Coroners Act 1996
[Section 26(1)]

Western *Australia*

RECORD OF INVESTIGATION INTO DEATH

Ref: 42/16

I, Sarah Helen Linton, Coroner, having investigated the death of ***JBA*** *with an inquest held at the* ***Perth Coroner's Court, Court 51, CLC Building, 501 Hay Street, Perth*** *on* ***21 November 2016*** *find that the identity of the deceased person was* ***JBA*** *and that death occurred on* ***26 May 2015*** *at* ***36 Mueller Street, Lockyer****, as a result of* ***bronchopneumonia following epileptic seizure in a boy with a history of cerebral palsy*** *in the following circumstances:*

Counsel Appearing:

Sgt L Housiaux assisting the Coroner.
Ms J O'Meara (State Solicitor's Office) appearing on behalf of the Department for Child Protection and Family Support.

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SUPPRESSION ORDER

The deceased name and any evidence likely to lead to the child's identification are suppressed from publication. The deceased is to be referred to as JBA.

INTRODUCTION

1. JBA (the deceased) was born on 9 August 1997. The deceased was born with a congenital condition, which resulted in a number of serious health issues that affected him throughout his short life. His health deteriorated further as he grew older and in April 2015 he lapsed into a coma, from which he did not recover. The deceased died on 26 May 2015, at the age of 17 years. His death, although tragic for a person so young, was not unexpected.

2. When the deceased was only a few years old he had been placed into the care of the Chief Executive Officer of the Department for Child Protection and Family Support (the Department) for the period until he turned 18 years old. As he was nearing his 18th birthday, plans were being made for the deceased's care to transfer to the Disability Services Commission (the Commission). However, as he died prior to his 18th birthday, he was still in the care of the CEO of the Department at the time of his death.

3. As a result, the deceased's death came under the definition of a death of a 'person held in care' under section 3 of the *Coroners Act 1996* (WA). In such circumstances, a coronial inquest is mandatory.[1] I held an inquest at the Perth Coroner's Court on 21 November 2016.

4. The circumstances of the death were investigated by police based at the Albany Police Station. At the conclusion of the investigation Senior Constable Craig Tester prepared a comprehensive report of the death, which was tendered at the inquest.[2] Senior Constable Tester also gave evidence at the inquest.

5. The inquest focused primarily on the care and supervision provided to the deceased prior to his death by foster carers arranged by the Department. To assist in that regard, Ms Julieanne Davis, the Executive Director of Country and Therapeutic Care Services for the Department, gave evidence at the inquest.

6. The evidence before me showed that the deceased was cared for by the same foster carers from 2003 until his death. His foster carers provided a safe, nurturing and caring environment for the deceased throughout his relatively short life. They were still caring for him right up until the time of his death. They ensured that one of them was with him at all times, so that he did not die alone.

7. Taking into account all of the circumstances, I am satisfied his care and supervision was appropriate and of a very high standard.

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

THE DECEASED

8. As noted above, after birth the deceased was found to have a number of very serious medical conditions. The deceased was born with a congenital condition, which resulted in an underdeveloped cerebellum with associated brain stem abnormalities. This resulted in severe global developmental delay, cerebral palsy, epilepsy (noting he had sustained brain damage from fits) stridor (noisy breathing), respiratory and breathing difficulties and also eating and swallowing difficulties. He also suffered from severe scoliosis (curvature of the spine), visual impairment, partial deafness, renal impairment and osteoarthritis.[3]

9. The deceased was fed via a PEG tube that passed liquid sustenance directly through his abdominal wall into his stomach.[4]

10. Initially, the deceased went home to live with his mother, her husband and the deceased's three half-sisters.[5]

11. Following his birth the deceased was referred to the Commission in view of his special needs. In January 1998 he was confirmed as being eligible for services.[6] Considerable supports were thereafter provided to the deceased's mother to assist her with his care. He had access to speech pathology, occupational therapy, physiotherapy services and a dietitian.[7]

12. Concerns were first raised for the deceased's well-being on 26 February 1998 while he was living with his family in Norseman. The Department became involved with the deceased's family in a family support capacity. When the deceased moved with his family to Busselton his care was referred to the Commission's Country Resource and Consultancy Team.[8]

13. In September 2001 concerns were raised with the Department about the level of care the deceased was receiving at home. He was admitted to Busselton Hospital on 27 September 2001. The hospital advised the Department that the deceased was underweight and malnourished and he was considered to be extremely vulnerable due to his specialised care requirements.[9]

14. A period of respite was arranged at the Lady Lawley Cottage but on 30 October 2001 the deceased was admitted to Princess Margaret Hospital (PMH) and recommendations were made that an enduring

[3] Exhibit 1, Tab 24, p. 2.
[4] Exhibit 1, Tab 24, p. 2.
[5] Exhibit 1, Tab 24.
[6] Exhibit 1, Tab 17, p. 1.
[7] Exhibit 1, Tab 17, p. 1.
[8] Exhibit 1, Tab 17, p. 2.
[9] Exhibit 1, Tab 17.

multiagency support network should be provided in order to attempt to preserve his placement within his own family.

15. On 4 November 2001 the deceased returned to Busselton with his mother. Regular meetings occurred in early 2002 at Busselton Family and Children's Services to discuss the deceased's ongoing care issues. The deceased's mother was informed of the hospital's willingness to help with meals, physiotherapy, speech pathology and respite care. A visiting teacher was also arranged to assist in developing a school programme for him.

16. On 2 May 2002 the deceased was taken into care by the Department due to concerns about the standard of care being provided, including his weight loss due to not being appropriately fed and not receiving appropriate medication.[10] On 23 May 2002 the deceased was readmitted to PMH as there were further concerns about his weight loss and care. He underwent insertion of a feeding tube. He remained in PMH until he was discharged into formal foster care on 17 September 2002.[11]

17. Due to a family illness his initial foster family were unable to provide care for the deceased long term. In mid-2003 a new foster family, Stuart and Dianne (Ellen) McKiddie, were approved to take care of the deceased. He was placed with the McKiddie's from 27 June 2003.[12]

18. The deceased was completely bedridden and required 24 hour care, which included: feeding, washing, toileting, turning and administering his medications twice a day. Mr and Mrs McKiddie were already caring for their disabled adopted son, so they were experienced in providing the type of high level care the deceased required.[13]

PLACEMENT WITH HIS FOSTER CARERS IN ALBANY

19. After the deceased was placed with his new foster family he moved to live with them in Albany. He was six years of age at that time.[14]

20. From that time the Commission's Country Resource and Consultancy Team liaised with Western Australian Country Health Service (WACHS) to ensure the deceased received the support and care he required.[15] Over the years the McKiddie's received support from the Department in the way of financial payments, assistance with equipment, occupational therapy, physiotherapy services, speech pathology and alterations to

[10] Exhibit 1, Tab 23 and Tab 24, p. 1.
[11] Exhibit 1, Tab 24, p. 1.
[12] Exhibit 1, Tab 23.
[13] Exhibit 1, Tab 9 and Tab 10.
[14] Exhibit 1, Tab 9 [5].
[15] Exhibit 1, Tab 17, p. 2.

their house to accommodate the deceased and his special needs. He attended primary school at Mt Lockyer Primary School and then later went to a special education class at North Albany Senior High School. Some of his occupational and speech therapy services were delivered through the school.

21. From 2003 the deceased's medical needs were managed by doctors from the Hillside Family Practice in Albany, with referral to specialists and therapists as required, including a specialist orthopaedic surgeon, Dr Holt.[16] Despite his significant health issues, the deceased remained relatively well for many years, and was only hospitalised three times (each time for pneumonia) in the twelve years that Mr and Mrs McKiddie cared for him.[17] It was noted that the deceased could not talk easily or convey his expressions, unless one knew him well, but Dr Darcy Smith, one of his regular doctors, noted that he enjoyed the love, care and support of the McKiddie's and he believed that the deceased had "good quality of life though it was very different than other people his age."[18]

22. The deceased's foster carers underwent annual carer reviews by the Department, with no concerns noted.[19] The Department's case notes reveal that the McKiddies provided excellent care for the deceased in the form of a stimulating, loving and structured life, in what must have been extremely challenging circumstances. Reports by the Department's staff, his teachers and his doctors indicate the deceased thrived in this environment. The deceased's biological mother and stepfather remained supportive of him remaining in the care of his foster carers and they remained in intermittent contact with the deceased over the coming years and were kept informed by the Department of significant events and allowed to participate in decision-making involving the deceased's ongoing care. They were supportive of the deceased staying with his foster family.[20]

23. The deceased suffered from epileptic seizures and was prescribed Epilim medication to manage his seizures. His foster carers reported that his seizures were exacerbated by fatigue.[21] Due to his complex and multiple health issues the deceased's health status was precarious and he could quickly deteriorate. His posture and chest shape meant he could not ventilate his lungs as well as other people, which predisposed him to chest infections and made him vulnerable to pneumonia.[22]

24. In November 2009 the deceased became unwell and was admitted to Mt Barker Regional Hospital. This prompted discussion about

[16] Exhibit 1, Tabs 11, 12, 15 and 24.
[17] Exhibit 1, Tab 10 [20].
[18] Exhibit 1, Tab 11.
[19] Exhibit 1, Tab 24.
[20] Exhibit 1, Tab 24.
[21] Exhibit 1, Tab 24, p. 2.
[22] Exhibit 1, Tab 11 and Tab 24, p. 2.

resuscitation options. During a Care Plan meeting held on 27 November 2009 the attendees (including the McKiddies and the deceased's biological mother and step-father) all agreed that should Joshua's health deteriorate to a point at which the medical team considered that resuscitation would be futile - or would result in such a poor prognosis that the distress caused by the resuscitation would be disproportionate to the outcome – then his care should include support and comfort only and that no CPR should be undertaken, nor should he receive intubation. All agreed that they would like everything possible done, but did not wish for Joshua to be kept alive solely by a machine. This decision was endorsed by the Director General of the Department on 15 February 2010.[23]

25. In August 2012 the deceased was admitted to Albany Regional Hospital with pneumonia, which was not responding to treatment. There were concerns that he might not survive and some thought was given to providing palliative care, but the deceased's general practitioner formed the opinion that he would recover and his condition did improve until he was discharged home on oxygen in September 2012.

26. Although the Department initially offered the McKiddie's some respite care on a weekly basis, they apparently did not take up the offer as it was difficult to find a placement for him.[24] Later an arrangement was reached for the deceased to go into respite care for a period of two to three weeks at a time. This allowed the deceased's foster carers to travel to Bali several times a year for some well needed respite. During those respite periods the deceased was initially cared for at Mt Barker Hospital and in more recent times he was cared for at a home run by Community Living Association.[25]

EVENTS IN 2014 – 2015

27. The deceased did not travel to Perth for any specialist appointments during 2014 or 2015. When he required a new wheelchair, technicians from Perth travelled to Albany to measure and fit him as it was easier for this to occur than for him to travel to Perth (as he had done in the past).[26]

28. Silver Chain care aides attended the deceased's home regularly to assist the McKiddie's with the deceased's personal care.[27]

[23] Exhibit 1, Tab 19 and Tab 24, p. 2.
[24] Exhibit 1, Tab 9 [16] – [17].
[25] Exhibit 1, Tab 24.
[26] Exhibit 1, Tab 24, p. 2.
[27] Exhibit 1, Tab 14.

29. The last carer review of Joshua's foster carers was conducted on 1 September 2014. No actions requiring follow-up were identified. Their continued registration as Joshua's carers was recommended.[28]

30. The following month Mr McKiddie informed the Department that his wife was in hospital and he was struggling with the care of the deceased. The Department offered further assistance to the family.

31. The McKiddie's noticed that the deceased's epileptic seizures began to increase in severity. On 18 November 2014 the deceased was reported to have suffered a couple of really big seizures and he was admitted to Albany Regional Hospital where it was felt that he may have aspirated. He was treated with intravenous antibiotics and oxygen. His Epilim medication was increased to twice a day by his doctor.

32. In early 2015 steps were taken to lodge applications for the deceased's administration and guardianship to manage his finances and care support needs after he turned 18 years old. The Local Area Coordinator for the Commission, in conjunction with the Department, prepared an Individual Plan for Joshua dated 12 January 2015. One of the actions was the completion of an application for funding, through the Combined Application Process (CAP), which was dated 2 April 2015.[29]

33. Community Living Association, who had provided respite care to Joshua, agreed to be his support providers when he turned 18 years old.[30]

34. A Care Plan was prepared following meetings with various relevant parties, including the deceased's biological family and foster carers on 5 and 7 May 2015 to further plan the transition for the deceased as he became an adult and his care transitioned from the Department to the Commission. It was noted that when the full transition had been completed, the McKiddie's planned to retire to Indonesia.[31]

DECLINING HEALTH IN MARCH – MAY 2015

35. On 11 March 2015 Mr and Mrs McKiddie went on their regular trip to Bali. The Community Living Association arranged for carers to care for the deceased at home while they were away. On their return the McKiddie's noticed a change in the deceased, in that he appeared more lethargic than usual.[32]

[28] Exhibit 1, Tab 24.2.
[29] Exhibit 1, Tab 17, p. 3.
[30] Exhibit 1, Tab 24, p. 2.
[31] Exhibit 1, Tab 24.7.
[32] Exhibit 1, Tab 9 [22] – [23].

36. On 16 March 2015 the deceased was sent home from school unwell. A doctor from the Hillside Family Practice, Dr Charles Prasad, visited the deceased that afternoon and he was commenced on antibiotics. By the April school holidays Joshua was requiring more oxygen.

37. The deceased returned to school after the school holidays but on 21 April 2015 the school contacted his foster carers to report that the deceased needed to be collected from school as he was turning blue. His GP reviewed him, ordered tests and started the deceased on antibiotics again.

38. On 24 April 2015 the deceased was reported to be still quite unwell. He was receiving continual oxygen and his doctor was visiting every second day. His doctor indicated that the deceased might require oxygen daily to stay alive. Mr and Mrs McKiddie asked Dr Prasad whether the deceased would require additional care, necessitating hospitalisation, but Dr Prasad indicated that he didn't think the deceased would get better care in hospital than he was receiving at home. His foster carers elected not to send the deceased to hospital since they were well equipped to provide care to him at home.[33]

39. Mr McKiddie discussed the matter with staff from the Department, who he did not feel provided much in the way of any offer to assist, although they did speak to him shortly afterwards to express a view that the deceased might be better off in hospital. Mr McKiddie explained the nature of his discussion with Dr Prasad and the Departmental staff agreed that the deceased could remain at home with the McKiddie's.[34]

40. On 6 May 2015 staff from the Department visited the deceased at home in the presence of Mr and Mrs McKiddie and Dr Prasad. The deceased was in bed and appeared to be semiconscious. Dr Prasad had reviewed the deceased and discussed his case with Dr Darcy. They felt that he had probably suffered a major seizure and was in a coma like state.[35] It was thought that he may have suffered irreversible brain damage. It was not known if the deceased would recover and regain full consciousness. It was not possible to undertake an MRI or chest x-ray due to positioning issues. Given that the deceased did not have a fever there was no indication of a lung infection at that time, but he continued to require oxygen and it was felt that he may have now reached the stage where he was oxygen dependent. He was prescribed antibiotics and a series of blood tests were ordered.[36]

[33] Exhibit 1, Tab 9 [32] – [33] and Tab 24, p. 3.
[34] Exhibit 1, Tab 9 [34] – [38].
[35] Exhibit 1, Tab 9 [31].
[36] Exhibit 1, Tab 24.

EVENTS ON 25 – 26 MAY 2015

41. By the time of his death, the only medication the deceased was taking was Epilim to regulate his epilepsy.[37] He was, however, on permanent oxygen.[38]

42. Dr Prasad last reviewed the deceased during the day on Monday, 25 May 2015.[39]

43. That evening, at around 11.00 pm, Mr McKiddie attended to the deceased's needs and then stayed with him until about 2.00 am the following morning. He then woke his wife so that she could take over looking after the deceased. At that time Mr McKiddie reported to his wife that the deceased had sounded as if he was developing a chest infection. Mrs McKiddie then went to sleep with the deceased in his room and Mr McKiddie went to bed.[40]

44. When Mrs McKiddie entered the deceased's room she noticed that his breathing was a little noisier than usual and he sounded like he was getting a chest cold or infection. Mrs McKiddie got down next to the deceased on his bed and cuddled him whilst speaking to him in an effort to calm his breathing. At some point she thinks she fell asleep, while still lying next to the deceased. At about 4.00 am Mrs McKiddie suddenly noticed that the deceased was very quiet. Mrs McKiddie went and informed her husband that she thought the deceased had died. Together they went to the deceased and checked him, noting he was not moving or breathing.[41]

45. Mr McKiddie telephoned Crisis Care, as he had been instructed to do by the Department, and was advised to call an ambulance and commence CPR.[42] They performed CPR for approximately ten minutes, until the ambulance arrived at 4.24 am. On arrival the paramedics assessed the deceased and confirmed that he had died.[43]

46. Senior Constable Tester and his partner Senior Constable Craig Turton attended the home at 4.46 am. They spoke with the paramedics and then to Mr McKiddie. Mr McKiddie provided the details of the deceased's doctor, Dr Darcy Smith of the Hillside Family Practice. The police officers contacted Dr Smith who advised them that he would be willing to issue a death certificate as the death was not unexpected.[44] The deceased's regular doctors later noted in reports provided to the

[37] Exhibit 1, Tab 11.
[38] Exhibit 1, Tab 2 p. 5 and Tab 12.
[39] Exhibit 1, Tab 24.
[40] Exhibit 1, Tab 9 [47] – [52].
[41] Exhibit 1, Tab 9 [53] – [54].
[42] Exhibit 1, Tab 9 [55] – [57] and Tab 24, p. 3.
[43] Exhibit 1, Tab 2, p. 2.
[44] Exhibit 1, Tab 2, p. 2, 4.

coroner that the deceased's death "was not unexpected because of his severe and deteriorating lung disease."[45]

47. After speaking to Dr Smith the police officers initially advised Mr and Mrs McKiddie that on the basis the death certificate was to be issued, no further police involvement would be required. They then left the residence.

48. Dr Prasad, from the same medical practice as Dr Smith, purported to sign a medical certificate of cause of death for the deceased that day.[46] However, later that morning it became apparent that the deceased's death was a reportable death under the *Coroner's Act* and, hence, a doctor's medical death certificate was not able to be accepted. The police were informed and a coronial investigation then commenced.[47]

CAUSE AND MANNER OF DEATH

49. On 29 May 2015 the Chief Forensic Pathologist, Dr C.T. Cooke, performed a post mortem examination. The examination showed developmental abnormalities, including malformation of part of the skull, kyphoscoliosis of the spine and maldevelopment of the base of the brain. There was congestion of the lungs, raising the possibility of early infection. Further investigations were then undertaken.[48]

50. Microscopy showed bronchopneumonia in the lungs. Microbiology showed Staphylococcus and Streptococcus bacteria. No significant viral infections were found. Neuropathology examination of the brain showed abnormalities of development with reduction in the sizes of the cerebellum and brain. Toxicology showed no common drugs, alcohol or illicit drugs.[49]

51. At the conclusion of all investigations Dr Cooke formed the opinion the cause of death was bronchopneumonia following an epileptic seizure in a boy with a history of cerebral palsy.[50] I accept and adopt the conclusion of Dr Cooke as to the cause of death.

52. It follows that I find that the manner of death was natural causes.

[45] Exhibit 1, Tab 11 and Tab 12.
[46] Exhibit 1, Tab 7.
[47] Exhibit 1, Tab 2, p. 2.
[48] Exhibit 1, Tab 5.
[49] Exhibit 1, Tabs 5 and 6.
[50] Exhibit 1, Tab 5.

QUALITY OF SUPERVISION, TREATMENT AND CARE

53. 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.

54. At the conclusion of the police investigation for the coroner, Senior Constable Tester concluded that there were no suspicious circumstances surrounding the death. He also expressed the view that the facilities were "second to none" and appeared to be a professional medical facility. He noted at the time of his attendance that Mrs McKiddie was distraught at the deceased's passing, although his death was not unexpected, and Mr McKiddie was also significantly affected, although less demonstrative.[51]

55. Ms Davis, who gave evidence on behalf of the Department, also confirmed that the McKiddie's were "extremely dedicated carers" who provided the deceased with "exceptional care."[52] Ms Davis also noted that it was, in her experience, quite rare to see such a high level of care provided over such a long-term with such emotional attachment as shown by the deceased's carers.[53]

56. All of the evidence provided at the inquest supports the conclusion that the supervision, treatment and care provided to the deceased while in the care of the Department, in particular being provided by Mr and Mrs McKiddie, was of a very high standard.

CONCLUSION

57. The deceased was a 17 year old boy who was born with severe global developmental delay and cerebral palsy. He was confined to a wheelchair and required permanent 24-hour care. His mother had difficulties coping with his significant care needs, which had led him to be placed in the care of the Department on a protection order at a young age. The order remained in place until he turned 18 years of age.

58. Not long after he was taken into care, the Department placed the deceased with a permanent foster family in Albany, Mr and Mrs McKiddie. By all accounts they provided excellent care and stimulation for the deceased. They also clearly loved him and treated him as if he were their son. In that loving and supportive environment he thrived. With the support of the Department, who provided equipment as needed and extra funding to assist with modifications to the house and

[51] T 5 – 6.
[52] T 8.
[53] T 8.

respite care, the McKiddie's were able to provide the deceased with a nurturing environment that met all of his needs while he was a child.

59. Unfortunately, the deceased's health deteriorated as he grew older. His spinal condition made it more difficult for him to breathe and he suffered from recurrent chest infections and increased epileptic seizures. In April 2015, apparently after a seizure, the deceased lapsed into a coma from which he did not recover. Mr and Mrs McKiddie continued to provide loving care to the deceased, with regular input from his doctor. His death ultimately appears to have been due to a natural progression of his condition, which is when his doctor was initially willing to certify his death until it became apparent this was a coronial case.

60. The community is very fortunate to have people such as Mr and Mrs McKiddie, who are prepared to take on the great responsibility of caring for a child with significant health needs. Not only did they tend to his physical needs, but they also opened their hearts to him and cared for him like he was their own son. It is apparent from the evidence that they gave the deceased a remarkable gift, as the love and care they provided enabled him to have a high quality of life despite his significant physical and mental impairment. His death, although premature for one so young, could not have been prevented and occurred with dignity at home in the company of someone who loved him.

S H Linton
Coroner
28 November 2016