NSW HACC Issues Forum

Supplementary Submission to the Senate Community Affairs Legislation Committee Inquiry on the Draft *National Disability Insurance Scheme Bill 2012*

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Introduction

Following an appearance from NCOSS at the hearing for the Senate Community Affairs Legislation Committee Inquiry on the Draft *National Disability Insurance Scheme Bill 2012*, the NSW HACC Issues Forum was asked to prepare stories about how people accessing low level supports may experience escalation of their support needs if those low level supports were not provided. This submission supports the NSW HACC Issues Forum's previous submission to this Inquiry (submission no. 508).

The following stories illustrate how low level interventions can prevent much more serious consequences for the person, and for government funded services. Low cost interventions that are put into place can support people to improve their functional capacity, and their ability to achieve their aspirations. These are real stories from members of the NSW HACC Issues Forum, and names and some identifying details have been omitted to protect the identities of the people involved.

Consequences of a lack of support

Unlike the NDIS, the HACC Program/CCSP is not based on entitlement. People accessing HACC/CCSP services are prioritised at the point of intake on the basis of service availability and relative need within the local area. This has tended to mean that in some areas there are service types which are at full capacity, and people have not been able to access those service types despite being assessed as requiring support. This has tended to mean that the person's needs escalate, often due to their carer's health and wellbeing deteriorating.

The following stories illustrate how this has occurred.

A 57 year old woman had a neurological spinal injury leaving her with complete paraplegia. Her husband has left the household due to the stress of providing support, leaving her full-time working daughter as her only carer. A service provider is brokering personal care and domestic assistance five days a week which significantly exceeds the budget available and cannot continue indefinitely.

A 56 year old man with a brain tumour and paralysis of one side was being cared for by his sister and mother. He requires full assistance with two people. After two hospital admissions, some temporary community care support was arranged. However, eight referrals had been made, but the service provider did not have the capacity to assist. The sister/carer of this man is now experiencing back and shoulder difficulties due to the stress and physical demands of providing care. The man has now been assessed as eligible for service.

A 59 year old man with a non-compensated ABI is living with his wife, who was serving as his carer. They were receiving a small amount of respite per month. However, this was stopped. His wife can no longer cope with the stress of 24/7 care for her husband and the relationship has broken down.

The man's need for support and services has escalated. He now needs assistance with Housing NSW, case management to assist in meeting his complex needs for care which includes personal care, shopping, cleaning, meals, medication monitoring, social support and transport.

The outcome has been that the couple are still together however there has been a large increase in the services required to patch up the gaps in service that could have been prevented if reliable ongoing respite and support had been available before his wife/carer got to breaking point.

Lack of support can also have financial and social consequences for a person. Where a person is not able to access government subsidised support, they may be required to pay for services privately, resulting in financial hardship, which can have other consequences for the person such as social isolation or malnutrition.

A 57 year old woman with a mental illness has been on the waiting lists for every provider providing domestic assistance in her area since 2011. In the absence of service she relies a lot on her family for support and has recently commenced paying for a private service as her family is unable to provide the domestic support she needs. She is finding it extremely difficult to pay for the service and as a result she can only afford one hour per week which does not meet her physical needs.

Costs associated with increased needs for service are not the only consequences of low-level supports not being in place for a person with disability. Costs relating to health and legal issues can arise for a person who does not have access to appropriate disability support, as the following story illustrates.

A woman with alcohol related brain injury is able to manage with case management support. She is required to manage medication for epilepsy, getting to medical appointments and counselling sessions, which are required for compliance with legal good behaviour requirements. The case manager also had strategies in place to manage behaviours of concern. When short term case management ended without effective hand over to longer term support, the woman ceased her medication, resumed drinking alcohol, and was arrested and charged with criminal offences due to behaviours of concern.

The lack of consistent supportive case management support means that the client's medical progress was impeded, there have been costs to the justice system including police, legal aid court and gaol time and resources, and she is at risk of further imprisonment. These are high cost resource intensive interventions that could have been avoided. This is not the first time that these consequences have followed after the woman's case management ceased, and it is likely that this cycle will continue unless case management support is in place on an ongoing basis.

Falling through the gaps between aged care and disability services

Although aged care and disability support, at basic levels, can be very similar, the administrative barriers between these two systems can have adverse consequences for people reliant on both systems. The growing number of people with disability who are ageing, and living with ageing parents, requires co-ordinated support to ensure that the person's relationships are maintained, while also supporting each person's individual needs. The following story illustrates the consequences of seamless and person centred support not being available.

A 52 year old man with a Traumatic Brain Injury from a motor vehicle accident has been living with his mother with a domestic assistance service in his mother's name. His mother passed away suddenly and there is no other family where he lives. The man continues to live in the family home but cannot manage the relationship with the service provider, so the service is terminated. The home then falls into squalor.

As the man cannot manage his finances and has an issue with alcohol he is soon involved with the criminal justice system.

If services had been person centred and seamless between the aged care and disability support systems, this consequence may have been avoided.

Benefits of low level interventions

The Enabling Approach, or Enablement, is an approach in community care which is focused on supporting a person to become more independent by using targeted, short term interventions to improve the person's functioning. With targeted, short term support, a person's need for ongoing services can be reduced. However, without this type of support, the person's needs would be likely to escalate quickly, and possibly result in a need for intensive service interventions, such as hospitalisation, which would also be less likely to support the person to achieve their goals and to live independently.

The Better Practice Project is an initiative of NSW Ageing, Disability and Home Care, in which four HACC service providers were given specific funds to work with clients using the Enabling Approach. The following stories from the Better Practice Project pilots illustrate how low level interventions have prevented people's needs from escalating, restored their independence, improved their functioning, and helped to maintain the person's relationships. All of these interventions cost less than $3,000.

A 45 year old woman with Multiple Sclerosis referred herself to a service provider working with the Enabling Approach as she was experiencing poor mobility, anxiety and depression. She was concerned about leaving the house due to minor continence issues, and anxious in the shower due to fear of falling. She wasn't eating well and was regularly skipping meals. She has 2 children living at home (aged 5 and 17 years) and is a single mother, relying heavily on her 17 year old daughter for help and support.

The woman had five goals, with the highest priority being to make space to rest and relax. She also wanted to increase her exercise, address her continence issues, and increase her safety in the shower.

The service provider supported her to undertake cooking lessons and purchase some new kitchen equipment. Some modifications and assistive devices were put into place. Some fall reduction training was also arranged. Ongoing domestic assistance was arranged by the service provider, so the woman was able to renegotiate domestic tasks. Appointments with a urologist were arranged, in her own area.

As a result of these and other interventions, the woman was able to better manage her own personal care, ensure that her mental health was supported, and was overall happier and more confident. She was more socially active, with the support of community transport services.

A 34 year old man with an Acquired Brain Injury from an accident 2 years ago has been receiving speech, physiotherapy and occupational therapy for rehabilitation. He lives at home with his parents and sister. His father gave up his employment to become the man's full time carer, and there was associated financial and carer stress issues. His family was concerned that he was socially withdrawn, and not confident in expressing himself. He was using a neurological feedback device through his iPhone, however was not using it to its full potential, as he was unable to inform people about how to communicate with him through the device.

The man's goal was to go to the beach with friends.

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A service provider supported him through providing communication training. A mainstream device (iPad) was purchased to allow him to connect with friends through social networks. Specialist supports were also arranged to improve the man's balance. Carer counselling for the man' father was arranged, and a minor modification to the shower was made. Ongoing neurological physiotherapy and case management are being provided.

As a result of these interventions the man is able to communicate with more people, initiating conversations himself, and his balance was improved.

A 44 year old woman with mild-moderate intellectual and physical disability, and who is legally blind, lives at home with her parents. However, her mother's health is deteriorating, prompting her family to consider alternative long term care arrangements. Miss B had a strong startle reflex associated with her disability, and was a major falls risk. She frequently fell, and often fell quite heavily due to no protective extension reflex.

The woman attended a day program, however her parents felt she was consistently grouped with participants with much higher care needs than their daughter, which resulted in her "copying peers behaviour" and developing higher levels of dependence. There was a sense that some of the longer term therapies such as speech and movement therapies had 'slipped' resulting in a stagnation in progress, and in some areas, a decline in functional capacity.

The woman's goals related to movement and balance, and her fine motor functions.

Support with balance and walking was arranged, which involved intensive work on stopping, rebalancing, gait and posture awareness, and management strategies for her startle reflex.

As a result, the woman was not falling over as often, was able to walk without a walker. Marked differences were observed by the physical therapist and the woman's parents in relation to her ordering of tasks and her 'care' in thinking through the sequencing of activities. The woman was much more confident and willing to try new things.

The NSW HACC Issues Forum thanks Eliza Pross and Community Care Northern Beaches for providing some of these stories.