Coroners Act 1996
[Section 26(1)]

Coroner's Court of Western Australia

RECORD OF INVESTIGATION INTO DEATH

Ref: 70 /19

I, Sarah Helen Linton, Coroner, having investigated the death of ***Child AC*** *with an inquest held at the* ***Perth Coroner's Court, Court 51, CLC Building, 501 Hay Street, Perth*** *on* ***19 November 2019*** *find that the identity of the deceased person was* ***Child AC*** *and that death occurred on* ***10 August 2017*** *at* ***Unit 2, 18 Hertford Street, East Victoria Park****, as a result of* ***renal failure due to focal segmental glomerulosclerosis*** *in the following circumstances:*

Counsel Appearing:

Sgt L Houisaux assisting the Coroner.
Mr B Loftus (State Solicitor's Office) appearing on behalf of the Department of Communities.

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SUPPRESSION ORDER

The deceased's name is suppressed from publication. The deceased should be referred to as Child AC in any external publication.

INTRODUCTION

1. Child AC, who I will hereafter refer to as the deceased as I can't use her first name due to the suppression order, was born in June 2009. There were complications during her birth. Her parents had hoped for a natural birth and to deliver in the Family Birth Centre at King Edward Memorial Hospital, but after a lengthy labour a decision was eventually made that a natural delivery was not possible and the deceased's mother was moved into the main hospital. Due to concerns about fetal compromise, the deceased was born by emergency caesarean section just after midnight on 8 June 2009.

2. The deceased took some time to breathe on her own after birth and she had to be resuscitated. She then spent a short time in the Special Care Nursery due to mild respiratory distress. The deceased and her mother were eventually discharged home on 12 June 2009 after four days in hospital.

3. The deceased's mother noted her development was slow. She was referred to more than one paediatrician, and at about 15 months of age it was felt that the deceased could be suffering from cerebral palsy. Rett Syndrome, caused by a genetic mutation, was also suggested at a later stage as there were strong indicators she had the condition, although it was never confirmed by genetic testing.

4. The deceased's health conditions affected her brain development, ability to communicate, mobility and capacity to live independently. She had complex high care needs. Her parents were initially able to meet these care needs, but as they added to their family, they struggled to cope. After the birth of their third child, and following discussions with social workers from the Department of Communities[1] (the Department), her parents indicated they were unable to provide the care the deceased needed and agreed to relinquish their parental rights.

5. Proceedings were commenced in the Children's Court of Western Australia for Provisional Protection and Care and in August 2012 a Protection Order was granted until the deceased turned 18 years of age. The deceased was placed in foster care with a woman who had cared for her during respite periods in the past. The deceased remained living with the same foster carer until her death and they formed a strong attachment. The foster carer and the deceased's biological parents also developed a supportive relationship. I will not refer to any of them by name, in line with the suppression order.

[1] At the time known as the Department of Child Protection.

6. Periodic assessments found the deceased was well cared for and her placement enabled the deceased to receive consistency in her personal care, schooling, medical care and social activities. She received input and support from multiple medical specialists, organisations and allied health professionals and was provided with appropriate equipment to support her care in the community. Importantly, it is also apparent she was loved by her foster carer.

7. In 2016 the deceased developed a serious form of nephrotic syndrome and her prognosis was poor. She developed worsening kidney failure and it became apparent that further intrusive medical management was no longer in her best interest. It was agreed between the deceased's foster carer, biological family, Department representatives and medical team that when her condition deteriorated she would be referred for palliative care.

8. The paediatric palliative care team took over her care from 8 August 2017 after her renal failure had progressed to the stage where she required end of life care. She was discharged from hospital and kept comfortable, with the support of the Silver Chain Hospice Care Service, until she died peacefully at home on 10 August 2017.

9. The fact that the deceased was a child in care at the time of her death was unfortunately overlooked, so her death was not reported to the Office of the State Coroner. Instead, a doctor completed a death notification form, indicating the cause of death was renal failure on a background of focal segmental glomerulosclerosis. Her body was released for a funeral service to be conducted.

10. Following a Departmental review, the WA Police Coronial Investigation Unit were notified by the Department of the deceased's death in July 2018. It was acknowledged that she was a child in care, for the purposes of the *Coroners Act 1996* (WA), at the time of her death, and her death was a reportable death.

11. The circumstances of the death were investigated by police. Significant material was provided by the Department as part of the investigation. At the conclusion of the investigation a comprehensive report of the death was prepared.[2]

12. The death of a 'person held in care,' as defined in section 3 of the *Coroners Act 1996* (WA), requires a coronial inquest be held.[3] I held an inquest at the Perth Coroner's Court on 19 November

[2] Exhibit 1.
[3] Section 22(1) (a) *Coroners Act.*

2019. The only witness formally called to give evidence at the inquest was Mr Andrew Geddes from the Department (now known as the Department of Communities). Mr Geddes provided clarification on the initial failure of the Department to advise the Coroner of Child AC's death, and provided information about the new systems in place to ensure a similar failure is unlikely to reoccur. I am satisfied the new processes described by Mr Geddes are appropriate and should ensure all reportable deaths are reported in a timely manner by the Department.

13. In addition, the deceased's father voluntarily gave some evidence on behalf of himself, his wife and the foster carer. He commended the care and support the Department provided, but raised some concerns about the family's dealings with individual staff members. After the inquest, the deceased's foster carer also provided the Court with some text messages in support of this evidence. I will refer to this issue at the end of my finding, but note for now that it underscores a common theme raised in inquests of communication.

14. In summary, the evidence before me showed that Child AC was cared for by the same foster carer for many years until her death. Her foster carer was committed to providing a safe, supportive and loving environment for her. Her biological parents and siblings also remained a part of her life and were included in decision-making until her death. Child AC was treated by a multidisciplinary team of doctors, all of whom appear to have provided a high level of medical care. When her health deteriorated to a stage where active treatment was no longer appropriate, she was given palliative care to keep her comfortable. Taking into account all of the circumstances, I am satisfied Child AC's care and supervision was appropriate and of a very high standard.

OVERVIEW OF CHILD AC'S LIFE AND HEALTH ISSUES

15. Child AC was her parents' first child. Her mother had been under the care of a general practitioner and staff at the KEMH Family Birth Centre during her pregnancy. Her pregnancy was considered low risk and she was hoping to give birth under midwife care at the KEMH Family Birth Centre.[4]

16. Child AC's mother began to experience contractions in the early hours of 6 June 2009. She was driven to the Family Birth Centre and assessed then sent home to wait until the contractions became more frequent and regular. She returned later that day

[4] Exhibit 1, Tab 3.

and was admitted and checked into a room. The deceased's mother was awake for most of the time she was admitted to the Family Birth Centre and she quickly became exhausted.[5]

17. On the morning of 7 June 2009 the deceased's mother had been in labour for well over 24 hours and was still experiencing contractions. Discussions were had regarding a caesarean section as the labour was not progressing. At midday on 7 June 2009 the deceased's mother was transferred from the Family Birth Unit to the Maternity Unit within KEMH. The deceased's mother was given an epidural to ease the pain and she felt more comfortable. However, after approximately 45 hours of labour there began to be signs of fetal distress, so just after midnight the deceased was delivered by emergency caesarean section.[6]

18. The deceased did not cry at birth and was manually assisted to start breathing. Her APGAR scores were low but then improved. She was taken to the resuscitation unit where her oxygen levels were monitored. She was transferred to the Special Care Nursery later that morning as her blood gases were low. She was discharged back to the main hospital after one day.[7]

19. The deceased and her mother spent four nights in hospital before being discharged home. There was no indication given on discharge that the deceased had any serious health concerns that would not resolve.[8]

20. The deceased's development was slow and she was referred to a private paediatrician and seen at Princess Margaret Hospital as her parents were concerned that she was not reaching milestones. Initial findings were of 'floppy baby syndrome' (hypotonia) and developmental delay, although the deceased's parents suspected something more might be wrong and that the cause might have originated during the extended labour. Subsequent appointments and specialist examinations sadly confirmed their suspicions that their daughter had serious medical issues. At 15 months of age the deceased saw a developmental paediatrician and it was suggested for the first time that the deceased might be suffering from cerebral palsy.[9]

21. At a later appointment with Dr Simon Williams, who eventually became the deceased's regular paediatric neurologist, the possibility of Rett Syndrome, a genetic disorder, was raised, although genetic tests conducted on blood samples did not

[5] Exhibit 1, Tab 3.
[6] Exhibit 1, Tab 3 and Tab 5.
[7] Exhibit 1, Tab 3.
[8] Exhibit 1, Tab 3.
[9] Exhibit 1, Tab 3.

confirm it.[10] Dr Williams felt that the deceased presented very much with the clinical symptoms of Rett Syndrome and this was his clinical diagnosis. The deceased's mother felt that the deceased's cerebral palsy most likely related back to her extended labour, which she felt was mismanaged, so she was not accepting of the diagnosis of Rett Syndrome, which she felt diverted attention from the real cause.[11]

22. In any event, Dr Williams indicated the deceased's overall condition could be described as cerebral palsy for the purposes of her management and medical care.

TRANSFER TO DEPARTMENTAL CARE

23. The deceased suffered from severe neurological impairment and she needed someone to care for her at all times due to her complex health needs. The deceased was non-verbal but was able to communicate through an application on an iPad. She woke most nights and was not easily soothed, often crying inconsolably for hours.[12]

24. The deceased's parents' second child, a baby brother for the deceased, was born in December 2010. In March 2011 the deceased's parents spoke to a social worker at Kaleeya Hospital seeking assistance as they were finding it very difficult to care for a newborn and the deceased.[13]

25. This enquiry led to the family's first contact with the Department. They had previously contacted the Disability Services Commission for referral to a particular program but the referral was unable to be made until the deceased turned 12 years of age, unless it was funded by the Department. As a result, the deceased's family had begun to consider their options.

26. On 30 June 2011 the deceased was seen by Dr Williams, a Paediatric Neurologist. He noted that investigations thus far had failed to yield any diagnostic clues. As noted above, Dr Williams thought her clinical presentation and history that indicated her development was slipping was suggestive of Rett Syndrome.[14]

27. On 2 August 2011 the deceased was registered with the Disability Services Commission and she received services through Therapy

[10] Exhibit 1, Tab 3 and Tab 8.
[11] Exhibit 1, Tab 3.
[12] Exhibit 1, Tab 7.
[13] Exhibit 1, Tab 7 and Tab 11.
[14] Exhibit 1, Tab 7 and Tab 27A.

Focus and the Carson Street School. She also attended regular respite at Alkira Respite Care Services.[15]

28. The deceased's mother gave birth to their third child in October 2012. During the third pregnancy, the deceased's parents gave careful consideration to their ability to manage the deceased's complex care needs within the context of a growing family. In April 2012 the deceased's parents contacted the Department's Adoption Unit and indicated they had made a decision to relinquish their parental rights over the deceased due to their inability to continue to care for her at home.[16]

29. In May 2012 the Department conducted a Safety and Wellbeing Assessment regarding the deceased. It was noted the family had been offered considerable respite and other support services, which they had taken up, but they felt that a more permanent, stable and loving placement was the most appropriate option. The deceased's parents expressed their hope that the deceased could be placed in a foster or adoptive family environment where she could receive specialist care but still have family contact.[17]

30. On 13 August 2012 a Protection Order was granted placing the deceased into the care of the Chief Executive Officer of the Department until the deceased turned 18 years of age. The deceased moved in with an approved foster carer, who had offered to care for the deceased after acting as her respite carer at Lady Lawley Cottage. She was already known to the deceased's family as a result.[18]

31. The deceased remained with the same foster carer for the rest of her life and it is clear they had a loving relationship. The deceased's parents and siblings also continued to play a role in her life, initially having her stay over for the weekend regularly until December 2014, around the time of the birth of another child. From that time their level of involvement decreased, but they continued to have day visits with the deceased. Her parents were kept informed of her healthcare needs and consulted about decisions, although I will return later to the question of whether this was done in an ideal manner.[19]

32. During her time in care the deceased also had regular respite with other services, such as Lady Lawley Cottage and Alkira Services. In January 2016 there was an incident at the deceased's respite placement. The deceased was left unsupervised with another child and was then found on the floor

[15] Exhibit 1, Tab 6.
[16] Exhibit 1, Tab 6 and Tab 11.
[17] Exhibit 1, Tab 7.
[18] Exhibit 1, Tab 10 and Tab 11.
[19] Exhibit 1, Tab 6 and Tab 7.

crying and the other child was in her wheelchair. The deceased was taken to PMH and examined and found to be uninjured.[20]

33. During 2016 the deceased was able to participate in a number of activities, including an ocean cruise from Brisbane, the Colour Run, a helicopter ride and a motorcycle ride.[21] She also enjoyed being in the water, and even when her school hours reduced later in her life for health reasons, she continued to have access to the school pool.[22]

DECLINE IN THE DECEASED'S HEALTH 2016 - 2017

34. In March 2016 an issue with the deceased's kidneys was suspected due to an ongoing vomiting illness. A biopsy in April 2016 indicated nephrotic syndrome.[23]

35. In May 2016 the deceased was diagnosed with Focal Segmental Glomerulosclerosis, a serious and aggressive form of nephrotic syndrome (kidney disorder), which was steroid resistant. It was predicted that she would suffer a progressive decline in her renal function, ultimately resulting in kidney failure. The deceased was not a suitable candidate for dialysis or renal transplant.[24]

36. On 17 October 2016 the Department accepted medical advice that further intrusive medical procedures should be ceased as they were not in the best interests of the deceased. A decision was made that she be certified 'not to be resuscitated' in the event of a major health event and not be subject to any invasive treatment.[25]

37. On 10 November 2016 the Department initiated a home visit to check on the deceased's wellbeing after receiving an anonymous letter suggesting that the deceased's foster carer did not have a full understanding of the deceased's condition and prognosis and would not listen to advice.[26] The Department attempted a number of unannounced home visits between November 2016 and January 2017 but her carer was not present. However, it was noted that prior to receipt of this letter of concern, a visit had been conducted on 8 November 2016 and the two officers who attended reported that the deceased was clean and well groomed, animated, laughing and giggling throughout the visit. The house was said to be cluttered and untidy, as it had also been on a

[20] Exhibit 1, Tab 7.
[21] Exhibit 1, Tab 7.
[22] Exhibit 1, Tab 7.
[23] Exhibit 1, Tab 7.
[24] Exhibit 1, Tab 6 and Tab 7.
[25] Exhibit 1, Tab 6 and Tab 47.
[26] Exhibit 1, Tab 7.

previous visit on 19 July 2016, so eventually the Department arranged for cleaners to attend the property.[27] In January 2017 the deceased and her foster carer relocated to specialised housing for people with disabilities, which appears to have resolved the home cleanliness problem in the short term.[28] The deceased continued to attend respite services and school and there were no concerns raised about her care and wellbeing from either of those sources, so the allegation of neglect was found to be unsubstantiated and the investigation was closed.[29]

38. In July 2017 the Department completed a Standard of Care Assessment and noted that the placement with her foster carer had enabled the deceased to have consistency in her care, schooling, medical needs and social activities. Her foster carer was also reported to be a strong advocate for the deceased. Some concerns were once again raised about clutter and hygiene in the home now that they had been living for some months in the new house. There were also some concerns expressed that the deceased's foster carer was not willing to listen to advice from the PMH medical team and had on several occasions requested a new case manager from the Department. I note later in this finding that the deceased's biological parents also expressed concern about the last Departmental case worker, so there may be conflicting viewpoints on this issue. However, the Foster Care Association also expressed concern about the level of the foster carers' animosity towards the Department.[30]

39. In any event, all the parties appear to have acknowledged the foster carer's level of attachment to the deceased and their belief that the importance of this relationship overrode any other concerns, as it was felt the deceased could be adversely affected by a change of carer.[31] At this time the deceased's renal function was deteriorating and an ongoing decline in her health was reported, suggesting she was reaching the terminal phase of her condition.[32]

40. On 7 August 2017 Departmental staff attended a meeting held at PMH due to a recent blood test indicating that the deceased's kidney function was now at zero. The specialist physician advised that the deceased was 'pre-terminal'. She was felt to have only days to a few months of life remaining and the focus was on maintaining her comfort and wellbeing during this time. The medical team noted that their focus was on supporting the

[27] Exhibit 1, Tab 7.
[28] Exhibit 1, Tab 7.
[29] Exhibit 1, Tab 7.
[30] Exhibit 1, Tab 7.
[31] Exhibit 1, Tab 7 and Tab 35.
[32] Exhibit 1, Tab 7.

deceased's foster carer. On 8 August 2017 the deceased returned home and home-based palliative care was commenced.[33]

41. The deceased died two days later, on 10 August 2017, at her carers' home in the company of her foster carer, a Silver Chain carer and her pet dog.[34] The deceased's biological parents were also informed and her father was able to come shortly after to say goodbye.[35]

CAUSE AND MANNER OF DEATH

42. The deceased's death was certified at 7.00 pm on 10 August 2017. Dr Lisa Cuddeford, a doctor at Princess Margaret Hospital, verified the death. The disease or condition identified as directly leading to the death was acute renal failure.[36]

43. On 11 August 2017 Dr Cuddeford completed a Medical Certificate of Cause of Death. Dr Cuddeford recorded the cause of death as renal failure with the antecedent cause focal segmental glomerulosclerosis. Other significant conditions were noted as cerebral palsy and Rett Syndrome.[37]

44. As noted above, notification of the deceased's death was not provided to the Coroner's Court as the doctor overlooked the fact that her death was a reportable death.[38] Dr Cuddeford approved the release of the deceased's body for cremation on 11 August 2017 and she was cremated on 17 August 2017.[39] By the time her death was reported nearly a year later, there was no obvious opportunity for any further enquiry to be made into the deceased's cause of death.

45. Based upon the medical records and medical certificate of death, I find that the cause of death was renal failure on a background of focal segmental glomerulosclerosis.[40]

46. I find the manner of death was by way of natural causes.

[33] Exhibit 1, Tab 6 and Tab 7 and Tab 34.
[34] Exhibit 1, Tab 6 and Tab 7.
[35] T 17.
[36] Exhibit 1, Tab 4B.
[37] Exhibit 1, Tab 4C
[38] Exhibit 1, Tab 4.
[39] Exhibit 1, Tab 4D and Tab 4E.
[40] Exhibit 1, Tab 4C.

QUALITY OF SUPERVISION, TREATMENT AND CARE

47. Under s 25(3) of the *Coroners Act 1996*, where a death investigated by a coroner is of a person held in care, the coroner must comment on the quality of the supervision, treatment and care of the person while in that care.

48. The information obtained during the coronial investigation shows that the deceased was a much loved little girl who had very complex health issues that shortened her life expectancy. She received multidisciplinary specialist medical treatment to treat her health conditions until active medical treatment was no longer appropriate. From that time, she was given palliative care to keep her comfortable until her death. All the evidence suggests her medical management was of a high standard.

49. The foster carer chosen by the Department proved to be a dedicated carer who was able to provide a stable, loving home environment for the deceased.[41] Mr Geddes expressed the opinion that it was the best outcome that the Department could hope for.[42]

50. I am satisfied the Department provided a very high level of supervision, treatment and care to the deceased from the time she was taken into care until her death.

Comments about Communication

51. The deceased's father gave some evidence at the inquest and also provided some written notes on behalf of himself and his wife. He expressed their gratitude to the Department for their swift action in taking the deceased into care and it was apparent they were very happy with the choice of foster carer for their daughter, who the deceased's father described as "a very good match"[43] and someone who they came to consider like another family member.

52. However, the deceased's father did express some concerns about their communication with the Department's social workers, referring to the deceased's final case worker in particular. The deceased's father indicated that they had felt that there were often delays and failures in communicating critical health information to the deceased's parents and they understood that the case worker would also tell the foster carer not to provide information to them. However, they indicated that the deceased's foster carer ignored that direction and they were grateful to her

[41] T 9.
[42] T 8.
[43] T 13.

for keeping them informed, as they had lost faith with the case worker.[44]

53. Prior to her death, the deceased's parents were told by text message that the deceased was in a critical condition in hospital, which they felt was inappropriate given the serious nature of the information conveyed, and the information was also provided much later than it could have been. They also felt there was a lack of respect from the case worker towards the deceased's carer.

54. The deceased's foster carer also provided information to the Court after the inquest about text messages she received from the deceased's case worker informing her the deceased was in a critical condition in hospital and might not make it through the day. She noted that she hoped that no other foster carer will receive text messages like this in the future. The deceased's foster carer acknowledged she did butt heads with the Department on occasion, but only when strongly advocating for the deceased. However, she also expressed her gratitude to the Department for supporting her while she was a part of the deceased's life for so many years.[45]

55. This information was not anticipated prior to the inquest, so I gave the Department an opportunity to investigate and respond. On 16 December 2019 the Department provided a supplementary report to the Court acknowledging the comments made by the deceased's father on behalf of his family and the deceased's foster carers on the management of communications from case workers. They advised that in August 2017 the Department rolled out the new *Child Protection Learning Pathway,* which included learning outcomes for new staff on how to engage and sustain the relationship with the child, parents, carers and safety/support network. The Department has also actively been involved in the development of a charter of rights for parents and families involved with statutory child protection in Western Australia, with a focus on:[46]

    - supporting a culture of respect for parents and families,
    - encouraging staff to work with parents and families as equal partners, and
    - listening to and including parents' and families' voices when working with children.

[44] T 14.
[45] Email to Counsel Assisting dated 20 November 2019.
[46] Supplementary Report of the Department dated 12 December 2019.

56. I am advised that the Honourable Minister for Child Protection has provided her support for the draft Charter and it is moving towards final publication.[47]

57. I am sure this information will be heartening for the deceased's parents and foster carer to hear, with the anticipation that such a Charter should hopefully improve communication between families and carers and the Department, and give them a greater platform for raising their concerns.

CONCLUSION

58. The deceased was a little girl who faced adversity in her life from birth due to her medical conditions. When her parents were no longer able to cope with her care on their own, the Department stepped in to ensure that she was given the extra support and care that she needed, by placing her with a foster carer.

59. Not long after the deceased moved into the care of her foster carer, she was noted to be "smiling, happy, relaxed and loved."[48] Contact with her biological family was able to be arranged between the foster carer and the deceased's parents with little involvement from the Department, and it was apparent at the inquest that they had forged a strong and mutually supportive relationship. To be cared for by people who love you is such an important aspect of a child's life, and it is heartening to see that the people in the deceased's life were able to put her needs first and work together to ensure that she was always living in a loving environment that could meet her needs.

60. All the evidence before me indicates that the Department worked effectively to provide a loving, caring home environment for the deceased, as well as expert medical care and stimulation in the form of education and social activities.

61. The deceased's foster carer, in particular, deserves to be singled out for her willingness to take on the care a little girl who had extra needs and to do so while also giving her all the love she would give her own biological child. In her foster carer's words, the love she and the deceased had for each other was wonderful, and it is indeed a wonderful thing for the rest of us to see.

S H Linton
Coroner
19 December 2019

[47] Supplementary Report of the Department dated 12 December 2019.
[48] Exhibit 1, Tab 9.