



29/03/2018

Submission to the Standing Committee on Health, Ageing and Social Services.

Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT

This submission from Community Connections includes responses to the Terms of Reference that are most relevant to the services provided to NDIS participants.

Community Connections

Community Connections, a not for profit community organization based in Kambah, has operated since 1998 as a specialist independent coordination service. Since the start of the NDIS in the ACT in 2013 Community Connections has been an NDIS registered provider, offering Coordination of Support and Plan Management Services to NDIS participants in the ACT.

Community Connections work is strongly based on Social Role Valorisation Theory: promoting the right of all people with a disability to have valued roles and to be actively involved in their community. Coordinators provide a personalized service, building strong relationships with each person and working towards achieving what is important to them in order to build a good a life.

Community Connections currently works with 161 NDIS participants and their families and guardians. Coordination or Plan Management is available for participants of any age, gender and referrals from culturally and linguistically diverse community members and people who identify as Aboriginal and Torres Strait Islanders are welcomed. Currently approximately 10% of participants use Plan Management services only, 70% use both Plan Management and Coordination services and 20% use Coordination services only (of these 3 use another Plan Manager and 3 self manage their funds).

a) The relationship between the ACT Government and Australian Government in regard NDIS and National Disability Insurance Agency (NDIA) as it affects the ACT; particularly gaps or duplicate roles and responsibilities.

The NDIS makes clear that participants will engage with mainstream services including those provided by government health, education, transport, justice and that the NDIS is not responsible for funding these services. While Community Connections supports this position in principle, in practice it is difficult to delineate areas of responsibility. This has been particularly apparent in the health domain where initial confusion arises because there is no clear advice from the NDIA about what funding can be used to address the impact of the disabling consequences of a health condition. The plan does not include information about the diagnosis the disability, or the functional impacts of the disability and no guidance is provided about what services can be purchased.

Other examples of the confusion between the responsibilities of ACT Health and those of the NDIS include:

- There is no clear information about how “in kind” services provided by ACT Health are managed administratively by the NDIA and ACT Health.
- It is unclear what services are available through ACT Health for people who have NDIS plans and even when the service is provided there is a lack of transparency about whether the service can be funded by the NDIS plan or whether ACT Health should fund the service.
- People who want to use ACT Health services (usually because they have been doing so for many years and have an established relationship with therapist or nurses) have been told they cannot do so because “in kind” funding is not included in the plan or because the plan managed (not NDISA managed)
- Some types of equipment designed to help a person manage a condition that overlaps the health and disability boundaries, is funded by the NDIS while others is not. For example: continence supplies are funded so that people can manage the effects of bowel and bladder dysfunction that impacts on their everyday life but suction equipment to help manage a swallowing dysfunction that also impacts on everyday life cannot be funded by the NDIS and other funding must be sourced. This causes delays in obtaining advice and decisions about these matters delays the equipment supply and results in high levels of confusion and anxiety for the participant and family.
- Confusion and overlap between NDIS and ACT Health funded services in the disciplines of Community Nursing, Podiatry, Physiotherapy, Dietetics and Occupational Therapy cause stress to participants and often result in prolonged waiting times e.g. Podiatry is funded for some people in plans but others are told to use ACT Health Podiatry services. It is unclear if this is because a foot disability that reduces mobility is therefore NDIS funded or if funding is provided if a person is unable to care for their feet because of a physical disability (e.g. a stroke) or a cognitive problem. Physiotherapy for someone with a medical condition that is disabling causes more confusion. For example a participant with Lymphoedema, a medical issue that resulted in restricted walking, and reduced independence in showering, dressing and toileting was told she could not use her NDIS funds for Physiotherapy.

Additional clarity around the ACT Health and NDIS responsibilities is urgently required.

b) Practical outcomes of implementation in relation to disability workforce development strategies; the Human Services Registrar; the availability of services for eligible NDIS participants; the availability of early childhood intervention services; the implementation of local area coordination; and supports for people with psycho-social disabilities; and

Disability Workforce Development

Community Connections is not directly involved in workforce development but comments from the people we work with particularly in relation to support workers are offered for consideration.

Committed and skilled support workers are highly valued and acknowledged as vitally important in facilitating the participation of people with disabilities in the community and supporting people to live in their homes. In the current environment of increased funding and limited support worker availability the NDIS participants often feel they are let down over and over again because of the high turnover of staff, inadequate skills and training levels and inconsistent availability.

People tell us they want consistent reliable support workers who treat them with respect and listen to them. They are less concerned with qualifications and experience and tell us they usually know the first time they meet a support worker if the arrangement is going to work successfully. These criteria do not sound daunting but time and time again people are unable to find one or a team of support workers to provide support when, where and in a way that meets their needs. Even when a worker commences regular work this often breaks down within a few weeks and the participant has to find new workers yet again.

Community Connections supports the work of the NDS Workforce Impact Collective and believes that for NDIS participants to be able to access skilled, quality support workers building a high quality and professional workforce is vital. To achieve this Community Connections believes the following are required:

- Options for permanent full or part-time employment
- A range of pay levels that recognize both the complexity of the work being undertaken and the qualifications and experience of the worker.
- Comprehensive work health and safety measures to ensure the wellbeing of both the participant and the worker. Workers need training, support and suitable equipment and resources including manual handling equipment and personal protective equipment.
- Opportunities for career development and progression
- Ongoing training, including an emphasis on attitudes and values, and specialist training in areas such as positive behavior support.
- A variety of employers including large and small organizations, sole traders, multifunction agencies and platforms such as Hire Up My Choice My Support and Better Caring.
- Ongoing day-to-day support and monitoring of work quality from an employer, mentor or training provider

Another area of workforce concern includes allied health professionals

There are a limited number of allied health professionals who have the necessary skills and experience to work with people who have complex needs and who require therapy, assessments and prescription of equipment. Frequently participants and their Coordinator struggle to find therapists with both the availability and skills to accept referrals and due to high levels of demand

and there are often significant waiting times especially for those therapists who have both the both the clinical therapy skills and a knowledge of NDIS requirements. A highly skilled workforce of allied health professionals is required to work with NDIS participants if real progress is to be made in improving disability management, improved function and skills and confidence so that people will be successful in employment, living independently and being active members of the community.

Availability of services

Since the introduction of the NDIS, Coordinators have been responsible for assisting participants to implement their plan. Helping people to identify the types of support and the service they want. Identifying the provider of supports and services that can best meet their needs is an integral part of the Coordinator's role and each Coordinator develops an in depth knowledge of community services activities and opportunities.

Community Connections Coordinators have observed an increase in specialist disability services and activities particularly supporting people with intellectual disabilities and autism. These services offer a range of group based activities and 1:1 supported activities in either a 1:1 or in a group setting. The broad range of services including day programs offering a both "centre" and community based activities, specialised groups such as dancing, art and music classes, social groups, fitness programs and skills building classes in services have given people more choice and opportunities within the disability sector. Using NDIS plan funding for such activities is generally easy and convenient as the providers of such activities are usually registered with the NDIS, have extensive experience working with people, have quality and safeguarding measures in place and understand the complexities of making service bookings and claims through the NDIA.

Community Connections aims to see the same increase in choice and opportunity for people who want to use the funds in their NDIS plan to pursue very individual interests and goals and to be part of mainstream groups and activities where they are not immediately identified as "disabled". To achieve this, our community needs to be open to, and indeed welcoming of all, giving each person the chance to meet, learn, enjoy and to genuinely feel accepted and valued. While there are inspiring examples of where people are engaged in their local community and feel valued and accepted (refer to the work of Imagine More and Belonging Matters) the experience of Community Connections Coordinators is that success requires a commitment of time and energy working individually with each person. With limited Coordination of Support hours being funded for participants by the NDIS, Coordinators now have little time to build connections within the community that allow each participant to find a place where they feel they belong, where they have a valued role and can make a contribution.

Community Connections strongly advocates for higher levels of Coordination in NDIS plans to enable Coordinators to work with people to build genuine community inclusion.

Implementation of local area coordination

As a specialist provider of Coordination services Community Connections saw a major change when the Local Area Coordination service commenced in the ACT in mid-2017.

In the first three months of the introduction Local Area Coordination service in the ACT many participants who had previously engaged Community Connections to provide Support Coordination (Coordination of Supports or Support Connection) were advised that a Local Area Coordinator (LAC)

would conduct the scheduled plan review meeting and assist them to implement the plan. With no Support Coordination funds in their plan, participants were forced to cease their involvement with Community Connections. For some this caused high degree of distress some failed to establish a new relationship and to use their plans effectively. Despite having no formal relationship with Community Connections some of these people reported their concerns to Community Connections. These included a lack of information about the role of the LAC, not receiving assistance with plan implementation, several changes in LAC personnel, and only being given a list of providers rather than actual assistance, to set up successful supports.

Community Connections recognises the complex role required of the LACS in conducting review meetings and then providing support to implement the plan but is concerned that there is insufficient time allowed to enable LACs to prepare a comprehensive plan. In addition the LACs role seems to be too limited in time and scope to meet the needs of some vulnerable people who not only need help to implement complex support arrangements and also need more intensive help with a wide range of issues including employment and training, health, housing, justice and behavior management concerns.

In what appears to be an acknowledgement of this concern eight people who did not have Coordination of Supports in their previous plan and had who had some contact with an LAC have had Coordination of Supports reinstated in the most recent plan and have reengaged Community Connections as their provider.

Supports for people with psycho-social disabilities

Community Connections has recently seen an increase in requests from people with psycho-social disabilities for Coordination of Supports and Plan Management services.

Learning from these people, who have shared their stories and experiences, has helped us to enhance our skills in how to work effectively with people with a psycho-social disability and how to find and create the best supports and the best community links. The most important learnings from this experience are that:

- People with a psycho-social disability want to be accepted as valued members of their community and do not want to be viewed a “disabled”.
- Having a support worker on a regular basis or attending a disability specific activity is often not the best option.
- People often need time and timely support to decide their priorities and what is important to them.
- Trying to implement multiple changes rapidly can cause undue stress and anxiety and be destructive.
- The best support is based on trust and respect.
- Coordinators must be prepared to walk alongside the person.
- Supports need to be responsive to changing needs, especially when mental health concerns arise.
- Community acceptance and is very important but sadly lacking and consequently people are often isolated and excluded.

Coordinators working with people with Psycho Social disabilities need to:

- Be clear about the role the Coordinator can play and set realistic expectations.
- Understand mental health illnesses and the services that support people during these illnesses.
- Work with the mental health services that are important to the individual and be clear about the different roles of different workers.
- Think “outside the box” –offer suggestions for supports and services that truly reflect the individual’s needs and goals.

Our experience highlights that Support Coordination is a highly valuable support service in it’s own right and not just a service to connect people to existing specialty services. Coordination of Supports should be funded accordingly or people allowed to choose use Core funds for Coordination services. Some people have little and a lot for Core Supports that might never be used. For example: Jane has \$58,000 for Core Supports and \$4,200 (44 hours) for Coordination. Jane has no interest in having any regular support (other than a small amount of gardening) in the community or home but she has benefitted from a Coordinator who “checks in” with her regularly and who has supported her to find options to enable her to start activities she has long wanted to do. She needed someone to negotiate the initial arrangements, and to accompany her to the first sessions. She is now feeling confident and attending independently. The Coordinator also communicates with the Mental Health Clinical manager and will be informed if there are any health concerns or events that will temporarily reduce Jane’s ability to participate in her activities and to manage her life at home and in the community.

Debra Hogg
Acting Executive Director
Community Connections