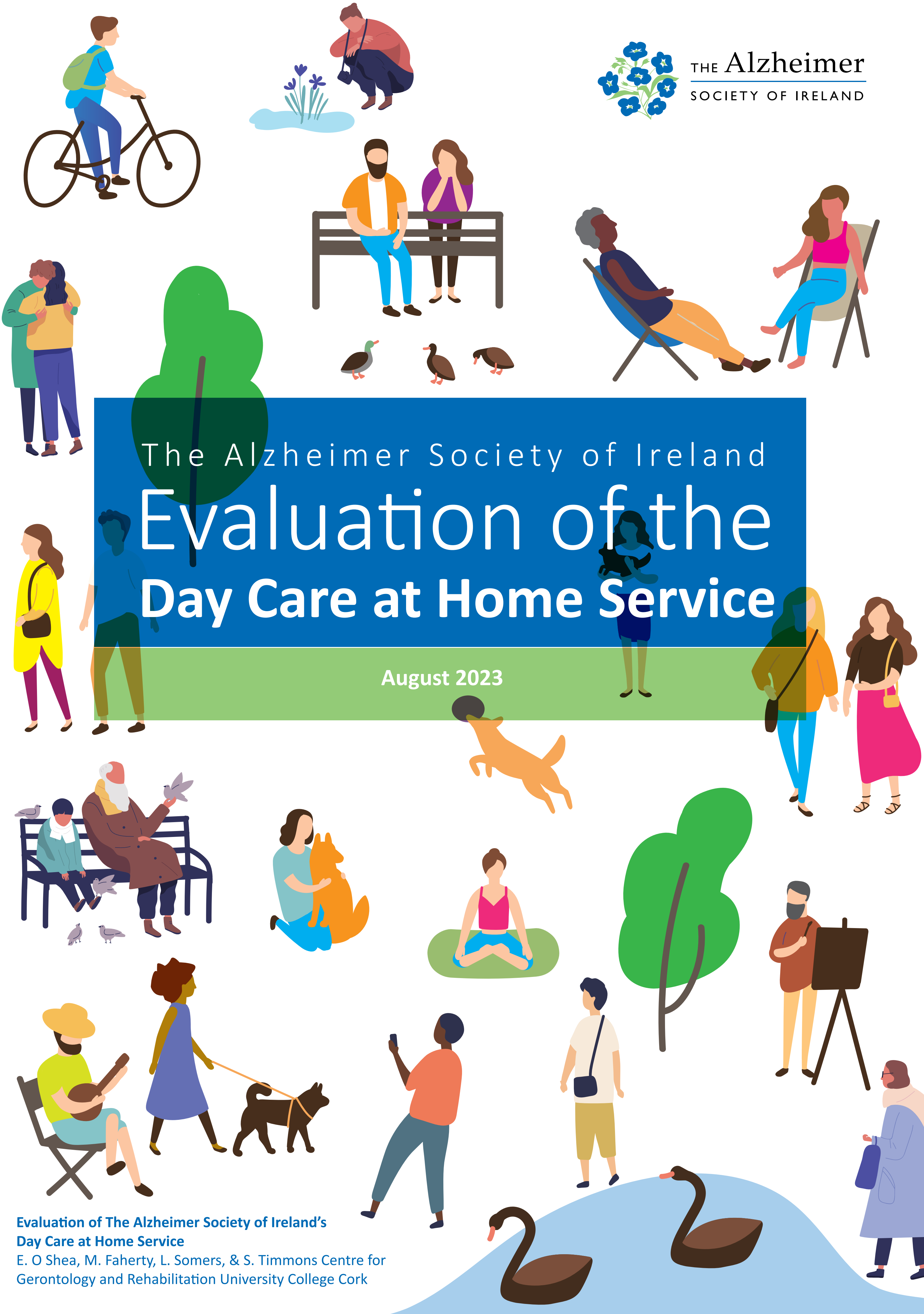

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The Alzheimer Society of Ireland

Evaluation of the
Day Care at Home Service

August 2023

Evaluation of The Alzheimer Society of Ireland's
Day Care at Home Service
E. O Shea, M. Faherty, L. Somers, & S. Timmons Centre for
Gerontology and Rehabilitation University College Cork

AUTHORSHIP AND ACKNOWLEDGEMENTS

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With significant contributions from:

- PPI Expert Advisory Committee (appendix A)
- Project Steering Committee (appendix B)

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FOREWORD

I am pleased to present this evaluation report of The Alzheimer Society of Ireland's Day Care at Home service. As an organisation committed to evidence-based practice, The Alzheimer Society of Ireland commissioned this work to understand the value of the service and ways to optimise it to best serve people living with dementia and their families across the country.

When the COVID-19 Pandemic forced The Alzheimer Society of Ireland to temporarily close all its Day Care Centres and suspend vital face-to-face supports, Day Care at Home was set up to provide an interim alternative model of care and support to people with dementia and families to address the absence of the Day Care Centres. It became apparent that Day Care at Home filled a critical support gap by providing stimulation, personalised activities and socialisation to people living with dementia while providing respite to their families.

People affected by dementia have reported to our team that Day Care at Home is life-enhancing. They told us that social stimulation is invaluable and that the focus on meaningful activity brings wellbeing and a sense of purpose. This report supports that feedback in a more formal manner. I am proud of my colleagues who co-ordinate and deliver this service and I believe the overwhelmingly positive outcomes and feedback outlined in the report is a testament to their hard work, innovation and personal approach to care.
As we plan for the future, I look forward to working with those colleagues to expand the Day Care at Home Service and to move from a pandemic-specific response to an embedded service offering and support many more people living with dementia in communities across Ireland.

I am very grateful to Dr Emma O'Shea and her team from University College Cork who undertook this evaluation, and all those who provided their time and expertise to develop this report. My sincere thanks to the National Dementia Office who funded this research.

Mr Andy Heffernan
CEO
The Alzheimer Society of Ireland

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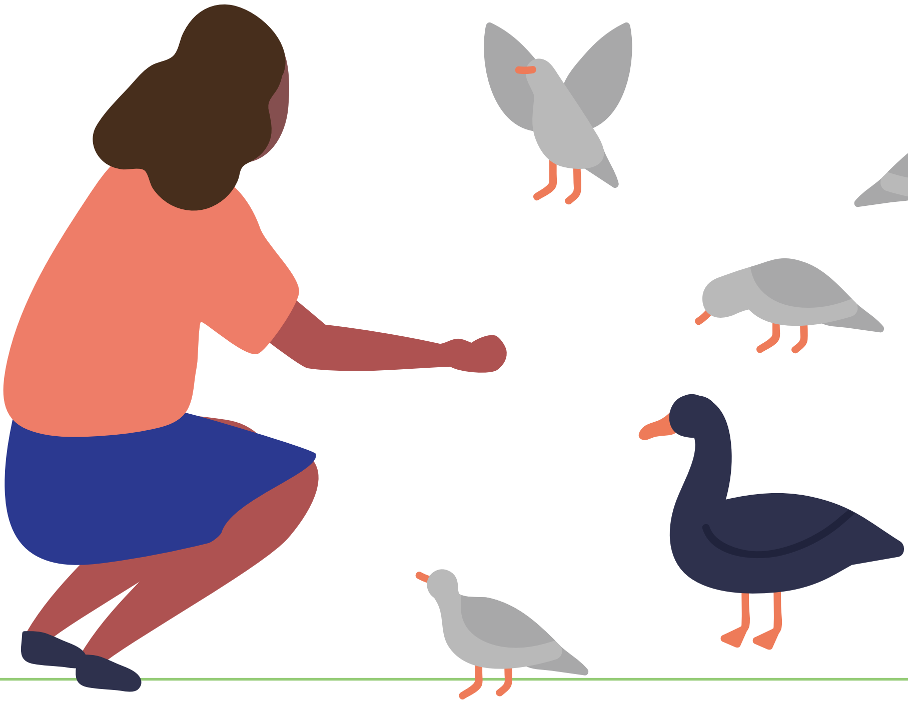
ACRONYMS AND ABBREVIATIONS

ASI	The Alzheimer Society of Ireland
CW	Care Worker
DCAH	Day Care at Home
DCC	Day Care Centre
DOH	Department of Health
FC	Family Carer
GP	General Practitioner
HSCPs	Health and Social Care Professionals
HSE	Health Service Executive
NDS	National Dementia Strategy
NDO	National Dementia Office
PHN	Public Health Nurse
PPI	Public and Patient Involvement
YOD	Young onset dementia

TABLES



PLAIN LANGUAGE SUMMARY

BACKGROUND

People living with dementia and their family carers experience significant and challenging changes, many of which present obstacles to optimal daily living. Often families are left alone, without any formal psychosocial support in a setting appropriate to their needs. While day care centre services can be of benefit in this respect, this model of care is not acceptable or beneficial to all. Day Care at Home (DCAH) was borne of necessity during the COVID-19 pandemic; however, the national need for home-based social care for families living with dementia long-preceded the pandemic. This report details the external evaluation of the DCAH service, which is still running, albeit with a significantly reduced level of funding post-pandemic, as the DCCs have reopened.

HOW WE EVALUATED THE DCAH SERVICE

We used a qualitative research design to understand the experiences and viewpoints of many different groups with a stake in DCAH, e.g., people with dementia, family carers, ASI staff and management, primary care professionals, and HSE officials. We carried out in-depth interviews and a series of home visits across the country, to directly view DCAH in action. The research team had oversight from a Steering Committee and collaboration with a Patient and Public Involvement (PPI) group. The PPI group advised on and refined our approach, e.g., regarding design; data collection tools and processes; recruitment pathways; troubleshooting recruitment and data collection issues; and data interpretation.

WHAT WAS FOUND

This evaluation found that DCAH is highly regarded as unique, necessary, and beneficial across stakeholder groups for a wide variety of reasons, e.g.,

- Caters to a previously underserved cohort, for whom day care centres are not practical, acceptable or beneficial
- Takes a dyadic approach to social care, with a view to psychosocial restoration
- Supports personhood, identity and independence for the person with dementia; psychological breaks for family carers, via trust-based relationships
- Makes family care more sustainable, i.e., avoiding/delaying care home admission.

Several key areas for development are also detailed, from across stakeholder viewpoints.

WHAT THE FINDINGS MEAN

This evaluation actively tried to unearth ‘negatives’ in relation to DCAH. While stakeholders identified potential areas for development, the service model and care approach had universal support. DCAH is a unique service model, adding significant value to the dementia support landscape nationally. Stakeholders indicated that as well as improving the everyday lived experience and life quality of clients, DCAH service use can help to delay/avoid care home admission, by creating a more sustainable family care situation. However, the demand is growing, stretching service capacity, and leading to lengthy waitlists and inequities in access. Increased funding is needed to sustain and democratise this service.

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Section 1

Introduction

SECTION 1: INTRODUCTION

1.1 INTRODUCTION

Globally, an estimated 55 million people are living with dementia (PwD), with nearly 10 million new cases every year (World Health Organization, 2023). Today in Ireland, there are approximately 64,000 PwD (Health Service Executive, 2020). Given the country's ageing population, it is estimated that this number will more than double from current figures to over than 150,000 people by 2045, with the majority of this cohort (approx. 92,000) expected to be women (Health Service Executive, 2020). Dementia is the loss of cognitive function that interferes with a person's daily life and activities, with Alzheimer's disease being the most common cause (National Institute on Aging, 2022). Dementia is more common as people grow older, but it is not a normal part of aging.

When the COVID-19 pandemic forced the Alzheimer Society of Ireland's (ASI) Day Care Centres to close in March 2020, the Day Care at Home (DCAH) service was established as an alternative, delivering a day care experience to people with dementia in their own home and satisfying their need for social and occupational support while also facilitating a break for the family carer (The Alzheimer Society of Ireland, 2021).

Funded by the Health Service Executive (HSE), DCAH is a dementia-specific, person-centred service delivered by trained care workers (CWs), providing one-to-one support to PwD for a set number of hours with the same care worker every week. The emphasis is on providing social and activity-based care, as opposed to personal care. Activities can include music-based sessions, reminiscence therapy, arts & crafts, exercise, conversation, companionship, and/or other recreational activities of the client's choosing.

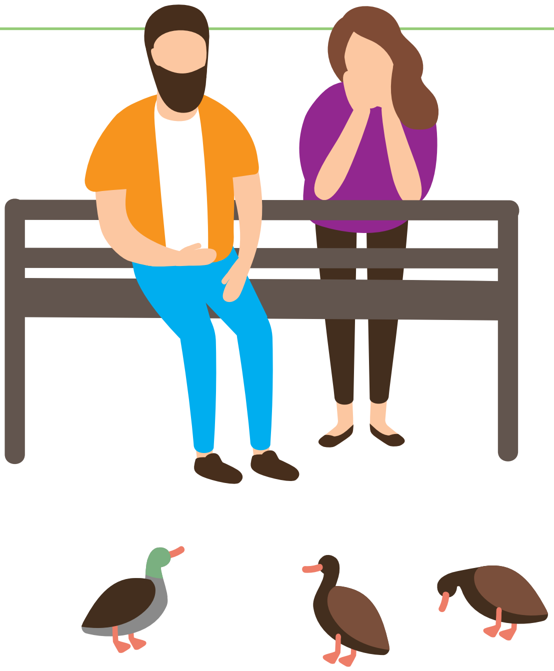
This report is the output from a call to tender by the ASI to evaluate the DCAH service. It identifies and explains the contextual factors and causal processes that facilitate and/or hinder the effectiveness and sustainability of the service from the perspective of multiple stakeholders.

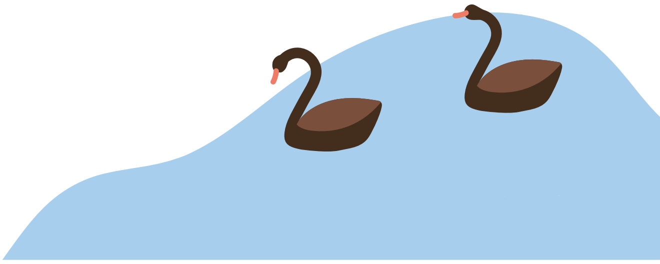
1.2 BACKGROUND AND CONTEXT

Ireland's National Dementia Strategy (NDS) was launched in 2014 (Department of Health, 2014). Since then, key national research and policy advancements have included a review of dementia diagnostic processes for Ireland (Reves et al., 2018), a review of post-diagnostic support for PwD and their carers (O'Shea et al., 2018) and the publication of the Model of Care (MoC) for Dementia (Health Service Executive, 2023). The Model of Care for Dementia in Ireland identifies five strands of post-diagnostic support for people living with dementia and their families on their journey: understanding and planning; staying connected; staying healthy; supporting cognition; and supporting emotional wellbeing (Health Service Executive, 2023).

The DCAH service is well-placed to support the implementation of targets 30 and 32 of the MoC (pg. 15). These are as follows:

- *Target 30: "Every person with dementia assessed as requiring home-based care should be provided with personalised and flexible supports that meet both their personal and psychosocial care needs in their home."*
- *Target 32: "The five strands of post-diagnostic support should be considered in the provision of day services for people living with dementia; having the dual benefit of restorative care for both the person with dementia and their family carer / supporter".*





In Ireland, the ASI Day Care Centres (DCCs) provide dementia-specific care in a community-based group setting, with activities, gentle exercises, personal care and a hot lunch (Alzheimer Society of Ireland, 2023). DCCs can offer effective psychosocial interventions for PwD and support for family carers (Mossello et al., 2023). They can also meet the person living with dementia's need for social community, physical activity, structure and variety (Tretteteig et al., 2017). From the family carer perspective, DCCs can provide a break from caring, and time to complete practical tasks or meet their own social needs (Tretteteig et al., 2016, 2017). This break, or respite, can help sustain the relationship between PwD and family carers (Laird et al., 2017).

However, for respite to be a meaningful experience, family carers need to trust that the service provided is safe, enjoyable and beneficial to the person living with dementia (O'Shea et al., 2019). A person-centred and flexible approach is key to delivering acceptable and effective respite services; in this respect, day services in the community or in the home tend to be more acceptable than other models (e.g., residential respite) (O' Shea et al., 2020).

While DCAH differs from DCCs in many aspects, both are support services providing social care in community settings. However, while DCC models are well-established and widely provided across the country, DCAH is based on a more novel service model, with just a handful of other similar initiatives, albeit on a smaller scale. For example, community- and home-based supports for PwD were a core focus of the HSE & GENIO Dementia Programme (2012-2018), which piloted an alternative respite service, similar to DCAH, in Tipperary. This provided high quality, flexible, person-centred care in the home to PwD and their families (Genio, 2016). Western Alzheimers' 'In Home Respite Service' is an existing service similar to DCAH that provides a one-to-one individualised support service tailored to the ability, interests and hobbies of the person living with dementia (Western Alzheimers, 2023). However, the ASI DCAH service is the first nationwide service of its kind in Ireland.

In 2021, the ASI conducted an internal evaluation of DCAH (The Alzheimer Society of Ireland, 2021). While the research did not include first-hand experiences of people living with dementia, data was gathered from families and ASI staff. There was strong support for the service, with 49% of the families and 73% of ASI staff indicating that DCAH should continue after COVID-19 restrictions were lifted and normal DCC services resumed. When asked how DCAH made them feel, 62% of family members felt they could cope "more than usual", 28% said "same as usual", 10% said "less than usual". When family members were asked how beneficial DCAH was for the person living with dementia, 68% said it was extremely beneficial. ASI staff recognised the dual benefit of DCAH, providing "me time" for the person living with dementia and "peace of mind" for family carers. One noted limitation was the lack of social interaction that DCCs can facilitate, where the person living with dementia can be comforted by meeting with other people who may be having similar experiences (The Alzheimer Society of Ireland, 2021).

1.3 RESEARCH AIM AND OBJECTIVES

The aim of this evaluation is to answer the following research questions:

- What are the experiences and perspectives of service users (i.e., people living with dementia, family carers) on i) accessing and ii) using the DCAH Service?
- What are the experiences and perspectives of DCAH front-line staff and management on their professional needs, and the planning, provision, and sustainability of the service?
- What do i) service users and ii) service providers perceive as key areas for development within current DCAH services?
- How do external stakeholders (i.e., General Practitioners, Public Health Nurses, Senior HSE officials) perceive the role, value, and potential impact of the DCAH service, within the current dementia support landscape?
- Why do some people living with dementia and/or their family members/family carers choose not to use the DCAH service, despite it being available to them?

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Section 2

Design & Methodology

SECTION 2: DESIGN AND METHODOLOGY

2.1 RESEARCH DESIGN

A qualitative research design was employed, with data collected through semi-structured interviews. A purposive sampling technique was used to recruit participants and facilitate maximal diversity. Home visits enabled overt observations of the service in action in the clients' home. The ASI's Person Public Involvement (PPI) group, the Dementia Research Advisory Team, provided expert advice and insights at the early stages (regarding project design; refining data collection tools and processes; recruitment pathways) and mid-way through the research project (regarding troubleshooting recruitment and data collection issues; interpretation of preliminary findings).

2.2 PARTICIPANTS

Semi-structured interviews were held with 37 individual participants, across four different key stakeholder groups:

- ASI Management
  - DCAH coordinators (n= 13)
  - Senior management (n=1)
- ASI Care Workers (CWs) (n=7)
- DCAH Clients
  - People living with dementia (n=3)
  - Family carers (FCs) (n=8)
- External stakeholders
  - Primary care professionals (n=3)
  - HSE officials (n=2)

Originally, we had intended to also interview people living with dementia who had been offered, but chose not to use, the DCAH service. While this was ultimately not feasible, ASI coordinators provided us with many key insights into factors influencing service refusal.

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INDIVIDUAL PARTICIPANTS

ASI STAFF

One-to-one semi-structured interviews were conducted with 13 Coordinators, seven CWs and one senior ASI staff member. Interviewees were all female, except for one male coordinator. These interviews took place by phone or videoconference and were digitally recorded, with written and verbal permission. DCAH service coordinators were recruited using the contact details posted on the ASI website in the first instance. Where coordinators could not be reached, ASI management supported us in making direct contact. CWs were recruited through the DCAH service coordinators.

CLIENTS

In total, seven home visits were held in clients' homes across the Republic of Ireland, to observe DCAH in practice. While eight visits had been scheduled, one FC ultimately participated in a phone interview only. The clients (i.e., PwD and families) were recruited via the ASI coordinators and CWs, and the home visit scheduling was organised by the researchers, with the ASI. The home visits allowed the researchers to observe the environment, behaviours, activities, and social interactions between the person living with dementia and the care worker.

The visits also provided an opportunity to interview FCs and gather their feedback on the service. Where it was deemed appropriate by the FC, interviews were also offered to the person living with dementia, either on a one-to-one basis, or together with their FC.

In total, eight semi-structured interviews were conducted with FCs (i.e., seven home visit interviews, one phone interview) and three interviews were conducted with people living with dementia (accompanied by the CW or FC, or both, during home visits).

All interviews were digitally recorded with verbal and written permission. See Table 1 for details.

HOME VISIT	RELATIONSHIP	SEX	INTERVIEW CONDUCTED	OBSERVATION CONDUCTED
1	Family Carer	Female	Yes	Yes
	Person living with dementia	Male	Yes (CW present)	
2	Family Carer	Female	Yes	Yes
	Person living with dementia	Male	Yes (CW and FC present)	
3	Family Carer	Female	Yes	Yes
	Person living with dementia	Male	No	
4	Family Carer	Female	Yes	Yes
	Person living with dementia	Male	Yes	
5	Family Carer	Female	Yes	Yes
	Person living with dementia	Male	No	
6	Family Carer	Female	Yes	Yes
	Person living with dementia	Female	No	
7	Family Carer	Female	Yes	Yes
	Person living with dementia	Male	No	
NA	Family Carer	Male	Yes (via telephone)	No

EXTERNAL STAKEHOLDERS

Primary Care professionals

Three primary care professionals (i.e., one GP and two PHNs) were interviewed. Data collection occurred in parallel with the interviews and home visits with ASI staff and clients.

Senior Officials

Two senior HSE decision-makers/officials were also interviewed once the preliminary data from ASI staff and DCAH clients had been collated. We were able to use the preliminary findings from the ASI staff and client interviews and the home visits to give the decision-makers context, and to enquire about their reactions to the findings.

2.3 DATA COLLECTION

Ethical approval was granted by the Social Research Ethics Committee at University College Cork. Data was collected between March and July 2023, through i) online and in-person semi-structured interviews with stakeholders and ii) overt observations of the DCAH service in action. The observations involved viewing and reflecting on the interpersonal interactions between clients and CWs, activities, and the environment (i.e., the client's home space), as the service was being delivered. The CWs and families were aware that we were researching the DCAH service. These data were collected via structured observation sheets, which were designed in collaboration with the PPI advisory group.

All interviews were conducted by experienced researchers, with support from the Principal Investigator. Interviews with ASI staff were held virtually, by phone or videoconference. Where videoconference was used, only audio was recorded. Interviews with FCs were held either in-person before or after the home observation visits, or by phone. Interviews with PwD took place in-person. Interviews with clients lasted approximately 20-60 minutes (mean: 41 minutes), while interviews with other stakeholder groups lasted 25-90 minutes (mean: 52 minutes). The topics on the interview schedules for both clients and other stakeholder groups were decided on after input and feedback from the PPI advisory group. Encrypted recording devices were used to record interview data. Research assistants transcribed the data under the guidance and supervision of the Principal Investigator. During the transcription process, interview and observation data was anonymised and any potentially identifiable information was fully redacted. Once the anonymised transcriptions were completed, checked for accuracy, and securely stored in a password-protected UCC-hosted data storage platform (login-in access only), the original audio recordings were deleted from the recording device and the cloud, in line with the terms of the ethical approval, to minimise data protection risks.

2.4 ETHICAL CONSIDERATIONS

The Principal Investigator is experienced in conducting psychosocial research and assumed responsibility for ensuring best practice guidelines were followed. A study information sheet and an informed consent document were provided to participants. All interviewees were advised on how their confidentiality would be upheld, that their participation was completely voluntary, and they could leave the study at any point (and up to two weeks after the data collection session). Service users were clearly advised that if they chose not to participate, it would have no impact on the services that they receive from the ASI. Before agreeing to participate, each person was given an opportunity to ask questions about the study, what it involved for participants, and details about the storage and use of their data.

All participants signed a consent form, confirming their agreement to participate in the research. The family carer provided proxy consent for the people living with dementia who could not give informed consent. A 'process consent' approach (Dewing, 2007; 2008) was used throughout the data collection process, with PwD. This involved the researchers continually monitoring for signs of agitation, distress, or significant distraction or disinterest, which might indicate the PwD was no longer happy engaging in the research process.

In addition to considerations regarding consent, measures were taken to minimise discomfort for all participants during the data collection process. The researchers indicated that their approach to home visits would be flexible and would work around the usual format (and activities) of the DCAH session as much as possible, as well as allowing for participant breaks. We also indicated they could end the visit at any time, without explanation.

2.5 DATA ANALYSIS

Qualitative data from the interviews and observations was coded and analysed in accordance with Braun and Clark's seven stages of thematic analysis: 1. Transcription, 2. Reading and familiarisation, 3. Coding, 4. Searching for themes, 5. Reviewing themes, 6. Defining and naming themes, 7. Writing – final analysis (Braun & Clark, 2013). The audio data was transcribed verbatim by two researchers, with potentially identifiable information removed to uphold anonymity. The interview transcriptions and observation sheets were read through multiple times to gain familiarisation with the content, with brief written memos used to record ideas, statements and viewpoints of potential interest. Coding was undertaken by two researchers, and a 50% subset of transcripts (n=18) were double-coded, before the research team began systematically comparing the initial codes. This led to a second round of coding and refinement, which allowed us to eliminate duplicative codes, and to determine key patterns in the data. At this point, the refined codes (and comprising raw data) were used to develop provisional themes and sub-themes, with the original research questions always in mind.

2.6 SYNTHESIS OF FINDINGS

In the synthesis of the interview and observation findings, particular attention was given to i) identifying both confirmatory and opposing experiences, perspectives, and behaviours, ii) considering the positionality of the participants (i.e., in terms of stakeholder group, sex, location, etc.). The researchers consulted regularly to discuss themes and subthemes, and potential biases in our coding and/or interpretations. Once preliminary themes were developed and defined, the researchers once again reverted to the raw data, to ensure no key findings/patterns or alternative perspectives were overlooked, and that our interpretations fairly and reasonably represented the data collected.

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Section 3

Findings

SECTION 3: FINDINGS

Seven common themes encompassing the findings of the evaluation, each with several sub-themes, were identified and are outlined in this section.

3.1 A UNIQUE MODEL

3.1.1 Social Model of Care

Day Care at Home is a unique service that differs from other formal services available to PwD in the community. This uniqueness was recognised across stakeholder groups, both in terms of its inception as an innovation borne of necessity during the COVID-19 pandemic; along with its unique focus as a psychosocial model of care, delivered in clients' homes.

"It's one of the best things that's come out of the pandemic" (Co3)

"It adds values…It's meeting needs that no other service is meeting as it's very social-focused" (CW4)

Unlike existing models of home care, DCAH does not entail any personal care. Coordinators and CWs indicate that they try to communicate the boundaries of DCAH as clearly as possible.

"You have to say to families, 'I'm not here to do personal care, you know, I'm here for the social aspect of it'" (CW2)

The family carers included in this evaluation largely understood the boundaries of DCAH, as being exclusive of personal care tasks.

"They [sic: CWs] wouldn't involve themselves in any cleaning duties or anything, they're there to be keeping her active and keep her mind active" (FC8)

3.1.2 Serving a distinct client cohort

DCAH is also unique in that it is serving a previously unserved cohort of PwD i.e., those for whom a DCC is not a suitable or preferred option, and who would otherwise not be able or willing to avail of support in the community, e.g., those who prefer not to socialise in a group environment, prefer a more flexible service, or struggle with mobility issues.

"If you have a client who cannot attend Day care or doesn't want to be in a group of people it's great to have that service for the clients themselves and the families" (CW5)

The logistics of getting the PwD to a DCC might also be a barrier in terms of functional ability to get up and ready in time, and/or sourcing suitable transport to and from the DCC.

"A lot of people who are getting the day care at home service at the moment are people who maybe from a mobility point of view or maybe they don't have access getting to the day care, or their illness has progressed – so it's more appropriate to receive DCAH as opposed to going into a DCC" (Co1)

On the other hand, family carers, coordinators and CWs highlighted that many DCAH clients have little mobility problems and minimal functional decline, demonstrating that dementia 'stage' is not a prominent factor in determining the suitability of DCAH for clients.

"A lot of our [DCAH] clients or service users would be extremely able-bodied" (Co9)

Most coordinators and CWs stated that even for those in the later stages of dementia, there are many activities and interventions that can be of benefit (e.g., sensory-based therapies, including massage, music), and that DCAH can be appropriate across all dementia 'stages'. However, some (albeit a minority) were of the belief that for some clients, there can come a point where other service models might be more appropriate.

"If you have somebody that is that the stage where they just like to sit back and listen to their music or watch their movies, maybe we're looking at something a little different than DCAH" (Co9)

Personality factors were also cited as a central consideration, with coordinators, CWs and family carers indicating that DCCs don't tend to suit introverted personality types.

"Some people in a million years wouldn't go into a day centre…They're not that type of person...They find it too overwhelming. From that aspect DCAH is brilliant." (CW1)

"[DCAH is] a brilliant service…I think it works for a lot of people. Other people, I think the day centre is suitable for them, because they are social beings." (Co2)

One CW additionally pointed out that there are other more nuanced individual differences that tend to be overlooked, e.g., neurodivergence. She noted how the often-overstimulating nature of DCCs might not be suitable, regardless of their dementia diagnosis.

"Also, people who might be on the spectrum and a day centre to them would be an environment that wouldn't suit them whatsoever, dementia or not" (CW1)

Some CWs and coordinators indicated that sex differences can play a role in preferences for DCC versus DCAH, whereby some women can be more open to the group setting of DCCs than men:

"I think especially for men some don't want to go to a day care centre…I suppose women prefer being out and about and doing things…" (CW4)

3.1.3 Comparison to DCCs

Participants agreed that DCAH shares some of its characteristics with DCCs: both services provide dementia specific, person-centred care that provides support and stimulation for the PwD in a safe environment. However, while DCCs provide group activities in an external setting, DCAH is a one-to-one psychosocial service delivered in the person's home, with strong continuity of care, and activities that are directly matched to the interests and values of the PwD.

While our evaluation, by design, encouraged comparisons between DCAH and DCCs, some pointed out that in an ideal word, it wouldn't necessarily be an 'either-or' scenario. In some cases, a client can be suited to and benefit from availing of both DCAH and the DCC service, given PwD can have different needs at different times, even on a short-term basis. One coordinator highlighted an individual who likes attending the DCC, but on days where he is more anxious or agitated, he can become irritated and lash out at other service users.

"He'd see someone doing something and he'd give out about them doing this or whatever, but then there's none of this when he's at home. He's a different person at home, but still very happy to come into the service some days" (Co13)

Additionally, many more pointed out that people's needs tend to change significantly over the longer term, and this can mean that a transition from DCC use to DCAH use is appropriate, indicating the ongoing need for both DCCs and the DCAH service.

"There have been situations where they're no longer gaining anything from going into the day centre ...they might benefit from one-on-one better" (CW1)

"You can't fit everyone into the one box. Not every service is going to suit every person so of course it should be hybrid" (Co3)

3.1.4 Service Refusal

While acceptability is very high, DCAH is not something every family is open to. It wasn't possible to directly interview people who had refused DCAH, but we determined, through interviews with coordinators and CWs, the main reasons why the DCAH service might be refused.

These include a reluctance or lack of readiness by the family or the PwD to accept help, the shorter duration of DCAH sessions compared to DCC, a preference for social interaction with peers, or the family and/or the PwD not wanting someone coming into their family home.

"I haven't had anybody that said no to [DCAH], but I have had people who, when we were opening up the DCC again that decided they wanted to come back to the centre instead - these would have been people that were going to the centre prior to COVID" (Co7)

"It sometimes presents that the person doesn't want the care, the person you know may not, may not realise that they need any help." (Co4)

"Sometimes they aren't ready, or they don't want someone in the house" (Co5)

3.2 DYADIC FOCUS

DCAH is a dual focus service, satisfying the needs of two primary recipients, i.e., the PwD and the primary carer. The needs of these two members of the dyad differ greatly, but both share a common need for psychosocial support.

3.2.1 Needs of people living with dementia

The PwD needs support in dealing with identity issues, the sense of loss and displacement that comes with declining abilities and changing roles and circumstances, and the need for support with meaningful occupation and engagement.

"It was a very bad time because he couldn't drive, and we were trying to hide the car" (FC1)

"It's hard for him not being able to garden anymore" (FC3)
"I'd be hopeful of getting back to playing golf someday" (PwD3)

DCAH can help PwD cope with the associated loss, helping the PwD to reinforce their sense of identity, through personhood-supporting interactions, and interest-driven and strengths-focused activities.

During one home visit (no. 2) a man living with dementia lamented the loss of abilities, telling his ASI carer "I can't do some things" and "I can't help it". He spoke about his hobbies, saying "I used to be a good footballer". The ASI carer validated his concerns, but also pointed out that he still has other strengths: "Some things yeah… You can still do a lot of things".

DCAH can also address the PwD's need for a greater sense of independence, by supporting them to keep active and engaged in their local community in a variety of roles, e.g., as a customer, a neighbour, a friend.

"I go for walks with a couple of my clients, and we can stop off in the shop…I would help her walk and open her bag…she would get her messages – to just to empower them to do what they kind of always did…so much is possible" (CW3)

Another primary carer spoke of the loss her husband is dealing with because of Alzheimer's disease: "The changes, it's awful hard on him… It's all he wanted, to be out on the farm" (FC5). When the CW comes to visit, she meets this need, by bringing the man on walks around the farm. The researcher noted during the observations that:

"He seemed withdrawn indoors but came alive outside while giving the story and tour of his farm. It genuinely felt like friends going for a walk. There was nothing contrived about it." (R2)

Some CWs explicitly point out that meeting the PWDs' needs is not formulaic, and a good CW will be vigilant and cognisant of the client's mood and energy levels at different times of the day, and adapt their behaviour accordingly. Another important consideration identified was how needs can differ based on the life stage of the PwD, noting how those with young onset dementia (YOD) may have very different needs to those diagnosed later in life.

Some coordinators spoke about the increased prevalence of YOD in the community, meaning more and more younger clients are presenting to DCAH services. This is an important consideration for the future of the service, as one coordinator summarised:

“We’re seeing this by younger people who, you know, who are also... Now, they are being diagnosed too like… Before it was more people who were 65 and older, but we’re having to rethink that. Because there’s more younger people coming in now that need care” (Co6)

3.2.2 Family carers’ needs

One of the most prominent findings of the evaluation, from across perspectives, is that there is a very high level of responsibility and strain on family carers; and thus, a huge need for breaks from caregiving to make the family caregiving situation sustainable.

“You can’t imagine what the families are going through you know, you only have that two hours and they have the other 22 hours you know what I mean? They need it, basically, they really do” (CW2)

“I think she [spousal carer] has home help three mornings a week for thirty minutes and our service [sic: once/week], and that’s it for the whole week. No family members or anything helping her.” (Co1)

Family carers described the unrelenting pressure that they often feel, with one carer likening it to the transitional and all-consuming experience of new parenthood.

“When you have someone with Alzheimer’s it’s like having a new baby again…You really don’t switch off at all” (FC4)

The primary carer’s world shrinks, as their sense of independence and freedom is curtailed by the enormity of the caring role. In some cases, this means they can’t foster/maintain other friendships and relationships or even attend carer support groups.

“I always love to join different things and meet people and whenever I think maybe I might like something, I think straight away, now, how am I going to get out?” (FC1)

“I can’t go anywhere if I don’t have a carer or home help and they can only come during the hours that suit them… So I can’t go anywhere really…there’s (a dementia night) once every month in [town]…but [last time] he wasn’t well, so I couldn’t go” (FC5)

Another FC highlighted how, even on the seldom occasion she gets to socialise, she is so engulfed by the strain of the caring role, it can be a challenge to switch off and get true benefit from the situation:

"Your world becomes very centered around the PwD… So even when I do meet friends it's an effort to turn your mind off" (FC4)

A key point associated with this combination of isolation and strain is the effect it has over time, which was described by many as a process of 'wearing', 'breaking' and/or 'grinding' carers down. Inherent to this is the notion that family carers are often giving more of themselves than they have the support, time and space to restore, resulting in growing feelings of burnout, which are accelerated in the absence of appropriate support.

"Caring for someone 24/7 is hard and it would wear you down…I've seen it" (CW3)

Coordinators, CWs and family carers all point out that many family carers are also struggling with their own physical and mental health issues, which influences their capacity to meet their own needs and the PwDs needs, as well as they would like to. One carer described such an instance:

"Once it comes to 10 o clock, I'm ready for bed but he's not ready for bed. And he's asking why did he have to take this medication? I remember one day there about a week ago or two ago, I wasn't well myself. I had a very bad infection and I said to him, 'take them if you want them. If you don't, leave them there', and I just walked away" (FC3)

Some primary carers can struggle to take the break for themselves; however, CWs described how part of their role is to encourage family carers to take the duration of the DCAH session, and use it for a break from caring, specifically to focus on their own needs.

"You're just telling them you're here now… And you do have to tell them to take their break. Sometimes they're so involved in the care, they want the respite, but they don't know how to take it…Sometimes they don't know how to avail of it because they get so little of it" (CW1)

With DCAH, the primary carer can use their time in whatever way they believe will be most restorative for them. How the time is used is extremely varied, e.g., tackling a build-up of errands and administrative tasks, meeting up with other family and friends, and engaging in their own hobbies.

"For me, it's a chance to go out meet pals and keep in contact with people" (FC3)

"I go into [town], do some shopping, visit my brother…" (FC5)

"At least when you know the two hours that they're there, there's someone with her… You can go on plan and do something on them days you know. Without [DCAH] you'd be just tied" (FC8)

What was clear from the family carer perspective is that they need to believe that the PwD is safe and secure with the CW in order to take time to meet their own needs.

"They need that little bit of head space that they can just go to the post office, go to the bank without worrying about their loved one" (Co10)

This is important, because effectively meeting the primary carer's need for a break is fundamental to preventing/delaying admission to a care home. If their respite needs aren't supported, they can't sustain their carer role in the home.

"For them to be able to get a break, that is the key to keeping people at home. This service is just as important, if not more important to some than a home help service" (Co5)

Another need of family carers is for a sense of shared responsibility, i.e., that they are not completely alone shouldering all the responsibility, all of the time. ASI CWs can function as a sort of ally in supporting everyday care, which contributes to the carer's need for felt support from others.

"[CW] might say, well, her tablet box isn't full today or something like that you know the they make a general

comment [name] there's no toilet paper in the toilet or something but you know, they just keep a general eye on the whole thing that's happening like you know." (FC8)

However, for family carers, while the service can serve to give them a break, several carers indicated that the duration of DCAH sessions is shorter than they would like, and that they would benefit from more hours. For some, this means having more than one session per week, while for others it means wanting a longer session.

"I usually do my food shopping and then try and get a walk in as well. I have to say, it's quite a short time, like 3 hours sounds like a lot but it's not really because you can't really go very far. For instance, I couldn't really go into [town] because I wouldn't be back in time" (FC2)

DCAH coordinators and CWs also referred to the need to expand DCAH to more flexibly meet the carer's need for a break: "for example, a day away or an overnight, an extension to DCAH" (Co3)

3.3 PERSON-CENTRED CARE APPROACH

3.3.1 Trust and Relationship-Building

The relationship dynamic between the ASI carer and the PwD is central to the success of the DCAH service in implementing a person-centred care approach. Building the relationship means establishing trust with the PwD and the family, and this process can take some time, while they get to know each other.

"I always say to families, you know this will work if it's a trusting relationship and trust doesn't build up overnight. So that's a massive part of our care is building that relationship… Sometimes there are lots of cups of teas with the couple before that trust is built up." (Co4)

"That whole process of building that relationship and the trust, that's something that kind of takes kind of weeks or months" (Co6)

While the CWs are the main face of this relationship, the coordinators also have an important role in facilitating this, by supporting both the CWs and the clients:

"I would be in continuing contact with the family. Constant engagement with the care worker and constant communication with the family, so we're aware of both needs at all times" (Co1)

One carer indicated that what she especially values in the relationship is that she knows that the CW is "conscientious" and thus knows her husband is in safe hands.

"Like, when he goes to the bathroom say, he can get a bit disoriented and she goes and waits outside the bathroom for him" (FC4)

A successful relationship means having a respectful, compassionate, and empathetic approach to both the PwD and their family, in a way that is often more intimate and personal than a typical service-based relationship. One family carer notes:

"[CW] gives her time…They get on great, she's like a friend. The other girls, the home help girls, are great, but they're so busy - they don't have time. What she needs is the chat, something to talk about" (FC6)

"He loves her absolutely. Probably tomorrow he will say, 'when is (CW) coming again?' My children love her as well" (FC3)

The PwD himself described his relationship with his CW as somewhat team-like, indicating a felt sense of reciprocity within their relationship:

"Myself and [ASI carer name], we are a great combination" (PwD2)

Another PwD similarly characterised his relationship and bond with his CW:

"I must say…we have meshed very well" (PwD3).

3.3.2 Personhood supporting care

DCAH is intended as a person-centred service, delivering an individualised and holistic care approach in the home. There is a clear recognition amongst ASI coordinators and CWs that effective and acceptable DCAH is “not a one size fits all” (Co2), and so “we can’t be homogenised in our approach” (Co11). CWs also demonstrated an awareness of this:

“You can’t fit everyone into the same mould, everyone is different” (CW1).

Coordinators note that this approach is often supported using formal tools, e.g., ‘This is Me’:

“We focus on ‘This is Me’ and a person’s likes and dislikes, but I suppose it’s that holistic approach, you know the physical, mental, psychosocial and get it all together” (Co11)

Supporting the person-centred philosophy guiding the care approach, the nature of the activities vary widely, guided by the initial assessment and the ‘care plan’, which is developed and frequently updated in consultation with the family and the PwD.

“You do the initial assessment, so you know what their likes and dislikes are, what their interests are. You ask them what they want to do, because it’s very important that the person with dementia obviously can say what they want to do. We very much involve the PwD” (Co1)

Coordinators point out the importance of continuity of care to the successful implementation of a person-centred care approach, which is facilitated by the one-on-one nature of the service:

“It is completely person-centred - it’s the same carer coming in, and it’s one to one” (Co2)

One CW noted that her approach to care is about figuring out how to ‘live in the PwD’s world’, as a means of fostering engagement.

“You need to be able to find their happy place and live in their world. You get to finding their interests and that might start off a conversation” (CW3)

One CW explicitly and eloquently recognised the importance of personhood and purpose as universal psychosocial human needs, which fall within the remit of the DCAH service:

“There’s a couple of things we all need in our lives. One is to be recognised as a person, and another is to have purpose. You know, we all have a purpose in life… And when you get to know your clients and see what that person is like, then when they can’t remember how to do something or they can’t physically do it anymore, we can find a way around it” (CW4)

In some cases, where abilities to engage in certain activities are limited, CWs note that the focus can simply be on being present with the person, and using sensory interventions, e.g., touch, as a form of communication:

“It can mean sitting down with the person and you know picking up their hands and holding them in yours…It’s not always the words, it’s how you make them feel.” (CW1)

During the home visits, the person-centred approach was evident. In home visit 1, it was noted that interactions between PwD1 (‘Jim’) and the CW were person-centred throughout. The focus remained firmly on Jim in relation to memories of his childhood, summers farming as a child, local customs, poems, and folk songs (one of which he performed) and social norms of his time, e.g., he recalled, “if you liked a girl, you would buy her a bottle of orange and then she would know [laughs]”.

It was clear to the researcher (R1) that keeping the focus on Jim was intentional on the CWs part, but importantly, it was made possible by her in-depth knowledge of Jim’s life and interests, that the CW had previously accrued over time. In this way, the interactions felt authentic and likely representative of a usual DCAH session.

In another home observation visit (no. 2) the relationship between the PwD and the CW was strong (R2) and like the above home visit, 'John' was kept at the centre of every interaction. The CW kept John engaged in conversation and positioned their relationship as an equal and reciprocal alliance: "We make a good team, don't we?". His wife appreciated the CW's ability to engage her husband in conversation, something which she notes others can find difficult.

"She chats away with him, which is great because a lot of people find it very hard to talk to him" (FC2)"

This notion of the CW and PwD being a 'team' was observed at another home visit (no. 4), also one evidencing a warm relationship between the PwD and CW (where they 'joked with each other affectionately'). The researcher (R2) noted that 'when the CW suggested they were "a team", the PwD grinned and replied, "absolutely"'.

3.3.3 Meaningful occupation and activity

DCAH offers a range of different activities to PwD depending on their interests and values. Activities range from physical (walking, swimming, football, hand massage), psychosocial (puzzles/games, reminiscence therapy, doll therapy, going for coffee in local café, neighbourhood walks, conversations) and spiritual (listening to mass on tv or radio, visiting local church, meditation).

This social model of care means a range of hobbies are incorporated into the service, driven by the interests of the PwD. Music seems to be a common activity that many PwD get enjoyment from, with other activities ranging from singing, knitting, art, baking, gardening, woodworking, flower arranging, or visiting the local hair and beauty salon.

"We follow a social model of care – encourage stimulation, social involvement, doing activities – depending on the care plan and what the person likes to do" (Co1)

"It's more to engage them in whatever their interests are, get them out for exercise, meditation, hand massage… It's a person-by-person basis really" (CW1)

For PwD, the time with the CW can be a combination of physical or cognitive activities combined with a hobby, all the while providing them with meaningful companionship.

"I love watching the Shadows music show … I love music, guitar music… A good long walk on the road. Yeah, we have a great auld chat. We look out at the sea or the stadium like, you know" (PwD3)

Other home-based services cannot provide this approach to care. Indeed, for all stakeholders, one of the primary advantages of DCAH is that the CW can spend a significant block of time with the PwD, and the direction and pace of the session is dictated only by the needs and preferences of the PwD.

"The home help, they're only going in and out only in for half an hour or 45 minutes and that's not long enough to be either able to help the client or to help the family member that needs the break" (CW7)

"The home helps have only the half hour and they have to get him up and give him a wash … they haven't time for him, not like the way [CW] has the time for him" (FC5)

One area for development noted by CWs related to the supply of technology and other materials/ consumables to support them to engage clients in activity.

"What probably needs to be worked out with the activities is where we source materials from and who pays. Like at the minute, the onus is put on the family to pay for moisturisers/creams, colouring packs, things like that. Families have to buy that so staff can use them." (Co13)

CWs are supplied with tablets for use with clients during DCAH sessions to virtually support engagement with, e.g., puzzles and games. However, CWs pointed out that the tablets could be used more extensively for engaging PWD, if the user permissions were recalibrated.

"The only problem is I could do with more on it, because there are a lot of restrictions. I know they have the restrictions for a reason, but sometimes they're so restrictive we can't look up anything with the person." (CW1)

3.4 REFERRAL PATHWAYS AND ACCESS

3.4.1 Referral pathways

Awareness of the DCAH service is ad hoc and variable, with some primary carers reporting they became aware of it by accident.

"I just happened to come across it by chance" (FC6)

Often, it's the initiative and proactive approach taken by the family that leads to an awareness of the DCAH service.

"I actually got in touch then with the ASI to see if I could get somebody in" (FC2)

"It was my daughter. Ages ago she rang the ASI and they gave a whole load of information…and we kept in touch" (FC3)

This suggests access to the service is at least partially based on the ability of the family to identify and advocate for services.

Coordinators indicated that the same referral process is typically used for DCAH and the DCC service. Many referrals come through the PHNs, with referrals in some areas also coming from Geriatricians.

"I get referrals mainly from public health nurses" (Co8)

Several coordinators corroborated this, as did two PHNs, but some interviewees further indicated that GPs tend to be less likely to make DCAH referrals than PHNs or Geriatricians.

"The PHNs are out there in the community. They're sitting with people in their kitchens, and they could see the need for support, you know. The GP should do, but they just don't refer them as much… The geriatrician in [local hospital] refers a lot now, so really PHNs and Geriatricians." (Co8)

Perhaps in line with the above findings, when trying to recruit GPs for this evaluation, most refused participation on the basis that they didn't know much about the service, and didn't feel they could provide any insight that would be of benefit to the evaluation of the service.

One GP did speak with us briefly, indicating that he had "a hand in one referral", but the initiative was largely driven by the family, who requested "supporting paperwork".

3.4.2 Accessing DCAH

The demand and need for more DCAH was a resounding and recurring theme, for external stakeholders, ASI coordinators and CW, and family carers. There are lengthy waiting lists for DCAH across all regions.

"What we're giving out in the month, we could give that out in the week" (Co8)

"We have a huge volume of referrals coming in, so people could be waiting months before we get to them because we only have a certain number of hours that are allocated by the HSE" (Co2)

The number of hours currently on offer for the DCAH service have been cut significantly, compared to the volume available during the COVID-19 pandemic (associated with the re-opening of many DCC services). A key problem is that concurrent with the reduced supply of DCAH, the demand is increasing, as more families become aware of the service and its potential benefits.

"We got the hours increased…But now the funding has been reduced again, which is so disappointing because there is a huge demand" (Co2)

"I do find more families are bringing [DCAH] up to me, the

want is going up" (PHN2)

One coordinator indicated that another driver of demand relates to effects of the pandemic, with many older people who were cocooning now fearful of being in groups and/or having declined in their mobility because of the associated restrictions.

"Since COVID, people are scared to come out of their houses but another reason is people's mobility has gone down a lot and it's hard for people to get into their car and come into us" (Co2)

In coordinators' experiences, many families that they encounter who are seeking help from them are in dire straits and in urgent need of support, which ASI cannot always provide.

"You have families ringing up, going 'mum's really struggling, is there any way that you have any more hours because she really can't look after dad…They're crying on the phone and I can't help. Unless somebody died or went into long term care you know…I have nothing to offer them" (Co10)

Family carers were also aware of, and cited the limited nature of the funding, but all would welcome more hours if they were available.

"Four to five hours would be brilliant, because then you can go that little bit further. I'd have more time for myself because normally like I say, you do to the shopping, you go pay a few bills, might have to go to the bank you know…" (FC2)

When asked about the greatest challenge faced by DCAH, coordinators consistently indicated: insufficient funding. Two coordinators stated that they have had calls from local politicians, advocating for their constituents who cannot access DCAH and other supports, but they are powerless to help. One noted:

"I mean [local politician] will ring us up and say you need to give hours and I'm like, 'well you know actually, you need to give us more funded hours'. That's what we need." (Co8)

Given that demand exceeds supply, coordinators indicated that they must choose which clients can access the service. In most cases, coordinators prioritise those who have been on a waiting list the longest. However, other factors relating to the level of unmet need are also taken into consideration, e.g., people living alone with no family, those struggling with a YOD diagnosis, where the primary carer is older/frailer, or where the family has no other support services available to them.

"Usually, we go by the waiting list order, although occasionally there will be a sad story when someone doesn't have family, so it's important to know that we need to prioritise them at times" (Co2)

"We'd always look at those who are there the longest. Unless there was a person or family that were really in dire straits…" (Co6)

Another factor influencing access is whether ASI has the fiscal capacity to hire staff in each catchment area; this is a particular problem in more rural areas.

"To be honest we do not have the funding to put people in some areas…Anyone in South [area] will more than likely get a service, whereas clients in North [area] are not guaranteed this. For example, someone in [location] would never get a service because the closest CW to them lives 45 minutes away" (Co5)

Outside of funding, occasionally the demand cannot be met owing to the inability to source candidate CWs to deliver the service in an area. If a PwD happens to live in an area where there is a shortage of CWs for hire, they may remain on the waitlist even longer.

"Other factors come into play, e.g., there's a massive shortage in recruitment at the moment, so the client that is closer to our available staff members unfortunately, will kind of get in there first… It's just because, you know, we don't have staff and capacity in that area. It's a sad reality." (Co9)

3.5 SERVICE MANAGEMENT

3.5.1 Human Resources

Recruitment

For many coordinators, the recruitment of new staff is a key challenge. This is complicated by the growing number of private domiciliary care services coming to market, acting in competition with ASI for the same pool of potential CWs.

"At the moment we're trying to recruit carers, and it's hard for us, competing against the private companies. Everywhere is trying to recruit at the moment, you know" (Co6)

"We have to go massively out with recruitment campaigns… but the HSE have the same issue. With the private providers, we're all looking for the same pot of people, that's the problem" (ASIM1)

One coordinator indicated this as being one of several indicators of need for regulation across all models of home-based care:

"I suppose we're up against it in terms of competitiveness from the private side, there is a lot of private care work… Probably regulation is needed because you have different actors and private carers coming in and we're all singing off different pages, competing for wages and money and mileage… It's so competitive, it's a carer's market in that sense" (Co11)

The recruitment issue brings other challenges for coordinators, because they then have less choice in terms of selecting appropriate candidates to provide DCAH:

"I feel a little pressure (and I say this in inverted commas, as its more of a general comment) with metrics and to meet targets and to take on any person applying just to fill the role, but then that's not always a fit for the service." (Co11)

Retention

Conversely, coordinators overall felt that staff retention within the ASI is high, and that many staff, both coordinators and CWs, have life-long careers with the organisation, with many transitioning from long-standing DCC roles, to DCAH, on service inception.

"I'm here a long time, and some of my team have been here as long as I have" (Co12)

Generally, coordinators reported very few issues relating to staff retention:

"At the minute there is no issue with staff retention. All the staff that I have are staying" (Co13)

"We're not having any difficulty retaining at the moment" (Co2)

"You know with retention of staff, I've been lucky. I feel we've all gelled well as a team and we've worked well as a team over the years and you know as I said, I can't really see any of them leaving now at this point in their careers" (Co4)

Some coordinators did make a distinction between long-standing career staff, and new recruits, highlighting that retention of newer staff can be an issue:

“We have the staff that started with us in the beginning, they are still with us. I think newer staff that we have employed recently one or two of them have left us” (Co7)

One coordinator clarified that in her experience, this is because of the limited funding for DCAH hours, which means ASI can’t always offer new CWs enough hours to make the job worthwhile.

“The problem is obviously, you know if you can give 20 hours a week it’s easier to keep people… whereas it’s very difficult to retain new staff, if they’re only doing 3 or 4 hours a week. The next thing is you’ll have trained them and they’ll go to a nursing home… They can get their three shifts in the week there you know, so that’s the difficult thing” (Co8)

3.5.2 Training and qualifications

Training and experience of dementia are essential for ASI CWs delivering the DCAH service. FETAC Level 5 is considered ‘desirable’, but not ‘essential’. However, many coordinators responsible for hiring and managing CWs believe that it should be a mandatory requirement.

“I would like everyone to have their FETAC Level 5 course done and be qualified healthcare assistants.” (Co2)

Even though DCAH doesn’t comprise personal care, many coordinators pointed out that DCAH CWs need to have the skills to deal with urgent personal care needs; part of the reasoning for this, is that if family carers need to be ‘on call’, this undermines trusts and potentially revokes the benefit for the family carer.

“We do not undertake to do personal care. However, if someone has an accident, absolutely you have to have the skills to support that person… You cannot ring the family member to come home” (Co3)

As well as the formal qualifications and the completion of various online learning courses through HSeLanD, coordinators also spoke about the importance of having staff with hands-on experience of working with PwD previously, for honing a person-centred approach.

Some coordinators spoke about how they have used DCCs to help with the initial onboarding and induction of CWs that are hired to deliver DCAH, to give new CWs more experience with dementia care, first under supervision, in a more controlled environment.

“We might take them into the day centre for a day or two to work there just to get them just to get a feel of what it’s like to be working with a person living with dementia” (Co7)

3.5.3 Operational factors

Management (senior management, coordinators) indicate that as an organisation, ASI are becoming increasingly more focused on collecting and harvesting high quality data about service operations to help them demonstrate the value of the DCAH service:

“We weren’t selling ourselves well as an organisation… We couldn’t tell them our story properly without the data” (ASIM1)

Ensuring that the internal data collected relating to service use and performance is current (i.e., ready for analysis in as close as “real-time” as possible) is important, to facilitate DCAH being as responsive as possible to issues relating to governance, service visibility, accessibility and acceptability, care quality, and client satisfaction.

“Now we do KPIs…I get a file every week to tell me about the cancellations in each area and the reasons, I see how many referrals, I see how many assessments, so all that is powerful data that you can react to each week.” (AISM1)

This type of data can also be used by ASI to maximise resource efficiency when used in collaboration and communication with other services, especially those provided by the HSE.

“It can go out to the community, to the PHNs, older person services managers, they’ll send it out and it refreshes

again for them that there is, or isn't, places available, or we have some extra hours to give in one area" (ASIM1)

While collecting and harvesting service data is a priority for management, another element to growing and integrating DCAH into the service landscape relates to creating dialogues and nurturing relationships with external stakeholders.

For coordinators, this means integrating with community based HSE services and local county councils.

"Working with the community mental health nurse, the PHNs, you know the team it's very much team effort to make it more integrated, you know that everyone's working off the same page and that they're able to integrate and liaise easily with the GPs and stuff…I know in [county] and [county] we have done a lot to defragment care, but I think there's a lot more that needs to be done" (Co11)

"I have linked up with the HSE services. We would also link in with the county council. Like, we worked with the HSE and the county council in putting together an emergency list…that started off as under the older person group in the county council." (Co3)

For senior ASI management, the focus is on building relationships with other external senior managers in decision-making roles (e.g., within the HSE, Department of Health) and politicians. While many external decision-makers understand and appreciate the added value of DCAH ("this service is a lifeline to families at home" (HSEM1) some are less open to integrating this unique service model into their service roster. This means ongoing and constant negotiations with multiple different groups, all with their own perspectives and demands to weigh up.

"And there are 9 different stakeholders, so we negotiate 9 different budgets. I have 36 meetings a year about this alone. They are all so different. Some really believe in the service, others kind of go 'ah sure, it's home care, it's only more of the same thing', you know?" (ASIM1)

HSE operations management that see the value of DCAH, and are supporting the provision of the service in their area, must "walk a tightrope" in supporting the growth of the service:

"Since its inception the service has a growth of 75% [laughs] - that's a nervous laugh. As I have told them in ASI, it's to maintain what we have now at the minute, because if I go over budget too much, I will be told to pause…You can understand the predicament I'm in" (HSEM1)

3.6 STAFF EXPERIENCE

3.6.1 Challenges faced by CWs

CWs must navigate a variety of challenges in delivering the DCAH service. Managing family expectations and navigating complex family dynamics can be par for the course in the daily work of CWs.

In some cases, family members might not understand dementia and how the symptoms manifest for the person with dementia, which can lead to CWs witnessing unsettling interactions.

“You mightn’t be too happy with conditions, or how they [families] are speaking to the clients [sic: PwD] so you bring that up with [the coordinator]. You have a chat around it. Nine times out of ten it gets resolved” (CW1)

While most families are aware that DCAH provides social care, there can be confusion initially, if primary carers expect personal care to be included.

“You sometimes have to say to families well I’m not here to do personal care, you know, I’m here for this social aspect of it” (CW2)

Another CW noted a similar experience, highlighting the need for diplomacy and boundary-setting in situations where family carers misunderstand the purpose or remit of DCAH, or confuse one service for another.

“A client’s wife said to me, ‘will you be showering him’? I said ‘no, no that’s not why I’m here’… She was getting all confused about what she was saying to whom. She was trying to say he wouldn’t be showered if I didn’t do it…but I knew there was a different homecare provider coming in. You just don’t know what you’ll be faced with. You have to be very diplomatic” (CW1)

Some CWs feel the strain and confusion of the family spilling over into their interactions, when families turn to CWs seeking them to answer highly complex health-related questions.

“When the family come and talk…[they say] ’they’re the complete opposite person to who they were before’…and ‘they are frustrated’ and ‘they are different’…That they are ‘looking after someone different…Especially when they go downhill, the family are asking you so many questions… There is pressure on how to answer them and I cannot give them the answers” (CW6)

In some cases, clients have opened up to CWs about sensitive and serious personal issues, which the CW must then process and decide what, if anything they can and should do about the situation. This CW felt that while she did get support, such processes could be more comprehensive:

“There have been some situations. One lady opened up to me and told me that her ex-husband used to beat her…I wasn’t expecting this and it was a lot to take on… there needs to be somewhere for me to go…in fairness my managers are supportive…what if someone is holding it in? The carer needs to be looked after too” (CW3)

One coordinator spoke about part of their role being to protect the CWs, as they know they are lone workers in sometimes unpredictable situations.

“I would really have to keep an eye on some families and some CWs with those families and say, you know, ‘this is getting too much, we need to take you out’. Sometimes that’s the only way because unfortunately, families can get too involved at times, and for the care worker, it’s too much on them” (Co4)

One suggestion for improving boundary-setting capacity amongst CWs is to provide them with formal training, supervision and/or counselling on the issue, so they are better equipped as lone workers.

“There is a lack of is support for the carers. There is nowhere for them to offload. There is no training offered to deal with that. We have an EAP line which gives six free counselling sessions, you know but really, someone’s not going to use that unless they’re in a crisis situation. (Co4)

Despite these challenges, there was strong appreciation amongst CWs for the supportive culture fostered by the DCAH coordinators. CWs experienced the coordinators and other management as highly accessible and responsive, in a way that makes them feel less alone as lone workers:

"I have great support. If I'm not happy with anything, I know that I can ring [coordinator] and that she is going to fully support me...I think that is huge" (CW1)

"They're brilliant like you can just ring them if there's any issue, anything at all" (CW7)

3.6.2 Complexity of the CW role

There is agreement that the primary skills CWs need relate to training and hands-on experience in dementia care. However, many coordinators and CWs note that while training and experience are necessary, they are not necessarily sufficient. CWs working with people's homes must also be adept in utilising a range of complex interpersonal skills and have high levels of emotional intelligence.

"You have to have the proper mindset to do it. You know it's not just the training" (CW2)

"I think you need to be able to read your clients really well" (CW4)

Other skills noted as central to the role include, empathy and compassion, conflict management and active listening and observation skills, to continually assess dynamic situations.

"You have to be alert and watching the whole time" (CW5)

As CWs move between clients, they are faced with various family situations; different diagnoses of dementia; verbal and non-verbal people; all at different stages and with different needs, daily.

3.6.3 Staff Morale and Satisfaction

Coordinators and CWs both largely indicated that staff morale and job satisfaction is typically very high, and the nature of the job is rewarding.

"I love working on the one-to-one basis. I get a lot of personal satisfaction from the one on ones and I build stronger relationships with those clients and their families" (CW1)

"I am delighted to be a part of it because I can see the positive impact it has on families" (Co5)

"They're delighted with the support, and you know that's why we're here at the end of the day. It makes it all worthwhile" (Co6)

One coordinator also highlighted that her CWs value the flexibility that the CW role gives them, which she believes contributes to better staff retention rates.

"People are happy working here because they're getting the hours that suit them, so they can work around their family lives. I think it helps hold onto people if you do suit them as well. There is flexibility and we can work around the service to suit people's hours" (Co2)

That said, some areas for improvement relating to CW morale and experience were highlighted, albeit mostly by coordinators rather than the CWs. For one, there appears to be discrepancy in the terms and conditions offered to CWs in different regions of the country hired at different points in time. In some cases, CWs are paid regardless of whether a client cancels at short notice, whereas in other areas it appears they are not paid when that situation arises.

"There's still funny practices going on over the country, e.g., where staff aren't paid if somebody cancels on them" (Co4)

There was also some divergence and confusion around processes relating to travel expenses for front line CWs. One coordinator reported CWs are "not paid for the commute, they're paid for their mileage" (Co8), while another coordinator declared, "our staff aren't getting petrol expenses" (Co2). Another coordinator indicated a different process again:

"Apparently, they're not paid for the first eight miles from their home" (Co11).

The discrepancy between the travel allowance offered to recent new hires versus existing staff was also raised, although there was no clarity on the specifics of the situation.

"It has come up as an issue with CWs that apparently people that were taken on in the last 12 months, that there's a disparity between the new hires and people who were previously working and they're not getting the same. I can't go into the full details…I don't know for sure" (Co11)

3.7 CLIENT OUTCOMES

Both DCAH service providers and clients were unanimous in their view that DCAH leads to a range of positive outcomes, both for the PwD and the family carer.

3.7.1 People living with dementia

With DCAH, the PwD gains positive socialisation from their one-on-one relationship with the CW.

"The daughter said to me, 'the minute you come in the door she's a different woman'" (CW2)

"They love to be listened to and not corrected. [PWD] might tell me five times the same thing in the one conversation, but I am just as eagerly engaged the fifth time as the first time they've told me" (CW3)

The benefits to the PwD are accrued regardless of whether they recall the ASI care worker between visits, as observed by one primary carer.

"It does [husband] great good. I would say to him, '[CW] is coming'; He'd say, 'Who?' But the minute she's here, they're chatting away happily…he needs that interaction" (FC1)

Another primary carer (FC2) confirmed the "definite" improvement in her husband's mood during and after the CW has been for a DCAH session. One CW noted this has a knock-on effect on the family carer's mood, and the overall quality of family life:

"If they [PwD] are in better form, then the carer is in better form. I mean if they're happy after a session…they might be sleeping better, that means the carer is in better form, and the whole family unit is better" (CW3)

Coordinators also reported positive feedback from families on the impact of DCAH on the PwD.

"Family members have been very grateful that when they come back that [PWD] would be smiling and they'd be happy and you can see that there's a difference in them." (Co13)

"When I assessed him, I was unsure if he would get much out of the service, and now the wife is saying he is like a different man" (Co2)

Improved community inclusion and citizenship is another positive outcome of DCAH for the PwD. Simple activities such as going for a walk together or going to the local café means the PwD is more engaged with community life.

"He loves to go down for his coffee, and he always meets someone down there" (FC3)

"It's inclusion in the community when they're going out for cups of coffee and walks and, you know, it enables them to, to retain that kind of social inclusion" (Co9)

CWs note that PWD are also buoyed by the chance to avail of the services in their community that are meaningful to them. This can reconnect them with their sense of identity and boost self-worth.

"Another lady, she likes to go to the beautician… So, we pop in and when she comes out, she feels like a new woman. She is delighted, over the moon. That little thing makes her so uplifted in herself" (CW3)

There is also the benefit of increased physical activity and maintaining or improving the person's mobility. During one home observation visit (no. 6), the PwD (who has limited mobility) and CW sat outside in the sun, while the CW encouraged the PwD to do physical exercises, passing a ball and lifting her legs one by one. During this visit, the family carer corroborated that the CW often challenges the PwD to complete more physical activities than she would otherwise. The notion of CWs being able to 'get more' from the PwD in terms of engagement, than the family carer can, was a common theme across carers, with one noting:

"I used to take him for a walk and he'd only go maybe two houses down and wouldn't go any further… but now [CW] can get him to go down the end of the road, which is a nice walk. You know, it might take them an hour…" (FC3)

CWs and carers further indicated that PwD can also be more receptive to engaging in cognitive activities with CWs, which family carer's especially appreciate:

"My clients won't like do any brain activities, or won't do anything with their family person, but like with me they do it. I've one person and the wife kept saying 'he won't do anything with me…I'm glad that he does it with you'" (CW7)

"[He] wouldn't do anything for me on the cognitive side… She can get things out of him and to do things that he won't do for me. It's very good, you know what I mean" (FC2)

Some attributed this greater willingness to engage with CWs, to family carers not having the time to give to such activities, while others felt that there is something about the nature of engaging with an external person that facilitates and maximises engagement:

"I think it could be a person is just more comfortable with someone that's not a family member when doing stuff like that" (CW7)

3.7.2 Family carers

While the ASI CW provides companionship for the PwD, the primary carer also benefits from the service, with outcomes including improved mood, increased socialisation, and reduced isolation. Since the primary carer can leave the home during DCAH, this gives them temporary relief and a break from the weighty responsibilities of the caring role.

"People are glad to have DCAH. The family members get very emotional that someone has thought of them and that it's there for them and they feel heard and validated" (Co11)

The service provides much needed relief for the primary carer, who sometimes has very little other support.

"I mean the minute you go in…He has got to go and do bits because he is a farmer…He is so relieved, you can actually see it in him... It's so valuable" (CW5)

One primary carer (FC4) said they come back "refreshed" after a DCAH session, pointing to the psychological benefits of the restorative break in caregiving: "it's my sanity".

Interestingly, a HSE senior manager noted that in her area, they refer to this service as 'home respite' rather than 'DCAH':

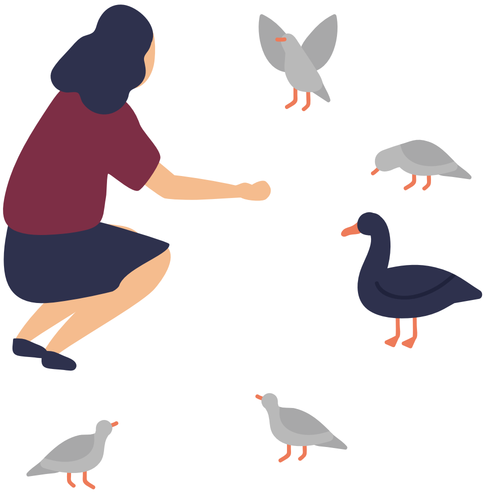
"We call it home respite, the day service at home" (HSEM1)

Just as the carer benefits from knowing there is dual benefit for the dyad from using DCAH, the reverse is also true; when the primary carer achieves a true psychological respite via DCAH, the PwD one also benefits from having a family carer that is in a stronger place psychologically, as they have more to give.

"I know we're all about the person with dementia, but sometimes when you're not about the carer – when the carer is happy the person with dementia is happy because they'll be in a happier place to give better care" (Co1)

In this way, DCAH can foster a more positive cycle of interactions, improving the dyad's relationship by providing both members with the time and space to have their individual needs met.

"When the primary carer has gotten a break and is in better form, then the PwD is being cared for by someone who is happier…so that's going to help them as well… they won't feel like such a burden" (Co5)



3.7.3 Preventing care home admission

Almost all stakeholders noted that the most important outcome of DCAH is that it can contribute to avoiding or delaying the move to a care home, by creating a more sustainable caregiving situation and dynamic.

This is important, as it is in line with the wishes of most PwD and many family carers. One primary carer (FC6), an octogenarian, specifically stated DCAH was actively helping to keep her sister out of a care home. Another carer, agreed and spoke about her main aim being to keep her husband at home, in line with his wishes, and in her view, to protect his wellbeing.

"I couldn't see [husband] accepting going into a home. I couldn't see it and I don't want it. I think when anybody goes into a home, they deteriorate beyond hope" (FC1)

ASI coordinators and CWs indicated that in their experience, DCAH helps to sustain the family carer, enabling the PwD is to remain in the home environment for longer than might otherwise be possible.

"It keeps them at home for longer. You need services like this so that [family carers] can get a break" (Co5)

Many believed that increased DCAH funding could reduce the prevalence of care home admission, by supporting sustainable caregiving, and empowering and energising families to continue look after their loved ones at home.

"We need more funding that is really it, you know what I mean? It would make such a difference to keeping people at home and keeping them out of nursing homes." (Co8)

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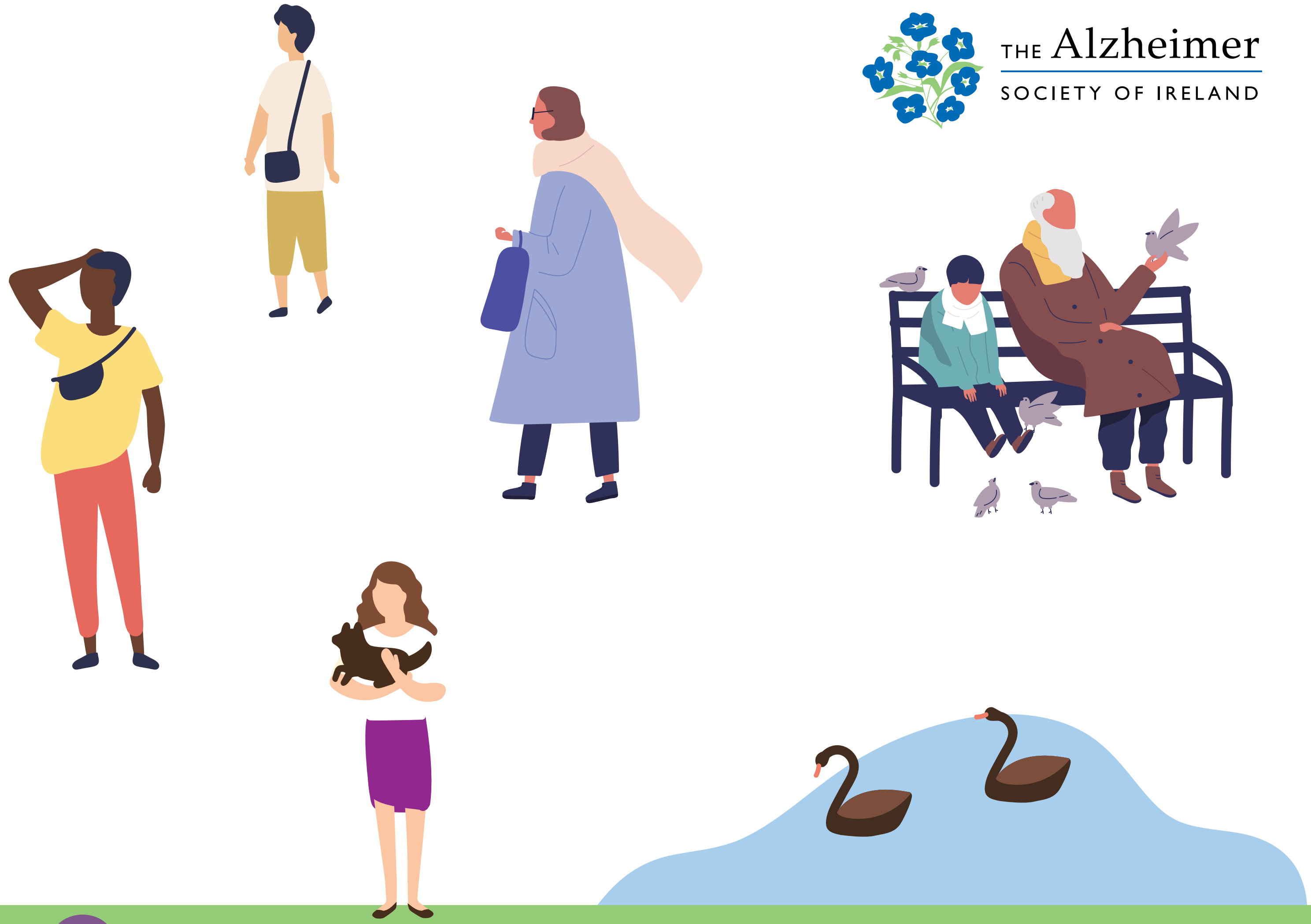


Section 4

Conclusions

SECTION 4: CONCLUSIONS

Day Care at Home (DCAH) is a unique service in the Irish context, developed out of necessity when the ASI day care centres closed due to the COVID-19 pandemic. Almost four years later, it continues to deliver a day care experience at home by providing meaningful companionship to the person with dementia, while also offering a variety of activities tailored to their values, interests, and strengths. Simultaneously, DCAH facilitates an important break for the family carer.

DCAH attends to the five strands of post-diagnostic support outlined in the Model of Care for Dementia in Ireland. A care plan is developed for each person with dementia to identify their individual needs and ensure the service is tailored to their interests (understanding and planning). The relationship with the CW provides the PwD with regular personhood-supporting social contact, which is often further enhanced through community engagement activities such as outdoor walks or visits to local establishments where they meet neighbours/friends and enjoy fulfilling other important identity- and citizenship-supporting roles, e.g., as a local customer (staying connected).

Many of the activities also involve a physical and/or cognitive focus, with a view to maintaining current abilities, and maximising the independence of the PwD (staying healthy, supporting cognition). With support and guidance from coordinators, trained CWs adapt and cater to the needs of each family, on a daily basis, but also over the longer-term as the condition progresses.

A UNIQUE MODEL

DCAH is a unique service underpinned by a social model of care, delivered in the home environment. It provides a bespoke, dyad-centred service to a previously underserved cohort of PwD and their FCs, i.e., those who don't avail of DCCs, either because they are unable to do so (owing to logistics, travel impediments, mobility limitations or service absence) or because they are unwilling to do so (due to personality factors, not enjoying group activities, or becoming cognitively or neurologically overstimulated by same).

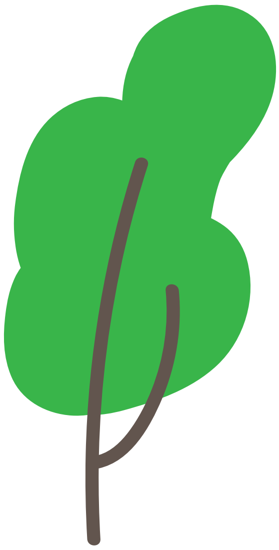
While DCAH has some advantages over DCCs, the converse is also true. DCAH may be refused if the longer duration of DCC sessions better suits the family, if there is a preference for peer/group-based interaction, or if the PwD or family members don't want CWs entering their home. Because there is no one-size-fits-all solution, DCAH and DCC models are both necessary offerings nationally; they are mutually inclusive. This aligns with reality: needs change over time, in a variety of directions; where one service may be appropriate to a family now, an alternative may be more appropriate in the future, and for some dyads, needs are different day-to-day (e.g. DCC may be overstimulating or overtiring for the PwD if too frequent, but occasional attendance allows a longer break for the carer to do particular tasks).

DYADIC FOCUS

Due to its dyadic focus, DCAH offers direct benefits to two cohorts: the PwD and the FC. While the needs of each differ greatly, both share a common need for psychosocial support which DCAH can deliver. Families are interconnected, interdependent units; any benefits experienced by the PwD or FC can ripple out and ease the strain on wider family experiences and dynamics.

The PwD needs tailored support and meaningful engagement to help deal with losses relating to identity, and displacement due to declining abilities and changing roles; this is achieved through physical, psychosocial and spiritual activities, individualised to each person with dementia depending on their needs and interests, and delivered through meaningful companionship with care workers.

The family carer needs support in shouldering the weighty responsibilities of care. Many FCs, including participants in this evaluation, experience significant stress and can be overwhelmed, as the care role tends to fall predominantly on one family member. Since the carer role is 24/7, this can lead to chronic loneliness, isolation, and psychological and relational stress, which has a cumulative effect on wellbeing. For these reasons, FCs are desperate for the brief respite DCAH provides, giving them the freedom to do what they need to do; whether that's completing life administration tasks, meeting up with friends, or having the time to deal with their own health issues. While FCs are desperate for respite, they need the assurance of good quality of care to fully switch off and fully avail of the break, i.e., they need to trust that their loved one is in the hands of someone trained and experienced in dementia but also someone who cares. While DCAH is welcomed, most FCs in receipt of the service would like more hours each week. There is also a gap in terms of little availability of any home respite in the



evening or at weekends. If FCs are not provided with breaks that can facilitate true psychological restoration, the sustainability of their role is in jeopardy.

PERSON-CENTRED CARE APPROACH

There is a clear recognition amongst ASI staff that effective and acceptable DCAH must take a person-centred approach. By ‘living in the world of’ the PwD, the CW meets them where they are, recognising their personhood and other basic human needs by being fully present with the person. The CWs’ respectful, compassionate, and empathetic approach to supporting the dyad helps build trusting relationships over time, provided the CW-client fit is optimal. It seems that across perspectives, there is acknowledgement that the building and nurturing of trusting and personhood supporting relationships is the single most important active ingredient in DCAH, for achieving positive outcomes for the dyad. For this reason, continuity of care is essential, with the same CW visiting the same clients every week.

Other home-based services don’t provide the social model of care that DCAH delivers on a national scale, either due to time restrictions, having a different focus (e.g., personal care), or a lack of training and experience in dealing with PwD. With DCAH, physical or cognitive activities are combined with hobbies while providing the PwD with meaningful social interaction. Because the CW can spend a significant block of time with the PwD, the direction and pace of the session is dictated by the needs and preferences of the PwD. There is also time to strengthen the bond between the PwD and the care worker, who is often viewed as a friend.

REFERRAL PATHWAYS AND ACCESS

Some FCs reported becoming aware of DCAH inadvertently, while some attributed their awareness of to a proactive approach to surveying the range of locally available supports postdiagnosis. Most referrals come through PHNs, with referrals in some areas also coming from Geriatricians and, to a lesser degree, GPs.

There is a strong demand for more DCAH, with lengthy waiting lists across all regions. The current supply of DCAH is insufficient to meet the demand that exists in communities across Ireland for the DCAH service. Coordinators report that many families seeking help are in dire need of support. While recruiting new staff may be a challenge, the main barrier to expanding the service is funding.

SERVICE MANAGEMENT

Coordinators believe staff retention within the ASI is high, and that many coordinators and care workers have life-long careers with the organisation. However, recruitment is a challenge in some regions. The challenge of recruiting new staff is exacerbated by competition with private domiciliary care providers. Some coordinators noted retention of newer staff can be an issue, possibly due to the limited weekly hours offered, which may not be an attractive offering to a CW.

Training in dementia is essential for CWs delivering the DCAH service. FETAC Level 5 is considered 'desirable, but not essential'. However, many DCAH coordinators believe that it should be a mandatory requirement. As well as formal qualifications, care workers also need hands-on experience of working with this cohort to hone a person-centred approach.

ASI's focus on collecting and analysing data on DCAH and other services has increased in recent years. Gathering relevant information on the service is important to highlight the value of the service and facilitate decision-making on operational issues. Some coordinators also highlighted the importance of integrating ASI services with other community-based services and local councils.

STAFF EXPERIENCE

While training and experience are necessary, they are not sufficient. Care workers working in people's homes must also have strong interpersonal skills and high levels of emotional intelligence. They must skilfully manage the challenges brought by both parties in the dyad: the PwD and the FC (or indeed the wider family network).

As they move between clients, the CW must also contend with different need and symptom constellations, and clients at different phases in terms of understanding, accepting, and managing the dementia experience. CWs also navigate managing family expectations, complex dynamics, the setting of healthy boundaries with families (e.g., regarding complex health-related questions, and the disclosure of sensitive and serious personal issues not relevant to the provision of DCAH).

While all CWs spoke highly of the support provided to them by coordinators, some coordinators noted that carefully managing the risks that CWs are exposed to as lone workers can be challenging; some coordinators feel that more resources would support them to expand to their capacity to ensure CWs are given the training and supervision they need to safeguard their wellbeing.

Consistent feedback from both coordinators and CWs was that staff morale and job satisfaction is high; these roles are rewarding because they directly observe and experience the value that DCAH adds to their lives. One issue that arose was an apparent discrepancy in the terms and conditions offered to CWs in different regions of the country, hired at different points in time. In some cases, CWs are paid regardless of whether a client cancels at short notice, whereas in other areas they are not. There was also some confusion and divergence around processes relating to travel expenses for CWs. This issue could be addressed via a policy standardising and clarifying CW terms, conditions, and entitlements.

CLIENT OUTCOMES

DCAH offers positive socialisation, community inclusion and citizenship to the PwD. The PwD is buoyed by the chance to avail of the services in their community that are meaningful to them. CWs can often coax greater engagement from the PwD compared to the FC as the PwD can be more receptive to engaging in physical and cognitive activities with CWs. This increased physical activity may help to maintain or improve the person's mobility, and potentially their mental and cognitive health. It appears the positive experience of the PwD occurs regardless of whether they remember the CW between visits, while some PwD do remember the CW and actively look forward to their visits.

The service provides much needed relief for the primary FC, who often has very little other support of this calibre. The FC benefits from improved mood, increased socialisation, and reduced isolation. Since the FC can leave the home during DCAH, they get a break from the full-time responsibility of the caring role. When the FC achieves true psychological respite via DCAH, the PwD also benefits from having a FC that is in a stronger place psychologically.

A key outcome of DCAH is that it can help avoid or delay a move to a nursing home by creating a more sustainable caregiving situation in the home environment. Many believed that increased DCAH funding could reduce the prevalence of care home admission, as it would sustain the family carer in the caring role. This is important not only from an economic perspective but also since it aligns with the wishes of most people living with dementia and many family carers: to care for their loved one at home for as long as possible.

Section 5

References

SECTION 5: REFERENCES

Alzheimer Society of Ireland. (2023). *Day Care Services.* Alzheimer. https://alzheimer.ie/service/day-care-services/

Department of Health. (2014). *National Dementia Strategy.* https://www.gov.ie/en/publication/62d6a5-national-dementia-strategy/

Genio. (2016). *Community Supports Model for People with Dementia* (p. 24). Genio.

Health Service Executive. (2020). *Health Atlas Ireland: Estimated prevalence of dementia by gender 2020 and 2045* [dataset].

Health Service Executive. (2023). *Model of Care for Dementia in Ireland.*

Knapp, M., Thorgrimsen, L., Patel, A., Spector, A., Hallam, A., Woods, B., & Orrell, M. (2006). Cognitive stimulation therapy for people with dementia: Cost-effectiveness analysis. *The British Journal of Psychiatry,* 188(6), 574–580. https://doi.org/10.1192/bjp.bp.105.010561

Laird, E. A., McGurk, P., Reid, B., & Ryan, A. (2017). “Making the best of what we have”: The lived experiences of community psychiatric nurses, day centre managers and social workers supporting clients with dementia attending a generic day care service. *International Journal of Older People Nursing, 12*(4), e12157. https://doi.org/10.1111/opn.12157

Mossello, E., Baccini, M., Caramelli, F., Biagini, C. A., Cester, A., De Vreese, L. P., Darvo, G., Vampini, C., Gotti, M., Fabbo, A., Marengoni, A., Cavallini, M. C., Gori, G., Chattat, R., Marini, M., Ceron, D., Lanzoni, A., Pizziolo, P., Mati, A., … Masotti, G. (2023). Italian guidance on Dementia Day Care Centres: A position paper. *Aging Clinical and Experimental Research, 35*(4), 729–744. https://doi.org/10.1007/s40520-023-02356-4

National Institute on Aging. (2022, December 8). *What Is Dementia? Symptoms, Types, and Diagnosis.* National Institute on Aging. https://www.nia.nih.gov/health/what-is-dementia

O’Shea, E. (2007). *Implementing policy for dementia care in Ireland: The time for action is now.* Alzheimer Society of Ireland.

O’Shea, E., Keogh, F., & Heneghan, C. (2018). *Post-Diagnostic Support for People with Dementia and their Carers* [Report]. CESRD and NDO. https://www.lenus.ie/handle/10147/623091

O’Shea, E., Timmons, S., O’Shea, E., Fox, S., & Irving, K. *(2019). Respite in Dementia: An Evolutionary Concept Analysis. Dementia. https://journals.sagepub.com/doi/abs/10.1177/1471301217715325*

Reves, A., Timmons, S., Fox, S., Murphy, A., & O’Shea, E. (2018). *Dementia Diagnostic Services for Ireland: A literature review.* https://www.lenus.ie/handle/10147/623887

O’ Shea, E., O’ Shea, E., Timmons, S., & Irving, K. (2020). *The perspectives of people with dementia on day and respite services: A qualitative interview study. Ageing & Society, 40(10), 2215–2237. https://doi.org/10.1017/S0144686X1900062X*

Spector, A., Thorgrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M., & Orrell, M. (2003). Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: Randomised controlled trial. *The British Journal of Psychiatry, 183*(3), 248–254. https://doi.org/10.1192/bjp.183.3.248

The Alzheimer Society of Ireland. (2021). *Evaluation of Day Care at Home for The Alzheimer Society of Ireland.*

Tretteteig, S., Vatne, S., & Rokstad, A. M. M. (2016). tad, A. M. M. (2016). The influence of day care centres for people with dementia on family caregivers: An integrative review of the literature. *Aging & Mental Health, 20*(5), 450–462. https://doi.org/10.1080/13607863.2015.1023765

Tretteteig, S., Vatne, S., & Rokstad, A. M. M. (2017). *The influence of day care centres designed for people with dementia on family caregivers – a qualitative study. BMC Geriatrics, 17(1), 5. https://doi.org/10.1186/s12877-016-0403-2*

Western Alzheimers. (2023). Our Services – Western Alzheimer – *Sharing the Care.* https://westernalzheimer.ie/our-services/

World Health Organization. (2023, March 15). *Dementia: Key Facts.* https://www.who.int/news-room/fact-sheets/detail/dementia

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Section 6

Appendices

SECTION 6: APPENDICES

APPENDIX A:

PPI Expert Advisory Committee

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