Harnessing community information and support for people with young onset dementia and their families

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Harnessing community information and support for people with young onset dementia and their families.

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Foreword

I am delighted to present this report, and supplementary guidance focused on supporting community groups and service providers to enhance accessibility and inclusivity to people with young onset dementia and their families.

People affected by younger onset dementia have significantly different needs than those diagnosed at an older age. Many psychological and social impacts of Younger Onset Dementia are connected to the time of life at which it presents (e.g. work, financial commitments, family responsibilities). Dementia-specific services are often tailored toward older people which exacerbates this.

We know that people with young onset dementia prefer to continue their everyday lives in their communities and locality. As an organisation committed to empowering and championing the rights of people with dementia and their families to quality support, The Alzheimer Society of Ireland was delighted to commission this work to assist communities in supporting people affected by young onset dementia.

I sincerely thank the authors of this work, Dr Caroline Kilty, Dr Siobhan Fox and Dr Catriona Curtin from University College Cork, and all those who provided their time and expertise to bring this work to fruition.

Dr Laura O'Philbin

Research & Policy Manager
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ACRONYMS AND ABBREVIATIONS

AD	Alzheimer’s disease
ASI	The Alzheimer Society of Ireland
CWOs	Community Welfare Officers
DA	Dementia Advisor
FTD	Fronto-temporal Dementia
GP	General Practitioner
HCPs	Healthcare Professionals
HSE	Health Service Executive
JAM	Just A Minute
LOD	Later Onset Dementia
MCI	Mild Cognitive Impairment
NDS	National Dementia Strategy
NDO	National Dementia Office
OT	Occupational Therapist
PDS	Post-diagnostic Support
PHN	Public Health Nurse
PPI	Public and Patient Involvement
PwD	People with Dementia
PwYOD	People with Young Onset Dementia
WHO	World Health Organization
YOD	Young Onset Dementia

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PLAIN LANGUAGE SUMMARY

Background.

People living with YOD, and their families, experience significant changes in many aspects of their daily life. However, to date, services and supports for people with YOD are lacking. Services are often not relevant or appropriate for people living with dementia under the age of 65. This report sets out to identify how dementia service providers and community groups can support people with YOD living in their communities. For the purposes of this document, the term *services* is used to describe formal health or dementia services. The term *supports* relates to a wide range of community-based activities and can be either structured or informal in nature, such as social support groups. Also discussed are a range of resources and organisations (such as banks and transport organisations) which are available in the community.

What work was done.

A literature review was conducted to explore existing literature and to identify national and international examples of good practice in this area. Focus groups were held with healthcare professionals and people working in community settings. Focus groups were held with people with young onset dementia and families/care partners. Key stakeholders were consulted in order to gather feedback and obtain consensus on areas of priority.

What was found.

Findings highlight the need to increase awareness in the community. It is important that any models of support are individualised and consider the person's preferences and needs. Dementia care professionals should consider social models of support and refer people to supports outside of dementia services. The report highlights ways in which communities can support people with YOD, such as increasing access to transport, using dementia-friendly practices, and YOD-specific training and awareness. The report also discusses some innovative examples of community-based supports which may be of benefit.

What this means.

There are many examples of innovative and responsive practices throughout our communities. However, there are additional steps we can take to ensure communities are aware of YOD and are ready to support and include people with YOD. It is important that there is increased clarity on, and access to, support in the community. Mapping existing community supports and resources could help with this. Also considered essential is that people with YOD and families should have a nominated point of contact to provide information and to signpost supports that may be relevant.

What happens next.

This report identified areas of priority and focus in order to harness support in the community. These include awareness and training; individualised approaches & social approaches; mapping and signposting of community supports; and making community supports more accessible for people with YOD.

1 Introduction

1.1 Introduction

There are approximately 64,000 people living with a diagnosis of dementia, a number forecasted to double within 20 years, and to treble within 30 years (Alzheimer Society of Ireland, 2022; The National Dementia Office and The Department of Health, 2018). Dementia is an umbrella term used to describe a range of conditions that impact on cognitive functioning such as memory, at a level that it interferes with daily life (NIH National Institute on Aging (NIA), 2021). Dementia is typically diagnosed in people over 65 years (Department of Health, 2014), however, there is a growing awareness of the impact of dementia upon individuals under the age of 65. This is referred to as 'young onset dementia' (henceforth YOD), a term used in line with recommendations from the literature (van de Veen et al., 2022). Although exact figures are difficult to establish, recent accounts indicate that between 2,906 and 4,311 people are living with YOD in Ireland (Pierse et al., 2019).

YOD is known to have significant impact upon people with dementia, families and wider society (World Health Organisation (WHO), 2021). Many of the psychological and social impacts for people living with YOD are connected to the time of life at which YOD presents (Carter, et al., 2018): YOD can generate issues relating to family life, employment, and finances (Roach, Drummond and Keady, 2014; Mayrhofer, Mathie, McKeown, Bunn, & Goodman, 2018). In particular, a dementia diagnosis can magnify challenges for people living with YOD who may be in active employment and may have significant financial and family-related responsibilities (Department of Health, 2014). Marked age differences, and differences in stage of life mean that people with YOD struggle to integrate into mainstream dementia services (Withall et al., 2014). Supports are customarily designed to cater for the requirements of people experiencing dementia onset later in life, whose requirements can differ significantly to people with YOD (Fox et al., 2020). Insights into the provision of care appropriate to people with YOD is minimal, despite a large body of evidence highlighting the unique support needs of people with YOD (Mayrhofer et al., 2020). This shortfall between research and practice requires attention, particularly since people living with YOD continue to experience daily challenges, oftentimes with little assistance (Spreadbury and Kipps, 2020).

1.2 Background & Context – YOD and Models of Support

In Ireland, many positive advancements have been progressed since the implementation of the National Dementia Strategy (Dept. of Health, 2014). These include a review of diagnostic processes in Ireland (Reves et al., 2018) and a review of post-diagnostic support for people with dementia and their carers (O' Shea, Keogh and Heneghan, 2018). The Dept. of Health has also identified a need to explore the level of compatibility between present services for people living with dementia and those living with YOD (Dept. of Health, 2014). A recent report was published reviewing diagnostic and post-diagnostic processes and pathways for people with YOD (Fox, Cahill, McGown and Kilty, 2020). The report by Fox et al. (2020) examined existing models of support for people living with YOD in Ireland. Findings from that report highlighted that existing services and supports available to people living with YOD and their families are suboptimal and often deemed inappropriate and unacceptable by the person with YOD, and their families.
Over the years, healthcare professionals (henceforth HCPs) have identified a lack of awareness about the needs of people living with YOD and which supports may be suitable (Jefferies and Agrawal, 2009). HCPs are often unable to access age-appropriate and relevant post-diagnostic supports for people with YOD, and equally, criteria to access health services can be inflexible and age-dependant (Kilty, Naughton, & de Roiste, 2019). Indeed, a shortfall in services that are age-appropriate is a challenge experienced internationally (Bakker et al., 2022; Carter et al., 2018). Where supports are available, these tend to be formal medical supports, although for many people with YOD, primary needs are for practical, or social support, rather than medical interventions (Fox et al., 2020).

1.3 Community-based support

The benefits of community-based approaches for individuals with YOD and their families has been documented in dementia literature. The Community Supports Model as described by Genio (2016) aims to ensure that “*people with dementia have access to a ‘care and support ecosystem’ that integrates community and voluntary organisations, mainstream services and health and social care services”* (2016, p10). Community and voluntary organisations alone have the potential to empower and promote quality of life amongst people with YOD by facilitating their social engagement and ensuring that crucial connections with society are retained (Fox et al., 2020). Across Ireland (and internationally), cities and communities have taken significant strides to ensure they are more inclusive of people with dementia (ASI, 2016). However, there remains a limited evidence base pertaining to supports that are appropriate for, and valued by, people living with YOD (Mayrhofer et al. 2018). There has also been little exploration of ways in which wider communities can support people with YOD. While there are a wide range of community-based supports that may hold relevance for people with YOD, whether these are signposted to, or how they are accessed, is not widely known.

The Alzheimer Society of Ireland have identified as a priority a need to empower community supports and resources to become inclusive for people affected by YOD. To this end, in 2021 the ASI put out a tender for research to develop guidance on how dementia service providers and community groups can support people with younger onset dementia and their families. This report entitled *‘Harnessing community information and support for people with young onset dementia and their families’* is a research output responding to this call.

1.4 Research Aim and Objectives

The aim of the current study is to develop evidence-driven and consensus-based guidance on how (a) Dementia Service Providers and (b) Community Groups can and should support people with YOD and their families within communities.
To address the research aim, two overarching objectives were explored:

1. Establish how well current community interventions for people with YOD enable them to connect and engage within the community
2. Identify ways that both existing and future community interventions might be adapted to align more closely with the requirements of people with YOD.

2 Research Design and Methodology

2.1 Research Design

A rapid review of the evidence, including both empirical and grey literature, was conducted. Following this, primary qualitative data were collected from two sets of focus groups: (i) focus groups with healthcare professionals and community workers, and (ii) focus groups with people with YOD and family members. In line with the Co-researcher Involvement and Engagement in Dementia Model (Swarbrick et al., 2016), an External Advisory Board (EAB) was convened and constituted an integral part of the project, providing feedback and consultation throughout.

2.2 Rapid Review

2.2.1 Methodological Considerations

A rapid review was selected as the means of literature review. Rapid reviews are pragmatic and efficient means of evidence gathering and synthesis (Tricco et al., 2017; Garritty et al., 2021). This review followed the iterative and flexible guidelines developed by the 'Cochrane Rapid Reviews Methods Group' (Garritty et al., 2021). The research aim was refined via consultations with the research team, and a review strategy was developed.

2.2.2 Population, Inclusion and Exclusion Criteria

The population of interest was people living with YOD (dementia onset before the age of 65), family members/care partners of people living with YOD, and service providers. The interventions of interest were community-based informal and/or formal services. Community interventions within residential or acute settings were excluded. Outcomes reviewed included the nature and efficacy of existing interventions for people living with YOD from the perspectives of people living with YOD, family members of people living with YOD, and service providers. Additional outcomes considered included descriptions of supports that might be made available to people with YOD, along with guidelines on the development of community supports for people with YOD. Included in the review were guidance documents, literature reviews, and policy documents. As per rapid review recommendations, and to ensure relevant and available literature relating to the research topic is identified, literature was not restricted by year published (Garritty et al., 2021). Review searches were conducted between February and March 2022.

2.2.3 Review Selection and Extraction

A grey literature search was conducted to identify literature relative to the research questions (see Appendix A for the detailed search strategy). A total of six databases were searched, including Google, Google Scholar, Lenus, ‘Guidelines International Network’ (GIN), the ‘National Institute for Health and Care Excellence’ (NICE) and ‘Social Care Institute for Excellence’ (SCIE).

A white literature search strategy (Appendix B) was devised to identify both nationally and internationally published literature that responded to the research questions. Protocol-driven search strategies were supplemented with ‘snowballing’ methods such as reference list and citation searches, key author searches, and hand-searching of key journals. The databases searched were Medline (via Ebsco), Embase, Cochrane and CINAHL. The software ‘Covidence’ was employed to aid the process of literature data screening and extraction. Titles, abstracts and full texts were screened dually by two reviewers (CC and CK). In addition, a third researcher (SF) resolved any conflicts.

The grey literature search retrieved a total of n=659 records from search string 1 and 2 combined across the databases. Following removal of duplicates, and screening for eligibility, n=60 records were selected for inclusion in the review. The white literature search retrieved n=264 studies, following removal of duplicates eligibility screening, and full text review, a total of n=21 studies were selected for inclusion. A summary of the relevant findings from the rapid review is presented in Section 3.

2.2.4 Data Synthesis

Following data extraction, relevant evidence was gathered and aggregated. As per Dobbins (2017), synthesis sought to explore the included research for overall conclusions. The literature was reviewed taking consideration of the review questions in Section 1, and a pragmatic approach was taken to ensure implications for practice were highlighted. Following this, a narrative synthesis approach was taken, and findings organised under thematic headings.

2.3 Focus Groups

Focus groups were held in two phases. The first phase consisted of focus groups with healthcare professionals and community workers. The second phase consisted of focus groups with people with YOD, and family members.

2.3.1 Participants

Convenience and purposive sampling strategies were utilised. People with YOD and family carers were recruited via a number of channels. The research team details were circulated by the Alzheimer Society of Ireland through their research volunteer network (TeamUp for Dementia Research). The research was also circulated via websites, social media sites, and mailing lists of reputable and well-known organisations (e.g., the ASI and the National Dementia Office). Interested parties opted-in by contacting the research team for further information, who then sent information leaflets and consent forms. For people with YOD who expressed an interest in participating, a member of the research team discussed the study with them further by email or phone, to ensure adequate opportunity to ask questions. Eligibility was also gleaned through these conversations and later confirmed prior to data collection.

(i) For the first phase, eight focus groups were held with 16 healthcare professionals and 10 community workers. Examples of healthcare professional roles included Dementia Advisors, Social Workers, Occupational Therapists and Nurses. Examples of community worker roles included Community Development Officers, staff from voluntary organisations, and staff from community services such as banking (see Table 1).

Table 1

Number of particpants	n = 26
Number of focus groups	n = 8
Healthcare professionals	n = 16
Community workers	n = 10

(ii) For the second phase, six focus groups were held with six people with YOD, and 10 family members. All participants with YOD had received diagnosis of dementia under age 65. Family members included spouses, offspring and siblings (see Table 2).

Table 2

Number of particpants	n = 16
Total number of focus groups	n = 6
People with YOD	n = 6
Family members	n = 10

2.3.2 Data Collection

Ethical approval was granted by the Social Research Ethics Committee at University College Cork. Data were collected between March and May 2022. Participants were offered the choice of in-person or virtual focus groups using teleconferencing software, however, all focus groups were held virtually. All focus groups were conducted by experienced researchers and were audio-recorded with permission. A short focus group schedule was developed and tailored with feedback from the project external advisory board.

2.3.3 Ethical Considerations

The Principal Investigators are experienced in conducting psychosocial research with people with dementia and took responsibility to ensure that best-practice guidelines were followed. The Alzheimer Europe position paper (Gove et al., 2018) was used as a sensitising influence, in addition to other relevant publications on ethical considerations and the active involvement of people with dementia in research (Bartlett and Martin, 2002; Dewing, 2007; Dewing, 2008; Hellström et al., 2007; McKeown et al., 2010). All audio and transcripts were handled and stored according to the host university’s Data Protection Policy.

2.3.4 Data Analysis

Data from the focus groups were analysed using reflexive thematic analysis as described by Braun and Clarke (2006). This reflexive approach allows for flexibility in the data analysis, and involves six phases: familiarization, coding, generating themes, reviewing themes, defining and naming themes, and writing up (Braun, Clarke and Hayfield, 2022). Following transcription of focus group recordings, the researchers familiarised themselves with the data, and initial notes and ideas were taken. Preliminary codes were induced from the data. While the codes were driven by the data, researchers were cognisant of the research questions during the process of coding. This process was followed for all transcripts. All initial codes and data extracts (along with additional data for context), were collated and grouped to form themes.

2.3.5 Synthesis of findings

Findings from across the three studies were reviewed and analysed. There followed a process of integrating and synthesising findings from each of the studies. To do this, the authors used the results to identify areas of similarity, from which overall themes were constructed (Noyes et al., 2019). A draft summary of overall findings was shared with key stakeholders in order to gather feedback and to establish consensus on areas of priority and focus. These areas of priority formed the basis for the accompanying brief guidance document.

3 Literature Review

3.1 Introduction

Three key areas were identified from the overall literature and are outlined in Table 3 below.

Table 3

Key area 1	**Building awareness, collaboration, and accessibility of information**	- Collaborative approaches - Harnessing existing community supports - Accessibility and clarity of existing supports
Key area 2	**The Attributes of Effective Community Supports**	- Training to improve YOD Knowledge, and Support - Accessibility and Transport - Service Sustainability and Continuity - Information Design - Flexible Service Provision
Key area 3	**Community Activities for People with YOD**	- Individualised approaches - Community-based activities for people with YOD - Arts Orientated Interventions - Peer Support Groups - Virtually Supported Community Interventions Service Provision

3.2 Findings

3.2.1 Key area 1

The Attributes of Effective Community Supports of information

The literature highlighted a need for a wider awareness of YOD amongst both HCPs and the general community, with a greater awareness associated with better service design and better support for people with YOD. Literature relating to interventions for people with YOD and families suggested that the creation of suitable health and social care interventions demands a wide awareness of YOD and how it impacts upon families (Shnall, 2015). Chirico et al. (2021) explored experiences of YOD from the perspectives of family carers and identified insufficient knowledge relating to YOD. The authors concluded that increased understanding and knowledge of YOD amongst the wider public could address a number of areas. These include reducing self-isolation in families and increasing connection socially, growing policy support, and improving practical and emotional support.

Increased awareness can be facilitated through education (Shnall, 2015). Through education, strategies for knowledge-sharing can be developed. Potential interventions can be shared with social services, HCPs, governments. Awareness can also be advanced through the development of post-secondary curriculum, as well as via professional workplace training (Shnall, 2015). Furthermore, it was suggested that third-level institutions and research centres are avenues for information distribution and awareness raising about YOD. Dementia services have a role to play in creating a wider awareness within the community (Shnall, 2015). However, methods used in awareness raising are key (such as media) and need to be selected taking cognisance of the relatively low numbers of people living with YOD (Bakker et al. 2022).

Collaborative Approaches.

A common theme in the literature was that the nature, design and implementation of meaningful community interventions have been steered by people impacted by YOD (Mayrhofer, Mathie, McKeown, Bunn and Goodman, 2018). This is a point echoed by The Alzheimer Society of Ireland (2016) in their work on dementia-friendly communities. Discussing the Irish 'Dementia Care Model', Pierce (2020) highlighted the concept of citizenship, the core of which is the inclusion of individuals living with dementia in any decisions which impact them.

A study by Mayrhofer et al. (2020) discussed the efficacy of service co-design: this joint approach allows service providers to establish priority areas for service commission and planning for people with YOD. Findings from the UK 'Angela project' (Stamou et al. 2022) highlighted the importance of collaborations whereby services work in partnership with people with YOD to address their ongoing support needs. It is also used to identify ways of adapting supports to work responsively and flexibly, to allow services to adjust supports to facilitate individuals' different needs. The use of collaboration and co-design in community supports means that people with YOD can steer community responses by participating in events, training and contributing to raising awareness (Nuffield Council on Bioethics, 2009).

In Ireland, the Irish Dementia Working Group (IDWG) project with Irish Rail is a recent example of key stakeholders being enabled to influence policy development through collaboration (Blake & Hopper, 2019). The IDWG project explored experiences relating to the use of public transport amongst people living with dementia. Significantly, people living with dementia were empowered to commission research and engage with consultants, setting rather than responding to questions (Blake & Hopper, 2019).

Mayrhofer et al. (2020) in consultation with a Public and Patient Involvement (PPI) panel, suggested that communication between advocates of people and families living with YOD, and businesses, restaurants and clubs is important to grow accessibility and help nurture services that are dementia-friendly. In the UK, the 'Dementia Friends' (Department of Health 2015) programme, trains staff in a range of businesses and sectors in dementia awareness, including Argos, Marks & Spencer, 'Lloyds Banking Group', and Asda. There are some considerations to a collaborative approach. Mayrhofer, Shora, et al. (2021) warned against an overreliance on volunteers in third-sector organisations and propose the integration of collaborative practices that ensure future stability and continuity. Commissioning of services that are properly integrated between voluntary, social care and health care sectors is key (Mayrhofer, Shore, et al., 2021).

Harnessing existing community Supports.

The literature highlights the need for local community bases that are accessible to people with YOD. Mayrhofer et al. (2020) called for the identification and development of community networks and activities for people with YOD, by people with YOD. In this study, PPI participants with YOD and care partners argued that a local community base for advice, for instance a local voluntary branch, may enable future groups/services to organise themselves, facilitate peer support and forge ongoing connections. Such socially-driven networks amongst the YOD community could help create supports that are valued by people with similar interests, and which are locally based, whilst also connecting people whose conditions may be alike. A further idea discussed was 'skills swapping' to link people with YOD together for peer support and assistance (Mayrhofer et al., 2020). An exemplar of such a community base is the 'ConnectWELL' project in the UK. The service identifies the unique needs of people (across a wide range of conditions) and identifies models of support such as non-pharmacological interventions (Warwickshire County Council, 2022). Another UK example was peer support activities offered through a charity organisation (ONSIDE, 2018): here, mentors offer customised support relative to participants' interests and skills, so that people can effectively engage within the community and create networks that are socially driven.

Accessibility and clarity of existing supports.

Accessing support in the community after diagnosis is challenging: supports are often variable and dependant on the geographic location of a person with YOD (Spreadbury and Kipps, 2020; Chirico et al., (2021). The provision of supports that are specialised and targeted are in short supply considering the numbers and wide geographic spread of people with YOD (Mayrhofer, Shora, et al. 2021; Shnall, 2015). One suggestion for overcoming this issue was virtually supported groups (Draper & Withall, 2016). Other suggestions included better clarity regarding the range of existing community-based supports, to connect people with YOD to supports in their locality (Stamou et al. 2022). The Dementia UK website and the Irish Understand Together website provide detailed information relating to a variety of services for people with YOD (Dementia UK, 2022; Health Service Executive, 2022). Draper & Withall (2016) recommended use of key workers early following diagnosis to link people with YOD and families in with these local supports, a point also highlighted by Kilty et al. (2019). Primary care centres and centre websites were also cited as a means to creating awareness of and signposting to community supports (Penny Lane Surgery, 2021).

3.2.2

Key area 2

The Attributes of Effective Community Supports

Training to improve YOD Knowledge and Support.

The literature provided examples of training interventions for people working in community settings. The 'Dementia Friends' initiative was a training intervention whereby staff in participating businesses become champions or 'Dementia Friends' (Department of Health, 2015). A similar UK exemplar was the 'Worcestershire Works Well' Project which aims to create general awareness regarding dementia (not specifically YOD) (Worcestershire County Council, 2019). A study by Smith, Ooms, & Greenwood (2017) reported on a short training course for community-based care workers (n=24) supporting people with YOD, and cited findings relating to enhanced knowledge and confidence. On training interventions, several studies reported on the merits of including people with YOD and/or families and report increased awareness and knowledge amongst care workers in how to support and empower individuals with YOD (Smith et al., 2017; Nuffield Council on Bioethics, 2009).

Accessibility and Transport.

A lack of YOD-friendly transport was identified as a barrier to subsequent use of community and formal services (Cations et al. 2017; Healthwatch Manchester (2017)). People with YOD might no longer be driving, may have a lack of appropriate transport options and may be reliant upon family for them to get to services (Chirico et al., 2021). Appropriate transport is a requisite for people with YOD to participate wholly within their communities, to live autonomously, and reduce isolation (London Assembly Health Committee, 2018). A report by the London Assembly Health Committee (2018) emphasised that accessible transport services were especially important when it comes to YOD, particularly when transport constraints are magnified for people with YOD living in widely dispersed or rural areas (Giebel et al., 2021). Furthermore, community supports must be affordable (Stamou et al., 2022; Social Care Institute for Excellence 2019; Cations et al., 2017). In a survey of people with YOD and their families, (Mayrhofer, Greenwood, et al. 2021), the majority of participants indicated they require assistance with the cost of transport.

Some solutions to transport and accessibility are suggested in the literature. NICE (2018) stated it is important to generate a greater awareness amongst transport services and personnel of ways to support people with dementia using transport. One initiative provided transport specifically for access to social activities within communities and positive outcomes were reported for people with YOD and carers from survey data (Stamou et al., 2021). Amongst the recommendations by the London Assembly Health Committee (2018) was training to increase awareness of dementia/YOD amongst bus drivers, in addition to the need for subsided travel (e.g., taxis), a point echoed by Mayrhofer et al. (2020) in relation to subsidised bus travel for people with YOD. Likewise, the UK Department of Health (2010) recommended the importance of increasing awareness, and the use of visual cards for people with dementia to help facilitate safe, supported travel.

Service Sustainability and Continuity.

Sustainability and continuity of supports within the community is essential to support people with YOD. A survey conducted by the 'Angela Project' (Stamou et al. 2022) explored the characteristics of helpful supports for people with YOD and carers and identified consistency of services over time as a key theme. In a scoping review by Mayrhofer et al. (2020) service sustainability was also identified as key; a shortfall in continuity resulted in disconnections between newly acquainted groups of peers and networks. Overall, barriers to sustaining services and service continuity included inadequate funding, the commissioning of projects in the short term along with ad hoc planning of supports (Mayrhofer et al. 2018). Service sustainability issues escalated during the COVID-19 pandemic: the cessation of non-statutory groups and supports led to increased isolation and loneliness amongst those impacted by YOD (Giebel et al., 2021).

Information Design.

The design of information, and accessibility of information, was highlighted in the literature. Among guidelines relating to language, equality and diversity, was the provision of accessible information in written format that is available in the desired language of the person (National Collaborating Centre for Mental Health, 2006). Accessible information design and service provision was suggested to grow dementia awareness amongst minority groups (Moriarty, Sharif, & Robinson. 2011). Past examples identified include the utilisation of neutral language (Forbat, 2003), and the provision of dementia information resources such as video to support community members with reduced literacy or where English is not a first language (John, 2004). Such recommendations are a key consideration for social and health care professionals when one considers that inaccessible information can hinder comprehension of or access to care, services and treatment (National Collaborating Centre of Mental Health, 2006).

Cahill, O'Shea, & Pierce (2012) similarly identified a need for the tailored design of information for people with YOD and an intellectual disability, along with geographically accessible information for people with YOD post-diagnosis in rural areas. Cahill et al. (2012) highlighted the work of the British Institute of Learning Disabilities (BILD) who advocate use of larger print and plain language. Communities and businesses can create an awareness to the wider public that they are dementia-inclusive in several ways, such as through the use of signage, messaging via websites or other visual representations of dementia inclusivity (Department of Health, 2015). A specific example is badge wearing by employees in businesses who are trained in dementia. For instance, the 'Dementia Friends' initiative at Mark's and Spencer's is a participating organisation and the workforce who are 'Dementia Friends' wear badges to highlight this (Department of Health, 2015). On inclusive messaging, Oglesby & Hynes (2022) outlined a number of recommendations in their research on dementia service delivery for LGBTQIA+ community within the Republic of Ireland (ROI). Examples of recommendations included "inclusive ethos messaging and visible displays of LGBTQIA+ acceptance to be clearly displayed in leaflets and webpages of dementia services, accompanied by staff trained in LGBTQIA+ affirmative care" (Oglesby & Hynes, 2022, p.15).

Flexible Service Provision.

Optimal supports are ideally responsive and flexible to facilitate the shifting needs of a person with YOD, at times that are convenient and dementia-inclusive (Stamou et al., 2022). Similarly, to increase engagement, supports should be flexible to align with the needs of families (Bakker et al., 2022). Ideally, supports should be offered outside of business hours including weekends, with supplemental online options to enhance opportunities for engagement (Cations et al., 2017). Offering dementia-friendly practices was also suggested. Research co-produced with people with YOD and families suggested ways in which communities might support people with YOD, such as creating designated lanes within swimming pools during quiet times, or private spaces within restaurants (Mayrhofer et al., 2020). Giebel et al. (2021) reported on an initiative whereby participants with dementia were able to avail of designated quiet times at leisure centres.

3.2.3

Key area 3

Community Activities for People with YOD.

Individualised approaches.

This theme reports on examples of supports and activities are identified in the literature as being of potential beneficial to people with YOD. Examples which are varied but frequently interconnected include outdoor activities, physical activities, mental health activities and social/supportive interventions. It was evident that the provision of meaningful supports and interventions hinges upon age and stage appropriate considerations and crucially, are cognisant of individual preferences and interests. Noting the nuances of dementia, O'Shea et al. (2017), highlight that individualised approaches to supporting people with YOD are vital. Age, gender, ethnicity and ability all present complex and unique challenges for people with dementia (O'Shea et al. 2017). Communities and resources must be mindful of this, and consider ways to enact support for people at different stages of dementia

(Neurological Alliance of Ireland & Elan, 2002; Nolan, McCarron, McCallion, & Murphy-Lawless, 2006). It is vital to support people with YOD may wish to continue with their personal interests such as sports, holidays, community engagement, or instead pursue a new interest such as volunteering or fundraising (Social Care Institute for Excellence, 2020).

Community-based activities for people with YOD.

There is evidence to suggest that outdoor activities for people with YOD can provide meaningful options for support and engagement. A case study by Cook (2018) involved an 'urban forest', participants engaged in activities including photography, walks in the woodland, building bird boxes, planting trees, bird watching and cooking in woodland. Findings pointed increased social networking for persons impacted by YOD, and enhanced mental wellness (Cook, 2018). Carone, Tischler, & Dening (2016) investigated the efficacy of a men's football sporting group in supporting men with YOD and their care partners. Participants included men with YOD (n=5), care partners (n=5), and coaches (n=5), who attended regular football sessions. Participants expressed enjoyment and anticipation of a positive nature from the low-cost intervention, the inclusive environment and a focus removed from dementia (Carone et al. 2016).

In an ethnographic study in Canada, Phinney, Kelson, Baumbusch, O'Connor, & Purves (2016) discussed a social club, and identified an increased sense of social citizenship amongst participants. This intervention included early morning coffee, newspaper reading/discourse, and group activities such as lunch and an afternoon walk within the neighbourhood, and within the streets of the city. Findings show that walking created a safe space for participants to engage and connect with others in the community and served to remove the focus on dementia (Phinney et al., 2016).

Findings from a pilot of a YOD gardening scheme by 'Thrive', a UK charity, reported that a structured intervention positively influenced the mood, cognition and wellbeing of people with YOD (Joplin, 2017). Likewise, a "Medway Horticultural Project" (Kent County Council, 2011) was created as a result of research identifying the therapeutic benefits of the natural environment, and of the efficacy of activities that are social and productive. The group meets weekly, operates a feedback system from members, and places particular attention upon the concept of inclusion, social interaction and the support of peers (Kent County Council, 2011).

A UK survey investigating post-diagnostic supports for people with YOD suggests that people are most positively disposed to activities that assist in maintaining mental and physical health (Stamou et al. 2021). Giebel et al. (2021) report that physical and cognitive interventions can positively influence the wellbeing of people with YOD. The authors investigated the experiences of individuals with YOD (n= 14) and family carers (n= 11) participating in community-based, socially prescribed mental and physical wellness classes. These were held on a weekly basis by a local leisure centre and community, and range from non-high impact exercises, techniques for relaxation, Tai Chi, and mindfulness. Findings indicated a positive impact upon participants and an increase in wellbeing (Giebel et el. 2021).

The sudden cessation of work can significantly affect people's quality of life and relationships (Roach, Drummond, & Keady, 2016). The significance of implementing employment support for people with YOD was cited, and participation (paid or unpaid) in occupational activities of particular value to those who express a wish to stay in employment (McCulloch, Robertson, and Kirkpatrick, 2016). The literature provides some examples of ways to support continued occupation or employment using strategies such as peer support, collaboration and training for colleagues (Nwadiugwu, 2021; Robertson & Evans 2015). Kinney et al. (2011) explored the efficacy of a work-based program, whereby people with YOD work and to interact with others in similar situations. Findings highlighted that men identified well with the program and benefited from socialising with others.

Arts Orientated Interventions.

Arts orientated interventions can be associated with increased engagement, enhanced wellbeing, and reduced isolation amongst people with YOD. A paper by Kelson, Phinney, & Lowry (2017) explored the use of art in public spaces and social citizenship amongst individuals with YOD. Participants reported increased levels of enjoyment, meaningful social interactions and increased feelings of belonging within the community (Kelson et al. 2017). Likewise, Strohmaier et al. (2021), identify positive associations between arts-based interventions and reported wellbeing of people with dementia. Findings were based upon data from participants (n=201) with different types of dementia, inclusive of YOD.

A study by Thompson, Duncan, & Sack (2021), explored the efficacy of a museum program entitled 'Arts in Mind' developed for people with YOD or at an early stage of cognitive impairment, and care partners. Participants engaged in a collective arts program centring on accessible, responsive, and experiential arts encounters. This initiative was multidisciplinary in nature, linking art therapies, the medical profession and educators within museums/students, and offers a sustainable replicable model for arts/museum programs to support people with YOD or early stages of dementia (Thompson et al., 2021). Baker and Irving (2016), explored the efficacy of a social prescribing pilot program to target issues of loneliness amongst individuals in danger of being isolated socially (such as people experiencing depression or who have YOD). This study included arts orientated interventions such as crafts, dance, film making and movement, and participants reported increased connection and community involvement from workshop participation (Baker and Irving, 2016).

'Arts4dementia' is a further initiative which centres upon empowering persons impacted by dementia, through the arts. It offers both a signposting and social prescribing service for people at different stages and with different types of dementia, inclusive of YOD. Services within this initiative include dementia-friendly programs, events, venues, details of art facilitators trained in dementia, and professional development events for disciplines of arts (Arts4dementia, 2022). To enhance accessibility to arts and cultural activities in the community, a US initiative was formed entitled the "*Culture Bus*" to provide people with YOD with a means of transport to visit events in the community and in cultural spaces (Phinney et al., 2016)

Peer Support Groups.

Peer support groups or networks for people with YOD, and their families can offer a valuable source of support and social connection (Henwood, Larkin and Milne (2018). Hasse (2005), stresses that supportive interactions with friends and neighbours within the community play a primary role in reducing isolation amongst people with YOD. Connecting socially, having regular gatherings with people of similar situations, and creating channels of support for times when needed, has been emphasised in the literature (Mayrhofer, Shora, et al., 2021; Mitchell, 2012).

Findings from a recent survey by Stamou et al. (2021), highlight the importance of opportunities for social interactions and active participation for people with YOD post-diagnosis. The findings are predicated upon data from 233 people with YOD and carers, and report that peer social outings which enable people to identify with others in similar situations were positively received by participants. Findings from the INSPIRED study advocate for socially-based support groups that allow people with similar experiences to connect and learn from one another (Cations et al. 2017). Likewise, a 'Pilot Cafe' with people with dementia identified that social and peer supported supports are a priority area for policymakers (Keogh et al. 2021).

A leading example of peer supported social interventions are 'Dementia Cafes', which offer a valuable support for people with YOD (Council, Cluster, & Cluster, 2012). Research by Teahan, Fitzgerald, & O'Shea, (2020) conducted interviews to explore family carers perspectives of utilising Alzheimer Cafés in Ireland (n=9). Findings reported that Cafés provide emotional support, friendship, equality and inclusion, in addition to information provision. 'Young Dementia UK' provides individualised support and services to people with YOD and families, including cafes specifically designed for people with YOD, coupled with social clubs (Health Service Executive, 2016). Providing other examples of peer support models, a UK group called 'Time Out Together' (TOT) is an intervention for people with YOD and families, and aims to optimise participant wellness by encouraging social interactions and nurturing peer networks (Health and Wellbeing Board North Yorkshire, 2018).

Virtually Supported Community Interventions.

The use of virtual social networks can be a meaningful source of support for people with YOD. The Alzheimer Society UK (2022) provides an online community entitled "Talking Point" that includes information on supports for people impacted by YOD, specific to their locality. The Dementia UK website offers information on services within relating to selected geographic areas, and also details relevant social media groups for people with YOD (Dementia UK, 2022). A recent study by Talbot, O'Dwyer, Clare, & Heaton (2021) explored the use of the social media platform Twitter by people with YOD. The authors report that 'Twitter' enables participants to become part of a community of people with dementia, and allows users to gain insights into dementia whilst also contributing to the education and support of peers. The authors suggest that the use of social media by people with YOD can also remove a degree of stigma surrounding dementia (Talbot et al., 2021). Also on the topic of peer support, Ivory (2021) discusses a variety of blogs created by people with YOD to connect with peers and to share experiences.

A UK based app offers information surrounding dementia-friendly community businesses, services and shops, and was created to encourage local business to become dementia-friendly and in turn to support people with YOD to live independently (Jopling, 2017). Vafeas, Jacob, & Jacob (2020) report on an interactive resource developed in Australia (Prescription for Life, a talking e-Flipbook) with the aim of increasing knowledge of YOD amongst communities, businesses and organisations. Shastri et al. (2022) looked at technology use in the workplace developed by and for individuals with YOD or mild cognitive impairment, and provided a range of recommendations including ways technology could be designed to support individuals' with YOD, such as a preference for technology that is clear and straightforward, and user interfaces that are adaptive and can facilitate personalised and dynamic support. Lastly, online environments offered access to supports and information for people during COVID-19. For instance, a 'Dementia Action Week' was held throughout Liverpool whereby a wide range of social and informational activities were held online by businesses, councils and dementia groups (Penny Lane Surgery, 2021).

3.3 Section Summary/Conclusion

This section reported on evidence-based examples of ways to build awareness in the community, ways of fostering collaborative practices and ways to optimise accessibility of information. Following this, some key attributes of effective community supports as described in the literature were presented, including pragmatic suggestions to improve inclusivity within supports. Finally, literature relating to community-based support was discussed, including such areas as peer support and virtually supported community interventions. It is important to note that while a wide range of community interventions for people with YOD is addressed in the research literature, further information is needed on the efficacy of such programs. Future research should focus on the manner in which the design and delivery of activities align with the individual preferences and needs of people with YOD (Sansoni et al., 2016).

4 Focus Groups with HCPs and Community Workers

Participants in the first phase of focus groups consisted of healthcare professionals (n= 16) and community workers (n =10). Three themes were constructed from the focus group data: (i) awareness, recognition and planning, (ii) ways community supports might be enhanced and (iii) examples of community-based supports.

4.1 Findings by theme

Table 4

Theme 1	**Awareness, Recognition and Planning**	• Recognition of YOD within policy • Increasing clarity around supports • Collaborative Practice • Harnessing existing supports
Theme 2	**Ways Community Supports Might be Enhanced**	• A Nominated Point of Contact • Social approaches • Transport and Connection within the Community • Awareness raising and training • Information and Communication • Technology (ICT)
Theme 3	**Examples of Community-based Supports**	• Examples of community-based supports • Examples of inclusive practices

4.1.1 Theme 1

Awareness, Recognition and Planning

Community awareness and understanding of YOD was identified as an important issue. Participants felt by nurturing a greater awareness of YOD, communities will be better equipped to foster inclusive practices. A healthcare worker discusses the importance of awareness.

> “ *There’s not enough knowledge and awareness within the community about dementia…Often community groups …feel ...unsure of how to engage somebody once they receive a diagnosis of dementia and make them feel welcome …the person has received a diagnosis, but they’re still the same person ...it doesn’t mean that the group are going to be engaging somebody with really high needs ...that’s a bit of a misconception that is out there.* (T8)

It was highlighted that people with YOD often receive inappropriate referrals, with community supports being underutilised.

> “ *Because of the absence of …knowledge and …general awareness, people are shoehorned [into certain dementia services] …it’s just such a waste of ...opportunity …* (T7)

It was felt that providing awareness of YOD is required to improve understanding and remove stigma surrounding YOD, and ultimately to increase use of supports within the community.

> “ *There’s so little available for people with younger onset dementia …part of that is because dementia is seen as an older person’s condition.* (T7)

> “ *Taking the stigma away from it …comes back to education …busting some of the myths…it could be a start just trying to kind of normalise.* (T2)

Recognition of YOD within policy.

A need to integrate YOD into policy was discussed in many focus groups. Participants called for a review of existing policy and practice, in order to be more inclusive.

> “ *There’s just not enough policies in place in relation to supporting somebody with [young onset] dementia so that they can continue to, you know, live individually and not rely on someone else.* (T8)

This lack of information and clarity in policies and procedures was cited to be a key issue. There was a sense that, outside of dementia services, options for support were unclear and lacking transparent processes.

> “ *How we access services in Ireland...From either chronic illness? ...or disability? (or) older person’s services? ...Dementia for younger people fits in nothing ...Because dementia isn’t seen as a disability …(or) even a long-term condition …Or recognised as a chronic condition. Services would be available then as part of being a chronic condition* (T7)

This lack of clarity was more keenly felt when the family had not received the correct channels of support from the beginning.

> *It always shocks me when I might get a call from somebody with a diagnosis of dementia, or they're at that stage where they're looking for support. And I would say, have you linked him with your dementia advisor, and they have never heard of the service.* (T8)

Participants argued that clear definitions and lines of responsibility would be beneficial. Of particular importance was establishing where YOD 'sits' in terms of health service funding.

> *Dementia is not seen as a disability. And if you're under 65, you don't fit into older person services, which is where the funding for dementia services ...traditionally comes from. And that is the biggest issue. So, you know, that I think if we can define what younger onset dementia is, and where it sits in healthcare, I think would be very helpful.* (T7)

Participants identified funding as a key constraint to meaningful support in the community. Related were the challenges around continuity, and over reliance on the voluntary sector. This is discussed by a community worker.

> *There has to be some line there of financial support to somebody to be able to keep these programs on the go …you need workers as well …to be there to be able to be there to commit to the program.* (T9)

They further explain that funding for service development for people living with YOD, and allocation of public sector funding, is challenging owing to the age profile, with funding allocation often based on particular age cohorts.

> *Funding wise, as a public sector and voluntary worker, a lot of the funding I can find is ... age friendly and including older people ...[it is] hard to find an avenue to money that focuses in on people with dementia.* (T9)

Increasing clarity around supports

Participants highlighted a need for the identification and mapping of community-based resources, to connect people with YOD to supports in their area. Information on dementia services by county was said to be clear, however, participants highlighted a lack of information about additional generic community supports. A community worker outlined issues in her local catchment area, and what might be helpful.

> *We need a repository ...online ...of all the services that are available, because there's an awful lot of people out there doing a lot of good work, but nobody knows about it. And I think that's a good place to start, even if we could do it within our own, you know, our own kind of catchment areas.* (T7)

Likewise, a healthcare professional identifies a need for better practice amongst HCPs regarding social prescribing to community supports.

> *There needs to be a lot more education…when it comes to social prescribing ...it's a relatively new concept …A lot of primary care teams, PHNs, doctors, nurses don't know …those services exist …it's just a bit of more joined-up kind of thinking and signposting I think is necessary.* (T8)

This was deemed to be particularly relevant for persons who did not wish to engage in dementia services. Including social models of support would provide greater choice for the person and their family, to identify relevant avenues themselves.

> *[if we could tell people on diagnosis] ...that there are services there …like 'Understand Together' …key places somebody can be signposted towards …a suite of services that they can …decide themselves whether they want to engage with or not, rather than …need for the person to …do their own research around, and families.* (T3)

The challenge of mapping all available services and supports was highlighted, and it was specified that the identification of local community supports that may be beneficial to people with YOD was a starting point.

Collaborative Practice.

Participants highlighted the importance of creating inclusive practices within the community. This was felt to be reliant upon collaborations between multiple stakeholders across sectors, channels of communication between HCPs and people who work in community settings, and partnerships with media outlets and national organisations.

> *It's about getting everyone involved. It's everybody's business. It's a bit like (HSE initiative) Every Contact Counts. And that's really important for us in terms of dementia… it's providing an inclusive community that people are aware that 63% of people with dementia are residing in the community. So, it's important that when they meet someone with dementia, that they are somewhat prepared.* (T5)

An example of ways to increase community awareness and collaboration was via sports organisations with scope across different generations, locations and media.

> *They have huge TV coverage, the GAA ...even if it's signs up in parks …and it spans the generations …* (T2)

Another participant discusses business partnerships as a potential area to offer training to become dementia-inclusive. Several participants noted the efficacy of media outlets in raising awareness surrounding YOD. Particular emphasis was given to regional and local radio as a way to reach individuals and community organisations.

> *Local papers, and particularly local radio ...where you let your local community group or community support go on the radio …advertising …that they are inclusive of people younger onset dementia …Certainly, in our community, [more rural] … local radio is where people get almost all of their information I think … (in addition to) raising awareness.* (T9)

Similarly, the many benefits of collaborating with organisations outside of dementia services was highlighted.

> *County councils and community development officers are very good. We recently got one on our meeting on our group, and it's working very well. They have the finances as well to develop (initiatives).* (T9)

Harnessing existing supports.

Participants discussed the issue of creating specific services for small numbers of people living with YOD who are geographically dispersed. Rather than developing supports specifically for people with YOD, it was suggested that community-based supports could be empowered to be more inclusive.

> *It's about empowering …community leaders to include people living with dementia [in their services and providing community leaders with guidelines to support that person] …the numbers are smaller in younger onset, rather than having specific groups [it's] about trying to include them in their existing community groups.* (T9)

Capitalising on existing resources could potentially address issues surrounding sustainability and also reduce the focus on the dementia. To facilitate this, existing communities should be informed in relation to understanding of YOD and practices that are dementia-inclusive.

> *It shouldn't be …dementia-specific services. …There needs to be a whole awareness there in the community …The facilities that are out there…Have an awareness of young onset dementia, so that you can actually go to whatever you like to do, but that it can be accommodated to facilitate, whatever needs, whatever extra supports you might require.* (T7)

Participants argued that the needs and preferences of a person living with YOD must guide how they are supported within the community.

> *It's meeting the needs of the individual …what interests that person has and how we can support those interests. And everyone's going to be individual. We're all very aware of this. Everyone will need a different, you know, array of [supports] to be offered.* (T2)

Specialist supports already available in the community could address the specific needs the person with YOD may have by providing issue-specific support (e.g., financial and legal advice) as opposed to dementia-specific services.

> *Young onset dementia is very different. You're looking at the likes of mortgages, kids, and financials, you know, wills ...It's a whole different ballgame for young onset. So, it's more the [specific] organisations that are out in the community for everybody …to access.* (T7)

4.1.2 Theme 2

Ways Community Supports Might Be Enhanced.

A Nominated Point of Contact.

Participants highlighted the importance of having a nominated point of contact who supports and links with the person living with YOD. It was considered important that every person with YOD be assigned a nominated point of contact from time of diagnosis.

> *I think when someone is diagnosed …there needs to be a young onset dementia advisor …the numbers probably wouldn't allow us, but there needs to be a link worker for them.* (T6)

A nominated point of contact can provide signposting to relevant community-based supports that may be needed, such as information around legal issues and applying for entitlements.

> *A parent [with YOD] has gotten to the stage whereby her son needs to apply for a power of attorney, and they did not know …they should have been looking into this years ago. There are steps to be followed to achieve this … these are things that need to be explained at the start, and the dementia advisors are an excellent service.* (T8)

> *[Community welfare officer] They're still available. Just have to find them. They have moved out to the unemployment centres, they were health centre based. [whilst they are now generally city based] …they're still there and have, provide good services all the time.* (T9)

There was variation in relation to who should provide this support. Examples mentioned include dementia advisors, public health nurses, and social workers.

> *Somebody who has a good understanding, good knowledge of dementia, be it a ...support worker or that, you know, is ...fully trained ...and will support you to do what you want to do.* (T6)

Social approaches.

Participants expressed that social models of care should be prioritised amongst healthcare professionals. Supports of a social rather than medical focus was deemed to be more appropriate in many ways.

> *The supports are now very much, you know, under medical [and other] hierarchical systems…* (T3)

Participants reported that health service options are often more well-known or more readily utilised by HCPs. This could mean that people diagnosed with YOD are signposted to health or dementia services rather than connecting with community supports.

> *A lot of young persons' needs with dementia are not health related. Their (needs are) social or …support or …engagement. I think those of us who work in the health services find all that can be difficult to navigate.* (T3)

It was further argued that solely focussing on dementia-specific supports might add to the stigma surrounding dementia.

> *I think we need to take away the stigma from the whole dementia element. So, I think often providing specific supports can be equally stigmatising.* (T5)

Social prescribing was regarded as a valuable approach when it comes to connecting people living with YOD to supports. This practice was referred to by several participants and revolves around identifying and matching the social interests of the person.

> *Social prescribing …we know from other countries the benefits ...The pairing up of that support is so vital …you really have to be taking a social snapshot of the person with the dementia, and then going back to your ...database and going … what's the common denominator here …And if you can just find one thing that there's a commonality ...that's where you start.* (T6)

Interestingly, one participant suggested that the increased use of wider community supports might serve as a means of identifying and engaging with people who are not connected to formal services.

> *I've been primarily using existing dementia networks of people who are already known to dementia services in the county…but we're missing those who aren't already engaged ...* (T9)

Transport and Connection within the Community.

The topic of transport and accessibility featured within focus groups. One participant described the issue of transport for people living with YOD within larger counties, who need to travel considerable distances to access services.

> *Transport could be an issue for some, especially in the larger counties, just because…It's so vast…there's varying degree of services and supports. So, your location, your address, can nearly dictate, you know, what's available to you. And that's unfortunate.* (T6)

Arranging transport to and from supports was deemed to be important, particularly as it could be a barrier for engaging in community supports.

> *[When] there is a resource…how do you get people over and back? And very often that could be one of the problems that the family members are busy and that person who used to be independent prior to a diagnosis, and was able to make their own way, is not able to make their own way anymore, for whatever reason. And then it's either a transport or companion which is missing.* (T2)

Ensuring connection to the community was felt to be of particular salience in rural settings.

> *Life can pretty much grind to a halt pretty quick, if you're living rurally, or you don't have... access to transport.. if you can't get out of your house… if you feasibly can't get somewhere, If [family]…is working all day, life can come to a stop.* (T2)

Suggestions were made by participants to help address such challenges, notably providing transport to and from community activities. One participant suggests that HSE policy be reconsidered to allow companion to assist with travel around home care packages.

> *The HSE relaxing even a bit... the rules and regulations for the care packages and allowing a companion to (assist with transport)... (Private homecare) can bring people in their cars, the HSE can't. And that is a reality. So, if I have a (private) carer, she can bring me to the [local community], and I can do my shopping ...and meet people and be out and about. I can choose my own piece of salmon or whatever it is. Whereas if I have a HSE carer…. not an option for me.* (T2)

Awareness raising and training.

Training and education was suggested as a means of enhancing awareness for community supports that are inclusive and accessible. Participants suggested delivering training across networks to obtain a wider reach, and training flexibility to allow for the varied nature of organisations and staff. A healthcare professional stated that she would be more confident in signposting people with YOD to community supports that have received training.

> *Training or that awareness outreach …. to community organisations. …. If we are trying to link somebody, we can kind of have the confidence to say, yes, I know that that particular group has had some training and that would be a nice one for you to link in with if you're interested.* (T3)

A number of community-based organisations were suggested as a means to raise awareness and education, such as local businesses, and libraries.

> *We have training in the libraries now. The librarians… a person with a younger onset dementia is more likely to go to a library.* (T2)

> *MABs and citizens information...getting them to have that education piece about YOD and what the complexities or their needs are and how they can deal with them and help them.* (T7)

Education in schools was proposed by a number of participants, in order to ensure the next generation has an awareness of dementia and inclusivity. Intergenerational activities were also suggested.

> *We really need to start focusing say on… teenagers and younger kids…there's a piece of work there for transition year students…because they're the future. And if they understand (dementia and YOD)… it will just make it easier for people in the future.* (T7)

This model of training within the community has already been rolled out in relation to dementia generally, and it was suggested that training already being provided could be expanded or modified to include specific information on YOD.

> *We are training security staff in shopping centres…if we could train (more) community services, even very briefly, perhaps we could help bring down that*

fear. You know, take the mystery out of it …You know, it's just a person who needs (support) like everybody else. (T2)

We're working in partnership with [name of organisation delivering online training] … trying to build a geographic base around pockets of the county in terms of awareness. (T6)

In addition to training, it was argued that more in-depth work was required, with training being only the first step in the process.

It's not just about training…. It's about working with them at the grassroots and foundational level. And they're part of the process… that whole interagency design. (T5)

Participants suggested that for organisations that wish to become more dementia-inclusive, or who are engaging in dementia training, visual indicators could be used to signify this.

It might be an idea that if organisations have completed training in dementia, or their volunteers had, that you would have …a logo or a sticker. So then, somebody with dementia would see that on a window, and know, 'I can go in here, and I will be understood and welcomed'…no words have to be spoken about it. (T8)

Also discussed was the importance of supports for communities who are engaging with people with YOD, including additional written guidance or contact details for a dementia organisation.

People are working voluntarily, and they want to include people …so it's about really easy, simple to find guidelines …maybe even like someone at the end of a phone [to help with]… really simple questions (T9)

Information and Communication Technology (ICT).

The use of ICT was described as being both a barrier and a facilitator to community engagement. On the one hand, technology can facilitate accessibility and inclusivity. In the next extract a participant discusses the use of social media to access information relevant to their role in healthcare.

Social media, because that's actually where we get a lot of information, and groups... for families and groups for people with young onset dementia, is like the likes of Twitter and Facebook. They're the supports and usually from the UK. (T7)

The use of apps to support connection amongst community groups was discussed, such as What's App. However, it was also acknowledged that using ICT may be challenging to people with are living with cognitive issues, and who may have issues with access.

[Online club] biggest challenge is helping, you know so there may be a family member who helps the person connect up, and once they're connected up they are okay. (T4)

Realities of broadband connectivity for some …. rural clients. And we also have the technology, some don't have the technology. (T4)

Several participants suggested that to be accessible and inclusive, community-based services should provide both face-to-face and virtual options. A prime example provided by a community worker was services that have moved almost entirely online, such as banks.

> *That's where the big fall down is, to be able to have the person to meet with there, the face-to-face meetings …I think it's still needed …It's not all available online.* (T9)

4.1.3

Theme 3

Examples of Community-Based Supports

Examples of supports encountered by participants.

Across focus groups with healthcare professionals and community workers, supports such as support groups, peer support and social community groups/programs were discussed as potentially beneficial. The majority of supports and interventions discussed were non-dementia focussed. Suggestions surrounding innovative practices in the community as opposed to structured activities, were also discussed. A participant discussed importance of social groups such Mens' Sheds in facilitating connections within the community amongst people living with YOD.

> *Social groups ...[for example] Men's Shed [or similar groups] ...it's meeting people within your own community. I think that's really important. That they are connected, connecting with people.* (T8)

Arts-based community initiatives were also discussed, such as engagement with museums and libraries.

> *Art in particular is very good ...and valuable for the people with dementia...That they have that creative [outlet], it's very fulfilling and meaningful... So it would be great to look at developing areas of that even [further].* (T9)

> *The libraries are a fantastic resource which is not dementia specific. So, they feel a little bit like they fit, you know, they look like everybody else.* (T2)

Music-based social clubs are another example of community-based support for both people with YOD, and also family members.

> *Music led social clubs, you know, a fantastic space, and a fantastic space for carers as well. Because I saw natural networks of support develop behind the scenes.* (T6)

Participants discussed examples of physical activities and outdoor activities they had encountered in their line of work and in their communities.

> *Physical exercise...the structure and I suppose the presence of a trainer and that, that you know, it's…people seem to enjoy it, feel well, physically well, and you know if we feel, you know, release the endorphins and do something maybe that they haven't done before.* (T2)

Another community worker discussed a community-based intervention which organises farm visits.

> *[Attendees] get a chance to work on the farm, walk around, feel part of that, that working farm. And there were farms throughout the country that signed up to that. And then the people facilitating it received training. And that was a wonderful initiative.* (T2)

On a different note, a community worker suggested that local businesses are ideally placed to support areas such as volunteerism or employment for people with YOD.

> *Occupation is big…meaningful occupation for those under 65. So, trying to identify businesses in the community that would support employment … If they were engaged in that meaningful activity, and a quality of life to get up and be engaged, you know, and stimulation mentally, and communication. Because it's all about maintaining communication if they are occupied.* (T9)

Examples of inclusive practices.

When aiming to be more inclusive, participants suggested that a support person might be available to assist the person to feel welcomed, initially.

> *[If you know] you're going to be met at the door, and you know you're going to have somebody to sit with and chat with for the very first session really does ease anxieties* (T8)

Another participant suggested that with awareness, this type of support could be forthcoming from volunteers within community groups.

> *Good resources there within any sort of community support, to have good volunteers, so that if they see someone withdrawn that there's someone available to offer, sit down and spend the time with that person, or just to link in with them and say 'is everything okay?. So it's a big team effort.* (T6)

Participants suggested that within public spaces, there could be regular quieter times offered, such as an hour in the morning once weekly, to provide a calm space.

> *… You go at the quieter time, or you go at a time where there's a trickle of people so that …you know it's quiet, but you know that there will be few knocking around.* (T6)

Participants stated that a referral is still required to attend certain services, which could pose a barrier to access. In community-based supports, having an open-door policy was proposed.

> *A person in a community organisation, which has an open door and a friendly face, and you don't have to have, you don't have to have a diagnosis or an appointment or referral, you can knock on the door and talk to somebody.* (T1)

One participant working in community banking discussed an intervention their organisation established; a helpline available to customers as part of a vulnerable customer support initiative.

> *We have a helpline, which is an external helpline for customers to call directly or their family or carers. …Vulnerability, being kind of broad…everything from gambling to financial abuse, to you know mental capacity issues…[also a] website… points to where to call.* (T1)

Other helpful initiatives included more examples of visual indicators to alert staff, for example the 'Just A Minute' cards to prompt people in the community to afford more time and patience that the bearer may benefit from.

> *...A national initiative, and in essence, it's called JAM – 'Just A Minute', to give people an extra minute, and it's acknowledging, without having to broadcast it, that ...I have an issue with recollection or with learning or hearing, or whatever the issue.* (T1)

4.2 Summary

This section provides an overview of findings from focus groups with healthcare professionals and community workers. Key areas discussed include the centrality of awareness of YOD and recognition within policy and practice. There are suggested ways to increase connection within communities. Examples include the provision of a nominated point of contact for signposting to community supports and social approaches to planning care. Participants discussed ways in which supports could be enhanced to be more inclusive of people with YOD. There are innovative examples of existing supports that could be helpful, and some examples of inclusive practices that could be implemented, such as supported volunteerism or employment in community organisations, and one to one support if required, in settings such as banks.

5 Focus Groups with people with YOD and families

Focus groups were held with sixteen people with YOD and family members. Drawing from the qualitative data within focus groups, three main themes were constructed and are presented in the table below.

5.1 Findings by theme

Table 5

Theme 1	**Awareness and clarity**	• Wider community awareness • Advertising of community supports • Key Worker to connect with the community
Theme 2	**Wider issues impacting people with YOD and engagement in communities**	• Employment or Meaningful Occupation • Accessing entitlements and benefits • Support to continue everyday life in the community
Theme 3	**Suggestions on preferred supports**	• The importance of social supports • Examples given of helpful community supports

5.1.1 Theme 1

Awareness and Clarity

Wider community awareness.

The importance of community awareness of YOD was discussed widely. One family member discussed the importance of a basic level of awareness and understanding of YOD in the wider community.

> *There's a certain amount of reticence among people that, you know, there's something different about this person… you might have a broken arm or you might be in a wheelchair and they'll accept you much easier than if maybe they have to repeat things to you...Like in the bank, you might be slow about using your ATM card.* (T13)

Community awareness was further cited as important in reducing stigma around YOD and to better support people to participate in the community.

> *We can be quite dismissive of people who we feel are not on the same page cognitively as us... We need to know that people come in all shapes and sizes, with all kinds of disabilities and that that doesn't make them less than.* (T14)

Participants called for YOD-specific awareness campaigns to address this stigma and improve understanding by the public so that people with YOD may participate fully within communities. Media campaigns were suggested in the following example.

> *[Referring to a previous campaign] It was ordinary people saying, 'you know, I have dementia, I have dementia'... It's not even necessarily dementia specific, but it's just about helping people do the things they want to do in their lives... and dementia just makes it hard or the dementia itself is a barrier. You know, and people reading the signs and going out to assist them in what they're doing...* (T12)

Other participants suggested that increasing awareness of YOD in the community could be achieved by providing information around YOD and encouraging people in the community to become active participants in inclusive practices.

> *If a leaflet is ... given to people who work in services, say in the community, like, you know, people who check tickets in the trains, for example, or people in banks or shops, would be to be able to read the signs, you know, to know that there's an issue… that might be an embarrassment around paying or that something is wrong…Sports groups or like [community] groups, and all of that, people could be made aware that they might be needed ... That they would be somebody who would volunteer depending on how big your club or an activity is.* (T12)

Participants suggested that a review of restrictions, or usual practice, to better facilitate people with YOD and their specific needs might improve inclusivity. Awareness is needed so that existing supports and services within the community can be accessible to people with YOD.

> *People don't realise that they have the key, you know, by just taking away some of the requirements. People then can participate... in the community.* (T12)

Advertising of community supports.

There was a consensus that people would like to access support in their local communities, and that there were some examples of relevant supports already in operation. However, knowledge of where they are, and how to access them, was said to be unclear among the participants with YOD and families.

> *From the outset, it should be discussed that there are like a spiderweb of possibilities, you know lectures in the community, activities, there's Alzheimer's, there's you know research projects going on, and all of that information is held by the various bodies. But I think it needs to be pooled, like constant feeds on what's happening in your area, what's happening across the country.* (T12)

Focus groups discussed a need for clarity relating to supports and activities both locally and nationally and clear communication of these through multiple channels. Several participants highlighted the particular usefulness of online repositories for information on services/supports, combining both local dementia services and generic community-based services. Participants felt that HCPs also lacked information on community supports, and that clarity of community supports should be addressed.

> *A lot of the supports seem to be random, and hit and miss, and you come across them…by chance it seems…I think whether it's in your GP or in a memory clinic, should have an ongoing…a requirement to provide ongoing at least information. And that information should be good.* (T12)

Key Worker to connect with the community.

Following diagnosis, it is felt that HCPs should focus upon helping people engage with the community and connect them with a nominated point of contact. Participants discussed the importance of dementia advisors as a link to the community. Participants also variously described roles such as link workers, key workers, or support workers (as used in other sectors).

> *Honestly, it's a link worker people need in the beginning…and that link worker could be …someone from the community. It's not about medical [care] it's about keeping your social connections….and help you to maybe fill out a form…or go to the social welfare office....you can help the person to engage, continue engaging.* (T10)

It was stated that a nominated person could provide practical support on an ongoing basis, in particular for the first year. This person could connect the family to relevant supports within the community.

> *I think that each family should really have a support worker who actually really does support them...who actually comes out on a regular basis and discuss with you face-to-face, just your family, what do you need right now, and where can we kind of guide you...because he is deteriorating. And with the correct help it could be a slower deteriorating.* (T14)

There are specific needs faced by a family living with YOD, and these needs change as time goes by. It was suggested that regular support from a nominated point of contact would help ensure supports are offered as required. The specialised nature of the needs (e.g., financial, work-related) means that timely signposting is vital.

> *That key worker can be like (a) a psychological support, but (b) would know what exactly is needed at that particular point in the journey. Because needs change. And a keyworker because they would know exactly what is going on with the family, would know what is needed at this particular time. If you had a key worker assigned to your family, they wouldn't necessarily be able to help you do the form, but they would be so [knowledgeable about dementia]…that they would be able to [sign-post you to services that will help].* (T14)

5.1.2

Theme 2

Wider issues impacting on engagement in communities

Employment or Meaningful Occupation.

The topic of employment was discussed within many focus groups. In addition to financial impacts, loss of employment following a diagnosis of YOD often caused psychological and social impacts for the person with YOD and the spouse.

> *I went out to work, I had to get a full-time job. And I went out to work. And [person with YOD] was at home all day, every day at the age of 44...it was a disaster. He was alone with the diagnosis ...* (T12)

Employer and employee information and training was cited as important. It was stated that increased awareness of YOD could ensure employers are more vigilant and more confident in supporting employees experiencing a diagnosis.

> *[Discussing information for employers and upskilling for employees]… Upskilling… I think that's really a very, very important part, because they don't understand, and they don't know...[it even more challenging for self-employed]… It's about everybody knowing how you're protected within employment law.* (T10)

It may be more suitable or preferable for the person with YOD to seek a different form of employment, and participants suggested that communities might be open to this. Employers could offer positions and roles to people with YOD in the community that align with their abilities, rather than the person leaving the workforce.

> *There's all kinds of jobs people could do, if they were encouraged.. and this is when we talk about what can- how the support could be there in the community… maybe some people might be really happy [working] in a [different type of job in the local community] supermarket, stacking shelves… as long as they're shown...I think there are tasks… that some people, not all, but some people could do, which could be meaningful.* (T10)

Accessing entitlements and benefits.

There was a consensus amongst people with YOD and family members that YOD is not adequately acknowledged or addressed in policy and practice. Systems in place for accessing government benefits and entitlements such as disability allowance were described as complex and difficult to access. Specific examples included the disabled person's parking permit and travel passes. This lack of clarity can negatively impact the ability of people with YOD to navigate and connect with their local communities. The following example highlights the particular difficulty people with YOD have in accessing these supports.

> *To get on state disability it's quite difficult…and then then you then you eventually get it and then you apply to get your parking badge. And then you can't get your parking badge because Ireland only will give a parking badge to people with a physical disability...Cognition is not part of [the assessment].* (T10)

Support to continue everyday life in the community.

Participants highlighted ways that people with YOD can be supported in continuing with everyday life activities. A social prescribing approach was highlighted as a means to ensure people are linked to and supported within communities.

> *What I think is the most important, I think, helping us to do the things we always did [locally]... And if that's what are we doing in our life, our social health to me is one of the most important things in particular for younger onset...It is [linked to social prescribing]... and that is back to the community.* (T10)

The importance of individualised preferences was discussed. Participants made the point that people differ in their interests and must be supported to continue with activities pre-diagnosis. It was suggested that rather than creating new dementia-related supports, it was preferable for existing activities to be accessed. To do this, minor changes might help to nurturing inclusivity and enable participation in meaningful ways.

> *It's not about setting up activities, it's about joining in or finding ways to facilitate life in the community…Each person is different...what I would see as really important is support for people to continue with the engagement they already have.* (T12)

The Public health nurse was identified as a key person to support social models of planning for people living with YOD in the community. In the next extract, a family carer describes how a public health nurse allocated home care hours for the person to engage in community activities.

> *Our public health nurse was really good. And she gave him six hours, but they were two sets of three hours. And [names person with YOD] used to go out with that person. We have a dog as well, so they'd walk the dog, they'd go out for a walk, have coffee, they'd go into town to a museum, all sorts of things...* (T12)

Transport and accessibility was cited as important, in order to access community-based supports. For people who are not entitled to free travel, affordable and easy to use transport was advocated for. A positive example of engagement with a community-based organisation was shared by a family carer.

> *[Husband with YOD] wasn't able to manage money and tickets...he was very reluctant to use the train ... I spoke to somebody in Irish rail. And it took a lot of*

explaining and persuasion. But eventually, we paid for a ticket that let [name] go in and out of the train whenever he wanted... It just meant he didn't need to negotiate the ticket styles...because he actually got off the [train] a number of times and got taxis because he was afraid … he couldn't remember if he had a ticket. (T12)

5.1.3 Theme 3

Suggestions on preferred supports

The importance of social support.

Participants shared suggestions of community-based supports such as social groups and peer support. Participants highlighted the centrality of social interaction and groups that offer support within the community. The nature of the activity was deemed less important. A person with YOD described attending a knitting group: because it was socially orientated, it connected the participant with the community and provided a sense of belonging.

> *It was great for me who needed a connection…back into the community…and of course every one of them in it didn't like to knit or sew…it was a bit of fun. And that is one of the real…I can't say it often enough, the real difficulties is that sense of purpose taken out of our lives. That sense of not belonging taken out of our life. That sense of us afraid to go out and say we have a brain disease.* (T10)

Community centres or a centralised local base where activities could be developed was considered important. Additionally, a person living with YOD highlighted the key role that family resource centres play in facilitating positive community activities.

> *I think having those positive community things, family resource centers, up and down this country are running all the time. So there's loads of events…mental health programs, if people are suffering from depression through this... there are all kinds of supports there for them. I think we should tap into all of those resources that are there that are never talked about.* (T10)

Having a contact person within community supports, even for the first session or first few sessions, can help people feel more comfortable and included.

> *I think when people start with dementia, they're tending more towards one-to-one support. So sometimes in a big group, they get lost. If they have a contact name, if they have a person that they kind of sit beside and then that they know to have coffee with and have a chat. That's, that's good.* (T12)

Crucially, it was deemed important that supports offered to people with YOD, and families, be age and stage appropriate. Participants argued that this is often difficult to achieve in dementia-specific supports.

> *[Discussing a cognitive stimulation program]…I actually became really depressed coming home…because people….were much further along than me, even though they were called younger onset because they were under 65….early onset...some of them were over 65… they were really advanced…I think we need to be put into [supports that are] age and stage appropriate.* (T10)

There was a sense that peer support for families, though welcomed, was not available. Here this participant provides the suggestion of 'Family matching' as a means to enact peer support for families and people with YOD.

Why can't I just meet somebody who is actually on the same page as me, with the same disease, in roughly the same age range...Families with YOD should in some way be connected to one another. (T14)

Examples given of helpful community supports.

Within organisations, having an awareness about dementia and a practice of inclusiveness was said to be key.

Men's Sheds…they very much accept people...if they want to talk, if they don't...All of that lends itself to somebody being able to go and not being under pressure to perform. (T12)

Engaging with community activities that are dementia-friendly but not dementia focussed can provide a sense of normality and belonging.

They went to an [organized museum tour]...It wasn't just all about dementia. It was about being involved... It takes you out of the dementia world altogether. (T11)

Participants discussed opportunities for volunteering in their local communities. Again, it was deemed to be important that the focus was upon the person not the condition.

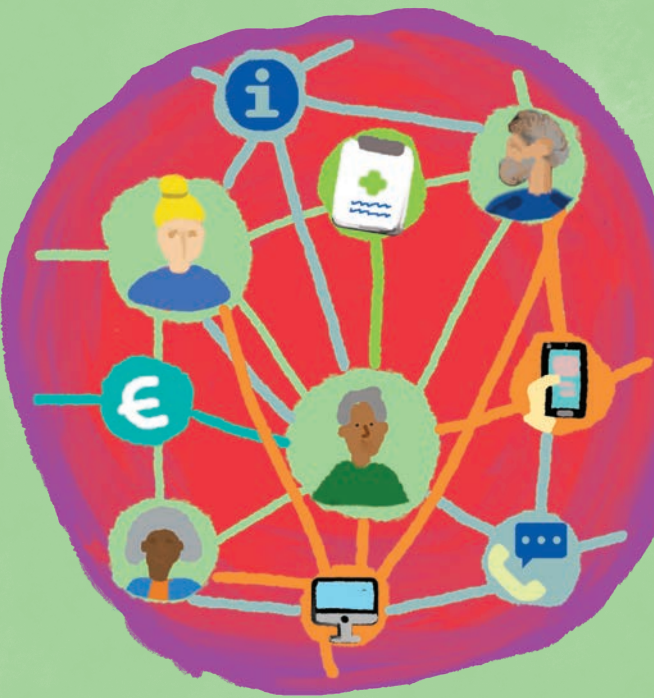
Tidy towns … there was a few people there [with dementia] that were involved in nothing else [no other dementia-specific supports]...They were part of the group... For that two hours while they were tidying up the [community] they were all equals. It's a leveller. (T11)

Supports that promoted physical activity were also seen as beneficial. A family carer gives the example of how a local gym offered a community engagement initiative, whereby one to one time was offered to the person with YOD on a weekly basis.

[Our] ordinary public gym...had an officer or a trainer who – there was a scheme once we paid for his membership, that somebody would give him time every week. And that was amazing to see. She had [person with YOD] running on a treadmill, while they talked about sport. (T12)

5.2 Conclusion

Findings from focus groups with people with YOD and family members highlighted the importance of awareness of YOD in the community. It was felt that encouraging a wider community understanding about YOD and the associated challenges will help to foster an understanding of the importance of community participation and inclusive practices. People with YOD should receive support to access relevant information and services in the community. This could be facilitated by a nominated point of contact, or via an appropriate information package, such as a mapping of community supports nationally which might usefully be made available online. Findings also identify a need for HCPs to place a greater emphasis upon a social model of supports. Finally, findings show that many benefits can be harnessed from within communities, by adjusting existing supports rather than developing dementia-specific supports.

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6 Summary

This research project reported on the findings from three studies; a review of the literature, focus groups with healthcare professionals and community workers; and focus groups with people with YOD and family members. Findings were also reviewed and discussed with key stakeholders in order to gather consensus on key areas of focus. Regarding models of support for people with YOD in the community, findings point to a preference for continuing preferred day to day activities, rather than a focus on developing dementia-specific interventions. It was highlighted that there remains a lack of relevant supports for people with YOD and families, which further illustrates the importance of harnessing support from within communities. Findings point to key areas identified across the studies which warrant consideration.

Individualised approaches.

When discussing models of support for people living with YOD, a particular challenge is that individual needs and preferences are complex and unique. It is essential therefore that all facets of support recognise the inappropriateness of a ‘one size fits all’ approach to supporting people with YOD (Fox et al., 2020). A significant strength of communities is the wide range of supports and initiatives that are already in existence. In turn, fostering community interaction serves to grow accessibility and help nurture supports that are dementia-inclusive (Mayrhofer et al., 2020). In line with recent findings of Fox et al (2020) in order to address the specific and varied needs of people with YOD, a “whole-of-community” approach to care is needed.

Social models of support.

Aligned with this, findings suggest that a key way to harness community-based supports that could be relevant or beneficial to people with YOD is by using a social model of support. Social models of support are holistic means of addressing issues such as social isolation, loneliness and fear, along with lack of engagement, which can negatively impact a person’s wellbeing, particularly amongst those with existing health conditions (Health Service Executive, 2021). HCPs and community workers can use this approach to identify what is important to an individual, as opposed to focussing on needs or limitations (Polley, Fleming, Anfilogoff, & Carpenter, 2017).

Specifically, social prescribing is an ideal means by which health and non-healthcare professionals can ensure people with YOD are referred to and connected with a variety of services, including non-clinical community based and/or voluntary organisations (Health Service Executive, 2021). In Ireland, social prescribing is receiving more focus. Endorsed by Healthy Ireland, Sláintecare and the HSE, social prescribing services are dispersed nationally in more than 30 communities (Health Service Executive, 2021). In addition to improved outcomes for individuals and families, past research on social prescribing points to the economic gains such as reduced use of resources within hospitals, and the social advantages including investment growth and increased funding into community/voluntary sectors (Dayson & Bashir, 2014).

However, the current study findings suggest that social prescribing practices in relation to people with YOD are underutilised, a finding supported by the evidence base (Husk et al., 2020)**.** Chatterjee, Camic, Lockyer, & Thomson (2018) propose growing the level of social prescribing development and provision via the evaluation of wellness and health benefits of planned and current schemes, relative to both communities and individuals therein. Such research could be made widely available to promote social health at a national level (Chatterjee et al., 2018).

We know that people with YOD experience many unique challenges in relation to employment, finances and legal matters. Current findings indicate that using a social model of planning and support means that the person can be supported to access salient and reliable information relating to these specific matters. Health and social care professionals should ensure they are familiar with key organisations in their areas to support with signposting in this regard (Gibb, O'Caheny, Craig, and Begley (2019).

How to improve supports.

Across the focus groups, examples of pragmatic improvements to community supports were shared, in addition to some exemplars of innovative practice. These include steps that could be taken to optimise community environments, and extending of existing supports to be inclusive of people with and YOD. At a wider level, there is a lack of awareness and understanding of YOD in the community, and of the unique needs and challenges faced by people living with YOD. Within their guide on creating dementia-friendly communities, the ASI (2016) also identified awareness raising as a key consideration.

Within the current study, training was cited as a key mechanism to improve awareness in the community, and was suggested as a means to implement dementia-inclusive practices within community-based organisations. Training and organisational knowledge has been linked to other, important concepts. For example, for communities, supports and resources to be inclusive of people with YOD, there may be elements of positive risk taking required. A holistic approach to care is needed, requiring innovation and flexibility. It is vital that we acknowledge the rights of people living with dementia to live a full life, and to continue to engage with the places and activities they enjoy (Mapes, 2017). There is now a growing evidence base and related legislation to safeguard these rights, and it is important that the relevant organisations in the community are informed and supported in this regard (Morgan and Williamson (2014).

Accessibility.

From the current findings, there are striking examples of interest and innovative practices within community-based organisations. Findings highlight additional ways in which communities can adapt to become more inclusive and supportive of people with YOD. Owing to the disparate nature of supports, and wide geographic spread in some areas, findings point to a need for accessible and affordable transport for people living with YOD so they may access supports in their community. Furthermore, costs associated with services presents as a barrier to people living with YOD who may have reduced financial income, and so should be considered. There is a role for volunteers or community members to support people with YOD attend community activities, in particular at the beginning.

Clarity and connection to community supports.

The ability to readily connect people with YOD to local supports was highlighted by many HCPs and community workers. On this note, it was felt that whilst there was clarity in relation to dementia services county by county, there remains a lack of information about additional generic community supports. Findings point to a need for greater clarity around community-based supports, for example, identification of and mapping of resources and supports in local areas. Findings also highlight the importance of a nominated point of contact for people with YOD and families who can ensure that they are aware of or connected with the appropriate community supports, when needed.

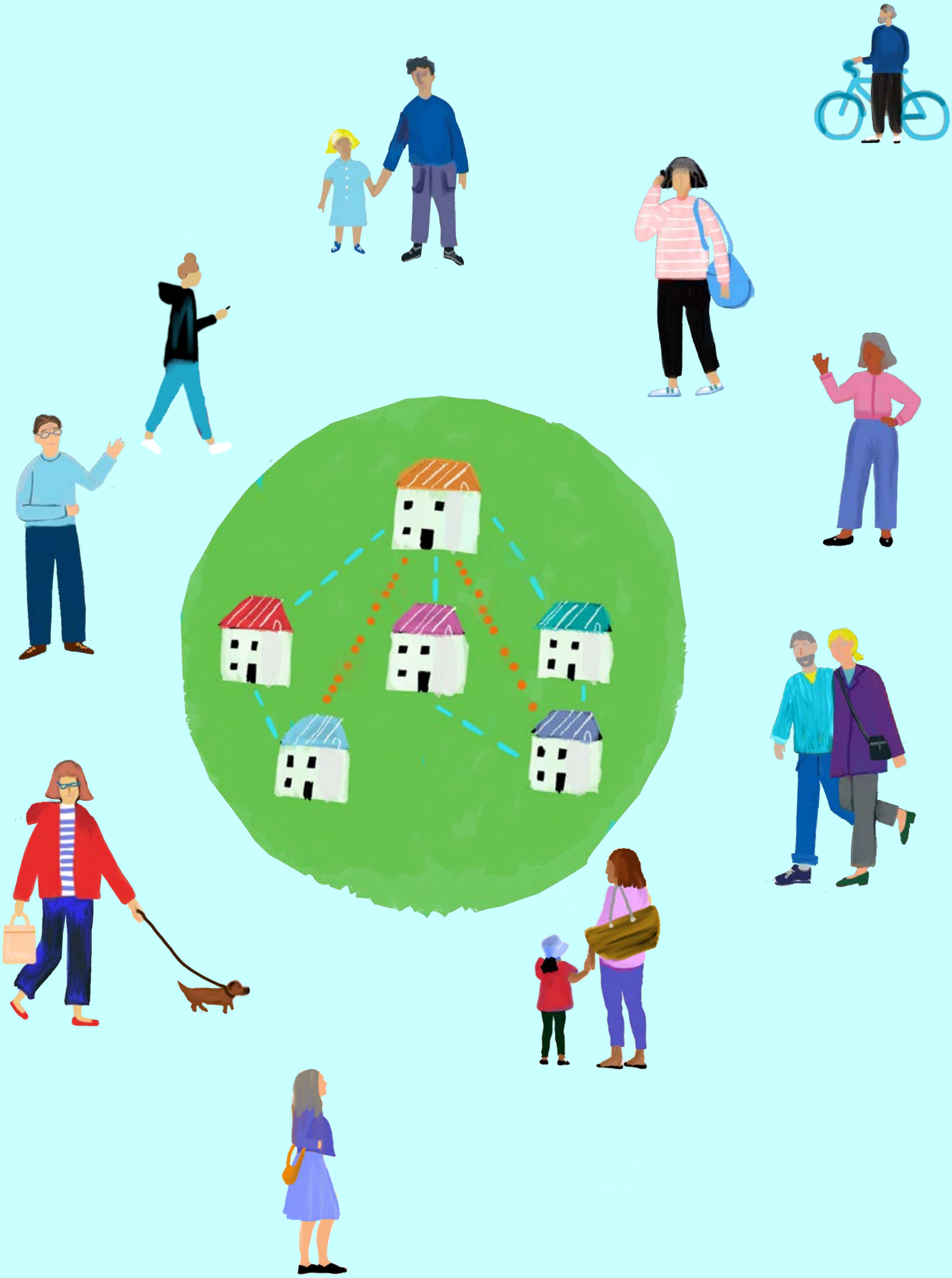
Practice examples.

Many positive changes have emerged in recent years; there is well-supported evidence around interventions such as support groups, peer support and community groups that foster interaction and participation. This is further supported by the perspectives of people with YOD and families expressed herein. Enhancements in information and communication technology during the advent of Covid-19 were noted, and findings point to many varied examples of innovative practice originating within our communities. Virtual technologies can facilitate community engagement by offering flexibility to those geographically challenged or restricted in their movements, facilitate information access, and support people with YOD with planning/organisation. On the other hand, technology can be a barrier to community connection due to difficulties using technology, poor broadband connectivity, lack of access to the technologies being used, and impersonal online communications. Participants called for relevant supports to be made available both virtually and face-to-face to optimise accessibility.

There are further examples of positive initiatives within the community. In the coming months, there will be a national launch of a universal icon for use within organisations and communities which are working towards becoming dementia-aware. Also under development is a dementia champion induction program, to be available to community members and organisations to support the creation of dementia-inclusive communities.

In 2020, the World Health Organisation published guidance on promoting dementia-inclusive communities. Key recommendations identified were the need to develop awareness campaigns, to engage in capacity building and civic participation in order to optimise the social environment of communities from a dementia-inclusive perspective (WHO, 2020). At a local level across Ireland, it is evident that advances have been made when it comes to supporting people with YOD to engage and connect within the community. As an example, amongst the recommendations from a recent report on transport by the Irish Dementia Working Group (IDWG), are the benefits of training for both people working within the transport industry as well as the wider public (Blake & Hopper, 2019). That report recommends that training should provide information on cognitive issues, to generate wider understanding of the challenges faced by people with dementia. Training can serve to reduce stigma and enable those working within transport to better support people with dementia and consequently nurture dementia inclusivity within such organisations. This is a finding which was echoed in the current study, where a need for specific awareness in relation to YOD was cited. In addition to targeting transport and access, areas of focus included arts-based organisations, sport-based organisations and organisations with a national reach. Another positive development will see updated training programs geared towards retailers, financial services and transport providers on topic such as dementia awareness and inclusive design (Dementia Elevator).

The area of dementia more broadly is experiencing an increase in focus and seeing many positive advancements. However, there remains a lack of awareness relating to the unique challenges faced by people living with YOD (Carter et al., 2018). People with YOD have been historically excluded from policy, planning and services (Mayrhofer et al., 2018; Rabanal, Chatwin, Walker, O' Sullivan, and Williamson 2018), an oversight which has resulted in significant social and psychological impacts amongst people with YOD in our communities. Current findings support the need for increased awareness, greater integration of sectors and the inclusion of YOD within dementia-inclusive practices across services and wider community supports, resources and organisations.



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8 Appendices

8.1 Appendix A

Grey Literature Search Queries

Non-Academic Gray Literature	
Search Engines/Databases	Keywords/Search Queries
The non-academic literature searches (n=2) employed similar terms to the academic literature searches. Examples include; 'young onset dementia', 'younger onset dementia', 'early onset dementia', 'community support', social prescribing', 'guidelines', 'guidance'	
1. Google **2. Google Scholar** **3. Lenus** **4. GIN** **5. NICE** **6. SCIE**	1 (young onset dementia OR younger onset dementia OR early onset dementia) AND (community support OR social prescribing). 2 ('young onset dementia OR younger onset dementia OR early onset dementia) AND (community support OR social prescribing) AND (guidelines OR guidance). **Search Limits:** The first 10 pages were reviewed in instances whereby searches exceeded (n=100).

8.2 Appendix B

White Literature Search Queries

White Literature **Option 1**	
	Keywords/Search Queries
Concept 1 Defining terms for young onset dementia Title or Abstract	“Young* onset dementia” OR “early onset dementia” OR “young* onset Alzheimer” OR “early onset Alzheimer” or “young* onset vascular dementia” OR “early onset vascular dementia” OR “young onset mixed dementia” OR “early onset mixed dementia” OR “young* onset frontotemporal dementia” OR “early onset fronto temporal dementia”
	Which were combined with **AND**
Concept 2 Defining terms for intervention Title or Abstract	“community*” or “community support*” or “community care program*” or “community care intervention*” or “community intervention*” or “community service*” or “community participation” or “Social prescribing” or “occupation” or “post-diagnos*” or “post diagnos*” or “postdiagnos*” or “support service*”

White Literature **Option 2**	
	Keywords/Search Queries
Concept 1 Defining terms for young onset	young onset or “early onset AND dementia”
Concept 2 Defining terms for dementia, and individual diagnoses	“Alzheimer’s” or “vascular dementia” or “frontotemporal dementia” or “Huntington’s disease” or “HIV” or “AIDS” or “acquired brain injury” or “Parkinson’s disease” or “Lewy bodies” and “cognitive impairment” or “neurocognitive disorder”
Concept 2 Defining terms for intervention or context of interest	“community support” or “community care programs/ interventions” or “community services” or “community participation” or “Social prescribing” or “employment or participation”

Search Strategy	
	Keywords/Search Queries
Databases	Medline (via Ebsco) CINAHL Embase Cochrane

THE ALZHEIMER
SOCIETY of IRELAND

The Alzheimer Society of Ireland is a national service delivery and advocacy organisation. It is person centred, rights based and grassroots led with the voice of the person living with dementia and their carer at its core.

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The Alzheimer Society of Ireland Helpline is open six days a week

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and Saturday 10AM – 4PM**

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