National Younger Onset Dementia Key Worker Program National Evaluation: Final Report

September 2016
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Glossary

AANO Alzheimer’s Australia national office
Carer Spouse, partner, family member friend
DBMAS Dementia Behaviour Management Advisory Service
KWP Key Worker Program
LWML Living with Memory Loss
NDIA National Disability Insurance Agency
NDIS National Disability Insurance Scheme
Executive Summary
In the three years it has been operating, the forty Younger Onset Dementia (YOD) Key Workers have supported nearly 3,500 clients; this includes over 1,500 people living with younger onset dementia, and nearly 2000 carers and family members.

Many of these clients are facing significant relationship, emotional, financial and social disruptions due to the impact of dementia during mid-life. The majority of services with expertise in dementia are designed for the frail aged and don’t fit the needs of people who are seeking to live active and engaged lives.

The highly skilled Key Workers have been able to navigate across ageing, disability, health and general community services, earning them the moniker of ‘system wranglers’, as they work with clients to develop tailored solutions for their needs. The benefits of being co-located within the broader Alzheimer’s Australia network has meant clients are able to link in with a range of dementia education and support services, including specialist counselling.

Having a dedicated Key Worker available to support people with dementia is internationally recognised best practice, regardless of age; the ability of the program to also support carers and family members has been highly valued and pivotal in enabling people to continue to live at home for longer.

The Key Worker Program has created new opportunities for people to keep active, socialise and play a role in the lives of their families and social and community networks. Resources have also been produced to enable other community groups to learn how they can adapt and better include people with younger onset dementia, their families and carers.

The broad remit of the program, with its focus on individual support as well as sector development and capacity building, has required significant thinking ‘outside the box’, especially for those working in rural and regional areas. Key Workers have partnered with local indigenous, culturally diverse and other community groups to improve understanding and develop better services.

As with all newly established programs there have been challenges. The exact quantum of the client population and nature of their needs was a relative unknown at the outset, and the ability to develop solutions has been iterative and time-intensive. Key Workers report many clients are at crisis point when they first commence with the program. This often requires an immediate response and a complex array of service relationships to be formed to support them over time.

The impacts of the aged care and disability policy reforms have inadvertently caused greater pressures for many clients, as entry criteria are tightened and similar case management type services have disappeared. Partnerships within and across sectors are critical to supporting clients with complex needs and can be at odds with the ethos of competition that underpins the consumer-directed nature of these reforms. Key Workers therefore require advanced negotiation and service development skills to develop solutions that are tailored to the clients’ needs.
The time-limited funding for the KWP has presented organisational challenges, in particular the investment in new processes and skills that have an uncertain future. In many respects the program has been a victim of its own success, as client numbers increase and staff placed under pressure to maintain expectations.

Despite these challenges, the achievements of the KWP have been considerable in terms of the numbers of clients supported and the breadth of service development initiatives developed. The strengths of the program include the expertise of its staff and their enterprise in building capacity within communities to enable people with YOD to have meaningful lives. The philosophy underpinning the program is about enabling people with dementia to continue to be active participants in their relationships, families, workplaces and communities and not only enhances the life of the individual, but of society more generally. It will be important to ensure that these twin objectives – individual and communal – continue to be addressed in any future consideration of the program.
1 Introduction
This is the Final Report of the evaluation of the National Younger Onset Dementia Key Worker Program (KWP).

1.1 Objectives of the Key Worker Program
The KWP has been established to enable individuals to be referred to a Key Worker and to have access to relevant and appropriate support. This will be achieved in three ways:

1. Providing individualised services and support for individuals with younger onset dementia and their families and carers in a way that meets their needs across the dementia journey.

2. Linking individuals with younger onset dementia to appropriate services and supports in their community to encourage care assessment, service planning and delivery process integration across agencies. Individuals will also be empowered to manage and access services themselves and remain socially engaged within their community.

3. Building capacity in existing services to better meet the needs of people with younger onset dementia. This will be achieved through consultation, education and training, networking and collaboration. The younger onset dementia Key Worker role will be flexible enough to allow change to meet local and evolving needs.

The Key Worker acts as a single point of contact for people with dementia, their carer and family members, and seeks to help coordinate care within existing aged and disability care services, as well as across systems (legal, education, social services, financial resources, recreation, transportation, etc.). The philosophy underpinning the key worker's role is to empower clients by assisting them to access services by providing support, resources and information tailored to meet their individual needs.

This activity is accomplished by a variety of means which may include:

- being available on a regular basis and when required (during the working week) by the person with dementia, carer and family members;
- helping people with dementia, carers and family members to understand the system(s) and, if required, helping them to navigate the system(s);
- being present at various meetings/appointments if requested;
- assisting with the interpretation of assessment results or outcomes of meetings related to their care;
- supporting the skills of the client, carer and family members and providing additional skills or tools to facilitate empowerment; and
- supporting the client in obtaining a diagnosis of dementia if the signs and symptoms are clear.
2 Evaluation Methodology

Our evaluation strategy was designed to allow the evaluation team to form a judgment as to how successfully the KWP has been implemented, whether the desired results have been achieved and what lessons have been learnt that will lay the ground-work for future support for people with younger onset dementia and their carers.

2.1 The CHSD Evaluation Framework

The foundation of our evaluation is a framework (referred to as ‘the CHSD evaluation framework’). It is represented by a matrix with three levels of analysis on the vertical axis ensuring we explore the impact and outcomes for clients (including carers, their families and friends), providers and the broader aged care sector (refer to Table 1).

Across the horizontal axis of the matrix are six key issues that a comprehensive evaluation should address – program delivery, program impact, sustainability, capacity building, generalisability and dissemination. Through systematically exploring each of the six key issues or questions posed, where possible at each level of the framework, we have sought to address the formative and summative requirements of this evaluation.

Table 1 The CHSD Evaluation Framework

<table>
<thead>
<tr>
<th>EVALUATION HIERARCHY</th>
<th>What did you do?</th>
<th>How did it go?</th>
<th>Can you keep going?</th>
<th>What has been learnt?</th>
<th>Are your lessons useful for someone else?</th>
<th>Who did you tell?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PROGRAM / PROJECT DELIVERY</td>
<td>PROGRAM / PROJECT IMPACT</td>
<td>PROGRAM / PROJECT SUSTAINABILITY</td>
<td>PROGRAM / PROJECT CAPACITY BUILDING</td>
<td>PROGRAM / PROJECT GENERALISABILITY</td>
<td>DISSEMINATION</td>
</tr>
<tr>
<td>Level 1</td>
<td>Impact on, and outcomes for, clients (including carers, their families and friends)</td>
<td>Describe what was implemented and, if necessary, contrast to what was planned</td>
<td>Impact on clients and carers</td>
<td>Sustainability assessment</td>
<td>Capacity building assessment</td>
<td>Generalisability assessment</td>
</tr>
<tr>
<td>Level 2</td>
<td>Impact on, and outcomes for, providers (staff, formal carers, professionals, volunteers, organisations)</td>
<td>Describe what was implemented and, if necessary, contrast to what was planned</td>
<td>Impact on professionals, volunteers, organisations</td>
<td>Sustainability assessment</td>
<td>Capacity building assessment</td>
<td>Generalisability assessment</td>
</tr>
<tr>
<td>Level 3</td>
<td>Impact on, and outcomes for, the system (structures, processes, networks, relationships)</td>
<td>Describe what was implemented and, if necessary, contrast to what was planned</td>
<td>System level impacts, including external relationships</td>
<td>Sustainability assessment</td>
<td>Capacity building assessment</td>
<td>Generalisability assessment</td>
</tr>
</tbody>
</table>

2.2 Adapting the framework for the Key Worker Program

The Younger Onset Dementia KWP seeks to have an impact at each of the three levels identified in the CHSD framework. However, given the relatively short timeframe of the initiative (3 years) it was recognised that some of the longer-term objectives of the KWP, particularly those seeking inter-sectoral or system changes, would not be fully realised within timeframes.

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the life of the evaluation. Similarly, being able to measure the impacts of the program on individuals who have a progressive illness or disease trajectory was also recognised as challenge, given the multi-factorial aspects associated with living with younger onset dementia. Consequently, not all cells within the CHSD Evaluation Framework were relevant; however, the discipline of reviewing each cell of the matrix ensured that we explored all potential program impacts and outcomes.

The KWP objectives provided the platform upon which the evaluation questions were established; from this, the relevant data items and sources were identified that could help determine the extent to which the objectives were met. The evaluation drew extensively on the data that was already being collected, including client demographics, service usage, and client goals.

The KWP evaluation framework\(^2\) articulates the evaluation agreed questions, data items and sources. These are summarised in table format in Appendix 1.

**2.3 Methodological Issues**

Prior to the evaluation commencing, the reporting requirements of the KWP by AA to the Department were already in place, and quite detailed. Where possible, we sought to build on those data collection processes, rather than impose additional burden on teams. The evaluation tools and processes identified at the outset underwent a number of revisions as details regarding the program implementation were clarified and in response to broader policy reforms. These changes are summarised in Appendix 2.

Ethics approval was received from the University of Wollongong Human Research Ethics Committee (Approval No: HE14/341) to conduct the evaluation, including amendments to tools and processes that arose as details of the program unfolded.

**2.4 Evaluation activities**

The evaluation framework developed by CHSD aimed to strike a balance between minimising the data collection burden placed on individual Key Workers and other informants including people with younger onset dementia and their carers, whilst ensuring that sufficient information will be available to meet the program evaluation requirements. The data sources, tools and processes are summarised in this section.

**2.4.1 Routine data collections within KWP**

The evaluation drew on program level information as well as individual client level data that was routinely collected and reported on within the Key Worker Program. The Program Reporting Template highlighted data elements required by the Department of Health (formerly Social Services) established as part of the funding agreement; these included general client information including diagnosis, referral processes, diagnosis etc., as well as the capacity building activities undertaken by Key Workers. More specific client level-information was available through the Goal Attainment Scale (GAS) reports that were commenced at the outset of the KWP. The GAS was chosen for use within the program due to its consistency with the client-directed philosophy of the KWP as it facilitates the clarification of goals according to clients’ priorities and measures the extent to which the goals are achieved. Scoring with the

tool is based on a symmetrical five point scale, from +2 to -2 where scores of ‘0’ indicates the individual reaches the expected level of achievement; positive scores indicate indicating incremental improvements in outcomes and negative scores corresponding to less than expected levels of achievement. The GAS data was provided to the evaluation team in a de-identified format, and included information about the nature of client goals and progress against goals made during the reporting period. The limitations of the GAS have been documented previously and relate to its subjectivity, aspirational focus and dependence on assessor capacity to set realistic goals.\(^3\)\(^4\) That said, the GAS data has provided an opportunity to clarify the nature of supports requested by clients of the KWP and present it in a way that can assist ongoing individual care planning and program develop.

### 2.4.2 Site visits

Site visits to metropolitan and regional teams were major activities within the evaluation data collection process. Two rounds of site visits were conducted overall; one at the outset of the evaluation in 2013 and a second round after the program had been operational and more embedded within its local service delivery context and processes, during 2015. The first site visits were opportunistic as they were incorporated within the context of a parallel project being undertaken by members of the evaluation team on behalf of the Australian government to better understand the needs associated with people with younger onset dementia. That project, *Literature Review and Needs and Feasibility Assessment of Services for People with Younger Onset Dementia* relied heavily on Alzheimer’s Australia network to facilitate consultations with people with younger onset dementia and their carers; many of these were also clients of the (then) recently established Key Worker program. The consultations therefore doubled as an opportunity for the evaluation team members to familiarise themselves with Key Workers and operational aspects of the Key Worker Program.

Insights gained at this first round of site visits were used to contextualise the written information received by the evaluation team during subsequent months, especially the jurisdictional reports that formed part of the overall national YOD KWP Reports. These, in turn, fed into the planning of the second round of site visits and allowed for refinement of the stakeholder questions and processes to better capture the operational and contextual factors likely to impact on local implementation of the program.

### 2.4.3 Stakeholder interviews

The major purpose of the site visits was to engage with a variety of key stakeholders through interviews and focus groups to discuss the impacts and outcomes of the program. Participants included consumers (including people with YOD, carers and family members, as well as members of the AA Dementia Advisory Committee – DAC), government and industry representatives, and KW program management, Team Leaders and Key Workers. In the main, consumer representatives were those nominated by relevant Key Workers, or who were made aware of the consultations through the related activities undertaken by the evaluation team (e.g., webinar with AA DAC) or via related consumer networks. While the range of stakeholders approached to participate in the interviews was consistent across each jurisdiction, their availability and/or capacity to respond in detail to the issues raised was mixed. With site visits

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Evaluation of Younger Onset Dementia Key Worker Program: Final Report

Scheduled for between two and three days in each jurisdiction, it was not possible to always meet face to face with those who had agreed to be interviewed, and follow-up telephone interviews were organised in such cases. Given the constraints of the consultation selection process, the evaluation team was aware of the risk of a positive bias amongst participants; this potential was mitigated by the overall evaluation utilising a mixed methods approach, with interview outcomes triangulated with a range of other data sources to clarify themes and findings. The interviews sought to elicit information about the following domains:

- Program rationale, design and management;
- Operational factors: impact, efficiency and effectiveness;
- Relationships, working with others and capacity building; and
- Program sustainability, barriers and enablers and unintended consequences.

The full list of questions per participant group is at Appendix 3.

The consultations included all states and territories, and included meetings and interviews with 120 individuals as outlined in Table 2.

<table>
<thead>
<tr>
<th>State / Territory</th>
<th>ACT</th>
<th>NSW</th>
<th>NT</th>
<th>QLD</th>
<th>SA</th>
<th>TAS</th>
<th>VIC</th>
<th>WA</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with YOD</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>23</td>
</tr>
<tr>
<td>Carers and family members</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>6</td>
<td>2</td>
<td>30</td>
</tr>
<tr>
<td>AA key Workers</td>
<td>2</td>
<td>9</td>
<td>3</td>
<td>4</td>
<td>3</td>
<td>4</td>
<td>7</td>
<td>4</td>
<td>36</td>
</tr>
<tr>
<td>AA Key Worker management</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td>Service providers</td>
<td>4</td>
<td>2</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>21</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
<td>17</td>
<td>13</td>
<td>20</td>
<td>10</td>
<td>13</td>
<td>20</td>
<td>11</td>
<td>120</td>
</tr>
</tbody>
</table>

Initially anticipated to take between twenty and thirty minutes, the majority of interviews lasted between 45-60 minutes as subjects were keen to share their experiences and/or expand on the complexities of the program’s implementation. Consequently, the interviews yielded a diverse range of views regarding the impacts and outcomes of the program.

2.4.4 Client assessment

Prior to the commencement of the evaluation, representatives from Key Worker teams had explored potential client assessment tools that could be used to support care planning and goal setting. At that time there were no evidence-based assessment tools that appropriately captured the needs of this client population, and a review of the Camberwell Assessment of Needs of the Elderly (CANE) had commenced to identify the aspect that could be adapted for use within the program. The evaluation team was approached by AA NO to support the development of a suitable assessment tool, given AHSRI’s expertise in outcomes measurement and assessment tool development.

\[\text{Camberwell Assessment of Needs of the Elderly (CANE)}\] (edited by Martin Orrell and Virginia Hancock, Gaskell Publications 2004).

of the Evaluation Steering Group, two assessment tools were developed that addressed the broad range of domains of relevance for these two groups and which had the potential to be incorporated into routine practice. Summaries of the two core assessment tools are provided below.

**Assessment of Needs Scale – Younger Onset Dementia (ANS-YOD)**

The ANS-YOD tool is based on a selection of items/topics from the Camberwell Assessment of Need Short Appraisal Schedule – CANSAS, the Camberwell Assessment of Needs of the Elderly (CANE) and other items included by representatives of the Evaluation Steering Committee. This is a 28 question tool designed to collects information across three domains that are important for people with younger onset dementia and their carers, and is designed to underpin care and goal planning. The domains are:

- Living arrangements, e.g. accommodation, food, looking after the home, telephone and communication, caring for another, safety issues for self and to others, money management and benefits.
- Health and care, e.g., self-care, physical health, care needs, sensory difficulties, sleep and memory, psychological symptoms and distress, continence, medication management, information on condition and treatment.
- Participation and meaning, e.g. meaningful activities and employment, social activities, mobility and transport, alcohol, cigarettes, illicit drugs, intimacy and self-expression.

**The Assessment for Needs and Services – Carers of people with Younger Onset Dementia (ANS-CYOD)**

The ANS-CYOD tool addresses five key domains: health and well-being; relationships; practical issues; information; and, support needed.

- Personal health and well-being, e.g., physical health; energy levels; psychological and wellbeing; feelings about caring; dealing with change/loss; self-care
- Relationships, e.g., with the person who has dementia, other family members, friends and social networks.
- Practical Issues, e.g., accommodation, looking after the home, financial matters, care tasks and, transport.
- Information, e.g., about YOD, support/care for the person with YOD, services available, planning for emergencies, planning for the future, entitlements and, legal matters.
- Support needed.

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8 Slade, M et al. CAN: Camberwell Assessment of Need, Royal College of Psychiatrists [http://www.rcpsych.ac.uk/publications/books/rcpp/1901242250.aspx](http://www.rcpsych.ac.uk/publications/books/rcpp/1901242250.aspx) 1999

9 Camberwell Assessment of Needs of the Elderly (CANE) (edited by Martin Orrell and Virginia Hancock, Gaskell Publications 2004.)
Details regarding the assessment tool development process and associated documentation are included in Appendix 4. Full copies of the tools are available in Appendix 5 and 6.

2.4.5 YOD Key Service Attributes
The evaluation was underpinned by the findings of the Literature Review and Needs and Feasibility Study and in particular the Younger Onset Dementia Key Service Attributes. These describe the models of ‘good practice’ which have the strongest evidence base to support people with younger onset dementia. Evaluation activities sought to clarify the extent to which the Key Worker Program met the KSA’s identified in the research through a survey of Key Workers and the inclusion of questions within the interview schedules used with stakeholders during the national consultations. The KSAs have been used as a framework for the Discussion section of this final report.

Table 3 Key service attributes

<table>
<thead>
<tr>
<th>Individualised model of service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Listen to people with younger onset dementia and their carers</td>
</tr>
<tr>
<td>Individualised service planning / person centred approach</td>
</tr>
<tr>
<td>Whole of family approaches</td>
</tr>
<tr>
<td>Ongoing needs assessment</td>
</tr>
<tr>
<td>Recognise and respond to the different diagnostic groups and their needs</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appropriate skills and attitude</td>
</tr>
<tr>
<td>Holistic approach to care and support</td>
</tr>
<tr>
<td>Enabling and consumer centred approach</td>
</tr>
<tr>
<td>Care co-ordination / case management skills</td>
</tr>
<tr>
<td>Effective communication and interpersonal skills</td>
</tr>
<tr>
<td>Flexibility</td>
</tr>
<tr>
<td>Capacity building</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Organisational attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Integrated specialist diagnostic and ongoing symptom management services</td>
</tr>
<tr>
<td>Organisational change capabilities</td>
</tr>
<tr>
<td>Regionally based, integrated and coordinated interagency partnerships and pathways</td>
</tr>
<tr>
<td>Timely service provision</td>
</tr>
<tr>
<td>Dementia friendly environments</td>
</tr>
<tr>
<td>Cost effective and flexible fees policy</td>
</tr>
<tr>
<td>Cultural Safety</td>
</tr>
<tr>
<td>Cater for needs of people in rural and remote communities</td>
</tr>
<tr>
<td>Individualised service planning / person centred approach / continuity</td>
</tr>
<tr>
<td>Respect and consideration for staff and clients</td>
</tr>
<tr>
<td>Manage risk effectively</td>
</tr>
<tr>
<td>Effective exit policies: re suspension and withdrawal of services.</td>
</tr>
</tbody>
</table>

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3 Results

This section details the KWP’s impacts and outcomes, as well as lessons learned, at each of the three levels of the evaluation framework: the client; provider; and system. Each section draws on data collected during the evaluation, and seeks to address the evaluation questions (see Appendix 1) raised at the outset, in order to make an overall judgement about the extent to which the program’s objectives were achieved.

The KWP has made substantial impacts on the lives of people with younger onset dementia and carers and on the service system that supports them. The experience of conducting the KWP over three years has helped clarify the particular needs of people with younger onset dementia and their carers, and identified supports and options not previously available in the traditional aged care service sector. As such, it highlights the unique challenges, and opportunities that have arisen, as a result of experienced practitioners facilitating tailored approaches to meeting clients’ needs.

The Program has evolved iteratively, with the service model and operational aspects developing as challenges emerge, and in response to issues as they arise. The dynamic policy and service delivery contexts in which it operates has presented significant challenges. The reforms have been implemented unevenly across different jurisdictions, reducing the capacity to embed generalizable service models across the national KWP network more broadly. As awareness of the KWP, client referrals and caseloads have increased over time, a number of operational adjustments have been required to maximise the impact of the resource and time-limited initiative and challenged expectations across all three levels of the evaluation framework.

3.1 Impacts and outcomes for people with younger onset dementia, carers and families

The first two objectives of the KWP seek to directly impact on people with younger onset dementia, their families and carers:

- Providing individualised services and support for individuals with younger onset dementia and their families and carers in a way that meets their needs across the dementia journey.

- Linking individuals with younger onset dementia to appropriate services and supports in their community to encourage care assessment, service planning and delivery process integration across agencies. Individuals will be empowered to manage and access services themselves and remain socially engaged within their community.

These objectives were broken down into a series of key evaluation questions, the answers to which could be aggregated to determine the extent to which the objectives had been realised. The questions relating to the first objective focussed on the details of the client cohort (numbers, reasons for presentation, services provided) as well as the outcomes of the support provided. The second objective included questions about the broader services and networks that were drawn on and the extent to which clients were empowered to initiate and/or sustain service connections.

As indicated in the evaluation framework, there are multiple factors that influence the outcome of service provision for people with younger onset dementia including: the declining and/or unstable nature of the dementia; predisposing individual, familial and social resources; and, the broader service delivery context. Each of these can impact on the ability of the Key Workers to achieve the outcomes identified for individual clients.
This discussion draws on several data sources to answer the evaluation questions, both routinely collected data sets and program-specific activities, such as client assessment tools. The ANS-YOD and the ANS-CYOD have been designed to capture a detailed picture of the impact of the dementia on the lives of clients, assist identify and prioritise appropriate responses, and to provide a benchmark against which to measure progress. The GAS builds on this needs assessment platform, facilitating clients to identify meaningful and relevant goals which are appropriate to their particular situation. The GAS was implemented early on in the program, and the practice of reviewing and documenting goals appears to be well embedded; however, this has not been the case for the client and carer needs data and consequently the data can only show a ‘snapshot’ of a percentage of clients’ needs. The stakeholder consultations conducted during 2015 and client satisfaction surveys issued by each Team help ‘round out’ our understanding of the client and carer outcomes that have arisen within the program.

The following results relating to clients provide a ‘snapshot’ of the overall findings. More detailed results can be found in Appendix 7.

3.1.1 Profile of KWP clients
The number of clients that were registered in the KWP at the end of December 2015 was 3,401. This was made up of 1,562 people with YOD and 1,839 carers. Just over two thirds of these came from metropolitan areas (n=2,355) and almost a third of clients came from regional or remote areas (n=1,003).

Almost 90% of clients with YOD had a confirmed diagnosis of dementia at the time of referral (n=1,406) and almost three quarters were aged between 55 and 69 (n=1307). The clients were evenly split by gender with 804 males and 778 females registered.

Carers, on the other hand, ranged in age from teenagers to clients over the age of 75 with 55% between 55 and 69 (n=1035). Approximately two thirds of carers were female. Just over half of all carers were the partner of the person with dementia and 20% were children (n=375). On a national level, slightly more carers (55%) were enrolled in the program.

3.1.2 Assessing clients
The program used three evidence based client assessment tools to support care planning (more detailed information about these tools can be found in the Section 2.4:

- Assessment of Needs and Services – Younger Onset Dementia (ANS-YOD) (client and carer perspectives);
- Assessment of Needs and Services – Carers of people with younger onset dementia (ANS-CYOD); and,
- Goal Attainment Scale (GAS).

3.1.2.1 Assessed needs of people with YOD
The ANS-YOD was implemented nationally in early 2015 following a brief trial in the months prior. Just over two-fifths (43%) of clients (n=673) nationally had an initial needs assessment; of these, 13% (n=90) participated in review assessments. There is much variation between the states and territories with regards to the number of assessments undertaken, ranging from 92% of Queensland clients to 14% and 15% in Western Australia and Victoria respectively. The ANS-YOD is used to assess the need of people with dementia and is divided into three domains:
- Living arrangements
- Health and care
- Participation and meaning

Living arrangements
The living arrangements domain covers issues such as: accommodation, food, looking after the home, telephone and communication, caring for another, safety issues for self and to others, money management and benefits. Of the responses recorded, just over 15% (n=123) of clients indicated they required changes to their accommodation situation (Q1) and between 10-13% of people experienced difficulties associated with activities of daily living (Q2, Q3, Q4). Around one-fifth (18%, n=130) needed assistance with financial matters (Q28) and communication (21%, n=159) (Q26). 16% (n=118) had accidentally harmed themselves (Q14).

Health and care
The health and care domain of the ANS-YOD covers areas such as: self-care, physical health, care needs, sensory difficulties, sleep and memory, psychological symptoms and distress, continence/difficulty using toilet, medication management, information on condition and treatment. Of the responses recorded, just over one-third (37%, n=284) of people with dementia identified problems with their memory (Q13) and almost a quarter (24%, n=183) of respondents wanted further information about dementia, its treatment or care (Q7). A similar amount (24%, n=169) experienced feelings of sadness, depression and self-harm (Q11). Around one in five (n=130) clients experienced difficulties with sleep (Q12) and one in six (n=122) required additional care to meet their needs (Q16). A similar amount of clients experienced problems with their eyesight, hearing or speech (16%, n=118) (Q8) and physical health problems (15%, n=112) (Q6).

Participation and meaning
The participation and meaning domain covers areas such as meaningful activities and employment, social activities, mobility and transport, alcohol, cigarettes, illicit drugs, intimacy and self-expression. Of the responses recorded, two-fifths of clients struggled with insufficient meaningful daytime (41%, n=329) (Q5) and social (40%, n=310) (Q19) activities. Just under one-fifth (18%, n=135) experienced difficulty using public transport (Q24).

3.1.2.2 Assessed needs of carer/family
Of the 3,452 clients registered in the program, 1866 were carers/family/friends (54%). The much lower number of carer assessments, 228 in total (12%) is in part due to the shorter time period in which the ANS-CYOD was operational. The ANS-CYOD was used to assess the need of carers of people with dementia and is divided into six domains:
- Physical health and well-being
- Relationships
- Practical issues
- Information
- Support
- Burden
Physical health and well-being
The physical health and well-being domain covers issues such as: physical health, psychological health and well-being, feelings about caring, valued roles, self-care and future goals. Of the responses recorded, almost a third of carers (30%, n=63) indicated that they had health issues that interfered with their normal activities (Q1a) and experienced difficulties sleeping (30%, n=57) (Q2a). Despite 50% (n=111) of respondents indicating they had difficulties adjusting to their caring role (Q5a), just over two thirds (n=151) were able to continue with their usual routine/activities along with their caring responsibilities (Q6a) and two-fifths (81%, n=152) were able to identify goals that they would like to achieve in the near future (Q8a).

The psychological health and well-being of carers were also canvassed in the ANS-CYOD (Q3a, 3b and 3c). Of the responses recorded, one in ten carers felt sad or depressed most or all of the time (10%, n=16), just over a third some of the time (35% n=59) and a further third a little of the time (37%, n=64). One fifth (19%, n=32) did not experience any sadness or depression. Over two thirds (n=112) had noticed changes in the way that they reacted emotionally to certain situations some/a little/or most of the time. Despite these difficulties, the vast majority (91%, n=135) never had thoughts of self-harm.

Relationships
The carer relationships domain covers issues such as: communication, intimacy, companionship, sustainability, shared understanding, conflicts and friends and social networks. Over half the responses recorded (n=119) indicated that being a carer had caused stress, strain and/or friction in the relationship with the person with dementia (Q10a) and just under a half (n=100) indicated difficulties communicating with the person with dementia (Q13a). One third of respondents (n=63) felt isolated from friends and social networks (Q11a). Only one third of clients were asked Q12a which dealt with intimacy in the relationship; of these, just over half indicated that changes had occurred (n=43).

Based on the information gathered during the carer assessment, Key Workers were asked to use their professional judgement in assessing the sustainability of the caring relationship (Q14). Where this occurred, just over half of carer relationships (n=104) were viewed as sustainable without additional support, however nearly two fifths (n=72) were at risk of breakdown within the next year.

Carer practical issues
The carer practical issues domain covers issues such as: accommodation, looking after the home, care tasks, transport and financing. Of the responses recorded, the vast majority (90%, n=187) had stable accommodation arrangements (Q15a) and over two thirds (71%, n=118) felt their financial arrangements were adequate (Q19). Despite this, two-fifths (n=69) indicated they were not confident they were receiving all the financial benefits they were entitled to e.g., superannuation, carer allowance (Q20). Nearly two fifths (n=78) of carers were also providing care to someone else in addition to the person with dementia (Q22), and only one-fifth (n=47) required practical assistance with looking after the home, personal care tasks and transport arrangements (Q16).

Support
This domain relates to support for the future and navigating the service system. Data relating to the kind of support for the future was not recorded in the assessment documentation. However, data was available for the question relating to whether assistance was required to
access appropriate services and support, with two thirds \((n=121)\) of the responses recorded indicating assistance was required.

**Information**
The information domain covers issues such as: information about YOD and what to expect, ways to support the person with dementia at home, relevant services, planning for emergencies, planning for the future and financial and legal matters. From the responses recorded, the vast majority \((79\%)\) of carers had noticed changes in the behaviour of the person for whom they were caring \((n=187)\), however around one in ten noticed no changes \((n=27)\). Legal arrangements were in place for around fifty per cent of carer relationships with regards to enduring power of attorney \((n=120)\) and guardianship \((42\%, n=99)\). Just under a quarter \((24\%)\) of carers had an emergency care plan in place \((n=57)\).

**Carer Burden**
The final domain of the ANS-CYOD includes four optional questions from the *Zarit Burden Interview: Short version*, that ask whether carers have time for themselves or experience stress, strain and uncertainty in their caring role. Thirty percent \((n=71)\) of carer assessments recorded responses to the burden questions, two fifths of which \((n=57)\) scored a rating that in routine community care assessment processes would trigger a more fulsome review and/or referral to a mental health professional.

### 3.1.3 Goals of KWP clients

A corollary to the identification of client needs discussed above is a mechanism to capture client wants or expectations. The Goal Attainment Scale (GAS) was chosen as the tool to be used to identify goals (wants) and measure the extent to which these had been achieved.

GAS data shows a broad range of client goals which have been used to determine service planning and support provided by the program. In total, 7,928 goals were set over the life of the program for both the people with YOD and the carers. The most common goals related to support for the family \((n=1,174)\), access to services \((n=1,155)\) and social engagement \((n=715)\).

There are some notable differences between the goals of people with YOD and those of carers and family members. For example, GAS data for 2015 shows that people with YOD are more likely to want access to services and carers are more likely to want health education and health planning (see Figure 1).

**Figure 1 Health related goals in 2015: PWD versus carers**
Goals directly related to support for the family are the most common recorded, with people with YOD more likely to want to maintain their independence, while carers are more likely to value family support. For people with YOD, social engagement and leisure goals and connection to others with YOD have become more important over time. Carers, on the other hand, are more likely to want improved opportunities for peer support (see Figure 2).

**Figure 2 Family support goals in 2015: PWD versus carers**

Many goals were reported in the ‘other’ category (n=1,265), more detail was provided to this category in 747 cases. The responses were varied and several themes could be extracted from the data. Dominant themes were:

- Assisting with access to the NDIS
- Finding suitable respite
- Attending the Living with Memory Loss course
- Access to Counselling service
- Organising driving assessment
- Regular contact with the Key Worker
- Assisting with transition to residential aged care
- Accessing some sort of volunteer work

Clients were asked to rate their experiences of the goal in terms of goal outcomes. A total of 2,663 goals were completed between January 2014 and December 2015. Overall, 45% of clients experienced ‘much better’ or ‘somewhat better’ than expected outcomes. Another 43% of clients had an ‘expected’ outcome. Only 12% experienced a less than expected outcome.

### 3.1.4 Services provided

The GAS is the only source of information routinely collected about service provision within the program. From the GAS data, there are four broad types of services provided to clients, namely: information and support; referral; service liaison; and, counselling. Since the program commenced, 15,626 individual services have been provided to 3,401 clients. On the whole,
these were fairly evenly distributed between people with YOD (7,701 services) and carers (7,925).

Just under half the services provided to people with younger onset dementia and carers is information and support. Service provision has steadily climbed overtime commensurate with the increased number of clients. Counselling and information and support have become more important for both people with YOD and carers as the program has matured, with carers more likely to use counselling services, and people with younger onset dementia more likely to require support in service liaison (see Figure 3).

**Figure 3 Service use by client type: People with YOD (inner ring) and Carers (outer ring)**

![Service use by client type](image)

3.1.5 Client satisfaction

During 2015 the evaluation team conducted a series of national consultations with a broad range of KWP stakeholders, including people with YOD and carers. In total, 53 consumer stakeholders were consulted, comprising a mix of people with YOD and carers as highlighted in Table 4. Consultations were conducted either face-to-face, one-to-one or in focus groups, or over the telephone with people with YOD and carers/family members. In the main, the consultations were facilitated by local Key Workers who participated in individual and group discussions, and assisted in putting together a schedule of related interviews to be undertaken during the visits.

Initially anticipated to take between twenty and thirty minutes, the majority of interviews lasted between 45-60 minutes as subjects were keen to share their experiences and/or expand on the complexities of the Program’s implementation.

**Table 4 Client consultations**

<table>
<thead>
<tr>
<th>State / Territory</th>
<th>ACT</th>
<th>NSW</th>
<th>NT</th>
<th>QLD</th>
<th>SA</th>
<th>TAS</th>
<th>VIC</th>
<th>WA</th>
<th>Total</th>
</tr>
</thead>
<tbody>
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<td>People with YOD</td>
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<td>0</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>5</td>
<td>2</td>
<td>23</td>
</tr>
<tr>
<td>Carers and family members</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>2</td>
<td>3</td>
<td>6</td>
<td>2</td>
<td>30</td>
</tr>
<tr>
<td>TOTAL</td>
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<td>4</td>
<td>10</td>
<td>5</td>
<td>6</td>
<td>11</td>
<td>4</td>
<td>53</td>
</tr>
</tbody>
</table>

Over the course of the interviews four key themes emerged as follows:
Program implementation;
Impact on people with YOD and carers;
Capacity building - broader sector engagement;
Operational Issues – impact on staff, organisational and contextual issues

This section of the report focuses on the impact on people with YOD and carers. Where relevant, we have included some quotes taken from the interviews as examples of the point being made. In other instances, we have presented short case studies or ‘vignettes’ and dispersed them throughout the document in coloured text boxes. In these cases we have use pseudonyms to prevent individuals being identifiable.

The clients interviewed included a mix of people with YOD and carers who had been identified by Key Workers, as well as individuals who had heard of the consultations through client networks. The interviews were conducted predominantly in person either directly with clients and/or carers, and in groups; approximately one third of interviews were conducted over the telephone, with the majority of these with carers of people with dementia. Those participating in the interviews came from a variety of backgrounds including people who: live alone, live in residential aged care, of cultural and linguistically diverse (CALD) background, from Aboriginal and Torres Strait Islander (ATSI) communities, lesbian, gay, bisexual, transgender and intersex (LGBTI), and clients living in rural and remote communities.

An Indigenous example

Betty is an Aboriginal woman from the stolen generations who does not wish to be identified as such on the public record. She had no proof of identity and consequently was at risk of becoming homeless. The Key Worker developed a bond with Betty and after much effort managed to obtain a copy of Betty’s birth certificate and place her on a waitlist for public housing. This process has enabled Betty’s family to trace their family history. Betty has also become less suspicious of services and now happily participates in social program organised by Alzheimer’s Australia.

The majority (around eighty percent) of client and stakeholder responses were overwhelmingly positive about the impact of the KWP on the lives of people with younger onset dementia and their carers. The benefits most cited include emotional support provided to carers; information and education; facilitating access to services and funding; and, negotiation and advocacy with individuals, family members and other stakeholders.

It is important to point out that many clients first reach out for assistance from the KWP at a point where their living arrangements are in a state of flux due to compromised decision making and changes in behaviour associated with cognitive deterioration. These factors are compounded by grief and loss, uncertainty and/or denial that can accompany a diagnosis of dementia. Consequently, the opportunity for clients to meet with a key worker who understands their situation, and can provide practical assistance through information, education and support services (in particular referral to Living with Memory Loss programs and Counselling Services) is a major advantage.
Key to this is the responsiveness of the Program. Many clients felt that their Key Worker was ‘only a phone call away’. As described by one carer:

I keep their number in my phone because if something happens I know the Key Worker will answer or get back to me...if things go haywire I know who to call.

Just knowing that someone was ‘out there’ looking after their cause was very important. The following quotes reflect this:

The KWP makes me feel at ease
It takes the stress out of a stressful situation
The KWP has provided us with confidence that you’ve got some back up somewhere

The KWP is underpinned by a philosophy of enablement and even within the midst of a client’s crisis the focus on goal setting remains strong. For the majority of people with dementia and carers we spoke to, the fact that the Program was targeted to meet their individual circumstances is its most critical and defining aspect. Many spoke of the importance of the close personal relationship that they had developed with their Key Worker.

Having one point of contact at AA is very important – I have built a relationship with my Key Worker – it is a very personal service

### A one-stop shop

Brian is a 61 year old man with a diagnosis of vascular dementia. Brian’s wife, Tracey, finds it difficult to accept the diagnosis and struggles to watch whilst her husband’s verbal and practical abilities deteriorate. Brian became very anxious and wanted to have his wife around him for support 24/7. The Key Worker was able to assist family members by referring them to a counselling service and providing them with relevant education. Brian has built up a rapport with his Key Worker and now feels confident enough to participate in a local walking group and a woodworking group. More recently, he has even attended a weekend retreat independently of his wife. The Key Worker is now focussing their attention on navigating the NDIS with Brian’s family and working with local speech pathologists to work on Brian’s language skills.

Many clients felt an overwhelming sense of isolation. Another key element of the Program was to reduce this sense by linking them in with others in a similar situation. This was most commonly facilitated through various peer support groups. These peer support groups were either targeted at the carer, the people with YOD or both and were highly valued by clients. This is articulated by the following quote:

When you ‘hit a wall’ you can talk to someone in a similar situation; they understand how you feel. You can’t put a price on this...someone who understands what you are going through...it’s as if you are ‘talking to a friend’. They understand the particular condition of the person you are caring for.

Attending the memory café is important...we get to meet other people who are experiencing the same things as us at the same stage. We can discuss the whole practical side of things including legal and benefit arrangements.
Connecting peers in this way is not limited to the peer support group. Many friendships have blossomed between people with YOD and carers as a result of these connections.

*My social life has blossomed since I have been involved in the Program.*
*We have lost friendships but the memory lane café has been great...I have met many new friends.*
*As the disease progresses, my social support circle has shrunk and there is increased need for support to be facilitated. To meet someone like me is reassuring. I would never have met them if we hadn’t met them through AA.*

Another factor mentioned in the client consultations was individual capacity building. This was mentioned mostly in light of the provision of education to both people with YOD and carers alike. The access to AA resources was considered by many clients as very important.

*You wouldn’t know anything unless you know who to look to and what to ask. Our Key Worker anticipates our information needs and responds with information there and then, as well as providing resources to share with family.*
*Key Workers...it’s like they have a toolkit of information and strategies...they provide clarity when confronted with a new change. They are great listeners, they make suggestions...they don’t impose. It is very much a partnership...they are looking out for your interests.*

Capacity was also built in the people with YOD through providing individuals with meaningful activities. Many clients commented that there was a lack of services for people with YOD. This certainly appears to be the case in most states and territories. However, there are many examples where Key Workers have worked with local agencies such as Greening Australia to facilitate them in taking on people with YOD on a voluntary basis one day per week.

### Capacity building at the organisational level

Greening Australia were approached by a Key Worker at the end of 2013 to see if they would be interested in building a partnership focussed on building their organisational capacity to enable them to take on volunteers with younger onset dementia. Management were supportive of this idea and staff from Greening Australia participated in in the Younger Onset Dementia training provided by Alzheimer’s Australia. This initiative started with a couple of men, supported by the Key Worker, volunteering to assist with basic nursery tasks on Tuesdays. Since then the initiative has grown and now supports the participation of ten men on Tuesdays and on Wednesdays, up to five ladies with younger onset dementia meet with other local community volunteers to assist in nursery tasks. The key worker who initiated the partnership is now in discussions with other states and territories to see if the program can be broadened in scope.

Other examples of providing people with YOD with meaningful activities can be found with partnerships with local men’s sheds, gymnasiums, bush care associations and community arts programs. Providing links with existing services was also an important feature of the Program. The Key Worker was able to link the people with YOD and their carer/s into relevant local services such as respite and Home and Community Care.
Advocating for the individual

Steven is a man with frontotemporal dementia who was discharged from community based respite due to troublesome behaviours. After a family breakdown and repeated attempts by Steven to escape from residential respite facilities he became a high risk of becoming homeless and in urgent need of suitable and affordable accommodation. The key Worker was able to step in and facilitated meetings between the client, the carer and respite facilities to negotiate longer term respite options. This culminated in the Key Worker successfully negotiating funded in-home respite through the Commonwealth Respite and Carelink Centre on behalf of the client.

Carers also appreciated the practical administrative support that was provided by the Key Worker. This was particularly relevant to accessing service or financial support. Examples include assistance with Centrelink forms and procedures, driving licence renewal or applying for a pension. During the last twelve months the Key Workers were active in assisting carers accessing NDIS services and support.

However, not all people consulted had positive experiences of the Program. Concerns included:

- delays in initiating contact and/or providing follow-up
  
  *It was a long time before anyone visited us and when they did, the Key Worker promised us ‘very much’ and delivered ‘very little’*

- limited service and support options offered
  
  *I don’t want to only go to events with People with YOD; I want to continue to go to clubs and activities that I used to …*

Others spoke about the inappropriateness of brokering services for respite, citing experiences of workers turning up with limited or no knowledge of dementia in general, or of the client in particular.

Some of these clients felt the partnership that underpins the service delivery component of the KWP was not matched by other aspects of its administration. Examples include the lack of action on potential service development opportunities that clients had identified within their local communities; the limited and/or absence of communication regarding changes to staffing arrangements; and, changing operational policies such as the introduction of entry and exit criteria within some Teams. Concern was also expressed that the perspectives of carers appeared to dominate service development and policy within the organisation more broadly. While each of the issues raised related to particular localised contexts, they were consistent across most of the States and Territories we visited, suggesting there are systemic barriers to meaningful client engagement that need to be addressed at a broader Program management level.

**Client satisfaction surveys**

Client perspectives were also drawn from the information provided to the KW teams through the client satisfaction surveys distributed as part of each jurisdiction’s routine quality assurance processes. The same short survey was used in all teams apart from NSW, where a more comprehensive approach was taken. Following a mapping exercise of the range of questions included in the surveys, it was clear that a large number of questions were consistent with those previously identified by the evaluation team.
The total sum of responses is by no means representative of the KWP’s reach or client groups: most responses were from NSW while SA had the least; and, 80% of respondents were carers. Most responses came from clients that had participated in the program for over six months. Summary results from the survey are highlighted in Error! Reference source not found..

Table 5  Client satisfaction survey results

<table>
<thead>
<tr>
<th>State</th>
<th># People with YOD</th>
<th>Carer</th>
<th>Time in programme (months)</th>
<th>Needs met?</th>
<th>More supported?</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>&gt; 1</td>
<td>1 - 6</td>
<td>&lt; 6</td>
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<td>184</td>
<td>32</td>
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<td>4</td>
<td>10</td>
</tr>
</tbody>
</table>

The following is a summary of responses to the client satisfaction surveys.

Do you feel like your needs are currently being met by the program?
Overwhelmingly people with YOD and carers felt that there needs were being met by the program. Respondents from NSW were not asked this question but for the 94 responses from other states and territories, needs were being met 91% of the time (n=86). Respondents were then asked to explain why / why not there needs had been met. Many themes emerged from the data. However, the three most common themes relating to people with YOD and carers needs were; the provision of general support (n=15), the availability of information and resources (n=14), key worker availability (n=12) and the provision of services / programs (n=12).

General support in this context was quite varied and was valued by both the person with YOD and carers. The nature of this support most commonly related to the provision of services or practical support such as assisting with filling in forms for benefits (e.g. Centrelink). The availability of information and resources was also highly regarded with regards to the provision of support. This is captured in the following responses from two carers:

_**I have never encountered a question that has not been answered or and dealt with in a positive and professional manner. Always delivered in a short time frame**_

_**...we have attended a number of informal meetings with others who have YOD, and to date our needs regarding information about and expectations for the future have been addressed. I have found these most helpful as a carer for my husband who has YOD.**_

The availability of the key worker was seen as important to meeting the needs of the people with YOD as well as carers. There was a general perception that ‘help is always at hand when needed’, ‘key workers are open and responsive’. Regular contact with the key worker was highly valued, particularly when this was made in person as opposed to telephone contact.

Clients also valued being linked in with appropriate services and/or programs. The most valued were those involving socialising and peer support, particularly those that were activity based.
such as movie clubs or walking groups. Peer support groups were equally as valuable for the clients with YOD, as well as carers.

**What aspects of the program do you find most beneficial?**

Answers to this question were quite varied but numerous themes were identified as highlighted below in Table 6. The most beneficial aspect of the program according to respondents was the provision of education, information and resources, followed by support, peer support and social activities. In general terms, the Key Worker was likened to a ‘security blanket’, in the words of one carer, “knowing that there is someone to talk to and get ideas is comforting”. Or from another carer, “Having someone we can call to ask certain questions, I feel like we’re not alone in this”.

**Table 6 Most beneficial themes**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Number of occurrences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education / information / resources</td>
<td>29</td>
</tr>
<tr>
<td>Support</td>
<td>21</td>
</tr>
<tr>
<td>Peer support</td>
<td>21</td>
</tr>
<tr>
<td>Social activities</td>
<td>17</td>
</tr>
<tr>
<td>Service provision</td>
<td>9</td>
</tr>
<tr>
<td>Regular contact</td>
<td>8</td>
</tr>
<tr>
<td>Empathy and understanding</td>
<td>8</td>
</tr>
<tr>
<td>Counselling services</td>
<td>6</td>
</tr>
<tr>
<td>Practical support</td>
<td>5</td>
</tr>
<tr>
<td>Personalised approach</td>
<td>5</td>
</tr>
</tbody>
</table>

One of the major benefits of peer support was the opportunity it provided to meet other people who are on the same ‘journey’. In the words of one carer:

…the opportunity to meet with others on the same journey at the Cafe sessions. People who are not familiar with the day to day reality of living with dementia do not understand what it is like.

This was similarly important for people with YOD:

The most beneficial aspects...have been the connection with others and sharing of problems and situations we have encountered and how others have dealt with these. Knowing we are not alone has an enormous impact on coping with the condition as it has affected us.

Being social and feeling part of a group is clearly important for this cohort. With regards to this, one carer stated:

The enjoyment my mum has had, particularly the cognitive stimulation group for women. It is great to know she’s having some social stimulation

It is perhaps surprising to see that only nine clients reported that service provision was a beneficial aspect of the program.

**Are there aspects of the program that you feel could be improved?**

There were 78 responses out of a possible 104 completed surveys (NSW did not ask this question). Of these responses, 33 offered no suggestions for improvement. As a result there were 45 suggestions for improvement to the program. The four most common suggestions included; access to more services (n=7), the provision of more information (4), more social
group activities (3) and more peer support (3). Other suggestions included raising community awareness about YOD and more regular contact with the Key Worker.

**Do you feel more supported as a result of accessing the program?**

Overwhelmingly clients and carers felt more supported as a result of accessing the program. Again, respondents from NSW were not asked this question but for the 96 responses from other states and territories, needs were being met 91% of the time (n=87).

Respondents were then asked to explain why they felt more supported. Eighty people responded, however, 24 of these responses provided no explanation as to why they felt more supported. The most common way that clients felt supported was simply due to the fact that the program existed – such as the ‘security blanket’ alluded to earlier (n=11), and the fact that the ‘Key Worker is only a phone call away’. Other clients felt more supported due to the extra social contact experienced as a result of participating in the KWP (10). This social contact related to the peer support groups or activity groups that the clients participated in. Information and support provided by AA was also valued (4) as was regular home visits from the Key Worker (4).

**What makes this program unique?**

By far the most common response as to what makes the KWP program unique was due to the fact that it is specifically tailored for people with YOD (n=25). Clients also indicated the peer and social support opportunities provided by the program were unique (11), and that it offered personalised and holistic support to the whole family and not just the people with YOD (10), was responsive and provided one on one support.

**What impact has the program had on your life?**

The responses relating to the impact of the program again related to the fact that the program felt like a ‘security blanket’. Many comments were made that summed this up: clients felt more optimistic, more positive, had peace of mind, didn’t feel so alone, felt less isolated, less stressed and less scared (n=16). Clients also appreciated the social support that came from participating in the program and felt less isolated as a result (n=10).

**Additional comments**

Additional comments were provided by 85 clients. Of these, 57 (67%) were considered positive comments and 21 (25%) negative (eight responses were unable to be classified).

The most common negative comment about the KWP was a perceived lack of contact or follow up from Key Workers (n=5). This is summed up by the following quote from a carer:

*When I was desperate for info/support the Key Worker was on leave and I could only leave a message - Key Worker did not contact me for about 1 week later during which time I was in tears and found my own solution after a lot of stress*

Other comments related to a shortage of Key Workers and a perception that the program needed more funding and the lack of services for people with YOD living in regional or remote locations.

The positive comments were mostly made up of clients wanting to express their thanks for the existence of the KWP, and the helpfulness and friendliness of the Key Worker staff (n=12). A
common theme in this was ‘keep up the good work’. Many comments capture these positive responses including:

I could not speak highly enough of this program. From the time I made contact to find out what was available I have received nothing but support. It is very reassuring to know that all in one place is a team who provide all the resources and information to make not only my life easier but also for my husband. We are very relaxed with our team who sometimes feel more like friends but keep their professionalism. All of the program has certainly helped our quality of life and the understanding of the disease.

We have been through so much and our world has been turned upside down we would not have been able to keep our family unit together without the support from our Key Worker and the KWP.

What are the three things that you believe clients have found most helpful from being supported by the KWP?

Six key themes emerged from this answer relating to what Key Workers perceived as most helpful about the KWP. The most common responses related to providing clients with education and information about younger onset dementia (n=11), providing a one-stop-shop for clients (9) and assisting clients to navigate through a complex health system (8). The last two themes related to the KWP being totally client focussed (5) and providing advocacy for its clients (5). The flexibility of the service, ability to provide ongoing support as required and focus on capacity building in clients and families were also cited as important.

What are the three things that you believe clients have found most difficult whilst being supported by the KWP?

The most common difficulty for clients perceived by Key Workers is the lack of appropriate services to which clients can be referred (n=17). Other difficulties included the perceived slow response time from KWs due to an increasing number of referrals (7), financial hardship experienced by clients (6), closely followed by issues relating to the sustainability of the KWP (5). Other difficulties included client eligibility for services, the isolation of some clients from services and key workers and difficulties getting a diagnosis.

Unintended consequences

Only eleven clients responded to the question relating to unintended consequences. The only negative comment related to the perception that clients felt stigmatised because of their diagnosis. The ten positive comments included a wide variety of responses with no real themes running through them. Essentially they related to connecting clients to services, peers and new social groups. The de-stigmatisation of their disease and empowerment were also mentioned.

3.2 Impacts and outcomes for providers

The evaluation of the KWP seeks to identify the extent to which it effectively delivered on its objectives of linking clients to appropriate services and supports in their community and improving the quality and coherence of service provision to meet the complex issues they face at this stage of their lives. To assess this, the evaluation framework asks whether staff were appropriately skilled and resourced to undertake their dual roles of individualised client support and broader sector development. This section of the report draws on several data sources including routinely-collected de-identified staff profiles, feedback from team members and other stakeholders during consultations and meetings, and national progress reports.
Jurisdictional differences are discussed, including impacts of organisational, service delivery and policy reforms on the ability of the KWP to realise its objectives.

### 3.2.1 Team profiles and staff attributes

The KWP was provided with funding for forty full-time equivalent (FTE) positions to be deployed on a national basis. The initial allocation of team members across jurisdictions was determined according to population data and anticipated client demographics, as well as geographical considerations. Subsequent to its commencement, the WA, SA and NT teams have been provided with additional funding for staff to meet the particular challenges faced in supporting people living in rural and remote areas, and indigenous communities. This translates to a total of sixty key worker staff and managers (excluding administration) working nationally. The teams range in size from 10.8 FTE in NSW to 1.6 FTE in ACT, with the vast majority of staff employed within the Program on a part-time basis, often in conjunction with their other roles within the AA network. These data are summarised in Figure 4.

**Figure 4 Distribution of Key Workers, FTE and actual**

![Graph showing distribution of FTE and actual key workers across jurisdictions.](image)

The majority of teams have remained relatively stable over the past three years, with no staffing changes in NSW and ACT and only a small number (2-3) in NT, TAS, SA and VIC. Both WA and QLD have undergone significant staff changes due to a combination of internal and external factors. The WA team experienced 8 staff changes in total, including a complete rotation in staff within the first year, and a second tranche leaving during 2015 and early 2016. Half of the changes were due to internal transfers to other programs within the organisation. The QLD team saw 16 changes, half of which occurred within a five month period during mid 2015 as the organisation was amalgamating and restructuring along regional lines.

The teams are comprised of highly qualified and experienced staff (See Figure 5). The majority of disciplines amongst those with tertiary qualifications are psychology/counselling (n=14), social work (13), health sciences such as physiotherapy, occupational therapy and diversional therapy (8) and nursing (6); many also have additional qualifications at Masters, Certificate and Diploma levels. A further 12 have significant industry experience in conjunction with one or more diploma/certificate level qualifications.
Each team includes a mix of professions and expertise, as is shown in Figure 6. Where teams appear to be more uniform in staffing mix, this is due to their relatively smaller FTE, or the particular service model of the team. For example, ACT has staff with broad psychology/counselling qualifications, within which there is specific expertise in drug and alcohol support (post-graduate qualifications) and psychomotoric. Similarly, the NT team comprises staff with nursing qualifications, one of which is has specialist psychogeriatric expertise, and two enrolled nurses with qualifications in case management and behavioural science. The VIC team comprises predominantly social work and psychology/counselling expertise, which in turn reflects the historical origins of its service delivery model.

As expected, each team has operated in slightly different ways depending on internal and external contextual factors. The KWP was designed to supplement and support, rather than replace, the existing services available for people with younger onset dementia, and therefore the staffing profile was expected to reflect this. The requirement for the KWP to be fully operational within six months of receiving funding meant that the new service was overlaid onto existing processes and procedures within the national Alzheimer’s network as a matter of
expediency. For example, in AA SA a similar KWP had been in place for some time, and the YOD KWP has been aligned closely to these existing operational processes and practices. AA NSW had developed expertise in YOD through its partnership projects with the NSW Government, University of New South Wales and UnitingCare Ageing NSW / ACT, and its facilitation of regular YOD service provider network meetings.

The composition and focus of several teams has developed in response to external factors, in particular the localised impacts of health, aged and disability reforms. For example, the WA team has a higher percentage of staff with health sciences qualifications, in particular occupational therapy, reportedly due to high levels of applicants from these sectors following the closure of previously publicly-funded allied health services. This has resulted in the WA team having a strong focus on enablement and engagement activities for its clients, reflecting the philosophy underpinning that particular discipline. The aged care and disability reforms in NSW have resulted in an overall reduction in case management-type services available, particularly in the Hunter region where the NDIS pilot has been underway. This has required the NSW team to have a greater focus on coordination and cross-sector advocacy than initially anticipated. The team profile includes a large number of staff with significant amount of industry experience which, in turn, enables them to effectively undertake their ‘system wrangler’ roles.

Importantly, despite these different staffing and contextual factors, each team has operated in a relatively consistent manner and as expected by the national program management. Each has a focus on providing individualised care and support for people with younger onset dementia and their carers, as well as advocating on their behalf and building capacity within relevant services and across sectors.

3.2.2 Resources and support
The evolutionary nature of the KWP has required significant investment of support to Key Workers to assist them manage emerging issues and trends. While staff are highly skilled in supporting people with dementia, the complexity and acuity of client needs has presented numerous challenges to the finite resources of the Program. A number of mechanisms have been developed to support staff including professional development opportunities and resources, as well as refinements to systems and protocols.

Professional development
The KWP utilises a number of processes to support its national operations, including regular teleconferencing amongst Team Leaders as well as face to face meetings with all staff on at least an annual basis. The nature of the engagement has shifted over time as the KWP has become more established and there is greater coherence and consistency amongst teams in regard to their objectives, processes and outcomes. Early events were more information-sharing meetings, but as the recent national meeting’s agenda shows, there is now a far greater emphasis on workshopping ideas, collaborative problem solving about client- and program-level issues as well as strategic directions for the program.

Support is also provided by members of the Royal Melbourne Hospital (RMH) Neuropsychiatric Team. RMH Team members are a core source of expert clinical support to the KWP overall, providing regular fortnightly case conference teleconferences with KWs to discuss complex cases. Feedback received from Key Workers indicate that it is not only the expert input that is highly valued, with the RMH team playing an important role in supporting staff to clarify
professional boundaries. This is most beneficial for those Key Workers who feel professionally isolated or challenged, and is neatly captured in the summary notes of two national case teleconferences:

This case indicates consideration of referral to sources of social control...; this disempowerment is confronting, and again may be against the needs or wishes of the other. ...It is a positive example of (Key Worker) ability to sit with a case over a long duration and remain engaged and supportive in what is a very confusing and often exhausting family unit ... (12/01/15)

Overall, (Key Workers) appeared to us to be relieved of confirmation of the wife having a complex and challenging personality; and confirmation that disengaging at this point from what has become a chaotic engagement ... is strongly indicated. (22/10/15)

On a more localised basis, Key Worker teams have developed their own professional development processes, often building on existing support within their local organisation or service network. The NSW team has developed a peer model of professional development that is tailored for its members. Known as Professional Ongoing Development groups – or PODs – these generally consist of five or six members working in different geographic locations who teleconference on a regular basis to discuss cases and share experiences and resources. In 2015 the model was expanded to include the ACT KWP team members.

These professional development processes have emerged as important vehicles of support for staff faced with increasing numbers, complexity and intensity of client caseloads, declining service alternatives and experiencing professional and geographic isolation. According to staff, many clients present to the service for the first time at a point of crisis due to the prolonged periods of decline that generally precede a diagnosis of YOD and the impacts on family relationships and social networks as well as financial and employment situations.

The complexity of time and effort in working with clients to achieve their goals is what is unique to this Program.

This level of intensity does not appear to have been fully anticipated at the outset of the KWP, with the position description for the Key Worker indicating the role would be

responsible for the provision of information, advice and support services to individuals and families living with younger onset dementia, to help improve their quality of life

The documentation indicates the rather generic skills, knowledge and experience required of Key Workers that includes

- counselling (one to one and groups)
- facilitation of support groups
- delivering support services to clients
- coordinating other support services and
- ensuring continuity of care.

Consequently, the impact of dealing with the more intensive client casework has been significant, as Key Workers have noted

the accumulated grief of dealing with people in crisis takes its toll...
I often have unresolved feelings of guilt for not being able to meet the needs of clients...

At the time of reporting, it is understood that consideration has been underway regarding a common framework to provide professional development and support for Key Workers as well as clarify program guidelines and role definitions. These will be clarified over the course of the two year transition period leading to full integration of the KWP under the NDIS.

**Program support**

A number of program parameters have been refined over the course of the KWP in response to the greater acuity and complexity of client cases and the changing external service delivery context described previously in this report. Refinements include the clarification of program entry and exit criteria, as well as developing new processes for client assessment.

The capacity of the Program to meet the needs of clients has been significantly impacted on by the initial expectation that the program will provide ‘continuity of care’ to clients after they turned 65 years of age and/or entered residential care and that families would continue to be supported during bereavement. While in theory the program does not provide case management, in practice many staff indicate that the absence of alternative services with which they can refer clients means that they often do take on a de facto case manager role. A recent report indicates the KWP is operating “well over capacity” with approximately one Key Worker per 76 clients;\(^{11}\) this is around three times the number recommended by the Case Management Society of Australia for its members.\(^{12}\) Consequently, a number of processes have been introduced to contain client numbers to a manageable level. These include incorporating a triage function within the intake processes of the program that are implemented on a jurisdictional level, as well as supporting clients transition to alternative programs and services as they become available (e.g. NDIS), or when they reach 65 years of age (aged care).

The development of a client assessment tool was a major undertaking of the KWP. Designed to support evidence-based care for clients, the ANS-YOD and ANS-CYOD were derived from related assessment tools and tailored for use within the KWP in conjunction with researchers, key workers, clients and program managers (see Appendix 4). The rationale for the development of a YOD-specific assessment tool was to underpin care and goal planning and monitor client progress. Over the longer term, it was anticipated that the tool would support priority rating and triage to manage demand, assist benchmarking of outcomes and support program planning.

As indicated in Section 3.1, the assessment tools were not implemented evenly across the teams. While the majority of staff appreciated the value of evidence-based assessment tools in a general sense, there appeared to be concerns about the rationale, processes and imperatives of those developed for use within the program.

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\(^{11}\) Alzheimer’s Australia Younger Onset Dementia Key Worker Program Performance Report 1 July 2014 - 30 June 2015, p2

Service development activities
The second major objective of the KWP focuses on enhancing the broader service delivery sectors to better meet the needs of people with YOD and their carers and families. According to the position description, the Key Worker

... provides consultation and advisory services to service providers and actively contributes to the development of a service sector that is responsive to and can meet the needs of people living with younger onset dementia.\(^{13}\)

This generally includes two broad functions: education and awareness, and capacity building.

Education and awareness
From its beginnings, the KWP has contributed to raising awareness of YOD and providing education to better support people living with YOD amongst the general public, health and care service providers, and targeted community groups. Topics have included broad-brush details about the incidence and presentation of dementia which have been designed to encourage people to recognise potential symptoms and seek appropriate diagnosis and support and, importantly, help reduce stigma. More targeted topics have focussed on specific needs associated with YOD, including care and support needs that people with YOD may have, as well as the implications for their immediate networks such as partners and children, social and community groups and workplaces.

By far the largest number of presentations has been on the topic ‘What is younger onset dementia’ (n= 569 over three years). The need for general information was greatest in the early years of the KWP, as organisations responded to promotional activities and started to access the expertise and resources available within the program and the broader AA network; this is quite clearly demonstrated in Figure 7 below. The second most frequently presented cluster of topics has been those that focus on meaningful, engaged and active lives (185), followed by personalised care approaches (112), relationships and communication (68) and financial and regulatory matters such as the workplace impacts and the NDIS (38). The increase in presentations on topics related to meaningful activity in Year 2 is consistent with expectations, given the stage of life which clients are at and the need for more appropriate social and activity based services. The only other topic to increase over time, and continue that trend, is relationships; again, this is not surprising given the client group, and increased awareness of the relationship elements that can be impacted by YOD.

Figure 7: Awareness and Education topics

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\(^{13}\) Position Description, Younger Onset Dementia Key Worker
The audiences of the various education and awareness activities are shown in Figure 8. As expected, Year 1 targeted the broad groups that had the greatest need for information about YOD and the KWP, and/or the capacity to adapt practices to better support People with YOD. The predominantly downward trend of presentations across nearly all target audiences is consistent with the shift from general awareness raising and information that typically occurs during the establishment phase of a new service, to more targeted presentations to groups directly involved in supporting clients, on subjects appropriate to their needs. Of note, however, is the increase in presentations to carer support services during the latter part of the evaluation period, perhaps reflective of the increased awareness amongst these services of the particular, and quite different, needs of this client group.

**Figure 8: Awareness and Education target audiences**

![Graph showing awareness and education target audiences](image)

**Capacity building**

The second function of sector development activities undertaken by the KWP is building capacity within services to better meet the needs of People with YOD and their carers (see Figure 9). Capacity building activities have reflected the trends described above in the discussion regarding awareness and education topics and target audiences. By far the largest number of activities related to networking and promotion of the KWP (n = 2332 over three years). The second largest number of activities involved influencing service providers through the provision of specialist advice and service integration activities (924), followed by provision of education resources (556), participation in research and presentations (297), influencing community organisations (289) and development of partnerships with related services (257).

These trends are consistent with the feedback provided by Key Workers during the 2015 national site visits and consultations:

_We initially flooded the sector, with the view that ‘let’s build capacity and they will come’ ..... the focus was on identifying the key services that looked after people with younger onset dementia, and had the capacity to extend its range of supports ... this proved successful_
The target groups for the different types of capacity building activities are seen in Figure 10. As anticipated and consistent with trends in awareness and education activities, the first year targeted aged care and community and social groups that had the greatest potential and/or need to improve their provision of support for People with YOD. The overall downward trend is consistent with the increasing client caseload and the need for a more focussed approach to capacity building amongst services and communities around individual clients, their needs and interests. The shift to more targeted activities was evident during the 2015 national site visits and consultations.

*Capacity building has to have a purpose ... we now start working through individual clients ... and build from there*

Beneficiaries of capacity building activities highlight the important role played by the KWP, particularly in a service environment that is constrained by funding, organisational and
jurisdictional imperatives. This role is summarised in the following comments by a dementia adviser working within a local health service and service managers working in partnership with the KWP:

*One of the most useful things I find most helpful is they do a lot of one-to-one support which I don’t have time for ... but what is really the best is working with the rest of us and helping us be more appropriate for people with younger onset dementia...  

As a (generalist) organisation we have to support ‘hidden carers’ too. This is a hard to reach group and many hidden carers are carers of people with younger onset dementia who have to work full-time to support the mortgage etc....  

In talking with the Key Worker about (client) we also began to think of others who could do with this sort of activity; we got in touch with (service provider) and set up a group for men that looked at the things that are supposed to delay the progress of dementia … (group) met once a month after 8 months (service provider) took over the running ...*  

**Sector development approaches**

Over time the shift from broad-brush targeting of activities and information to more individually tailored responses has been necessary, particularly given the increase in client caseloads. In general, Key Workers would work alongside their clients, using the information gained through discussions of needs and goals to identify opportunities for service development activities. This suggests a relatively straightforward, linear process of consultation, information sharing, and implementing changed practices to better meet the needs of clients with YOD. In reality the process is often far more complex, involving multiple stakeholders, negotiation, specialised resource development, staff education, refinement of organisational policies and processes and formalised agreements to be in place prior to clients being able to access the service; as such, a time and resource-intensive process. With the increase in client numbers and the associated crisis-management that appears to accompany many new clients, the capacity of Key Workers to undertake these broader sector development activities has been reduced, as indicated by the following statements elicited during the 2015 national site visit consultations.

*Client work is intense so capacity building takes a back seat  

We’ve worked hard to get services going but it takes time to collaborate ... twelve months to develop (cross-sector venture) arrangement – capacity building takes time  

To address these constraints, the AA VIC team has appointed a dedicated member whose role is solely focussed on capacity building. While team members continue to play a role in capacity building within services directly related to their clients, having a dedicated position provides an opportunity for more cross-sector, multi-participant, program-based and generalisable initiatives. For example, by identifying a common interest among several clients of the Program, the Key Worker was able to negotiate with a local gym provider to develop an appropriate program that was tailored to the needs of several clients with YOD. The outcomes of this initiative were positive for the KWP clients and the staff working in the gym:

*This couldn’t have been done without the Key Worker approaching us and supporting us; I wouldn’t have known about the potential of these clients, or of the benefits of working with them ...*
The templates, protocols and resources developed from this initiative are now available to be accessed by Key Workers elsewhere to support the development of localised social and fitness activities. In a similar vein, the NSW team researched and developed a ‘Capacity Building Toolkit’ for use across the KWP more broadly. The Kit includes a number of resources, including a capacity building assessment checklist to help identify suitable organisations that are more amenable to engaging with change around the needs of clients with YOD.

Importantly, the KWP has recognised that change associated with improving services to better meet the needs of People with YOD is not without cost, particularly for services outside the AA national network. In order to better equip services with an interest and capacity to support people with younger onset dementia and their carers, AANO provided funding for Community Development Grants. Close to $35,000 has been distributed to external parties nationally to deliver innovative services that are responsive to their local situation. The initiative was established in response to opportunities that had been identified by clients, and proposals were considered by the National Dementia Advisory Committee for approval. While each project is tailored to the needs of a local context, the outcomes will be documented and disseminated to facilitate broader application of these new service models. The projects are listed in Table 7.

### Table 7 AA Community Development Grants

<table>
<thead>
<tr>
<th>St/T</th>
<th>Funding</th>
<th>Project</th>
<th>Partner provider</th>
<th>Purpose - local</th>
<th>National application</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vic</td>
<td>$6,000</td>
<td>Enhance support for people with FTD</td>
<td>Fronto-Temporal Dementia Association (FTDA)</td>
<td>Establish FTD support groups in two regional</td>
<td>FTD family caregiver support facilitation manual, DVD and training materials that can be used as resources.</td>
</tr>
<tr>
<td>NT</td>
<td>$6,000</td>
<td>Dementia Friendly Garden support</td>
<td>Joy Anderson Centre; DEEP website; ‘Gardens that care’</td>
<td>Provide direct client support to 12 clients including PEOPLE WITH YOD, YOD, Carers</td>
<td>Final Report detailing outcomes of funding, achievements, challenges, and lessons learnt.</td>
</tr>
<tr>
<td>ACT</td>
<td>$6000</td>
<td>Meaningful activities for men with YOD</td>
<td>Majura Men’s Shed and the Northside Community Services</td>
<td>Provide a dementia friendly supported environment at the Majura Men’s Shed; participate in development of a business opportunity</td>
<td>Final Report detailing outcomes of funding, achievements, challenges, and lessons learnt.</td>
</tr>
<tr>
<td>WA</td>
<td>$4,800</td>
<td>Support for People with YOD in residential aged care</td>
<td>Morrissey Homestead Inc.</td>
<td>Develop a dementia support program for carers of residents, and skills development for staff</td>
<td>Final Report detailing outcomes of funding, achievements, challenges, and lessons learnt.</td>
</tr>
<tr>
<td>TAS</td>
<td>$6,074</td>
<td>Art therapist to support and train staff at two aged care facilities</td>
<td>West Coast (Lyell House) East Coast (May Shaw Home)</td>
<td>3 training and 3 days follow-up at each site; resource kit for participants</td>
<td>Report detailing outcomes of funding, achievements, challenges, and lessons learnt.</td>
</tr>
<tr>
<td>QLD</td>
<td>$6,000</td>
<td>YOD support in Darling Downs region</td>
<td>Ozcare Dementia Advisory Service</td>
<td>Establish YOD support and/or social group and/or carers group in the Darling Downs South West Area</td>
<td>Report detailing outcomes of funding, achievements, challenges, and lessons learnt.</td>
</tr>
</tbody>
</table>

#### 3.3 Impacts and outcomes for the system

The evaluation of the KWP seeks to identify the extent to which it effectively delivered on its objectives of building capacity in the broader service system to better meet the needs of people with YOD. This was expected to be achieved through ‘consultation, education and training, networking and collaboration’. To assess this, the evaluation has sought to identify the
linkages, partnerships, networks and collaborations that have been developed as a result of the KWP, including within the AA National Network; between the YOD KWP and service providers and organisations across a range of sectors; and, at broader social, regulatory and policy contexts.

3.3.1 Alzheimer’s Australia national network
The KWP built on the existing national infrastructure and administrative processes which had been established and refined as the need to provide the national coherence required when implementing Commonwealth funded national programs such as the National Dementia Support Program (NDSP). A clear advantage for the clients of the KWP has been the capacity for AA to be a ‘one-stop-shop’ for their needs associated with dementia. Large numbers of clients utilised the Living with Memory Loss, peer support, education and counselling services, and Key Workers cited the ease of drawing on local behaviour management expertise through the co-located DBMAS (TAS, WA, SA, QLD, ACT). The engagement of KWP teams with the broader service sector has also facilitated greater penetration of awareness of services provided by AA, including education and training resources and behaviour management support through the DBMAS provided by AA TAS, WA, SA, QLD and ACT. By virtue of their intra- and inter-sectoral work, the Key Workers have also been able to extend the reach of awareness of the supports and resources available within the broader AA national network to those organisations outside their usual remit.

A clear outcome of the KWP has been the capacity of AA to advocate on behalf of people with younger onset dementia, their carers and families, with contributions to over 20 parliamentary, departmental and program inquiries using information drawn from experiences of the program.14 Public awareness of the issues facing people with YOD has also increased through the numerous awareness campaigns and publicity generated by the Program in its quest for continued funding. For example, the Younger Onset Dementia awareness campaign in June 2015 reportedly reached ‘a cumulative audience’ over 10m people over seven days.15 Subsequent to the campaign, an online petition was created by the Chairperson of AA’s National Consumers Advisory Committee calling on the Australian government to commit more funding for YOD services and to ensure the KWP does not become part of the NDIS. In the eleven months since, this petition has garnered over 7,600 supporters.16 These processes have included the direct involvement and personal stories of people with YOD and their families and carers.

As anticipated, the implementation of the KWP across the federated structure of the AA National Network has not been without its challenges; this is primarily due to the relatively autonomous State and Territory organisations and the need to balance aspects of local delivery within the context of a nationally coherent program. One area where this has been evident is in relation to governance of the program.

15 Isentia Report, Younger onset dementia key worker comms, 15 June 2015 (internal confidential report, provided by AANO)
A feature of the early stages of the KWP was the establishment of an Evaluation Steering Committee, comprising representatives of consumers, researchers, state and territory program managers and KWP staff. Their role included selecting the evaluation team, contributing to the development of the evaluation methodology and was expected to continue oversight of the evaluation in an ongoing manner. As internal program management challenges arose, decisions were increasingly taken within the organisational process already in place in the national network. Thus, the National Program Managers Working Group which comprised AA state and territory Program Managers and AANO, considered operational matters and consumer perspectives were subsumed within the remit Dementia Advisory Committee (DAC) meetings. This shift occurred during a time of staffing changes within the AANO and therefore was not well communicated to interested parties. Consequently, a number of consumers expressed feeling ‘sidelined’ by the change, particularly those who were closely involved in the program’s conceptualisation and establishment.

The relative autonomy of State and Territory organisations has presented a number of challenges for the coherence of the program, in part due to historical factors as well as emerging pressures. AAVic, for example, had been the site of the pilot for the KWP appeared to experience some difficulty adjusting to new systems and processes required of the national program. This was most evident in the discussions regarding the development of a client needs assessment where local practices had evolved and concerns expressed about the introduction of additional features and processes. The patchy implementation nationally of the client assessment tools, the ANS-YOD and ANS-CYOD, can likewise be attributed to a flexible approach to national coherence arising from a mix of factors including staff turnover within the national program management ranks, and local decision makers adapting to contextual factors.

3.3.2 External services and supports
In addition to the local capacity building initiatives described previously (Section 3.2.2), the KWP has engaged more formally with a number of groups across a range of sectors to develop more sustainable solutions for its clients. The following section outlines some of the major cross-sector relationships, partnerships and collaborations that have developed, as well as the more localised initiatives that are likely to have broader application and longer-term impact. Core to the success of each of these initiatives has been the expertise and flexibility of the Key Worker as they creatively problem solve and persistently negotiate on behalf their clients and others like them. In addition, Key Workers seek to influence services through their facilitation of, or participation in, networks of service providers, while others are designed to influence more broadly still providing input into cross-sector initiatives and resource development as well as seeking to influence regulatory and policy frameworks.

3.3.3 Services and supports
The localised capacity building role that Key Workers undertake in relation to individual clients has been the basis for the development of a number of more substantial programs/activities, many of which continue to be ongoing and having much broader reach and impact than initially anticipated. These often originate with the identification of the many barriers faced by clients who have generally experienced significant disruption to their family and social relationships, living arrangements, employment and financial situations due to the cognitive changes. Their needs are often too complex for routine services to address and can make it difficult to maintain stable support arrangements. Usual service options or community solutions, therefore, are not generally feasible without additional expert advice and resources. The KWP has had considerable success in overcoming these obstacles, working with clients and their
carers and families, often across different sectors and jurisdictions, to generate options that are appropriate, meaningful and sustainable; importantly, many also have the capacity to be generalizable to a range of settings and client groups.

A common experience of clients is limited access to age-appropriate services, particularly residential respite care. In addition to the capacity building that has occurred at the local level, several KW Teams have worked with organisations to provide a more sustainable respite service. One example is the partnership developed between AAWA KWP, aged care provider Juniper Rowethorpe’s Hakea House and the Independent Living Centre WA to provide residential respite services specifically suitable for people with YOD. Supporting carers has also required working across organisations, in particularly members of the Carers Australia network as the Townsville based KW of AAQLD has done in establishing a carer support group in Mackay. Younger carers have different needs again, and AAWA KWP has worked with three related organisations - ILC Younger Carers team, 4 Families and Carers WA – as well as coffee shops and restaurants to provide social opportunities that better meet their support needs.

Given the many causes of dementia and the likelihood of comorbidities, Key Workers have also developed expertise in collaborating with specialist health related organisations. In the Hunter region of NSW, KWs participate in the AIDS Dementia and HIV Psychiatry Services (ADAHPS) Consultation Committee, with the ADAHPS clinical team and Positive Life, the HIV peak body, and also partners with Motor Neurone Disease (MND) experts to support clients with Fronto Temporal Dementia (FTD). Partnerships have also been established with a number of disability services nationally. A common issue within this context is the conflict between the prevailing service philosophy of enablement and the declining abilities of clients who have cognitive impairment. Responses include the provision of consultancy services, education, training and resources for staff as well as families and co-residents of clients with dementia.

Consistent with the themes emerging in the research, a significant focus has been on developing partnerships with organisations that can provide meaningful activities and engagement for clients. Initiatives include assisting clients stay working and/or volunteering in their workplace, through negotiating with management about accessing Job in Jeopardy Assistance program support, and working with volunteer organisations to find suitable placements for clients. AAACT has extended this concept more fully with its Woodworking Enterprise in partnership with a local Men’s Shed. Initially involving two KWP clients supported by Men’s’ Shed volunteers (initially supported by the KW) who cut wooden toys into kit form, the initiative has since expanded to eight men now also painting the toys and packaging for sale. Several local aged care services have also expressed interest in participating in the Enterprise, with the view to selling the products and developing an ongoing revenue stream.
**Engagement in meaningful tasks**

A Key Worker has developed an ongoing arrangement with a local men’s shed to build their organisational capacity to take on two men with younger onset dementia for one day per week. The men are supervised by volunteers and work alongside other men in a friendly and relaxed shed environment. One of the many projects the men have been involved in is to cut wooden toys into kit form. These ‘blank’ kits are then passed onto another younger onset dementia group organised by Alzheimer’s Australia to paint, glue and finish the products for sale. This ‘Woodworking Enterprise’ has become very popular with the men and as a result two local residential aged care facilities and a day program have shown strong interest in developing the model for aged care. The local DBMAS have also shown interest and have identified a number of residents with behavioural problems that would benefit from participating in this Enterprise.

Other partnerships have developed to focus on those who with an interest in sport and fitness, such as the work of AAVIC KWP, Blind Sports Victoria and Parks Victoria to deliver a number of supported walks for people with Posterior Cortical Atrophy. The AACT KWP has worked with a local women’s gym to provide regular sessions for a group of six female clients who met whilst undertaking the Living with Memory Loss program and AAVIC KWP has worked closely over a long period with YMCA. This latter initiative has been formally evaluated and a program template developed for use by other gyms with an interest in supporting people with YOD.

### 3.3.4 System impacts

One of the implicit objectives of the KWP is to influence systems and processes beyond the traditional health and care sectors. This has occurred in several ways. In NSW, the Illawarra Shoalhaven KW has been active facilitating community changes, through partnering with the University of Wollongong and the local Council to make Kiama a Dementia Friendly community; this has involved facilitating consultations, resourcing clients to actively participate in the process, and disseminate findings. The QLD Team Leader has drawn on her significant clinical and industry expertise as a member of the Queensland Dementia Clinical Network to develop a Younger Onset Dementia Diagnostic Flowchart; this has recently been endorsed by the Australia and New Zealand Society of Geriatric Medicine. In the NT, the KWP’s Community Development worker is a participant on the Safety and Wellbeing Working Group of the NT Ministers Cabinet Committee; and in SA the Team Leader has worked with the Office for the Aged and related health and disability policy officials to develop the Aged Care Assessment Fact Sheet No. 7. Referral Pathways for clients aged 65 and under which provides a streamlined approach to accessing aged care services and assessment.

Key Workers have also contributed to, and/or facilitated the involvement of clients in, the publication of several resources including:

- Community Café Toolkit: Your manual and tools for establishing a café for people living with dementia (2015)
- Dementia in Disability Training DVD (2014)
- Online Younger Onset Dementia education module suitable for clients, carers and service provider staff.
- Dementia Friendly Communities White Paper (2015)
Superannuation and Dementia (2015)

The Community Development Grants detailed in Section 3.2.2 are also expected to produce a number of resources, with each funding agreement requiring recipients to provide copies of relevant manuals, DVD and training resources developed, and a final report outlining the challenges and lessons learnt.

In the weeks prior to finalising this report, the YOD Capacity Building Toolkit was launched, providing a checklist and resources to facilitate improving communities and organisations better accommodate people living with dementia. The document draws heavily on the experiences and feedback provided through surveys of Key Workers, and includes a brief overview of the literature about capacity building in general. It is unclear whether the document is intended for use within the AA national network or more broadly.

3.3.5 Special needs groups

Importantly, the needs of people in special needs groups have also been addressed through various collaborations and ongoing relationships. The majority of these partnerships are specific to the local area, however the processes involve engagement and collaboration and can be generalised to other contexts when shared across the YOD network.

Aboriginal and Torres Strait Islander (ATSI) communities

The employment of YOD Community Engagement officers by AANT has enabled the development of close working relationships with three very remote communities (Hermannsburg, Palumpa and Peppimianti). By partnering with Carers NT, a weeklong respite camp was run providing education and support opportunities for the women from two communities that attended. A multidisciplinary clinic was held on Thursday Island, where the Key Worker participated alongside clinicians to provide information and education sessions.

Cultural and Linguistically Diverse (CALD) communities

Key Workers nationally have engaged with different community groups for both individual client support as well as broader community education about YOD. Organisations include Multilink, Greek Orthodox Care, Cathay Community Care, Filipino Association and the Islamic Sisters Association.

Homelessness or risk of homelessness

Several teams have also worked closely with local authorities to resolve tenancy and accommodation issues for clients who are or at risk of homelessness. AATAS KWP worked closely with Housing Connect Tasmania and Centrelink regarding a client in financial distress and at risk of homelessness to provide access to the Disability Support Pension and more sustainable accommodation. AAQLD KWP has collaborated with community organisation ‘Partners in Recovery’ to support a client move out of residential aged care move into the community and, later when that client’s health deteriorated, a philanthropic foundation was partnered with to provide more suitable, accessible and sustainable accommodation.

Lesbian, Gay, Bisexual, Transsexual and Intersex (LGBTI) communities

During the national consultations in 2015, several participants indicated the support provided to them through the KWP working closely with community and residential aged care services to ensure staff were sensitive to the needs of LGBTI persons.
4 Policy and regulatory reforms

A major challenge for the KWP has been the parallel aged and disability policy reforms that have been implemented. As of July 1 2014 the responsibility for aged care policy and programs lies predominantly with the Commonwealth, and disability policy and programs with the States and Territories; WA and VIC being the only jurisdictions which have maintained dual responsibility for community aged and disability programs. At the same time, the NDIS has been progressively trialled in all jurisdictions, predominantly in localised geographic areas apart from SA which has chosen to limit the initial roll-out to children. Consequently, the impact of the reforms has not been uniform across the KWP, and localised interpretations of developing program policies have added a further layer of complexity to accessing suitable supports and services.

As the reforms have been progressively, and iteratively, implemented there has been an almost pre-emptive response on the part of service providers, in terms of availability of types of services in anticipation of future policy shifts. For example, it is understood that in some regions there has been a decline in the provision of case management services as a result of the expectation that this type of function will be undertaken within the NDIS. The impact of this has been especially felt by KWP clients who are outside the NDIS pilot areas, or who have not successfully completed the application process. Consequently, the KWs have been required to take a more intense role than initially anticipated at significant cost to the program objectives overall, and to the KWs involved (as discussed in Section 3.2.2). With the demise of the Home and Community Care Program, services such as respite and peer support groups that were previously available to clients with YOD have become much more limited as programs tighten their access according to purported eligibility criteria associated with the source of funding, e.g., if funded by State and Territory governments (i.e., under 65 years of age) or Commonwealth (65 years and over).

KWP teams have experienced mixed responses to the implementation of the NDIS. Some clients progress through the application process in a relatively straightforward manner and reportedly had significant packages of care and support provided as a result; these tend to be clients with a clear diagnosis of dementia. For others, however, the process has been quite complex, requiring significant amount of effort on the part of the Key Worker during the preparatory phase; these tend to be clients who do not have a formal diagnosis of dementia and have complex living and support arrangements. Concerns have been raised about the capacity of people with YOD to access NDIS if they reside in an aged care facility, with clients experiencing mixed feedback regarding the guidelines pertaining to this matter. Many of these issues are not unexpected, particularly given the relatively early stages of the NDIS and as program guidelines and funding rules are tested. The establishment of an internal working group within the KWP is expected to clarify some of these issues going forward, as is the consolidation of NDIS related matters centrally.

The introduction of the NDIS has caused much concern for the KWP, in spite of its potential to provide clear benefits – including certainty of funding - for clients with YOD. The main issues raised by the KWP relate to its inflexibility in relation to responding to a dynamic and deteriorating set of symptoms associated with YOD, which is unlike the situation for most other disability types. The exclusion of carers needs from the scheme also challenges the philosophy of maintaining care relationships, which can be particularly complex for people with YOD due to their life stage which often includes some level of spousal/partnership relationship and responsibilities for dependent children. Advice from NDIA to the evaluation team suggests that
currently these issues are taken into consideration within the care planning process of the NDIS. As the NDIS is progressively rolled out, the continued advocacy role of AA will be important to influence the evolution of its policies and processes to ensure carers are appropriately resourced to support the person with YOD to continue to live in the community.
5 Discussion

The provision of support with and to people with younger onset dementia, their carers and families is an emerging field. In the main, the types of services that are available have been developed within the aged care sector, and have been found to be inappropriate for people within this younger population group in terms of access, activities and interests, staffing skills and knowledge, and meaning, to name a few.

Prior to the commencement of the KWP there was limited international evidence to support best practice, although work had commenced in identifying the issues facing these clients, through various local research projects and consultation processes. Aged care services were increasingly being recognised for their limitations in support for people with YOD, and consumers themselves were beginning to advocate for changes both at the local level with service providers and more broadly through the AA national network. In mid-2013 the Australian Government commissioned the CHSD to undertake research in this field and conduct an International Literature Review and Needs and Feasibility Study of services for people with YOD. The research included both an international literature review, the first of its kind internationally, and a series of national stakeholder consultations; in this aspect, the AA national network played a significant role in identifying opportunities to meet with people with YOD, carers, service providers, government representatives and researchers.

From the literature review, a series of service attributes were identified that had the strongest evidence in supporting people with YOD; these were tested within the national consultations to check the extent to which they aligned with the experiences and aspirations of stakeholders, including people with YOD, their families and carers. From this, a series of YOD Key Service Attributes (YOD KSAs) were developed, to describe best practice in terms of service provision, staffing attributes and organisational and systemic facilitators. These have helped shape the design of the KWP evaluation and provide an overarching framework for the following discussion of program results and evaluation findings.

5.1 Individualised model of service

The first YOD KSA relates to the provision of an individualised model of service that seeks to address and respond to the needs of clients:

- Listen to people with younger onset dementia and their carers
- Individualised service planning / person centred approach
- Whole of family approaches
- Ongoing needs assessment
- Recognise and respond to the different diagnostic groups and their needs

These align closely with the person-centred and consumer directed care philosophies that underpin best practice in ageing and disability services, and include explicit acknowledgement

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17 Westera A et al (2014) op cit
of the broader social and relationship contexts that are associated with the ‘life stage’ of people with YOD.

Listen to people with younger onset dementia and their carers

The rationale underpinning the KWP and, indeed, its core service delivery model, is consistent with this first set of attributes in that it provides individualised services and support for individuals with YOD and their families and carers in a way that meets their needs across the dementia journey. In doing this, it aims to link people with YOD to appropriate services and supports in their community through comprehensive assessment, service planning and integration across agencies. An innovative program, the KWP has sought to reach a disparate population for whom there has been little or no appropriate support services. It is the first time in Australia that a national Program has been delivered to PWD and the first time the opportunity has presented itself for comprehensive client level data to be collected in a systematic way. Engagement with clients and listening to their ‘stories’ is a fundamental activity for Key Workers, and sets the groundwork for an ongoing relationship of trust and rapport; this can require significant sensitivity, patience and persistence during the early phases when clients may not have the insight to acknowledge their need for support, or be too overwhelmed by the impact of the dementia on their day to day lives.

Individualised service planning/person centred approach and ongoing needs assessment

The KWP is underpinned by a commitment to the provision of service and supports that are tailored to the needs of its clients. It does this through two main mechanisms that are reviewed in an ongoing manner: a comprehensive assessment of needs using evidence based best practice in the form of the ANS-YOD and ANS-CYOD; and, working with clients to identify appropriate goals of service provision, as per the GAS. From this information, the Key Worker is able to work with their client to identify suitable options in terms of current support requirements, plan for future support needs and provide a mechanism for quality improvement through regular review and refinement.

In terms of providing an individualised approach, this is underpinned by understanding clients’ needs, circumstances and expectations. The premise is quite different to that of traditional aged care services in that the KWP has a focus on enabling clients, building on their individual strengths and goals; while this is emerging within aged care, the general service provision model has been focussed on addressing deficits associated with functional impairment that is associated with ageing.

While the GAS data reported on in the Results Section (see Section 3.1.3) provides a description of the number and types of goals, it does not indicate whether the goals aligned with the identified needs of clients. Client level information regarding their assessed needs and outcomes is mixed due to the varied application of the ANS-YOD and ANS-CYOD amongst teams. On average, 43% of all clients with YOD received a needs assessment; the most comprehensive client level data is from the Queensland KWP, where 92% of people with YOD and 77% of carers received assessments, and the NT where 79% of clients with YOD have been assessed. The low number of ANS-YOD re-assessments – 90 overall – also makes it difficult to identify trends in client need, or the extent to which services and supports were appropriate. Given these data are unclear, the evaluation team can only reiterate the feedback provided by Key Workers in our discussions with them at national meetings and the consultations; that is, client goals are reviewed regularly, both informally and formally, however these are not always documented.
Whole of family approaches

A key attribute of the program has been the ability to incorporate those involved in supporting the person with YOD within its remit. This has included spouses and partners; family members including children, parents and siblings; as well as friends.

The explicit inclusion of carers, partners, spouses, family members including children as clients in their own right has been one of the cornerstones of the KWP. Overall, the program supports more carers and family members than people with YOD (55:45), with NSW (60%) and VIC (65%) slightly higher. The feedback received through the client satisfaction surveys and the national consultations indicates that the inclusion of broader members of the person with YOD’s family and social network is highly valued. In addition to the routine ‘carer’ services available such as respite care, carers have identified the flexibility of arrangements across a number of domains that meet the needs of several members of the client’s immediate circle of support. Examples include the ability to work with school counsellors to support the children of people with YOD who may be struggling with schoolwork due to a family member having dementia or additional caring responsibilities; organising meaningful engagement activities, peer support, respite and transport services that enable carers to continue to work and/or fulfil broader family and social commitments.

The KWP has demonstrated the key differences between the goals of people living with YOD and those who are carers or family members. People with YOD are more likely to require support in service liaison, social engagement and meaningful activities. Many examples were provided where KWs had worked with local community groups and services to including a person with YOD within their volunteers one or several days per week. Partnerships with local men’s sheds, gymnasiums, bush care associations and community arts programs were also common. For those still in employment, Key Workers had assisted negotiating with employers, identifying additional resources such as the Commonwealth-funded Jobs in Jeopardy program to enable them to continue working or as they transitioned to other opportunities within or external to the paid work environment.

Advocacy and support in the workplace

Beryl is a 51 year old woman with frontotemporal dementia. She lives with a supportive family and holds down a job locally. But the management at her workplace had concerns about her not being able to complete tasks as per her position description. Beryl loves the social aspects of her work and was concerned that she may lose her job as a result of her deterioration. As a result, the Key Worker met with management to discuss issues with Beryl’s employment and provides education to Beryl’s work colleagues about younger onset dementia. As a result of the Key Workers input, management have introduced the ‘Jobs in Jeopardy’ Program where a volunteer works alongside Beryl for six hours a day three days per week. Consequently, Beryl has retained her job and the workplace staff and management alike feel supported and have a better understanding of younger onset dementia.

Recognise and respond to the different diagnostic groups and their needs

At the time of presenting to the KWP, 90% of people with YOD had a confirmed diagnosis of dementia; close to half had a diagnosis of Alzheimer’s Disease (AD) and almost one fifth had fronto-temporal dementia (FTD). A number of specialist services have been facilitated to support clients with particular sub-types of dementia, such as peer support groups for people with FTD and a walking group for people with Posterior Cortical Atrophy (PCA).
The Program has had success in reaching special needs groups, with around one fifth of all clients, including CALD (14%), living alone (2%), ATSI (1%), LGBTI (1%) and having a disability (2%). Around one third of all clients resided in regional and rural areas of Australia. The issues facing each of these client groups are generally far more complex than for others, including issues of access to mainstream and/or appropriate services; communication and information; cultural expectations; and, trust-building with particular communities. The outcomes for consumers are generally extremely positive, particularly in cases where the Key Worker’s advocacy has facilitated a greater acceptance of the person with YOD within their own community, and where clients are able to live independently as a result of the coordination of complex arrangements, education and support across a range of stakeholder groups.

As can be expected with new programs that operate in unchartered territory, client expectations may not always match the service delivered. This has been the experience of some of the early clients of the KWP, particularly as client numbers grew and demand management strategies were implemented. The iterative nature of, and uncertainty surrounding, the aged care and disability reforms further compounded problems as previous service options which had the potential for adaption for YOD clients were no longer accessible. This was particularly difficult for those who live on their own and those in regional areas for whom the peer support program and activities have provided an important social outlet. Clients acknowledged the pressures faced by Key Workers, including limited staffing numbers, organisational context, and reducing services they could draw on; some believed these factors had diminished the capacity of the program to be as ‘client-focussed’ and ‘consumer-directed’ as intended.

5.2 Skills and attitudes
The YOD Key Service Attributes highlights the skills and attributes that are needed to provide best practice support for people with YOD, including:

- Appropriate skills and attitude
- Holistic approach to care and support
- Enabling and consumer centred approach
- Care co-ordination / case management skills
- Effective communication and interpersonal skills
- Flexibility
- Capacity building

In order to continue to live in the community, people with YOD require support from family, friends, local communities, workplaces as well as formal support services, and Key Workers need to interface with an array of people and organisations to facilitate support networks to be established and sustainable. With the general community awareness about younger onset dementia very low, education and information are a core part of the Key Worker’s role, together with engagement and negotiation that is needed to establish changed routines and practices that may be required to accommodate the needs of their clients. Having the skills and...
sensitivity to provide emotional support within an enablement context is also necessary, as it generally underpins all interactions from the point of presentation. Many clients present in a state of ‘crisis’, and over time as needs and circumstances change, new challenges emerge with the progression of the dementia. Managing expectations is a major balancing act for the Key Workers, particularly in light of the limited staff numbers, large client case-loads and lack of appropriate services available.

The KWP teams are staffed by highly qualified and experienced professionals who are clearly passionate about the opportunity to improve the lives of their clients and advocating on their behalf. In the main, the skills and expertise of the KWP staff have been acquired within the context of aged care and/or mental health and consequently even the most experienced staff have had to break new ground in terms of their learning about YOD. The complexities arising from the diagnosis of YOD, and the preceding impacts that may have had on relationships and support networks as well as living and financial arrangements mean that no one client is the same, and there are no neat solutions that can be applied to others with similar diagnoses. Some of these have been described previously in Section 5.1. The resulting intensity of support required by people presenting to the program also has had implications for the well-being and professional development of staff within the KWP (Section 3.2).

A surprise finding of the evaluation has been the mixed response to the implementation of the client assessment processes developed, particularly given the highly experienced and professional backgrounds of staff members. According to the Good Practice Guidelines for Person-Centred Planning and Goal Setting for People with Psychosocial Disability18

> ‘person-centred planning’ appears simple but is actually complex. Its success depends primarily on the characteristics of its facilitator/planner; the selection of appropriate planning team members; the quality of the ‘Plan’ then produced; and the ‘Plan’s’ ongoing review and the learning of lessons involved...

The rationale for using internationally-agreed standardised outcome measurement tools includes their potential to be ‘used broadly as evidence of the effectiveness of service provision’19 and ‘open up new possibilities to compare performance globally, allow clinicians to learn from each other, and rapidly improve the care’ provided to clients.20 This will be even more important as the KWP revises its role in relation to the NDIS given the NDIA’s explicit expectations outlined in its Outcomes Framework:

> Monitoring outcome measures over time will enable assessment of how well the Agency is assisting participants to achieve their goals.21

Many of the attributes of the KWP are consistent with those increasingly being used internationally. The individualised support and coordination role of the Key Worker is similar to

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18 Richmond PRA (2013) Good Practice Guidelines for Person-Centred Planning and Goal Setting for People with Psychosocial Disability A Project Report for DisabilityCare Australia
19 McKay R and T Coombs (2015) An exploration of the ability of routine outcome measurement to represent clinically meaningful information regarding individual consumers, Australasian Psychiatry 20(5) p433
the post-diagnostic support services provided under Scotland’s National Dementia Strategy, whereby each person with dementia is promised that they

\textit{will be accompanied throughout their journey by a Dementia Practice Coordinator who will provide an individualised approach to lead the care, treatment and support of the person and their carer. They will be an appropriately skilled worker with the ability to provide, commission and control interventions.}\textsuperscript{22}

Similarly, the Netherlands has instituted a program of case management for people with dementia, comprising

\textit{systematic provision of coordinated care and support in treatment, health and social care, by a permanent professional, who is part of a regional network aimed at community-dwelling people with dementia and their family during the whole trajectory from (suspected) diagnosis until institutionalisation or death or even beyond}\textsuperscript{23}

Despite these initiatives having been underway for some years now, most have not specifically targeted people with younger onset dementia and the evidence base regarding staff skills and organisational attributes is still emerging (for example, see Peeters et al 2016\textsuperscript{24}). Similarly, getting the balance right in terms of client caseload continues to be unclear, although there is strong evidence regarding the role of client assessments in determining caseloads:

\textit{the load depends on the patients’ demand for care, the amount of activities (CM [case management] intensity), and the timing of CM commencement (stage of the disease)}\textsuperscript{25}

In moving forward to the new competitive service delivery environment that underpins the NDIS and aged care reforms, there are clear opportunities for AA to clarify its service model, the qualities and attributes of its staffing profile and organisational processes, so it can demonstrate client outcomes that are in line with contemporary best practice.

\textbf{Capacity building}

Capacity building has occurred at three levels within the KWP: at the individual level, by educating, upskilling and enabling individuals and their families; at the policy level, through providing evidence based data about this client group; and, most substantially, at the social and service provision level, helping services and communities better support people with YOD and their families. Consequently, staff need to have highly developed communication and negotiation skills to work across a broad range of individuals and organisations to develop options for clients. They also need to demonstrate a high degree of flexibility and creativity as they seek to identify more meaningful opportunities for participation and engagement for their clients.

\textsuperscript{22} Alzheimer’s Scotland, Delivering Integrated Dementia Care: The 8 Pillars Model of Community Support, p17  
\url{http://www.alzscot.org/assets/0000/4613/FULL_REPORT_8_Pillars_Model_of_Community_Support.pdf}

\textsuperscript{23} Alzheimer’s Netherlands/Vilans. (2013). Zorgstandaard Dementie [The national standard for dementia Care], in de Lange, J et al (2016) Factors facilitating dementia case management: Results of online focus groups, Dementia 0(0) 1-16

\textsuperscript{24} Peeters J et al (2016) Does the organisational model of dementia case management make a difference in satisfaction with case management and caregiver burden? An evaluation study BMC Geriatrics 16:65

This latter aspect of capacity building has generally provided the most challenges – and rewards – for the KWP. Innovative responses have been built through identifying common interests amongst clients, and from there working with external stakeholders that may be able to meet the interests. Examples of these have been described elsewhere in this report (for example see Section 3.3.3). What is common to all, however, is the need to work with local services, identify staff with the aptitude to work alongside people with YOD, provide education and training to those staff and ensure appropriate controls are in place at the local level to enable the Key Worker to exit and the initiative to be self-sustaining. Importantly, there generally requires a degree of organisational commitment, often in the form of a Memorandum of Understanding, whereby accountabilities are clarified and responsibilities documented prior to longer term arrangements being put in place.

An important feature of capacity building is to have an understanding of risk assessment both in terms of choice of service intervention, as well as organisation with whom to partner. For most Key Workers, their expertise has developed working alongside individuals, families and related service providers and they have had limited experience with broader organisational or strategic negotiations. To support staff, a Capacity Building Toolkit has been developed, based on a literature review and results of a survey amongst Key Workers. The Toolkit includes background material on what is meant by capacity building, as well as examples of processes that can be used. Importantly, the Toolkit also includes resources such as a Capacity Building Assessment Checklist, example Referral Pathways, and a template for developing a Memorandum of Understanding. What is missing from the Toolkit are examples of capacity building models that have occurred outside the KWP, such as those identified in the Feasibility Study discussed previously. Given the dearth of information currently available that can support the development of appropriate services for people with YOD, it would be worthwhile reviewing the report when the Toolkit is next revised.

5.3 Organisational attributes

As can be seen above, the ability to provide an individualised model of service requires staff with relevant attributes; it also requires organisational infrastructure and capabilities to support its operations. These attributes fall into three types:

- Organisational systems and processes, including clear entry and exit policies, role definition, fees policies and timely service provision.
- Organisational culture that is person-centred, respectful and culturally sensitive in regards to clients and staff; has capacity for organisational change and effective risk management.
- External relationships, including catering for people across geographic regions, being regionally focussed, encouraging integrated service and interagency pathways, and working toward creating dementia friendly environments.

Organisational systems and processes

Appraisal of the organisational attributes of the KWP needs to be premised on an understanding of the context in which it has been funded, conceptualised and delivered. The KWP was funded to operate primarily as a resource for people with YOD and their carers and families, to identify support needs and coordinate service provision, as well as build capacity within services to better meet the needs of those clients. The service delivery model was

26 Westera A et al (2014) op cit
designed to meet these objectives within the parameters of 40 Key Worker positions nationally. Operationalising the KWP, however, has proved far more complex and resource intensive than initially anticipated due to the large amount of unmet need experienced by clients presenting to the program and the diminishing capacity of the broader sector as service providers respond to policy reforms.

In establishing the KWP, AANO established parameters and processes that would support national coherence which also took into account local priorities and contextual factors of state and territory members within which the KWP staff and teams were located. While a collaborative approach was taken in developing overall program policies and guidelines, local implementation has been the responsibility of jurisdictional members. Consequently, each KWP team is comprised of a staffing mix that complements existing services and operates slightly differently according to their local service delivery context.

Some of the national features were in place prior to the local operationalisation of the program; these included broad program guidelines, position descriptions, reporting and accountability processes, the use of the National Dementia Helpline as a point of entry to the Program, and the GAS to work with clients regarding their goals. The KWP has been refining its processes over time in response to the issues that have emerged, such as the development of the client assessment tools and enhancements to the IT platform to support their use. The external service delivery and policy reforms have also impacted on the program’s implementation, particularly as the service mix changes and eligibility criteria have become more tightly controlled.

The KWP was established to address unmet needs of a client group for whom not a lot is known about, and presented an opportunity not only to meet those needs, but also to better clarify what those needs are for future service planning. As a recent AIHW report notes:

**Effective dementia management and treatment programs must be informed by an accessible, reliable and relevant evidence base. Building such an evidence base requires well-targeted and supported research and the development, collection and reporting of sound dementia data**

As discussed previously, there has been much variability in the implementation of the client level assessment tools and in the quality of the data which has been collected. This has been a major opportunity lost, particularly given the KWP is building the knowledge base about its clients at the same time it is being implemented.

The ANS-YOD and the ANS-CYOD were developed using evidence based assessment tools that have been internationally validated, which in turn were collated and tailored to the particular needs of the KWP with input from key stakeholders. It was expected that this would allow for comparability between client types across different contexts. As an example, one of the most defining points of difference between people with YOD and those who are older and have dementia is around their need for participation and meaning. This is captured conceptually in diagram below YOD (see Figure 11).
The ANS-YOD data confirms this, with forty per cent of clients wanting to be engaged in more meaningful daytime activities and almost as many again were unhappy with the current status of their social life (Figure 5). On the surface, this seems to be supported by the GAS data of 2015 (Figure 15) which demonstrated that people with YOD had almost double the level of goals related to social support, leisure and connection to others with YOD compared to carers.

Another example is the opportunity to clarify the anecdotal evidence that carers of people with YOD experience higher levels of stress compared to those caring for people who are older. A review of the raw ANS-CYOD data supports the fact that caring for a person with dementia impacts on carers’ psychological health and well-being, with one in ten feeling sad or depressed most or all of the time, one third some of the time, and a further third a little of the time. However, only 30% of these assessments also completed the four questions of the Zarit Carer Burden screen. Within this group two fifths scored a rating that, in routine community care assessment processes, would have ‘triggered’ a more fulsome review and/or referral to a mental health professional. The value of having robust and coherent data protocols not only facilitates targeted service provision at the individual level, but it also supports service planning and policy development more generally.

Organisational culture
The second group of organisational attributes that are important for supporting people with YOD focuses on the organisational culture, which is person-centred, respectful and culturally sensitive in regards to clients and staff, and also has capacity for organisational change and effective risk management.

In all our discussions with the KWP team members, their commitment to working with clients to identify goals and empowering them to achieve those goals is clear. In doing so, the KWP appears to utilise a co-design approach much like that of the NDIA (see Figure 12).28

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28 NDIA (2015) NDIA Co-Design Framework, Full Scheme Transition Division
Staff are very supportive of the philosophy underpinning and the processes utilised to clarify and monitor goals. This is primarily demonstrated in the way the high level of compliance in the use of the GAS tool within the program. During the national consultations, the relationship between Key Workers and clients was frequently cited as being one of the key facilitators of the program which was clients being able to ‘tell their story’ within the context of a responsive and supportive environment (as per co-design principle – cdp 2). Staff also indicated a desire to ‘engage early and often’ (cdp 3) however were constrained over time due to increasing client caseloads, requiring them to develop strategies to manage client expectations (cdp 7). As discussed previously, this is not unexpected given the evolving nature of the KWP and its implementation within a context of significant ‘unknowns’ regarding their target group’s needs and the impacts of aged care and disability service reforms.

The fourth principle of the NDIA co-design principles relates to the way in which the process is conducted. The KWP is clearly focussed on providing a flexible model of service in order to ensure responses are developed that take into account the diverse interests and needs of clients, and of those who support them.

This dynamic internal organisational context as well as the broader sector environment and reform have highlighted the importance of having robust governance and communication processes (cdp5 and 7). The Good Governance Guide developed by the Victorian Government provides advice for government organisations which is equally relevant to those in the non-government sector,29

> Good governance is about the processes for making and implementing decisions. It’s not about making ‘correct’ decisions, but about the best possible process for making those decisions.

The Guide clarifies the characteristics of good governance, which include transparency, accountability, abiding by the rule of law, responsiveness, equitable and inclusive, effective and efficient, and participatory. These characteristics were apparent at the outset of the KWP, where an Evaluation Steering Group had been established comprising key stakeholder representatives and participated in the selection of the evaluation team as well as advising on the client assessment tools and processes. These arrangements have changed over time with

the National Program Management Working Group (NPMWG) overseeing operational aspects of the program and the Dementia Advisory Committee providing input regarding consumer-related program issues. There have also been a number of staffing changes both within AA NO as well as across the AA national network which has impacted on the flow of communication within the program. Consequently, the information-sharing between teams about best practice options has not always been optimal, and these disruptions have also accounted for different interpretations relating to the use of the client assessment tools. During the last six months or so, however, the program has seen a greater degree of coalescence around important operational and strategic issues. This is evident in the structured change management approach employed by National Office in relation to the NDIA relationships and NDIS processes, and negotiations with government regarding the KWP’s future. The recent national forum (May 2016) included all Key Workers participating collaboratively to clarify the KWP attributes that can be harnessed and built on during the next two years as the program transitions to a service provider of NDIS participants.

In a similar manner, it would be timely to consider the engagement of consumer representatives within the ongoing governance and oversight of the KWP. As the evaluation has progressed, a number of consumers who were heavily involved in the initial stages of the KWP have gone on to make significant contributions locally, such as the Eastern Younger Onset Dementia Association (EYODA) and the Lovell Foundation30 in Victoria, as well as internationally as part of Dementia Alliance International (DAI).31 The individuals involved in these initiatives come with a wide range of skills, experience and capacity to influence not only program and policy development related to people with YOD, but also people with dementia more generally. Locally, they have had success across a range of areas including negotiating resources to develop local services, establishing dementia friendly communities, and influencing the next generation of university graduates.32 Internationally, DAI has campaigned for human rights of people with dementia and their inclusion within the UN Disability Convention at the World Health Organisation’s First Ministerial Conference on Dementia in Geneva in March 2015.33 As such, there are clear opportunities for AA to harness the expertise of this highly articulate and active group of individuals to inform the ongoing service delivery of the KWP and related initiatives.

**External relationships**

The third group of organisational attributes that best support people with YOD focus on the interaction with the external environment, requiring organisations to cater for people across geographic regions, being regionally focussed, encouraging integrated service and interagency pathways, and working toward creating dementia friendly environments. Much of these have been facilitated through the capacity building work of the KWP. For example, additional resources have been directed to areas of need by employing additional Key Workers to support people living in regional South Australia, Queensland, Western Australia and Tasmania; similarly, additional funding has enabled outreach services to indigenous communities in remote areas of the NT. Capacity development funding has also been provided to a number of

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31 http://www.dementiaallianceinternational.org/
33 http://www.dementiaallianceinternational.org/human-rights/
services that are external to the AA national network, to assist them develop appropriate supports and services for clients with YOD.

While these initiatives are all highly localised, their broader value lies in the fact that they are part of an overarching national program and organisation that has the capacity to incorporate findings within its program and policy streams. Furthermore, the AA national network provides the potential to disseminate good practice findings, resources and models of care across a wider audience through its cross-sector engagement initiatives (such as the YOD Networks) and strategic policy and advocacy activities.

The capacity building work undertaken as part of the KWP will provide a firm foundation going forward in its refined role within the context of the NDIS. Over time, the focus has shifted from the broader sector-wide approach to more localised effort around the needs of individuals.

The maturation of the program sees more clients accessing the support they need, with more capacity building targeted specifically in the areas where there are immediate needs.\(^{34}\)

The KWP has clearly developed expertise through this tailored approach to capacity building, having clarified the needs and goals of clients, identified opportunities to meet those goals, and negotiated with a variety of external stakeholders – community groups, aged care services, employers – to provide a meaningful response for their clients. These skills are also being applied more broadly, for example in working with multiple stakeholders in the development of dementia friendly communities. Consequently, there is clear alignment between the expertise provided under the KWP and the Information, Linkages and Capacity Building framework of the NDIS which seeks to:

Promote collaboration and partnership with local communities and mainstream and universal services to create greater inclusivity and accessibility of people with disability.\(^{35}\)

\(^{34}\) AA Progress Report to DSS, Dec 2015, p21.

6 Conclusion

In the three years it has been operational Alzheimer’s Australia YOD Key Worker Program has provided individualised and tailored support to nearly 3,500 people who have younger onset dementia and the people who support them. For many clients, their lives have been transformed as Key Workers have been able to work alongside them, help identify their strengths and interests and negotiate with a range of organisations and services to develop responsive, innovative and, ideally, sustainable solutions. It is clear that these outcomes would not be possible without the investment of funding to support the employment of forty ‘system wranglers’ that comprise the Key Worker Program. Prior to the KWP, the existing service delivery programs did not have the expertise, capacity, licence or culture to work with people with YOD and their support networks across a range of service types and sectors. The KWP was established to support this client group who were ‘falling through the gaps’ between disability and aged care programs.

The primary focus of the KWP has been to work with individuals, their families and communities to tailor interventions and activities that meet their needs. Underpinning this has been a focus of enablement, which is quite different to the traditional culture of care provided in aged care services for people with dementia. A major feature of the KWP has been the ability of teams to go beyond the boundaries of traditional service types and to identify local community activities that can be adapted to support their clients. The desire to continue to participate in a meaningful way within their families, communities and broader society is a recurring theme of the majority of clients, and through the capacity building focus of the KWP many clients have been able to access aspects of everyday life which had been closed to them. Participating in sporting activities, continuing in employment, contributing to family life and to the lives of others have all been achieved through education and negotiation undertaken on their behalf by Key Workers. Consequently, the KWP has developed a wealth of knowledge about different models of support that can be put in place for clients with YOD, many of which have the potential to be replicated in a variety of settings nationally.

An asset for the KWP has been its ability to draw on the broader range of services of the AA national network to support its clients, including education programs and resources, Living with Memory Loss program, counselling services, peer support and DBMAS where these are co-located. Teams have also established intra- and inter-sector networks to build capacity and extend awareness of the services available within the KWP. Going forward, it will be important that the KWP continues to have this broader cross-sector approach in order to continue to influence traditional service paradigms as well as ensure it stays abreast of contemporary developments as they arise.

New programs generally face significant up-front challenges, primarily due to the unmet need that has prompted their establishment and low level of awareness about their needs amongst potential service providers. Clients presenting to the KWP reportedly are experiencing greater levels of acuity of need than initially anticipated, with many ‘in crisis’ due to the impact of delays in diagnosis and the availability of appropriate support services. For the KWP, these challenges have been compounded by the impact of policy reforms that have further limited access to service delivery and options for service development.

Organisationally, the AA national network has also had a number of challenges, particularly in terms of restructuring teams and aligning processes and procedures to provide greater coherence across the autonomous state and territory members. This has resulted in some
aspects of the KWP not being implemented as smoothly as anticipated, such as the client assessment tools and data collection. With the commencement of NDIS pilot sites, several teams have been required to focus on enhancing the understanding within to ensure clients with YOD are appropriately supported. A major challenge for the regional and remote areas has been the almost complete lack of infrastructure that Key Workers can draw on to support their clients. This has resulted in additional funding being made available to support these communities.

Against this backdrop, the achievements of the KWP have been impressive. As the evaluation concludes, the KWP is moving into its next iteration in preparation for the national roll-out of the NDIS. The strengths of the program include the expertise of its staff and their enterprise in building capacity within communities to enable people with YOD to have meaningful lives. The consumer-directed philosophy that underpins the KWP not only enhances the life of the individual, but of society more generally. It will be important to ensure that these twin objectives – individual and communal – continue to be addressed in any future consideration of the program.
# Appendix 1 Younger Onset Dementia Key Worker Program Evaluation Framework

<table>
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<tr>
<th>Objectives</th>
<th>Evaluation questions</th>
<th>Indicators / data items</th>
<th>Data sources</th>
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<tbody>
<tr>
<td><strong>Level 1: Processes, impacts and outcomes for consumers (residents, families, carers, friends, communities)</strong></td>
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<tr>
<td>Providing individualised services and support for individuals with younger onset dementia and their families and carers in a way that meets their needs across the dementia journey.</td>
<td>1a DELIVERY How many clients received support from Key Workers? What were the key reasons for presentations, nature of service and supports provided, and intensity of support required? Proportion of people with dementia/carers/children supported by Key Workers. Did consumers (including those with special needs) receive individualised services and support to meet their needs across the dementia journey?</td>
<td>Consumer opinions i.e.: people with younger onset dementia, their families and carers and those with special needs. Support provided to individuals, carers and family members by service type; amount; frequency etc. Feedback from Key Workers</td>
<td>Key Worker Program (KWP) progress reports GAS data Site Visits Stakeholder interviews</td>
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<td>1b IMPACT Did the individualised services and support improve the quality of life for consumers?</td>
<td>Quality of life; isolation and social participation; satisfaction and burden</td>
<td>Client interview schedule incorporating tools @ baseline and 6/12 thereafter.</td>
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<td>1c SUSTAINABILITY Can the provision of individualised services and support and improvements in quality of life be sustained?</td>
<td>Feedback from key workers</td>
<td>KWP progress reports Site visits Client interview schedule</td>
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<td>Linking individuals with younger onset dementia to appropriate services and supports in their community to encourage care assessment, service planning and delivery process integration across agencies. Individuals will be empowered to manage and access services themselves and remain socially engaged within their community.</td>
<td>2a DELIVERY Were consumers linked to appropriate services and support to encourage interagency integration of assessment, service planning and delivery?</td>
<td>Referrals made; referrals declined; referrals acted on; Feedback from key workers Feedback from services receiving referrals from Key Workers</td>
<td>KWP progress reports Site visits Stakeholder interviews</td>
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<td>2b IMPACT Did the individuals feel empowered to manage and access services themselves and to remain socially engaged within their community?</td>
<td>Peer support groups established – type, frequency, activities.</td>
<td>Client interview schedule KWP progress reports GAS data</td>
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<td><strong>2c</strong> SUSTAINABILITY</td>
<td>Can the provision of individualised service linking and interagency integration of assessment, service planning and delivery be sustained?</td>
<td>Consumer opinions i.e.: people with younger onset dementia, their families and carers. Feedback from key workers Feedback from services receiving referrals from Key Workers</td>
<td>Client Interview Schedule KWP progress reports Site visits Stakeholder interviews NHS Sustainability Tool</td>
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<td><strong>2d</strong> IMPACT</td>
<td>Are there any unintended consequences for individual consumers arising from the Key Worker program?</td>
<td>Consumer opinions Feedback from key workers Feedback from services receiving referrals from Key Workers</td>
<td>KWP progress reports Client Interview Schedule Stakeholder interviews Issues and lessons log</td>
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<td>Documentation of any unintended consequences for Level 1 Objectives</td>
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**Level 2: Processes, impacts and outcomes for providers (professionals, volunteers, organisations)**

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<th>Objectives</th>
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<tr>
<td><strong>2a</strong> DELIVERY</td>
<td>Were staff appropriately skilled and resourced to undertake the KWP role? Were referrals made by the Key Worker to other services and support appropriate? Did the Key Worker facilitate the interagency integration of assessment, service planning and delivery?</td>
<td>Staff profiles; Position descriptions; Baseline data from service providers (including special needs agencies) re pre-Key Worker referral patterns for people with younger onset dementia Feedback from services receiving referrals from Key Workers</td>
<td>Staff Establishment Profile Tool Referral records KWP progress reports Stakeholder interviews Minutes of interagency meetings / case conferences Victorian Health Partnerships Analysis Tool</td>
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| **Linking individuals with younger onset dementia cont’d** | 2b IMPACT Were individuals more empowered to manage and access services themselves and to remain socially engaged within their community? | Baseline and post-implementation data about service changes arising from KWP in partner/referral services  
Consumer opinions i.e.: people with younger onset dementia, their families and carers.  
Feedback from key workers  
Feedback from service providers receiving referrals from Key Workers | KWP progress reports  
Stakeholder interviews  
Minutes of interagency meetings / case conferences  
Client interview schedule  
Site visits  
GAS data |
| 2b IMPACT Has integration of assessment, service planning and delivery across the sector improved? | Baseline and post-implementation data from provider  
Feedback from services receiving referrals from Key Workers  
Interagency referral / service pathways developed and utilised | KWP progress reports  
Victorian Health Partnerships Analysis Tool  
Stakeholder interviews  
Minutes of interagency meetings / case conferences |
| 2c CAPACITY BUILDING Do services / community groups or employers that have increased capacity to provide opportunities for people with younger onset dementia to remain socially engaged in their community? | Community Organisations providing relevant activities for individuals with younger onset dementia  
Employment and / or volunteer opportunities available for individuals with younger onset dementia | KWP progress reports  
Stakeholder interviews  
Client interview schedule |
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<td>IMPACT</td>
<td>Are there any unintended consequences for service providers arising from the program?</td>
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**Level 3: Processes, impacts and outcomes for the system (structures and processes, networks, relationships)**

Building capacity in existing services to better meet the needs of people with younger onset dementia. This will be achieved through consultation, education and training, networking and collaboration. The younger onset dementia Key Worker role will be flexible enough to allow change to meet local and evolving needs.

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<th>3a</th>
<th>DELIVERY</th>
<th>Project documentation</th>
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<td>evolving needs of</td>
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<td>the system?</td>
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<td></td>
<td>SUSTAINABILITY</td>
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<tr>
<td>Objectives</td>
<td>Evaluation questions</td>
<td>Indicators / data items</td>
<td>Data sources</td>
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</tr>
<tr>
<td>Building capacity in existing services to better meet the needs of people with younger onset dementia cont’d</td>
<td>What linkages have been developed and/or strengthened between individual projects and education and research organisations?</td>
<td>Project documentation</td>
<td>KWP progress reports Stakeholder interviews NHS Sustainability Tool</td>
</tr>
<tr>
<td>3c IMPACT AND CAPACITY BUILDING</td>
<td>What linkages have been established between Key Workers / AA and education and research organisations?</td>
<td>Formal partnerships / have been developed</td>
<td>KWP progress reports Stakeholder interviews Victorian Health Partnerships Analysis Tool</td>
</tr>
<tr>
<td>3d GENERALISABILITY</td>
<td>Do the results of the evaluation indicate a preferred model for implementing evidence-based practice for the Key Worker role in supporting people with younger onset dementia?</td>
<td></td>
<td>KWP progress reports Stakeholder interviews</td>
</tr>
</tbody>
</table>
### Appendix 2 Evaluation process changes and where documented.

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<tbody>
<tr>
<td>1. AA KWP Progress report</td>
<td>In place</td>
<td>→*</td>
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</tr>
<tr>
<td>2. Goal Attainment Scale</td>
<td>In place</td>
<td></td>
<td>→</td>
<td>→</td>
<td>→</td>
</tr>
<tr>
<td>3. Site Visits</td>
<td>-</td>
<td>Introduced</td>
<td>→</td>
<td>→</td>
<td>→</td>
</tr>
<tr>
<td>4. Client Assessment</td>
<td>In place</td>
<td>Revised</td>
<td></td>
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<td>→</td>
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<tr>
<td>5. Carer Assessment</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Introduced</td>
<td>→</td>
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<tr>
<td>6. Stakeholder interviews</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>Introduced</td>
<td>→</td>
</tr>
<tr>
<td>9. Staff establishment profile</td>
<td>In place</td>
<td>Revised</td>
<td></td>
<td>→</td>
<td>Revised: internal reports</td>
</tr>
<tr>
<td>10. Issues and Lessons</td>
<td>-</td>
<td>Introduced</td>
<td>Revised</td>
<td>→</td>
<td>Revised: Confluence</td>
</tr>
<tr>
<td>11. Client Satisfaction</td>
<td>-</td>
<td>Introduced</td>
<td></td>
<td>→</td>
<td>Revised: Compilation State &amp; Territory data</td>
</tr>
<tr>
<td>12. Carer Satisfaction</td>
<td>-</td>
<td>Introduced</td>
<td></td>
<td>→</td>
<td>Unclear</td>
</tr>
<tr>
<td>13. Key Service Attributes</td>
<td>-</td>
<td>Introduced</td>
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</table>

*Legend: → = continues*
### Appendix 3 National stakeholder interviews - questions

<table>
<thead>
<tr>
<th>Consumers</th>
<th>Government bodies</th>
<th>Industry providers</th>
<th>KW Program management</th>
<th>KW Tls and staff</th>
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</thead>
<tbody>
<tr>
<td><strong>1. Program rationale, design and management</strong></td>
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<tr>
<td>What is the role of your agency in regard to people with younger onset dementia?</td>
<td>What is the role of your service in regard to people with younger onset dementia?</td>
<td>What is the role of your service in regard to people with younger onset dementia?</td>
<td>What is the role of your service in regard to people with younger onset dementia?</td>
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<tr>
<td>As far as you are aware why was Key Worker program structured in the way that it was e.g. in terms of funding, selection of Alzheimer’s Australia to deliver program?</td>
<td>As far as you are aware why was Key Worker program structured in the way that it was e.g. in terms of funding, selection of Alzheimer’s Australia to deliver program?</td>
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</tr>
<tr>
<td>Do you have any comments about how the Key Worker program has been managed?</td>
<td>Do you have any comments about how the Key Worker program has been managed?</td>
<td>Do you have any comments about how the Key Worker program has been managed?</td>
<td>Do you have any comments about how the Key Worker program has been managed?</td>
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</tr>
<tr>
<td>To what extent is the Key Worker designed to meet individual, and community, needs?</td>
<td>To what extent is the Key Worker designed to meet individual, and community, needs?</td>
<td>To what extent is the Key Worker designed to meet individual, and community, needs?</td>
<td>To what extent is the Key Worker designed to meet individual, and community, needs?</td>
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</table>

<p>| <strong>2. Operational factors: impact, efficiency and effectiveness</strong> | | | | |
| What is your experience of the Key Worker program? | What is your opinion of the Key Worker program? | What is your opinion of the Key Worker program? | What is your opinion of the Key Worker program? |
| How has the Key Worker program assisted you (person with younger onset dementia, carer, family member)? | Does your organisation have any specific links with the Key Worker program? | | |
| In your opinion, what has the program achieved? | In your opinion, what has the program achieved? | In your opinion, what has the program achieved? | In your opinion, what has the program achieved? |
| In your view has the program been successful and, if so, why do you think that is so? | In your view has the program been successful and, if so, why do you think that is so? | In your view has the program been successful and, if so, why do you think that is so? | In your view has the program been successful and, if so, why do you think that is so? |
| Have you experienced delays in accessing Key Worker services? If so, why do you think this | | | |
| Have there been delays in accessing and/or liaising with Key Worker services, and if so, can | Have there been delays in accessing and/or working with Key Worker services? | Have there been delays in establishing the Key Worker services? If so, why |</p>
<table>
<thead>
<tr>
<th>Consumers</th>
<th>Government bodies</th>
<th>Industry providers</th>
<th>KW Program management</th>
<th>KW TLs and staff</th>
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<tr>
<td>occurred, and what impact did the delays have?</td>
<td>you explain why this has occurred?</td>
<td>If so, why do you think this occurred, and what impact did the delays have?</td>
<td>do you think this occurred, and what impact did the delays have?</td>
<td></td>
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<tr>
<td>Do you think the program is worth the amount of money it costs?</td>
<td>Do you think the program was worth the amount of money it cost?</td>
<td>Do you think the program was worth the amount of money it cost?</td>
<td>Do you think the program was worth the amount of money it cost?</td>
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</table>

### 3. Relationships, working with others and capacity building

| What other services (other than the Key Worker program) are you aware of that seek to support people with younger onset dementia, their families and carers? | What other services (other than the Key Worker program) are you aware of that seek to support people with younger onset dementia? | What other services (other than the Key Worker program) are you aware of that seek to support people with younger onset dementia? | What other services (other than the Key Worker program) are you aware of that seek to support people with younger onset dementia? |  |
| Are you using any of these other services? Did you know about and/or use these services prior to the involvement of the Key Worker? | What linkages are there between Key Worker program and other programs within and outside your portfolio? | What linkages are there between Key Worker program and other programs within and outside your portfolio? |  |  |
| Consumer representatives only: In what ways has knowledge gained from the Key Worker program been shared across your agency? | In what ways has knowledge gained from the Key Worker program been shared across your service? | In what ways has knowledge gained from the Key Worker program been shared across your service? |  |  |
| What have you learnt as a result of this program (e.g., skills, knowledge, networks)? | What do you think has been learnt from developing and implementing this program? | What do you think has been learnt from developing and implementing this program? | What do you think has been learnt from developing and implementing this program? |  |
| How would you describe your relationship with the Key Worker program i.e., Networking; Coordinating; Cooperating; Collaboration? 36 | How would you describe your relationship with the Key Worker program i.e., Networking; Coordinating; Cooperating; Collaboration? | How would you describe your relationship with the Key Worker program i.e., Networking; Coordinating; Cooperating; Collaboration? | How would you describe your relationship with other services that you work with? i.e., Networking; Coordinating; Cooperating; Collaboration? |  |

### 4. Program sustainability, barriers and enablers and unintended consequences

| Do you have any | Do you have any | Do you have any | Do you have any |

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<table>
<thead>
<tr>
<th>Consumers</th>
<th>Government bodies</th>
<th>Industry providers</th>
<th>KW Program management</th>
<th>KW Tls and staff</th>
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</thead>
<tbody>
<tr>
<td>comments about the role of the Key Worker program in relation to current aged care and disability reforms, e.g., National Disability Insurance Scheme?</td>
<td>comments about the role of the Key Worker program in relation to current aged care and disability reforms, e.g., National Disability Insurance Scheme?</td>
<td>comments about the role of the Key Worker program in relation to current aged care and disability reforms, e.g., National Disability Insurance Scheme?</td>
<td>comments about the role of the Key Worker program in relation to current aged care and disability reforms, e.g., National Disability Insurance Scheme?</td>
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</tr>
<tr>
<td>From your agency’s perspective, what are the barriers and enablers to delivering the Key Worker program currently, and into the future?</td>
<td>From your service’s perspective, what are the barriers and enablers to delivering the Key Worker program currently, and into the future?</td>
<td>From your perspective, what are the barriers and enablers to delivering the Key Worker program currently, and into the future?</td>
<td>From your perspective, what are the barriers and enablers to delivering the Key Worker program currently, and into the future?</td>
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<tr>
<td>How sustainable is the Key Worker program?</td>
<td>How sustainable is the Key Worker program?</td>
<td>How sustainable is the Key Worker program?</td>
<td>How sustainable is the Key Worker program?</td>
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<tr>
<td>What do you think needs to be done to make the program sustainable?</td>
<td>What do you think needs to be done to make the program sustainable?</td>
<td>What do you think needs to be done to make the program sustainable?</td>
<td>What do you think needs to be done to make the program sustainable?</td>
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</tr>
<tr>
<td>Have you experienced any unintended consequences from the Key Worker program?</td>
<td>Have there been any unintended consequences arising from the Key Worker program?</td>
<td>Have there been any unintended consequences for your service arising from the Key Worker program?</td>
<td>Have there been any unintended consequences arising from the Key Worker program?</td>
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<tr>
<td>If you were designing a future program to support people with younger onset dementia what would it look like?</td>
<td>If you were designing a future program to support people with younger onset dementia what would it look like?</td>
<td>If you were designing a future program to support people with younger onset dementia what would it look like?</td>
<td>If you were designing a future program to support people with younger onset dementia what would it look like?</td>
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<tr>
<td>Do you have any other comments regarding the Key Worker Program?</td>
<td>Do you have any other comments regarding the Key Worker Program?</td>
<td>Do you have any other comments regarding the Key Worker Program?</td>
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Appendix 4 Development of KWP Assessment tools

At the commencement of the evaluation, there was an expectation that the Program would be underpinned by common data elements and collection processes, which in turn could be aggregated and analysed for the evaluation. The Program collects data on a range of activity measures which are reported regularly to the Department. There is less consistency, however, in the data that is collected on outcomes for clients with the primary tool being used in the program being the Goal Attainment Scale. While work has progressed to clarify the additional assessment measures, these have not been sufficiently developed for use in a nationally consistent manner. Consequently, the evaluation team agreed to work with the Program team to identify and/or develop a suitable evidence-based assessment tool for use nationally.

The CHSD has a long history of research and development of assessment tools for use within aged and community care contexts, and these have provided an important basis from which to start the development of an assessment tool for the Key Worker Program. Consideration of appropriate tools was led by A/Prof Jan Sansoni, Director, Australian Health Outcomes Collaboration in conjunction with the CHSD project team. The process involved clarification of the domains for assessment in conjunction with the GM- Policy and Programs within AA National Office, feedback from the KWP Team Leaders via their nominated representative, together with the KWP Evaluation Steering Committee. Of primary concern for consumer representatives on the Evaluation Steering Committee was that people with dementia ‘drive’ their own support and care planning processes, rather than be ‘driven by’ the traditional service options available.

As noted above, the Goal Attainment Scale (GAS) was the only agreed standardised tool being used within the KWP. In line with the consumer-directed nature of the KWP, the GAS is a mechanism for identification of clients’ goals or aspirations but it does not include a comprehensive assessment of need. While each jurisdiction used some form of needs assessment, the absence of a common approach posed challenges for national service development and quality assurance as well as the evaluation. The value from an individual client perspective is equally important; it not only enables KWs to undertake a stocktake of a range of factors that can impact on quality of life for people with younger onset dementia, but it also addresses the changes in cognition and perception of need that develops over time. For example, Bakker’s work in the Netherlands highlighted the disparity in perceptions of need between clients with younger onset dementia and their carers, with clients generally reporting fewer unmet needs than carers. The research showed that while there was generally agreement between the two groups regarding a person’s need for support around concrete issues such as medication use and incontinence, there was less agreement about need of areas which required a higher level of cognitive functioning, such as insights into abuse or neglect, accidental or deliberate self-harm, food and memory and intimate relationships. Furthermore, over time clients reported significant decrease in areas of unmet needs, where carers did not.

Consequently, it was recommended that Key Workers be able to identify the client and carer perspectives on unmet need separately at the initial contact and also to regularly revisit and review this during the disease trajectory as the needs, and symptoms of dementia, change over time. The proposed assessment tool, therefore, needed to have the capacity to capture both the client’s perspective of need, as well as the carer’s perspective of the client’s need.
The following domains were considered to be core elements for any assessment tool used by the KWP: physical, wellbeing, social and meaningful activity, relationships and sexuality, financial and legal, services and carer and family. Following a number of iterations and considerations of psychometric properties of proposed tools, an assessment structure was agreed, comprising the following tools:

- **Assessment of Needs Scale – Younger Onset Dementia (ANS-YOD):** (J Sansoni, A Westera, C Duncan and L Carlson 2014). This is a 28 question tool developed by CHSD specifically for the Key Worker Program. The ANS-YOD collects information across a broad range of domains that are important for people with younger onset dementia and their carers. This information forms the basis of the care plan the Key Worker will develop for the client. The ANS-YOD is based on a selection of items/topics from the Camberwell Assessment of Need Short Appraisal Schedule – CANSAS, the Camberwell Assessment of Needs of the Elderly (CANE) and other items included by CHSD and Key Worker representative. There is a client ANS-YOD which is to be completed by the KW in consultation with the person with YOD and a ‘carer perspective of client need’ version of the same tool.

- **Friendship Scale:** This is a six item tool developed to measure social isolation and participation, and will be applicable for clients as well as carers.

- **Kessler 10 (Modified):** A ten question tool to identify depression and anxiety. The tool comprises ten questions each with five scored possible responses. The modification is that two initial ‘screening questions’ have been chosen from the scale to identify if further completion of the tool is recommended.

- **Health status:** One question from the 36 item Health Survey developed at RAND as part of its Medical Outcomes Study (MOS).

- **The Zarit Burden Interview:** Short version. This is a 12 question scale designed to measure carer burden and was used by a number of the research papers included in the recently concluded international literature review on younger onset dementia.

- **Client satisfaction – using the Short Assessment of Patient Satisfaction instrument (SAPS)** which contains 7 questions. The scale has been slightly modified to make it more applicable to assess satisfaction with the services provided by the Key Worker. The tool is to be provided to clients and carers and completed independently of the KW, with confidential responses directed to the evaluation team via a pre-paid return address envelope provided with the survey.

It was proposed that client assessments be undertaken using these validated tools, and conducted by Key Workers using a guided conversation with individual clients. Parallel to this, it was proposed that carers provide their views on the needs of their relative/friend, using the ANS-YOD (carer), Kessler 10 and health status questions. Carer needs would also be assessed using questions from the Zarit Burden Interview and Friendship Tool. Together, these two perspectives would be used to assist in establishing goals as well as care planning for both the client and their carer/family situation.

The nature of the data being collected was beyond the scope of what was then available in the existing client management system used by AA, requiring the Evaluation Team to identify a suitable on-line data collection tool to underpin the Key Worker Program while further work
was done to develop data collection within the existing Client Management System. The RedCap (Research Electronic Data Capture) software (see http://www.project-redcap.org/) was chosen for its ability to capture data in a relatively user-friendly manner, while at the same time ensuring client confidentiality. The assessments will be individually coded, to ensure client anonymity while at the same time enabling data linkage and monitoring of trends. Data is stored on secure servers at the University of Wollongong, with no one outside the Program and the evaluation team members able to access these data.

A pilot implementation was planned to commence on 1 September 2014 and a training session for Key Worker Team Leaders was held the week prior in Brisbane. Following significant concerns raised at the session, training was postponed and further discussion regarding the assessment tools deferred to the next meeting of the State and Territory National Program Manager Working Group meeting. Agreement was reached to pilot the tools commencing in early October 2014 however there was not agreement on the inclusion of the Zarit, Kessler and Friendship scales. There was a consensus view that these tools had the potential to pose a risk to the client-key worker relationship and therefore may not appropriate for this program. At this time there was agreement regarding the need for the development of a Carer Assessment tool that could be used in a similar manner to the ANS-YOD.

Consequently, the new assessment process was refined and the pilot commenced from 1 October 2014. The tools being piloted were the client related tools: one for the Key Worker to complete in consultation with the client, and the second being the ‘Carer perspective of client need’ to be completed by the carer. The ANS-YOD tools (both versions) include 28 questions across three broad categories:

**Living arrangements:** Accommodation; Food; Looking after the home; Telephone and communication; Caring for another; Safety issues for self and to others; Money management and benefits.

**Health and care:** Self Care; Physical Health; Care needs; Sensory difficulties; Sleep and Memory; Psychological symptoms and distress; Continence/difficulty using toilet; Medication management; Information on condition and treatment;

**Participation and meaning:** Meaningful activities and employment; Social activities; Mobility and transport; Alcohol, cigarettes, illicit drugs; Intimacy and self-expression;

Six possible responses were provided, with room for additional commentary and/or information:
- No need
- Met Need
- Unmet Need (please specify)
- Need identified, but client declines action
- Not asked
- Unable to be asked

The pilot did not continue through to a formal evaluation, as the NPWG agreed in late 2014 that the ANS-YOD would be integrated within TCM for routine use. At this time it was also
apparent that there was no consensus nationally regarding the use of the ANS-YOD Carer Perspective tool, and progress in promoting its use was halted.

Importantly, the KWP has reiterated the role of the ANS-YOD and the ANS-CYOD as decision support tools; that is, they are designed to guide assessors to ask the questions and capture the information which is needed to form a judgement about the needs of the client, and the most appropriate response to support them to live as independently as possible in the community. The questions and domains have been designed to elicit information which, when entered into TCM, has the potential to categorise care needs and classify priorities as well as triggering areas for assessors to consider exploring further with the applicant such as how recent stressful events may contribute to the reasons for their current emotional state.

Subsequent to the development of the ANS-YOD, the evaluation team commenced on identifying appropriate domains and questions for inclusion in a carer/family assessment process for use within the program. An initial scan of carer assessment processes being used across the program found that teams were using a range of both structured and unstructured assessment tools and processes to identify the supports and services of carers and families, most of which reflected the local service culture and context.

In December 2014, a proposal from the evaluation team was presented to AA National Office to research, consult, develop and pilot a suitable carer assessment tool for use within the program; the proposal included implicit acknowledgement for the significant work that the evaluation team had previously undertaken in developing the ANS-YOD. The expectation was that the new carer assessment tool would operate in parallel to the ANS-YOD, and its development would similarly draw on the international evidence regarding carer assessment tools.

With the assistance of A/Prof Janet Sansoni, Director, Australasian Health Outcomes Centre within AHSRI, we identified draft domains of assessment, and consulted members of the NPMWG as well as State and Territory KWP Team Leaders regarding the appropriateness, priority and framing of proposed domains and example questions. Agreement was reached, and the composite tool called the Assessment for Needs and Services – Carers of people with Younger Onset Dementia (ANS-CYOD) was incorporated within TCM for use nationally (except South Australia, which continues to use the RedCap system). As with the ANS-YOD, this assessment information is expected to be obtained through exploratory conversation style interaction with carers; the suggestions provided in the tool are not a script, but rather prompts to assist Key Workers consider the various aspects associated with caregiving that may inform the overall care plan/s for the person with YOD and their carer/s. The tool addresses four key domains: health and well-being; relationships; practical issues; and, information. Each domain has a set of questions to assist explore underlying issues:

- Personal health and well-being
- Relationships
- Practical Issues
- Information

A pilot period was initially anticipated, however given the successful implementation of the ANS-YOD, and the consensus about the need for, and substance of, the carer assessment tool, the NPMWG members agreed that it be incorporated into routine practice from the outset.
Appendix 5 Assessment of Needs and Services – Younger Onset Dementia (ANS-YOD)

Key Workers may find it useful for themselves to make notes as they go through the ANS-YOD to enable them to gather a full picture of the client’s situation; e.g.: a note that the client lives in rental accommodation and that this isn’t a sustainable situation

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<thead>
<tr>
<th></th>
<th><strong>Accommodation</strong></th>
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</table>
| 1 | Does your accommodation require any changes to meet your needs? | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |

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<thead>
<tr>
<th></th>
<th><strong>Food</strong></th>
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| 2 | Do you have any needs related to your food/diet? (Consider food preparation issues and the management of hydration) | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |

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<tr>
<th></th>
<th><strong>Looking after the home</strong></th>
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</table>
| 3 | Do you need any assistance in looking after your home? (Consider safety issues) | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |

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<tr>
<th></th>
<th><strong>Self-care</strong></th>
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| 4 | Do you need some help in keeping yourself clean and tidy? | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |

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<tr>
<th></th>
<th><strong>Meaningful activities and employment</strong></th>
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</table>
| 5 | Do you have enough meaningful daytime activities or do you need more? (Consider opportunities for volunteering or employment) | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |

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<tr>
<th></th>
<th><strong>Physical Health</strong></th>
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</table>
| 6 | Do you have any physical health problems that you need help with? (Consider whether there is a need for an Advanced Health/Care Directive or similar) | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |

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<tr>
<th></th>
<th><strong>Information on condition and treatment</strong></th>
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</table>
| 7 | Do you need more information about your condition, treatment or care? | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |

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<thead>
<tr>
<th></th>
<th><strong>Sensory difficulties</strong></th>
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| 8 | Do you have any problems with your eyesight or hearing or speech? If so do you need any help with this? | No need  
Met Need  
Unmet Need (please specify)  
Need identified, but client declines action  
Not asked,  
Unable to be asked |
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<th>9a</th>
<th>Continenace</th>
<th>Do you experience any form of incontinence? If so, do you need any help to address this problem? (Consider toileting issues more generally)</th>
<th>No need</th>
<th>Met Need</th>
<th>Unmet Need (please specify)</th>
<th>Need identified, but client declines action</th>
<th>Not asked, Unable to be asked</th>
</tr>
</thead>
<tbody>
<tr>
<td>9b</td>
<td>Toileting</td>
<td>Do you experience difficulty using the toilet at home or when in the community? If so, do you need any help to address this problem?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>10</td>
<td>Psychological symptoms</td>
<td>Do you ever hear imaginary voices, see imaginary things or have problems with your thoughts? If so, do you need help to address these problems?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>11</td>
<td>Psychological distress</td>
<td>Have you recently felt sad or depressed or had thoughts about self-harm? If so, do you need help to deal with this?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>12</td>
<td>Sleep</td>
<td>Do you experience difficulties with your sleep? If so, do you need any help with this?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>13</td>
<td>Memory</td>
<td>Do you have problems with your memory and if so, do you need some help with this?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>14</td>
<td>Safety Issues</td>
<td>Do you ever do things or have accidents (e.g. falls) that cause some harm to yourself? If so, do you need some help to cope with this?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>15</td>
<td>Safety to others</td>
<td>Do you think you could be a danger to other people's safety? If so, do you need help with this?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>16</td>
<td>Care Needs</td>
<td>Do you feel you receive adequate care or do you need more help with this?</td>
<td>No need</td>
<td>Met Need</td>
<td>Unmet Need (please specify)</td>
<td>Need identified, but client declines action</td>
<td>Not asked, Unable to be asked</td>
</tr>
<tr>
<td>17a</td>
<td>Alcohol use</td>
<td>Does alcohol use cause you any problems? If so, do you need any help to address this?</td>
<td>No need</td>
<td>Met Need</td>
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<td></td>
<td>so, do you need any help with this?</td>
<td>Unmet Need (please specify)</td>
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<td>17b</td>
<td>Cigarette use</td>
<td>No need</td>
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<td></td>
<td>Does cigarette use cause you any problems? If so, do you need any help with this?</td>
<td>Met Need</td>
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<td>17c</td>
<td>Illicit drug use</td>
<td>No need</td>
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<td></td>
<td>Does illicit drug use cause you any problems? If so, do you need any help with this?</td>
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<td>18</td>
<td>Medication management</td>
<td>No need</td>
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<td>Can you manage your medication or do you need help with this? (Also consider any non-prescription medications)</td>
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<td>Company</td>
<td>No need</td>
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<td></td>
<td>Are you happy with your social life? If not, do you require more social activities?</td>
<td>Met Need</td>
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<td>20</td>
<td>Intimacy</td>
<td>No need</td>
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<td>Is there sufficient intimacy in your close relationships or do you need more? If so, do you need some help with this?</td>
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<td>21</td>
<td>Self-Expression</td>
<td>No need</td>
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<td>Do you have any concerns regarding your ability to express yourself (e.g., by choosing the type of clothes you wear, friends you see, etc.?) If so, do you need some help with this?</td>
<td>Met Need</td>
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<td>22</td>
<td>Caring for an other</td>
<td>No need</td>
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<td>Do you provide care to someone else? If so do you need help with this?</td>
<td>Met Need</td>
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<td>23</td>
<td>Mobility</td>
<td>No need</td>
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<td></td>
<td>Do you have any problems moving around their home or in the community? If so, do you require help with this?</td>
<td>Met Need</td>
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<td>Unmet Need (please specify)</td>
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<td>24</td>
<td>Transport</td>
<td>No need</td>
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<td></td>
<td>How do you find using the bus, train or tram?</td>
<td>Met Need</td>
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<td></td>
<td>Do you need any help in getting to places?</td>
<td>Unmet Need (please specify)</td>
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<td></td>
<td>Need identified, but client declines action</td>
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<td></td>
<td>Question</td>
<td>Not asked, Unable to be asked</td>
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<tr>
<td>25</td>
<td><strong>Telephone</strong>&lt;br&gt;Can you use the telephone or if not, do you need help to manage this?</td>
<td>No need&lt;br&gt;Met Need&lt;br&gt;Unmet Need (please specify)&lt;br&gt;Need identified, but client declines action&lt;br&gt;Not asked, Unable to be asked</td>
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<td>26</td>
<td><strong>Communication</strong>&lt;br&gt;Do you experience any difficulties in communicating with others? If so, do you need help with this? (Also consider cultural background and whether they experience any difficulty reading, writing or understanding English)</td>
<td>No need&lt;br&gt;Met Need&lt;br&gt;Unmet Need (please specify)&lt;br&gt;Need identified, but client declines action&lt;br&gt;Not asked, Unable to be asked</td>
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<td>27</td>
<td><strong>Money Management</strong>&lt;br&gt;How do you find budgeting and managing your money? Do you need any help with this? (Consider Power of Attorney issues)</td>
<td>No need&lt;br&gt;Met Need&lt;br&gt;Unmet Need (please specify)&lt;br&gt;Need identified, but client declines action&lt;br&gt;Not asked, Unable to be asked</td>
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<tr>
<td>28</td>
<td><strong>Benefits</strong>&lt;br&gt;Are you getting all the money you are entitled to? Do you need help in finding out about and applying for benefits you may be eligible for?</td>
<td>No need&lt;br&gt;Met Need&lt;br&gt;Unmet Need (please specify)&lt;br&gt;Need identified, but client declines action&lt;br&gt;Not asked, Unable to be asked</td>
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<td>29</td>
<td><strong>Other</strong>&lt;br&gt;Is there anything else you would like assistance with?</td>
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</tbody>
</table>
Appendix 6 Assessment of Needs Scale – Carers of people with Younger Onset Dementia (ANS-CYOD)

**a) Personal health and well-being**

<table>
<thead>
<tr>
<th>1. Physical Health</th>
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<tbody>
<tr>
<td>Do you have any health issues that interfere with your normal activities (outside and/or inside the home)?</td>
<td>Yes</td>
</tr>
<tr>
<td>If yes, how much did your health interfere with these activities during the past four weeks?</td>
<td>Not at all</td>
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<tr>
<td>If moderately or quite a bit, provide details.</td>
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<table>
<thead>
<tr>
<th>2. Sleep</th>
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<tbody>
<tr>
<td>Do you experience difficulties with your sleep?</td>
<td>Yes</td>
</tr>
<tr>
<td>If yes, provide details. (May require discussion of potential options to improve sleep patterns; consider sleep loss as a possible symptom of depression/anxiety and potential referral to GP/mental health professional)</td>
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<tr>
<th>3. Psychological and wellbeing – mood</th>
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<tbody>
<tr>
<td>In the past 4 weeks about how often did you feel</td>
<td></td>
</tr>
<tr>
<td>- Sad or depressed</td>
<td>None of the time</td>
</tr>
<tr>
<td>- noticed changes in the way you emotionally react to situations</td>
<td>None of the time</td>
</tr>
<tr>
<td>- had thoughts about self-harm?</td>
<td>None of the time</td>
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<tr>
<td>If the answer to any of these is “Some of the Time” or more, consider referral to mental health professional</td>
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<tr>
<th>4. Memory</th>
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<tbody>
<tr>
<td>Do you have problems with your memory (Some carers may be fearful that they also have dementia)</td>
<td>Yes</td>
</tr>
<tr>
<td>If Yes do you think that you may need some assistance with this?</td>
<td>Yes</td>
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<tr>
<td>If yes, what sort of assistance would be best?</td>
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<tr>
<th>5. Adjustment to caring role</th>
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<tr>
<td>Have you had difficulties adjusting to taking on your caring role?</td>
<td>Yes</td>
</tr>
<tr>
<td>Explore possible unresolved issues of grief and loss, feeling undervalued</td>
<td></td>
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<tr>
<td>If yes, do you need some assistance with this?</td>
<td>Yes</td>
</tr>
<tr>
<td>If yes, what sort of assistance would be best?</td>
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<th>6. Routine activities</th>
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<tr>
<td>Are you able to continue with your usual routine / activities along with</td>
<td>Yes</td>
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</tbody>
</table>
your caring responsibilities?  [ ] No
If No, provide details

7. Positive care giving aspects
What would you say are the positive aspects about being a carer?
Do you need assistance to maintain and/or build on these, or develop new approaches and/or skills?

8. Future goals
Are you able to identify any goals that you yourself would like to achieve in the near future?

- [ ] Yes
- [ ] No

Lack of future goals can be an indicator of depression
If Yes, what are they

9. Drug and Alcohol use
Does alcohol use cause you any problems?

- [ ] Yes
- [ ] No
If yes, do you need any assistance with this?

- [ ] Yes
- [ ] No
If yes, what would help

Does illicit drug use cause you any problems?

- [ ] Yes
- [ ] No
If yes, do you need any assistance with this?

- [ ] Yes
- [ ] No
If yes, what would help

b) Relationships

10. Family Relationships
Have the changes that arise from you now being a carer caused distress, strain and or friction / conflict in your relationships with the person with younger onset dementia or close family members / friends?

- [ ] No obvious problem
- [ ] Slight problems
- [ ] Moderate problems
- [ ] Extreme problems
If problems, specify with whom

- [ ] Other family members.
- [ ] Person with YOD
Details

11. Social isolation
Do you feel isolated from your friends / social networks?

- [ ] Yes
- [ ] No
Do you require some assistance to enable you to stay connected to others?

- [ ] Yes
- [ ] No
If Yes, What would help

12. Intimacy (for partners of YOD clients)
Have there been any changes in your intimate relationship?

- [ ] Yes
- [ ] No
If so, do you need some counselling or support to talk through this?

- [ ] Yes
- [ ] No
If yes, what help would assist

13. Communication / Health literacy
Are you having difficulty communicating with the person you are caring for?

- [ ] Yes
- [ ] No
Do you experience any difficulties in communicating with others (e.g., health professionals, service providers)?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>If so, do you need assistance with this?</td>
<td>Yes</td>
<td>No</td>
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<tr>
<td>If yes, what help would assist?</td>
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### 14. Sustainability - Assessor judgement

Taking into account all information available to you, is the carer relationship sustainable without additional services or support?

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<thead>
<tr>
<th></th>
<th>No - carer relationship likely to break down within weeks to months</th>
<th>No - carer relationship likely to break down within the next year</th>
<th>Yes - carer relationship is sustainable without additional support</th>
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</table>

### c) Practical Issues

Note: This may have already been collected in the process of completing the ANS-YOD. Only ask these questions if you suspect the carer may have different responses

#### 15. Accommodation

Do you have stability in your current accommodation arrangements?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
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If No, provide details

Does your accommodation require any changes to meet your needs?

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<th></th>
<th>Yes</th>
<th>No</th>
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If Yes, provide details

#### 16. Looking after the home

Do you need any assistance in looking after your home?

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<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Consider safety issues, garden, housework

If Yes, provide details

#### 17. Care Tasks (personal care, previous ‘roles’ in the relationship etc.)

Do you have any difficulties assisting the person you care for with personal care tasks such as showering / dressing or tasks they may have done previously such as cooking or home maintenance?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If Yes, provide details

#### 18. Transport

Are there any difficulties with current transport options for you and the person you are caring for?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If Yes, provide details

#### 19. Finances

Are your current financial arrangements adequate?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If No, provide details

#### 20. Benefits / Superannuation (carer payment / pension / superannuation)

Are you confident that you are getting all the financial support you may be entitled to?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
</table>

If no or not sure; do you need assistance in finding out about and applying for benefits you may be eligible for?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

If yes, what type of help do you need
21. Meaningful activities
Do you need assistance with organising meaningful activities for the person you care for?  
☐ Yes  ☐ No
If yes, what type of help do you need

22. Caring for an other
Do you provide care to someone else as well as the person with younger onset dementia?  
☐ Yes  ☐ No
If yes, who are they
If yes, do you need assistance with this?  
☐ Yes  ☐ No

**d) Information**

*Nb. Response to Q13 Communication may inform this series of questions*

23. Information on condition and treatment
Are you confident that you have enough information about Younger Onset Dementia and what to expect?  
☐ Yes  ☐ No  ☐ Not sure
Consider information regarding other health conditions the person with YOD may have
If No or Not sure, explore what information is needed

24. Behaviour
Have you noticed any changes in the behaviour of the person you care for?  
☐ Yes  ☐ No
If yes, what level of support is required to address this behaviour?  
☐ High level of support  ☐ Medium level of support  ☐ Low level of support  ☐ No support required
Do you require further assistance to manage the behaviour of the person you care for?  
☐ Yes  ☐ No
If yes, what type of assistance would you like?

25. Emergency Care Plan
Do you have an emergency care plan in place if something happens to you?  
☐ Yes  ☐ No
If no, consider what assistance the carer requires to develop an emergency care plan

26. Enduring Power of Attorney
Do you have enduring power of attorney for the person you are caring for?  
☐ Yes  ☐ No
If No do you need any assistance with arranging this?  
☐ Yes  ☐ No
Enduring Power of Attorney in some states covers life / medical decisions as well as finances.
What sort of assistance would be best?

27. Enduring Guardianship
Are you the legal guardian of the person you are caring for?  
☐ Yes  ☐ No
If No, Have you considered making arrangements to become a legally appointed guardian
In some states, an Enduring Power of Attorney includes life / medical decisions as well as finances. Application to the relevant Guardianship Tribunal or other legal process may be required
### e) Support Needed

28. What kind of support would make the biggest difference for the future?

*Consider referral to a wide range of support services*

<table>
<thead>
<tr>
<th>Type of assistance (what)?</th>
<th>For who – carer or person with YOD?</th>
<th>Who from (e.g. agency, family, friends?)</th>
<th>How often (hrs/wk)?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

29. Service System

Do you need assistance getting the right services and support?  
☐ Yes  
☐ No

If No, what assistance would be best

### f) Burden

*NB: The following four questions are optional*

30. Zarit Carer Screen

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you feel that because of the time you spend with the person with YOD that you don’t have enough time for yourself?</td>
<td>(1) Never; (2) Rarely; (3) Sometimes; (4) Quite frequently; (5) Nearly always</td>
</tr>
<tr>
<td>Do you feel stressed between caring for the person with YOD and trying to meet other responsibilities for your family or work?</td>
<td>(1) Never; (2) Rarely; (3) Sometimes; (4) Quite frequently; (5) Nearly always</td>
</tr>
<tr>
<td>Do you feel strained when you are around the person with YOD?</td>
<td>(1) Never; (2) Rarely; (3) Sometimes; (4) Quite frequently; (5) Nearly always</td>
</tr>
<tr>
<td>Do you feel uncertain about what to do about the person with YOD?</td>
<td>(1) Never; (2) Rarely; (3) Sometimes; (4) Quite frequently; (5) Nearly always</td>
</tr>
</tbody>
</table>

Subtotal

*If score is 9 or over, consider referral to specialist carer support service*

31. Other

Is there anything else you would like assistance with?  
☐ Yes  
☐ No

If Yes, what is it?
Appendix 7 Impacts and outcomes for people with younger onset dementia, carers and families

Profile of KWP clients
Recent figures from Deloitte Access Economics estimated that in 2011 there were 16,329 people in Australia with Younger Onset Dementia (a diagnosis of dementia under the age of 65; including people as young as 30)\(^\text{37}\). The number of clients that were registered in the KWP at the end of December 2015 was 3,401. This was made up of 1,562 people with YOD and 1,839 carers. For people with YOD this represents approximately 10% of the projected population. The progress of client registration is highlighted in Figure 4. Between years one and two there was an increase in client registrations by approximately 45%. Trend data for the last six months to the end of December 2015 shows that overall the numbers have steadied suggesting that the Program may have reached capacity.

Figure 1 Numbers of clients over time

![Graph showing numbers of clients over time]

The total number of clients registered as of December 2015 per state and territory is shown in Figure 2. NSW and Victoria have the largest number of clients registered and the NT and the ACT have the smallest number.

Of these clients, 18% (n=610) were self-referrals, 14% were from the family/significant others (n=486) and 13% from AA (n= 447). Twenty two percent of referrals were provided by a range of healthcare providers (n=765). Eight percent of these came from general practice (n=272) and 6% from a community care provider (n=190). Other healthcare providers referring to the program included: aged care assessment teams, acute care providers, multi-purpose respite services, mental health services, medical specialists and residential aged care.

With regards to where the clients came from, just over two thirds came from metropolitan areas (n=2,355) and almost a third of clients came from regional or remote areas (n=1,003). In terms of reach, 329 people with YOD came from other special needs group (21%) as highlighted in Table 1.

**Table 1  People with YOD with special needs**

<table>
<thead>
<tr>
<th>Special needs group</th>
<th>Number</th>
<th>Percentage of all dementia clients</th>
</tr>
</thead>
<tbody>
<tr>
<td>People from culturally and linguistically diverse backgrounds</td>
<td>219</td>
<td>14%</td>
</tr>
<tr>
<td>People that identify as Aboriginal and/or Torres Strait Islander</td>
<td>15</td>
<td>0.9%</td>
</tr>
<tr>
<td>People who identify as Lesbian, Gay, Bisexual, Transgender and/or Intersex</td>
<td>15</td>
<td>0.9%</td>
</tr>
<tr>
<td>Prisoners</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>People experiencing homelessness</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>People living alone</td>
<td>50</td>
<td>3.2%</td>
</tr>
<tr>
<td>People with other chronic conditions</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>People with another form of cognitive disability who may be at a higher risk of younger onset dementia</td>
<td>30</td>
<td>1.9%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>329</td>
<td>20.7%</td>
</tr>
</tbody>
</table>

Almost 90% of clients with YOD had a confirmed diagnosis of dementia at the time of referral (n=1,406). These diagnoses came mostly from neurologists (23%) and geriatricians (21%). Of the clients diagnosed, just over 40% (n=655) had been diagnosed with Alzheimer’s Disease (AD) and a further 20% (n=311) had Frontal lobe dementia (includes Picks disease).
With regards to people with YOD, almost three quarters were aged between 55 and 69 (n=1307). The clients were very evenly split by gender with 804 males and 778 females participating in the program. Carers, on the other hand, ranged in age from teenagers to clients over the age of 75 with 55% between 55 and 69 (n=1035). Approximately two thirds of carers were female. Just over half of all carers were the partner of the person with dementia and 20% were children (n=375). Of the 328 carers identified as having special needs, two thirds were from a culturally and linguistically diverse background (n=219).

Assessing clients

The program used three evidence based client assessment tools to support care planning (more detailed information about these tools can be found in the Section 2.4:

- Assessment of Needs and Services – Younger Onset Dementia (ANS-YOD) (client and carer perspectives);
- Assessment of Needs and Services – Carers of people with younger onset dementia (ANS-CYOD); and,
- Goal Attainment Scale (GAS).

The relationship between the tools is clearly articulated in the documentation supporting the GAS\textsuperscript{38}:

The first step in the goal setting, planning and attainment process is the completion of a needs assessment ... it is important that the ANS-YOD and the YOD Carer Assessment are completed before working through the GAS tool.

The assessments help identify areas of need as well as ability, which in turn assist in identifying potential goals that are realistic and relevant for the client. Identifying a level of unmet need through the assessment process can assist in motivating clients that may not be initially interested in goal setting.

If the person with YOD has needs that they want to fulfil, then those needs will act as a motivator to set goals to achieve those needs. But if they do not see, or cannot acknowledge potential needs, then this will hinder their pursuit of goals.

Assessed needs of people with YOD

The ANS-YOD was implemented nationally in early 2015 following a brief trial in the months prior. The number of needs assessments carried out during the program is summarised in Table 2. Around two fifths of clients with dementia (43%, n=673) nationally had an initial needs assessment. There is much variation between the states and territories with regards to the number of assessments completed. The most comprehensive use of the ANS-YOD was in Queensland, with 92% of clients having completed assessments; this contrasts with South Australia (21%), Victoria (15%) and Western Australia (14%).

Assessments such as the ANS-YOD are only a snapshot in time, and the real value of these tools is through review and repeat assessment to ensure services continue to be tailored to the needs of clients as well as quality improvement purposes. As with the initial assessment, the

\textsuperscript{38} Alzheimer’s Australia (2015) *Guidelines for Using the Goal Attainment Scale: Goal Planning in Younger Onset Dementia*
implementation of reviews was variable across teams. Around one in eight (13.3%, n=90) clients with dementia had a documented review assessment, ranging from 37% in the NT to less than 4% in NSW and VIC.

### Table 2: People with dementia (needs assessments)

<table>
<thead>
<tr>
<th>State/Territory</th>
<th>Number of assessments</th>
<th>Number of clients assessed</th>
<th>Clients with multiple assessments*</th>
<th>Date range</th>
<th>Total number of clients with dementia</th>
<th>% of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>21</td>
<td>19</td>
<td>2</td>
<td>22/12/2015 to 15/3/2016</td>
<td>32</td>
<td>59%</td>
</tr>
<tr>
<td>NSW</td>
<td>245</td>
<td>236</td>
<td>9</td>
<td>5/8/2014 to 18/4/2016</td>
<td>404</td>
<td>58%</td>
</tr>
<tr>
<td>NT</td>
<td>47</td>
<td>27</td>
<td>10</td>
<td>26/11/2014 to 7/4/2016</td>
<td>34</td>
<td>79%</td>
</tr>
<tr>
<td>QLD</td>
<td>311</td>
<td>213</td>
<td>44</td>
<td>24/7/2014 to 20/4/2016</td>
<td>232</td>
<td>92%</td>
</tr>
<tr>
<td>SA</td>
<td>36</td>
<td>36</td>
<td>0</td>
<td>5/11/2014 to 16/12/2015</td>
<td>180</td>
<td>21%</td>
</tr>
<tr>
<td>TAS</td>
<td>75</td>
<td>57</td>
<td>17</td>
<td>28/10/2014 to 19/4/2016</td>
<td>91</td>
<td>63%</td>
</tr>
<tr>
<td>Vic</td>
<td>64</td>
<td>62</td>
<td>2</td>
<td>27/6/2014 to 30/3/2016</td>
<td>426</td>
<td>15%</td>
</tr>
<tr>
<td>WA</td>
<td>30</td>
<td>23</td>
<td>6</td>
<td>23/10/2014 to 24/8/2015</td>
<td>163</td>
<td>14%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>829</strong></td>
<td><strong>673</strong></td>
<td><strong>90</strong></td>
<td><strong>1562</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The ANS-YOD is used to assess the need of people with dementia and is divided into three domains:

- **Living arrangements**
- **Health and care**
- **Participation and meaning**

**Living arrangements**
The living arrangements domain covers issues such as: accommodation, food, looking after the home, telephone and communication, caring for another, safety issues for self and to others, money management and benefits. The questions in this domain are as follows:

26: Do you experience any difficulties in communicating with others?
28: Are you getting all the money you are entitled to?
1: Does your accommodation require any changes to meet your needs?
14: Do you ever do things or have accidents (e.g. falls) that cause some harm to yourself?
2: Do you have any needs related to your food/diet?
3: Do you need any assistance in looking after your home?
4: Do you need some help in keeping yourself clean and tidy?
27: How do you find budgeting and managing your money?
25: Can you use the telephone or if not, do you need help to manage this?
15: Do you think you could be a danger to other people’s safety?
22: Do you provide care to someone else?

Figure 3 highlights responses to the questions within the ANS-YOD related to these issues in order of areas of most need (as indicated by green and purple bars). Of the responses recorded,
just over 15% (n=123) indicated they required changes to their accommodation situation (Q1) and between 10-13% of people experienced difficulties associated with activities of daily living (Q2, Q3, Q4). Around one-fifth (18%, n=130) needed assistance with financial matters (Q28) and communication (21%, n=159) (Q26). 16% (n=118) had accidentally harmed themselves (Q14).

**Figure 3 Living arrangements**

Health and care
The health and care domain of the ANS-YOD covers areas such as: self-care, physical health, care needs, sensory difficulties, sleep and memory, psychological symptoms and distress, continence/difficulty using toilet, medication management, information on condition and treatment. The questions in this domain are as follows:

13: Do you have problems with your memory?
7: Do you need more information about your condition, treatment or care?
11: Have you recently felt sad or depressed or had thoughts about self-harm?
16: Do you feel you receive adequate care?
12: Do you experience difficulties with your sleep?
8: Do you have any problems with your eyesight or hearing or speech?
6: Do you have any physical health problems that you need help with?
10: Do you ever hear imaginary voices, see imaginary things or have problems with your thoughts?
9a: Do you experience any form of incontinence?
18: Can you manage your medication?
9b: Do your experience difficulty using the toilet at home or when in the community?

Figure 4 highlights responses to the questions within the ANS-YOD related to these issues in order of areas of most need in regards to health and care (as indicated by green and purple bars). Of the responses recorded, just over one-third (37%, n=284) of people with dementia identified problems with their memory (Q13) and almost a quarter (24%, n=183) of respondents wanted further information about dementia, its treatment or care (Q7); a similar amount (24%, n=169) experienced feelings of sadness, depression and self-harm (Q11). Around one in five (n=130) clients experienced difficulties with sleep (Q12) and one in six
(n=122) required additional care to meet their needs (Q16). A similar amount of clients experienced problems with their eyesight, hearing or speech (16%, n=118) (Q8) and physical health problems (15%, n=112) (Q6).

**Figure 4 Health and care and need**

![Health and care and need diagram]

**Participation and meaning**
The participation and meaning domain covers areas such as meaningful activities and employment, social activities, mobility and transport, alcohol, cigarettes, illicit drugs, intimacy and self-expression. The questions in this domain are as follows:

5: Do you have enough meaningful daytime activities?
19: Are you happy with your social life?
24: How do you find using the bus, train or tram?
23: Do you have any problems moving around their home or in the community?
20: Is their sufficient intimacy in your close relationships?
17a: Does alcohol use cause you any problems?
17b: Does cigarette use cause you any problems?
21: Do you have any concerns regarding your ability to express yourself?
17c: Does illicit drug use cause you any problems?

Figure 5 highlights responses to the questions within the ANS-YOD related to these issues in order of areas of most need relating to participation and meaning (as indicated by green and purple bars). Of the responses recorded, two-fifths of clients struggled with insufficient meaningful daytime (41%, n=329) (Q5) and social (40%, n=310) (Q19) activities. Just under one-fifth (18%, n=135) experienced difficulty using public transport (Q24).

The proportion of questions within this section of the needs assessment that did not record a response is worthy of note. For example, only one third of assessments recorded a response to the question relating to intimacy, and many did not record responses to the questions relating to alcohol, cigarette and drug use.
ANS-CYOD – Carer/family (needs assessments)
The number of needs assessments carried out with carers during the program is summarised in Table 3. According to national data, of the 3,452 clients registered in the program, 1866 were Carers/family/friends (54%). The much lower number of carer assessments, 228 of them (12%), is in part due to the shorter time period in which the ANS-CYOD was operational. As with the ANS-YOD, Queensland had the highest number of carer assessments, with data recorded on 88% of carer clients. Victoria and Western Australia reported the lowest numbers of assessments, and no carer assessments were conducted in South Australia.

Table 3  ANS-CYOD – Carers of people with dementia (needs assessments)

<table>
<thead>
<tr>
<th>State Territory</th>
<th>Number of assessments</th>
<th>Number of clients assessed</th>
<th>Clients with multiple assessments*</th>
<th>Date range</th>
<th>Total number of carers</th>
<th>% of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACT</td>
<td>7</td>
<td>6</td>
<td>1</td>
<td>5/1/2016 to 15/3/2016</td>
<td>28</td>
<td>21</td>
</tr>
<tr>
<td>NSW</td>
<td>96</td>
<td>92</td>
<td>4</td>
<td>13/8/2016 to 4/4/2016</td>
<td>550</td>
<td>17</td>
</tr>
<tr>
<td>NT</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>14/9/2015 to 2/3/2016</td>
<td>31</td>
<td>13</td>
</tr>
<tr>
<td>QLD</td>
<td>70</td>
<td>68</td>
<td>2</td>
<td>3/9/2015 to 18/4/2016</td>
<td>77</td>
<td>88</td>
</tr>
<tr>
<td>SA</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>n/a</td>
<td>179</td>
<td>0</td>
</tr>
<tr>
<td>TAS</td>
<td>28</td>
<td>28</td>
<td>0</td>
<td>21/9/2015 to 19/4/2016</td>
<td>86</td>
<td>33</td>
</tr>
<tr>
<td>Vic</td>
<td>26</td>
<td>26</td>
<td>0</td>
<td>14/9/2015 to 19/1/2016</td>
<td>742</td>
<td>4</td>
</tr>
<tr>
<td>WA</td>
<td>4</td>
<td>4</td>
<td>0</td>
<td>23/9/2015 to 19/10/2015</td>
<td>146</td>
<td>3</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>236</strong></td>
<td><strong>228</strong></td>
<td><strong>8</strong></td>
<td></td>
<td><strong>1839</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

*Clients with 2 or more assessments

The ANS-YOD is divided into six domains: Physical health and well-being; relationships; practical issues; information; support; and, burden.
Physical health and well-being (carer)
The physical health and well-being domain covers issues such as: physical health, psychological health and well-being, feelings about caring, valued roles, self-care and future goals. The questions are as follows:

8a Are you able to identify any goals that you yourself would like to achieve in the near future?
6a Are you able to continue with your usual routine / activities along with your caring responsibilities?
5a Have you had difficulties adjusting to taking on your caring role?
1a Do you have any health issues that interfere with your normal activities (outside and/or inside the home)?
2a Do you experience difficulties with your sleep?
4a Do you have problems with your memory?
9a Does alcohol use cause you any problems?
9b Does illicit drug use cause you any problems?

Of the responses recorded, almost a third of carers (30%, n=63) indicated that they had health issues that interfered with their normal activities (Q1a) and experienced difficulties sleeping (30%, n=57) (Q2a). Despite 50% (n=111) of respondents indicating they had difficulties adjusting to their caring role (Q5a), just over two thirds (n=151) were able to continue with their usual routine/activities along with their caring responsibilities (Q6a) and two-fifths (81%, n=152) were able to identify goals that they would like to achieve in the near future (Q8a).

Figure 6 Physical health and well-being (carer)

Three questions explicitly relate to psychological health and well-being of carers. The questions cover issues such as: mood (happiness, anxiety, depression, stress), coping, leisure time (poor
memory, lack of future goals, and drug and alcohol use as indicators of stress / possible depression / anxiety.

The first question was, ‘In the past four weeks how often do you feel sad or depressed?’ Of the responses recorded, one in ten carers felt sad or depressed most or all of the time (10%, n=16), just over a third some of the time (35% n=59) and a further third a little of the time (37%, n=64). One fifth (19%, n=32) did not experience any sadness or depression.

The second question was, ‘In the past four weeks have you noticed changes in the way you emotionally react to situations?’ Over two thirds of carer (n=112) responses recorded indicated that they had noticed changes in the way that they reacted emotionally to certain situations some/a little/or most of the time. The vast majority of carer respondents (91%, n=135) never experienced thoughts of self-harm.

Relationships
The carer relationships domain covers issues such as: communication, intimacy, companionship, sustainability, shared understanding, conflicts and friends and social networks.

The questions are as follows:

10a Have the changes that arise from you now being a carer caused distress, strain and or friction / conflict in your relationships with the person with younger onset dementia or close family members / friends?
13a Are you having difficulty communicating with the person you are caring for?
11a Do you feel isolated from your friends / social networks?
12a Have there been any changes in your intimate relationship?
11c Do you require some assistance to enable you to stay connected to others?
13d Do you experience any difficulties in communicating with others (e.g., health professionals, service providers)?

Figure 7 highlights responses to the questions relating to relationships. They are listed from left to right in order of the number of ‘yes’ responses. Over half the responses recorded (n=119) indicated that being a carer had caused distress, strain and/or friction in the relationship with the person with dementia (Q10a) and just under a half (n=100) indicated difficulties communicating with the person with dementia (Q13a). One third of respondents (n=63) felt isolated from friends and social networks (Q11a). The question relating to intimacy (Q12a) was addressed in one third of assessments, with just over half of responses recorded indicating that changes had occurred (n=43).
Based on the information gathered during the carer assessment, Key Workers were asked to use their professional judgement in assessing the sustainability of the caring relationship (Q14). Where this occurred, just over half of carer relationships (n=104) were viewed as sustainable without additional support, however nearly two fifths (n=72) were at risk of breakdown within the next year.

**Carer practical issues**

The carer practical issues domain covers issues such as: accommodation, looking after the home, care tasks, transport and financing. The questions are as follows:

15a Do you have stability in your current accommodation arrangements?
19a Are your current financial arrangements adequate?
22a Do you provide care to someone else as well as the person with younger onset dementia?
16a Do you need any assistance in looking after your home?
17a Do you have any difficulties assisting the person you care for with personal care tasks such as showering / dressing or Tasks they may have done previously such as cooking or home maintenance?
18a Are there any difficulties with current transport options for you and the person you are caring for?
15d Does your accommodation require any changes to meet your needs?

Figure 8 highlights responses to the questions relating to carer practical issues. Of the responses recorded, the vast majority (90%, n=187) had stable accommodation arrangements (Q15a) and over two thirds (71%, n=118) felt their financial arrangements were adequate (Q19). Despite this, two-fifths (n=69) indicated they were not confident they were receiving all the financial benefits they were entitled to e.g., superannuation, carer allowance (Q20). Nearly two fifths (n=78) of carers were also providing care to someone else in addition to the person with dementia (Q22), and only one-fifth (n=47) required practical assistance with looking after the home, personal care tasks and transport arrangements (Q16).
Information
The information domain covers issues such as: information about YOD and what to expect, ways to support the person with dementia at home, relevant services, planning for emergencies, planning for the future and financial and legal matters. The questions are as follows:

24a Have you noticed any changes in the behaviour of the person you care for?
26a Do you have enduring power of attorney for the person you are caring for?
27a Are you the legal guardian of the person you are caring for?
25a Do you have an emergency care plan in place if something happens to you?

Figure 9 highlights responses to the questions relating to information. From the responses recorded, the vast majority (79%) of carers had noticed changes in the behaviour of the person for whom they were caring (n=187), however around one in ten noticed no changes (n=27). Legal arrangements were in place for around fifty per cent of carer relationships with regards to enduring power of attorney (n=120) and guardianship (42%, n=99). Just under a quarter (24%) of carers had an emergency care plan in place (n=57).
Carers were then asked, ‘Are you confident that you have enough information about YOD and what to expect? Of those who were asked, around half felt that they had enough information (n=107), with just over a quarter indicating they did not (n=61).

**Support**
This domain relates to support for the future and navigating the service system. Data relating to the kind of support for the future was not recorded in the assessment documentation. However, data was available for the question relating to whether assistance was required to access appropriate services and support, with two thirds (n=121) of the responses recorded indicating assistance was required.

**Carer Burden**
The final domain of the ANS-CYOD includes four optional questions from the Zarit Burden Interview: Short version, that ask whether carers have time for themselves or experience stress, strain and uncertainty in their caring role. Thirty percent (n=71) of carer assessments recorded responses to the burden questions, two fifths of which (n=57) scored a rating that in routine community care assessment processes would trigger a more fulsome review and/or referral to a mental health professional.

**Goals of KWP clients**
A corollary to the identification of client needs discussed above is a mechanism to capture client wants. According to the Guidelines developed to support the GAS within the KWP,

> The first step in the goal setting, planning and attainment process is the completion of a needs assessment … it is important that the ANS-YOD and the YOD Carer Assessment are completed before working through the GAS tool.

The Goal Attainment Scale (GAS) was chosen as the tool to be used to identify goals (wants) and measure the extent to which these had been achieved. Originally developed in 1968 to
assess outcomes in mental health, the tool sets a person-centred goal focussed on individual’s priorities and measures the extent to which the goals are achieved. Scoring with the tool is based on a symmetrical five point scale. If the individual reaches the expected level of achievement they score ‘0’ and ‘+’ scores relate to incremental improvements in outcomes and ‘-’ scores correspond to less than expected levels of achievement.

Goal Attainment Scale

The Goal Attainment Scale (GAS) data shows a broad range of client goals which have been used to determine service planning and support provided by the program. In total, 7,928 goals were set over the life of the Program for both the people with YOD and the carers. The most common goals during the Program related to Support for the family (n=1,174), Access to services (n=1,155) and Social engagement (n=715). Data distinguishing goals for the people with YOD and the carer were only available for the last six months of 2015. The following discussion of GAS domains, therefore, includes an initial table comprising aggregated data for the Program as a whole, followed by a table with separated data for the last six months of 2015.

For ease of analysis the 15 goals have been broken down into three groups as follows:

- Health related (includes: Obtaining a diagnosis, Advance health planning, Access to services, Health education and Health and Well-being)
- Family support (includes: Home support, Maintaining independence, Support for family, Employment, Financial/legal planning and Safety)
- Social (includes: Social Engagement, Leisure interests, Connection to others with YOD and Peer support)

Figure 10 highlights how health related goals have changed in emphasis over the Program period. As mentioned above, access to services is a popular goal. Interestingly, the number of access to services goals really ‘spiked’ in the last six months of the Program. A similar trend is demonstrated by advance health planning goals. On the other hand, goals relating to obtaining a diagnosis and health education have remained steady over the Program period.

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40 Turner-Stokes, *op cit.*
GAS data for 2015 shows, for health related goals, people with YOD are more likely to want access to services whilst carers are more likely to want health education and health planning (See Figure 11).

**Figure 10 Health related goals**

The emphasis of family support goals is highlighted in Figure 12. Goals directly related to support for the family are the most common goals throughout the Program period. Other goals in the family support category have been less significant over the Program period.
GAS data for 2015 shows, for family support goals, people with YOD are more likely to want to maintain their independence, whilst carers are more likely to value family support (See Figure 13).

**Figure 13 Family support goals in 2015: PWD versus carers**

The frequency of Social goals is highlighted in Figure 14. Social engagement and leisure goals and connection to others with YOD have become more important as the Project has progressed.
GAS data for 2015 shows, for family support goals, people with YOD are more likely to want access to social engagement and leisure activities together with greater opportunities for connecting to other people with YOD. Carers on the other hand are more likely to want improved opportunities for peer support.

Many goals were reported in the ‘other’ category (n=1,265), more detail was provided to this category in 747 cases. The responses were varied and several themes could be extracted from the data. Dominant themes were:

- Assisting with access to the NDIS
- Finding suitable respite
- Attending the Living with Memory Loss course
- Access to Counselling service
- Organising driving assessment
- Regular contact with the Key Worker
- Assisting with transition to residential aged care
- Accessing some sort of volunteer work

Goal status is summarised in Table 4. The number of goals set has increased with each year and proportionally more goals are in progress as opposed to being completed.

**Table 4  Goal status**

<table>
<thead>
<tr>
<th>Goal Status</th>
<th>Jan to June 14</th>
<th>July to Dec 14</th>
<th>Jan to June 15</th>
<th>July to Dec 15</th>
</tr>
</thead>
<tbody>
<tr>
<td>In Progress</td>
<td>914 (58%)</td>
<td>1107 (62%)</td>
<td>1350 (71%)</td>
<td>1831 (71%)</td>
</tr>
<tr>
<td>Finalised</td>
<td>663</td>
<td>692</td>
<td>544</td>
<td>764</td>
</tr>
<tr>
<td>TOTAL (7,865)</td>
<td>1577</td>
<td>1799</td>
<td>1894</td>
<td>2595</td>
</tr>
</tbody>
</table>

Clients were asked to rate their experiences of the goal in terms of goal outcomes. It is noted that the ability of clients to achieve their goals is fundamentally a function of the clients’ individual capacities and local resources, the foundations of which are often the result of patience, persistence, negotiation skills, professional expertise and the intuitive and creative abilities of the Key Workers. Table 5 summarises the client’s goal outcomes and only includes goals that were marked as complete. A total of 2,663 goals were completed between January 2014 and December 2015. Overall, 45% of clients experienced ‘much better’ or ‘somewhat better’ than expected outcomes. Another 43% of clients had an ‘expected’ outcome. Only 12% experienced a less than expected outcome.

**Table 5  Goal outcome**

<table>
<thead>
<tr>
<th>Goal Outcome</th>
<th>Jan to June 14</th>
<th>July to Dec 14</th>
<th>Jan to June 15</th>
<th>July to Dec 15</th>
<th>% of Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much better than expected</td>
<td>96</td>
<td>171</td>
<td>127</td>
<td>246</td>
<td>22%</td>
</tr>
<tr>
<td>Somewhat better than expected</td>
<td>164</td>
<td>174</td>
<td>187</td>
<td>158</td>
<td>23%</td>
</tr>
<tr>
<td>Expected Outcome</td>
<td>325</td>
<td>374</td>
<td>276</td>
<td>276</td>
<td>43%</td>
</tr>
<tr>
<td>Somewhat less than expected</td>
<td>45</td>
<td>90</td>
<td>67</td>
<td>33</td>
<td>8%</td>
</tr>
<tr>
<td>Much less than expected</td>
<td>21</td>
<td>29</td>
<td>40</td>
<td>16</td>
<td>4%</td>
</tr>
<tr>
<td>TOTAL</td>
<td>651</td>
<td>838</td>
<td>697</td>
<td>729</td>
<td></td>
</tr>
</tbody>
</table>

**Services provided**

The GAS is the only source of data collected by AA where service provision is routinely collected by Key Workers. Within the context of the GAS, there are four broad types of services provided to clients, including: Information and support; referral; service liaison; and, counselling. Since the Program commenced, 15,626 individual services have been provided to 3,401 clients. Service provision was provided fairly evenly between people with YOD and carers, 7,701 services were provided to people with YOD and 7,925 to carers.

Figure 16 and Figure 17 summarise the types of services provided to both people with YOD and carers over a two year data collection period. Just under half the services provided to people with younger onset dementia and carers is information and support. Service provision has steadily climbed...
over the program period with the increased number of clients. There is an upward trend for all services apart from counselling. As you can see information and support has become more important for both people with YOD and carers as the Program has matured.

**Figure 16 Service provision to people with YOD (Jan 14 to Dec 15)**

There are slight differences between the two groups in terms of other services provided. As highlighted in Figure 18, carers were more likely to use counselling services, and people with younger onset dementia more likely to require support in service liaison.

**Figure 17 Service provision to the carer (Jan 14 to Dec 15)**
Figure 18  Service use by client type: People with YOD (inner ring) and Carers (outer ring)