

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Name: Name suppressed
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Partially
Confidential

SUBMISSION TO THE INQUIRY INTO THE IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICE PROVIDERS IN NEW SOUTH WALES

We have a 37-year-old son with multiple health concerns, including a mental disability which means he has a functioning age of around 6 to 7 years old and Type 1 Diabetes, which requires daily administration of insulin. My husband and I are his primary carers.

As part of the NDIS plan developed for our son, he was allocated 28 days of respite. While not a significant amount of days for a year, we were very grateful to have some days of respite provisioned for as part of his plan.

On the weekend of 13-15 July 2018 our son attended a planned respite weekend. On the morning of Monday 16 July, we received a call to advise that our son was on his way to hospital in an ambulance following an amount 2.5 times the required insulin dosage being administered to him. He was kept in hospital for three days following this for monitoring and we are thankful that he seems to date to have recovered from this incident, however it could have ended with far more serious outcomes.

In addition to the incorrect administration of his medication, when we attended the respite home to pick up our son's belongings on Monday 16 July 2018, we discovered both unused insulin and needles indicating that no insulin had been administered to him for the entire duration of his stay at respite. It is worth noting that he should receive insulin three times a day and that the respite provider has received both a Diabetic Plan and Medication chart completed by our son's treating GP.

Following a similar incident in May this year (i.e. insulin not being administered during the weekend of respite) we raised concerns with the respite provider. An internal investigation was conducted, and we were assured that following the completion of this investigation that all staff would be retrained on administering medication, ensuring the Diabetic Plan and Medication Chart were followed.

It is not easy for us to place our son into care and an incident such as this was extremely concerning to us, however his care needs require us to be available 24/7 and the little respite we have available is important to ensure we can keep caring for him as we do. We needed to trust that this matter has been dealt with and addressed appropriately.

During our attendance at the respite home on Monday 16 July 2018 the staff on duty advised my husband that they had not been trained to administer our son's insulin. This was surprising and distressing to us given the commitments made to us following the investigation in May.

Since the incident on 15 July 2018, we have raised complaints directly with NDIS, the Health Care Complaints Commission, the NSW Disability Minister and our local Federal Member for Parliament. Additionally, an independent investigator has been appointed by to investigate the matter. While we must hope that the above avenues will see some sort of

resolution to this matter, we feel this is an important example to have raised as part of the inquiry into the implementation of the NDIS scheme and the provision of disability service providers in NSW.

We are angered that something like this could have happened while our son was meant to be in the care of people trained to correctly meet his (and others) care needs. When you consider the cost of a night's respite accommodation is \$550, it concerns us that there are service providers out there that do not appear to be using this charge to ensure that they have adequate and competent staff, trained to meet the needs of all their clients.

While we appreciate our son requires significant care he is not unique in this. It worries me that we have had a similar incident now occur on two occasions, I can only imagine that this has also happened to other families and in our mind, this is unacceptable and a failing of these service providers and the government departments that should be monitoring and auditing them and ensuring the highest standards of care are met and maintained.

For us this inquiry could not come at a better time. While under no circumstances will our son be returning to the care of the managed respite home, we will need to look at alternative providers. We hope that this inquiry takes the opportunity to examine all the NSW providers providing care for those with disabilities and that those providers who are failing to provide the high standard of care that we would all expect for our loved ones are held accountable up to and including a loss of licence to operate in the care space.