

Dear Minister Linda Reynolds,

We are writing to ask for an acknowledgement and an apology from the Government and the National Disability Insurance Agency (NDIA) for failing to provide our son Liam Dunbar with essential assistive technology before he died in February.

Liam died of a seizure in his sleep on 5<sup>th</sup> February 2021. He was 23 years old. Liam had a severe intellectual disability, was autistic and had epilepsy. Before he died, an independent assessment recommended Liam be provided with a seizure mat so we and his carers would be alerted to any night-time seizures he had. The mat never arrived, and Liam died alone in his bed from a seizure while we slept next door.

The Minister for the National Disability Insurance Scheme (NDIS) ask a lot from families of the disabled. You seek our input into the scheme in many different ways. We are asked to contribute to forums and senate inquiries, we are told that our lived experience is vital for the NDIS to be improved and be fit for purpose. We are asked about our disabled children and to provide up to date reports and assessments to help the NDIS to understand the level of disability so they can provide a plan to improve their life.

Personal and sometimes very private information is requested over and over and in great detail from complete strangers & health professionals to assess

disability.

When your lawyers asked us to get an updated Positive Behaviour Support plan, we did it.

When you asked for an independent assessment from an Occupational Therapist and an independent psychiatrist to assess Liam, we did that too. One of the recommendations that came out of the original assessments we provided and the independent assessments you asked for was for Liam to be provided with a 'seizure mat' to alert those providing overnight care that Liam was having a life-threatening seizure.

We were effectively cut out of the process from there and Liam died without ever receiving a piece of equipment that could have saved his life. We were tasked with providing information and seeking quotes, even receiving phone calls for further urgent quotes for the mat even after Liam died.

We have not received any acknowledgement of Liam's death from anyone who was involved in his care, even the Government.

Liam's death has had a devastating effect on our family as a whole. Tracy's heart is

truly broken and will never mend. Words cannot express our grief to you, with respect, yet another stranger who gets to hear the most intimate of personal information & emotion.

Why has none reached out? All those professional organisations took their share of his funding.

We need some answers about who failed our son.

Sincerely,

Kevin and Tracy Danker