren't really required to. There needs to be implemented a system or Unit which is prepared, resourced and to discharge its responsibilities under Chapter 16A of the C&YP (C&P) Act. There will be medical neglect cases that involve significant risk of harm as well as those which fall below the

high risk category identified in the multi-agency review of April 2012 report to the Ombudsman (recalling that the risk was identified as high risk or threat to life).

The Establishment of a Child Protection Unit at JHH JHCH RNC

I have formed the view that the Hospital should have a properly established and administratively supported Child Protection Unit rather than a team or a service. The Unit should be physically accommodated in an area where it can be identified by both hospital staff and non-hospital agencies. My view has been informed by the evidence from Ms Dimmock, Professor Vimpani and Dr Marks (a paediatrician who heads the Child Protection Unit at Westmead Children's Hospital) though Professor Vimpani did not necessarily support the establishment of such a unit explaining that the members of the team occupy different offices relative to their field of medicine or practice.

My view is also informed by the reviews conducted by the Child Death Review and the Ombudsman Review and the evidence in relation to the Keep Them Safe Initiative, the changes implemented by Community Services in connection with that initiative, the fact that the ability of CS to allocate a caseworker is still less than 30% and the legislative changes invoking Part 16A of the Children and Young Persons (Care and Protection) Act 1998 which places obligations upon other agencies and the establishment of the Interagency Case Discussion protocols. The Hospital's interagency obligations are no longer simply discharged by a mandatory reporter making a report to the Helpline. The Hospital now has, under the amended legislation, ongoing obligations to the child's wellbeing, care and treatment.

One of the outcomes of the 2012 Multi-Disciplinary Review Meeting was an agreement that an Interagency Case Discussion will be indicated to Health whenever child reported as a high risk medical neglect case cannot be allocated by CS. An ICD can also be requested in other circumstances by the agency. There is evidence that there is no system in place at the Hospital to ensure the notifications are received and reviewed. The Hospital does not have a system whereby it knows how many mandatory reports have been made to the CS Helpline and what has become of those reports. There needs to be such a system.

- A mandatory reporter has a personal obligation to report arising out of their position of employment with a Health Service Provider. The hospital has a policy in place whereby a mandatory reporter makes the report effectively on behalf of all mandatory reporters involved in a patient's care.
- I have heard evidence that the Hospital rarely receive letters from CS and are constantly chasing them up. Ms Braye said that a letter is always sent, it is auto-generated by computer but it may be weeks after the report was made. One of the difficulties is that due to the legislative confidentiality requirements CS is unable to place the name of the mandatory reporter on the letter so without a system in place there is no way of knowing who the letter should be given to. There is also a difficulty due to a number of fax machines being used and the fact that doctors work rostered shifts so the continuity of treatment and information is difficult to maintain when there is no central co-ordination.
- Professor Vimpani confirmed what other staff told the Inquest about lack of response from CS. He also observed that the confidentiality regime surrounding the mandatory reporting process means that any response letter from CS often is not brought to the attention of the treating doctor who was the Reporter.
- Unless the letter is received and the reporter or someone on their behalf gives consideration to its outcome the opportunity for the Health Service to request an Interagency Case Discussion (ICD) is lost. Given the limited capacity of CS to allocate cases, the implementation of the ICD may well be the outcome that saves a child such as AA from an extremely adverse outcome. The Hospital's capacity to participate in an ICD relies on a structure such as a Child Protection Unit.
- The Child Protection Team currently at the Hospital comprises the Clinical Chair of Kaleidoscope, Social Worker Co-ordinator, Clinical Nurse Specialist, Developmental Psychologist (Part-time .4) a Social Worker (part-time .7), and a community paediatric fellow or Registrar (part-time .8). One of 6 paediatricians (there are 6 who are on call weekly) would attend a weekly intake/review meeting.
- 172 The Child Protection Meeting is a function of the Child Protection Team and accordingly is the responsibility of the Clinical Chair of the JHCH and the Child Protection Clinical Coordinator. The attendees are the members of the CPT and anyone who may be invited

to attend such as a treating doctor. A quorum for the meeting is a doctor and a CPT member.

- The meeting is conducted between 12.30-2.00 pm each Monday and issues arising from the meeting may be directed to other meetings such as a CPT Business meeting, JHH/JHCH Child Protection Management Meeting, and Violence Prevention & Care Stream Executive. There may be other additional meetings that a case might be referred to. Administrative tasks such as emailing the child's name and details to be discussed at the meeting are completed by 10 am prior to the meeting so that a record of what is discussed is made on the file. If the child is an inpatient, the notes from the meeting are made on a Progress Note which forms part of the hard copy medical record.
- A format called ISBAR (Introduction, Situation, Background, Assessment, and Recommendation) for each child's presentation is required. (This is consistent with one of the recommendations of the Ombudsman). The agenda of the meeting is standardised with the meeting starting with a discussion of previously presented/ongoing cases, followed by new cases. In relation to the new cases, those present during the meeting develop a case plan and allocate management of the case to a CPT member for follow-up. The recommendations/case plan is documented.
- Following the presentation of a new case, three people being the Senior Paediatrician, the Child Protection Paediatrician and the Coordinating Social Worker are allocated responsibility for overseeing the case. In that respect, the responsibility of each professional varies according to their background: the doctors are responsible for the medical aspects and the Social Worker for Psycho/social matters which would include relevantly non-attendance at medical appointments, parental drug use, parental engagement with diagnosis and treatment.
- The next matter on the Meeting's agenda is referrals for Child Wellbeing Assessment unit, s173 Orders, Systemic Issues/Training, and Meeting Evaluation.
- It is intended that all CPT members attend the Monday meeting either in person or by teleconference and any on-call paediatricians who are on duty are also asked to attend. If a child is readmitted to the hospital and has ongoing case management with the CPT, they are admitted under both the treating doctor and the CPT. Now that all medical records are

digitalised, all health staff engaged in treating a relevant patient should be aware that CPT is involved and able to see the plan for that patient.

- The Local Area Health Service has placed on the Hospital's Intranet a document dated 26 May 2013 titled "Guideline/Procedure to staff relating to the Management of Suspected Physical or Emotional Abuse and Neglect in presentations of children and young persons at JHCH, JHH and RNC" ("the Guide"). The Guide advises hospital staff to follow certain steps to refer relevant matters to the hospital's Child Protection Team and then if appropriate to make a mandatory report to CS. There is also document titled "Terms of Reference Child Protection team Intake & Review Meeting" has been produced which seeks to formalise roles and procedures and policy of the Child Protection Team Monday meetings.
- The Guide excludes presentations relating to sexual assault as they are referred to the Local Sexual Assault Service. There are three Aims of the Guide: (1) to provide practical guidance for managing suspected abuse and neglect of children presenting to the hospital, (2) to promote collaborative and accountable assessment of child protection concerns and (3) to ensure children and families are treated respectfully and in a timely manner when a level of suspicion of abuse and neglect arises during presentation.
- The Guide reminds health workers of their obligations as Mandatory Reporters and to share information and to make appropriate referrals where abuse/neglect forms part of the health assessment. The CPT is identified as being responsible for ensuring that a suitable assessment occurs, is documented, and is done in consultation with the treating teams and services.
- Ms Dimmock said that the MRG and Child Wellbeing Unit is a resource used as part of the assessment process in the meeting. The Treating team is responsible for the day-to-day health care and management. The Community Services and NSW Police may have a role in the assessment of the Child Protection concerns.
- The Guide sets out matters to look for evidence child abuse but it seems heavily loaded to "injury" and though briefly refers to neglect the only reference about parental refusal to follow medical advice is in relation to injury. The Guide should include medical neglect

such as parents failing to follow medical advice or failing to attend appointments or accept referrals within its indicia for "possible signs of neglect".

- There was some evidence about the NSW Health Policy and Procedures 2013 regarding neglect and medical neglect. Dr Marks commented on the policies in a report she prepared to assist the inquest. She identified that whilst section 7 contains half a page on neglect with a brief definition and list of indicators, section 10 headed "Responding to Child sexual abuse and serious abuse or neglect" does not include responses for anything other than sexual abuse. This deficit needs to be repaired, probably by having a separate section called "Responding to neglect and medical neglect".
- In her report Dr Marks sets out a possible content for such a section in the following terms:
 - (i) Initial Step: Identify Problem, Consultation between doctor and parents, work to engage with family, develop treatment plan, multidisciplinary approach, provide information
 - (ii) Next steps: Gather more information e.g. from school, multidisciplinary team meetings, document all attempts to instigate change and progress, flagging when there is an issue e.g. of families missing appointments (case manager role). The next step she suggests is required when there is clear objective evidence of the parents behaviour over a sustained period where they understand what is required but are not engaging or are actively promoting treatment failure and there is a reasonable likelihood of benefit from statutory intervention;
 - (iii) MRG- report to CS; and then
 - (iv) CS involvement, increase supports, mandatory participation in treatment, monitoring attendance and actual participation, consider temporary change in care arrangement admission to hospital, temporary foster care, to achieve goal, in obesity- weight loss.
- Dr Marks also identified that the MRG for non-professionals to assess neglect has an option for "Food" which then is dedicated to underweight features. I agree with her suggestion and recommend an amendment to include features relevant to obesity.
- The HNELHD Guide mandates a procedure for a clinical staff member who has concerns about possible physical abuse or neglect of a child as follows:
 - Notify Registrar or Senior Doctor (if Emergency Department) and discuss those concerns, if the concern is not confirmed continue with child's health care

management, but if concern continues (or is confirmed?), the Treating Team Registrar is to inform the Treating Consultant that there are physical abuse or neglect concerns.

- The Clinical Staff is then to contact the Child Protection Team as soon as possible, by calling the Child Protection Intake Worker in business hours or if after hours the Rostered Social Worker. If the matter is urgent the Senior Treating Doctor can directly contact the On-Call Child Protection Consultant.
- Complete the Referral/Consultation Medical Record Copy (which forms part of the child's medical record).
- The CPT Intake Worker/Social Worker notifies the Paediatric Registrar, Child Protection Consultant and Senior Social Worker as appropriate.
- A joint medical and social work assessment is to be carried out.
- Following the assessment, the Treating Team Registrar is to:
 - o Liaise with Child Protection Consultant to discuss any action
 - o Document assessment outcome on the Medical Record
 - If assessment results in child protection concerns being no longer present,
 advise Treating Team to continue child's health care management

If those child protection concerns remain,

• The Registrar is to complete the Mandatory Reporters Guide, print it out and place the copy with the Case Notes. The MRG recommendations are to be followed be it to make a report to Community Services, Police or Child Wellbeing Unit. The Registrar may consult with nursing, social work and/or medical staff in this process (but it is the Registrar's task to answer the questions in the guide). The step of reporting can be completed by any of the health professionals who have the most relevant knowledge about the Child Protection Concern (though it would make sense if the person who completed the MRG also completed the Report to CS Helpline and it would be useful for CS to know that a Report which has come through this Policy/Guideline has already been subject to medical and social work assessment.

- The Guide's next step is for a Care Management Plan to be developed and documented in the medical record. It does not say who does this or what a Care Management Plan should entail. Given that the Terms of Reference for the Child Protection Intake and Review Meeting includes a process of assessment and case management, the Guide should be clear about who is responsible for drafting the Plan. If it is to be at the CPT meeting on the next Monday, the Guide should direct that following a report to Community Services, a copy of the Report should be kept on the medical file and a copy attached to the referral document for a CPT Monday meeting.
- The Guide directs that where a child with child protection issues is admitted to the Hospital, it is to be a joint admission between the Treating Team and the Child Protection Team. The General Paediatric Registrar is to keep the Child Protection Consultant informed of the results of any investigations so the Treating Team must keep the General Paediatric Registrar informed when the results become available. The Child Protection team nominates a CPT member as Case Manager to liaise with the treating staff and with any external agencies.
- Though the Guide does not refer to the CPT Monday Meeting and the Terms of Reference do not identify that a case can be assessed and allocated to a Case Manager at any time other than the Monday meeting it is somewhat difficult to reconcile the two documents.
- The Guide directs that the discharge of a child is not to occur without prior discussion between Treating Team and the Child Protection Consultant regarding ongoing medical care and follow-up. Even, if a child is not being admitted to the hospital (for example has presented at ED or as an outpatient, discharge is not to occur without prior discussion with the Child Protection Consultant and again ongoing medical care and follow-up is to be decided by the Treating Team (but this may involve a joint review).
- If the child is discharged, there is no further involvement. If there had been a referral to a service such as a dietician, there is no control of whether an appointment can be made or when, and it may be a case of having that team contact the CPT if there was a problem, or alternatively as part of follow-up the CPT inquire if the appointment was attended.

- Ms Dimmock said that though there is some outpatient capacity the CPT would remain involved after the child's discharge for a couple of months. This would not generally entail a long term involvement, but there is no rule that casework must stop after a particular period. Ms Dimmock said that most of the cases involved with CPT are significant harm cases and if CPT had concerns about the child after a couple of months, there would also be another report to Community Services.
- Whilst the CPT says that they have operated differently since 2010, the evidence before me from staff specialists in ICU and ED were not familiar with any of the changes. Neither Dr Tang (ED) nor Dr Brevia (ICU) knew about the CPT's Monday meetings and did not know how the system of referrals to the meetings works. Dr Rowley, whilst familiar with the meetings, as he had been to a couple prior to 2010, could not say how they are organised nor did he know of any changes since 2010.
- Dr Tang said that the process of dealing with a child presented to ED who had child protection issues was to first discuss the case with social worker and a paediatrician Child Protection Consultant and a collective decision would be made whether to Report to CS so without knowing about the Guide or the CPT Meetings he has adopted that consultative practice.
- Ms Mendoza, the social worker at the ICU, appears to have a good liaison relationship with CS. She gave evidence that she is able to call and discuss a case with them but she didn't seem to appreciate the difference between contacting the Child Wellbeing Unit and making a report to CS after making use of the Mandatory Reporters Guide. Given her experience, I think, she is probably less likely to need to rely on the MRG to determine whether a matter should be reported. However, it seems that staff at the Hospital has the choice of Reporting to CS either through the CPT formally or individually on an ad-hoc basis despite the Guide of May 2013.
- 196 Professor Vimpani, in his evidence, made it very clear that the CPT member can engage in strong advocacy to CS with a view to assisting, for example, HELPLINE personnel to understand the issues, particularly of medical neglect, and identify a level of risk from which allocation and intervention would follow. The Child Death review suggested that the success of interagency collaboration was largely dependent on which staff member

from Health was involved in the Report. This indicates the need for trained child protection staff to be specifically involved in the Reporting process.

The treating teams who made the reports to CS in March and October 2009 did not follow up with CS. Doctors Gulliver and Hilton had no idea whether CS was involved with AA or not. Had there been a referral system, the CPT could have followed up the reports, particularly the October 2009 report. Though there was the ability to call CS to discover what if anything was occurring, the culture at the time was much more closed than it is presently. It appears that CS personnel are presently more open to dialogue and discussion about whether a case meets the threshold for allocation or action than they were in the 2009/2010 period.

There is merit in having a centralised and standardised system. Indeed in NSW Health's Child Wellbeing and Protection Policies and Procedures such a system is required high risk birth alerts and Chapter 16 information sharing. The NSW Health policy requires each area health district to have a system whereby the shared care approach is facilitated. Newcastle's tertiary hospital is ideal to have an established Child Protection Unit consistent with those established at Sydney Children's Hospitals at Randwick and Westmead.

Section 27A of the Act allows for "alternative reporting" arrangements. The Director General of the Ministry of Health can appoint or designate a person to be an "Assessment Officer". The designation may be to a number of people or class of persons (27A (9)). The Director-General of Family and Community Services and the Chief Executive Officer may enter into an arrangement under which a person who is a staff member employed by the Health Service (a Mandatory Reporter), may in accordance with the terms of the arrangement, refer to an assessment officer of the agency any matter that the staff member would otherwise be required to report to the Director-General under that section. (27A (2)).

The assessment officer then determines if the matters should be reported to the Director-General under section 27. As soon as practicable after the assessment, the assessment officer or staff member is to report the matter to the Director-General under that section. (s27A (4)). Any such requirement applies in relation to the assessment officer as though the officer was a person to whom section 27 applies. If the matter is assessed as not

requiring reporting to the D-G but still raises concerns for the wellbeing of the child, the assessment officer may make such referral or take such action as the officer or staff member considers necessary or appropriate to safeguard or promote the safety welfare and wellbeing of the child (s27A(5)).

- Importantly, under 27A(6): If a staff member has referred a matter to an assessment officer in accordance with the arrangement under section 27, that staff member is taken to have satisfied his or her obligations under section 27 in relation to the matter concerned.
- The Policy says that a Report to CS be made after the child has been referred to the Child Protection Team. The Guide does not refer to whether the treating Registrar or any staff should or should not make a Mandatory report to Community Services without following the procedure set out in the Guide however my understanding is that the Guide does not seek to restrict the means by which a mandatory report is made. The Guide does not refer to the Children and Young Persons (Care and Protection) Act which mandates reporting. Nor does it refer to sections 24, 25 or 27 of that Act. The Guide does not refer to reporting information to the CWU if the MRG so advises. The Guide does not tell the reporter that they can ask the CWU to report on their behalf to CS. The Guide does not tell the reporter that by reporting a matter to the CWU (rather than the CS Helpline) they have discharged their s27 obligations.
- In February of this year the Crown Solicitors Office on my behalf asked HNELHD if there were any designated assessment officers under section 27A. By letter of 3 March 2014 Ms Henry of Curwood's Lawyers who appear for HNELHD forwarded a letter of 21 January 2010 by which the then Minister had made such designations to the Child Wellbeing Unit Assessment Officer, Manager, Director and Co-ordinator. An Inquiry was then made as to whether any Health staff had been advised that their mandatory reports to such officers at the CWU were taken to have fulfilled their obligations under \$27 to report a matter to CS.
- Ms Henry responded by letter of 1 May directing my attention to the 2013 NSW Health Child Wellbeing and Child Protection Policy and Procedures (at Tab 93 Vol 6 of the Brief). She also enclosed the NSW Health Child Wellbeing Unit Manual as at June 2011. Her letter also enclosed a 2 page document "NSW Health Response to the further query from Her Honour Deputy State Coroner Truscott in the Caleb Fahey matter dated April

2014. That document refers to the CWU Operating Guidelines (3rd ed Nov 13) and the enclosed CWU Manual.

There is no provision whereby a Mandatory Reporter is informed that their report to a CWU is a discharge of their obligations though a CWU is empowered to make a report of ROSH to CS where the Mandatory Reporter declines to do so. The Mandatory Reporter is encouraged to make the report directly to CS as that is best practice to ensure that all the necessary information is passed on directly. The explanatory document says "It is noted that the NSW Health policies and training around the role of the CWUs do not explicitly state to Health workers that, by contacting the CWU to report a concern they have fulfilled their responsibility as per 27A, because this may cause worker to perceive that all of their child protection responsibility has been met. When the CWU is discussing concerns with health staff, the responsible Health workers may have to take additional action, such as refer the family to support services. Making referrals or taking other action to promote a child's safety, welfare or wellbeing is also considered to be a health worker and CWU responsibility as per the additional requirements of \$27A."

I note that the document also sets out the rationale "In the development of information for Health workers on the role of the Health CWUs (as well as CWUs in other agencies) it was identified that the key message of 'shared approach to child wellbeing' involved changing worker's understanding about the breadth of their child protection responsibilities. The workforce culture change required reframing the perception that the only legislated role Health workers had in child protection was one of mandatory reporting to one where workers understand the need to identify, report AND respond to child protection and wellbeing concerns."

The establishment of a properly constituted Child Protection Unit at JHH is consistent with the shared approach required so that the hospital has its own systems in place which would include a system whereby it would know how many ROSH reports are made to CS and what the responses were and what the follow up was and whether an Interagency Case Discussion was required where the case is unable to be allocated to a CS caseworker. The Child Protection Unit would obviously use the Child Wellbeing Unit to its fullest potential but be the best placed from a hospital/institution perspective to coordinate it as the Child Wellbeing Units perform significantly different tasks covering non-ROSH reports, cumulative assessments and referrals to community based services.

At the time of Ms Henry's response the 2011 Manual was under review and following its completion she forwarded a copy by letter dated 27 May 2014. (The manual is actually dated April 2014). Unlike the earlier one this manual sets out the s27A Alternative Reporting Responsibilities and designations of the assessment officers (as per the 21.1.2010 letter from Ms Piccone). It indicates that s27A enables any matter that a Health worker would otherwise be required to report to the Helpline can be reported to an assessment officer. Any report of a concern made to the CWU means that the staff member making the report is taken to have satisfied his or her mandatory reporter obligations.

209 With respect I do not think that is a correct statement of the legislation at all. Section 27 casts an obligation to report where the worker suspects that a child is at risk of significant harm not "any report of a concern". The MRG directs a mandatory reporter to report matters which fall below significant harm to CWU – this does not effect and discharge of obligation under s27. However, under a practice note it is specified that the CWU must report to the Helpline on behalf of a Mandatory Reporter who "would prefer to only provide their suspected ROSH report in full to the CWU and not repeat the details again by calling the Helpline". I do not know whether NSW Health or HNELHD intend to amend their policies advising their mandatory reporters of this alternate reporting system.

In any event, as a consequence of receiving that correspondence I then instructed the Crown Solicitors Office to distribute draft recommendations relating to the establishment of a Child Protection Unit at the Hospital and the consideration of whether relevant workers of the Unit should be designated as assessment officers for the purpose of the Hospital's Mandatory Reporters discharging their s27 obligations when enlisting the help of the Unit prior to reporting to the Helpline. (Letter of 2 June 2014).

The submissions in response from CS and HNELHD strongly oppose s27A designations of Child Protection (Unit) Staff. A letter dated 10 June 2014 at the hand of Roderick Best, Acting Director Legal Service Unit Community Services Department of Family and Community Services and a letter dated 28 August 2014 from Michael DiRienzo Chief Executive HNELHD contain those submissions.

212 Mr Best makes the following points:

- The CWUs are already a developed infrastructure and mechanism to enable
 the exchange of information and reporting between FACS and medical
 professionals; which ought to be strengthened rather than building further
 new processes.
- Rather than have more designated assessment officers it would be preferable
 for Health to raise staff awareness of the mandated role of their CWU and
 ensure that staff better use this resource in order for the CWU to operate as
 it is intended under the NSW Government's Keep Them Safe: a shared
 approach to Child Wellbeing Action Plan.
- Health underutilises the CWU (in 3 months to 30 June 2013 there were 154 concern reports to FACS compared to 2850 from the Police CWU)
- CWU are trained and familiar with SRPT used by HELPLINE and interpreting an MRG so when a reporter is directed by MRG to report a concern to a CWU (rather than HELPLINE) the CWU may better interpret the MRG so a ROSH is identified and because the CWU has a strong interface with HELPLINE child protection reporting and interagency cooperation is enhanced.
- If a Child Protection Unit at the hospital had designated assessment officers
 they would need to be trained in the information systems used by all the
 CWUs, requiring a consideration on broadening access to sensitive and
 confidential information held by FACS which would have financial
 implications for both FACS and Health.
- Other departments at the hospital report to the HELPLINE which would undermine the purpose of having assessment officers at the hospital. If there was a centralised hospital based reporting processes there would need to be new advice and training about it.
- Changes to reporting processes would involve changing messages already conveyed under the Keep them Safe reforms.

- Designation of assessment officers at the JHH raises the issue of whether they should be introduced at other hospitals and if not this would need to be justified.
- CWU is the ideal conduit to report to HELPLINE, given the different systems in place within Health
- The Hospital does not know how many ROSH reports its staff have made to the HELPLINE. There is no adequate system in place to deal properly with responses from CS in keeping with the shared care approach. Mr Best does not refer to the JHH Child Protection Guide where staff from all departments at the hospital are directed to the CPT so a matter can be assessed before a report is made to the HELPLINE and that this process involves the use of the MRG, Child Protection assessment tools and consultation between CP team members and clinical staff.
- Mr Best's submission that Health under-utilises its CWU does not indicate whether he means all NSW Health CWU or just the Northern CWU (housed in Newcastle- there are 2 others in NSW). However, Mr DiRienzo's figure that Northern CWU has had 387 calls from JHCH and 959 from JHH (many relating to concerns about parental behaviour) from commencement of operation in 2010 to end of May 2014 is consistent with Mr Best's view of the figures. Mr DiRienzo cites the statistics to contradict evidence given at the inquest which he says "may have indicated that the CPUs (as well as other staff at the three tertiary children's hospitals) do not access the Health CWUs".
- Caution should be used in interpreting these figures as relevant to mandatory reports to the HELPLINE. As Dr Marks indicated to me, there are many cases where the risk of significant harm is so obvious that a staff member does not need to seek guidance from the MRG and just makes the report to HELPLINE forthwith.
- Designating assessment officer/s at a CPU would not undermine staff at other departments reporting to the HELPLINE because the policy already is that they first consult with the CPT. Mr Best is correct in identifying the Deputy State Coroners concerns as being directed to considering a central conduit of hospital mandatory reports of ROSH to the HELPLINE. He suggests that the conduit be CWU rather than via CPU however, that does not address the concern of a co-ordinated and systemic response. At

the moment there are so many systems and pathways to reporting to the HELPLINE and few follow up procedures in place that the Hospital would have difficulty meeting its shared care or interagency obligations.

- The Hospital's Child Protection Team Guide and Policy and Procedure directs a centralised approach in the reporting process of ROSH matters and if that policy and procedure was followed then the CPU would be in an ideal position to have a designated role yet Mr DiRienzo submission says that HNELHD is opposed to a centralised reporting system through the CPU. Obviously such opposition is accompanied by opposition to any designations of assessment officers.
- Whilst Mr DiRienzo does not oppose the establishment of a "formal administratively supported" Child Protection Unit, he says that this should not be perceived as an opportunity or platform to alter the existing and fundamental mode of operation which is to provide specialist clinical advice and provision of forensic medical examinations. They focus on actual harm and serious matters relating to both inpatients and ambulatory patients while other staff respond to many "lower level" concerns. The CP/CPT are consulted by other specialist colleagues about whether child protection concerns relating to their patients warrant (a) a review by the CPU/CPT or notification to the HELPLINE or referral to the CWU. Staff would be encouraged to complete the Mandatory Reporters Guide before carrying out (b) or (c).
- Mr DiRienzo says "Throughout the hospital there are a significant number of other child protection concerns which are reported to either the HELPLINE or CWU but which do not necessarily required referral to the CPT". This is inconsistent with the CPT Guide, policy and procedure which raises the issue yet again of how many pathways should there be for ROSH reports from the Hospital where the pathway "to" should have a pathway "from" under the share care approach?
- 220 Mr DiRienzo opposes the s27A designations on the basis of not only not wanting a centralised reporting pathway through the CPU but also because to do so would undermine the CWU process. Given the very low Northern CWU usage over the 4 year period and the lack of statistics as to how many direct HELPLINE reports of ROSH have been made by the Hospital I don't accept the basis of this submission. It is difficult to see how an underutilised service for non-ROSH reports can be undermined by another

service relating to ROSH reports without. Likewise I don't accept Mr DiRienzo's submission that "from the perspective of HNELHD, the existing reporting arrangements are working effectively, particularly in relation to the role played by CWU" as relevant to reports of ROSH to the HELPLINE. There is no new policy directing these reports to be made through CWU and my reading of the policy is that reports of ROSH are generally only made by CWU where the Mandatory Reporter refuses to.

- Mr DiRienzo "if this recommendation was implemented it would mean that any health worker who tells the CPT/CPU of their concern would have discharged their responsibilities and so it would rest with the CPUs to assess all risk and record and plan a response to all concerns which are brought to their attention". That is incorrect and if it is relying on the new CWU Manual April 2014 I have already pointed out that error. An obligation to report to HELPLINE does not relate to "concerns" it relates to a staff member having reason to suspect that a child is at risk of significant harm".
- Both Mr Best and Mr DiRienzo have taken the position that introducing a s27A designation to CPU duplicates that of CWU and Mr DiRienzo says it would detract from the focus of the CPT/CPU. I do not think it does either. It would only duplicate CWU's role if Health directed its staff to report to the HELPLINE via the CWU. It's policy and the MRG does not direct that at all. Its policy directs it staff to the CPT/CPU so that the CPT is consulted and can be involved in the assessment before a ROSH is made.
- The hospital needs to decide what system it is going to use. If it is content to use both CPT/CPU, CWU as well as "allowing" is staff to report directly to HELPLINE without using either then it needs to have policy and procedure to reflect this BUT it still needs a follow up co-ordinated follow up system at the hospital. I do not see how that follow up system can be directed through the CWU. It needs to be done by people who are based at the hospital. Further, it seems to me that to the co-ordination should commence from the beginning of the process which is the Reporting end which brings me back to the recommendation of the designations.
- Mr DiRienzo says that Professor Vimpani considers that because all health workers are already mandated reporters, individuals need to be able to report directly rather than be required to first go through CPT. That contradicts Mr Vimpani's own guide which

requires staff to go to CPT first however the guide does make it clear that reporting is not the role of the CPU rather a nominated member of the treating team.

Mr DiRienzo says that the CPT does not have the requisite resources to properly fulfil an "assessment officer" role. These recommendations do not envisage keeping the limited resources available to the CPT as it stands. It does not even have a telephone and secretary or its own fax number or office and has part-time staff occupying positions which should probably be full time. Clearly the implementation of the recommendations involves a properly funded and resourced unit.

Mr DiRienzo submits that there would be a potential loss of information because the CPT/CPU do not record all telephone/direct advice provided to clinicians about cases they are not directly involved in. If that is the case the information is lost now under the current system so I don't quite understand that submission. As Mr Best submits, an introduction of a s27A designated officer would involve putting computer and information resources typically available at a CWU at the Hospital. Perhaps this could be by secondment (which the legislation allows for) and would mean better utilisation of the Northern CWU — being a conduit for the hospital's mandatory report of ROSH mechanism.

Mr DiRienzo adopts Mr Best's submissions in relation to training staff which I do not think is an unsurmountable problem. In any event this seems to contradict Mr DiRienzo's Given that the CPT policy is for staff to come to it and they would be advised to complete the MRG in any event, it would seem to be a difficult proposition.

I do understand that opposition to the implementation of s27A designations but there thrust that it would detract from the CWU as a point of reporting ROSH to HELPLINE is not substantiated and if the CPT/CPU are fulfilling its role as per its Guide and Policy and Procedure, such a designation is supportive of that role rather than creating a new one in its entirety. However, by not implementing such a recommendation the role of CPU/CPT as a point or conduit of mandatory reports of ROSH to HELPLINE with the antecedent follow up response system still needs to be implemented, with or without s27A designations. The designations would have simplified the pathway for those matters.

- Professor Vimpani gave evidence of the need for a paediatric weight management unit at the JHH akin to that at the other tertiary hospitals and said that obesity and failure to participate in ongoing treatment is a child protection issue. Dr Marks supports the need for such a unit, remarking on the prevalence of childhood obesity. As Professor Vimpani said, it is an issue of resources and there are other needs that have priority. Mr DiRienzo opposes the establishment of such a unit in his letter of 28 August 2014. The reason for such opposition is that "...we believe that there are more effective ways of addressing this important problem in the context of the already available but scarce resources. We consider that there are sound clinical, service delivery and outcome grounds for our position in this respect". "HNELHD considers that a clinic-based approach is not necessarily the most effective way of approaching the problem".
- He says that there are no staff or resources to establish such a unit and even if there was such a unit, the metropolitan referrals would outstrip the unit's capacity so that the needs of regional and remote children would not be met. HNELHD has partnerships with Mental Health Services and General Practitioners and community based programmes and initiatives which provide effective ways of seeking to address to childhood weight management and other morbidity issues. HNELHD considers it preferable to focus on increasing overall paediatric capacity rather than set up a separate weight management unit. Whilst I appreciate the cost-effective approach sought, given what I heard in this case there is certainly reason in this community to establish such a clinic based unit as a multi-pronged approach to the child obesity.
- In relation to the establish of a formalised CPU at JHH Mr DiRienzo says that such a facility is incorporated in the John Hunter Health Precinct Master Pan 2014, anticipating that there will be a space for CPU within the precinct at the western end of the site being dedicated to women and children.

AA's Final Admission to the John Hunter Hospital

There is scant direct evidence before me about the circumstances immediately preceding AA's last admission to hospital on 17 September 2010. As already noted, his parents refused to provide statements to the police, and indicated that they would not willingly

give evidence in the Inquest. File notes were made at the hospital about what the family told the Doctors and Social Workers and I have heard evidence from AA's sister who drove him and his mother to the hospital.

- On the evening before his admission, AA had been out for a couple of hours at a school disco. It was a Thursday night. He had been to school for an hour or so in the morning and went home so that he would be well enough to attend the disco. He had been complaining to his family of a sore stomach and he had a cough for a couple of days.
- There is some evidence from the school that he complained to his father that he had had "a turn" that morning at school similar to something he had recently had, differentiating this from just falling asleep. There is no clear evidence as to whether AA had had a "turn". It is possible that if his body had not exhaled sufficient CO2 he has lost consciousness for a moment, a sequelae of OSA. In any event, he was well enough to attend the disco but the following day he was very difficult to rouse.
- By the evening his parents had left the home to obtain takeaway food for him and upon their return he was unable to be roused to eat it. Despite this difficulty, he was it seems assisted by his mother to get dressed for hospital and was walked to the front passenger seat of the car.
- AA was very drowsy but BB said that she did not think he was about to die because he was always drowsy and she did not distinguish his presentation on this occasion with any other. On the way to the hospital they stopped to get petrol. The car was filled and the video footage of BB paying for the petrol is consistent with her not appreciating that her brother was in a life threatening condition. She said they didn't call an ambulance because from an experience when her father needed an ambulance, it took too long, so she thought it would be quicker or just as easy to take him to hospital in the car.
- The JHH is about 5 km away and though there is another hospital with an emergency department significantly closer, BB said she took him to the JHH rather than the closer hospital because JHH is a children's hospital. In any event, I remind myself, she did not realise that AA was in an emergency because "He seemed drowsy when he was in the car

which was nothing uncommon". BB said she didn't know whether AA was awake or not after they left the petrol station

- A few minutes later, when they arrived at the emergency area of the hospital BB and her mother tried to get AA out of the car. They then realised AA was not breathing, they screamed and a security officer came to their assistance and removed AA from the car into a wheelchair. He was quickly taken to a resuscitation bay in the emergency department. After about 4 minutes of resuscitation AA's heart beat returned and he was put on ventilation and life support. The estimate of the time that AA was in cardiac arrest is difficult to identify with precision, but it seems likely that AA had gone into cardio-respiratory arrest around 5-8 minutes before he arrived at the hospital.
- BB gave evidence that she had left her father's home to go to work at about 11.30am. She couldn't remember if AA was dressed for school or where he was or whether she spoke to him. She returned home at 3pm leaving again at 4.45pm. She couldn't remember if she saw AA but says she "would have" but couldn't say how he seemed. She returned back from work at about 8 pm. She and her parents were home and she thinks AA was in bed, she thought he was asleep. She also said he "would have had the mask on" because he was asleep and that every time he was at home asleep her parents would put the mask on".
- Counsel Assisting asked a series of questions, which were met by "I don't know" and "I don't remember". These questions were related to a statement given by BB to her parent's solicitor just 2 days before she gave her evidence. The questions related to her parents going out to get takeaway food and bringing it back for AA.
- BB gave evidence that AA ate like a normal child, and that her mother cooked meals according to the diet plan stuck on the fridge. Again, she said that he wore the CPAP mask each night. Dr Hilton is of the view that given the presentation of AA in September 2010 it would appear that he was not using the CPAP machine nor making effective attempts to lose weight. AA's weight gain, the continued lack of compliance his mother admitted to the dietician in 2009, AA's right heart strain is consistent with not being properly ventilated and his poor school attendance generally and the fact that he would soon fall asleep when he did attend leads me to find that AA did not use the CPAP machine as the doctors had advised in 2009 and his parents failed to attend to this essential requirement

just as they failed to take him to the hospital for review at the sleep unit and the dietician. Whether the machine worked adequately in any event is questionable given that they also failed to attend the non-invasive ventilation unit to have the CPAP machine serviced. The parents having decided in September 2009 that AA was not going to have the surgery left him with two interventions to address his health—one was to lose weight and the other was to use the CPAP machine correctly.

- The parents have made a statement through Mr Cavanagh, although it does not go to any of the facts relevant to AA's final year or hospital admission. He says that they thought AA would grow out of his weight problem as their other sons had and that his sleep apnoea would resolve in that way. They had been told otherwise by the doctors to no avail.
- Mr Cavanagh said that AA's parents had nothing but love care and concern for AA. I accept that. But parenting a sick child requires more than love care and concern it requires commitment, and a capacity to accept inconvenience and change. Mr Cavanagh said that AA's parents had done their best. I accept that the parents did not really comprehend or believe that AA was actually in a life-threatening situation even though they were told by the medical staff he was. Mr Cavanagh said they didn't really understand. If they did understand they were completely unable to translate that into action and fell into denial, dysfunction and drug abuse.
- I accept that the parents, particularly YY, felt judged by the Hospital. I am sure she feels badly judged by me. It is difficult for a parent to deal with those feelings whilst struggling to improve another aspect of parenting to meet a sick child's needs. That is why it was so important in this case for Child Protection case workers to be involved. They have the skills to communicate and engage with parents so that rather than feeling judged, she may have experienced being understood so that a level of trust and engagement and support could have been developed.
- Had CS been involved with AA, this would have been a case which required a great many resources to address AA's weight and OSA, the parent's drug abuse, and a raft of apparently highly dysfunctional and challenging dynamics in a family which was held together by very strong bonds of love and loyalty to each other. Maintaining, even for a

moment, a healthy basic diet and simple exercise programme for AA was apparently as hard a task as it was for the mother to address her own problems.

The mother was not AA's only parent though she has received a large amount of comment in this Inquest. AA was mainly at his father's house but his father, though present in person, seems to have been ineffectual in the matters the Hospital staff had spoken to them about. His passivity and inaction is difficult to comprehend. Mr Cavanagh submitted that the parents being were on a methadone programme does not mean they are not caring and capable parents. Nobody has suggested that their parenting of AA was effected in anyway by their methadone use. I think the evidence in this regard speaks for itself.

Cause of AA's Death

- Dr Irvine, Pathologist gave evidence further to her report and I have received into evidence the report of Dr Cala, pathologist. Dr Cala determined that AA died of hypoxic ischaemic encephalopathy following respiratory arrest, citing antecedent causes as obstructive sleep apnoea, pulmonary thrombo-emboli, pneumonia and presumed sepsis with obesity as a significant condition contributing to the death but not relating to the disease or condition causing it. Dr Irvine concluded that AA may have presented with thrombo-embolic disease, a respiratory tract infection or cardiopulmonary complication of his obesity and OSA, any or all of which may have caused cardiopulmonary arrest and hypoxic ischaemic encephalopathy.
- Dr Hilton treated AA upon his admission to ICU. She was firm in her view that AA did not have pneumonia but he did have an upper respiratory infection. Dr Rowley said that, in light of AA's elevated white blood cell count, he may have had pneumonia even though the scans showed AA's lungs to be clear. However, that count could also have been caused by the hypoxic event. Dr Irvine raised the possibility of thrombo-embolic disease but having heard about the presence of the subclavian thrombosis, AA's immobility and Dr Hilton's evidence that there was no embolism, I am of the view that there is no evidence of thrombo-embolic disease or that it had any involvement in AA's death. Though he may have had a pulmonary thrombosis at the time before his death 12 days later, this was not likely a factor in his cardio-respiratory arrest.

- Dr Irvine distinguishes her findings from Dr Cala on a limited basis in her report. She says "I would not have used "obesity" as a contributing factor because it is almost certainly central to the pathological processes that caused the death of this child. Dr Cala's cause of death statement may not be wrong, but it does not in my opinion embrace the varied clinical possibilities in this situation and the seminal role of obesity".
- The circumstances or manner of AA's death involve the parents not attending to his medical appointments or requirements for weight loss and usage of the ventilation system by CPAP machine. They failed to identify that he was in an extreme life threatening state even when they made the decision to take him to hospital. This is evidenced by their attempt to rouse him with his favourite takeaway food.
- 251 Child Protection Intervention was necessary for AA's medical condition to be addressed, as his parents were unable to help him. That intervention did not occur for a number of reasons including a lack of communication between one area of health and another, lack of engagement and follow up of Child Protection Team at JHH, lack of communication between Health and CS, a lack of understanding health staff of CS processes by, a lack of understanding by CS staff of AA's medical condition due inadequate records and a failure to share and seek appropriate information so the full risks to AA were not properly identified and followed up. Even when high risks of harm were identified, intervention was not available due to a lack of case worker staff to provide further assessment of AA let alone provide case management. Department of Education staff at AA's school failed to inquire whether he was receiving medical treatment to address his school attendance requirements.
- Depressingly, I agree with Mr Cavanagh's submission that the lack of CS intervention may still occur today despite the massive changes that have taken place since the inception of the "Keep Them Safe" Reforms of 2010. My recommendations do not address the obvious necessity for more funding to employ more CS caseworkers to meet the needs of more children who are at significant or even high risk of harm. The recommendations below are directed at the shared care approach that the Reforms seek to develop.

- Counsel Assisting suggested that I make a recommendation that the HNELHD, FACS (Hunter Community Services and DEC Hunter) establish an Interagency Standing Committee to facilitate ongoing consultation and co-operation in respect to exchange of information, training of staff with respect to the effect exchange of information and the development of guidelines for the identification of children at risk of significant harm due to neglect.
- I have received evidence that CS are engaged in reviewing the policy and definition of neglect including medical neglect and that there already exists an Interagency Forum which meets monthly to address the matters raised by Counsel Assisting. I note the Forum document, which includes a Health and Community Services exchange of information process, and collaboration on matters generally so that any ongoing difficulties with operational or policy and procedure matters can be addressed.
- I have also heard that the CS operating regions are or have been restructured to align with those of Health so that there will be even closer collaboration on all matters. I think that that forum is probably sufficient but will very much depend on intra agency communication so that the key members of the forum are aware of the difficulties and the needs that must be addressed. Whilst it is commendable that an interagency workshop to develop an education package about medical neglect and how to use the assessment tools occurred in November 2013, I do point out that (to my knowledge) there have been only 2 meetings as a result of the Ombudsman recommendations: April 2012 and then September 2013 preceding this education workshop and, as at the time of the inquest, CS was yet to address its policy definition for neglect and medical neglect.
- The other recommendation by Counsel Assisting is that consideration be given to the establishment of a Weight Management Unit with the JHCH. I support that recommendation for the reasons expressed earlier. The other recommendations relate to the development of a Child Protection Unit at the JHH and also those relevant to s27A designations which I have also discussed earlier. Though I have considered the submission opposing those recommendations, on balance to facilitate Health meeting its shared care child protection obligations, I have decided that those recommendations should proceed.