



NDIS Young Onset Dementia Residential Provider Roundtable

Melbourne, 19 February 2024

“...a valuable opportunity to consider the challenges in providing residential services and the reforms needed to make specialist young onset dementia services more viable and better equipped to meet the needs of people living with this condition.”

As part of the work of the *Joint Solutions Consortium*¹ to map a system of care for people living with young onset dementia, the Young Onset Dementia Roundtable series brings stakeholders together to consider how specialist supports and services can be developed.

The first in this series - the NDIS Residential Provider Roundtable - brought residential providers and clinicians together to discuss the experience of providing residential services for people with young onset dementia, share information about barriers and success factors and canvass components of a gold standard service model.

With only a small number of residential providers specialising in service provision for this group, the Roundtable was uniquely positioned to discuss the service provision experience in detail. It also provided the first opportunity to discuss how service delivery might benefit from the proposed reforms to the NDIS and Aged Care systems, and development of the NDIS Foundational Supports strategy.

Common ground

Over the course of the meeting, a number of common themes emerged. Providers spoke about their experience with starting and operating services, and clinicians addressed key issues related to disease and symptom management, risk mitigation, information, service navigation, training for providers and development of a skilled workforce.

Other themes covered were:

- **Funding:** transparency of decisions made around funding, including evidence-based decision making, and funding decisions informed by understanding of the dynamic nature of the condition and a multidisciplinary approach to support.
- **Residential aged care as the default option:** the NDIS has adopted a policy position that sets the expectation that individuals close to 65 years old should enter permanent RAC.

¹ The *Joint Solutions Consortium* is a collaboration between the Young People In Nursing Homes National Alliance (YPINHNA), the Young Onset Dementia Special Interest Group (YOD-SIG), the Eastern Cognitive Disorders Clinic (ECDC) and Dementia Australia (DA).

- **Navigation:** there is a well documented need for skilled navigation across service systems (including aged, disability and health) to provide certainty and timely supports for people living with young onset dementia.
- **Early intervention:** early intervention pathways are needed for those living with young onset dementia, including into the NDIS.
- **Community engagement:** all specialist services for people with young onset dementia need to have strategies for maintaining links for the individuals to relationships and communities as this is important for identity and quality of life.
- **Staff education, training and mentoring:** a skilled workforce is the cornerstone of all specialist young onset dementia services. Managing workforce needs includes addressing systems for professional development, mentoring and support for staff.
- **Awareness:** there needs to be a high level of understanding within government agencies of dementia (including how it manifests in families, communities and services) to inform good policy and enable mature engagement with people living with young onset dementia and providers.
- **Research and data collection:** it is vital a database is established to provide baseline statistics and changes in prevalence; and evidence relating to support and service needs, including gold standard care practice.

Key themes explored

Data

A significant issue for all attendees was the lack of relevant data.

Providers find it difficult to develop business cases for investment in specialist young onset dementia services when reliable demand data is insufficient, unavailable, fragmented or unreliable. The incomplete data capture processes of Government agencies and the progressive and highly individualised nature of the disease process, make it challenging to find reliable demand data.

There was agreement that the data that is gathered rarely reflects the spectrum of needs of people living with young onset dementia, and often focuses on formal or paid disability services, rather than considering the many different kinds of supports required.

Because the individual's needs inevitably change over time, the length of time taken to receive a definitive diagnosis can also be a confounding factor in forecasting service needs and delivering appropriate supports. Providers supporting people to access the NDIS agreed that what is a comprehensive list of needs when an access application is first made, will often be outdated by the time a formal diagnosis is confirmed, or even by the time the person's first planning meeting occurs.

The role of clinicians in a residential service

The active presence of clinical services across the young onset dementia disease course was seen as essential for disease management for individuals and families, and a critically important resource for service providers.

In speaking about the importance of an integrated team approach to managing the disease, clinicians noted that the enthusiasm of service providers wanting to establish themselves in the young onset dementia space is often not matched by a good understanding of the clinical aspects of this condition. Clinicians were aware of cases where entry to a residential disability service had failed because the provider did not understand the young onset dementia disease process or how to manage the changing needs of the person.

Other points raised on this topic included:

- **Clinical input to general service models:** A very important first step in establishing a more capable and skilled service in this area is the development of comprehensive service models that actively involve clinicians.
- **Clinical input at times of change:** It is critical to providing appropriately targeted support for the person and also for the team of workers delivering that support that clinicians be available and involved during changes in the disease process and transitions into residential support settings.
- **Person-centred clinical advice:** A core feature of a gold standard young onset dementia residential service is the involvement of a clinician who knows the person well and who can provide guidance to the residential service about the design and delivery of support from pre-admission through to assisting decisions around palliative and end-of-life care.
- **Avoidable hospital admissions:** Clinicians noted that gaps in understanding by providers and families means that people are often admitted to hospital inappropriately at key transition points or because of a breakdown of supports.
- **Easy and timely access to clinical advice:** There was general agreement that real time access to clinical input (including for staff debriefing, professional development and for family communication) was needed to address the dynamic changes in support needs that people with young onset dementia experience. A team approach was seen as critical to a gold standard service model.

It was also noted that the clinician's role extends to working with individuals, families and providers to assist with decisions about a person's care and the need for palliative care (which the person may need at multiple points while they live with young onset dementia). Attendees gave examples of people being inappropriately sent to hospital and having poorer quality of life at times when clinical advice was not available.

- **Clinical oversight of admission to residential care:** There was agreement that it was important for clinicians to be involved early in the consideration of admission to a SIL/SDA or other service outside the home.
- **Links to mental health:** There was agreement that in addition to medical and allied health input, there is a need for links to be maintained with mental health professionals. Liaison with the mental health system needs to be built into service provision and maintained by providers.
- **Clinicians provide an essential disability-related health service:** There was agreement that clinicians need to be funded to provide disability-related health services that are in addition to the clinical care funded under the health system. This includes providing necessary clinical insight and support along the continuum of care for the person with young onset dementia, involvement in case conferencing, visits to the home and behavioural support. At present, provision of these services by specialist clinicians including doctors, are not funded by the NDIS, Medicare or private health insurance.

Residential service models

While providers at the Roundtable all approached service delivery somewhat differently, their experiences and reflections were similar. For example, some providers had nursing as part of their SIL service, while others utilised allied health services funded separately from their individual NDIS plans. All saw the funding of nursing as a precarious but critically important feature of their service.

Other reflections included:

- **Lack of consistency in the NDIS planning process makes funding precarious:** Changes to funding - particularly decisions to reduce funding (often in the absence of any evidence of reduction in disability needs); or decisions to refuse requested increases in funding (to address evidence of increasing need) - weigh heavily on providers, and often result in the provider having to subsidise the care needs of the person while they apply for review or appeal.
- **NDIS funding 'model' seen as unsuitable for people living with young onset dementia:** A number of providers expressed the view that the current NDIS funding approach was unsuitable for specialist young onset dementia services. They urged that a funding model be developed that (a) recognises the volatile nature of this condition, (b) gives providers capacity to address the dynamic needs of each individual in their service and (c) avoids funding decisions for individual participants that risk the viability of the service provider's support model.
- **Commissioning services:** There was general agreement that the NDIS should consider funding the service - either in addition to or instead of allocating funding via individual participant plans - to deliver services for people living with young onset dementia. This would lead to both lower long-term costs and better quality of services.

- **NDIS funding of nursing services is critical:** The recent decision by the NDIS to withdraw funding for nursing services for participants living in SIL was considered to be high-risk to participants and detrimental to service delivery.

Ongoing conflict about the funding of health needs for people with a disability more generally (including how disability-related health supports are funded and the NDIA's expectation that state/territory health systems should fund nursing services in SIL) are leaving providers as 'the meat in the sandwich' and making service continuity uncertain. There was concern that service providers who are unable to remain financially viable would inevitably need to avoid offering services to people living with young onset dementia.

In the absence of any state or territory health systems programs for these supports, and their expectation that this type of nursing is a disability-related health support and therefore more appropriately funded by the NDIS, resolving how these clinical services are funded is essential if specialist services for people with young onset dementia are to be developed, maintained and sustained.

- **Community connection is key:** It was generally agreed that a sense of belonging, and continued engagement in the local community by services and individuals living with young onset dementia, are critical to delivery of a gold standard residential service.

Workforce

There was universal agreement that an appropriately skilled workforce and workforce management are essential to providing residential services for people living with young onset dementia. Workforce issues are a constant challenge for providers.

This resonated with feedback from families at the Alliance's 2022 *Young Onset Dementia Roundtable* who stated that finding, training and keeping good support workers was one of the most challenging aspects of supporting a family member living with young onset dementia.

The main issues raised in this area are:

Strategy is essential: Young onset dementias are complex and require a specialised service model and, therefore, require detailed workforce management strategies

The need to define best practice: A definition of quality young onset dementia practice and guidance for practice leadership for support workers were considered essential elements of a gold standard young onset dementia service

It is vital to care and protect staff: Supervision and debriefing are essential to provide support to workers who are constantly managing stressful and/or challenging situations with residents, including instances of physical aggression from young people who may remain physically robust even as their cognitive capacity wanes

Choosing the right people: Providers employ a range of workforce approaches that are all directed at ensuring they select staff with the right values and personality attributes needed

to work with people with young onset dementia - patience, flexibility, and the ability to remain non-judgemental and a team player. All providers had ongoing professional development arrangements, some of which were in-house while some utilised external services including clinicians

Free training: The Wicking Institute's free online MOOCs (massive open online courses) were mentioned as being beneficial in providing initial training to workers entering the field.

Paid training: Rather than having training funded via individual participant plans that are often precarious and don't enable planning for structured, progressive and accredited training that is a key factor in retaining staff, providers recommended that ongoing training and clinical advice for staff should be built into the NDIS funding model and directed at the whole service.

They saw this as underpinning their specialist service rather than the current NDIS practice of embedding minimum training expectations in unit prices, which does not reflect the specialist supports required and level of staff competence required for this work.

Working with the NDIS

There was unanimous agreement that the NDIS had low awareness or understanding of young onset dementia across all business areas. This has resulted in poor funding outcomes, poor data, conflict and hardship to individuals, their families, providers and provider staff. To address this, attendees recommended that the NDIS quickly develops a young onset dementia pathway that recognises the progressive, neurodegenerative, terminal nature of the disease and links funding policy and approach to support needed at all stages of the disability.

With the level of NDIS funding provided to NDIS participants, the majority of providers said they find it very challenging to deliver even basic requirements in their residential services for people with young onset dementia.

The progressive and volatile nature of the disability means that funding needs to be able to accommodate rapid changes in support needs, something that is not built into NDIS plans. Even though providers actively make themselves available to support participants and their families and support coordinators, and provide key information for the planning process about the changing needs of their residents, they report that delays, lack of recognition of the needs of residents, and the lack of transparency in decisions by the Home and Living team meant that the mismatch in funding outcomes and participant need constantly threatened their financial viability.

In addition, access to the NDIS is not always straightforward for people with young onset dementia and their families. The progressive nature of the disease, and the scarcity of capable and knowledgeable clinicians to assess and diagnose individuals, means that securing suitable evidence for the application process remains a challenge. Even when a person can get access to a suitable clinician, the diagnostic process is complex and can take years. Despite the fact that diagnosis is not essential for access to the NDIS, the absence of a confirmed diagnosis often becomes a stumbling block to access being granted.

In other forums, families have said that while individualised funding was good, sustained effort was needed to get the most out of a funding package. Getting funding was one thing, but managing it, finding and coordinating services and locating skilled workers was something they found difficult alongside managing the disease in their spouse. The experience of support coordination for these families was variable, with some proving to be proactive and others needing to be coached by the families. Providers reinforced these experiences, saying that often the needs of families were overlooked in the quest for funding and services.

It was suggested that it may be useful for NDIS access teams and planners to have additional training with a specific focus on people with young onset dementia. Included in this training should be instruction on supported decision making.

Other points discussed included:

- **Underfunding of necessary support:** Providers advised that requests at planning meetings for 1:1 or 2:1 support for residents with dementia in SIL services who have high support needs that can include the person being highly mobile, incontinent, agitated and/or not sleeping, are being increasingly met with NDIS planning decisions that approve 1:3 funding and a sleepover only in direct contradiction to the evidence provided.

Approval of passive sleepovers assumes people are actually sleeping at night. This is often not the case and can vary frequently in the young onset dementia disease process. Some individuals rarely sleep but pace continually and need active support and direction throughout the night. Funding on a default 1:3 basis will not provide the active supervision required by individuals who have these needs.

Providers advised that funding for 1:3 supports has become a default setting for NDIS participant funding and fails to address the dynamic and intensive nature of supports required at certain points in the young onset dementia disease course.

- **Young onset dementia complexity:** Young onset dementias commonly result in complex presentations that require individualised support and a multidisciplinary approach. Because they have acquired a disability later in life, people with young onset dementia have established routines and roles, and preconceived expectations for their life.

The diagnosis of young onset dementia inevitably disrupts these at the same time as the disease progressively robs them of the capacity to plan, organise and carry out action to address their new reality. For example, the realisation that they need to transition from their own home to living in supported living can be very confronting. When supported living means a SIL house with insufficient funding for the supports they need, the transition can be overwhelming.

One provider described a situation where NDIS participants living in the service (one of whom is approaching 65 years of age, along with three other residents over 65) were rejected for SDA funding as the NDIS determined that they should go to permanent residential aged care. This was despite each having a goal to live as long as possible in the community and maintain their existing social relationships. This provider noted that there is nothing in the NDIS Act that limits funding on the basis of the age of participants.

In addition, the proposed new Aged Care Act will restrict eligibility to aged care services for younger people to those who are Aboriginal or Torres Strait Islanders, homeless or at risk of homelessness. It will mean that NDIS participants 50-65 years with high or complex needs who are denied NDIS funding for SDA and SIL will be forced into permanent RAC. Residential aged care has already been found by the Aged Care Royal Commission to be inappropriate for young people.

Interaction with other systems

The Roundtable heard that no single service system can address the many and varied needs of individuals with young onset dementia. It was acknowledged that as the NDIS is a disability service funder, its scope is limited.

It was agreed that (a) continuity of care and (b) cross-program service coordination for people with young onset dementia must be prioritised. An example of this for people living in residential settings was the importance of maintaining links with the community and trusted clinicians and having access to family support, as well as legal and financial services.

Comments concerning the interaction between disability services and other systems also included:

- **Anomalies in access to DSP:** Providers explained that many people living with young onset dementia are not being approved for a full disability support pension (DSP) when they move from the family home to a residential disability service. This is usually because Services Australia considers people who move to a residential disability service as being 'separated by illness' from their partner.

While they are usually entitled to the illness separated rate of the DSP (paid the same as the single rate), the person is subject to the combined income and assets test of both members of the couple.

This means that in the case of a couple where the other partner is still working and living in the family home, the person in the SIL often receives a very small fraction of the full DSP rate and their partner must pay the rest of their expenses (rent, food, clothing etc) from their wage which is often also needed to support dependent children. This also impacts on the person's ability to access Commonwealth Rent Assistance.

This additional financial burden can be enough to put the residential placement at risk, and can place families in financial peril. This appears to be despite the provision in the legislation that allows for the decision maker to make a discretionary judgement to consider the two people as not being part of a couple for the purposes of the DSP eligibility - see <https://guides.dss.gov.au/social-security-guide/2/2/5/40>

- **Advocacy:** There is a significant unmet need for advocacy and representation for people with young onset dementia. Navigating administrative complexities in many programs is beyond the capacity of many individuals and families, especially as the disease progresses. People have difficulty knowing when to apply for access to the NDIS. Working knowledge of NDIS systems and policies is patchy in other service systems, so misinformation is unfortunately too common
- **Service coordination:** Service coordination must be mandated to operate across service systems and coordinate services across more than one sector. At present, most service coordination happens within a single service system only, as is the case with support coordination funded by the NDIS. This is a major barrier to delivering the joined up services that a person living with young onset dementia requires.
- **Community care vs residential care:** Although it may be necessary for some people with young onset dementia to move into residential care at a certain point, many have a preference and desire to remain at home and receive support in the community for as long as possible. There is a strong need for coherence between the community care and residential care systems to ensure that the preferences of young people can be supported and transitions are made as easy as possible.

Key features of a gold standard young onset dementia service

A key question put to the meeting was ‘What does a gold standard service look like for people living with young onset dementia?’

A range of components were put forward, with adoption of multidisciplinary service models being at the core. As well as promoting greater awareness of the needs of people with this condition living in residential settings, providers agreed it was important to develop and document service models in public policy.

Doing so would:

- **guide the development of funding models** that allow the implementation of tailored support, collaborations with clinicians, development of a professional workforce and SDA and SIL dementia friendly housing design
- **include capacity for care planning** that can respond to dynamic and changing needs of individuals and/or households
- **define the role of clinical intervention** and establish professional development and secondary consultancy systems to underpin development of a skilled specialist young onset dementia workforce

- **collect data consistently** to guide policy making and service development
- **enable collaborative engagement with individuals and families** in service design and delivery, including information and reporting
- **reinforce the importance of community connection** and meaningful activity in and outside the residence for individuals
- **describe transition processes** to introduce individuals to out-of-home support, including the design of short term accommodation and respite options.

It was noted that we need good data and buy in from a range of clinical and research bodies to give life to a gold standard residential service. Input from people living with young onset dementia will also be central to ensuring it is relevant and person focused.

A process to document a robust gold standard young onset dementia service needs to be designed and resourced. It was agreed that this should be addressed as a distinct piece of work that would contribute to putting the necessary focus on service delivery for this group.

System reforms

At the conclusion of the meeting, Roundtable participants were invited to nominate their priorities for system reforms that would enable development of specialist young onset dementia services.

The list was extensive and included:

- **Assistive technology:** Funding to support the development of technology and other tools to assist people to navigate the young onset dementia space.
- **Workforce plan:** A young onset dementia workforce development plan, including targeted funding to develop and maintain skilled workforces.
- **Systems integration:** Service continuity through seamless integration of systems.
- **Awareness:** Improved awareness for government bodies about the dynamic and complex nature of young onset dementias, including the NDIA.
- **Funding transparency:** Transparency in participant funding that recognises dynamic needs.
- **Fairness in social security entitlements:** Review of Government benefits so that younger people are not penalised by systems intended to engage with older people who have acquired assets over a working life.
- **Service pathway:** Development of a young onset dementia service pathways to address the knowledge gap and provide integration of systems and joined up services.

- **Research and data:** More research and data for evidence of integrated support required.
- **Navigation support:** Service navigation across systems to address the push and pull around funding and service responsibility, including the establishment of community hubs for navigation and connections.
- **Support worker training:** Research to look at support worker training in managing behavioural changes in people with young onset dementia.
- **Accommodation security:** Security of tenure for people living in residential services.
- **Funding for Young Onset Dementia research:** Funding research and innovation into cause, management, cure and service development.
- **Clinical training:** Training for clinicians/doctors/GPs.
- **Sector-agnostic approach to management:** Holistic approach to young onset dementia disease process management through NDIS and aged care.
- **Diagnostic pathway:** Improved diagnostic pathways and support with early intervention.
- **Third tier of government:** Engagement of local government.
- **Public awareness:** A public awareness campaign on young onset dementia to remove the stigma.
- **Communication:** Better communication and collaboration.
- **Carer support:** Support and education for carers around the journey of dementia.
- **Targeted programs and capacity building:** Funding the development of age and disease appropriate programs, community capacity building.
- **Supported decision making:** Integrating supported decision making in funding for residential services.

A young onset dementia residential provider network

There was strong interest in ongoing engagement and attendees were keen to maintain contact. The group supported establishment of an ongoing network for providers supporting people with young onset dementia. This network would facilitate sharing of information, collaboration and structured engagement with the NDIS and clinical and research sectors.

The Alliance offered to auspice a follow up network meeting with Roundtable participants.

Young Onset Dementia Residential Provider Roundtable Participants

Brightwater Care Group

Janet Wagland, General Manager Disability

Naomi Moylan, Project Coordinator - Younger Onset Dementia

Community Home Australia

Rodney Jilek, CEO

Nicole Smith, COO

Craig Hooper

Connectability Australia

Margaret Taylor

The Cooperative Life

Margaret Ciarka, Regional Director/CoFounder

Dementia Australia

Nikki Gilbertson, General Manager Client Services

Eastern Cognitive Disorders Clinic

Professor Amy Brodtmann, Director

Laine Bradley, OT

Dr Chris Kyndt, Cognitive Neurologist

Hammond Care

Angela Raguz, General Manager, Residential Care & Dementia Centre

Heathcote Dementia Alliance

Sandra Slatter, Founder/President

Marg Rae, CarerConnect Coordinator

Independent Community Living Australia (ICLA)

Bill Campos, CEO

Melbourne Neuropsychiatry Centre, Royal Melbourne Hospital, Melbourne University

Associate Professor Samantha Loi, neuropsychiatrist, Principal Research Fellow

National Disability Services

Fiona Still, Consultant

Sydney University

Victoria Hollick, Project Manager

Villa Maria Catholic Homes (VMCH)

Elizabeth Baxter, Dementia Services Specialist

Yooralla

Melissa Cofre, COO

Vipin Malik, Director Home and Specialist Services