

**Submission
No 116**

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

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Legislative Council

I would like to include a submission into the inquiry into the implementation of the NDIS and the provision of disability services in NSW.

I am the niece of Kevin Russell who was born with Down syndrome 60 years ago. He is unable to talk or communicate in any way except for some learned behaviours which indicate his needs. Kevin has no concept of how to care for himself and requires full care. Until his parents passing Kevin lived in the family home which at some point also included my parents my sister and me. My mother Kay has been his primary carer for the majority of Kevin's life as their parents aged and become incapable of his ongoing care.

Kevin went into permanent care with Ageing, Disability and Home Care ADHC in May 2003. He has been in three group homes since this time with the most recent at Cannell Ave Towradgi where he has lived happily for the last eight years.

Kevin's overall care and wellbeing has been overseen by my mother who is now in her 70's. She ensures he is well looked after at the group home and oversees his finances and in this regard reports to the Guardianship board on an annual basis. We have endeavoured to keep Kevin's care simple so that he is happy and settled in his environment and keeping the stress on my mother to a minimum.

Once the changeover to NDIS began, there have been meetings, forums and one on one discussion. His plan was determined and funding advised. This resulted in increased pressure on my mother, trying to understand the overall concept and ensuring Kevin wasn't overly impacted.

Mixed into this equation was the privatisation of group homes in the Illawarra. Kevin's group home was taken over in November 2017 by House with No Steps (the only provider choice in our area) with Compass Housing Service becoming the property owners/maintenance. Where previously 75% of Kevin's pension was paid to ADHC now 50% is paid to HWNS and 25% (plus admin fee) is paid to Compass, leaving just under 25% of his pension for personal expenses including chemist bills. Having both NDIS and privatisation on the ADHC Service happen simultaneously has caused confusion for everyone.

The below are a few points regarding the "terms of reference" I would like to highlight that relate to Kevin-

(d) the effectiveness and impact of privatising government-run disability services –

The most significant impact was as recent as May 2018 when Kevin's pension was substantially reduced. Upon investigation by my mother and I, we found that Compass Housing notified Centrelink of rental payments which were incorrect as they didn't include HWNS component. Centrelink then reduced the Rent Assistance which affectively reduced the overall pension payable.

Upon speaking to a representative at Compass Housing it became apparent that there was a major blunder in that all clients who were residing in formally ADHC owned residences were impacted in this blunder! Had my mother not been diligent, who knows how long it would have taken for Compass to notice their error? This is simply not good enough.

Whilst Kevin's payments have now been rectified and backdated they have a whole database of clients to investigate and correct.

Another concern is maintenance of these group homes. Given 25% of their pensions are going toward this aspect you would assume there is a budget for minor problems. Recently one of the clients bedroom light globes needed replacing. Under this new system, HWNS staff must contact Compass Housing Services to advice and have approval for replacement. This took *over three weeks* and the only reason it was done after three weeks was when a family member intervened and contact Compass Housing to complain about safety. *Surely they would have an individual house budget for immediate incidentals like a light globe!*

(f) The adequacy of current regulations and oversight mechanisms in relation to disability service providers -

With regard to the NDIS, I personally hold concerns about the number of businesses and individuals who are coming 'into the market of NDIS' as providers. Can you be sure they are in it for the disabled or for the dollars? There must be stringent regulations put in place to ensure persons with a disability are not being disadvantaged. I feel strongly that there needs to be tough and stringent regulations overseeing NDIS providers.

(g) Workforce issues impacting on the delivery of disability services –

A commitment was given by HWNS re staffing remaining unchanged for two years. Already they are looking to stop the ten hour shift and replace with four hour shifts. The ten hour shift provides an overlap in staffing at peak times when needed to allow a staff member to be attending to meals whilst the other two care for clients. These shifts cover for morning (breakfast, toileting, and prior to attending day centres) and late afternoons (dinner, showers). Taking away these shifts reduces staff at these peak times and could put clients in danger if left unattended in a shower etc.

Staff are now being placed under increased pressure to cover shifts due to the lack of casual staff. Previously employed ADHC and Disability Trust casual staff were not all kept or blocked from being included in the casual pool due cost issues associated with former employers. Stretching existing staff to cover absences places clients in potential danger should the staff member be tired due to the lengthy shifts they are required to fulfil.

Kevin's NDIS support coordinator, from the Benevolent Society, charges excessive hourly rates for their 'services', which include overseeing payments from individual's plans. Recently my mother was asked to attend their office to sign paperwork for which they charge a fee. My mother doesn't get compensated for 'her' time/travel but this shows one area where she is impacted with additional personal cost and time by the change to NDIS. The changeover to the NDIS has basically created jobs, like these support roles, which were never previously required.

Provision of incontinence pads were previously supplied and paid through Medicare, however these now come from within the NDIS plan and they are sourced through another privately run organisation approved under the NDIS. Our concern here is that when you limit suppliers the costs will be increased due to lack of fair competition.

A large portion of disabled people do not have the means to voice their satisfaction in services provided to them and rely on family to be their advocate. Parents of disabled children are always concerned about how their child will be cared for when they pass away and we need to ensure that they are provided with the best and safest care possible. NDIS and the provision of disability services in NSW need to be operated with the disabled person in the forefront of everyone's mind.

Cindy Harrison