Adequacy of existing Residential Care Arrangements available for young people with severe physical, mental or intellectual disabilities in Australia

Supplementary Submission to Senate Inquiry
Impact Assessment: Transitioning the YODKW Program to NDIS

April 2015

Overview

Alzheimer's Australia welcomes the opportunity to provide a supplementary submission to the Senate Standing Committee on Community Affairs on the adequacy of existing residential care arrangements available for young people with severe physical, mental or intellectual disabilities in Australia.

Alzheimer's Australia's previous submission addressed the Terms of Reference of the Inquiry and highlighted the significant role that access to appropriate community supports plays in ensuring that people with dementia can avoid placement in residential care for longer.

Our submission also raised our concerns and reservations around the transition of the funding for the Younger Onset of Key Dementia Program (YODKWP) to NDIS (contract ends 30 June 2016).

The YODKWP was funded as part of the 2012 aged care reforms in recognition of the difficulties faced by people with younger onset dementia in getting access to appropriate care and support. People with younger onset dementia have for decades faced being juggled between the disability and aged care systems with neither system having the funding nor knowledge to provide appropriate care. The program is the culmination of decades of advocacy by consumers and Alzheimer's Australia. It provides essential supports to people with dementia and their families as well as building capacity in the community sector to provide services to this group of clients.

The transition of the funding of this program to NDIS will essentially mean that the holistic, early intervention approach of the program will be lost and the program will be dismantled. The transition of this program to the NDIS is an ill-informed approach that is not reflective of the desires of consumers, carers or experts in this area and will lead to significant gaps in services for people with younger onset dementia in the community. It is likely that this decision will lead to people seeking access to residential care services and other crisis supports earlier at a significant cost to Government.

This submission provides the Committee with further evidence on the Program as well as ongoing issues clients of the Program face in getting access to appropriate supports through NDIS in current Trial sites. These issues have also been communicated to the Department of Social Services.

Background

During a meeting with the Dementia Policy Section of DSS on 28 January 2015, Alzheimer's Australia was informed that the YODKWP was one of 17 Commonwealth funded Programs that had been earmarked for funding to be transitioned to the NDIS. The Department indicated that this was part of the Commonwealth funding arrangements for NDIS and that this decision could only be overturned at a Ministerial level.

Alzheimer's Australia was informed on 28 January 2015, that as a result of this decision the management of the contract for the program would be moved from the Ageing and Service Improvement Branch to the NDIS Transition and Disability Service Branch on 2 Feb 2015.

To date, funding from the YODKW program has been provided 'in-kind' in the trial sites. Essentially this in-kind funding is an acknowledgment that the Commonwealth is block funding a program that provides services that will fall under the remit of NDIS. After some discussions about options around cashing-out components of the program to provide funding to NDIS, it was decided that this in-kind arrangement will remain in place until the end of the YODKWP contract in 2016.

Proposed Transition Arrangements

Alzheimer's Australia will continue to provide NDIS with 'in-kind' services in the trial sites as part of our contract until 2016. This currently accounts to $99,000 across trial sites in NSW, VIC and ACT at present, which will increase to $198,000 by 2015-16. The in-kind arrangement in its current form is more of an accounting mechanism, with the Program writing down these amounts against services delivered in trial sites, rather than an actual transfer of funds.

DSS has made it clear that post-2016, the funding for the program will be decreased as the NDIS is rolled out and funding is transitioned to NDIS. Essentially this means that post-2016 the program will be dismantled as NDIS begins to provide services to people with younger onset dementia.

The difficulties that people with younger onset dementia have faced in the trial sites illustrates that without continued block funding, people with younger onset dementia will face difficulty getting access to much needed services and supports. The services provided by NDIS will not be equivalent to that provided by the YODKWP. Key workers provide a comprehensive range of services and it is impossible to carve out certain responsibilities to be provided by NDIS in future without losing the integrity of the program.

Core services of the YODKWP which NDIS currently does not support:

1. *Capacity development*

A critical objective of the YODKWP is to provide sector support and capacity development to meet the specific and unique needs of each client. This could include:

- Addressing gaps in services (e.g. Developing programs for social engagement, assisting services to develop YOD-specific respite)
- Building capacity in the local service sector to ensure appropriate services are available

- Networking with local GP's, geriatricians and other specialists to ensure that individuals with younger onset dementia are referred to the key worker soon after diagnosis

These are services that the NDIS does not formally support. While it is intended that the Tier 2 targets of NDIS will be able to support capacity development, progress and firm objectives including whether condition-specific capacity development will be supported are uncertain.

2. Support for family and carers

The YODKWP provides a primary point of contact for people with younger onset dementia, their carers, families and friends. They support individuals and families to take an active role in their own health and wellbeing through the provision of information, counselling, advice and advocacy. Keyworkers also assist individuals and their carers to work together to develop goals and action plans, navigate the health system and engage with services appropriate to their own unique needs, i.e. younger-onset specific social clubs, respite, retreats, etc. Our experience has shown that in most instances, it is not just the individual who needs assistance but the family, friends and partners. The NDIS provides very limited support for carers and virtually no support for other family members. This important component of the program would be lost in the transition.

3. Information

Key workers provide comprehensive information to clients about services and supports that are available in the community. Provision of timely information, advice, crisis prevention, and referral are vital supports that the block-funded YODKWP provides to meet client needs. This component of the program would be lost in the transition of the funding to NDIS.

4. Functional Disability

As detailed earlier in the submission, accessing a timely diagnosis of younger onset dementia can be a challenging part of the consumer's journey, and the NDIS's current focus on a documented 'functional disability' creates an additional barrier for people with YOD. Often people need support and advocacy in traversing the service system before their disability has been fully documented. In addition, early in the diagnosis some people may not yet have a significant functional impairment and as a result they may not be eligible for support in the early part of the condition. As a result, the opportunity for early intervention, counselling and support will be lost.

Information, Linkages and Capacity Building (ILC) component of NDIS

Throughout our discussions with DSS, there have also been several indications that essential services that are currently not covered in the Tier-3 service delivery may be covered under Tier-2 or the Information, Linkages and Capacity Building' (ILC) component of the NDIS, but there continues to remain ongoing uncertainty around when and how this will eventuate.

As we have mentioned in our response to NDIS ongoing consultation on ILC the YODKWP currently provides support to clients and their carer's and families that could fit broadly under the activity streams proposed by the ILC framework. However, it is important to note that the services provided under the YODKWP are specialised to meet the needs of people living with dementia. As noted in our detailed submission to the Committee, people living with younger onset dementia already fall through the cracks between disability and the aged care sector, so the focus on a specialised program that is flexible to the needs of dementia, and that can follow the person with dementia through all care settings is critical.

Experience from the Trial Sites

The experience in the trial sites of NDIS in Barwon, Hunter and the ACT suggest that the NDIS will not be providing a key worker model of service but instead be providing components of that service through NDIS funding. In essence the key worker program will no longer exist as NDIS is rolled out.

We have identified some specific issues in the trial sites which highlight the gaps in NDIS pathways to currently deal with the specific needs of people living with YOD.

1. YODKWP Services are provided before people are eligible for NDIS (focus on function not diagnosis)

Much of the value of the key worker approach lies in engagement with people before access to services including getting access to assessment. Younger people with dementia would not seek services through the NDIS or may not be eligible for services through the NDIS until much later in the progression of the condition.

Sometimes people with younger onset dementia and their families do not actively seek service support in the early stages of dementia due to the stigma of dementia and the low acceptance or understanding about the cognitive impairment.

But research has indicated that specialist services such as dementia specific counselling for the person with younger onset dementia can help the person to accept the diagnosis and acknowledge their strengths and remaining capacities. [1]Support at an earlier stage, especially that received through dementia specific pathways can also assist clients in obtaining a timely diagnosis.

For this reason, even the activities which could be considered 'in-scope' may not fit under the NDIS as in many cases they are provided at an early stage in the disease before there is significant functional impairment.

This early-intervention approach is essential in supporting people to understand the condition and obtaining a timely diagnosis , remaining independent for as long as possible and reducing early placement into residential aged care.

2. Fitting the KW model to NDIS

a) Service integration

In Victoria it has become clear in the context of the Barwon trial site that the key worker model will be transferred to a role in providing support coordination.

It is important to note that this role is broader than the services KW are currently providing and could include managing/coordinating the provision of external services such as gardening or cleaning, or providing emergency services. In addition, the role will only include support, information and counselling services if these are listed specifically on the persons NDIS plan. Feedback from the Barwon trial sites highlights the difficulty that clients

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[1] Jo-Ann Brown, Kylie Sait, Ariella Meltzer, Karen R Fisher, Denise Thompson, Robyn Faine (2012) Service and Support Requirements of People with Younger Onset Dementia and their Families, for NSW Department of Family and Community Services, Ageing, Disability and Home Care, Sydney.

have had in claiming these supports from NDIA when a person has not specifically requested them in their plan.

Significantly, much of the key worker function is being lost when applied to NDIS in the trial sites. At the moment key workers are continuing to support clients in the trial sites as per the usual key worker model- but if this was scaled back to just service coordination the major functions of the key worker would be lost.

b) Loss of continuous one-on-one support: Core principal of the KW Model

There remains serious concerns from stakeholders about the continuity of care for people who are ineligible for the NDIS but are currently receiving services which are in scope for the NDIS. While there is a guarantee of continuity of care in the government bilateral agreement, people have been told in trial sites they are no longer able to access a service because they are not eligible for the NDIS.[2]

If the YODKW program is transferred fully to NDIS- this would apply to people with Younger Onset Dementia as well. Many people who were not yet qualified for NDIS would not have any support and this would lead to crisis situations. People with cognitive impairments are disadvantaged compared to people with a physical disability because they cannot clearly articulate what they need, and this can be a barrier in requesting appropriate supports and services in their care plans with NDIS.

The person living with younger onset dementia and their family are currently *supported by the YODKWP* through every aspect of their journey. This can start at diagnosis, to support referrals for legal and financial matters, future planning, supports at home, counselling, linkages to carer support groups, social support groups and the transition and planning into permanent care if required.

The NDIA may deem someone to be eligible for supports but it is still up to the discretion and experience of procured agency staff to support families with long term planning. Usually agency support will provide staff scheduling only. The YODKWP's objective of providing specialised dementia services to clients appears to be beyond the scope and resourcing of the NDIS in its current form.

3. Broader issues with YOD and appropriate Residential Aged Care service delivery:

As detailed in our earlier submission with 30% of all younger RAC residents estimated to be diagnosed with Dementia, the YOD specific needs the NDIS needs to be able to deliver are considerable. The NDIS will be unable to meet these needs without a large injection of capital funding and a building plan and program.[3]

There needs to be clarity about the role of NDIS once people require residential care services. Residential aged care is often the only option for people with YOD- but it is often not an appropriate service model for people with YOD. There is a need to identify what role NDIS can play in providing alternative residential arrangements.

It is critical to ensure that services that provide early intervention for people with YOD, help develop the service sector and build capacity, as well as create pathways back to the community for people inappropriately committed to RAC's are essential to the ongoing

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[2] Commonwealth of Australia 2014. Joint Standing Committee on the National Disability Insurance Scheme: Progress report on the implementation and administration of the National Disability Insurance Scheme. Canberra

[3] Winkler, D. et al. (2013). National Disability Insurance Scheme Launch Sites: Projection of the number of people in residential aged care. Sydney, NSW & Melbourne, Victoria: PwC and Sumner Foundation Ltd.

management of this cohort. This is where programs like YODKWP are vital, as they are principally designed to support people with YOD across the whole of the dementia journey, from pre-diagnosis to possible residential care entry. The KW program also aims to build capacity with existing services and explore new partnerships, to better meet the care needs of younger people with dementia in the community, so that they do not end up turning to inappropriate RAC as the only resort.

Summary

The research, consumer experience, and feedback from the sector all strongly support the continued block funding of the Younger Onset Dementia Key Worker Program. Transitioning the YODKW program to NDIS will lead to the dismantling of a key service for younger people with dementia. Key components of the program will be lost including:

- ***Provision of services and supports to the family and carers.*** This is outside the remit of NDIS in most cases- and is an important support that enables families to continue caring for the person in the community for longer
- ***Access to early intervention and supports.*** Eligibility for NDIS is based on functional impairment. People with younger onset dementia benefit from early intervention even before significant functional impairment occurs. Delaying support services often means that people need earlier access to more costly formal services, such as presentations to acute care.
- ***Capacity Building.*** Key workers provide training, education and service development to disability and aged care services.
- ***Services and Supports that fall outside NDIS***. Key workers provide a range of services including provision of information, awareness, advocacy and planning that are not included within the NDIS funded services.
- ***Access and Reassessment.*** In the trial sites most people with dementia have found access to NDIS to be extremely difficult due to the paperwork required. Without a dedicated advocate, access is impossible and most clients give up. In addition, an accurate plan is hard to develop as the needs of people with dementia change so rapidly. Although there is provision within NDIS for reassessment, waiting periods to access assessment mean that people may wait months to get access to services they desperately need.

The integrated approach of the key worker program in working with people from the point of diagnosis throughout the dementia journey and being linked in to the service sector is essential to supporting the person with younger onset dementia and their family and carers. While the NDIS can provide supports in some aspect, if particular functions are carved out this would detract from the benefits of having a single point of contact which can provide support throughout the dementia journey and link people to appropriate services and supports.