

## **Submission: Joint Standing Committee on the NDIS – Assistive Technology**

**By Peter and Beverley Rubenach and Hannah Rubenach-Quinn**

### Introduction

We believe there are a number of factors (including the significant delays by NDIS to provide assistive technology) leading up to and contributing to Timothy Rubenach's decline in health and wellbeing and ultimately to his death (aged 32) on 22<sup>nd</sup> May 2018. We are hoping by sharing Tim's story, that recommendations can be made which might prevent others suffering and dying the way Tim did through being 'let down' by NDIS. Of particular concern in Tim's case were the delays in access to a tilt-able/lowerable bed (with mattress designed to prevent bed sores) and a supportive, posture controlling, all terrain wheelchair.

A brief summary: Tim acquired a brain injury from bacterial meningitis at 5 months of age, then developed epilepsy 11 months later. We have had to fight endlessly for basic/adequate disability supports, initially for many years from Disability Services and then from January 2018 (when Tim became eligible) from the NDIS in attempts to get adequate support services and basic equipment that we believe might have prevented Tim's death by providing vital posture support that would have reduced his pain, reduced the chances of his oesophagus ulcers from bleeding, and thus the need for so many hospitalizations, blood transfusions, etc, and ultimately Tim's decline in wellbeing to the point that he gave up hope of receiving the much anticipated and promised wheelchair he so desperately needed. Tim was non-verbal, and as such we, his family advocated strongly for him, but found our many requests of and much pleading with the disability system ignored or significantly delayed. Tim's health and wellbeing had deteriorated significantly in his final months (see attached photos – Appendix A2)- he had lost so much weight (estimated he weighed just 35kg on his death), acquired significant bed sores, lost all hope and was suffering extreme pain – we believe much of this could have been avoided with adequate and timely assistive technologies.

### *Issues relating to the implementation of the NDIS*

The failings we see are: a) the convoluted and in some cases extraneous system requirements, b) the considerable delays caused by the NDIS planner failing to pass on contact details to the service coordinator and totally ignoring our emails for weeks asking for this contact to occur, c) failure of having an agreement between the NDIS (and its contractors) with the hospital system to allow assessments whilst hospitalised, and community equipment scheme to allow continued access to equipment and maintenance, and d) the delays caused by failing to provide adequate funding for the contractor assessors to travel to Tim's remote area. These are expanded as follows.

- a) Whilst some assistive technologies were 'funded' in Tim plan, there were no funds as such attached, with the proviso that assessments would be completed by contractor OT/Physios, prescriptions issued, then quotes obtained, with the final approvals given, and the equipment ordered – a very lengthy process, which completely failed Tim. The wheelchair was promised to Tim in mid- February during the initial intake phase, by his planner – Tim

waited every day since then for his chair which never arrived. He longed to go to the beach on his final birthday (9<sup>th</sup> May) but was unable to do so because he did not have a suitable wheelchair. His health and wellbeing declined rapidly after this and he passed away at home on 22<sup>nd</sup> May (still waiting for the funding approvals to be released). Furthermore, much of the requested services, funding and technologies were not even included in Tim's first plan (please see the attached list of funding requests made in February 2018 – Appendix B1, B2, B3 and B4). We were not given an opportunity to approve the plan, it was simply posted to us (after we were briefly shown a draft, during which we stated it was grossly inadequate to meet Tim's urgent and increasing needs). Additionally, why does some standard equipment, such as a tilt-able, lowerable bed require a prescription (when it was deemed necessary by the planner) – we had already visited suppliers in Launceston in January, and over a period of just one and half hours, had determined exactly the type of bed Tim needed to support his needs (and our choice was supported by the OT contractor in early May when she finally visited for the assessment), but the bed was still unable to be provided even then, despite when we looked in January, there were several beds available from suppliers in Launceston, able to have been collected that day, had we had the funding. In regards to the wheelchair, a provider in Launceston indicated it would take approximately 6 weeks to provide a wheelchair once prescriptions were received – Tim waited more than three months from when he was told he would get a wheelchair and died after having only received the initial assessment - as far as we know the prescription had not even been written by then. Why can't assessments be provided in advance to someone becoming eligible for NDIS so that as soon as the funding is approved, the prescriptions can be supplied and the equipment ordered immediately? The lengthy process required by NDIS contributed to Tim's pain and suffering, and his loss of hope, and eventually his death. The processes were worsened even further as;

- b) The NDIS planner failed to pass on contact details to the coordinator of supports resulting in several weeks additional delay. The attached emails (appendix E1) show that we selected the coordinator of supports (HR plus) on 6th March and that we made contact with the planner three times (19th, 20th and 27th March) asking when things will progress and HR plus contact us – these emails were all ignored. Then on 28th March, due to Tim's deteriorating health and wellbeing, and our own wellbeing, Hannah eventually found an email address to the coordinator of supports, [REDACTED], who contacted us almost immediately – she claimed NDIS did not supply her with any contact details for Tim and thanked Hannah for taking the initiative to contact her directly). This **three week delay** along with other delays below has likely cost Tim's life;
- c) In early April, Engage Therapy was contracted to provide OT and Physio assessments for Tim's assistive technologies (a whole month after the plan was approved), the initial meeting was planned for 13<sup>th</sup> April, however, as the emails attached (Appendix G1) show, Tim was hospitalised, and as such it was planned for them to visit Tim in hospital and do the initial assessments then – this would have saved time and travelling expenses money (as Tim lived in a remote area of Tasmania). After being told this had been organised with the Launceston General Hospital, we then were informed that they could not do so, because there was no agreement between the hospital and NDIS (and NDIS contractors) to allow

them to do assessments whilst a client is hospitalised. We understand the NDIS is supposed to have (or should have) these type of agreements in place – surely this should be a necessity to ensure all participants receive timely assessments (in particular, rural/remote participants). Furthermore, when Tim became eligible for the NDIS (1<sup>st</sup> January 2018), we were informed that his old broken wheelchair would no longer be maintained by the Community Equipment Scheme and that he could not access further equipment through the scheme. This meant Tim suffered even further due to not being able to go for ‘walks’ in his wheelchair, as the support service provider would not allow their workers to use the old wheelchair due to the brakes not working, etc. Furthermore this old wheelchair was grossly inadequate for Tim’s posture (please see attached photos – appendix A1). Eventually we received some pieces of equipment through the Community Equipment Scheme over the almost five months before Tim passed away – a damaged (and repeatedly repaired) roho cushion, which kept going flat, and as such as useless to provide support to aid his pressure sore, and a roho mattress which provided some relief for the pressure sores, and finally in the last few weeks before his death a king single tilt-able bed; and

- d) NDIS significantly underfunded the remote travel cost component of Tim’s assessments for the OT/Physio, etc, leaving the contractors to have to negotiate further funding – this caused a **further two weeks delay** (as the contractor OT/Physio have a heavy case load with bookings many weeks in advance). Furthermore, it created extreme stress and a further deterioration of Tim’s and his mother’s wellbeing (please see attached emails – within Appendix G1) as there was a failure to communicate that the booked appointment would have to be rescheduled due to the lack of funding and delays to seek further funds for travelling.

Urgency was identified in many emails (see attached various documents, as well as Appendix C1 and D1 ) regarding Tim's health and wellbeing and this was repeatedly ignored/not acted upon/not even acknowledged by return email from NDIS, and our 8<sup>th</sup> March letter, sent the NDIS and to the Disability Minister was ignored as well (Appendix D1). Furthermore, we had requested (Appendix I1) early access to the NDIS for Tim in October 2016 whilst Tim’s mother and full time carer was recovering with a broken leg and we were unable to access adequate Tasmanian disability support services. This request too was ignored. Out of desperation, media (Fairfax and ABC) was contacted in early May (see appendix J1). A final plea was made to politicians the day before Tim passed away (see Appendix K1).

Please also see: <http://www.abc.net.au/news/2018-05-31/tim-rubenach-death-hastened-by-ndis-family-says/9821384> and <http://www.abc.net.au/news/2018-06-01/tas-ndis-apology-after-tim-rubenach-ordeal/9824450> - there are many more news articles. Additionally, Tim’s case was discussed during the Community Affairs Legislation Committee - 01/06/2018 - Estimates - SOCIAL SERVICES PORTFOLIO - Department of Social Services (please see link) <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;query=Id%3A%22committees%2Festimate%2Fc0730a81-3382-47c0-9bce-8920288dad41%2F0002%22>

Finally, whilst we as Tim’s family having been grieving the loss of a much beloved and amazing young man, we (his parents) are still paying the loans we took out to purchase supportive equipment for Tim ourselves (for example a broda chair and another chair, as we were advised that these might

help ease some of Tim's pain and reduce his bedsores, and improve his posture) – it is heartbreaking to have to continue to pay for these and to see them sitting there empty. The NDIS should have benefited Tim, and provided him with much need pain relief, and freedom, however, we believe its failings contributed to his death, suffering, loss of hope and pain. Please do not let anyone else suffer like Tim did.

We can provide further information and documents (such the coroner's report when it is released) if required.

Peter and Beverley Rubenach and Hannah Rubenach-Quinn

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