Submission No 219

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

Name: Name suppressed

Date Received: 8 August 2018

Public Submission to the NSW Legislative Council's Inquiry Into Implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

This submission in particular refers to point (i) of the Terms of Reference "the incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services".

The Scenario: A person who is an NDIS participant is hospitalised. He is an adult who is non-verbal, has severe intellectual disability, has high and complex support needs, and in an alien environment is at risk of experiencing high anxiety. He may become very agitated and non-compliant with his medical care. This person could be my 33 year old son, or one of several others known to me who have significant intellectual disability and communication impairment.

People with such disabilities require high levels of support to maintain their life day to day. NDIS funding pays for such support at all times except when in hospital.

The Problem: The NDIS is quite clear that it is NOT responsible to fund *Personal care supports while a participant is hospitalised.* Where does this leave the person? Despite their best efforts hospital nursing staff cannot assume the role of familiar disability support workers. (Previously in the hospital/acute care setting ADHC disability support staff/nurses had an active role and they were funded by ADHC and covered by a MOU).

To date there is no formal NSW Health/NDIS position. My enquiries have revealed that support arrangements may be determined at the local level and on a case by case basis. Such assistance must be formally defined and agreed at the pre-admission stage and a protocol developed between the disability agency and the Local Health District as to who pays for the support provided by disability support staff. In the absence of a formal state-wide agreement a person with a disability who has an Emergency (non-planned) admission may languish in hospital for days before a one-off documented agreement is reached. **Forward planning for people with disability is critical and it is better to be proactive than reactive.**

Hospital nursing staff provides clinical care whereas disability support workers familiar with each person are essential as they are equipped and trained in the person's unique communication and behaviour management. They are the ones that have expertise in supporting the person one-on-one daily and can assist with patient safety and medication compliance. When at home or in the community the person's NDIS funding pays for the support they receive.

The research[1] of Iacono, et al. identifies that in a hospital environment a person with intellectual disability may:

- be fearful because of not knowing what to expect
- be fearful of an unfamiliar situation and environment
- be fearful of medical procedures
- be subject to diagnostic overshadowing (attributing symptoms to the intellectual disability)
- experience pain and not have it identified or treated
- experience lack of discharge planning and continuity of care

Hospital staff may:

- lack information about a patient in terms of presenting underlying conditions
- be unable to deal with challenging behaviours
- be unable to adjust communication to meet the person's needs
- fail to provide required assistance to enable a person to eat a meal or go to the toilet

If there is capacity in a person's support funding, then familiar disability support staff should be permitted to provide non-medical care and personal care (not involving the use of hospital equipment), as well as essential emotional re-assurance. When anxiety is reduced the recovery process is optimised and length of stay in hospital is reduced – it's win-win!

The Solution: I request as a matter of urgency that a formal arrangement is made between NSW Health and NDIA and that on completion this arrangement is widely publicised so all stakeholders are familiar with the arrangement. The NDIS promises Choice and Control and aims to normalise people's lives – that should include every aspect of a person's existence whether at home or in hospital.

Should my son or others like him be admitted to hospital I want to be sure in advance that they experience best practice management for their health, their wellbeing, and their mental health, for the duration of their hospital stay.

1. A systematic review of hospital experiences of people with intellectual disability
Iacono, Bigby, Unsworth, Douglas and Fitzpatrick
BMC Health Services Research 2014