



## Joint Standing Committee on the National Disability Insurance Scheme: NDIS and Health Interface

Governments have agreed on the [principles to determine the responsibilities of the NDIS and other service systems](#) but applying the principles has created boundary disputes.

Disability service providers often experience these when an NDIS participant is hospitalised. They may need to assist a participant with communicating information on admission, during their stay and at discharge—such as medical history, medication use, support needs and communication requirements. They may also be required to provide actual support.

The NDIA is clear that it does not fund mainstream services provided by other public systems, including health. Hospitals can refuse to fund disability support workers to assist with the support of a person with disability. This results in a provider giving unfunded support to a person with disability, which is not a sustainable situation.

The following case studies are examples from service providers which highlight some of the difficult interface issues which arise.

### Case studies (de-identified)

- 1 Sally is a 43-year-old woman with cerebral palsy and an intellectual disability. She lives in a group home with 24-hour care. She depends on supports for all physical and cognitive tasks and is PEG (Percutaneous Endoscopic Gastrostomy) fed via a tube in her abdomen for all nutrition and medication. She uses simple sign language (eg hands in a 'T' for toilet) and understands more than she can express (she is non-verbal). She has epilepsy and stable health.

On a weekend shift, Sally's PEG fell out. The hole closes up very quickly and if not kept open or replaced quickly with the correct procedures, it needs to be re-inserted in the hospital under a general anaesthetic (GA). Regular staff had training on how to do this and there were spare tubes at home. The staff member rostered on was not able to re-insert the tube. An ambulance was called and handed a piece of paper on which was written: "The tube fell out."

Sally went to the hospital in an ambulance on her own with this piece of paper. In the Emergency Department (ED), she was unable to explain what had happened to her and why she was there.

Sally wanted to go to the toilet and signed 'T' but hospital staff did not understand her. She consequently wet herself. She then started screaming because she was upset.

The ED staff read the piece of paper, but misinterpreted it. They inserted an in-dwelling catheter (via her urinary tract), thinking that this was the tube that fell out, instead of a PEG tube. Sally went home after about 10 hours in the ED.

Without the PEG tube, Sally missed her epilepsy medication and had a seizure at home, requiring her to go back to hospital. Hospital staff then realised the wrong tube had been replaced. By this time, the PEG hole had closed and she required a nasogastric tube (via her nose) to be inserted for her nutrition and medication. This was kept in for about a week and then she had to undergo a general anaesthetic to have another PEG procedure.

This whole episode was avoidable. It was distressing for Sally and could have had dire consequences. It was costly to the health and disability services. This case highlights the need for a disability support worker familiar with the participant to be present in hospital to assist her to obtain the appropriate healthcare.

- 2 James has autism, an intellectual disability, is non-verbal, and has a long history of presentations to the ED due to severe pancreatitis. His healthcare professionals and specialists confirm that this will be a lifelong health problem. James stays in hospital two to three times per year for up to three weeks at a time. For the past six years, James's disability support provider has been required to provide staff on a 24-hour basis due to his disability, communication impairment and behaviour (not being able to lay still in bed and being a risk to others). The hospital's response is to shackle him.

The provider has secured emergency funding from state government so that support workers who know James are able to be with him in hospital. Funding has not always been adequate and is often initially denied as there is no formal arrangement between the hospital and disability services. Consequently, the provider pays for James's support staff until an agreement is finally reached. The fact that there is no easy access to emergency funding under the NDIS is a gap. The greater issue relates to the additional trauma for James, who is in severe pain, confused, afraid and seriously ill. The hospital staff do not have the capacity to provide 1:1 support in the hospital setting, which is what he requires.

- 3 John has Multiple Sclerosis. He cannot move independently, is non-verbal, and receives 24-hour support (including overnight). John was hospitalised for 11 days with high fevers and symptoms relating to an infection. His usual disability support staff were with him during his hospitalisation to assist hospital staff with how to support and communicate with him.

The provider's manager had discussed John's specific needs with the Director of Nursing at his admission. However, poor communication between hospital nursing staff at handover meant that critical information was not passed on (e.g. the physio requested deep suctioning every hour to assist with breathing - the

nurse on duty did not pass this on and the next staff on shift said there were no notes written up so they could not do it).

Disability support staff and their management had to follow up to ensure correct treatment continued. John's disability support staff and their manager also alerted the dietician that some nursing staff did not understand how to use John's PEG feed and, as a result, meals were missed or refused to be given by nursing staff.

John was told that he didn't meet criteria to have a 'special' nurse, even though he cannot buzz for assistance or call out for help if required. Fortunately, John's regular disability support staff assisted him in hospital. They identified a change in his condition and pressed the buzzer for the emergency intervention team on two occasions when his condition rapidly deteriorated.

- 4 Penny lives in a group home and has a psychosocial disability. She can present with violent behaviours and has assaulted staff. To avoid any danger to other residents and staff, Penny sometimes requires an alternative environment. Penny's provider contacted the NDIA, but found it difficult to get a response. The state disability department recommended that the provider take Penny to a psychiatric hospital. The hospital tried to send Penny home until there were a number of 'code blacks' that required four to five hospital staff to hold Penny down to administer medication. As a result, Penny stayed in hospital overnight. This required the provider to organise staff to support Penny. It was evident that disability support staff were not able to support Penny at her home with limited staff numbers. Even so, the hospital discharged her in the morning and the provider needed to increase staffing levels to keep everyone safe – including Penny.

During this period, the provider had no additional financial assistance from state government or the NDIA despite many attempts to seek it. The provider has invoiced the hospital for staff support provided overnight. It is unclear if this has been paid.

Ultimately, it is the provider that responds to a crisis of this nature, carries the risk and the financial liability. Providers have a duty of care to respond to clients in crisis but struggle to recoup this funding, especially when it is an emergency response.

- 5 Adam was a 43-year-old who had a severe physical disability (due to ataxia and uncontrolled tremors) and required full assistance with all needs. He didn't have an intellectual ability but was non-verbal due to his physical deterioration. Adam developed a fever and was admitted to hospital for treatment of a urinary tract infection. His blood results showed some renal impairment, so the doctors ceased medications that might have been causing a decrease in renal function. Ceasing the benzodiazepines - which Adam had been on for over 10 years - resulted in sudden withdrawals and lack of ability to stop his tremors. His tremors became so severe in the hospital that his bed was moving. He was highly

distressed. The hospital sedated him to stop the tremors and he went into respiratory and renal failure and passed away.

If Adam's support worker had been able to accompany him, they could have interpreted his non-verbal communication. Adam's renal failure may well have ended his life in due course, but it may have been better managed and he could have died peacefully.

- 6 Michael had three admissions to hospital in a four-week period. On the first two admissions, the hospital pressured his support workers to assist him in the hospital. When the hospital was told that the provider did not have the funding to do this, the hospital arranged for security guards to provide the support as they did not have the nursing resources. Five other patients staying in the same room as Michael complained because they were distressed with security guards frequently entering their room. Michael was discharged within a day of admission, even though staff were told he would need to be in hospital for at least four days. The provider was put under great pressure to take Michael home and there was no liaison and no discharge planning.

On the third admission, the hospital told the provider that they would pay for familiar staff to be with Michael 24 hours per day. If Michael was displaying challenging behaviours some nursing staff would not enter the room, thus denying him medical attention. On other occasions, support staff were asked to implement restricted practices so medication and injections could be given and observations taken.

While the hospital eventually provided funding for the disability support, it was only for the third admission. There is no agreement to ensure disability support is available to assist Michael during future admissions.

## **November 2017**

**Contact:** Dr Ken Baker  
Chief Executive  
National Disability Services  
Ph: 02 6283 3203  
Mob: 0409 606 240  
[ken.baker@nds.org.au](mailto:ken.baker@nds.org.au)

**National Disability Services** is the peak industry body for non-government disability services. It represents service providers across Australia in their work to deliver high-quality supports and life opportunities for people with disability. Its Australia-wide membership includes over 1000 non-government organisations which support people with all forms of disability. Its members collectively provide the full range of disability services—from accommodation support, respite and therapy to community access and employment. NDS provides information and networking opportunities to its members and policy advice to state, territory and federal governments.