QUEENSLAND COURTS

CORONERS COURT OF QUEENSLAND

FINDINGS OF INVESTIGATION

CITATION:	**Non-inquest findings into the death of Mr D**
TITLE OF COURT:	Coroners Court
JURISDICTION:	CAIRNS
DATE:	01/08/2025
FILE NO(s):	2021/741
FINDINGS OF:	Melinda Zerner, Coroner
CATCHWORDS:	CORONERS: Epilepsy; Seizure; Seizure mat; NDIS and NDIA; Adult Public Guardian

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Introduction

1. Mr D was born on 23 September 1997 and died sometime between 4 February 2021 and 5 February 2021. He was 23 years old.

2. Queensland Police Service (Police) reported Mr D's death to the Coroner because his death was identified as sudden or unexpected within the definition of a reportable death in the *Coroners Act 2003.*

3. At the relevant time, the then Acting Coroner determined Mr D's death was not a reportable death.

4. On 22 June 2023, Mr D's father completed an 'Application to Coroner to Hold an Inquest'. Under the heading, 'Reasons for the application', Mr D's father states,

> *Mr D had significant disabilities and was an NDIS participant who died from a night-time seizure. Mr D required 2:1 supports 24/7 as noted in his first NDIS PLAN. After an internal review the NDIS reduced supports to 1:1 and reduced hours of supports. A subsequent AAT review and report stated Mr D needed a seizure mat for his safety. The mat was never provided in the months before his death.*

5. On 23 June 2023, the State Coroner wrote to Mr D's father advising he had decided to reopen the investigation into Mr D's death to enable the concerns set out in his application for an inquest to be investigated. The State Coroner advised the former Coroner was responsible for the investigation and for any decision about whether an inquest should be held. Mr D's file was transferred to me in February 2024.

6. I made several further inquiries. The investigation was delayed due to challenges in locating and obtaining a statement from the NDIS Support Coordinator who was involved in Mr D's care at the relevant time (she has since moved employers). I finally received her signed statement on 6 June 2025.

7. The role of a Coroner is to investigate reportable deaths to establish, if possible, the cause of death and how the person died. The purpose of a coronial investigation is to establish the facts, not to cast blame or determine criminal or civil liability. An investigation is about attempting to find the root cause of the incident that precipitated the death and in appropriate circumstances to analyse systemic failures that contributed to the death and to design remedial responses.

8. In making my findings, they are based on proof of relevant facts on the balance of probabilities. I am not able to make adverse findings against, or comments about individuals, unless the evidence provides a comfortable level of satisfaction that they caused or contributed to the death.

Circumstances of Death

9. Mr D lived with an intellectual impairment and epilepsy. He resided at home with his parents who were his carers, a sister, and a younger brother. His mother is a Registered Nurse. Mr D was further supported with NDIS funding.

10. Mr D's parents have advised Mr D also lived with Post Traumatic Stress Disorder from his time spent in a 'care house facility', separation anxiety disorder, and a pragmatic speech disorder. Mr D was prescribed various medications. His mother would ensure he would take his required medications.

11. A nurse from the Forensic Scientific Services has advised from her review of Mr D's medical history, Mr D had a history of refractory epilepsy, intellectual impairment, low functioning autism spectrum disorder, behavioural difficulties, and chronic right shoulder dislocation. He required full time care.

12. On 4 February 2021, Mr D's father had tucked Mr D into bed at around 9.30pm after having made him a bowl of two-minute noodles. He recalled Mr D seemed tired and just wanted to go to sleep. There otherwise was nothing unusual about Mr D's behaviour. He had been given and had taken his usual medications for the day.

13. On 5 February 2021 at around 8am, Mr D's father was watching television in the lounge room with his wife when they went to check on Mr D. They thought it was strange he was not up already, as he usually got up at about 6am. When Mr D's father opened his bedroom door, he realised Mr D was deceased due to the colouring of his skin.

14. At 7.59am, Mr D's father contacted the Queensland Ambulance Service (QAS). He advised he had found Mr D lying face down with blood pooling. Police were also tasked to attend the residence. It appears from the QAS Incident Detail report that on receipt of additional information, the QAS did not end up attending the residence.

15. The Police inspected the scene. They did not find anything untoward. Mr D's father thought Mr D may have been having epileptic seizures during his sleep due to the random large amounts of drool next to Mr D's mouth. Mr D was declared deceased at the scene.

Cause of Death

16. At the time of Mr D's death, an Autopsy was not ordered. This was because of Mr D's history and the circumstances of his death, and that the cause of his death could be established on the balance of probabilities.

17. The doctor who completed the death certificate recorded Mr D died from '*Asphyxia due to, or as a consequence of Convulsion, due to, or as a consequence of Refractory Epilepsy, due to, or as a consequence of Autism Spectrum Disorder*'.

Parents Concerns

18. Mr D's parents have raised concerns about the level of NDIS funding and equipment Mr D was provided.

19. They say measures had been recommended in the Positive Behaviour Support Plan (PBSP) dated 12 July 2020 and an Occupational Therapy Functional Assessment (OTFA) dated 29 October 2020. The reports having been commissioned by the National Disability Insurance Agency (NDIA) and provided to all persons involved in Mr D's care.

20. Mr D had previously been funded for 2:1 care but Mr D's NDIA plan dated 25 May 2019 reduced the available funding so Mr D would only have 1:1 support unless accessing the community. It is understood the funding was reduced in response to recommendations in the PBSP dated 23 August 2018.

21. Mr D's parents lodged an application for review with the Administrative Appeals Tribunal (AAT) on 21 August 2019. The application was ongoing when Mr D died. There had been a delay in the proceeding due to the NDIA raising concerns about Mr D's father representing Mr D at the AAT proceedings as it perceived there was a conflict of interest. This was because Mr D's parents were his paid carers. I have been advised by Mr D's legal advisors,

> *The AAT application was stalled while an unsuccessful application for legal aid funding was lodged, an independent advocate appointed, and an application was made to the Queensland Appeals Tribunal (QCAT) for the Office of the Public Guardian (OPG) to be appointed to act for Mr D.*

22. Mr D's parents believe his death was preventable.

23. On 1 May 2024, Mr D's family through their legal representative provided a list of concerns. The concerns included:

    a) *The NDIA reduced Mr D's funding in May 2019 in the context of Mr D's complex care needs and previous history of less than adequate care.*

    b) *The NDIA did not immediately provide additional funding to implement the PBSP (2020). Our client notes this plan was released on 12 July 2020 and NDIA reviewed Mr D's funding plan on the 25 July 2020. No additional funding was provided to Mr D at that time.*

    c) *The NDIA did not immediately provide additional funding to implement the PBSP (2020) following the release of the OTFR on the 29 October 2020.*

    d) *That a seizure mat was not provided to Mr D as per the recommendation of his neurologist and the PBSP (2020). Particularly noting the purchase of such a mat was first raised in May 2020 and the family were advised approval was given by the OPG for the purchase on 4 November 2020.*

    e) *The NDIA seemed overly concerned about our client representing Mr D in the AAT proceedings. Consequently, the AAT process was prolonged and critical decisions about Mr D's care needs were not made in a timely manner.*

24. I see the critical issue relevant to Mr D's death was the provision of the seizure mat prior to Mr D's passing. I have reviewed the voluminous material, and I set out a chronology of events below.

The Seizure Mat

25. On 19 February 2020, an Epilepsy Management Plan was drafted by Dr K, Neurology Advanced Trainee for Dr W, he states,

Mr D has a background of epilepsy, which has been difficult to manage on multiple medications which have been tried in the past. Mr D continues to have seizures once a month or so.

In regard to the Epilepsy Management Plan, we suggest that the criteria for presentation to hospital should be:

- *head trauma*
- *any signs of aspiration*
- *two seizures in quick succession*
- *three seizures a day*
- *a seizure that lasts more than five minutes*

Otherwise seizures can be managed at home, when his parents are around, as they are able to and well-experienced at managing seizures in acute phase. Mr D is known to our epilepsy clinic and will be followed up in our epilepsy clinic at Cairns Base Hospital.

26. On 24 April 2020, Mr D's father wrote to the author of the PBSP, he states,

> *We remain unsure as to whether Mr D has tonic clonic seizures at night. The only tell-tale sign is that Mr D will sleep in long some mornings and seems groggier and very pale after waking. Mr D has always fluttered his eyelids and still does daily, this was reported as a petit mal. Mr D can stop mid sentence and not return to the context prior. These episodes occur (when noticed) three to five times a day. No medication seems to have prevented these episodes.*
>
> *Is there a monitor you would suggest that could help for nocturnal seizure activity and if so can one be purchased with NDIS funding? It is something we would like to pursue.*
>
> *See epilepsy management plan attached.*

27. On 12 May 2020, it seems the author of the PBSP was inquiring with the NDIS Support Coordinator if a seizure blanket could be sourced. Mr D's mother was asked for a supporting letter from Mr D's neurologist. The NDIS Support Coordinator noted she would speak with the NDIA about purchasing a seizure mat. In an email she states,

> *So I have some more information, can you please advise me why Mr D has seizures, how often and the severity. We did not discuss this at our initial meeting and need this information for following up with the mat.*

28. On 24 May 2020, a Functional Capacity Assessment Report was carried out by an Occupational Therapist. No recommendation is made in relation to Mr D's history of epilepsy.

29. In an email of 23 June 2020, the NDIS Support Coordinator outlines some possible options for monitoring Mr D's seizures. She writes,

> *If there is an urgent need to purchase the mat due to the increase in seizures, I can express freight one here. I am just seeking direction on which will be the best suited product moving forward for Mr D, given that there is a possible concern that Mr D's seizures have increased in the last 4 months*.

30. On the same day, Mr D's mother responded stating,

> *Thank you for your email the last time Mr D had a neurological appointment in February we did discuss that maybe Mr D is having seizures at night and he did suggest that the mat would be beneficial to monitor any seizures at night, Mr D would not tolerate wearing the bracelet hope this helps*.

31. On 12 July 2020, a Positive Behaviour Support Plan (PBSP) was created for Mr D. The author states,

> *Mr D is reported as having tonic-clonic Seizures regularly…*
>
> *Absence seizures daily are currently being reported by the family – a sudden lapse in consciousness, awareness and responsiveness that look like brief staring spells or daydreaming, however, cannot be interrupted like a 'daydream' can.*
>
> *Last review was completed on the 19th February 2020, it has been reported that the seizure activity has remained the same since last review. Mr D is currently being treated by a Neurologist and GP in Cairns for his epilepsy. It has been reported that Mr D continues to have seizures approximately once a month and reported twenty-nine (29) occurrences of seizure activity since November 2018. Duration of seizures range from 30 seconds to 15 minutes with the average lasting 1.7 minutes.*
>
> *Refer to current epilepsy management plan.*

32. One of the comments/recommendations was,

> *Assistive technology should be reviewed and purchased to assist in tracking and understanding the seizure activity for Mr D with epilepsy. Seizure mat for the bed and other seizure tracking apps such as watch should be explored. An allocation for AT should be provided to support any additional equipment recommendations from Mr D's allied health team.*

33. On 10 August 2020, Dr W, Neurologist provided a report concerning Mr D. He states,

> *Mr D is a patient of the Neurology Clinic at Cairns Hospital. He has a diagnosis of refractory epilepsy on the background of autism spectrum disorder and intellectual impairment. Despite trying a number of different medications, he continues to have seizures. A number of seizure safety measures have been considered by his family and carers.*
>
> *One further device that could aid with his safety would be a under mattress seizure sensor (such as the ENFit device supplied by epi-assist). I believe that such a device would be beneficial for Mr D and hope this could be supplied as part of his NDIS package to improve his safety.*

34. On 30 September 2020, the Public Guardian was appointed as guardian for Mr D for a three month period.

35. On 9 October 2020, an independent expert occupational therapist (OT) assessed Mr D. The assessment was to provide a report in relation to a funding dispute with the National Disability Insurance Agency (NDIA) and Mr D's family. The OT notes, 'I acknowledge I have an overriding duty to provide impartial assistance to the Tribunal'. The OT records,

> '*Due to recent suspicion of night-time seizures, Mr D's parents were investigating seizure detection mats to go under his mattress, however these seizure had not yet been investigated by his Neurologist'*.

36. The OT determined Mr D's care needs to be 2:1 active care for 14 hours per day and 1:1 inactive overnight care. That is, the carer at night would be asleep and get up once or twice a night to attend to the client and then go back to sleep. She states,

> *It is noted that the information provided to me regarding Mr D's overnight support needs differed considerably to that which was reported during the PBSP assessment dated 12 July 2020 and the Occupational Therapy assessment dated 24 May 2020. I therefore recommend that Mr D's PBSP providers monitor his actual night-time needs as observed during their data collection phase and make recommendations accordingly. Consistent with the opinion presented in both the PBSP dated 12 July 2020 and the Occupational Therapy report dated 24 May 2020, I consider that following implementation of these interventions, Mr D's need for commercial support worker assistance is likely to reduce over time.*

37. Further, she notes,

> *I consider that the implementation of a PBSP would reduce the Applicant's need for support and see no reason why this could not commence immediately given the Capacity Building Budget is currently available*.

38. On 15 October 2020, the Office of the Public Guardian (OPG) telephoned the NDIS Support Coordinator. A few issues were discussed and the OPG was seeking further information. There was no reference to seizures or a seizure mat.

39. On 22 October 2020, Mr D's father sent an email to the NDIS Support Coordinator. He states,

> *Please see attached purchase request. Mr D's past three seizures have been overnight*.

40. On 22 October 2022, the NDIS Support Coordinator sent an email to the OPG with a letter from the neurologist. The coordinator was seeking consent from the OPG to obtain quotes. The support coordinator states,

> *Please find attached the recommendation letter from Cairns Base Hospital outlining the purchase of a seizure mat. Can you please provide consent for myself to organise the purchase out of low cost AT which is plan managed by Peak Plan Management*.

41. The OPG did not respond to the email.

42. On 23 October 2020, Mr D's Advocate wrote to the 'Lawyer for the Respondent' and copied in the 'Registry & Applicant's Legal Guardian'. She states,

> *On behalf of the Applicant, please find attached recent report of Dr W, Neurologist, dated 10 August 2020 which sets out that the Applicant continues to have seizures.*
>
> *The Applicant's carers have advised his NDIS Support Co-ordinator that the most recent 3 seizures have occurred at night.*

43. On 26 October 2020, a representative from the OPG spoke with Mr D's father. There is a note by the OPG representative,

> …*more evidence now he needs more funding for support as they have identified – having more seizures at night – seizure mat to assess what's happening at night time*
>
> And
>
> *neurologist coming Wednesday to assess seizure activity – violence could relate to seizures and may not be dealt with a PBSP*.

44. On 28 October 2020, Mr D's mother wrote to the Manager at the NDIS Support Coordinator organisation,

> *Lovely to meet you today I wonder if you would mind following up with the OPG re Mr D's seizure mat, I forgot to bring it up with him today. The letter of support was from Mr D's neurologist Dr W(Cairns Hospital) we sent this to Rachael and she stated that she has sent it to the OPG for their approval.*

45. On 29 October 2020, Mr D was seen in the Neurology Clinic. Dr W records,

> *Seizure every 1-2 months*
> *Sometimes associated with behavioural change*
> *Generalised behaviour remains an issue*
> *Facial grimacing several times daily ?sz*
> *…*
> *Leave medication as is for now*
> *Repeat EEG*

46. On 4 November 2020, the NDIS Support Coordinator sought a quote for an epilepsy mat. She states,

> …*as this will not be able to be purchased from low cost AT, thus I will need to forward a quote to the NDIA for approval*.

47. There is a quote dated 4 November 2020 which sets out the cost for the mat and associated accessories at $2,553.00.

48. The NDIS Support Coordinator advised Mr D's mother,

> *Please find attached the information sheet regarding the seizure mat that I am going to be requesting funding to purchase. Once I receive the quote I will action this asap*.

49. On 6 November 2020, the OPG had a conversation with the solicitor representing the NDIA. The discussion was about funding arrangements. There is no reference to seizures or a seizure mat.

50. In a letter of 10 November 2020 (recounting the consultation of 28 October 2020) to Mr D's GP, Dr W states,

> ***Assessment***
> *I reviewed Mr D in Neurology Clinic today together with his mother. He tried the lamotrigine but unfortunately developed a rash and has returned to his previous medications. He continues to have infrequent tonic-clonic seizures about every 1-2 months. His mother notes that he can sometimes be very behaviourally disturbed prior to the seizures but, equally, his behaviour can be bad at other times as well. She does note daily facial grimacing episodes where he holds his head, which she refers to as 'petit mal' episodes, but it is unclear whether these are true epileptic seizures.*
>
> ***Impression***
> *Mr D overall is relatively stable with ongoing occasional seizures and ongoing background issues with his behaviour. After discussing further options of further treatment, his mother was unsure whether to risk any changes at the moment, and we have decided to repeat a routine EEG and rediscuss in six months' time.*

51. On 13 November 2020, the Public Guardian was appointed as guardian for Mr D for:

    a. *Provision of services, including in relation to the National Disability Insurance Scheme (NDIS); and'*

    b. *Legal matters not related to Mr D's financial or property matters.*

52. On 27 November 2020, the OPG sent an email to the NDIS Support Coordinator confirming the OPG had been appointed. The OPG representative states,

> *There are no updates in relation to the AAT proceedings, as such this means that the current plan remains in place. If there is insufficient funding for implementation of the PBSP, including training from PODDSS, is this going to require a review of the current plan, or are there funds that can be used flexibly to ensure this is delivered*?

53. On the same day the NDIS Support Coordinator responds,

> *The plan extension does have enough funding for just the training component of the PBSP, but it does not have the required funding for the whole implementation of the PBSP or the commencement that the PBSP makes.*
>
> *Can I please ask for your feedback, would you like me to complete a change of circumstances request funding for all the supports recommended in the PODDSS assessment, for just the implementation of the whole PBSP or provide the training using the current funds?*

54. There is no evidence the OPG replied to the NDIS Support Coordinator.

55. There is an email dated 8 February 2021 from the NDIS Support Coordinator to the OPG [the NDIS Support Coordinator has confirmed she was not aware of Mr D's passing at this time]. The coordinator states,

> *I am seeking your input into how you would like me to proceed. Mr D's family attended a hospital appointment last year* (2020) *and it was recommended to purchase a seizure mat. With all of the current proceedings and none of the recommendations put forward being funded for, I am unable to purchase without a quote. I can get a quote for a seizure mat and provide this to the NDIA but I am unsure if they will fund for this purchase until the hearing has been completed. Which course of action do you recommend?*

56. On 15 February 2021, there is a file note made by the OPG regarding a conversation with the NDIS support coordinator. It concerns the email received on 3 February 2021 requesting consent for PODDSS to use additional funding to implement PBSP. The support coordinator had advised there was not enough funding in the plan for a seizure mat. The support coordinator was to review the current plan and recommend if this is within the plan. [the OPG and NDIS coordinator were not aware of Mr D's passing at this time]

57. On 16 February 2021, following a conversation with Mr D's father, the NDIS support coordinator sent an email to him, titled 'Seizure Mat'. [she was not informed of Mr D's passing by his father during the telephone conversation] She states,

> *Thank you for sending your email yesterday requesting me to contact you. Thank you for taking my call this afternoon. As per our discussion, I received a call from OPG yesterday asking me to follow up on the seizure mat, as per my email to OPG asking for feedback.*
>
> *I have phoned and then emailed, please see emails below, both Bestcare and Complete Mobility again requesting an updated quote for the purchase of a seizure mat.*
>
> *I spoke with a colleague to ensure the best outcome for the quote to be approved by the NDIA, with the support letter from the Seizure Specialist. I was advised that due to the seizure mat possibly being a level 3 or 4 Assistive Technology (AT) purchase, and not a level 1 or 2 which is funded for in the current plan, I may need to request a Generalised Assistive Technology Assessment (GAT Assessment) to go with the letter of support.*
>
> *I phoned the NDIA this morning and requested to speak with the planner to find out if the NDIA would approved the purchase of the seizure mat with just the letter of recommendation from the specialist. I have just spoken with the planner who has confirmed that yes this is a level 3 AT purchase so I will need to organise the AT assessment to be completed. I am going to contact the specialist at Cairns Base and request this to be sent asap.*
>
> *I will include you in all follow up communication regarding this. OPG has requested that I organise the other required support services. Please let me know if there is anything else I can help with.*
>
> *I hope you, Mr D and the family have been well.*

58. On 16 February 2021, the OPG was made aware of Mr D's death by an email from Mr D's Advocate.

59. The NDIS Support Coordinator found out about Mr D's passing from the NDIA sometime after his passing. Her manager was not aware and the OPG had not advised them of Mr D's passing. His family did not reach out to her.

NDIS

60. I sought a response from the NDIS to the legal correspondence outlining Mr D's family's concerns. I received a detailed response. It is clear there has been a protracted dispute between Mr D's family and the NDIS.

61. After Mr D's death, in July 2021, there was a review initiated by the Chief Executive Officer of the National Disability Insurance Agency (NDIA) into matters pertaining to Mr D as a participant in the NDIS (the Review). It was conducted between 17 May 2021 and 15 July 2021.

62. The Review considered two main areas:

    a. *To establish whether the Agency, in the context of its responsibilities and obligations under the National Disability Insurance Scheme Act 2013 (NDIS Act) and related legislation, operational guidelines, applicable policies and procedures, can identify whether a request was made for a seizure mat, the nature of any such request(s) and the nature of any response by the Agency to such request(s).*

    b. *To establish the availability of funding for reasonable and necessary supports with specific regard to:*

        i. *What funding was available to Mr D in his NDIS plan to continue to access ongoing reasonable and necessary supports which may include a seizure mat;*

        ii. *What support was available to Mr D to access and use the funding in his NDIS plan; and*

        iii. *What reasonable and necessary supports were being accessed at or around the time of his death (on 4 or 5 February 2021) and in the preceding six months.*

63. Mr D's family and other stake holders were provided a copy of the draft report (via their lawyer) which came out of the Review. Material feedback from the various parties was accounted for in the report and footnoted. I have been provided a copy of the final report, which is dated 20 October 2021. It is 37 pages in length.

64. In summary, the Review found:

    a. No specific request for a seizure mat or equivalent was received by the Agency.

    b. A seizure mat was referred to in two reports (PBSP and OT report) and a letter from Dr W.

    c. None of the documents conveyed there was an urgent need for a seizure mat, or that there was any immediate threat to Mr D's safety if a seizure mat was not available.

d. Only Dr W referred to a ‘mattress seizure sensor, compared to a seizure mat’. Dr W said it, ‘would be beneficial for Mr D’.

e. There was no engagement with the Agency from Mr D’s representatives specifically about a seizure mat prior to Mr D’s death.

f. Urgency or critical need for the mat was not established.

g. On or around 13 May 2020, Mr D’s NDIS Support Coordinator advised they would ‘try to source a company that hires the seizure mats but if I cannot find one, I will speak with the NDIS re purchasing the seizure mat’. There was no evidence the Support Coordinator raised this with the Agency. The support coordinator disputed this and advised there was a request and that they were advised seizure mats were considered level 3 or 4 Assisted Technology and a quote was to be provided for approval prior to purchasing. The NDIS has no record of this, and no quote was forthcoming, and the issue was not raised through the AAT proceedings.

h. Mr D had funding available in each of his plans which could have been used to purchase a seizure mat for less than $1500.00 or to undertake assessments from relevant clinicians to determine which AT (Assistive Technology) supports would be most appropriate for Mr D’s needs. There were such devices available for under $1500.00. If though there was a device for over $1500.00 and the device was considered ‘low risk’ a request could have been made for a plan review.

i. Mr D had a total flexible core budget of $713,563.25. This could have been used to purchase ‘low cost, low risk’ AT items.

65. In being provided a copy of the draft report, Mr D’s family claimed:

a. the ‘Support Coordinator’ had been excluded from the review. The Agency confirmed information was received from the NDIS Support Coordinator.

b. The NDIA had an obligation to implement recommendations by experts. The Agency confirmed it has not received a request from bodies external to the agency for a seizure mat.

c. The NDIA was required to ensure Mr D had a seizure mat. The Agency determined there was no evidence there had been a recommendation that there was urgency or that it was critical that Mr D be provided a seizure mat. In any event, a seizure mat could have been purchased within Mr D’s funding allocation.

66. I have reviewed the comprehensive submission provided by Mr D’s family to the Review by their lawyer. The lawyer sets out a chronological list of events concerning the seizure mat.

67. The author of the Review concludes,

> *The Review identified what can be described as certain misunderstandings and/or mistakes of fact raised outside of the Agency around Mr D's application to the AAT for external merits review relating to the decision to approve the statement of participant supports in his plan, the matters at issue in the AAT proceedings and the subject of a seizure mat.*

68. Several recommendations were made following the Review. They include:

a) *The Agency should consider whether there is any need to change its processes and guidance on seeking additional supports in a participant's NDIS plan where they have active AAT proceedings, to satisfy itself that participants are appropriately informed of their options to have their plan reviewed when AAT proceedings are on foot and that Agency staff are aware of when and how any additional supports can be included in a participant's NDIS plan in these circumstances.*

b) *The Agency should consider whether there is any need to change its processes in relation to where information received by it in the course of AAT proceedings make reference to matters of safety where those matters are not raised by the Applicant or the Applicant's representatives specifically and relate to supports that are not the subject of the AAT proceedings.*

c) *The Agency should satisfy itself that its internal and external guidance regarding AT, including in relation to risk levels of specific AT items and when 'low cost, low risk' AT can be purchased by a participant, is appropriately clear. In addition, the Agency should satisfy itself that when core funding is described specifically and generally in a participant's plan that it is understood there may be overlap in how the funding may be used to access supports.*

d) *The Agency should consider whether there is any need to change its processes and procedures with respect to the other matters raised in Part 8.9 to ensure:*
   - *that guardianship orders are appropriately considered and actioned;*
   - *there is adequate guidance on appointing nominees who are also paid providers of support;*
   - *that there is adequate guidance for Agency staff in respect to CEO initiated nominee appointments; and*
   - *cancellation of nominee appointments are made and recorded in the Agency's CRM.*

e) *The Agency should provide a copy of this report to relevant stakeholders within the Agency in order to garner any relevant learnings for the Agency and for its engagement with third parties from the tragic circumstances of Mr D's death.*

f) *The Agency should provide a copy of this report to the Support Coordinator, Advocate, OPG and OPG's lawyer and the Plan Management Provider.*

g) *The Agency should provide a copy of this report to the NDIS Quality and Safeguards Commission, as the body responsible for the regulation of NDIS providers (which includes Support Coordinators).*

69. The NDIS has confirmed that a copy of the report was provided to the relevant persons.

70. At my request, the NDIS responded to each of the family's recent concerns:

a. ***Reduction in funding:***

Mr D was a 23-year-old man who resided in Queensland. The NDIA's records reflect that he had a severe intellectual disability, unspecified psychosocial disorders, epilepsy, and Autism Spectrum Disorder. Mr D lived in a 5 bedroom house which was rented through the Queensland Department of Health and Human Services, modified for his specific support needs.

Mr D was an NDIS participant from 21 August 2018 until the date of his death on 5 February 2021.

*At the time of his death, an external merits review relating to the decision to approve the statement of participant supports in Mr D's plan was in progress in the Administrative Appeals Tribunal (**AAT**), commencing in August 2019 and ceasing informally on his death, and formally with the AAT on 2 March 2021.*

The AAT application made by Mr D's representatives was for review of the internal review decision that varied the decision to approve the statement of participant supports in Mr D's second plan.

The plan in dispute in the AAT had been approved as a result of a (s100) internal review requested by Mr D's mother. The Review noted that in the course of the internal review, it was identified that (as provided for in the plan under internal review) the transition from a paid family support model established under the Queensland state system to 'a service model that can be sustainably supported by the [NDIS] for his lifetime' was not being implemented. As such, the additional funding that increased the support ratios from 1:1 to 2:1 to support transition was removed because the family were not actually utilising funding to recruit and train non-family members to provide the funded supports.

The internal review decision varied the statement of participant supports in Mr D's second plan to include an annual value of $352,870.00 providing for:

1560 hours (6 hours per day) 1:1 support on weekdays

832 hours (8 hours per day) 1:1 support on Saturdays and Sundays

114 occasions of Night-Time Sleepover

114 occasions of 16 hours Weekday Daytime support

1515 hours Access Community, Social And Rec Activities Weekday Daytime (2:1) With 100% of the supports for daily activity and social and community participation being plan managed and able to be provided by the family.

The amount of $352,870 relates only to the supports in dispute in the AAT, which were a component of the relevant plan (core daily activities and social and community and civic participation (SCCP)), with the total annual value of the plan being $389,961.79.

The supports outlined in paragraph 22 above replicated the supports that had previously been provided to Mr D under the Queensland state system.

In addition, Mr D's NDIS plan provided for an increase of the ratio of support for community access than that had previously been provided to Mr D under the Queensland state system, from 1:1 to 2:1 as recommended in the transition summary. The value of Mr D's NDIS plan was significantly higher than the supports he received under the Queensland state system to ensure adequate funding for the supports under the NDIS price guide.

The AAT application lodged on behalf of Mr D sought funding for core supports of 24/7 care at a ratio of 2:1 with all care to be provided by members of the family, representing a cost of approximately $859,000 per annum, amounting to approximately 2.2 times greater than the value of the plan before the Tribunal and approximately 3.6 times greater than the value of the funding Mr D received under the Queensland state system.

This amount of annual funding was available to Mr D while his application for external merits review was before the AAT, noting that the plan put in place as a result of the internal review decision was replicated for an additional 12 months while the matter was being considered by the AAT.

b. **No immediate additional funding for 2020 PBSP:**

This assertion is not correct. The plan dated 21 July 2019 contained $16,727.52 of funding for Level 2 Behaviour intervention support package; up to 40 hours of behaviour management plan and 25 hours of individual social skills development as well as $8,729.55 for OT and Speech pathology, and therapists to contribute to the Positive Behaviour Support Plan.

The funding in this plan was replicated for the 2020 year, so another $16,727.52 was available for this support in the new plan.

c. **Seizure mat was not provided:**

*Mr D had funding available in each of his plans which could have been used at any time by his authorised representatives: Mr D's mother as plan nominee or the Office of the Public Guardian (**OPG**) delegate as the formal guardian to decide to:*

> *purchase Assistive Technology (**AT**) items of a value less than $1500; or*
>
> *undertake assessments from relevant clinicians to determine which AT supports would be most appropriate for Mr D's needs.*

Such AT supports or AT items could have included a seizure mat with a value less than $1500 and it would not have been necessary for any specific request to be made to the NDIA.

In the case of a seizure mat referenced publicly as already reflected, a seizure mat of that value, as included in information on the NDIS website, could have been purchased by Mr D's representatives using the funding in his then current plan without the need for a specific request to the NDIA.

If the item had been over $1500 or not considered to be a "low risk" item, Mr D's representatives could have made a request to the NDIA Planner who would have needed to consider whether a plan review was required and, if so, to determine whether the requested support was reasonable and necessary such that it should be included in the statement of participant supports in Mr D's NDIS plan.

If a request for a seizure mat (or other reasonable and necessary supports) was made by Mr D's representatives during or as part of the AAT proceedings indicating there was an urgent need, the NDIA's processes at the relevant time did provide that urgent requests could be accommodated with expediency. This could have been facilitated either by:

> *Conducting a plan review under section 48 of the NDIS Act; or*
> *Making an application to the AAT for the AAT to remit the matter back to the NDIA pursuant to section 42D of the Administrative Appeals Tribunal Act 1975, which was then and is currently a mechanism used in such circumstances.*

'Low cost, low risk' AT can be purchased from a participant's core budget to the value of $1500 without the need for a quote or assessment.

The "Emfit" monitoring device by Epi-Assist, which was recommended by Dr W in his letter dated 10 August 2020, was advertised on the Epi-Assist website in 2021 at a cost of $1496. 00.

Information obtained from Mr D's Support Coordinator as part of the Review suggests that the Support Coordinator had obtained two quotes: a quote dated 4 November 2020 for $2,553 for an Epilepsy Bed Mat, Controller and associated equipment, and a quote dated 23 October 2020 for an "Epilepsy Sensor" that was priced at $3,064.05 and was not the specific device.

recommended by Dr W. These quotes were not provided to the NDIA (until 1 June 2021 as part of the Review).

Mr D had a total flexible core budget of $713,563.25 in his third and latest plan, with his core funding being managed by a Plan Management Provider.

Although Mr D had $1040 specifically allocated within his NDIS plan for "Level 1 (basic) and Level 2 (standard) Assistive Technology items", he could have used his entire core budget flexibly in order to purchase 'low cost, low risk' AT items.

The Review notes however, that information provided to the Review by the Support Coordinator seemed to indicate that the Support Coordinator may have been of the understanding that only the allocated AT budget of $1040 could be used to purchase low cost, low risk AT.

Therefore, in practical terms, if a seizure mat (as recommended by Dr W) had been purchased on behalf of Mr D, the Plan Management Provider could have submitted a claim with an invoice to the NDIA through the NDIA's Provider Portal (which is the NDIA's online platform for registered providers to view and manage their services with a participant) and the payment would have been processed by the NDIA.

Alternatively, the Plan Management Provider could have submitted a claim to the NDIA through the NDIA's Provider Portal with a quote for the relevant item and the funds would have been released to enable payment to a relevant retailer or to a representative of Mr D to purchase the product.

There is a possibility that if one of Mr D's representatives had asked the NDIA specifically for advice on purchasing a seizure mat, the advice provided could have been either for them to proceed to purchase a seizure mat (as 'low risk' AT of less than $1500); or an assessment was required before the purchase could be made. This is because the guidance is not entirely clear on whether a seizure mat is considered to be 'low risk' AT. Mr D's Support Coordinator claimed that they received the latter advice. However, there is no evidence that this occurred. Further, the latter advice was provided when Mr D's Support Coordinator enquired about the seizure mat with the NDIA Planner on 16 February 2021.

d. ***AAT and representation:***

The NDIA has an obligation to act as a model litigant in all litigation where the NDIA is a party, including in AAT applications.

The model litigant obligation balances the NDIA acting honestly and fairly with it acting firmly and properly to protect its interests. This means that in handling NDIS AAT applications, the NDIA (and the lawyers who represent the NDIA) are required to act with honesty, integrity, fairness and in accordance with the highest ethical standards.

Where a vulnerable participant is represented by a provider who stands to gain financially from the outcome of the AAT proceedings there is a conflict of interest, which the AAT recognises and advises participants against this:

*We encourage you to find a representative who is independent and does not receive funding under your plan to provide you with services. Having a service provider represent you can lead to a potential conflict of interest if they, or the organisation they work for, are likely to receive funds from your plan. It is preferable for a service provider to provide a report as an expert witness. Read the **Persons Giving Expert and Opinion Evidence Guideline** for more information. If they also act as an advocate this may impact how the AAT views their report or evidence if the case goes to a hearing.*

As Mr D was a vulnerable participant who could not express his wishes it was particularly important that he be appropriately represented by an independent advocate. His father was being paid as a carer for Mr D and was seeking increased funding so he stood to gain financially from the proceedings and was therefore in a position of conflict of interest.

When the Tribunal considered the conflict of issue in relation to Mr D's father they noted:

> *the Tribunal accepts that Mr D seems unaware that it is undesirable for him to represent his son in an application where one of the outcomes sought is for him (and other members of his family with whom he resides) to be paid.*

The Tribunal did not make an order that Mr D's father not represent his son as at that point a Disability Advocate had been found and a Guardian appointed for Mr D, so the Tribunal considered it was unnecessary to make such an order.

The AAT process was somewhat delayed, as finding an appropriate independent representative and appointing a guardian for Mr D took time, but these were important processes to avoid any conflict of interest and to ensure he had independent representation.

OPG

71. I made enquiries with the OPG. I have been advised,

    a. The assistive technology portion of Mr D's NDIS plan did not contain sufficient funding for the purchase of the seizure mat.

    b. The information OPG received in relation to Mr D's NDIS plan was that there was insufficient funding for a seizure mat. No quotes were received from any parties and the OPG was not asked to make any decision in relation to same.

    c. While they were appointed, they did not attend any plan reviews.

    d. Regarding funding,

        It is important to note that it is the role of the support coordinator to obtain quotes, and this does not require OPG consent. It is also important to note that should there be any question in relation to the availability of funding, it is the role of the support coordinator to contact the NDIA to seek advice about utilisation of funds for requested items, obtain quotes if needed and provide this information to OPG.

72. The OPG has acknowledged there was a lack of follow up action by the delegate guardian and that the issues concerning Mr D's case had been discussed with the relevant staff member.

NDIS Support Coordinator

73. I made enquiries with the NDIS Support Coordinator. She has advised,

    a. She had been working as a level 2 support coordinator for less than two months when she started supporting Mr D on 28 January 2020.

    b. As a support coordinator she was responsible for engaging with all required services provided to best support Mr D. Mr D (through his parents) had choice and control regarding what services he engaged with.

    c. Regarding the steps taken when approached by the PBSP author about purchasing a seizure mat on 12 May 2020, she says,

        i. She liaised with a colleague (a level 3 support coordinator) who told her that seizure mats were level 3 or 4 assisted technology (AT) and that there would need to be an assessment to add that into Mr D's plan.

        ii. She understood at the time, if something was to be added to a current plan, a National Disability Insurance Agency (NDIA) change of circumstances form which would allow you to request the additional items was required. It had to be accommodated with evidence as to why

it was required. The NDIS would then decide as to whether the item was approved, and if so, the item would appear as an approved item under the Capital or Care section of the NDIS plan.

iii. She understood a change of circumstances form could not be submitted while a plan was under review by the AAT. This had been confirmed to her by the NDIA planner. She believed at the time; the NDIA planner was the sole decision maker for all of the funding allocated in Mr D's plan. She states,

> *I now understand there are different areas within the NDIA (such as the home and living team, and senior NDIS Planners) and the planner allocated to the plan may not be the decision maker re the funding in the NDIS plan*.

d. She reached out to the OPG because as a government department she thought they had more authority and might be able to override the requirement for the seizure mat to not be purchased from the low cost AT budget.

e. Due to the complexity of Mr D's case, she reported all her action to her manager and her manager was also liaising with the NDIS.

f. As to why the EmFit monitoring device (at a cost of $1,596) as recommended by Dr W was not pursued, she states:

> *I recall that Mr C from Professional Disability Development Supports and Services (PODDSS), the author of the PBSP, was communicating with the family and they advised that Mr D would not allow anything on his body as he would pull at things and take them off. The feedback was that because of Mr D's disabilities he had a lot of sensory issues. The Emfit monitoring device would not be suitable. I recall that there was discussion about Mr D having seizures while sleeping and the family was worried about being notified of seizures he was having while asleep. Therefore, the seizure mat was preferred so there was nothing on Mr D's body. There was also discussion with someone regarding the family (who were claiming from Mr D's NDIS plan for supporting him 24 hours a day, at the ratio 2:1) could monitor Mr D while he slept.*

g. In any event the EmFit regardless of the cost, would have been classified as a level 3 item because it was not a 'low risk' item.

h. The quotes for the mat were not forwarded to the NDIA as she understood Mr D's plan manager (a different organisation) would not approve the purchase of a level 3 or 4 from the core budget without a letter of support from an allied health practitioner.

i. She thought as Mr D's plan was flexible, if the OPG had put their foot down and instructed that the mat be purchased they could have possibly convinced the plan manager to buy it.

j. She did not complete a change of circumstances request as she was of the understanding the NDIA would never approve it while Mr D's plan was before the AAT. The NDIS planner was firm in advising her that no additional funding could be added to the plan while it was before the AAT.

k. In conclusion she states,

> *I believe that I tried every avenue that was possible to obtain a seizure mat for Mr D. Because the family, Mr C and the specialist had all advised that this seizure mat was needed. I tried by speaking to Mr D's NDIA planner who had made it very clear that they would not provide the money while the matter was before the AAT.*
>
> *I recall that people were telling me that the OPG are 'like god' and so I tried going through the OPG. I believed that if they approved the purchase, I would then be able to engage an OT or a nurse practitioner who would come out and do an assessment and write a support letter which would be provided with the application. I feel like I tried every possible outcome.*

Conclusion

74. After considering the material obtained during the coronial investigation, I consider I have sufficient information to make the necessary findings required by s45(2) of the *Coroners Act 2003*, in relation to Mr D's death.

75. Mr D was clearly loved and supported by his family. He was provided NDIS funding to assist with his care. Prior to Mr D's death there was a dispute between Mr D's family and the NDIA regarding the level of funding which had been allocated to Mr D. During the dispute, Mr D continued to receive NDIS funding.

76. The circumstances of the dispute have been detailed above. The funding arrangements were under review by the AAT at the time of Mr D's death. There has been no suggestion Mr D was not receiving appropriate care by his family in the hours preceding his death.

77. While there was a delay regarding the AAT hearing, I am of the view this has been appropriately explained, and that there was reasonable cause to ensure Mr D had independent representation due to the conflict or perceived conflict of his father, who was his paid carer, representing Mr D at a hearing to review Mr D's funding arrangements. This is a legal matter and was an issue to be addressed in the appropriate jurisdiction. It is not an issue for me to investigate. The same applies for the funding dispute.

78. Mr D's parents were clearly attempting to advocate on Mr D's behalf and had been requesting assistance to source some sort of device to monitor Mr D's seizure activity since in or around the end of April 2020. They followed up their requests and had secured the necessary medical report from Mr D's Neurologist by 10 August 2020.

79. The NDIS Support Coordinator tried to agitate the need for the mat with the OPG. The OPG has acknowledged there was a lack of follow up by the delegate guardian but also that it was not the OPG's responsibility to obtain the quotes and to lodge the required application for the seizure mat.

80. The NDIS Support Coordinator was advised by the NDIS planner that due to the AAT proceedings, a 'change in circumstances' would not be actioned. It appears there was miscommunication or a lack of knowledge regarding how to escalate such a request when a funding dispute was before the AAT.

81. In the NDIS review it is assumed the seizure mat could have been purchased from the existing Assistive Technology budget but on the evidence as the suitable device was above $1,500 and was unlikely to have been a ‘low risk’ item, a ‘change in circumstances’ was required. I accept there is no evidence the NDIS was aware of this information at the relevant time.

82. Mr D’s family had reported his seizure activity was increasing. I find the appropriate seizure mat for Mr D should have been sourced and approved in or around August 2020. This did not occur and on the balance of probabilities it has been determined that Mr D died from asphyxia associated with a seizure on or around 4 or 5 February 2021. Based on the information before me, I accept the cause of Mr D’s death as recorded on the Death Certificate.

83. It is not possible for me to determine whether the use of a seizure mat would have changed the outcome for Mr D. It seems though it was a necessary intervention to manage the significant risk Mr D faced in having overnight seizures. There was clearly a missed opportunity to ensure Mr D was provided the best chance of receiving the necessary care when he experienced a seizure overnight.

84. I am satisfied the recommendations made following the Review were appropriate to address the primary issues which arose in this case. Further, due to the passage of time, there have been many changes regarding how the NDIA/NDIS operates and the funding arrangements which are in place for participants. On this basis, I am not satisfied that it is in the public interest to hold an Inquest into Mr D’s death (formal court hearing). While I accept there were issues with sourcing the seizure mat in a timely manner in or around August 2020, I am of the view that drawing attention to the circumstances of Mr D’s death does not warrant holding an inquest. While I acknowledge and understand the distress this issue has caused Mr D’s family, I do not see this case as being one that justifies the significant resources required for the use of the judicial forensic process. On this basis I have determined that an Inquest is not required.

85. A copy of my findings will be provided to the NDIS and the NDIA so that it can remind stakeholders of the need to ensure appropriate processes are in place for the escalation of any concerns a family and/or carer may have when there is a funding dispute before the AAT.

86. I extend my condolences to Mr D’s family and friends for their loss. To lose someone in such circumstances is very difficult. I recognise that no words can adequately express the depth of your sorrow or the profound impact of this loss.

Findings required by s. 45

Identity of the deceased – Mr D

Date of death – 04/02/2021 - 05/02/2021

Cause of death – Asphyxia due to, or as a consequence of Convulsion, due to, or as a consequence of Refractory Epilepsy, due to, or as a consequence of Autism Spectrum Disorder.

I close the investigations.



Melinda Zerner
Coroner
CORONERS COURT OF QUEENSLAND - BRISBANE OFFICE
1 August 2025