

# Collaborative care for young people with dementia

The INSPIRED-II project team is developing and piloting a collaborative care intervention for people with young onset dementia (YOD), based on results from Australia's first national survey of people with YOD and their supporters. **Monica Cations** and **Sally Day** report

There are over 25,000 people aged under the age of 65 in Australia who are living with dementia (known as young onset dementia, YOD), accounting for over 6% of all dementia cases (Brown *et al* 2017).

People with YOD have different experiences to older people with dementia. The onset of symptoms usually occurs at a time of great personal and professional responsibility; many people with YOD are at the peak of their careers and with a young family. Young people with dementia and their families report high levels of burden and distress due to delays in diagnosis, difficulty navigating support systems, and a lack of suitable services (Draper *et al* 2016; Cations *et al* 2017; Bakker *et al* 2013).

## Existing services

In Australia, dementia services have traditionally been delivered by the aged care system and not specifically designed to meet the unique needs of younger people. Some initiatives have been introduced to support the specific needs of people with YOD. For example, the Federal Government-funded YOD Key Worker Program delivered by Dementia Australia was funded to support navigation of available services (Westera *et al* 2016).

In 2016 it was announced that people under 65 with YOD would be eligible to access support packages through the National Disability Insurance

Scheme (NDIS). This decision was received positively by the YOD community. The principles of the NDIS are aligned with the evidence-based recommendations for YOD service design (Cations *et al* 2017): individuals can identify what is most important to them; they are afforded choice and flexibility around how funding is spent, on which services, who delivers these services and how they are delivered; and, they can receive support and guidance from a consistent plan manager. However, sitting at the intersection of the NDIS and aged care sectors can create a risk that people with YOD will 'fall through the

cracks'. Collaboration between the sectors is critical to ensure this does not happen.

## INSPIRED-II

The INSPIRED-II project, led by Dr Monica Cations from Flinders University and funded by the Dementia Australia Research Foundation, is a two-part pilot project, running from 2019 to early 2021. We aim to bridge the gap between what is known about the needs of young people with dementia and what is available to them in the real-world setting.

### Nationwide survey

Although anecdotal reports exist, no research is available to tell us about the

experiences of people with YOD in the NDIS so far. As such, the first part of this project is a nationwide online, anonymous survey, asking young people with dementia and the people who support them about their experience with the NDIS and with aged care. This is the first national survey of people with YOD and their supporters to be conducted in Australia. The survey will remain open throughout the first half of 2020 and you'll find details at the end of this article on how to take part.

### Care intervention

We will then use the information obtained through

## INSPIRED-II in practice

The following scenario explains how we see the INSPIRED-II project's collaborative care approach being able to improve service provision for people with YOD.

Diane is a 63-year-old woman who has recently been diagnosed with Alzheimer's disease. With the support of her husband, Diane has a successful NDIS planning meeting and is allocated funding for transport and social support services. However, she does not know who to contact to access these services.

Diane is referred to the NDIS Local Area Coordinator (LAC) in her area, Damien. After participating in INSPIRED-II, Damien has a strong relationship with staff at both a disability provider and aged care provider in the area. The team members have a good understanding of how best to support a person with young onset dementia to maximise their independence. They also have access to guidance from experts at Dementia Australia.

Together, the team members have developed a blueprint to guide how they will work with Diane. They collaborate to determine which services they each can offer, and brainstorm how to make this fit with her funding.

Diane and her team regularly review the appropriateness of services and decide whether other supports are needed. In this way, Diane is supported to navigate between the complex disability and aged care sectors, ensuring that she does not 'fall through the cracks'.

*Monica Cations and Sally Day*

this survey to develop and pilot a YOD-specific collaborative care intervention. This work will build on the original INSPIRED study (Draper *et al* 2016; Cations *et al* 2017), which established recommendations for service design and delivery for young people with dementia. Implementation of these recommendations across the NDIS and aged care sector is a significant challenge.

The INSPIRED-II pilot will test the suitability of collaborative care for this purpose. Collaborative care is where multiple providers from different organisations work together and with the young person with dementia to coordinate and deliver services.

The national Agents of Change translational trial (Cations *et al* 2018) brought together evidence-based best practice in dementia care with knowledge of quality improvement and supported clinicians to embed these learnings in practice (see p14 for more on this project). Key lessons from Agents of Change will be used in INSPIRED-II to design a multicomponent online training package to support disability and aged care providers to work together to provide best practice care for people with YOD.

We will evaluate whether the intervention is acceptable and feasible for service providers, whether the impact extended beyond the professionals involved (that is, did it have 'reach'), how much it cost, and the extent to which the intervention improved knowledge and skills in YOD service provision. This will allow for adaptation and refinement for wider roll-out.

### Why be part of it?

The online survey is open to all people with YOD and the people who support them. This is a chance to share experiences and have a voice in what is working (or not) since the introduction of the NDIS.



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Involvement in part two of the INSPIRED-II project is open to service providers in NSW and SA who:

- work for an aged care/disability care organisation or work as a NDIS Local Area Coordinator;
- have scope to provide services to people with young onset dementia (or their care partners) in any context; and
- can commit 16 hours to the project over six months.

The professionals may work in any type of service provision, for example: housing and accommodation; employment; everyday activities; assistive equipment or technology; driving services; centre-based groups; community participation; or service coordination. The research team will support people interested in participating to obtain manager and/or organisational approval to be involved.

This project is an opportunity for service providers from both the disability and aged care sectors to:

- Receive training and support from academic experts on YOD, best practice YOD service design and delivery, and effective collaborative care approaches.

- Learn to develop collaborative service delivery plans for people with YOD with feedback and support from experts.
- Participate in online mentoring sessions with expert advisors and people with YOD and/or their care partners.
- Join a community of practice with other providers involved in the pilot.
- Become leaders in dementia care provision for young people.

All professional participants will have access to 'backfill' payments for the time spent on the project.

It is anticipated that the knowledge and skills attained by those involved in the project will spread to others in the organisation.

### Outcomes

This project will provide detailed information about the experiences of people with YOD with the NDIS so far.

This essential knowledge will help to guide service design and delivery for all people who access both disability and aged care services.

The project will establish whether a collaborative care approach can improve service provision for people who sit at the intersection of disability and aged care, and whether these improvements spread beyond the individuals directly involved in the intervention.

The outcomes from this pilot project will be reported

mid-2021 and will inform the widespread implementation of a revised intervention.

Our goal is to ensure people with young onset dementia can access the supports they need, when they need them, in the way that they want them. ■

### References

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## Are you INSPIRED II be part of this research?

INSPIRED-II is now recruiting aged care and disability providers to pilot the online multicomponent training package. To register your interest, contact study coordinator Sally Day on (02) 9351 9172 or email sally.day@flinders.edu.au

The online anonymous survey is now open to anyone living with young onset dementia and/or their families or support people. Visit [www.tinyurl.com/inspired-survey](http://www.tinyurl.com/inspired-survey)