

# Evaluation of the Role and Contribution of Dementia-specific Day Care Services in the evolving Dementia Care Landscape

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# Foreword

It gives me great pleasure to present this evaluation of The Alzheimer Society of Ireland's (ASI) Day Care service. As the primary provider of dementia-specific Day Care in Ireland, The ASI has grant-funded this evaluation to elicit greater understanding of the role of Day Care in supporting people with dementia and their family carers. This evaluation uncovers the experiences of people living with dementia, family carers and ASI staff working in day care centres.

There are approximately 64,000 people living with dementia in Ireland and if trends continue this will increase exponentially in the coming years. The publication of this evaluation is timely in the context of this growing dementia population but also within the context of the COVID-19 pandemic, which has dramatically altered the landscape of dementia service provision and impacted the needs of people living with dementia and their family carers.

The Irish National Dementia Strategy importantly states that local, well-co-ordinated support services are needed to assist people and their families to cope with the choices and dilemmas confronting them, as a diagnosis of dementia can often be a distressing and challenging time. People with dementia and their family carers should be supported to live and die well, and appropriate support services, including Day Care, should be available to meet their preferences and wishes and to optimise their quality of life.

At a national policy level there is commitment to developing a national post-diagnostic pathway to address the complex and unique needs and preferences of people with dementia of all ages. This evaluation offers crucial insight into the role and contribution of Day Care in addressing needs along the journey of dementia.

I would like to sincerely thank the authors of this evaluation report, Maria Pierce, Kevin Cullen and Richard Wynne, for undertaking this informative body of work, and ASI service staff for their role in facilitating the evaluation process. Although dementia-specific Day Care is not a new model of community-based care and has been in existence in Ireland for more than 30 years, this report represents the first study of the role and contribution of this important service. The findings outlined in this evaluation will assist The ASI and the National Dementia Office in future planning of dementia services, taking appropriate account of the current post-diagnostic landscape, recent progress in post-diagnostic supports in Ireland and potential new models.

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# Executive Summary

The Alzheimer Society of Ireland (ASI) grant-funded this study to support the development of a greater understanding of the role and contribution of day care in supporting community-dwelling people with dementia and their family carers. ASI are the main operator of dementia-specific day care centres in Ireland. Although day care centres specialised in providing a service for people with dementia (the ‘dementia-specific’ model of day care) have operated in this country for more than 30 years, the number available has grown substantially in recent years. However, before this study, relatively little was known about how these centres operate and their role and contribution to addressing needs of community-dwelling people with dementia and their family carers.

The results from the research provide a detailed perspective on this from experiences of people with dementia, their family carers and staff working in day care centres. Overall, 270 respondents provided data through the three main components of the extensive mixed-methods approach employed. These comprised an online survey of staff working in day care centres; an in-depth qualitative study with service users, family carers and staff from a representative sample of day care centres; and a survey of family carers and people with dementia using a range of ASI services in the wider surrounding areas of the centres covered.

## Purpose of dementia-specific day care

Consistent with an earlier study by Cahill et al. (2003), this study found that most day care centre management and staff consider the purpose of their service is equally to provide care and support to persons with dementia and provide respite for family carers. This is in keeping with the original stated purpose of dementia-specific day care when first developed in the 1980s – to provide cognitive and social stimulation to those with dementia and offer support to family carers (Working Party on Services for the Elderly, 1988).

## A highly valued service

Dementia-specific day care is highly valued by people with dementia and their family carers, both current and former users. Staff, family carers and people with dementia attending day care identified a wide range of benefits of day care for people with dementia. Chief among these was the opportunity to socialise, interact and engage with other people, and to have companionship and develop friendships with other people in a similar situation. Cognitive stimulation provided through participation in a range of activities was another main benefit. Other benefits include the opportunity for fun and entertainment, support to retain abilities and skills, having a nutritious meal shared with others, and partaking in physical activity.

Dementia-specific day care is also beneficial for family carers. It can afford an opportunity for a break or respite from caring for many, although the value of this is contingent on the extent to which family carers see it as a positive and useful experience for the person with dementia. It can support family carers in their efforts to keep a person with dementia socially engaged and cognitively stimulated. It can facilitate working family carers to remain in work, and can reduce worry about people with dementia living alone. Although many family carers report substantial benefits from dementia-specific day care, for some the degree of respite from the demands and stresses of caring is more limited. The experiences and levels of burden of these family carers requires more attention to identify the supports and interventions that might be necessary for them.

## Unmet demand

Overall, there appears to be considerable unmet demand for day care places, reflected in waiting lists for a place in the first instance and/or requests for more days for people who already have a place. Our study also found that many of the people with dementia and family carers surveyed who had not (yet) used day care expressed an interest in attending either now or in the future.

Experience suggests that people with dementia, and sometimes family carers, can initially be reluctant to avail of day care but often find it a very positive experience once they have tried it. Flexibility in initial access to day care, to try it out and get familiar with it, is therefore important. Nevertheless, although day care appears to be a positive option for many it is not for everyone, and it is important to provide as much choice as possible in the available forms of service and support for people with dementia.

## Person-centred philosophy

Earlier Irish research found that staff in dementia-specific day care showed a strong commitment to a philosophy of person-centred care (Cahill et al., 2003). The current study had similar findings and also identified the variety of ways staff working in dementia-specific day care try to tailor and personalise supports and activities to meet the diverse needs of people attending. Approaches include individual care plans, taking account of compatibility issues when grouping people together, providing a range of activities, small group working, and individualising activities and interactions.

Some centres had developed innovative forms of in-reach from and outreach into the community. Such innovation needs appraisal and support, and encouragement of spread to other centres. Some centres have found ways of involving people with dementia in everyday decision-making within the centre, a key element of person-centred care, and it would be worth considering incorporating more collaborative forms of day care across all centres.

Examples of innovation in day care for people with dementia from other European countries and internationally may also be helpful. Innovative centre-based approaches include evidenced-informed, structured forms of person-centred day care such as Cogs Club, and day care designed specifically for people at an advanced stage of dementia such as Enhanced Sensory Day Care. Another development is a move away from the traditional centre-based approaches to day care. Innovative approaches include socially integrated and multi-component day care; and green care or farm-based day care which enables people with dementia to get outdoors and engage in meaningful outdoor activities. These and other examples can help guide the further development and improvement of day care approaches in Ireland.

## Challenges and issues

Providing an optimal degree of personalisation in the day-to-day experience in dementia-specific day care faces a number of challenges and issues.

### Infrastructural constraints

In many centres, infrastructural constraints present important challenges for achieving personalisation and meeting individual needs. These include limitations posed by the physical premises and by staffing level ratios. In our study, staff reported that staffing ratios were very tight and not sufficient for providing an optimal level of support at certain periods of the day or when one or more clients required individual attention and support. Unsuitable buildings also pose many challenges for day care staff, and many of the same issues were previously raised by a study of dementia-specific day care conducted over 15 years ago (Cahill et al., 2003). Centres sharing premises with other groups face particular challenges, including lack of flexibility to set up the facilities in an optimal manner for the client group concerned and having to set up *de nouveau* each morning. Having only one room for activities and not having a quiet space are also important challenges.

Separately and in combination, these factors can make it difficult to provide a range of activity options simultaneously and to provide individualised attention to the desired extent. This can be an issue in finding optimal solutions when one or more attendees present with responsive behaviours.

### Catering for diversity

Dementia-specific day care centres cater for people with dementia with diverse and complex needs. While the available activity programmes work well for many, staff can find it hard to meet the needs of everyone; for example, some mentioned they would like to be able to offer more activities suited to men. More generally, there needs to be greater awareness that diversity in day care is more than simply about differences in age and gender among people with dementia, and centres need support to cater for an increasingly broad spectrum of attendees. Meeting the needs of people from different countries and ethnic backgrounds can also be a challenge, especially when English is not the person's first language.

### Supporting staff

Through their frequent contact with people with dementia, staff working in dementia-specific day care can play a central role in enhancing the quality of life and quality of care for those attending. In this study, staff working in dementia-specific day care centres came across as hard

working and highly committed. Generally, they felt that they had adequate training and education in dementia care and experienced a good sense of teamwork. However, the workload sometimes could be high, and they felt insufficiently supported and appreciated at the higher levels of the organisation's managerial structures, and this can potentially lead to stress, burnout and job dissatisfaction among day care centre staff. This emphasises the importance of attending to the needs of staff who provide direct care to people with dementia.

## Conclusions and recommendations

Collectively, the data generated through the three elements of the study provide a rich and nuanced insight into the role and value of dementia-specific day care centres, how the services are operating on the ground, and what might be an optimal model to strive for. The insights consolidated in this report can support strategic and operational decision-making and service development within ASI and can also inform wider dementia policy and practice in Ireland.

The findings from the study support four main recommendations:

- 1** Ensure the future sustainability and expansion of dementia-specific day care capacity

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- 2** Develop a focused strategic and operational framework and approach to further develop the dementia-specific day care model in Ireland

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- 3** Support quality improvement and innovation in dementia-specific day care

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- 4** Initiate further research on dementia-specific day care and its place in the wider care ecosystem.

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Recommendation 1:

**Ensure the future sustainability and expansion of dementia-specific day care capacity**

Given the high value people with dementia and family carers attach to dementia-specific day care, it is important to ensure the sustainability of existing provision and expand the capacity to provide more places and more days per week to meet the apparent levels of unmet demand in Ireland. At national level, estimates suggest that this form of service for people with dementia currently receives a relatively small share of the overall dementia care resource allocation. It is likely that the value-for-money case for existing and additional spend on dementia-specific day care is very strong. This comes not just from the economies of scale dimension offered by the group-based (congregate) features but also from the likely substantial quality of life and health/social care-related gain for people with dementia and family carers. A closer examination of both the (capital and revenue) funding and health gain aspects would be useful to support policy and resource allocation. However, already the evidence seems compelling that spend in this area contributes substantially to important goals of dementia policy in Ireland and core strands of the National Dementia Strategy.

Recommendation 2:

**Develop a focused strategic and operational framework and approach to further develop the dementia-specific day care model in Ireland**

Over the past thirty years, dementia-specific day care centres have tended to develop as a response to local need rather than within any deliberate or planned policy framework. It would be worthwhile for the main provider(s) and funder(s) to work on the elaboration of a coherent strategic plan/policy for the future development of dementia-specific day care services.

Dementia-specific day care services operated by the ASI are an important part of the overall system of day care for people with dementia in Ireland. Other voluntary sector organisations also provide some dementia-specific day care, and dementia-focused and generalist day care operated by the HSE also form part of this system. More generally, day care is only one component of the overarching ecosystem of community care. In this context, and given the increased capacity needed in day care for people with dementia, it would be important for the main provider organisations to get input from key stakeholders in the planning of dementia-specific day care services. This will be facilitated by the development of effective partnerships and relationships with public sector and other voluntary sector organisations working in dementia care. In the Netherlands, for example, this is a key element of the Meeting Centres Support Programme.

Broader issues also impinge on the delivery of dementia-specific day care services, including those within the remit of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services. The future development of day care services for people with dementia will involve both the public sector and voluntary sector organisations, and the Review Groups deliberations will have important relevance for this.

#### Recommendation 3:

### **Support quality improvement and innovation in dementia-specific day care**

The study found ongoing examples of good practice and innovation in dementia-specific day care centres in Ireland. In addition, the staff who contributed to this study provided many useful ideas and suggestions for service improvement and enhancement, and insight into the challenges faced on the ground to deliver the service they would ideally like. People with dementia and family carers also provided a range of ideas and suggestions on how services could be further enhanced, both for day care centres themselves and in their linking and dovetailing with other dementia services and supports.

A next step for the ASI and other providers could be to identify key existing factors that positively influence good practice and service innovation across their day care centres. The study found issues relating to physical premises and other resources, including funding, staff levels and time constraints, were hampering the ability of some centres to improve service quality. Leadership and management at different tiers (centre, regional and national) is important, supportive of and committed to positive change, but so too is the articulation of a clear and compelling vision for dementia-specific day care centres. It is also important that those affected – including centre managers, frontline staff and service users – are engaged early and on a continuous basis.

Whilst service audits may have a useful role to play in this, our research suggested that staff currently do not see the existing audit approach as a driver of quality improvement, and some were quite critical of this aspect. A specific programme of quality improvement/service innovation for dementia-specific day care centre would be useful. Some of this could be possible at low or no cost, but some will certainly require investment, and for this dedicated and continuous resourcing would be necessary.

The approach would need to allow for adaptation at centre level and to different local contexts, and quality improvement programmes could be initially trialled in a small number of centres. Monitoring and evaluation are important for providing an understanding of the processes involved

in quality improvement, identifying challenges and enablers of success, assessing impact and costs, and to provide learning from test sites which could then support spread of quality improvement to other centres. Approaches such as rapid quality improvement cycles could be considered for these purposes.

#### Recommendation 4:

### **Initiate further research on dementia-specific day care and its place in the wider care ecosystem**

This study drew mainly on new primary data collection from staff, people with dementia and family carers. The potential also exists to leverage additional routinely generated information and data from within the ASI and possibly other providers as well. Such data might be further analysed to inform the provision of dementia-specific day care, and for the future development of day care centres.

New themes for research attention have also emerged from the study and its results. One important issue is the need for development of better linkages and integration of day care within the wider ecosystem of supports for people with dementia. This could have support at the national policy level as well as on-the-ground at HSE regional and local levels.

A current HSE-funded exercise to prepare a detailed mapping of all forms of day care provision for people with dementia at regional and sub-regional levels will provide valuable evidence to help inform decisions on future service provision and resource allocation relating to day care more generally. As a follow-on exercise, it might be useful to build on the work of our study and their wider mapping to prepare a detailed mapping of regional and local (area-based) ecosystems of supports for people with dementia and associated service usage patterns, to examine how dementia-specific and other day care fits in the wider picture of community-based service structures and supports.

More generally, focused research on impacts and outcomes of day care attendance for people with dementia and family carers would be very valuable to inform policy and practice in Ireland and to contribute to the wider international evidence base. This could include examination of the value for money aspects mentioned under Recommendation 1, including delivery costs compared with potential cost savings in other parts of the health and social care ecosystem as well as the value of any health/social care related gain achieved.



## Section 1

# Introduction

At any point in time, most people with dementia in Ireland live in their own homes and wish to remain living there, even if some may eventually have to move to a nursing home. Like many countries across the world, government policy in Ireland has a broad aim to enable and support this, and day care is one of a range of community-based services identified as having ‘an important part to play in supporting people with dementia to remain viably and safely in their own homes for longer’ (Department of Health, 2014: 25).

The essence of day care is provision of day-time, centre-based facilities and supports that service users can attend in a congregate (group) arrangement for some or all the day. Although service models may vary, the aim generally is to provide supports and positive experiences for those attending day care, whilst simultaneously enabling family carers, who provide the bulk of the care to people with dementia living at home, to take a break from caring. In Ireland, we have both dementia-specific day centres, exclusively catering for people with dementia, and more generic day care centres for older persons that may have persons with dementia amongst the attendees (Cahill et al., 2012; Pierse et al., forthcoming).

The number of dementia-specific day care centres in Ireland has grown in recent years, and the overall numbers attending have grown substantially. However, relatively little is known about the services and supports provided, the perspectives of people with dementia and family carers using these services, and the broader role and contribution of dementia-specific day care amongst the spectrum of services and supports in the overall dementia care ecosystem.

As the largest operator of dementia-specific day care in Ireland, The Alzheimer Society of Ireland (ASI) grant-funded this study to support the development of a greater understanding of the role and contribution of this form of day care in supporting people with dementia and their family carers, and enabling them to remain at home. This would be useful not just internally to ASI – to support service development/improvement and broader strategic reflection and decision-making about the position of day care services within their portfolio of activities – but also for the wider audience of policy-makers, HSE (management and community services) and other players for whom dementia-specific day care is of relevance and interest.

Recent data indicates that ASI day care centres make up 15% of all the day care centres for older people in Ireland (Pierse et al., forthcoming). In combination with a broader review of day care centres and models operating in Ireland currently underway for the HSE (HSE, 2019), this study can provide an input to a further programme of research and service development addressing the entire ecosystem of supports for people with dementia in the community and the possibilities that may exist for better joining-up of services and pathways where appropriate.

As far as we are aware, the study is the first focused investigation of dementia-specific day care in Ireland, aiming to identify how it operates and what it provides for users as well as exploring the perspectives of the different stakeholders involved on a day-to-day basis in day care – service users and their family carers, and the staff that manage and work in day care centres. It follows an earlier study by Cahill et al. (2003) on staff views of dementia-specific day care centres in Ireland, which focused largely on day care design. The importance of including the perspectives of people with dementia in studies of day care services has been stressed by O'Shea et al. (2017).

Although funding available for the current study was quite modest, the mixed-methods approach enabled generation of an extensive empirical evidence base on the nature, role and contribution of this component of dementia care in Ireland.

The research included:

- national survey of ASI day centre staff;
- in-depth research with attendees, family carers and staff at eight day care centres in different parts of the country; and
- survey of a broader sample of users of community-based (day care and/or other) dementia care services in the surrounding areas of the eight day care centres.

## 1.1

### Structure of the report

Chapter two presents the policy background to this study, and provides an overview of day care in Ireland generally and more specifically in relation to dementia-specific day care operated by the ASI. Chapter three outlines the study methodology. Chapters 4 to 6 then present the findings of the study.

Chapter four reports perspectives on dementia-specific day care from staff working in the centres. It examines understandings of the main purpose of day care, perceived benefits of dementia-specific day care services for people with dementia and their family carers, whether and how personalisation of services is achieved, and areas where services might be improved in the future.

Chapter five presents the perspectives of people with dementia and their family carers on the role and contribution of dementia-specific day care. It reports on their satisfaction with dementia-specific day care, what they value about day care, what they like and how they benefit, issues that arise and changes they would like to see. This is an important and central source of evidence and perspective, as few studies have explored day care services, whether generalist or dementia-specific, from this perspective.

Chapter six then presents an overview of several innovative approaches to dementia-specific day care. Examples covered include the Meeting Centres Support Programme (MCSP) in the Netherlands, Cogs Club, Enhanced Sensory Day Care, and the Green day care model that has developed in several countries across Europe. The chapter also examines issues around demand, supply and take-up of dementia-specific day care, drawing on a range of sources including the literature, estimates of number of people with dementia using day care, and empirical findings from this study. It discusses the multiple factors that influence the utilisation of day care and the need for a multi-pronged response to enhance the availability and effective utilisation of dementia-specific day care in Ireland.

Finally, Chapter 7 presents conclusions and outlines some possible next steps.

## Section 2

# Background and context

Day care services have been recognised as an essential component of care provision for older people in Ireland for the past 50 years. The development of day care services dates to the 1970s following a recommendation in the Care of the Aged Report (Inter-departmental Committee on the Care of the Aged, 1968). Development of day care catering specifically for people with dementia came later.

To overcome limited availability and access in Ireland, The Alzheimer Society of Ireland (ASI) opened its first dementia-specific day care centre in Dublin in 1987. At that time, many day care services were not willing or able to cater for people with dementia. Towards the end of the 1980s, *The Years Ahead* Report recommended an expansion of day care services for people with dementia. It envisaged that people with dementia in each district would have access to day care separately from older people without dementia, and that voluntary sector organisations such as the ASI would play a key role. The vision was that day care for people with dementia would provide cognitive and social stimulation to those with dementia and offer support to family carers (Working Party on Services for the Elderly, 1988).

## 2.1 Expansion of day care over the years

Day care provision expanded over the ten years following the publication of The Years Ahead Report (Ruddle et al., 1998), with three types of day care centres emerging: generic day care centres; dementia-focused day care centres; and dementia-specific day care centres (O'Shea and Reilly, 1999). However, provision remained inadequate across all three types of day care (Ruddle et al., 1998), influenced by the low priority given to day care services by the then health boards (O'Shea and Reilly, 1999).

In the context of the under-funding of community care services for people with dementia generally, and the limited and variable access by people with dementia to generic day care across the country, O'Shea and Reilly (1999) recommended an expansion of dementia-specific day care, provided in buildings suitable for people with dementia, with staff trained in the care of people with dementia. They identified the existing work of the voluntary sector in this area as an important starting point on which to build. The important role that day care could provide for people with younger onset dementia was also highlighted. A number of key policy-related reports since have re-iterated the recommendation to expand dementia-specific day care (Haslett et al., 2003; O'Shea, 2007; Cahill et al., 2012).

Since the first dementia-specific day care centre opened in 1987, the number of dementia-specific day care centres operated by the ASI Ireland has grown, generally in response to local need: 15 by 1999 (O'Shea and Reilly, 1999), 21 in 2001 (Cahill et al., 2003), 31 in 2007 (O'Shea, 2007), 32 in 2012 (Cahill et al., 2012), and 48 in 2019.

## 2.2 Day care for people with dementia in Ireland today

As a consequence of the historical development of day care in Ireland, generic and dementia-focused day care centres are mainly operated by the HSE, whereas dementia-specific day care centres are mainly operated by Alzheimer Associations, primarily the ASI (Cahill et al., 2012; ASI and NDO, 2017; Pierse et al., forthcoming). This mirrors the situation in Scotland, where Alzheimer Scotland operates most dementia-specific day care, but is unlike other countries such as Norway where local authorities provide dementia-specific day care as part of their social care services (Rokstad et al., 2017). In Ireland, day care is generally offered to people with dementia living in the community, whereas in countries such as the Netherlands, long-stay residential care settings may also offer day care to residents with dementia as part of their daily support (van de Ven et al., 2017). Unlike countries such as Northern Ireland, Norway, Scotland and Canada, day care in Ireland is not currently regulated (HIQA, 2017). The

development of a regulatory framework for community and home-based health and social care services, while under consideration, is a complex undertaking (HIQA, 2017). However, the ASI audits its day care centres, as part of a strategy of continuous quality improvement (ASI, 2018).

Approaches to financing day care for people with dementia vary across countries. For example, in Norway, the Norwegian Ministry of Health and Care Services offers funding to local authorities that wish to provide day care to people with dementia close to their homes (Rokstad et al., 2014; Rokstad et al., 2017). For users, out-of-pocket costs for day care in Norway are relatively small (Vossius et al., 2019) and are waived if it is considered a health care service for the person with dementia. In Scotland, day care is means-tested and people with dementia pay according to their means (Rokstad et al., 2017). In Germany, the costs of respite services used by family carers including day care services are covered by social care insurance (Donath et al., 2011). Current statutory obligations do not specifically require the HSE to arrange or provide day care services in Ireland, but dementia-specific day care operated by the ASI is part-funded through block grants by the HSE. People with dementia make a flat rate contribution on each day that they attend, with an additional flat-rate contribution for transport by mini-bus where this is available and used.

Despite the growth in the number of dementia-specific day care centres in Ireland over the past thirty years, concerns have been raised about continued under-provision to cater for need and demand (Browne, 2016; Oireachtas Committee on the Future of Healthcare, 2017). The need for day care for people with dementia is likely to intensify as, like other countries, Ireland is witnessing significant increases in the number of people with dementia, a trend that will continue over the coming decades as the population ages (Pierce and Pierse, 2017; Alzheimer, 2020). While there have been projections of future demand for Home Support for older people (Wren et al., 2017), as far as we are aware, no such projections exist regarding the future demand for day care services for older people. However, recent work suggests that a very substantial increase in day care places for people with dementia will be required over the next ten years Pierce et al. (forthcoming).

Day care for people with dementia has received limited policy attention in Ireland, similar to the situation in Scotland and England. For instance, day care received only a cursory mention in the Irish National Dementia Strategy (Department of Health, 2014) and the development of day care does not form part of the implementation programme of the Irish National Dementia Strategy, which has prioritised the provision of home care (Keogh et al., 2019). In contrast, offering day care to people with dementia has been a main priority of both the First and Second Norwegian Dementia Plans, which emphasise that day care and other forms of day activity services are among the most essential and fundamental elements in an integrated home care service for people with dementia (Norwegian Ministry of Health and Care Services, 2008; 2015).

## 2.3

## Overview of ASI day care services and service users

ASI provides a range of services and supports for people with dementia including home care, day care, social clubs, dementia advisers, and family carer support groups. Day care receives the largest share of resources in financing and staffing (ASI, 2018). Some key statistics for the year December 2017 to November 2018 include:

- 48 centres across the country
- These provide a combined total of 161 service days each week
- 1,839 people attended ASI day care centres across the country that year
- There were 84,841 attendances in total, with an average of 46.13 per client
- Total day care hours utilised were 540,371, with an average of 6.4 hours per attendance

The ASI estimate utilisation of its day care services at 5.3% of community-dwelling people with dementia overall. Excluding CHO2 (where Western Alzheimer provide a substantial volume of services), utilisation ranges from 4.9 to 7.7% across the remaining eight CHOs.<sup>1</sup> Levels of HSE funding varies considerably across CHO areas and day care centres, with the majority receiving somewhere between 40% and 70% of funding from HSE (average 63%).

Of the 48 centres offering day care services, 10 (20%) are owned by the ASI. The number of days open per week varies across centres, with 20 (50%) open 5 days per week and 13 (26%) open just one day per week being the two most common situations. Across the other centres, 1 (2%) is open 6 days per week, 2 (4%) for 4 days, 7 (14%) for 3 days and 7 (14%) for 2 days per week.

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1 These estimates were prepared by the ASI based on the total number of people with dementia attending ASI day care in the year Dec 2017 to Nov 2018 as a proportion of the total estimated number of community dwelling people with dementia in Ireland in 2016.

## 2.3.1

## Profile of service users

Across the country, as well as variations in the number of days open per week, centres vary in the number of hours open per day, as well as in the maximum capacity for number of attendees per day. Overall, taken together the data indicate that the average or 'typical' client attends day care about 1 day per week, and for about 6.4 hours on the day attended.

The ASI data indicates that nearly two-thirds (62.7%) of current clients have been attending day care for more than one year, with more than one-quarter (27%) attending between one and two years, a similar proportion (28.2%) attending for between two and five years, and a sizeable minority (6.5%) attending for more than five years. The majority of clients (71.7%) are aged between 75 and 89 years, with about one-in-five (21%) aged between 65 and 74 years, and 7.3% aged 90 years or older. Regarding levels of dependency, the majority are assessed as either medium (46.9%) or high (32.6%) dependency, with smaller numbers assessed as low dependency (16.1%) and maximum dependency (4.4%).



Current clients age profile:

**21%**

65 – 74  
years

**71.7%**

75 – 89  
years

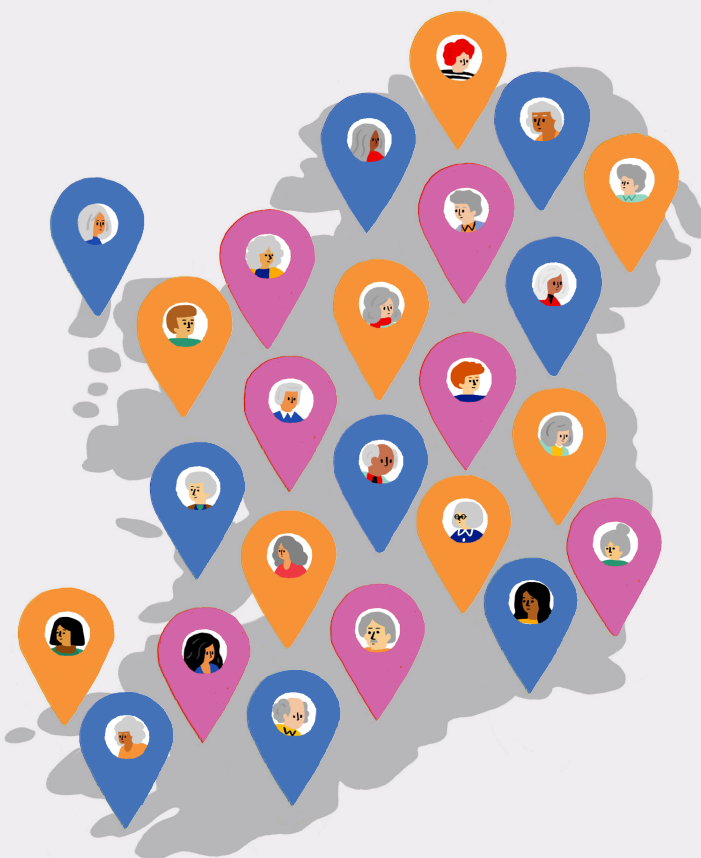
**7.3%**

90+  
year

## Section 3

# Methodology

This was a mixed-method study involving primary data collection through an online survey of staff working in day care centres; a paper-based survey of family carers and people with dementia; and an in-depth qualitative study with service users, family carers and staff from a representative sample of day care centres. It was anticipated that triangulation of data and perspectives from these three sources would help provide a rich and robust evidence base for the study and its purposes. The study also included a scoping review of the national and international policy and research literature to enable contextualising of the results in the wider context. Ethical approval was granted by the Research Ethics Committee of the Royal College of Physicians of Ireland in July 2019.



## 3.1 Overall approach

### Online survey of day care centre staff

The survey of day care centre staff targeted all staff (management and care staff) working in the ASI day care centres across the country, using an online survey approach for efficiency and effective reach. Its core aims were to generate a broad understanding of ASI day care service characteristics from the perspective of staff working in them, as well as their assessment of the role and contribution of day care for persons with dementia and their family carers, and how existing services might be enhanced or improved where necessary. The survey utilised a questionnaire specifically designed for this study.

### Paper-based survey of people with dementia and their family carers

This survey covered users of community-based (day care and/or other) dementia care services in the wider ASI service catchment areas, approximately coinciding with the eight day-care centres included in the in-depth study described in the next section. The target population were users of ASI services in group settings (social clubs and Alzheimer's Cafes) and clients of the Dementia Advisers service. The survey was open to both persons with dementia and family carers. Relevant ASI staff in the different settings made available the survey questionnaire for completion by interested service users on a voluntary and anonymous basis.

Given the method adopted, the respondents represent an opportunistic sample from the targeted settings. This was sufficient for the intended purposes within the study – to provide an indication of the views and/or experiences of a cross-section of ASI service users on day care services as one amongst a range of services and supports that they may currently be availing of, have utilised in the past, or might have an interest to utilise at some point. The questionnaire was purpose-built for the survey. It asked about the range of services utilised by respondents and the relative importance for them of different services they have had experience of. It also asked about their experience of day care services where applicable, and their possible interest in availing of day care services if not already utilised.

### 3.1.1 In-depth study of a sample of day care centres

This was a central component of the study, aiming to generate an in-depth understanding of experiences of day care from the perspectives of people with dementia attending the services and their family carers, and from staff working in the centres. The research covered a sample of eight ASI care centres across the country, with one day care centre from eight of the nine CHO areas to ensure good geographical spread and coverage.

Preparatory work with available data profiling the 48 ASI centres and discussions with operations staff in ASI indicated considerable variation among day centres across a range of parameters. These parameters are likely to influence the services provided in various ways as well as the characteristics and circumstances of people attending and their family carers.

Relevant factors identified included:

- Location (urban, town, rural)
- Number of days operating per week (1-2, 3, 4-5)
- Centre lead (nurse-led, social care-led)
- Building (ASI-owned or not)
- Transport (mini-bus available or not).

An additional dimension of interest was the concentration/availability of day care centres in the area (high, low), particularly for the wider user survey in the surrounding areas of the selected centres.

In discussion with ASI operations staff on feasibility of access to particular centres within the timeframes of the study, the research team applied an iterative process to identifying candidate centres to give good representation across the parameters outlined above. The final eight centres for inclusion emerged through this process.

Following identification of the sample of centres, a staff member in each centre acted as a liaison person for the study, and helped facilitate visits by the researchers to the day care centres, identify study participants, and assist with the practical logistics of organising the focus groups and interviews. Before commencement of the fieldwork, the liaison persons attended an interactive training workshop in preparation for the in-depth study. At each day care centre, the research involved a focus group with people with dementia attending the day care centres, focus group or individual interviews with family carers, and focus group or individual interviews with centre staff. Participants were recruited using convenience sampling. Participation was on a voluntary basis in every case and in all three strands of the research in the centres.

The sample of eight centres included a mix of geographical locations, such as on the periphery of villages or small towns, in or on the periphery of large towns, and in the suburbs of a large city. Specific locations included HSE hospital or nursing home campuses, community facilities attached to public sector housing schemes for older people, or a private house on a housing estate. ASI owned a few of the buildings but most centres were renting premises from the HSE or local authorities. Some rented premises were exclusively utilised for dementia-specific day care, whereas others shared the space with other community groups and organisations. As discussed later, the latter can present particular challenges for dementia-specific day care.

Some centres had nurse managers (nurse-led) and others had managers with a social care background (social-led). The centres varied in opening times, from one to five days per week. Some centres had limitations on the number of days offered because other community organisations and groups utilise the building on other days. The majority (6/8) of the centres in our sample had a minibus, which they utilise to bring people with dementia to and from the centre, although some limit transport to a specified catchment area. Most but not all the centres use the minibus for outings and day excursions. Two of the centres had stopped providing transport due to costs, and one of these centres has put arrangements in place with taxi drivers/companies as an alternative to transport by minibus.

The participating day care centres also varied in a number of other respects. The number of people with dementia that the centres could cater for per day varied widely, ranging from 7 to 20. All centres provided meals, in some cases prepared on site and in others prepared offsite and delivered to the centre. Differences across the centres with regard to the space available and the quality of the premises and built environment available for dementia-specific day care were striking, reflecting findings from an earlier study on day care design and dementia (Cahill et al., 2003), and Chapter 4 returns to this in some detail later.

All of the parameters above have influence on the day care provided for people with dementia attending. The research findings presented in Chapters 4 and 5 show how they facilitate or constrain services in various ways.

Although we do not have a detailed profile of the attendees at these day care centres, it was clear from our visits and from meeting and talking to people attending, family carers and staff that they reflect the quite diverse profile indicated in the ASI statistics for the 1,800+ clients attending the 50 centres they operate. They cater for men and women, people of different ages from the younger (under 65 years) to the oldest-old (85 years and over) age groups, people with different living arrangements, different family circumstances and occupational backgrounds, and although small in number, people from different countries and ethnic backgrounds. Attendees may have mild/moderate or more severe dementia progression, and the centres cater for people with different levels of cognitive and physical abilities, different types of dementia, and people with and without insight into their condition.

## 3.2

### Profile of respondents/participants in different components of the study

Table 1 presents an overview of the samples achieved in the three main components of the study.

Fifty-nine staff members of ASI day care centres completed the online questionnaire for the staff survey. Almost two-thirds (62.7%) of respondents were Centre or Nurse Managers and just over one-third (37.7%) were day care assistants or similar. The sample showed wide variation in the number of days and hours worked per week by day care centre staff, reflecting differences among day care centres regarding the number of days open per week and the different working arrangements of staff in day care centres.

For the wider survey of dementia care service users, the research team received back 105 questionnaires. Quite a number of responses were from 'dyads' (a family carer and person with dementia), and in some of these cases it was more appropriate to combine the two into a 'dyad' perspective. Overall, 80 were suitable for analysis as 'unique' responses representing either or both parties' perspectives and the results presented below are based on these.

Table 1:  
**No. of study participants**

Study element		N
Online staff survey		59
Survey of family carers and people with dementia		80
In-depth study of day care centres	Persons with dementia (attendees)	57
	Family carers	40
	Staff	35
<b>Total number</b>		<b>271</b>

A total of 57 people with dementia attending dementia-specific day care centres participated in the focus groups. Their ability to contribute to the discussions varied, with some less forthcoming than others. However, most contributed well, and day care centre staff were present to support their participation. A good deal of prompting was usually but not always needed to elicit responses. Some participants took an opportunity in the focus groups to refer to their past life, interests and memories or to ask

questions of the researcher. Forty family carers of people with dementia attending dementia-specific day care centres participated in either a focus group or one-to-one interview, which included a small number whose relatives were no longer attending day care. Thirty-five staff members participated in either a focus group or one-to-one interview.

### 3.3

## Strength and limitations

This study has a number of strengths. It examined dementia-specific day care from multiple perspectives – people with dementia, family carers and staff. Several techniques were used to enhance the quality of the research. The study was designed as a mixed methods approach to allow for triangulation. Concordance across perspectives and data sources increases confidence that the findings are robust, and a ‘constant comparison’ approach helped ensure that the data from all sources was treated as a whole and identify emerging themes and themes that were not anticipated. Contradictory evidence was also sought out, examined and accounted for in the analysis.

One challenge for the study was to identify a suitable sample of day care centres for the in-depth study at day care centre level. A first step was to develop a sampling frame against which to find a representative spread of dementia-specific day care centres across the country. As described earlier, it was also necessary to consider practical feasibility issues when finalising the sample of eight centres for inclusion, especially operational constraints that would make it very difficult for a centre to accommodate the research process because it would be too disruptive for the service on the day. Therefore, although the final set of eight centres included map well to the sampling frame, the approach of necessity included an element of convenience sampling to accommodate the operational realities of the candidate centres considered for inclusion.

For the research in each centre, practicalities and good (ethical) practice required recruitment of the samples of people with dementia and family carers with the help of staff working in the centres. The overall guiding philosophy was to provide all attendees on the day with the opportunity to participate in the focus group on the day of the visit by the research team, with allowance for the dynamics and logistical realities of the activity programmes of attendees and staffing commitments on the day. A similar approach was applied in the organisation of the focus groups/ interviews with family carers.

For the focus groups with people with dementia, the approach involved co-facilitation by the researchers and a staff liaison person in the day care centre. This was deemed important from an ethical perspective, as it helped ‘normalise’ the experience of participation for the persons with dementia and allow their voice to be heard in a non-stressful context.

ASI staff co-facilitated the focus groups as they knew the people with dementia and supported them to participate as fully as possible.

Inevitably, some elements of the approach introduce a certain degree of risk of selection bias in participant composition of the focus groups and social desirability bias in the contributions made during the focus groups. These aspects were discussed in advance at the interactive training workshop with staff acting as liaison persons for the in-depth study, particularly the challenges to avoid bias where possible whilst finding practical ways of enabling people with dementia to have their views included (Dewing, 2008).

Overall, the approach was judged to have worked well in balancing the ethical requirements – to maximise the possibility for people with dementia to contribute and have their voice heard – with requirements for as much methodological rigour as possible.

## Section 4

# The perspectives of staff

This chapter reports staff perspectives on the role and contribution of day care for persons with dementia and their family carers, and how existing services might be enhanced or improved where necessary. It draws on both the online staff survey and the focus groups with staff in the eight selected centres. A core focus is on the ways staff personalise dementia-specific day care services to meet the needs of people with dementia, and challenges staff identify for implementing personalised care for people with dementia.



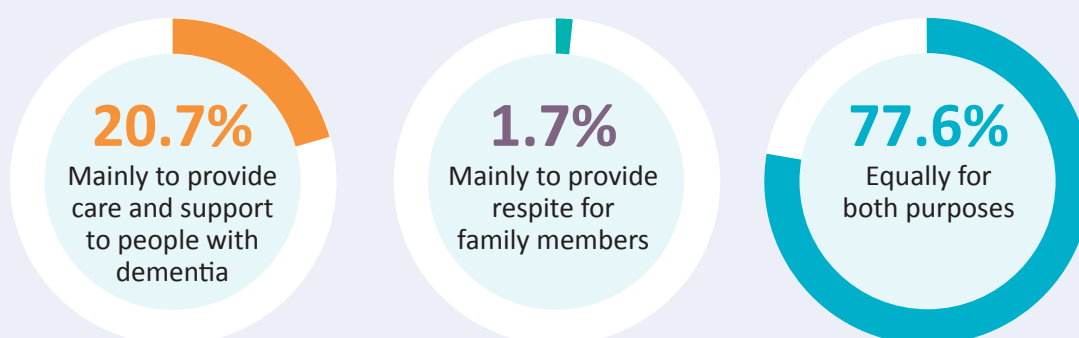
## 4.1

## Main purpose of dementia-specific day care

Figure 1 presents staff views on the main purpose of day care centres, selected from one of the three response options in the questionnaire. More than three-quarters (77.6%) felt the main purpose of day care was to equally provide care and support for persons with dementia and respite for family carers, and one-in-five (20.7%) felt it was mainly to provide care and support to the person with dementia. One respondent felt it was mainly to provide respite for family members, and that there was little or no direct benefit for the person with dementia.

Figure 1:

**Main purpose of the day care service, % (n=58)**



Expanding on their responses, staff pointed out that dementia affects both the person with dementia and their family carer and that both were important. They highlighted the interdependent relationship between the person with dementia and family carer, and that each needed support.

For the person with dementia, respondents viewed day care as providing support in various ways including enabling people with dementia to engage in activities, providing an opportunity for social interaction with other people in the community, and having an enjoyable experience in a safe, comfortable and supportive environment. Some staff viewed day care as important for helping people with dementia retain skills and abilities for as long as possible, giving them a sense of independence or control over their lives, or maintaining health and wellbeing. Some staff members referred to the ongoing changes associated with dementia and the role that day care can play in early intervention as changes occur. They also highlighted the important role that staff play in monitoring the health and social care needs of people with dementia.

According to staff, day care served as a support for family carers in their caregiving role, helping them to manage and continue in their role

by getting a short break or a few hours of respite from caring. Some respondents referred to how carers could utilise the time away from caregiving to attend to their own needs, engage in social activities, or get jobs done without having to worry about their relative with dementia. They felt day care gave family carers peace of mind. One respondent believed the provision of day care gave recognition to the demands of caregiving, whilst at the same time, giving recognition to the challenges that living with dementia presents to family carers.

One-fifth of staff respondents felt the main purpose of day care was to provide care and support to persons with dementia. Where they expanded on this, respondents tended to place an emphasis on person-centred care and importance of taking this approach to supporting people with dementia during their participation in social activities and interaction with others in the day care centre, and as a way of enabling them to have fulfilling life experiences. One staff member felt that the needs of person can be often overlooked, and day care can offer a place where they can feel valued and important.

## 4.2

### Benefits for people with dementia

Through the online survey and focus groups, staff identified a wide range of benefits of day care for people with dementia. Most frequently, they referred to the opportunity afforded by day care for people with dementia to meet, socialise, interact and engage with other people, and to have companionship and develop friendships with other people in a similar situation. They felt people with dementia may find it hard to come to terms with dementia, or be fearful or feel embarrassed and withdraw from usual activities, and day care was a way of including people with dementia in social and community life and helping them to engage, thus helping to prevent or address social isolation. Another main benefit identified by many staff was the cognitive stimulation provided by day care through the different activities in which people with dementia could participate such as music and singing, quizzes, games, art and dancing. They felt that this can enhance quality of life, and social, psychological and physical wellbeing. More generally, staff felt that day care is often the only time that many people with dementia are cognitively and social stimulated and that even those who are quiet and reserved when at the centre are benefitting from interaction and stimulation.

Some staff referred to the role that dementia-specific day care can play in helping people to retain abilities and skills, such as communication and making choices, and that in some cases it was successful in reversing excess disability through helping people regain lost abilities or skills, such as knitting. Others spoke about the sense of achievement that people with dementia experience when completing or taking part in an activity that they may have previously given up or never done before. Having fun and enjoyment while attending day care was also frequently identified as

a benefit. Staff felt that people with dementia benefited from having an outlet or a place to go to, and especially that day care allowed them to get out the house and experience a change of scenery or environment, where they could mix and chat with people outside of their family circle and have a social life beyond family. Other aspects highlighted, especially by staff in the focus groups, included the benefits of participating in physical exercise, having a nutritious meal in the company of others, emotional support and practical support with activities of daily living.

Although less frequently mentioned, some staff also referred to the role that day care can play in helping people with dementia to feel valued, develop a sense of self-worth, purpose or belonging. Staff were aware that day care may sometimes be perceived negatively, and felt that the adoption of a person-centred approach can help mitigate fears or anxieties that people attending day care may have. More generally, staff felt the provision of support in an environment that was welcoming and friendly, safe, secure, warm, homelike, and comfortable was beneficial to people with dementia attending.

Staff watched out for signs that people were happy to attend day care. One indication to staff of this is when people with dementia express gratitude for being able to attend the day care centre or say *'I would come here five days a week ... seven days a week if I could'*, a sentiment repeated often by people with dementia in the focus groups. However, staff indicated that it is mostly non-verbal expressions that tell staff how people are doing. Seeing people with dementia smiling and happy was an indication that day care was working well for the person. Indeed, staff also reported benefiting themselves from seeing people interact, relaxed and enjoying themselves.

## 4.3

### Benefits for family carers

From the staff perspective, the predominant benefit of day care for family carers was the break or time away from caring it allowed. An overwhelming majority (94.7%) of staff responding to the online survey felt day care was useful for family carers for respite purposes, enabling them to have a break or rest from the demands and stresses of caring. They could use the time for themselves, to rest and recharge their batteries, and to do what they want. This could be for taking part in social activities, getting exercise, completing every-day tasks such as housework or shopping, or just for planning. Staff stressed that, for carers, knowing that their relative was safe and having an enjoyable time was an important aspect of having this break.

Staff also identified a benefit for family carers from having access to staff at day care centres for information, practical and emotional support and advice, or to talk to about their situation. Slightly more than three-quarters of staff responding to the online survey felt that day care was beneficial for family carers for getting advice.

## 4.4

### Relative emphasis on different aspects of care and support in day care

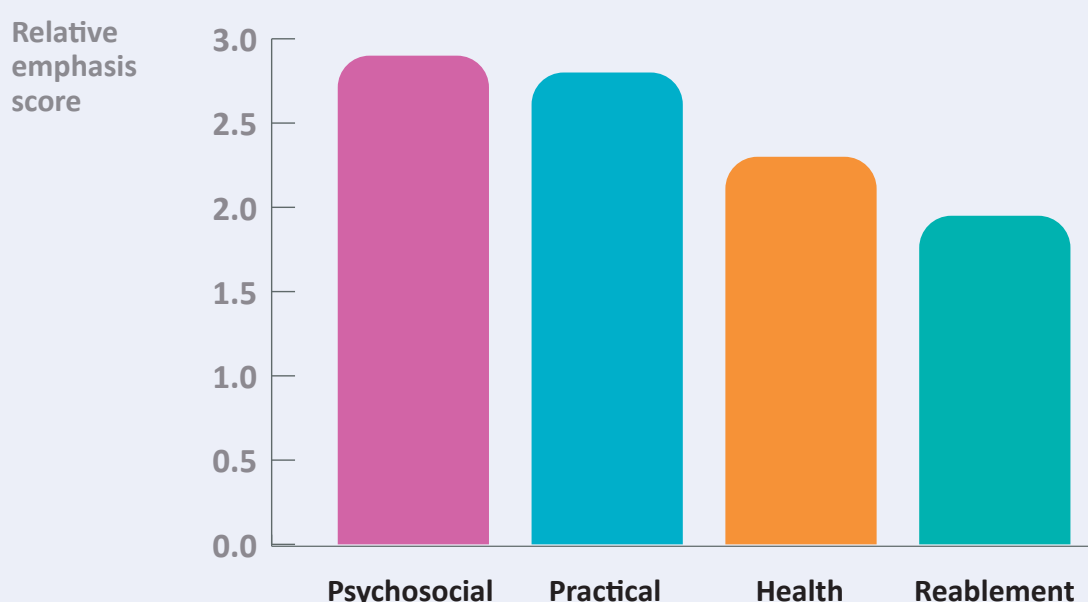
The online survey also asked staff what they felt was the relative emphasis in their day care centre regarding four aspects of care and support for people with dementia who attend:

- psychosocial (social contact, enjoyable activities, etc.)
- healthcare (identifying and addressing specific health needs)
- practical supports (meals, personal care, etc.)
- reablement (improving functioning in their home life).

Figure 2 presents the results from this question.

The staff responses suggest that all four aspects of support feature to at least some degree in dementia-specific day care provided across the ASI centres. The strongest emphasis appears to be on psychosocial and practical aspects, followed by health care and reablement. For healthcare, there was a tendency for staff from nurse-led centres to give somewhat higher ratings.

Figure 2:  
**Staff assessments of relative emphasis on aspects of care in their centre**



## 4.5

### Personalisation and meeting the range of needs and interests

ASI describes its day care services as providing ‘dementia-specific, person-centred care to meet the needs of the person with dementia in a warm, welcoming and safe environment while providing support and stimulation.’ In the online survey, staff were asked ‘does the day care centre in which you work manage to provide an appropriately personalised approach for the persons with dementia attending?’ The large majority (92.6%) of those who responded (n=54) gave a positive answer and indicated a range of ways staff personalise dementia-specific day care services to meet the needs of people with dementia. These include using individual care plans, considering compatibility issues when grouping people together, providing a range of activities, small group working, individualising activities and interactions; and attending to diverse and complex needs of people with dementia. Sections 4.5.1 to 4.5.6 discuss these in more detail.

A small number of staff responded ‘No’ to the question. Reasons for this included insufficient staffing levels and time, which constrain the possibilities for taking a personalised approach.



We try but due to staff shortages it’s very difficult. Two carers and one nurse for ten clients. Where there are already three clients requiring a one-to-one care, personalised approach can only be aimed at in theory and written in care plans, but in reality is very difficult to achieve.”

Other reasons identified included not enough activity co-ordinators, not able to provide activities outside of the day care centre, and insufficient finances. In the focus groups and interviews, staff frequently mentioned issues with buildings and staffing that impacted on the personalisation of care, and sections 4.4.9 and 4.4.10 discuss these aspects in more detail.

A number of other staff in the online survey mentioned in their comments that, although they tried to take a personal approach, it could be very challenging. Reasons given were similar to those mentioned above, including constraints placed on staff due to the design and space available in the day care centre buildings, and staff shortages or an insufficient level of staffing:



We strive to provide a personalised approach. However, it can be difficult to meet the individual needs of all clients at all times due to space and staff limitations. The nature of day care requires some aspect of group engagement, as we do not have a one-to-one staff to client ratio. This may be as one large group or several smaller groups but there are times when we cannot engage all clients in the particular activity ...”



We do provide a personalised approach but it can be quite difficult due to lack of space, no quiet room etc. so we are limited and feel we could do better.”

### 4.5.1

#### Using individual care plans

All ASI day care centres use the 'This is Me' document, a support tool to enable personalised care. In their comments on the online survey and in interviews, many staff cited the individual care plan drawn up for each person who attends the day care centre as evidence of a personalised approach, whilst others stressed the importance of knowing the person, their history, their likes and dislikes. While staff highlighted the role of the care plan in getting to know people attending, they stressed that people's needs can change from day to day.

Although in our survey, staff did not expand on how the 'This is Me' document is used in practice, a UK study provides some useful insight into the experiences and perceptions of staff using the document (Baillie et al, 2018). That study found the approach helped staff to focus on the person rather than on the medical condition and facilitate understanding of the person's life; it could serve as a useful communication tool and staff felt that it was essential for caring. The study revealed many rich examples of how the document can positively impact in practice. In the study, staff stressed the importance of agreed processes for completing the document and having easy access to it. However, it also found staff opinions can differ in various ways, including: who is best placed and when is the best time to complete the document; how best to involve the person with dementia; and where the document should be held. Another issue raised was that if the document is being completed multiple times as a person moves across care/service settings, it is in danger of 'losing its sense of appeal'. In addition, the authors note that little is known about the perspectives of people with dementia and their family carers about the 'This is Me' document. Although it was not something that was raised by either people with dementia or their family carers in focus groups or interviews in our study, this may be an aspect to consider by ASI, as well as more generally whether and how to make available the 'This is me' document to other services if appropriate.

### 4.5.2

#### Considering compatibility issues in grouping people together

Because of the diversity among people with dementia attending, staff reported that it can be highly challenging to tailor the activities to meet the needs of everyone. One strategy utilised, in an attempt to make the group more homogenous, is to group together on the same day people with similar levels of cognitive abilities and interests or compatible personalities, an approach also used by staff in other countries (Strandenæs et al., 2019). However, this approach is less of an option for day care centres that open only one or two days per week, and while staff in day care centres that open five days a week try to do this, they reported it was not always possible as they had to fill places on days as they became available and

they were also attempting to accommodate the needs and wishes of family carers who had work and other responsibilities and commitments.

### 4.5.3

## Providing a range of activities

Activity programmes are a core component of the service in all the day centres, and staff in both the online survey and focus groups referred to the activities offered as evidence of personalised care. Some staff used the terms ‘person-centred’, or ‘dementia-specific’ or ‘meaningful’ to describe the activities people with dementia could engage in whilst attending day care. However, the type and range of activities offered varies widely across centres covered in this study – some offer a limited range of activities, whereas in others staff have introduced a broader range of activities, programmes and interventions. Staff in centres with a limited range of activities reported a desire to offer more activities, but are often hindered and frustrated in this by the physical limitations of buildings. Staffing levels and the availability of funding also influence the type and range of activities provided.

### Entertaining and meaningful activities

Across the centres, staff reported a range of activities offered to meet the diverse needs and interests of people attending, including some more innovative approaches taken in some cases. Typically, activities include games such as bingo, quizzes, and crosswords. All centres have music and singing, which takes various forms and can include sing-songs, musicians coming in to the centre to perform, or in-reach singing or musical programmes such as one organised by staff from the National Concert Hall in one centre. Dancing is another activity in many centres.

Discussion of news items is an activity common to all centres, and films and documentaries are watched in some. Most centres have arts, which could range from colouring to an art therapy programme, and crafts such as knitting and crochet. One centre hosted an artist-in-residence throughout the summer, culminating in an art gallery exhibition of the art work created. Cooking and baking are available in some centres. Hand massages, shoulder and neck massages, hand and nail care and manicures are available or planned for introduction in some day care centres. In a few centres, people attending can get involved if they wish in everyday tasks alongside staff and volunteers, for example, drying the dishes, maintenance of the building (painting and decorating the centre and outdoor spaces), and creating, developing and maintaining the garden.

### Therapeutic interventions

Some centres have introduced therapeutic interventions specifically designed for people with dementia, including Reminiscence Therapy (which involves the discussion of past activities, events and experiences), I Hear Memories (a reminiscence programme using sound), the Sonas

Programme (an evidence-based multi-sensory programme for people with moderate to severe dementia), and Doll Therapy (a non-pharmacological intervention aimed at enhancing personal well-being and alleviating distress). Staff are not always trained in the delivery of some of these interventions and in this context may deliver them in a more informal and less structured way.

### **Exercise and health promotion**

Doing exercises is also a common activity in most centres and some have introduced chair yoga or a specific exercise programme, e.g. Go for Life, which staff have received training to deliver. One centre has developed links with a local college offering a sports degree programme, and students visit the centre to deliver the exercise programme. Another centre is promoting healthy eating via a breakfast club to replace tea and toast with more healthy and appetising options including cereal, fruit, and juice.

### **Spiritual practice**

Some centres hold religious activities such as prayers mid-morning or a priest visiting to give communion. Other centres, in an attempt to move away from a focus on any particular religion, have a multi-faith pastor, or have introduced mindfulness or meditation as a spiritual practice.

### **Barriers**

While activities are a central component of day care, staff in some centres highlighted the lack of funding available to them for providing suitable and meaningful activities for people with dementia, e.g. to purchase basic materials for arts and crafts activities or games developed specifically for people in day care centres or those with dementia, or even for photocopying news items for discussion. In some centres, staff have conducted fund-raising locally to help finance day care centre activities.

Centres that share premises with other groups have particular challenges because of limited space available to staff to store materials needed for activities, thus curtailing the range of activities they can offer.

Both men and women attend the dementia-specific day centres and staff reported finding it difficult sometimes to find or provide activities of particular interest to men. Other barriers mentioned included lack of space in buildings, lack of an outdoor space or garden, and lack of skills of staff to deliver particular activity programmes or interventions.

### **Informal time**

Activities in dementia-specific day care centres need not always be formally organised or strictly planned. For example, in one centre the staff and people attending sometimes took time just to sit and chat and let the afternoon take its own course. This allowed staff and people attending to spend time with each other, and people attending tended to dictate the pace and drive the conversation, facilitated by staff. Staff found this a very

important way of getting to know people, and the approach gave a sense of just 'being in the present moment', listening to the stories and paying attention to the details of people's everyday life. As well as making or sculpting-in time just to be together, staff in this and some other centres sometimes allowed activities to emerge spontaneously. They gave an example of one person attending who started to strip the wallpaper and, as all agreed that the wallpaper was not to anyone's taste, they decided to strip the wallpaper and redecorate the room, with the involvement of both staff and people attending.

#### 4.5.4 **Small group working**

The day care centres usually offer activities in a group setting and one of the challenges for staff is to find a balance between meeting the needs of the group and individuals. One strategy utilised in most day care centres was to divide people attending into smaller groups, also an approach used in other countries (Strandenæs et al., 2019). This could be harder or sometimes impossible to implement in centres with space restrictions, such as small room size and/or only one room for activities, poor building layout or inaccessible rooms. In some cases, people attending generally all had to do the same activities together. However, within these constraints, staff emphasised they interact with and give individual attention to each person and personalise activities as far as possible. Where space allowed, some centres overcame this by having small group activities going on simultaneously at different tables or areas within the room.

Staff reported that some activities such as singing and exercise lend themselves well to large groups, but other activities work best in small groups. Some interventions designed for small groups (e.g. the Sonas Programme or I Hear Memories) would be near impossible and undesirable to deliver in a room where other group activities are ongoing. In this way, centres with more than one room have an advantage over centres with only one room for activities. In interviews, staff remarked on how well people with dementia engaged with small group activities, and staff really enjoyed small group work and wanted to do more of it. However, they emphasised that, as well as adequate space, it was necessary to have enough staff and volunteers to facilitate small group activities, and this was not always the case. Staff reported they were often limited in the activities that they could offer because of staff shortages.

#### 4.5.5 **Individualising activities and interactions**

In all centres staff reported that they individualise or personalise activities as far as possible, and some gave examples of the ways they do this. They could, for example, become aware through discussions with the person or their family members of past interests and hobbies and introduce activities connected with this, e.g. knitting or crochet. Staff also mentioned choice regarding meals as part of a personalised approach.

Another issue mentioned was that some people attending may not want to participate at all in group activities, whether large or small. Others may not want to participate in a particular activity or on a particular day or time of the day. Staff look for ways to engage the person in these situations and gave examples of approaches they use. These could include spending time chatting with the person or sitting and reading a book or magazine. Staff in one centre gave the example of a woman who would not engage in any group activities, but when she showed an interest in the birds in the garden, staff developed an activity for her around making home-made bird feeders and she was eager to join in this.

Staff in another centre felt there will always be people with dementia in day care centres who don't really settle and don't like to interact much, and that staff have to accept that the person may be most content to sit and read a newspaper or just sit and be there without interacting much even with gentle persuasion. Other people may interact less and less as the condition progresses, sometimes because they are conscious of their communication difficulties and withdraw into themselves. Staff suggested that, for these people, social clubs operated by the ASI may be a suitable alternative to day care, but family members must attend with them and these groups are less suitable as a person's dementia progresses.

#### 4.5.6

#### **Attending to complex needs of people with dementia**

In general, personalising activities requires staff to know the person, and understand their needs and interests. Often staff have to be creative and can sometimes find it difficult to engage or personalise activities for some people with dementia attending day care who have complex needs. These include people with communication difficulties associated with dementia, vision or hearing impairments, learning disabilities, or because the person does not speak English as their first language. Some people are at an advanced stage of dementia and may be unable to participate in most group activities, and some staff questioned the appropriateness of day care for those with advanced dementia.

A recurring theme in staff interviews was that people with dementia attending day care with responsive behaviours require more one-to-one interaction. A person may become agitated, be having a bad day, find the group too noisy and need quiet, or simply may need their own space away from the group for a while. Staff described the approaches they took such in these situations, such as walking with them if they are agitated, or using doll therapy. Some centres have quiet spaces or are currently developing one. Staff felt having a quiet space was vital for people who get distressed or agitated or at a more advanced stage of dementia. Outdoor spaces were also useful in this regard. However, not all centres had a quiet space or an outdoor space. A downside of providing one-to-one interaction is that it distracts the attention of staff from the group, and makes it

harder to organise and facilitate group activities, particularly small group interaction / activities. This is an issue that was also identified in another study of dementia-specific day care (Strandenaes et al., 2019).

## 4.6 Other features and innovations

### 4.6.1 In-reach from and outreach into the community

The research found various forms and levels of in-reach into the dementia-specific day care centres. Examples mentioned by staff include bands or choirs visiting the centre to provide 'live' music; visits from students from local colleges delivering interventions related to their area of study; and an artist or musician in residence programme. Some of the in-reach in Ireland is highly innovative, and while as far as we are aware these have not been evaluated, staff report these kinds of innovations to be highly successful.

Out-reach into the community is also a novel feature of some day care centres. Dementia-specific day care has traditionally evolved as a primarily or entirely centre-based model. Three of the day care centres in the sample for the in-depth study were wholly centred-based - all of the activities and supports occur at the centre and people attending do not leave the centre during the day. Two of these centres did not have a minibus, and had no way of bringing people attending on day trips or excursions outside of the centre.

In the other centres, however, activities also take place outside of the day care centre. In this study, most centres (5/8) with a minibus use the minibus for outings and day excursions and/or as a way of connecting people into the community. These five centres out-reach and connect into the community to varying extents. Some centres out-reach by going on outings, or by going on walks in the fresh air or by the sea. Others get involved in local groups such as participating in community choirs or in film club or museum events. There are examples of centres that take out-reach even further, such as the participation by one day care centre in a community garden project, with an assigned allotment in the community garden centre. People with dementia attending the centre travel by mini-bus during the day to the allotment with staff and get involved in horticultural activities.

Projects such as these not only enable people with dementia to get outdoors but can allow the centre to act as a base from which to outreach and enable people with dementia to be part of and connected back into the community, and represent what might be referred to as a community development or assets-based approach to day care for people with dementia. Outreach and connection into the community is ultimately rewarding for people attending, staff, family carers, and has benefits for

the wider community. However, it is not without its challenges and needs resourcing and support. It requires transport and a sufficient level and mix of staff and volunteers, and, even then, it is not suited to everyone.

#### 4.6.2

### Client input and decision-making

The day care centres varied in how much people attending had input into the planning of the centre and its activities. In some centres, the everyday practice is for staff to plan and choose the activities on any given day or week. The planned activities are often informed by the 'This is Me' document and staff knowledge of the preferences, interests and needs of the clients attending, and staff plan activities to include as far as possible the people attending on a given day. Attendees may or may not participate in the planned or prescribed activities, but other than that have little choice or say. People who do not want to take part in the available activity typically make it known by getting up and leaving the table or walking away, and staff then respond by trying to engage the person on a one-to-one basis.

Some centres are involving people with dementia attending in the day care centre planning and decision-making by operating client councils.



Individual care plans done for each client. Everyone is given choices with regard to meals and activities etc. Their opinion matters and they are included in all their activities. We do client council meeting and their say counts.”

In one focus group, family carers highlighted the client council and how important it was for them to hear that staff were including and listening to people with dementia attending and taking account of their views about day care and what they liked and disliked. They said that their relatives with dementia had spoken to them about the client council and how much they appreciated it. However, not all centres have established a client council.

Some day care centres follow a very personalised approach, referred to by Brataas et al. (2010) as collaborative day care, whereby the people with dementia attending have a say each day; every morning begins with attendees planning the day and its activities, based on their preferences, together with staff. Since people attending do not always express a preference, staff reported having a number of suggestions to make as a back-up, from which the attendees can choose. Some centres are quite flexible and could make changes to the planned activities during the day depending on the mood and the preferences of those attending.

## 4.7 Structural issues

### 4.7.1 Building issues

As described earlier, the centres varied considerably with respect to the buildings in which they operated. In some cases, staff reported the buildings worked very well and they were aware how good their facilities were in comparison to some of the other day care centres. One such example is a day care centre that was purpose built, and has an open plan space that can be divided into smaller spaces. It has good light, a quiet room and a safe outdoor space.

In most other centres covered in the study, however, staff frequently mentioned challenges posed by unsuitable buildings. This included one purpose-built premises, which was a homely space, but had many limitations. Built over 20 years previously, it was now too small for current needs, had only one room for activities, no quiet space, inadequate storage and an unusable garden. In other centres, the rooms where activities took place were often problematic - either too small, or large enough but poorly laid out. Some buildings only had one room, or some rooms in the building were inaccessible, and several lacked a quiet space. Staff highlighted the significance of having an accessible outdoor space, and those that had one regarded it as an invaluable resource, but other centres had no outdoor space.

Toilet facilities in several centres were inadequate, and often not designed to easily accommodate people with dementia who needed help from one or two carers. Staff expressed concern about the impact of inadequate toilet facilities on the dignity of people with dementia. On the day visited by the researchers, one day care centre was cold and staff were wrapping blankets around people attending to keep them warm.

Some centres shared the space with other community groups and organisations, which meant that staff had to pack up everything at the end of each day. Staff had no say over the decoration of the space but felt that simple changes would make the room cheerful and more welcoming, such as a coat of fresh paint in bright colours. They would also like to have the possibility to make the space more homely and to personalise it, for example by displaying paintings or art created by people attending, or using seasonal decorations to give a sense of the seasons changing.

## 4.7.2

**Staffing, staff adequacy and related issues**

Staff in the dementia-specific day care centres comprise ASI employees and participants on the Community Employment scheme,<sup>2</sup> with all centres having a Centre Manager. The approach adopted by dementia-specific day care centres is a 'blended' model of day care (Lunt, 2020), with volunteers assisting ASI staff to deliver the service, although the level of volunteering varies across centres.

"It is not just a job – it is a calling."

In general, staff in the centres visited came across as highly committed and motivated, interested in the work and very caring. Many of the staff interviewed identified themselves as 'carers' and spoke about how much they love their work, while also emphasising how skilled the work is. Many spoke about how rewarding the work is, and some saw their work more as a vocation than a job: *'It is not just a job – it is a calling. It doesn't feel like work.'* Staff reported they were well trained, with FETAC level 5 training and training provided by ASI in dementia awareness, and some staff had undertaken additional training. They felt training on person-centred care was particularly useful in helping staff to pick up on non-verbal expressions, e.g. concerning people's willingness or reluctance to participate in specific activities.

"a strong community of professionals and volunteers"

Staff reported that all levels of staff and volunteers in the centres have to work very much as a team. They identified teamwork and having the support of each other as hugely important. In one centre, staff described their centre as: *'a strong community of professionals and volunteers'*. In another, staff noted that they are all different – everybody brings different strengths to the work at the centre and it is important to be able to build on the strengths of individual staff. Staff felt the support from the centre manager was highly important, and most described this as very supportive, with the manager approachable and available to listen and willing to address issues. Centre Managers may have a nursing or social care background, but either way the leadership role is extremely important,

One issue identified for centres that are not nurse-led was the importance of having nursing input into the centre because of the complex and comorbid needs of people with dementia. Non-nursing staff are not permitted to dispense medication at the day care centre, risking the exclusion of people with dementia who need to take medication during the day. This exclusion might be permanent or could be temporary – for example when a person has been directed by a doctor to take an antibiotic during the day – unless a family member is available to attend the day care centre and dispense the medication.

2 The Community Employment scheme, which is administered by the Department of Employment Affairs and Social Protection, is designed to help people who are long-term unemployed (or otherwise disadvantaged) to get back to work by offering part-time and temporary placements in jobs based within local communities.

A number of other challenging issues around staffing were mentioned, mostly around adequacy of staffing levels, the policy of employing relatively large numbers of CE scheme staff, and the value placed on the care work in dementia-specific day care centres.

With respect to staffing level adequacy, the client to staff ratio in ASI day care centres is 4:1 and the ratio includes the Centre Manager. Staff in some centres felt this ratio was sufficient to provide a quality, personalised day care service, but needs to be continually in place; however, this was not always the case when there were staff absences due to illness, leave, or delays in replacing staff. Any compromise to the client to staff ratio could undermine the centre's ability to provide a personalised service.

In other centres, staff felt that a 4:1 ratio was not sufficient, especially as the Centre Manager was often busy with other work (e.g. administration and paperwork, talking to and assisting family carers) and not routinely available for face-to-face interaction with people attending. They also explained that the ratio doesn't take account of the time it takes to help people with toileting, which is time-consuming and often takes longer than expected, and that some people need help from two care staff for this. Unforeseen events can also occur, such as when a person falls ill, and the client to staff ratio does not allow for this; if one staff member has to leave the floor, this compromises the staff ratio.



More staff would help – there can be a domino effect, where if one staff member has to leave the floor, then staff ratio can be compromised

Staff mentioned that the 4:1 ratio was critical at mealtimes because of the level of attention needed by people who have special dietary requirements, require help with eating, or have difficulty with swallowing and are at risk of choking.

The capacity to have one-to-one interactions with people with dementia was another key issue mentioned, and some staff felt that a better client to staff ratio would allow them to provide more one-on-one care to people with more complex needs, in particular people with responsive behaviours. Staff could see the benefits for a person who is anxious or agitated or simply having a bad day when staff spend time with them one-to-one or bring them to a quiet area. They also stressed that safety of people attending is a priority, and there are implications when people need a lot of one-to-one interaction, especially when there are staff shortages. It also means there are less staff available for the wider group, putting staff under pressure and impacting on the activities that can take place.

In one centre staff explained that on days where there are people who need a lot of one-to-one interaction or help with toileting, very little activities are going on, an issue that has been highlighted by service providers in other studies (O'Shea et al., 2017). *'Safety comes first, and when you are short-staffed you can't provide services you are meant to'.*

A way that one centre manages this, although not very often and only as a last resort, is to cancel the attendance of people with challenging behaviours when staffing levels are low. Staff suggested the extra staff, such as a relief or floating person, would be helpful.

#### **CE Staff**

Some day care centres do not have any staff from CE schemes, but many rely heavily on staffing from this programme. Staff opinions differed on this approach, with some reporting it worked very well and others feeling it had some problems. Positive aspects mentioned included the perception that many CE scheme staff have the qualities and attributes required for care work and it served as a useful way to access and employ good quality staff. Several staff participating in interviews commenced working with the ASI on a CE scheme, and were now ASI employees. One had begun at the centre as an administrator employed through a CE scheme and on seeing the work of care staff decided to make a career change and now plays a key supervisory role in the centre.

“Caring has to be in you”

However, some staff felt that not everyone employed through the CE scheme was suitable for or interested in care work with people with dementia. As one staff member put it: *‘Caring has to be in you’*. Those not suited for care work were a poor substitute for skilled care workers, and this had implications for both people with dementia as well as other staff working in the centre.

A difficulty mentioned about the CE scheme is that placements on the scheme are part-time and temporary, and when the placement comes to an end, participants are encouraged to look for permanent jobs elsewhere. Most CE staff leave the centre at this time and there can be difficulties retaining good CE staff. This can lead to high levels of staff turnover, and regular staff felt this was problematic for people with dementia who want and need familiarity and routine. Another downside of employing staff through the CE scheme is the commitment and time necessary to supervise and train CE staff, and the level of paperwork it produced for centre managers.

#### **Insufficient appreciation of staff**

Many staff felt their own and their colleagues’ commitment and hard work was undervalued and underappreciated. One indication of this was in the pay and conditions of care staff; their pay is relatively low and staff felt it was lower than for equivalent work by care staff in HSE-operated day care centres.

Despite their low pay, however, staff reported they often give extra time unpaid at the end of day, put huge efforts into fund-raising locally outside of work hours, and some reported paying out of their own pocket to purchase materials for activities. Another issue mentioned was that when care staff received a small pay rise linked with the Section 39 agreement,

“nobody does this type of work for the money”

“people who stay at it are there because they find the work so rewarding”

the result was no net value for staff as their working hours reduced by 15 minutes per day.

One comment was that *‘nobody does this type of work for the money’*, but rather *‘people who stay at it are there because they find the work so rewarding’*. While they loved their work and found it rewarding, the work was tough and could be very stressful, as illustrated by the following comments: *‘You can go home with a big headache’*; *‘You would have to love it or else you would burn out’*. Staff said that after a stressful day, they have to find ways of leaving the stress behind them as they leave, and it could also be upsetting for staff when issues around safeguarding or neglect arise.

More generally, staff expressed a feeling of disconnect between day care centre staff and head office, and would like more appreciation by ASI nationally of the commitment and hard work of care staff and of volunteers. Better pay and conditions would be welcome, as well as a bit more appreciation generally for all the effort of staff and volunteers, for example, through gestures such as a Christmas bonus or night out.

## Section 5

# The perspectives of people with dementia and family carers

This chapter presents results from the study concerning the day care perspectives and experiences of people with dementia and their family carers. Few studies appear to have addressed this in Ireland or internationally. The material draws on two elements of the overall study – the in-depth work with people with dementia and family carers in the eight selected centres and the wider survey of dementia service users in the surrounding areas of the centres.



## 5.1 Focus groups with people with dementia

The people with dementia who participated in the focus groups generally expressed high satisfaction with the day care centres they attended, reporting they liked and valued attending and describing the centres as homely and providing a positive atmosphere. The following are some of the key themes emerging from the focus groups

### 5.1.1 Opportunities for social contact outside of the family

People with dementia frequently referred to the opportunity for social interaction and conversation at the day care centres, and the social engagement through the activities. Attending day care provided company and friendship - having an opportunity to engage with other people, including people in a similar situation as themselves, in a safe environment without worrying about making mistakes. A number of people with dementia participating in the focus groups were living alone, and getting out of the house, having something to do and going to a place where they could interact with other people was especially important for them. If they were not at day care, they would be sitting in the house 'looking at the four walls' or looking for something to do.

In one focus group, participants spoke about how life had changed and that now, unlike in the past, it was unusual for neighbours and friends to drop in or visit. They missed the company of others. This highlighted how alone and isolated some felt at home, and from what some people living alone said, they gave a sense that they felt more relaxed when they were at day care as it gave them some relief from the worry and anxiety that they felt when home alone. Many did live with family members but did not always have company at home because family members were at work and, more generally, company of other members of the wider family could be limited because of work or having to look after their own immediate families.

Some people with dementia said that attending day care centre gave them a routine and a sense of normality in their lives. For others, while family was very important to them, attending day care afforded a sense of independence and a break from family carers.

### 5.1.2 Enjoyable activities

In general, people with dementia enjoyed the activities on offer at their day care centres, and at the focus groups none expressed a dislike of any activities. At some focus groups participants mentioned activities they liked best or were most enthusiastic about, such as music and singing and baking. Where offered, services such as chiropody and hairdressing were also welcomed. Some of the centres organised outings, and people with dementia reported enjoying these and some would like more outings. In one centre, people attending took part in a community garden project

and described this as the highlight of their year, and talked about which vegetables they would like to plant next summer.

### 5.1.3

#### Very few negatives mentioned

Participants mentioned very few things they disliked about day care. One woman suggested that it could be *'a little slow in the morning to get started'* but others seemed to like the slow start. The slow start seems inevitable in most centres as people arrive at different times – when they come in, they make their way to the main room to sit and chat or read newspapers or simply wait as staff need time to gather everyone together before starting activities.

Some felt the day was too short and wanted it to be longer, whereas others found it very long. One man explained that he much preferred attending day care in the summer months as he could go out into the garden and the day did not feel so long then; he found it very long in the winter months when the weather was bad and going outside to the garden was not usually an option.

Some said that they missed day care on days that they did not attend, and a common request was to attend day care more days per week, but this was often not possible either because places were not available on other days or the centre only opened one or two days per week. However, not everyone wanted to attend on extra days.

### 5.1.4

#### Positive views on staff

Focus group participants often praised the staff and commented on how well staff looked after them. They spoke about how friendly, approachable and respectful staff are, always having a smile and willing to help them with anything.

### 5.1.5

#### Having choice and an influence on day care activities

In general, when asked, people participating in the focus groups seemed happy with their level of engagement in decision-making within the centre, and were free to choose which activities to participate in:



Great freedom in coming here, you can choose what you do, you can choose to do nothing.

In several centres, focus group participants quite strongly asserted that if anything they disliked occurred or if they had any negative comments or complaints about the centre or staff, they would readily make this known to staff. Overall, the participant feedback made it clear people with dementia valued having their voices heard.

Some of the day care centres have client councils, and people with dementia valued the possibility to have a say in the centre and its activities.

In one centre without a client council, focus group participants liked the idea of a client council and stressed how important it was for their voices to be heard. One man suggested the centre could install a complaints box where people attending or a family member could anonymously post a complaint. While he emphasised that he had no complaint at the moment, he said that it would be reassuring to know that this process was in place if one arose.

## 5.2 Focus groups/interviews with family carers

### 5.2.1 Provision of care and support for the person with dementia

For most family carers participating in the focus groups or individual interviews, the main purpose of day care was to provide care and support to the person with dementia. Enabling people with dementia to socially interact with other people, and the cognitive and social stimulation, was especially important for family carers as well as knowing that the person with dementia was in a safe and supportive environment and happy to attend day care.

Family carers identified many of the same benefits of attending dementia-specific day care for people with dementia as staff. They generally showed broad agreement about the benefits, which included socialisation and engagement, stimulation through interaction and activities, structure and routine, change of environment, prevention of isolation, independence, enablement, mixing with people their own age or in similar circumstances, and a sense of normality and independence. Carer comments underlining this included:



My husband withdrew from contact when he realised he was developing Alzheimer's, but he has re-engaged since he has come to the Centre.



I'm a farmer and she can spend a long time on her own and doesn't get the opportunity to talk all the time. Even though she doesn't say much, being in an environment where people are moving around and even communicating non-verbally is important.

A study in Norway found that some family caregivers report a lack of individualised care and had the impression that dementia day care staff failed to be inclusive and give social support to the people with dementia, and that activities were not adequately tailored to the interests and functional levels of the individuals with dementia (Tretteteig et al., 2017). However, this was not an issue raised by the family carers participating in our study.

### 5.2.2

#### Respite for family carers

Family carers also frequently referred to the respite that day care offers them, but stressed that knowing their relative was safe and having an enjoyable time, engaged in meaningful activities, was an important aspect of having this break. Although getting a break from caring was important, it was mostly secondary for family carers and this finding is consistent with other studies on dementia care (e.g. Cullen and Keogh, 2018). Research on dementia-specific day care (O'Shea et al., 2017; Gustaffodir, 2018) indicates that, for family carers, dementia-specific day care represents a safe service and offers routine in the daily life of the person with dementia, knowing that the person is occupied with something meaningful. This is especially significant given the reality and challenges for family carers in keeping people with dementia engaged and stimulated at home or in the community, which they can find hard or lack the time for, as highlighted by family carers in this study. Nevertheless, some family carers reported that day care does not give them much respite from the demands and stresses of caring, which dementia-specific day care cannot alleviate alone.

### 5.2.3

#### Carers facilitated to remain in employment

Many family carers identified the role that day care plays in facilitating working family carers to remain in employment. One family carer working full-time explained that, before day care, she had to frequently leave work to attend to her mother who is extremely anxious and needs constant reassurance, but day care now allows her to work without constant interruptions throughout the working day.

### 5.2.4

#### Meals

The provision of a meal during the day marks day care centres out from many other community-based services and supports. This was a really important feature for family carers participating in the focus groups, particularly for those caring for a person with dementia living alone - on the day the person attends day care they know they are eating and don't have to worry about this. The issue of eating is a big concern for family carers of people living alone as they often don't know if or what the person has eaten, so the meal at the day care centre was a big help to them in this regard. It also helped overcome challenges family carers generally can face regarding food and mealtimes, such as a person forgetting to eat, poor diet, food going off, eating too much, and tendency to eat sweet and sugary food. In the focus groups, the value of having a meal at the centre was also mentioned frequently by people with dementia.

### 5.2.5

#### Physical exercise

Physical exercises provided in the day care centre were also of value to family carers. Some family carers explained that a physiotherapist

may have prescribed exercises, but getting people with dementia to do exercises at home could be very difficult and they were often met with a refusal to cooperate. Exercise programmes were available in most day care centres and it was a relief for family carers to know that exercises were built into the day and they felt that the day care environment seems to support people with dementia taking part.

### 5.2.6

#### Transport

Many of the day care centres in the sample for this study had a minibus to bring people with dementia to and from the centre, although some limited transport to a specified catchment area. Family carers whose relative availed of the mini-bus service described it as fantastic. It was a vital service for working family carers not available to drop their relative to and collect them from day care. It was also beneficial for family carers not in employment.

Not everyone could avail of the mini-bus service, either because it didn't serve their area or because a person with dementia couldn't or wouldn't use the bus. Because of the time involved, some family carers reported that bringing a person to and from day care eats into their time away from caring, especially if the centre is far from the person's home, and thus lessens the benefits of day care for family carers. Two of the centres had stopped providing transport due to costs. In one of these centres, family carers were accepting of the absence of a mini-bus – this was only a slight inconvenience for them and not an obstacle to day care. In their case, most lived nearby and were available to bring their relative, but they felt it might be an obstacle for people living in more remote areas of the county.



We live very near so it doesn't affect us. Look at, it's great to have the service, you just get on with things ... It [a mini-bus] would be a convenience but it is ok to bring her.

The other day care centre has put an arrangement in place with a taxi driver/company, but not all family carers seemed aware of this arrangement. Some described getting to the day care centre as quite arduous. One woman who lived nearby explained that it only takes her 10 to 15 minutes to walk to the day care centre on her own, but when she accompanies her relative to and from the centre it can take up to 40 minutes each way. Another adult child explained that she travels from quite a distance to get her parent's home, but because of traffic at rush hour, she has to leave her own home at 7.00 a.m. so that she is there to bring her parent to the day care centre on time. Another relied on the goodwill of relatives and neighbours. They also found parking outside the day care centre could be an issue. Family carers said that a mini-bus would be extremely helpful, including those using the taxi service, and all agreed that they would be happy to pay extra for the day care centre to have a mini-bus service.

### 5.2.7

#### Feedback from day centre staff

In some day care centres staff provide regular direct feedback and information to family carers about the schedules and the activities of the day, and family carers generally welcomed this. Some centres issue monthly newsletters. Other centres may provide feedback in a less structured manner, verbally as family carers collect their relative. Some family carers expressed a need for more direct feedback and information from these centres, consistent with findings from other studies on day care for people with dementia (Tretteteig et al., 2017). They explained that memory problems arising from dementia make it difficult for the person with dementia to communicate and share experiences about what has occurred during the day, and the information would be useful for prompting discussions at home, particularly when a person with dementia uses the mini-bus services and family carers do not have an opportunity to discuss the day with staff. However, not all family carers expressed a need for more feedback - some felt that it was unnecessary and that day care centre staff already had enough work to do.

### 5.2.8

#### Access to advice and support for carers

Family carers also mentioned the value of having access to staff at day care centres who they trusted and from whom they could seek information, practical and emotional support and advice, or talk to about their situation. It was particularly important to them that they could get advice and support from staff who knew their relative well and had regular contact with them. Another benefit was the link day care provided to other family carers.

### 5.2.9

#### More flexible opening hours

Many family carers participating in the focus groups expressed a desire for more flexible opening hours, particularly longer opening times to accommodate family carers in employment and juggling caring with other responsibilities. Some also suggested it would be helpful if day care was open in the evenings, or during the weekends. Family carers also expressed a need for an extended number of days.



It's amazing that it is only open two days a week. I would be down on my knees to say 'could we have another day?' **Family carer of person with dementia**

Some family carers also reported experiencing difficulties when day care centres are closed for bank holidays, especially when a person with dementia attends only one day a week on a Monday, or when family carers have to work on bank holidays. However, not all family carers in this study wanted more flexible opening hours or an extended number of days. Staff participating in our study reported that this is a common request from family carers and other studies, for example in Norway, have also identified this issue (Tretteteig et al., 2017).

### 5.2.10

#### **Better integration of day care and other services for people with dementia**

Finally, some focus groups discussed the potential and value of better integration of day care services with other services for people with dementia. The current model appears mainly to operate in a standalone manner, separate from other services such as home care and residential respite.

One possibility mentioned concerned offering residential respite on the same site as the day care centre (in centres where this might be a practical possibility because of their location). Advantages of this would include the likely greater acceptability by the person with dementia because of prior familiarity with the environment, as well as the possibilities for some continuity of staffing across the day care and residential respite services.

Another desirable service integration for some family carers would be better synchronisation of day care and home care services in situations where the person with dementia had access to both. This might be for purposes of helping the person with dementia get ready for day care in the morning and/or meeting and helping settling in when they get home, as well as the possibilities for some degree of continuity of staffing across the two service components (staff in day care centres may be part-time and some also work part-time in home care services).

## 5.3

### **Wider survey of dementia care service users**

This part of the study aimed to generate a broader perspective on day care from a wider population of persons with dementia and family carers than those included in the in-depth research in the eight selected centres. For this purpose, the study included a paper-based survey of dementia service users in the counties / wider areas around the eight centres, without aiming to be over-precise on the exact geographical or catchment areas covered. To try to get perspectives from both people who had experience of day care and those who had not, ASI frontline services distributed the survey questionnaire to people with dementia using a range of community-based services, mainly focusing on three services – ASI social clubs, Alzheimer Cafes and Dementia Advisers.

### 5.3.1

#### **Profile of respondents**

Given the approach adopted, the respondents represent an opportunistic sample of people using a range of community-based dementia services across the country. For the wider survey of dementia care service users, the research team received back 105 questionnaires. Quite a number of responses were from 'dyads' (a family carer and person with dementia), and in some of these cases it was more appropriate to combine the two into a 'dyad' perspective. Overall, 80 were suitable for analysis as 'unique'

responses representing either or both parties' perspectives and the results presented below are based on these.

Figure 3 presents a profile of the numbers of respondents with experience of different types of service, either currently or in the past. Day care was the most commonly reported service used (54), followed by social clubs (36), Alzheimer Café's (29), home care (22), dementia advisers (16), and family support groups (15).

Figure 3:

**Numbers with experience of the various dementia-specific services**  
(currently using or used in the past)

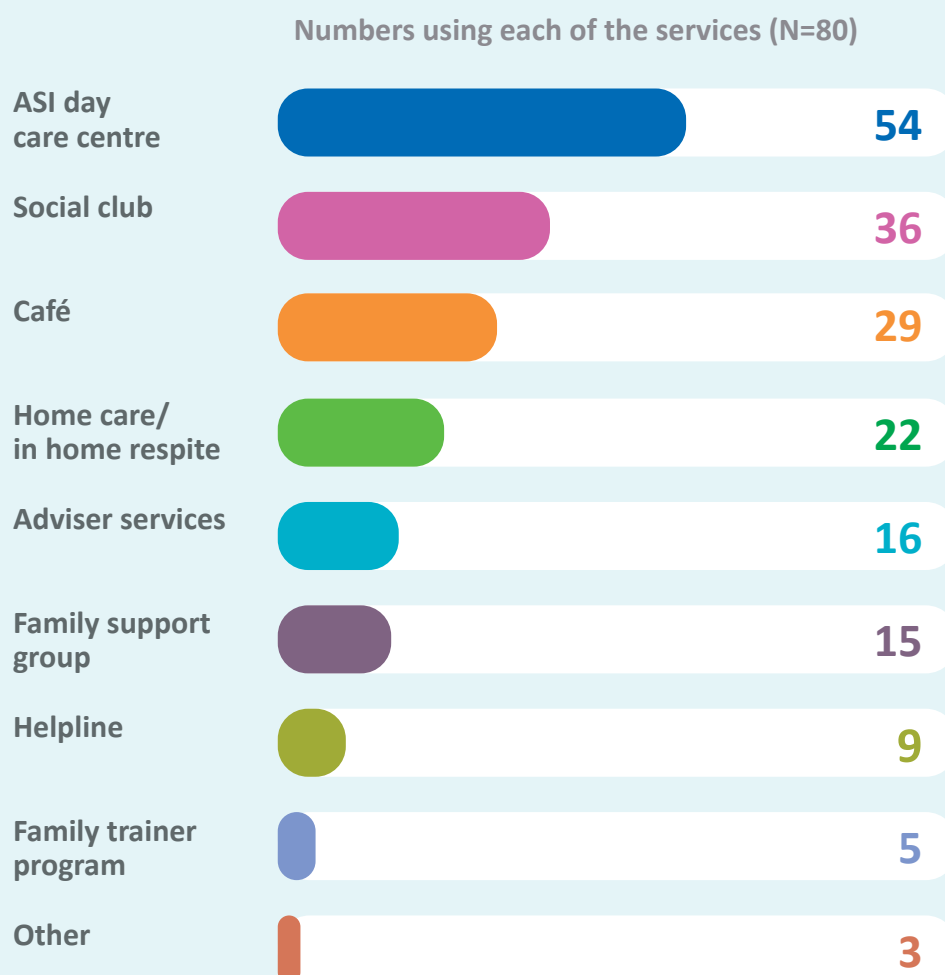


Table 2 presents the breakdown of respondents according to experience of day care. More than two-thirds of respondents had experience of day care, either currently using (53.8%) or had used in the past (13.8%), and one-third (32.5%) had no experience of day care.

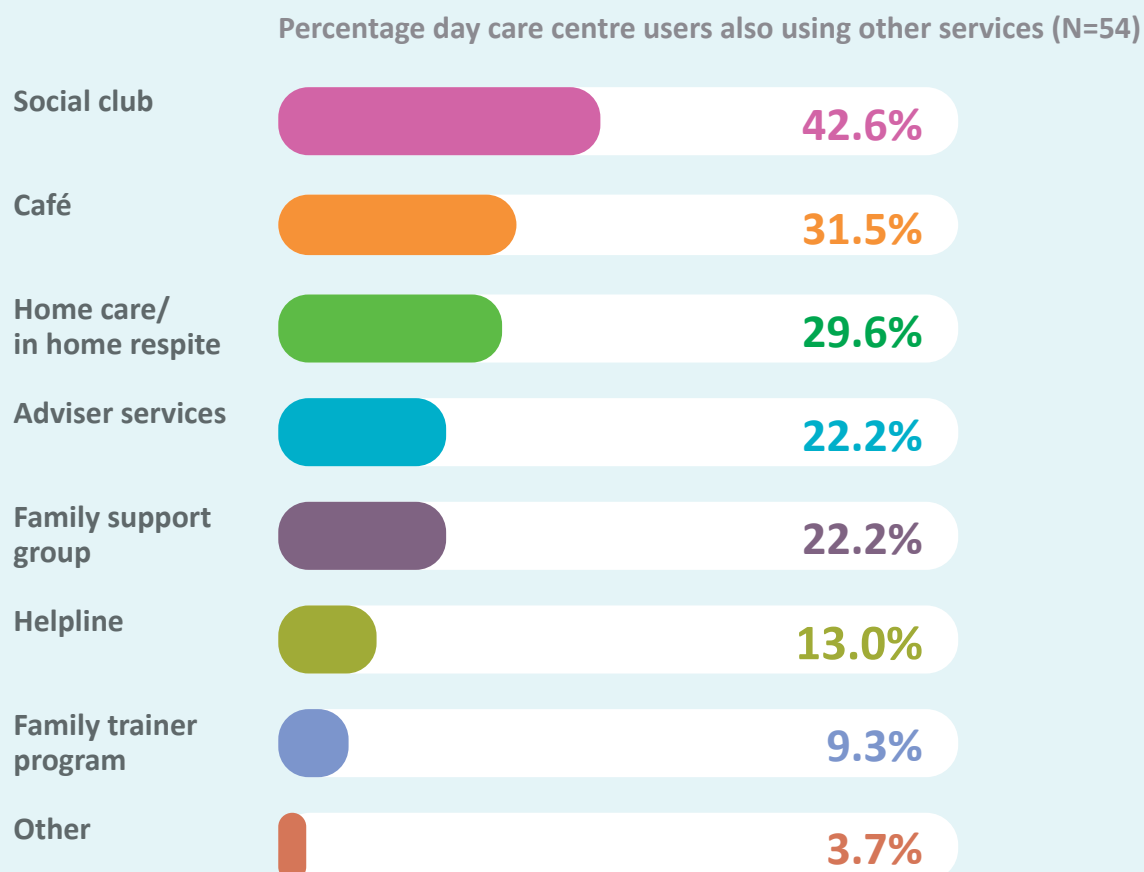
Table 2:  
Experience of day care

	Current	Past	Never	All
#	43	11	26	80
%	53.8	13.8	32.5	100.0

Figure 4 shows the percentages of day care service users (current or past) also using other services. This serves to illustrate the multi-service usage of this sample and is useful for providing a wider and more broadly-based perspective on day care in conjunction with the various other services available to people with dementia and their family carers. However, the precise proportions of day care centre users also using other services in this survey is likely to reflect the convenience sampling approach (mainly via social clubs, Alzheimer cafes, and dementia advisers) so any generalisation should be treated with caution.

Figure 4:

**Percentage of day care service users (current or past) also using other services (currently or past)**



### 5.3.2

#### Day care users

Table 3 presents respondents ratings of the usefulness of day care for respondents. Almost all said it was very useful and just one person rated it a little useful.

Table 3:

**Usefulness of day care**

	Very	A little	Not at all	Missing	All
#	52	1	0	1	54
%	98.1	1.9	0.0	–	100.0

Table 4 presents respondents' ratings of the quality of the experience of day care for the person with dementia. This shows that almost all respondents rated the experience as very good (74.5%) or good (19.6%), with similar patterns apparent from both persons with dementia and family carer responses. Two respondents felt it was neither good nor bad, and one respondent (a family carer) felt it was too early to tell as the person with dementia had just begun attending day care

Table 4:  
**Quality of the day care experience for the person with dementia**

	Very good	Good	Neither good or bad	Bad	Very bad	DK	Missing	All
No.	38	10	2	?	0	1	3	54
%	74.5	19.6	3.9	0.0	3.9	2.0	–	100.0

These results reinforce the picture emerging from the in-depth research in the eight day care centres, indicating generally very positive experiences of day care for persons with dementia and family carers. Reasons for the positive ratings were similar in both parts of the study.

Finally, Table 5 presents a range of possible improvements to the day care service that respondents mentioned. Again, these are generally similar to the suggestions made in the focus groups in the selected centres.

Table 5: **Suggestions for improvement of day care**

Respondent	Rating	Improvements
Person with dementia	Neither good nor bad	More pieces of interest, like old things and chatting about the past
Carer	V. Good	A centre specific building is needed in the the area, Rented accommodation not always suitable
Carer	V. Good	More day care centres for the elderly
Carer	V. Good	Perhaps some outdoor space. This is a fantastic service. I wouldn't manage without it
Carer	V. Good	In my opinion most people with dementia seem to love music, so the music is wonderful for them. Dance and sing song
Carer	V. Good	Maybe board games or jigsaws would be another suitable activity. There are some good items in the sensory room in xxx which might give some good ideas.
Carer	V. Good	The building is not great, but will be upgraded in the near future
Carer	Good	Cannot comment on improvements but would like to attend sooner rather than waiting on a place to be available
Carer	V. Good	Occasional feedback on users' time on the centre
Person with dementia	V. Good	Room could be bigger, around meal time it can be a tight squeeze
Carer	Good	Transport for people who live in areas outside the catchment area
Carer	V. Good	If day care could be extended to 5 days per week, for the patients it would help, for the carers even more
Person with dementia	Good	More music, more dancing
Carer	V. Good	In our case additional musical involvement would be beneficial. Possibly increased gentle and appropriate physical activity such as walking.
Carer	V. Good	If there could be official links to community workers or social workers as a starting point for accessing services we are entitled to
Person with dementia	V. Good	A little more communication (with people with dementia). To know more about people I'm sitting beside. Relaxation room. Head massage etc.
Carer	V. Good	Perhaps there could be more activities...My husband only attends one day a week and he does not like to take part in activities. This is not due to lack of encouragement – it is due to lack of motivation.
Carer	V. Good	I suppose I don't have many suggestions, but rather than sleep all the time, maybe someone to chat to him. Day care staff are really so busy, so more staff could be necessary
Carer	V. Good	Transport to and from the service could be more frequent
Carer	Good	More availability
Carer	V. Good	Maybe more funding
Carer	V. Good	Yes – more local for me as I have to drive to xxx presently. 2 days a week – living in xxx. This can be onerous – I have on a number of times requested a day in xxx centre – more days would be appreciated.
Carer	–	So the carers can work and keep the service user at home. It would help if the centre opened from 9–5.
Carer	V. Good	Prefer more transport to the day centre

### 5.3.2

#### Non-users of day care

People who did not (yet) use day care were asked how interested they would be in using day care now or in the future. Sixteen of the twenty-six non-users found this question applicable and provided their answers. Of these, ten (62.5%) said they would be interested (eight very interested and two a little interested), five (31.3%) did not know at the moment, and just one (6.3%) said they were not at all interested.

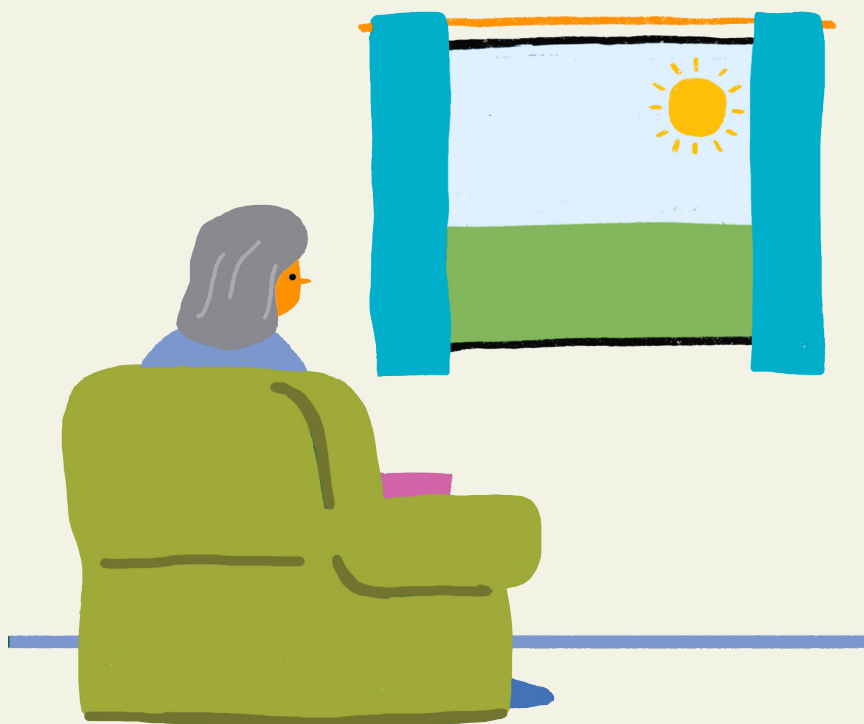
This generally very positive level of interest amongst non-users suggests that negative perceptions of day care are not very prevalent, at least amongst family carers of people with dementia. However, the in-depth research with family carers in the selected day care centres did indicate that reluctance on the part of persons with dementia can be an issue, especially when first broaching the idea with them and quite a lot of encouragement may be necessary to get people with dementia to try it out, an issue discussed in more detail in Section 6.2.

## Section 6

# Discussion and positioning the findings in a wider context

This Chapter discusses and positions the findings of the study in a wider context. It addresses three aspects:

- issues around demand, supply and take-up of dementia-specific day care
- innovative approaches to dementia-specific day care.



## 6.1 Issues around demand, supply and take-up of dementia-specific day care

### 6.1.1 Overall levels of supply and usage

Various sources suggest an under-supply of day care for people with dementia in Ireland (Browne, 2016; Oireachtas Committee on the Future of Healthcare, 2017), and the issue will likely intensify as the population ages. As indicated in Chapter 2, more than 1,800 people attended ASI day care centres across the country in 2018 and ASI estimates suggest that in that year approximately 5–6% of community-dwelling people with dementia in Ireland availed of dementia-specific day care services.<sup>3</sup> From a recent survey of day care services in Ireland, Pierse et al. (forthcoming) have estimated that between 8 and 14 per cent of people with dementia living in the community are attending day care services, including both generalist and specialist. However, accurate calculation is difficult due to the underdiagnosis of dementia in the population generally and incomplete survey data.

Although the numbers concerned are quite substantial, the proportion of people with dementia using day care in Ireland appears to be towards the lower end of the scale in comparison to a number of other countries. Studies have provided estimates of between 10% and 18% of community-dwelling people with dementia utilising day care internationally (Weber et al., 2011), with even higher proportions suggested for some countries. In Norway, between one-fifth and one-quarter of people with dementia use day care (Vossius et al., 2015; Moholt et al., 2018). Research in Ireland has also identified a significant variation and considerable geographical inequity in access to and take-up of day care services for people with dementia across the country in Ireland (Pierse et al., forthcoming).

### 6.1.2 Evident unmet demand

ASI waiting list data indicated 407 people awaiting a dementia-specific day care place at the end of November 2019, suggesting a minimum requirement for a 22% increase in available capacity. However, interpretation is complex because not all centres have waiting lists – some have none and others have quite large ones. Another complication is that take-up of available places varies across centres and across the country. One likely factor in this is the fairly organic historical evolution of day care through voluntary initiative at local level across the country, a feature shared with other areas of third sector service provision in Ireland as well. Another complicating factor is the likely variation across ASI day care centres in whether and how they compile and maintain waiting lists. Visible demand is also influenced by referral

processes, which vary widely across the country, and how these affect the numbers applying for day care places across the country.

Waiting list data in the main captures people who have applied for first acceptance to day care. Our study also suggests that a considerable portion of existing users would be interested in availing of more days per week than is currently possible. Therefore, a substantial increase in available places would be necessary to cater for existing numbers of people already interested to have access to day care, or to avail of more days of day care. This would be without any efforts to encourage greater interest in day care to levels indicated in the higher utilisation rates in other countries. Enhancement of the quality of day care, innovation in service models, and providing easier and more flexible access modes would likely further increase the numbers concerned.

### 6.1.3

#### **Awareness, accessibility and other potential factors of influence**

Availability of day care places is only one of several factors that influence the utilisation of day care centres by family carers of people with dementia. Awareness of day care services among family carers is a pre-requisite and international evidence suggests this varies widely across countries (Donath et al., 2011; Durand et al., 2009). In this study, both staff and family carers frequently mentioned low levels of awareness of ASI day care centres, and other research has highlighted the difficulties of navigating Ireland's complex and fragmented health and social care systems (O'Shea et al., 2019b).

Ease of access to day care services has been positively associated with utilisation (Donath et al., 2011; Durand et al., 2009). Our study found that dementia-specific day care centres are sometimes hard to find, and that some have limited or no signage. The lack of transport provision by some dementia-specific day care centres, or limitation of transport to a specified catchment area, are also potential barriers for some people with dementia and their family carers. More generally, attendance may not be an option for people with dementia who are incapacitated and housebound. The literature shows a broad consensus among stakeholders around improving access and better supporting the transition to day care service use (O'Shea, 2017).

### 6.1.4

#### **Perceptions of day care and receptivity to the idea**

Earlier Irish research noted that day centre care is not always appropriate for people with dementia (Haslett, 2003). Some will prefer to stay at home and may become distressed if away from their familiar home environments, and sometimes people with dementia may express discontent whether at home or at day care. As one family carer who completed a paper-based survey for this study commented:



The first few times my wife attended [day care] she was alright with it, but after that she wanted to be out of the centre, as it was when she was at home. She did not like to be confined to the house or the centre ... [but] ... I think the [day care] centre was very good and I don't think you could improve on it'.

(family carer of person with dementia)

Findings from studies of day care services in other countries are relevant here, showing that alternatives to day care are often not carefully explored unless the person with dementia is unwilling to attend day care. Even then, the available alternative options may be limited (and sometimes may also only involve group activities), so the choice can be to either to accept or not accept day care (van de Ven et al., 2017). In Ireland, it may also be the case that day care is not explored with people with dementia or their family carers as a service option (O'Shea et al., 2019b).

Although day care services tend to more acceptable to some people with dementia than residential respite (O'Shea et al., 2019a), a central issue is the often-found reluctance of persons with dementia to attend or even try out day care, sometimes driven by anxiety or feelings of insecurity. The most common reasons given by people with dementia for refusing day care include that they do not need it, they are used to spending time on their own, or they will not enjoy it, as well as fear that it will lead to loss of autonomy or mark the start of a progression towards entry to a nursing home (Durand et al., 2009). Although it is clearly essential that the wishes and preferences of people with dementia are respected to the greatest possible extent, reluctance to avail of day care sometimes presents dilemmas for family carers. One aspect of this is the extensive reporting that people with dementia initially reluctant may often have very positive and enjoyable experiences of day care once they have tried it out. On a more practical side, for family carers the take-up of day care can be of major importance if they are to sustain caring with other commitments and aspects of their own lives, including paid employment.

Family carers and health professionals may feel that day care is likely to suit the person they are caring for, so may have to decide whether and how to encourage them to give it a try. This can present difficult challenges for family carers who may struggle to reconcile their wish to ensure the person has access to appropriate supports whilst also respecting the autonomy of the person with dementia. There has been a growing body of international research exploring these aspects and best practice in addressing them, and an Irish briefing on this is in preparation (Pierce et al., forthcoming).

Family carers in our study also indicated the importance and value of flexibility and agility in day care intake processes, especially the possibilities to have flexibility through induction or trial days/periods, without having to complete lengthy application forms and processes at this stage. Other Irish research has referred to this as a 'settling in' process (O'Shea et al., 2017).

## 6.2 Innovative approaches to dementia-specific day care

The findings from this study suggest that staff in some Irish dementia-specific day care centres are already innovating through introducing activities, programmes and interventions tailored for people with dementia and adopting strategies aimed at personalising day care activities and supports to people with dementia. This provides a useful starting point for developing models of good practice to strive towards for all dementia-specific day care in Ireland.

To complement this, it is also useful to look at a range of innovative models of day care and innovations within day care developed for people with dementia in other countries. The following examples represent somewhat different models to the current one in Ireland: Meeting Centres (Netherlands), Green care farms (various countries); and two innovative interventions for utilisation within existing day care centres: Cogs Club (UK) and Enhanced Sensory Day Care (Scotland). A briefing paper is in preparation that provides more detail on these approaches and their potential value (Pierce et al., forthcoming).

### 6.3.1 Meeting Centres – Socially integrated day care

In the Netherlands, day care for people with dementia was traditionally located within psychogeriatric nursing homes where multidisciplinary treatment from geriatricians, physiotherapists, psychologists or other health care professionals (e.g. speech therapist, occupational therapist or psychomotor therapist) is available if necessary. As an alternative to traditional psychogeriatric day care, the Meeting Centres Support Programme (MCSP) began over 20 years ago for people with mild to moderately severe dementia and their family carers, based on an explorative inventory of needs among people with dementia, their informal carers and health care professionals.

To facilitate community integration, MCSP services are located in existing community buildings in accessible locations, such as community centres. People with dementia can participate for three days a week in an activity programme or social club, including recreational and creative activities and psychomotor therapy. Family carers can avail of a series of psychoeducational sessions on dementia, where they can learn and discuss how to deal with the practical, social and emotional consequences of dementia in daily life. Family carers can also attend on-going peer support groups, and can avail of a weekly individual consultation hour. Regular centre meetings bring the participants and carers together to discuss if the support programme meets their expectations and which social activities are planned for the coming period. To counteract fragmentation of care, the Meeting Centres organise the support

programme in close cooperation with local health, social care and welfare organisations, according to a collaboration protocol.

There have been several studies of MCSPs in the Netherlands, with very positive results on the value and acceptability of the approach (Dröes et al., 2000; 2004; 2006; Meiland et al., 2005; Szcześniak et al., 2019). The Netherlands currently has around 125 Meeting Centres and the model is being adaptively implemented and evaluated in three other European countries (Italy, Poland, and the United Kingdom) under MEETINGDEM ([www.meetingdem.eu](http://www.meetingdem.eu)), a European JPND funded project (2014 to 2017) (Dröes et al., 2017), and also in Spain and Australia.

### 6.3.2

#### Cogs Club

A key aim of dementia-specific day care is to provide cognitive and social stimulation to people with dementia through appropriate activity programmes. As shown in our study, the type and range of activities on offer in some of the dementia-specific day care centres in Ireland are quite traditional and relatively limited. Cogs Club is an innovative model of day care that offers an alternative to traditional day care, with an emphasis on cognitive stimulation for people with dementia (<https://www.cogsclub.org.uk/home/>).

The Cogs Club approach shares similarities with Cognitive Stimulation Therapy (CST), and is informed by the evidence on CST and guided by the same principles. Like CST, Cogs Club is a structured approach and uses thematic sessions. However, unlike standard CST usually offered as one to two-hours sessions once or twice per week, Cogs Club extends to a day of activity, music and fun so it provides family carers a longer break from caring. Feedback from participants has been positive, although the intervention has not yet been researched to the same degree as CST (Tuppen, 2010). Exploration and testing of the model are occurring already in Ireland (Pierce et al., 2019).

### 6.3.3

#### Enhanced Sensory Day care

Some people with dementia attending dementia-specific day care are at an advanced stage of dementia and may be unable to participate in most group activities. This presents particular challenges when the client to staff ratio is high (e.g. the 4:1 ratio in the centres covered in this study) and where the main focus is on group activities and interventions. People with advanced dementia require a high level of support that day care services can find hard to meet, and people with advanced dementia and their family carers may experience a lack of support and unmet needs (Tolson et al., 2015).

Against this backdrop, Alzheimer Scotland developed a new day care model based on sensory interventions, which has been piloted in South West Scotland. Enhanced Sensory Day Care is a sensory-based, non-pharmacological

intervention intended to optimise the well-being of people in the later stages of dementia. It seeks to support connection with the person through a programme incorporating some or all the five senses of the body: sight, smell, sound, touch and taste (Tolson et al., 2015).

The intervention is for delivery on dedicated days in an existing dementia day care setting, to a maximum of five people with advanced dementia, and participants attend two days per week. A small team of staff, supported by volunteers, deliver the intervention on a 1:1 ratio. Training of staff and volunteers is already to an enhanced level through the Scottish Government Promoting Excellence framework (Scottish Government, 2011), and they receive additional in-house training in the delivery of sensory interventions. Findings from an evaluation of a small-scale pilot intervention were generally positive, with perceived quality of life of people with dementia improving and family carers and staff valuing the intervention (Tolston et al., 2015).

#### 6.3.4

#### Green care farms / farm-based day care

Green care farms or farm-based day care is an innovative approach where people attending have access to outdoor environments such as gardens, green houses, farm yards and stables, and are encouraged and stimulated to engage in activities such as caring for animals, sweeping the farm yard, going for outdoor walks, gardening, and preparing meals. These outdoor environments and activities distinguish green day care from regular day care, and suggest they may be especially attractive to people with dementia with farming backgrounds or a background of interest in gardening, animal care and so on. They may also offer a model that may be of more interest and acceptability to some men who do not engage well with more typical indoor activities of traditional day care. The model is available in a number of countries, including the Netherlands, Norway, Belgium, England, the United States and Japan (de Bruin, 2009; de Bruin et al., 2010; de Bruin et al., 2015; Buist et al., 2018; Eriksen et al., 2019; Ibsen et al., 2018; Ura et al., 2018; Sudmann and Børsheim, 2017) and the availability of such day care centres is gradually increasing (Haubenhofer et al., 2010).

Several dementia-specific day care centres in Ireland have access to outdoor spaces and gardens. While none are green care farms, as such, one centre in this study participated in a very innovative community garden project, giving people with dementia access to an allotment within the community and engaging them in horticultural and other gardening activities. More generally in Ireland, the well-developed social farming model has many parallels with the green care farms / farm-based day care concept.<sup>4</sup> This may present useful opportunities to explore for dementia-specific day care purposes.

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4 Further information about Social Farming Ireland and social farming as a model of support can be found on the SFI website (<https://www.socialfarmingireland.ie/>).

## Section 7

# Conclusions and recommendations

Dementia-specific day care is not a new model of community-based care, and has been in existence in Ireland for more than 30 years. However, although the number of dementia-specific day care centres has grown substantially in recent years, little was known about how these centres operate and or about their role and contribution in supporting community-dwelling people with dementia and their family carers. The study examined dementia-specific day care from the perspectives of people with dementia, their family carers and staff working in day care centres. It was a mixed-method study involving primary data collection through an online survey of staff working in day care centres; an in-depth qualitative study with service users, family carers and staff from a representative sample of day care centres; and a paper-based survey of family carers and people with dementia.



## 7.1 Core findings

### 7.1.1 Main purpose of dementia-specific day care

The original stated purpose of dementia-specific day care, when first developed in the 1980s, was to provide cognitive and social stimulation for people with dementia and offer support to family carers (Working Party on Services for the Elderly, 1988). There has since been a quite widely-held perception that day care (and other respite services) for people with dementia operate primarily to provide a break for family carers (Cahill et al., 2003; O'Shea et al., 2019). If this were the case, then providers of dementia-specific day care might only give secondary consideration to the needs of the direct recipient of day care – the person with dementia; this would be contrary to the broad focus in social service reforms on personalisation and the requirement to start with the person (Armstrong & Shevellar, 2006). However, our study found most managers and staff in the dementia-specific day centres indicate the purpose of their service is equally to provide care and support to persons with dementia and provide respite for family carers. This finding is consistent with an earlier study by Cahill et al. (2003).

### 7.1.2 A highly valued service, with apparently considerable unmet demand

This study found that dementia-specific day care is a highly valued service by all the stakeholders surveyed. People with dementia attending day care were very positive, welcoming the opportunities for social interaction and participation in enjoyable activities. They reported day care to be a positive experience, spoke appreciatively about staff, and valued having their voices heard and having an input into everyday decision-making in day care. Family carers and other informal carers of people with dementia also highly valued the service, including those who currently use dementia-specific day care and those who have used it in the past. These findings are consistent with the results from studies in other countries exploring day care from the perspective of people with dementia (Aggarwal et al., 2003; Brataas et al., 2010; Rokstad et al., 2017) and family carers (Gústafsdóttir, 2014; Tretteteig, 2017a; 2017b).

Our study also found that many of the people with dementia and family carers surveyed who had not (yet) used day care expressed an interest in attending either now or in the future. Overall, there appears to be considerable unmet demand for day care places, reflected in waiting lists for a place in the first instance and/or requests for more days for people who already have a place.

Experience suggests that people with dementia, and sometimes family carers, can initially be reluctant to avail of day care but often find it a very positive experience once they have tried it. Flexibility in initial access

to day care, to try it out and get familiar with it, is therefore important. Nevertheless, although day care appears to be a positive option for many it is not for everyone, and it is important to provide as much choice as possible in the available forms of service and support for people with dementia.

### 7.1.3

## Benefits of dementia-specific day care

### **Social opportunities and cognitive stimulation for people with dementia**

Based on their day-to-day experiences of working in dementia-specific day care centres, staff identified a wide range of benefits of day care for people with dementia. Chief among these was the opportunity for people with dementia to socialise, interact and engage with other people, and to have companionship and develop friendships with other people in a similar situation. Another main benefit was the engagement and cognitive stimulation provided through a range of activities that people with dementia could participate in.

### **Benefits for family carers**

For family carers, dementia-specific day care provides a safe environment and offers routine and meaningful occupation in the daily life of the person with dementia. They also valued the break from caring that day care provides, but only to the extent that attending day care serves a useful purpose for the person with dementia. Gústafsdóttir (2014) coined the term ‘the perception of purposeful relief’ to indicate and emphasise that for family carers the relief that day care may provide depends on it being a positive experience for the person with dementia. Where relevant, day care can also facilitate working family carers to remain in work. For both working and non-working family carers, it can also free them up from worrying about a relative with dementia who would otherwise be at home alone without the practical and emotional supports they might need.

### **Practical elements of day care**

#### **Meals and nutrition**

The provision of a hot nutritious meal and snacks constitute an important part of day care and marks this service out from most other group- and community-based activities for people with dementia. As well as providing nutrition, mealtimes in day care are a social event, and enjoyed by people with dementia. Consistent with Trettenteig et al. (2017), this study found the provision of meals can be an especially important support to family carers worried about the person with dementia’s eating patterns.

More generally, while some centres have additional activities based around food (e.g. baking, growing food) there may be greater scope within day care centres for involving people with dementia in the preparation and cooking of meals, and in mealtime activities such as setting and clearing the table, especially when meals are cooked on site. This may help people attending to retain skills and boost their confidence.

Designing kitchen and dining areas in day care using universal design and dementia-friendly design perspectives would make this easier.

### **Physical exercise**

As well as the cognitive and social benefits for people with dementia attending day care and the respite it provides for family carers, this study also highlights the important role that day care can play in promoting physical exercise among people with dementia. van Alphen et al. (2016) refer to this as 'activating care'. Further development of this aspect may present a significant opportunity, as people with dementia living in the community are often sedentary for most of the day, and the little physical activity they perform is at a lower intensity level than people without dementia.

#### 7.1.4

### **Personalisation and meeting individual needs**

Over the last decade, Ireland has witnessed a paradigm shift in dementia policy and practice towards personhood and the social model of care (O'Shea et al., 2017). Internationally, the emerging predominant philosophy underpinning day care is that of a person-centred approach to care, which emphasises the person's unique qualities, life history, personal preferences and characteristics (Bulsara et al., 2016). In Ireland, dementia-specific day care advertises as person-centred and an earlier Irish study found that staff in dementia-specific day care showed a strong commitment to a philosophy of person-centred care (Cahill et al., 2003).

Our more recent study confirms this expressed commitment of staff working in dementia-specific day care centres, and also identified the differing ways they report trying to tailor and personalise supports and activities to meet the diverse needs of people attending. Approaches utilised include individual care plans, considering compatibility when grouping people together, providing a range of activities, small group working, and individualising activities and interactions.

### **Infrastructural challenges**

However, infrastructural constraints in many centres present important challenges for achieving personalisation and meeting individual needs. These include limitations posed by the physical premises and by staffing level ratios. In our study, staff reported that staffing ratios were very tight and not sufficient for providing an optimal level of support at certain periods of the day or when one or more clients required individual attention and support. Unsuitable buildings also pose a range of challenges for day care staff, and many of the same issues were previously raised by a study of dementia-specific day care conducted over 15 years ago (Cahill et al., 2003). Centres sharing premises with other groups face particular challenges, including lack of flexibility to set up the facilities in an optimal manner for the client group concerned and having to set up *de nouveau* each morning. Having only one room for activities and not having a quiet space are also important challenges.

Separately and in combination, these factors can make it difficult to provide a range of activity options simultaneously and to provide individualised attention to the desired extent. This can be an issue in finding optimal solutions when one or more attendees present with responsive behaviours.

### **Communication and other skills**

Generally, communication with and engagement of people with dementia with language and communication difficulties can be very challenging for staff in day care. Language and communication difficulties can be a consequence of dementia, especially as the disease progresses and goes from the moderate to severe stage, but can also link with other difficulties such as hearing or learning difficulties. Language and communication need prioritising in staff training.

Some people with dementia attending have very complex needs, and development of ways of communicating and engaging such clients is important to avoid social exclusion. Also important are skills to work with responsive behaviours of people with dementia when they arise. Recently published Irish guidance may provide helpful insight and ideas on these issues for day care services (McGowan et al, 2019).

### **Catering for diversity**

Dementia-specific day care centres cater for people with dementia with diverse and complex needs. While the available activity programmes work well for many, staff can find it hard to meet the needs of everyone; for example, some mentioned they would like to be able to offer more activities suited to men. More generally, there needs to be greater awareness that diversity in day care is more than simply about differences in age and gender among people with dementia, and centres need support to cater for increasing diversity.

Meeting the needs of people from different countries and ethnic backgrounds can also be a challenge, especially when English is not the person's first language and as the disease has progressed may have lost their ability to speak English. This may also be an issue for some native Irish speakers. While the numbers concerned are currently low, these are likely to increase with the ageing of ethnic minority communities (Pierce and Pierse, 2017). Catering for diversity in religion is also important, to embrace clients with any religion and those with no religion. Experience in other countries suggest staff need support in moving towards more individualised approaches to care that recognise people's ethnic and cultural backgrounds (Moriarty et al, 2011).

### **Supporting staff**

Through their frequent contact with people with dementia, staff working in dementia-specific day care can play a central role in enhancing the quality of life and quality of care for those attending. In this study, staff

working in dementia-specific day care centres came across as hard working and highly committed. Generally, they felt that they had adequate training and education in dementia care and experienced a good sense of teamwork. However, the workload sometimes could be high, and they felt insufficiently supported and appreciated at central and higher management levels. This can potentially lead to stress, burnout and job dissatisfaction among day care centre staff, and draws attention to the importance of attending to the needs of staff who provide direct care to people with dementia.

#### 7.1.4

#### **Innovation in the day care model**

In our study, some centres had developed innovative forms of in-reach from, and outreach to the community. Such innovation needs appraisal and support, and spread of good practice to other centres needs encouragement. Some centres have found ways of involving people with dementia in everyday decision-making within the centre, a key element of person-centred care. It would be worth exploring the incorporation of more collaborative forms of day care across all centres.

#### 7.1.5

#### **Irish dementia-specific day care in an international context**

To date, dementia policy in Ireland has given limited attention to the role and potential contribution of day care within the spectrum of community-based services and supports, and this is also apparent in the currently quite modest resource allocation to this domain. In these respects, Ireland shares similarities with some other countries (e.g. Scotland) but differs from others (notably Norway) where day care figures prominently and is identified as a priority area of action in the Norwegian National Dementia Strategies.

More generally, countries across Europe have been moving towards developing innovative approaches to day care. Innovations in centre-based approaches include evidenced-informed, structured approaches to person-centred day care such as Cogs Club, and day care designed specifically for people at an advanced stage of dementia such as Enhanced Sensory Day Care. Another development is a move away from the traditional centre-based models of day care. Innovative approaches include socially integrated and multi-component day care; and green care or farm-based day care which enables people with dementia to get outdoors and engage in meaningful outdoor activities. These and other examples can help guide the further development and improvement of day care approaches in Ireland.

## 7.2

### Recommendations

Collectively, the data generated through the three elements of the study, as well as insights from the wider international literature, provide a rich and nuanced perspective on the role and value of dementia-specific day care centres, how the services are operating on the ground in Ireland, and what might be an optimal model to strive for. This can support strategic and operational decision-making and service development within ASI, and can also inform wider dementia policy and practice in Ireland.

**The findings from the study support four main recommendations:**

- 1** Ensure the future sustainability and expansion of dementia-specific day care capacity

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- 2** Develop a focused strategic and operational framework and approach to further develop the dementia-specific day care model in Ireland

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- 3** Support quality improvement and innovation in dementia-specific day care

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- 4** Initiate further research on dementia-specific day care and its place in the wider care ecosystem.

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Recommendation 1:

## **Ensure the future sustainability and expansion of dementia-specific day care capacity**

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Given the high value people with dementia and family carers attach to dementia-specific day care, it is important to ensure the sustainability of existing provision and expand the capacity to provide more places and more days per week to meet the apparent levels of unmet demand in Ireland. At national level, estimates suggest that this form of service for people with dementia currently receives a relatively small share of the overall dementia care resource allocation. It is likely that the value-for-money case for existing and additional spend on dementia-specific day care is very strong. This comes not just from the economies of scale dimension offered by the group-based (congregate) features but also from the likely substantial quality of life and health/social care-related gain for people with dementia and family carers. A closer examination of both the (capital and revenue) funding and health gain aspects would be useful to support policy and resource allocation. However, already the evidence seems compelling that spend in this area contributes substantially to important goals of dementia policy in Ireland and core strands of the National Dementia Strategy.

### Recommendation 2:

## **Develop a focused strategic and operational framework and approach to further develop the dementia-specific day care model in Ireland**

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Over the past thirty years, dementia-specific day care centres have tended to develop as a response to local need rather than within any deliberate or planned policy framework. It would be worthwhile for the main provider(s) and funder(s) to work on the elaboration of a coherent strategic plan/policy for the future development of dementia-specific day care services.

Dementia-specific day care services operated by the ASI are an important part of the overall system of day care for people with dementia in Ireland. Other voluntary sector organisations also provide some dementia-specific day care, and dementia-focused and generalist day care operated by the HSE also form part of this system. More generally, day care is only one component of the overarching ecosystem of community care. In this context, and given the increased capacity needed in day care for people with dementia, it would be important for the main provider organisations to get input from key stakeholders in the planning of dementia-specific day care services. This will be facilitated by the development of effective partnerships and relationships with public sector and other voluntary sector organisations working in dementia care. In the Netherlands, for example, this is a key element of the Meeting Centres Support Programme.

Broader issues also impinge on the delivery of dementia-specific day care services, including those within the remit of the Independent Review Group established to examine the role of voluntary organisations in publicly funded health and personal social services. The future development of day care services for people with dementia will involve both the public sector and voluntary sector organisations, and the Review Groups deliberations will have important relevance for this.

### Recommendation 3:

## **Support quality improvement and innovation in dementia-specific day care**

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The study found ongoing examples of good practice and innovation in dementia-specific day care centres in Ireland. In addition, the staff who contributed to this study provided many useful ideas and suggestions for service improvement and enhancement, and insight into the challenges faced on the ground to deliver the service they would ideally like. People with dementia and family carers also provided a range of ideas and suggestions on how services could be further enhanced, both for day care centres themselves and in their linking and dovetailing with other dementia services and supports.

A next step for the ASI and other providers could be to identify key existing factors that positively influence good practice and service innovation across their day care centres (Nolte, 2018). The study found issues relating to physical premises and other resources, including funding, staff levels and time constraints, were hampering the ability of some centres to improve service quality. Leadership and management at different tiers (centre, regional and national) is important, supportive of and committed to positive change, but so too is the articulation of a clear and compelling vision for dementia-specific day care centres. It is also important that those affected – including centre managers, frontline staff and service users – are engaged early and on a continuous basis.

Whilst service audits may have a useful role to play in this, our research suggested that staff currently do not see the existing audit approach as a driver of quality improvement, and some were quite critical of this aspect. A specific programme of quality improvement/service innovation for dementia-specific day care centre would be useful. Some of this could be possible at low or no cost, but some will certainly require investment, and for this dedicated and continuous resourcing would be necessary.

The approach would need to allow for adaptation at centre level and to different local contexts, and quality improvement programmes could be initially trialled in a small number of centres. Monitoring and evaluation are important for providing an understanding of the processes involved in quality improvement, identifying challenges and enablers of success, assessing impact and costs, and to provide learning from test sites which could then support spread of quality improvement to other centres. Approaches such as rapid quality improvement cycles could be considered for these purposes.

#### Recommendation 4:

### **Initiate further research on dementia-specific day care and its place in the wider care ecosystem**

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This study drew mainly on new primary data collection from staff, people with dementia and family carers. The potential also exists to leverage additional routinely generated information and data from within the ASI and possibly other providers as well. Such data might be further analysed to inform the provision of dementia day care, and for the future development of day care centres.

New themes for research attention have also emerged from the study and its results. One important issue is the need for development of better linkages and integration of day care within the wider ecosystem of supports for people with dementia. This could have support at the national policy level as well as on-the-ground at HSE regional and local levels.

A current HSE-funded exercise to prepare a detailed mapping of all forms of day care provision for people with dementia at regional and sub-regional levels will provide valuable evidence to help inform decisions on future service provision and resource allocation relating to day care more generally. As a follow-on exercise, it might be useful to build on the work of our study and their wider mapping to prepare a detailed mapping of regional and local (area-based) ecosystems of supports for people with dementia and associated service usage patterns, to examine how dementia-specific and other day care fits in the wider picture of community-based service structures and supports.

More generally, focused research on impacts and outcomes of day care attendance for people with dementia and family carers would be very valuable to inform policy and practice in Ireland and to contribute to the wider international evidence base. This could include examination of the value for money aspects mentioned under Recommendation 1, including delivery costs compared with potential cost savings in other parts of the health and social care ecosystem as well as the value of any health/social care related gain achieved.



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## THE ALZHEIMER SOCIETY *of* IRELAND

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