



Performance Audit: Assisting Individuals with  
Dementia and their Caregivers within the Community

April 2022



Performance Audit  
Assisting Individuals with Dementia and their  
Caregivers within the Community

Report by the Auditor General  
April 2022

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## List of Abbreviations

AACC	Active Ageing and Community Care
CEO	Chief Executive Officer
CG	Clinical Geriatrician at the Karin Grech Rehabilitation Hospital
CN	Clinical Chairman in the Department of Neuroscience
CP	Clinical Chairman in the Department of Psychiatry
CRPD	Commission for the Rights for Persons with Disability
CSA	Ċentru Servizz Anzjan
DIT	Dementia Intervention Team
DPH	Department for Policy in Health
GDPR	General Data Protection Regulation
GP	General Medical Practitioner
HA	Housing Authority
ISCD	Income Support and Compliance Division
MDH	Mater Dei Hospital
MDS	Malta Dementia Society
MFH	Ministry for Health
MHS	Mental Health Services
MSCA	Ministry for Senior Citizens and Active Ageing
MSFC	Ministry for Social Justice and Solidarity, the Family and Children’s Rights
NAO	National Audit Office
NGO	Non-Governmental Organisation
PC	Policy Consultant
PCDC	Paul Cuschieri Day Centre
POYC	Pharmacy Of Your Choice
PPP	Public-Private Partnership
RHKG	Karin Grech Rehabilitation Hospital
SVP	Saint Vincent de Paul Long Term Care Facility
WHO	World Health Organisation

# Executive Summary

The Dementia Intervention Team (DIT) is received well by its service users but needs to further expand its visibility to reach more clients. Implementation of National Dementia Strategy objectives registered good progress so far.

## Why this study?

The National Dementia Strategy (2015-2023), amongst others, accentuates the need to provide adequate community support services for people with dementia. Central among these services is the Dementia Intervention Team, intended to serve as a point of reference for these individuals. NAO resolved to carry out a performance review to assess the extent of implementation of the dementia strategy community objectives, with particular emphasis on the DIT's operations.

## What NAO Recommends

NAO primarily recommends that the DIT's operation is extended to reach as many people diagnosed with dementia as possible. This can be achieved if the Unit further widens its visibility of potential service users, principally through enhanced communication systems with other related stakeholders. NAO also encourages the involved stakeholders to invest the necessary time and effort to give due consideration to the recommendations in this report.

## NAO's Key Observations

This Office acknowledges that the DIT (the setting up of which is one of the national dementia strategy objectives) is being received generally positively by its clients and perceives the establishment of this team as one of the central building blocks in the implementation of the objectives within the dementia strategy which relate to community support services.

However, this Office also considers the current DIT's active case load of around 600 clients as low when compared to the projected number of approximately 6,000 people with dementia living in the community. Even if not all people diagnosed with dementia would necessarily require intensive following or support by the DIT, NAO believes that the Unit should have as much visibility as possible on dementia cases in Malta so that it can have a wider understanding of the local situation and better identify potential clients who would benefit from its structured services. Notwithstanding, even if this Office is of the opinion that the DIT should be a larger operation than it currently is, it also acknowledges that the Unit cannot reasonably absorb a significant increase in its case load if its resources are not proportionately augmented.

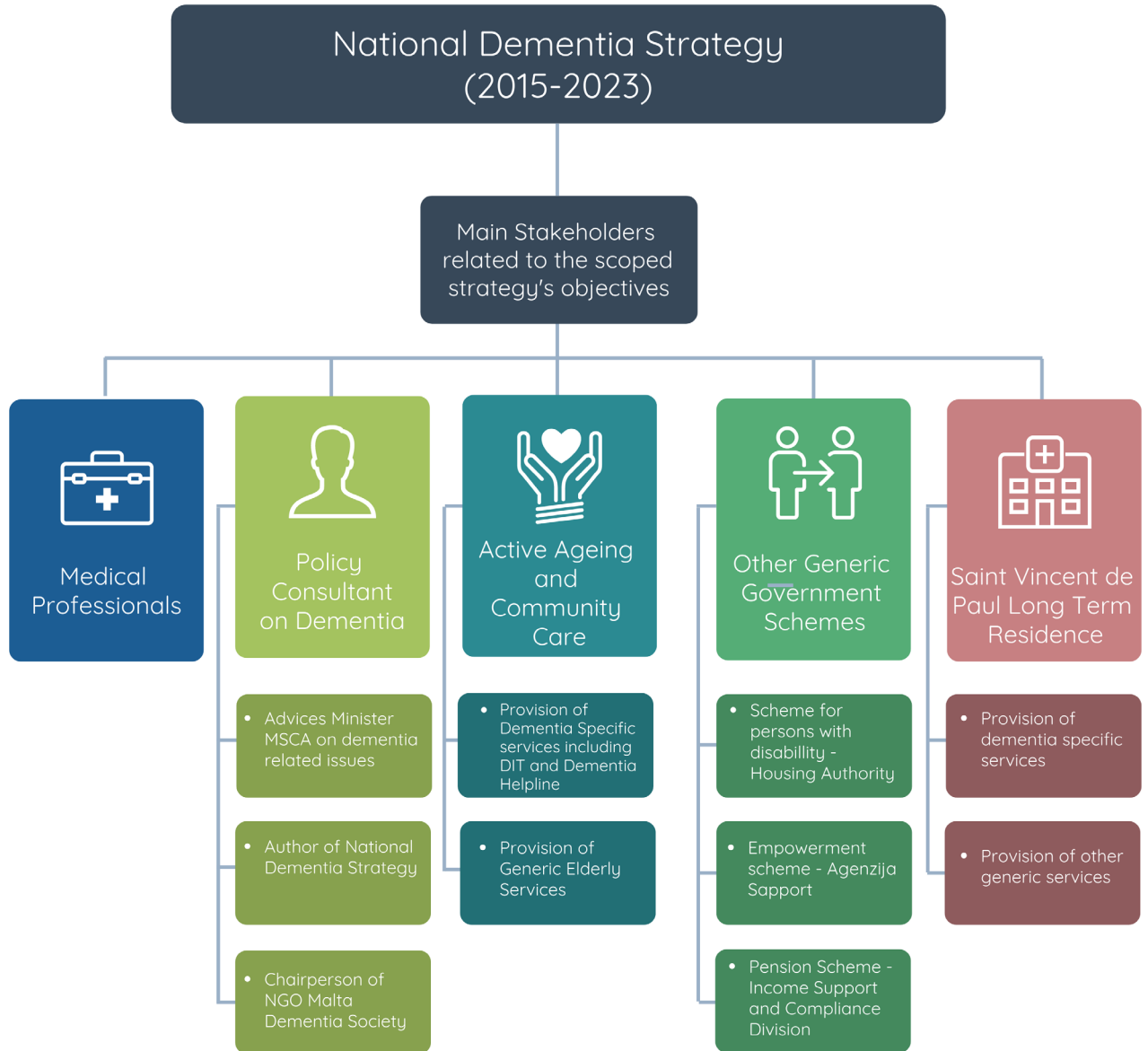
As dementia is a multi-faceted condition which heavily effects the individual's medical and social aspects, this Office feels that there should be an effective communication and data sharing system between the various government entities responsible to deal with different aspects of the condition. This would be of paramount importance for a seamless delivery of service. To this end, the identified apparent shortcomings in inter-stakeholder communication are of significant concern to the NAO.

This Office also observed that, besides a number of specialised services, the majority of services that are being offered to people with dementia by the Active Ageing and Community Care (AACC) are generic. While NAO does not contend the benefits which can still be reaped from a generic service, it still believes that dementia clients may have exigencies which would be best addressed through a specialised service and delivered through individuals who have been provided with related training.

This notwithstanding, NAO positively notes that the majority of the dementia strategy objectives which relate to community living have been fully implemented or registered significant progress in their implementation. Most notably, this Office acknowledges the opening of two additional dementia activity centres and launching of two night shelters, even if it has reservations on whether these are sufficient to be considered as nation-wide initiatives.

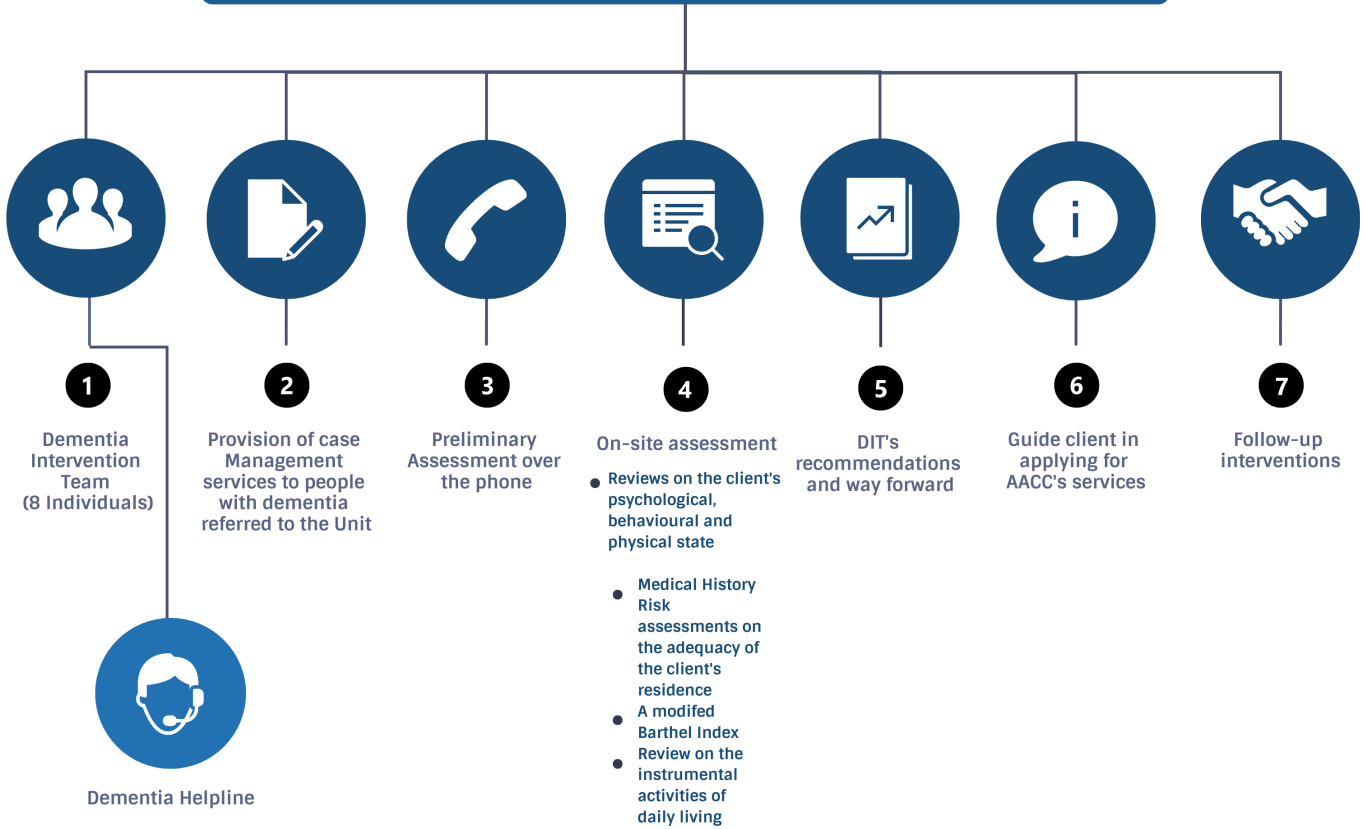


## Main Stakeholders in NAO’s Performance audit and their roles related to Community Care Services

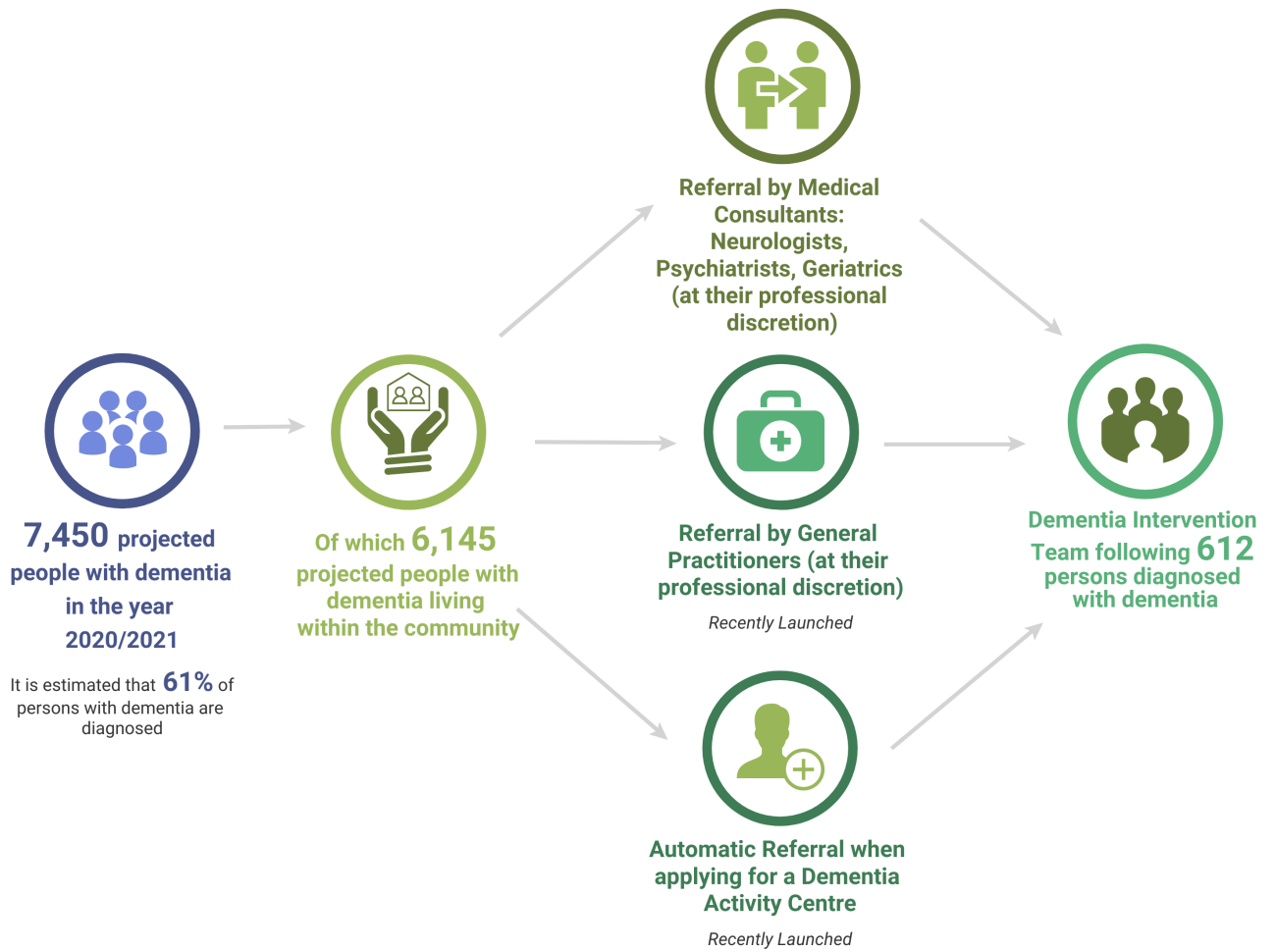




## Role of the Dementia Intervention Team



# DIT Referral Process



# Chapter 1 | Introduction

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**This introductory chapter lays out the National Audit Office’s rationale for embarking on this study, contextualises the audited area and presents a brief overview on the main stakeholders. It then proceeds to lay out the study’s overall scope, objectives, adopted methodology and limitations. A synopsis of the report’s chapters follows.**

## 1.1. Why this study?

1.1.1. A 2012 study entitled ‘Dementia in Malta: new prevalence estimates and projected trends’ (Scerri & Scerri, 2012), projected that approximately seven thousand people in Malta would have dementia in the year 2020. It is also estimated that 80% to 85% of people with dementia would still be living within the community and not in residential care.

1.1.2. The National Dementia Strategy – “Empowering Change”<sup>1</sup> was launched in 2015 and was set to be implemented over a number of years up till 2023. While this strategy covers the numerous facets of this socio-medical challenge, it accentuates the need to provide adequate community support services so that individuals with dementia can remain active within the community, thereby delaying institutionalisation for as long as possible. Central among these community-based services, is the proposal for the establishment of a Dementia Intervention Team (DIT), intended to serve as a point of reference and community support for individuals with dementia, their caregivers and family members.

1.1.3. In view of the above, the National Audit Office (NAO) resolved to carry out a performance review to assess the extent of implementation of the dementia strategy objectives which are related to community-based services, with particular emphasis on the operation of the DIT.

## 1.2. Background Information

### What is Dementia?

1.2.1. The World Health Organisation (WHO) defines dementia as a syndrome which is generally of a chronic or progressive nature, and that leads to deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from the usual consequences of biological ageing. WHO further reports that dementia is currently the seventh leading cause of death among all diseases and one of the major causes of disability and dependency among older people worldwide. Dementia has considerable physical, psychological, social and

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<sup>1</sup> The National Dementia Strategy can be freely downloaded in full from: <https://www.um.edu.mt/library/oar/handle/123456789/27845>

economic impacts, not only for people living with dementia, but also for their carers, families and society at large. This notwithstanding, WHO warns that there is often a lack of awareness and understanding of dementia, resulting in stigmatisation and barriers to diagnosis and care. Even though there is currently no treatment available to cure dementia, much can be offered to support and improve the lives of people with dementia, their carers and families. Amongst others, WHO lists the importance of optimising physical health, cognition, activity and well-being, while also providing information and long-term support to carers as the primary goals of dementia care.

### Benchmarking the National Dementia Strategy

1.2.2. In 2018, Alzheimer Europe<sup>2</sup> conducted a comparative exercise on the delivery objectives of different national dementia strategies in Europe (including that of Malta) and published its findings in the ‘Dementia in Europe Yearbook 2018’. Table 1 below presents an overview of whether different national strategies included delivery requirements related to a number of considerations.

Table 1: Comparison of National Dementia Strategies on multiple fronts

	Implementation	Human rights	Legal matters	Diagnosis	Post Diagnostic Support	Coordinated care	Residential & long-term	Acute & hospitals	End-of-life	Treatment & medication	Training & workforce	Support for carers	Prevention	Dementia Friendly Communities	Public awareness	Research infrastructure	Routine data	Technology
Malta	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Austria				✓		✓		✓			✓	✓			✓	✓		
Belgium (Flanders)	✓	✓		✓	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cyprus	✓	✓		✓		✓		✓	✓	✓	✓	✓		✓	✓	✓		✓
Czech Republic	✓			✓		✓				✓	✓	✓	✓		✓	✓	✓	
Denmark	✓			✓		✓		✓		✓	✓	✓		✓		✓		
Finland	✓	✓		✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓		✓
France		✓		✓		✓			✓	✓	✓	✓	✓	✓	✓	✓		
Germany	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Greece	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Ireland	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Israel	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓
Italy	✓			✓		✓				✓	✓	✓	✓	✓	✓		✓	✓
Luxembourg	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓				✓
Netherlands						✓								✓			✓	
Norway	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓	✓		✓	✓	
Portugal	✓			✓		✓			✓	✓	✓	✓			✓	✓		✓
Slovenia	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓	
Spain		✓	✓	✓		✓		✓		✓	✓	✓	✓	✓	✓	✓		
Switzerland	✓	✓		✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
UK (England)	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓
UK (N. Ireland)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓	✓	✓	✓
UK (Scotland)	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓	✓	✓
UK (Wales)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓

Adapted from the Dementia in Europe Yearbook 2018

<sup>2</sup> Alzheimer Europe is the umbrella organisation of 37 national Alzheimer's associations from 33 European countries.

- 1.2.3. This Office positively notes that the local dementia strategy compared well with other European countries, setting ambitious requirements in the large majority of areas. Insofar as care and initiatives for clients living in the community are concerned, the deliveries set in the local strategy also performed very well as, amongst others, they set requirements for dementia care at home, dementia activity centres, respite for caregivers and night-time shelters. Principally, however, NAO draws attention to the comparative study's finding that the Maltese National Dementia Strategy was distinct from others in its proposal to establish a multi-disciplinary DIT, intended to provide information and care coordination to their clients. As will become evident in subsequent parts of this audit report, this strategy objective takes central importance in NAO's scope of work.

### Implementing the local Dementia Strategy

- 1.2.4. The National Dementia Strategy's primary objective is to implement a number of measures in the various areas of dementia management and care with the overarching aim of enhancing the quality of life for individuals with dementia, their caregivers and family members. While this strategy tackles the multiple aspects and considerations surrounding this issue, this audit focuses on section 6.3 of the strategy in question which lays out objectives focused specifically on community care services.
- 1.2.5. Multiple governmental entities are involved in the implementation of scoped strategy requirements. For the purpose of this study, the following are the main stakeholders who are assigned with the responsibility of fulfilling the aforementioned objectives.

#### *I. Active Ageing and Community Care*

The Active Ageing and Community Care (AACC) presently falls under the Ministry for Senior Citizens and Active Ageing (MSCA) and offers a number of services to support the elderly. These initiatives include those intended to assist clients to continue living in the community through support in one's own residence and according to one's particular needs. These services feature those which are specifically intended for people with dementia as well as others which, though generic, are still offered to such clients. Each service is managed and monitored by a respective service manager within AACC.

#### *II. Dementia Intervention Team*

As already stated, the creation of the DIT is one of the National Dementia Strategy's objectives. It operates as one of the services offered to people with dementia by the AACC, and consequently falls under the latter's responsibility. This Unit was set up in 2016 and, as will be explained better in Chapter 2 of this report, its role is to support and guide persons diagnosed with dementia who are still residing within the community thereby ensuring that they have a good quality

of life, remain active and delay institutionalisation. The Unit endeavours to accomplish this through the design of multi-disciplinary care plans for their clients, as well as through guiding persons with dementia and their respective informal caregivers to make use of services which are currently being provided by the government.

### *III. Policy Consultant on Dementia*

The role of the Policy Consultant (PC) is to advise the Minister MSCA on matters related to dementia and is also the author of the National Dementia Strategy. PC's role is purely of an advisory nature and is therefore not bestowed with any executive powers. PC also holds the position of Chairperson of the Malta Dementia Society (MDS) which is the only local Non-Governmental Organisation (NGO) for persons with dementia, their carers, families and friends.

### *IV. Saint Vincent de Paul Long Term Care Facility*

Saint Vincent de Paul Long Term Care Facility (SVP), amongst its other roles and responsibilities, provides dementia specialised care to people with dementia who have challenging behaviour but who still reside within the community. More specifically and for the purpose of this study, SVP caters for dementia clients who, while still enjoying good physical ability, tend to experience wandering behaviour. Services offered by SVP intended for people with dementia who still live in the community include a day dementia activity centre as well as residential respite. It also organises dementia training for both formal and informal carers.

## **1.3. Audit scope and objectives**

- 1.3.1. This audit was scoped to focus on the objectives as laid out by the National Dementia Strategy which relate to services offered within the community. This means that considerations surrounding the phases prior to diagnoses as well as those pertaining to the period following admittance to long-term or palliative care, have been omitted from this study.
- 1.3.2. As already stated, this audit is scoped to cover section 6.3 of the dementia strategy which lays down the objective calling for the development of *“community care services that meet the needs of individuals with dementia, their caregivers and family members through:*
  - I. providing easy access to a range of community services
  - II. ensuring that dementia services strive to integrate individuals with dementia within the community
  - III. providing the necessary support through a holistic approach with the aim of improving the quality of life.”

1.3.3. The strategy proceeds to present 18 deliveries with which to address the above. This audit primarily focuses on delivery 'e' which calls for the setting up of the DIT. As the Dementia Helpline is managed by the DIT, its corresponding delivery (f) is also included in the main analysis. Progress on the rest of the deliveries was still assessed in this study, however, given that the National Dementia Strategy has up till 2023 to be fully implemented, this assessment is considered as an interim, and corresponding verifications were kept at a higher level than the main analysis.

1.3.4. Unless otherwise stated, considerations delved into in this report are as at December 2021. This study assesses performance in the implementation of the objective deliveries as scoped from the National Dementia Strategy. Financial considerations on the operations and developments in question have been omitted.

1.3.5. This audit has two primary objectives, namely:

- I. To evaluate the efficiency and effectiveness by which the DIT conducts its operations,
- II. To gauge interim progress on the implementation of the rest of the objective deliveries under section 6.3 of the National Dementia Strategy.

## 1.4. Methodology

1.4.1. To better understand this subject area, the audit team conducted preliminary desk research during the initial stages of this study. This phase included, amongst others, the review of local and foreign reports, including media articles and publications. At the initial stages of this exercise, the audit team also held meetings with the former Commissioner for Mental Health, as well as with the Commissioner for the Elderly to better contextualise the audit area.

1.4.2. After gathering insight on the main issues at hand and following preliminary meetings with the main auditee, the audit team was able to determine the main audit question and subsequent paths of analysis through an issue-analysis process. This laid out the route that the audit team pursued for the successful conclusion of this exercise.

1.4.3. Throughout its review, the audit team principally adopted qualitative analysis. A series of semi-structured interviews were held mainly with AACC's management and DIT. Other meetings were also held with PC, SVP, the Social Care Standards Authority, Department for Policy in Health (DPH), Pharmacy Of Your Choice (POYC), Department of Neuroscience at Mater Dei Hospital (MDH), Mental Health Services (MHS) and Rehabilitation Services at Karin Grech Rehabilitation Hospital (RHKG). As the audit team better understood the area at hand, it compiled lists of required documentation which, after being requested from and received by auditees, were analysed accordingly mainly for verification purposes.



- 1.4.4. The audit team also carried out site visits at the SVP dementia activity centre, as well as those at Mtarfa and Safi, even if the latter two were still not operational during the fieldwork stage, with the Safi centre still under construction and the Mtarfa centre still being finished.
- 1.4.5. As an added layer of verification, NAO designed and administered a questionnaire, intended to solicit feedback from informal caregivers on AACC services availed of by people with dementia. To this end, a sample of respondents was required, and from its work, the audit team found that, though not comprehensive, the most extensively populated compilation listing people who are diagnosed with dementia is retained by the DPH (section 2.5.11 refers). This compilation, referred to as the Dementia Register, is populated through the same Schedule V information as used by the POYC scheme, even if DPH and POYC retain information on each client to different extents. However, despite NAO's request and subsequent reminders for a copy of this register, this was never forwarded by DPH, even if this request was agreed to during meetings with this Office. Consequently, the audit team could not extract the required sample of respondents for its questionnaire through this avenue.
- 1.4.6. Due to the above, this Office resorted to put together a combined indicative sample through multiple sources. Specifically, the audit team solicited lists of clients from DIT and SVP Dementia Activity Centre and proceeded to select a sample of potential respondents from each. These were then approached by the audit team via telephone calls, with the team asking each question in the questionnaire and recording corresponding answers on a central electronic database. In addition, NAO published an advert on social media for any eligible prospective respondents (that is, informal caregivers to people with dementia who still live within the community) to partake in this questionnaire. This advert was also shared by the NGO MDS on its own social media. This advert was accompanied by a link which led participants to an online electronic form of NAO's questionnaire. Once filled-in, results were automatically recorded in a central database. As a result of these initiatives, NAO managed to obtain feedback from an indicative sample totalling 73 respondents.
- 1.4.7. The findings of this study, together with this Office's observations and recommendations were presented to the audited entity for its feedback prior to the publication of this report.
- 1.4.8. The NAO conducted this performance audit in accordance with the Standard for Performance Auditing, ISSAI 3000.

## 1.5. Limitations to the study

- 1.5.1. This study was carried out during the COVID-19 pandemic, and this presented certain challenges to the audit team. In particular, operations of the audited entities were not progressing normally and therefore the audit team could not observe first-hand certain interventions and operations being conducted in a manner which would better represent 'normal' operations. In addition, information and data, particularly on the usage of services, for the years 2020 and 2021 were

heavily influenced by clients' adaptation to the pandemic (mainly reluctance to use services). In view of this, in certain instances the audit team had to refer to information from 2019 (pre-pandemic) to create an indicative reflection of normal operations.

- 1.5.2. As will be discussed in detail throughout this report, information on this audit area was found to be kept in silos, with each department or entity generally retaining information that is relevant to it in isolation to others. While sourcing information from multiple sources is normal for any audit, the audit team felt that information on this area was kept particularly fragmented, with ease of access varying from one source to another. This obviously presented challenges to the audit team's work.
- 1.5.3. The audit team also reports that there were instances in which information being received from audited entities could have been clearer and more comprehensive first time, particularly insofar as new developments were concerned. This inevitably impacted on the smooth running of the assignment.
- 1.5.4. Given that, as already mentioned in section 1.4, NAO was not forwarded with DPH's Dementia Register, it had to piece together an indicative sample of respondents for its questionnaire through multiple sources, including by publishing an open invitation for eligible respondents through social media. This meant that the audit team had very limited control on the composition of its respondents' sample and that it could not conduct meaningful stratification. As a result, some of the questionnaire's queries did not attract replies from respondents in sufficient numbers for the resulting aggregate feedback to hold weight. In addition, despite the audit team's best efforts to present the questionnaire's queries in a manner in which they could be clearly interpreted by respondents of all ages and hailing from different academic backgrounds, it became evident to the audit team that some respondents were not clear or consistent in their replies. In such instances, and where reasonable, the audit team used its professional judgement on how to report on the received feedback. In cases in which the given replies departed significantly from the intended question, the audit team opted to omit them from its analysis.

## 1.6. Report structure

- 1.6.1. **Chapter 1** – This introductory chapter lays out the NAO's rationale for embarking on this study, contextualises the audited area and presents a brief overview on the main stakeholders. It then proceeds to lay out the study's overall scope, objectives, adopted methodology and limitations. A synopsis of the report's chapters follows.
- 1.6.2. **Chapter 2** – This chapter reviews the progress on the two strategy objectives which are directly related to the DIT. As this Unit is NAO's main auditee, these objectives merited a more in-depth analysis and are being reported upon independently from the rest.

- 1.6.3. **Chapter 3** – This Chapter presents NAO’s observations on progress registered in the implementation of those objectives within the Dementia Strategy which are directly related to the community living. Each objective is assigned, by NAO, with an implementation indicator and is then discussed in detail.
- 1.6.4. **Chapter 4** – This Chapter presents other salient findings on dementia community services which have emerged from the questionnaire administered by NAO. Besides feedback, which was specifically solicited through NAO’s queries, this chapter also highlights a number of recommendations which were put forward by the respondents themselves.
- 1.6.5. **Concluding Remark** – This report closes off with a concluding remark which sums up NAO’s overall opinion on the subject matter.

# Chapter 2 | The Dementia Intervention Team and Dementia Helpline

**This chapter reviews the progress on the two strategy objectives which are directly related to the Dementia Intervention Team. As this Unit is NAO's main auditee, these objectives merited a more in-depth analysis and are being reported upon independently from the rest.**

*Strategy Objective E: Develop a multi-disciplinary Dementia Intervention Team (coordinated by a Dementia Care Coordinator) which will serve as a point of reference and community support for individuals with dementia, their caregivers and family members in order for the family to easily access services according to their needs. Services for dementia will be integrated and work together to provide a holistic package of care to persons with dementia and their families.*

**Note:** Progress on this strategy goal was assessed on two fronts, namely the creation and operation of the Dementia Intervention Team (DIT) as well as on the effectiveness of communication between relevant stakeholders. NAO carried out its review on the Unit in question to evaluate whether different aspects of its operation could be enhanced to provide a better service. To this end, the following parts of this section will present NAO's verifications into DIT's processes. Discussions held in this respect with the Unit's officials and other stakeholders were substantiated through the review of hard copy case files as retained by the Unit for each client. Specifically, NAO chose a random sample of 20 case files out of DIT's list of active cases as at April 2021. Findings of this exercise will be reported throughout the following parts of this section. It is important to highlight that the audit team did not endeavour to assess the technical quality of interventions made by DIT with its clients. Rather, the following relates to administrative aspects of the Unit's operations. Finally, as already mentioned in Chapter 1, the audit team also administered a questionnaire with an indicative sample of informal caregivers. The most salient results of this questionnaire, which are relevant to this strategy objective, are integrated throughout this chapter to further substantiate the audit team's findings.

## **2.1. A Dementia Intervention Team was set up in fulfilment of Strategy Objective, and is received well by its clients**

**2.1.1.** In accordance with this strategy objective, the DIT was set up in 2016 with the primary aim of maximising independent living within the community for its clients. Active Ageing and Community Care (AACC) claims that, between its inception in 2016 and January 2022, the DIT has followed 1,823 unique cases from the clients' referrals, through to them being discharged. During meetings with NAO, DIT explained that its work with clients starts after a person who is diagnosed with dementia is referred to it by a medical consultant<sup>3</sup>. Consequently, DIT engages in the provision of case management services through a team of specialised personnel. These

<sup>3</sup> By the end of this audit exercise, GPs were also included as professionals who could formally refer a client to the DIT – discussed further in subsequent parts of this Chapter.

professionals' primary objective is to set up multi-disciplinary care plans for their clients (who would be still residing in the community) so as to ensure that the latter benefit from good quality of life, thereby delaying institutionalisation. DIT officials further elaborated that, in providing the abovementioned service, they adopt a partners in care approach, where there is a collaborative process between the team, the person with dementia and the respective informal caregiver.

- 2.1.2. As will be further elaborated upon in subsequent parts of this chapter, DIT highlighted that, upon receiving a referral, an assessment is carried out by the Unit so that it maps out the needs of its client and formulates a care plan. Following this, the client is informed of and guided accordingly to apply for services provided by the State, which could be of benefit and assistance for the person with dementia to continue, as much as possible, to reside within the community. NAO was also informed that the DIT acts as the focal point between their clients and the provision of these services. Subsequently, the Unit would monitor their client's situation and reassess their care plan where needed, up till the point in which the client is either admitted to long-term residential care, or if he/she passes away.
- 2.1.3. Through the administered questionnaire (as mentioned in Chapter 1), the audit team ultimately observed that the large majority of respondents who are DIT clients are satisfied with the Unit's services and are of the opinion that the DIT is fulfilling the clients' and caregivers' needs and requirements.
- 2.1.4. This notwithstanding, during meetings with the Policy Consultant (PC) on dementia, the audit team was informed that the original intention of the Dementia Strategy was for five DITs to be set up (including one in Gozo), for a better provision of service throughout the country. PC however acknowledged that, as will be discussed further in section 2.4, constraints in the availability of professionals in the local labour market has made this original target practically unachievable and consequently, this original target had to be revisited.
- 2.1.5. However, during discussions with the audit team, AACC asserted that, given that there is currently no waiting list for DIT's services, it feels that there is no need for additional teams to be created. AACC also asserted that it uses quantifiable and realistic measures of the demand for services in the community by analysing the request for a particular service, its trends, and projected future demands. When the audit team asked for copies of such analysis, however, AACC only furnished this Office with records of past usage of DIT's services (specifically new cases and discharges) which, in the audit team's opinion are not sufficient to substantiate the assertions made by AACC.

## NAO Observation

2.1.6. While NAO takes note of the strategy's original target of more DITs to be set up, it understands that this had to be revisited due to supply constraints in the local labour market. This Office therefore acknowledges that a DIT was set up in fulfilment of this strategy objective and notes that it is being received positively by its clients. NAO perceives the establishment of this team as one of the central building blocks in the implementation of the objectives within the dementia strategy which relate to community support services.

2.1.7. This notwithstanding, NAO disagrees with AACC's stated view that no additional DITs are required as no waiting lists currently prevail. This Office contends that waiting lists, in isolation, are not a sufficient indication of whether an expansion in service coverage is required or otherwise, as lack of demand may be caused by other considerations, such as insufficient awareness on the service's existence. This concern is compounded by the fact that, when asked to do so, AACC did not forward to NAO copies of documented projections which map out future demand.

## 2.2. Most people diagnosed with Dementia are not referred to the DIT

### Medical Professionals refer diagnosed patients to the DIT at their discretion

2.2.1. During meetings with various stakeholders, it was explained that persons diagnosed with dementia could only be referred to the DIT by medical consultants<sup>4</sup>. These professionals would hail from one of three professions, namely neurology, geriatrics and psychiatry, depending on each individual case. Through its fieldwork, however, the audit team noted that the referral of an individual diagnosed with dementia to DIT is not an obligation and, consequently, this referral occurs solely at the discretion of the prescribing consultant and only if the patient is willing.

2.2.2. In order to substantiate this, the audit team held individual meetings with the Clinical Chairman in the Department of Psychiatry (CP), Clinical Geriatrician at the Karin Grech Rehabilitation Hospital (CG), and the Clinical Chairman in the Department of Neuroscience (CN). When queried on the referral system of dementia patients to the DIT, all interviewed consultants agreed that not all persons diagnosed with dementia are referred to the Unit and that the decision to make this referral is entirely up to the consultants' professional judgement. Specifically, these professionals indicated that a written referral to the DIT is offered to a patient who, in their professional opinion, would require this service, particularly if he/she or his/her caregiver would be facing challenges to manage daily life within the community. This being said, CN also indicated that members of this profession need to be briefed on what services are offered by

<sup>4</sup> As already mentioned this system has changed to include referrals from GPs

DIT as some are not even aware that a DIT referral form exists. In fact, NAO noted that the majority of the 17 questionnaire participants who are not DIT clients stated that they were never referred to the Unit or that they were never informed about it. NAO also noted from the administered questionnaire that a higher occurrence of referrals was observed for moderate and severe cases as opposed to mild ones.

2.2.3. The audit team was further informed that, should an individual be referred to the DIT, it would be up to the patient or his/her caregiver to actually file the application (which includes the medical practitioner's referral) with the Ċentru Servizz Anzjan (CSA). CSA would in turn forward this application to the DIT.

2.2.4. In order to trace this referral process, the audit team tested the sampled DIT case files. NAO however noted that formal templated DIT application forms were only found in 3 case files out of 20. When queried on this by the audit team, DIT replied that there are instances in which the template referral documentation is not filled in, but rather clients would be referred through emails. In fact, through its review the audit team noted that in an additional 7 cases from the reviewed files, copies of ad hoc emails referring the person with dementia to the DIT were found from entities such as the Dementia Helpline (discussed further in subsequent parts of this chapter), Karin Grech Rehabilitation Hospital (RHKG) and Mental Health Services (MHS). NAO also noted that the remaining 10 cases did not have any referral documentation, through the DIT template or otherwise, recorded in the file.

### DIT visibility of cases within the community is very limited

2.2.5. When enquiring with PC on what the original intention of this strategy goal was, the audit team was informed that this objective was designed with the idea for all people diagnosed with dementia (irrespective of the condition's stage) to be referred to the DIT so that this Unit may guide them accordingly. The importance of this goal is highlighted through the administered questionnaire, in which the audit team observed that only a third of the respondents felt that they were adequately supported upon their diagnoses.

2.2.6. PC however further acknowledged that there are major challenges in this respect. In particular, PC indicated that the limited human resources at DIT (issue discussed in further detail in subsequent parts of this chapter) may be impeding medical practitioners from referring more cases, particularly the less severe ones. On this latter issue, most of the interviewed medical consultants agreed with this assertion. However, although they acknowledge the importance of DIT's work as a service which complements their medical interventions and understand the Unit's challenges due to its limited resources, they also expressed concern on the shortage in their own support structure. This, amongst others, presents challenges on administrative work, of which the referral process forms part.



- 2.2.7. NAO notes that this situation could be significantly contributing to reduced visibility by DIT on the total number of people living with dementia in the Maltese community. In fact, during meetings with PC, the latter indicated that, while no official total number of persons with dementia in Malta is available, based on the study he conducted in 2012 he projects that approximately 7,450 people in Malta would have dementia in the year 2021. PC further explained that of these, 80% to 85% would be still living within the community. This would mean that, according to these projections, approximately 6,145 people with dementia were living in the Maltese community in 2021. Even if PC directed the audit team to a study which showed that, in 2018, it was estimated that only 61% of people with dementia were diagnosed in Malta, NAO still notes that this is in stark contrast to the limited 612 cases that the DIT were actively following as at August 2021 (discussed further in point 2.4.3).
- 2.2.8. However, when NAO enquired with DIT whether it agrees that all people diagnosed with dementia are referred to it, the latter expressed apprehension. While NAO acknowledges DIT's justified concern that an increase in referrals would require more investment in the Unit's human resources (which issue will be discussed further in section 2.4) it still enquired whether, in principle, AACC and DIT agree to such a measure. In reply however, AACC asserted that they do not agree with this idea as they are of the opinion that even at referral stage, a needs-based approach should be adopted.
- 2.2.9. While this Office disagrees with AACC's stance, it nonetheless acknowledges that DIT can never force its services on any prospective client and, consequently, any person with dementia who refuses to engage with the Unit can never be adequately followed. In fact, from its questionnaire, the audit team noted that six out of the 17 participants indicated that they do not use DIT's services due to a refusal from the client's or caregiver's part.
- 2.2.10. During the latter stages of this audit, NAO was informed by the DIT that the process by which clients are referred to it has been revised, and a new referral process was made available to the public in August 2021. More specifically, referrals to the DIT could now be made by a general medical practitioner (GP) rather than solely through a medical consultant. In addition, the audit team was further informed that as at mid-September 2021, any client who files an application with CSA to make use of a dementia activity centre (discussed in Chapter 3), is being automatically referred to the DIT. In fact, DIT affirmed that, as at time of writing, 35 individuals were already referred to the Unit through this new process.

## NAO Observations

- 2.2.11. As the referral from a medical practitioner is a pivotal point for the Unit to commence its service provision to its clients, NAO is of the opinion that finding only 3 such formally documented referrals on DIT's own template application form from the 20 reviewed files is not optimal. This Office feels that, as there is a formal application through which a prospective client can apply for DIT's services, this form should be invariably used to preserve homogeneity of



documentation. To this end, NAO is of the opinion that, while accepting referrals through multiple channels is commendable to ensure wider catchment of potential clients, means of documenting referrals other than DIT's own template (as identified in the review of forwarded case files) impinges on this homogeneity.

- 2.2.12. While commending the shift to expand sources of referral to include GPs rather than limiting them solely to medical consultants, NAO disagrees with AACC's stated opposition to the principle of having as many diagnosed individuals referred to the DIT as possible, and perceives that a case load of 612 cases is low when compared to the projected number of people living with dementia in the community. Even if not all people diagnosed with dementia would necessarily require intensive following or support by the DIT, NAO believes this situation invariably leaves the Unit with much reduced visibility on the broader picture, possibly inhibiting it from identifying potential clients who need such structured assistance but, for one reason or another, have not been referred. Notwithstanding, NAO appreciates that an increase in case load will present significant challenges to the Unit's limited resources (issue discussed in further detail later in this section).

## NAO Recommendations

- 2.2.13. NAO strongly urges DIT and AACC to ensure that future demand is pro-actively mapped out so that any eventual shortage of supply in its services are identified at the earliest and plans for their address are made in time.
- 2.2.14. While this Office does not contend the merits of DIT accepting new clients even through ad hoc emails, it nonetheless recommends that the Unit invests more attention towards the retention of homogeneity in the documentation of referrals as this would better preserve the audit trail of the Unit's work.
- 2.2.15. As DIT's case load is perceived as low by this Office when compared with the projected number of people living with dementia in the community, NAO strongly urges the Unit to spearhead more initiatives intended to increase referrals to it so that it may be of service to as many prospective clients as possible. Such initiatives could include the setting up of a communication and data sharing system (which would preferably include automated elements) between DIT and medical practitioners, so that the Unit may receive information on potential new clients upon the latter's diagnoses. Naturally, this needs to be done with the full requirements of the General Data Protection Regulation (GDPR) in mind while respecting clients' free will. NAO also understands that any increase in the Unit's case load would require an increase in the human resource capacity for its address.

## 2.3. Documentation in DIT case files could be kept in a more standardised manner.

### DIT refers clients to AACC services following initial assessments

- 2.3.1. During meetings with NAO, DIT explained that following receipt of the referral, members from the team will contact either the person with dementia or the identified informal caregiver. A preliminary assessment is made by telephone to identify the main concerns and challenges of the respective client. Following this, DIT officials (generally a practice nurse), will conduct an on-site visit at the client's residence, in which an initial formal assessment is carried out. This assessment is intended to establish the extent to which the condition is affecting the client's and the informal caregiver's daily life. Through this process, an 'assessment for community services form' is filled in, which form amongst others includes reviews on the client's psychological, behavioural, and physical state; medical history; risk assessments on the adequacy of the client's residence; a Modified Barthel Index<sup>5</sup>; and a review on the instrumental activities of daily living. Following this review, DIT officials would put forward recommendations and devise a way forward.
- 2.3.2. As part of their assessment, DIT officials would also enquire whether the client is already making use of any community care and services administered by the AACC (Table 2 refers) so that due note is taken. At this stage, should DIT note that the client or his/her caregiver could benefit from more of these services, the latter would be guided and encouraged to apply accordingly. As will be discussed in subsequent parts of this report however, with the exception of the DIT and the dementia helpline, dementia activity centres, 'telecare on the move' and the two dementia night shelters<sup>6</sup>, these services are generic in nature and are not technically tailored for people with dementia. This notwithstanding, this Office acknowledges that even if not specifically intended for people with dementia, these services are still of benefit to such clients and in fact, through its questionnaire, the audit team positively noted that the vast majority of respondents who are DIT clients highlighted that they were referred to various such services by the Unit.

<sup>5</sup> The Modified Barthel Index is an ordinal scale used to measure performance in activities of daily living.

<sup>6</sup> During the final stages of this study, two night shelters specifically intended for use by dementia clients were made operational. These will be discussed further in Chapter 3.

**Table 2: Services offered by AACC**

Dementia Intervention Team	Dementia Activity Centre	Active Ageing Centres
Respite at Home	Residential Respite	Night Shelter
Home Help Service	Carer at Home Scheme	Home Admission
Telecare+	Telecare on the Move	Telephone Rent Rebate
Handyman Service	Meals on Wheels	Contenance Service
Domiciliary Nursing	Domiciliary Caring	Domiciliary Dietician Service
Social Work	Community Geriatrician	Podology
Physiotherapy	Occupational Therapy	Psychotherapy

Source: AACC Website

2.3.3. NAO’s review of the 20-file sample confirms that the process as explained above is followed by DIT at this initial stage of its work with a client. Specifically, the ‘assessment for community services forms’ were found in all the 20 files, with all of them bar one having the aforementioned information duly filled-in. It is to be noted that in the only case in which this form was not found to be filled-in, this was due to the fact that the client did not allow DIT to visit the place of residence.

### Most Care Plans for clients were not found in sampled DIT case files

2.3.4. On the other hand, during this same review the audit team observed that a detailed care plan or plan of action were only found in three case files, with 16 files featuring only brief notations on recommended actions. In one of the reviewed cases files, neither notations nor detailed plans were found.

2.3.5. Feedback on care plans from the administered questionnaire was mixed. Specifically, the audit team noted that out of the 56 respondents who are DIT clients, 36 indicated that, in one form or another, a care plan was devised by the Unit, 27 of whom further highlighted that they feel the care plan is adequate to the client’s needs. The remaining 20 DIT clients participating in this questionnaire could not recall that any such care plan or plan of action was prepared by the Unit. Of those who indicated that a care plan was prepared, 21 respondents stated that they are following this plan closely, while another six asserted that they are partially adhering to it.

## Formal Assessments on Caregivers not found in sample DIT case files

- 2.3.6. During meetings with NAO, DIT officials further explained that during the aforementioned initial assessment, observations are also made on whether the assigned informal caregiver is able to assume this responsibility or otherwise. During this process, should the caregiver be observed to be facing challenges to cope, DIT would direct him/her to services which may be of assistance, such as counselling and/or respite services (discussed in more detail in Chapter 3). NAO was informed that this process does not follow a recognised format, but DIT officials use their professional judgement to evaluate this factor.
- 2.3.7. While not contending the validity of this system, this Office still sought to determine whether this process is adequately captured in the case files. From its analysis however, NAO observed that such an assessment was not found to be documented in a structured manner throughout all reviewed files. Rather, the audit team found ad hoc brief notations in most of the client's files regarding the observations made by DIT's officials on the caregiver's situation (such as, whether the latter is observed to be suffering from an elevated level of stress or is coping with the situation) .

## DIT follows up clients through telephone interventions or house visits

- 2.3.8. During meetings with the audit team, DIT officials also highlighted that, following the aforementioned initial assessment and after assisting the client to apply for any applicable community care and services, the Unit proceeds to monitor each client as deemed necessary. More specifically, this Office was informed that, after the initial assessment, DIT would set a date for a follow-up intervention to be conducted, generally by phone. However, as the case manager provides the client with his/her respective direct contact number, it is possible for the client to reach out to the Unit before this date if he/she so wishes. As regards the latter assertion, NAO can confirm, through its questionnaire, that the majority of respondents who are DIT clients have indicated that there were occasions in which they actively initiated communication with the Unit, generally via phone or by email.
- 2.3.9. To trace this process, the audit team referred to the 20-file sample. In its review, NAO noted that in only two initial assessment forms out of the reviewed 20 files, was the date of the aforementioned follow-up telephone intervention found. This being said, all of the reviewed files showed that telephone interventions were made by the Unit subsequent to the initial assessment (with notations made during these interventions also being found) . It should also be noted that, in most of the reviewed files, there were instances in which DIT officials recorded when to contact their client again subsequent to these telephone interventions, even if these notations were not recorded consistently for all interventions listed in each case file. When queried by the audit team on this issue, DIT explained that appointments are currently being recorded in the officials' personal calendars. During the fieldwork stage of this report, NAO

was however further informed that the Unit envisages the eventuality that this information is incorporated in an online case management system that was being developed at the time. As at time of publishing of this report, this Office was informed that this system had been launched.

- 2.3.10. Through these telephone interventions, DIT officials would make use of their professional judgement to determine whether the client is either stable, thereby not requiring immediate attention (in which case a new date for the next contact by phone is set) or whether a full follow-up assessment (which would require another home visit) needs to be carried out. DIT explained that the need for a follow-up assessment would arise if a notable change in the client's needs is identified. Through the review of the 20-file sample, the audit team found more than one 'assessment for community services forms' in nine of the reviewed files, implying that full follow-up assessments in these cases were carried out.
- 2.3.11. From the administered questionnaire, NAO found that the majority of DIT clients (36) are satisfied with the Unit's follow-up process, while another ten stated that they were somewhat satisfied. Five of the respondents indicated that they are not satisfied with the DIT's follow-up process, with the remaining five not answering. This notwithstanding, NAO notes that only fifteen respondents out of the 56 clients felt that DIT's services in general could be rendered more efficient and effective. The majority of these fifteen proposed that there is scope for the DIT to make more frequent contact with them, either through telephone interventions or home visits.

## NAO Observations

- 2.3.12. This Office is concerned with the fact that multiple processes (such as care plans, DIT's assessment on caregivers, as well as planned dates for future follow-up interventions) are not formally and consistently documented in DIT's case files. This impinges on the retention of records which fully preserve an audit trail of the Unit's involvement in each case.
- 2.3.13. While NAO positively acknowledges the generally good feedback from the questionnaire's responses on DIT's follow-up process, it nonetheless highlights the perceived need from a segment of respondents that more communication is required.

## NAO Recommendations

- 2.3.14. NAO recommends that DIT takes more care in ensuring that all clients' details are consistently included in the case files to better preserve an audit trail of its interventions with each client. This Office augurs that the recent introduction of the new online management system should assist the Unit to ensure that all the required information is now being captured and a better audit trail is being preserved.

2.3.15. NAO encourages the Unit to ascertain that communication with its service users is maintained at a frequency which is deemed appropriate, both by the Unit itself as well as by the client. This should be given more attention particularly in the cases in which the client has severe dementia or is living with less than adequate support structure.

## 2.4. DIT's human resources complement is sufficient to cope with current number of referrals but will need to be augmented if case load increases

2.4.1. During meetings with NAO, DIT highlighted that the team is composed of eight individuals in total. These include the team's coordinator, an administrative clerk, four practice nurses specialising in dementia (who are also referred to as the case manager and who is each assigned with a specific region), and two occupational therapists.

2.4.2. NAO enquired with DIT whether it feels it is adequately resourced or otherwise. In reply, DIT officials stated that, with the current case load, the Unit's human resources are, as at time of writing, sufficient to cope even if some cases could be intensive and demanding.

2.4.3. As already stated, the Unit's case load as at August 2021 stood at 612 active cases (Table 3 refers). NAO notes that this implies that on average, every one of the four practice nurses deployed with the DIT has to follow approximately 150 active cases. During meetings with NAO, DIT officials explained that, ideally, each case manager would not be assigned more than 200 active cases and consequently, this confirms that current situation is considered to be manageable.

2.4.4. This notwithstanding, while the Unit's current complement may be sufficient to cope with the current case load, it is understood that an increase in the latter would automatically require an increase in the former. DIT officials however explained that increasing its specialised human resource complement is not an easy task, as the supply of such personnel is limited. As an example, NAO was informed that on multiple occasions, calls for applications for additional Occupational Therapists did not attract any successful applicants.

2.4.5. When enquiring whether a waiting list prevails for DIT clients to avail from the Unit's services, the latter replied in the negative. DIT explained that it is the Unit's policy to contact a new client within five working days from receipt of application and to set up a first appointment by not later than two weeks .

Table 3: DIT Caseload

	2019	2020	2021 (up to August 2021)
Number of new cases referred to DIT	304	241	288
Number of discharges	221	340	202
Current caseload at the end of the year	625	526	612

Source: DIT

- 2.4.6. In order to verify this, NAO requested the Unit to forward any database it retains that would show the date of referral as well as the date of its first intervention with new clients. Information (in electronic format) forwarded to this Office however only showed the date of referral and not the date of first intervention. When queried about this, DIT indicated that the latter is not included in this electronic compilation, however the Unit intends to include this information in the aforementioned new online case management system.
- 2.4.7. Even though NAO was not forwarded with the required information to assess the waiting period between date of referral and DIT's first intervention with its clients, it positively notes that the large majority of the questionnaire's respondents who are DIT clients stated that they have been contacted by the Unit shortly after being referred, though most did not indicate precisely the duration of this period.

### NAO Observation

- 2.4.8. While NAO acknowledges the difficulties posed on the Unit due to a lack of supply of qualified professionals in the local labour market, it still feels that the DIT needs to be a much larger operation than it currently is. With such limited resources, the Unit cannot reasonably absorb a significant increase in its case load which, at present is low when compared to the total projected number of people living with dementia in the community.

### NAO Recommendation

- 2.4.9. In acknowledging that recruiting additional professionals may have its challenges, NAO encourages DIT to find ways in which it could still increase its workload without generating undue need for further professionals. Specifically, NAO recommends that the DIT carries a thorough review of its operations to identify those tasks which could be carried out by support staff rather than professionals. As recruiting support staff may present itself to be a more feasible endeavour, this exercise could result in the better utilisation of professionals' hours already in the Unit's employ, thereby allowing the latter to expand its client base. This notwithstanding, it is understood that any significant increase in DIT's caseload will invariably require the recruitment of additional professionals.

## 2.5. **Communication and data sharing between stakeholders is limited and not set in a formal system**

- 2.5.1. The strategy objective in question calls for the DIT to be a point of reference for individuals with dementia. This Office feels that, in order for this objective to be met, DIT needs to build strong communication channels with all involved stakeholders so that a better and more seamless experience is provided to clients in the delivery of the different services offered by various stakeholders. To this end, NAO sought to assess the extent to which the Unit is fulfilling this goal.



- 2.5.2. During meetings with DIT, NAO enquired with the former on the communication channels it maintains with medical professionals who are involved in the care and support of its clients. In reply, DIT highlighted that this communication is usually carried out by phone or via email, even if such interactions generally occur only in instances in which behavioural issues are identified or if the need for a change in medication arises (as prescribed by the respective medical consultant).
- 2.5.3. The audit team was also informed that, apart from being a reference point to its clients, the Unit also liaises with service managers within AACC itself (who are responsible to administer AACC's outsourced community care and services as discussed throughout this report) particularly during the application phase for any such service by the client, or if any difficulties arise during the provision of the service.
- 2.5.4. While acknowledging the above assertions, NAO enquired whether communication with stakeholders operates within a structured system or otherwise. In reply, DIT confirmed that communication with stakeholders is not set in a formal system but rather occurs on a needs basis. This was also confirmed by interviewed medical consultants, with a segment of these even asserting that they never communicated with the DIT and that neither were they ever approached by the latter. Interviewed consultants agreed that there needs to be a more coordinated and centralised system of dementia related services and better communication through regular feedback, with an emphasis on the clinical and social aspects working closely together.
- 2.5.5. Chief Executive Officer (CEO) SVP, also concurred that dementia related services are currently disjointed. As an example, CEO SVP highlighted that those activities held at their dementia activity centre (discussed further in Strategy Objective (a) – point 3.1 refers) are not coordinated with the DIT. This, NAO notes, implies that no formal and structured communication on such activities occurs between these two entities, thereby impinging on the seamless continuation of the therapeutic process.
- 2.5.6. Meetings with PC also highlighted the same issue, with the former expressing that he finds the lack of sharing of experiences and data between different stakeholders in this sector as particularly concerning.
- 2.5.7. Indications of the prevalence of this issue were also evident in the reviewed case files. Through its review, the audit team only found six instances in which any form of communication with stakeholders was filed. In most of the remaining cases, NAO did observe that reference was made to communication with third parties, but no copies of this was found in the files.
- 2.5.8. As NAO delved deeper into the issue of apparent gaps in communication between stakeholders, it sought to determine whether any body exists intended at bringing these stakeholders together for better coordination. In this respect, the audit team held meetings with PC who



explained that, given that dementia is a medico-socio challenge, he had proposed the idea of an inter-ministerial board intended specifically to facilitate communication between these two fields. PC however indicated that this proposal was not accepted, but a board was set up in 2018, comprised of members hailing from different interested stakeholders, to oversee the overall implementation of the National Dementia Strategy (with PC himself chairing this board). The audit team was informed that members of this committee come from different professional backgrounds but all work in the field of dementia. PC however highlighted that, while this board was holding meetings every six to eight weeks, these were discontinued as from the onset of the COVID-19 pandemic.

- 2.5.9. NAO's interest in whether structured communication exists between different stakeholders primarily stems from the perceived need of effective and efficient sharing of data so that the end client would get as much of a seamless service as possible. To this end, this Office enquired, with different stakeholders, whether individual records on clients are integrated into a central national database to facilitate this. Through its discussions with these stakeholders, NAO however noted that data retained is generally done so in silos and sharing of data is not a pro-active practice.
- 2.5.10. Specifically, NAO enquired with the DIT if it is aware of any national database listing individuals diagnosed with dementia in Malta. In reply, the Unit stated that, to its knowledge, no such compilation exists, but directed the audit team to a database held by the Ministry for Health (MFH) of individuals who are prescribed related medication (that is, those registered on Schedule V and therefore availing of the Pharmacy Of Your Choice (POYC) scheme<sup>7</sup>).
- 2.5.11. Through its work, the audit team found that the above-mentioned database is managed by the Department for Policy in Health (DPH) and is referred to as the Dementia Register. During meetings with DPH, NAO was informed that this register is populated through the same Schedule V information as used by the POYC scheme, even if DPH and POYC retain information on each client to different extents. More specifically, during meetings with both DPH and POYC, this Office was informed that, after receiving Schedule V applications for dementia related medication, POYC only retains the details required so that the client can avail of the scheme, (such as name, address, referring consultant, type of medication to be dispensed and dosage), and then forwards copies of these applications (in scanned format) to the DPH every month by email. DPH then inputs all information within these applications (including for instance the caregiver's contact information) manually into the Dementia Register .
- 2.5.12. During meetings with the audit team, DPH asserted that the original purpose of the dementia register was to obtain, as much as possible, a representation of the number of people diagnosed with dementia in Malta. DPH further highlighted that this register, which inception preceded DIT's establishment, is solely intended for statistical purposes, with DPH officials expressing

<sup>7</sup> Schedule 5 includes a list of individuals who are entitled to free medicinal treatment by virtue of the Social Security Act Cap 318 Article 23 and the amendment of this act - Act No. I of 2012 and the Fifth Schedule to the same Act.

that they feel this compilation of information could be of more use if better communication and collaboration, particularly with the DIT, is secured. This notwithstanding, the audit team was also informed that, as this register sources its information only from Schedule V applications, it can never list all individuals with dementia in Malta. More specifically this register would not include: people with dementia who are as yet undiagnosed; diagnosed individuals who do not require medication; diagnosed persons who, though requiring medication, would opt to not avail of the POYC scheme but rather choose to procure the prescribed medication themselves; or individuals diagnosed with dementia who would require medication which does not fall under Schedule V .

- 2.5.13. As already mentioned in Chapter 1, NAO requested DPH to forward to the audit team a masked copy of this register so that it could use it to select a sample of potential participants for its questionnaire. However, despite sending this request and subsequent reminders, NAO was never furnished with this information.

### NAO Observation

- 2.5.14. As dementia is a multi-faceted condition which heavily effects the individual's medical and social aspects, this Office considers an effective communication and data sharing system between the various entities responsible for different aspects of the condition, as of paramount importance for a seamless delivery of service. To this end the identified apparent shortcomings in inter-stakeholder communication is a significant cause for concern to the NAO.

### NAO Recommendation

- 2.5.15. An effective communication and data sharing system between involved stakeholders would undoubtedly enhance the quality of service being received by the client, and possibly capture more people with dementia which are not being included in DIT's visibility through the current system. To this end, NAO strongly urges the Unit to be more pro-active in enhancing such collaborations and to spearhead initiatives which would see the creation and implementation of a structured system within which communication and information sharing can occur in a more efficient and effective manner, while keeping full GDPR requirements in mind. NAO notes that in so doing, the DIT would be better satisfying the strategy objective calling for it to be a reference point to all people diagnosed with dementia. In turn, NAO also urges related stakeholders to collaborate with the DIT so that any new initiatives are implemented successfully. This notwithstanding, NAO once again acknowledges that for DIT to increase the depth and/or spread of its current operations it needs to be bolstered with additional resources.

**Strategy Objective F:** *Provide additional support to the Dementia Helpline as this serves as an important source of information and support to individuals with dementia and their caregivers.*

## **2.6. Dementia Helpline is in operation though its usage is low**

- 2.6.1.** During meetings with PC, the audit team was informed that this helpline is intended to give specialised advice and guide callers (be it clients or caregivers) accordingly with any issues related to dementia and is available on a 24/7 basis. NAO was informed that this service was originally operated by SVP between 2015 and June 2020 and has, as from July 2020, been assigned to the DIT. In this respect PC asserted that members of the DIT are considered to be the most prepared to take on this particular task and as a consequence the quality of the Dementia Helpline as at time of writing has improved significantly, with the provided service being considered of good standard, even if this puts significant load on the Unit's resources.
- 2.6.2.** While acknowledging the above, NAO however notes that the usage of the Dementia Helpline is quite low. Specifically, according to information forwarded by the DIT, this Office observes that between the Unit's takeover of the helpline in July 2020 and end of August 2021, a total of 545 calls were received related to requests for information and emotional support. Given that this service operates on a 24/7 basis, this means that, on average, only 1.3 calls were being received per day since the helpline's operation was assigned to the DIT.
- 2.6.3.** It must also be highlighted that the abovementioned usage refers specifically to the number of calls received and not to the number of different callers, with NAO perceiving the distinct possibility of several calls being made by the same person. This low usage of the dementia helpline was also substantiated through the administered questionnaire, as 59 out of the 73 respondents stated that they never made use of this helpline. NAO also observed that, out of these 59 individuals, 21 further asserted that they were not aware that such a service existed. When queried in the questionnaire, it was noted that out of the 14 respondents that made use of the helpline, three affirmed that they only called the helpline once, two replied that they phoned more than once, one stated that the helpline is used more than once a week, and eight explained that they use the helpline according to the needs.
- 2.6.4.** When queried by the audit team on this low usage, both PC and DIT agreed that the dementia helpline needs to be better advertised with the general public. In view of this, PC explained that there is the intention for more effort on such information campaigns to be invested by 2022. It is worth noting that, during the latter stages of this audit exercise, AACC asserted that the number for this service has been distributed to all local households and various media channels were used to raise awareness on this during 2021.
- 2.6.5.** Through the questionnaire, the audit team also endeavoured to determine whether people making use of the helpline are satisfied with the service being rendered or otherwise. Out of the 14 respondents who indicated that they make use of this service, 13 affirmed that the

helpline assisted them adequately in their requests, while one person replied that s/he was not satisfied with this service. NAO further notes that nine respondents gave the service a rating of five out of five, three respondents assigned a rating of four, with the remaining two respondents rating the service as a 2 and 1 respectively.

- 2.6.6. In addition, the questionnaire's respondents were asked whether they were assisted to immediately or otherwise when they made use of the helpline service. In reply to this, most respondents indicated that they were attended to immediately when they called on the dementia helpline, both during the day and during night hours.

### NAO Observation

- 2.6.7. This Office agrees with PC and DIT that the Dementia Helpline, as at time of writing, needs to be better promoted, which fact could be a main contributor to the low usage of this service. This notwithstanding, NAO acknowledges PC's cited intention to invest more effort on this front by 2022. This observation becomes more prominent given that replies from the administered questionnaires show that those who make use of this initiative are mostly satisfied with the service being provided.

### NAO Recommendation

- 2.6.8. While NAO has taken note and acknowledges the cited intention to better promote the Dementia Helpline by 2022, it urges the involved parties to ensure that efforts are directed efficiently and effectively in this initiative so that the expected results are reaped at the very earliest. This Office also understands that, as this initiative would exert more pressure on DIT's resources (should it be successful), the Unit needs to be bolstered accordingly to be able to adequately cater for any increase in workload.

## Chapter 3 | Strategy Implementation

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This Chapter presents NAO's observations on progress registered in the implementation of those objectives within the Dementia Strategy which are directly related to the community living. Each objective is assigned, by NAO, with an implementation indicator and is then discussed in detail.

*Note: The Dementia Strategy was earmarked to be implemented during the period between 2015 and 2023. This means that, while most of the assigned time has already elapsed, close to two years remain for involved stakeholders to implement its requirements. To this end, this section is intended as a cursory review to report on the progress registered so far with respect to the strategy objectives in question. This notwithstanding, this Office still put forward its observations and recommendations on already registered progress, or lack thereof.*

### **3.1. Strategy Objective Delivery 6.3.4 (a) - Increase in the number of Day Centres specialising in dementia management and care. Such service should be managed by adequately trained staff.**

*Note: the second part of this strategy objective, which states that this "service should be managed by adequately trained staff", is deemed by the NAO to be a repetition of strategy objective delivery 6.3.4 (d) (Section 3.4 refers), which calls for the provision of "... training to staff working in community Day Centres in order to be able to deal with behavioural and physical needs of individuals with dementia as well as creating an activity program suitable for these patients." To this end, and to avoid repetition, this issue is not discussed in this section but delved into in Section 3.4.*

#### *Partly Implemented*

3.1.1. During meetings with DIT, the audit team was informed that the primary objective of these dementia activity centres is to provide a dedicated safe place for persons with dementia outside of their home, thereby giving respite to their informal caregivers. PC further highlighted that although these dementia activity centres are intended to be similar to other active ageing centres found within the community, they should be manned by staff who is specifically trained on dementia care. As a result, besides having expertise on the care required for people with dementia, the staff would ensure that activity programmes are specifically tailored according to each individual dementia clients' needs. DIT explained to NAO that these dementia activity centres are intended to cater for individuals whose advanced condition would be presenting behavioural challenges. In contrast, the aforementioned mainstream active ageing centres, while accepting people with mild dementia, are not adequately resourced to care for high dependency clients.

- 3.1.2. During the fieldwork stage of this audit exercise, the audit team was informed that there were two operational day centres which catered specifically for people with dementia, namely 'Paul Cuschieri Day Centre' (PCDC) which is located within and is operated by SVP, and 'Dar Padova' in Ghajnsielem, Gozo. This notwithstanding, through its research, the audit team found that the Ministry for Gozo has signed a public-private partnership (PPP) with Casa Amalia (situated in Gozo), which, amongst others, includes the provision of day centre services specifically for people with dementia. However, when NAO enquired with DIT and PC on whether there is a working relationship with this entity, PC and the Unit replied in the negative, with DIT further stating that it does not have any insight on its operations.
- 3.1.3. While the audit team deemed it preferable to visit these centres during their normal operation, fieldwork for this audit was carried out during the COVID-19 pandemic, which led to the temporary closure of these centres. In view of this situation and due to restrictions imposed by the Health Authorities<sup>8</sup> at the time, as well as to avoid exposing clients to unnecessary risks, the audit team resolved to only visit the PCDC and to do so during the period in which it was not operational, even if these centres re-opened while this exercise was still underway.
- 3.1.4. During the audit team's visit to the PCDC, the latter explained the daily routine of the centre and activities carried out. The centre's staff also showed the audit team some material which is used during day activities with their clients. During this visit, the audit team noted that the centre was very clean and spacious, even if furnished and equipped only with basic amenities. However, while spacious, this centre is laid out in an open plan setup which, in PCDC staff's opinion, is not ideal. Specifically, the latter explained that this open plan setup presents difficulties when different activities are scheduled for different groups of clients as one may be a source of interruption and disruption over the other. PCDC staff indicated to the audit team that, while this open plan setup does have its benefits, it needs to be supplemented with smaller, segregated areas to carry out particular activities with less disruptions. During this visit, the audit team was also shown the centre's designated outdoor area which, in PCDC staff's opinion, is too small to cater for the centre's needs.
- 3.1.5. During the audit team's site visit, PCDC staff highlighted that this centre could accommodate up to a maximum of 21 persons at any one point in time. Upon request, PCDC indicated that, as at November 2021, 27 clients were making regular use of this centre, with another three attending on a non-regular basis and an additional two clients attending depending on availability. The audit team was further informed that not all clients attend at the same time and consequently NAO understands that the 21-person limit is respected.
- 3.1.6. PCDC however also highlighted that, as at November 2021, there were a further 15 applicants on the dementia activity centre's waiting list, and another three awaiting assessment. In addition, the audit team noted that the longest standing application on this waiting list was received by

<sup>8</sup> At the time Covid19 restrictions included no travel of a non-essential nature to Gozo

PCDC in September 2021, that is a two month wait. While NAO understands that this period was invariably affected by the COVID-19 pandemic (during which the PCDC was operating at reduced capacity), it still enquired with CEO SVP on whether a waiting list generally features in the uptake of this service in normal periods of operation. In reply, CEO SVP informed the audit team that a waiting list still prevailed even before the pandemic and, as PCDC is adequately staffed, this situation is primarily brought about due to the centre's limited physical space. CEO SVP additionally highlighted that, in view of this situation, requests are prioritised according to urgency and severity of condition. This notwithstanding, as at time of writing NAO was informed that, due to the opening of two additional dementia activity centres in the latter parts of 2021 (point 3.1.10 refers) this waiting list has been cleared as, amongst others, some applicants have since been admitted to long term residential care, while others expressed preference to attend the new centres.

- 3.1.7. Even if this Office did not conduct a visit at Dar Padova in Gozo, it still sought PC's opinion on the adequacy of this centre. In reply, the latter highlighted that this centre is designed better than PCDC and is therefore more suited to address the needs of dementia clients. The audit team also enquired with DIT on this centre's capacity and usage. In reply, the Unit highlighted that this dementia activity centre can host up to 18 service users however, due to the COVID-19 pandemic, the number of available places was reduced to 12 at any one point, with clients being divided into two separate groups of six each. Nonetheless, the actual number of service users as at time of writing is of eight persons, though this number may fluctuate particularly in response to the changing situation of the COVID-19 pandemic. Information forwarded to NAO also showed that this centre is manned by 17 members of staff, namely one charge nurse, two staff nurses, nine carers, one clerk, two security personnel and two handymen.
- 3.1.8. Through its questionnaire, this Office positively notes that, out of the fifteen participants who attend a dementia activity centre, seven gave a rating of five out of five insofar as satisfaction with the service rendered is concerned, with the remaining eight assigning a rating of four.
- 3.1.9. The audit team also sought to determine whether these two centres are sufficient for the current requirements on a national level. In this respect the audit team consulted with PC, who asserted that, as a minimum, there should be a dementia centre in every region in Malta, implying that the current resources are insufficient. The audit team was further informed that this spread of centres throughout the country is deemed necessary particularly to mitigate undue stress and discomfort which people with dementia may experience during long trips to attend centres which would be a relatively long way away from their place of residence. On the other hand, PC further highlighted that, even if the strategy's objective is met and more dementia activity centres are set up, the recruitment of specialised personnel to man these centres remains a significant challenge, considering that there is a local staff shortage in this field.



- 3.1.10. During this exercise's fieldwork stage, the audit team was informed by AACC that there were plans to open two additional dementia activity day and night centres (both to be manned by AACC), specifically one at a residential home in Mtarfa and another in Safi. In order to verify this, the audit team carried out site visits in both locations, even if construction was still underway during the fieldwork stage of this audit.
- 3.1.11. During its visits, the audit team noted that the premises in Mtarfa consisted of one big open plan hall, which was eventually going to be set up with a kitchenette, tables where carers could hold activities with the persons with dementia, a tv area and recliners. Adjacent to this was an outdoor area offering a view and featured synthetic turf and a number of benches. DIT informed the audit team that there were plans to hold activities in this area when the weather permits. In the corridors next to this hall, the audit team noted that there were separate rooms which, the audit team was informed, were intended to be used for the night shelter service (which service is to be discussed in subsequent parts of this report).
- 3.1.12. On the other hand, the premises in Safi was located in a townhouse which, during the audit team's visit, was still undergoing substantial renovations. This premises features good-sized rooms situated at ground floor level which, the audit team was informed, is planned to include a kitchenette, tv area and recliners. The audit team noted that a lift was, at the time, in the process of being installed in the premises. DIT explained to the audit team that other rooms within the house were going to include a treatment room and a night shelter service. DIT further explained that, given its structure, activities in this particular dementia activity centre could be held in separate rooms within the house, with the roof also serving to hold a number of outdoor activities.
- 3.1.13. Eventually, during the latter stages of this audit exercise this Office was informed that these centres had been completed and had commenced operations in late 2021. To substantiate this claim, DIT forwarded the audit team documentation which showed that the Mtarfa centre is being manned by nine care workers, one charge nurse, one staff nurse and one clerk, and since its opening, 20 people were benefitting from its services. Similarly, NAO was informed that the Safi dementia activity centre is being manned by nine carers, one staff nurse, one clerk and two security personnel and that, as at time of writing, 13 clients are making use of this centre, with this usage expected to increase.
- 3.1.14. While this Office acknowledges the launching of two additional centres, it still enquired whether the new capacity is sufficient to cater for the entire local demand. In reply, AACC once again argued that in arriving at such a projection, data from waiting lists are crucial and highlighted that currently no waiting lists for this service prevail.
- 3.1.15. DIT further informed the audit team that both Mtarfa and Safi (as villages) are earmarked for the concept of a dementia friendly community. In fact, PC further explained that the concept of a dementia friendly village calls for a number of initiatives to be implemented within a



locality to create a more inclusive environment for people with dementia. Examples of such initiatives would include offering training to local service and amenity providers as well as including signage within the locality which is better and more easily understood by people with dementia. This initiative will be delved also in Section 3.14.

## NAO Observation

- 3.1.16. This Office positively notes the recent commencement of operations of an additional two dementia activity centres, which increased considerably the availability of this service and effectively doubled the localities in which such centres are available. NAO also further commends the good feedback received through the questionnaire on the service being received at PCDC and Dar Padova.
- 3.1.17. Despite the above, however, this Office still perceives the four current dementia activity centres to be insufficient to serve as a nationwide initiative. Considering especially the challenges which may be faced by people with dementia during relatively long commutes, having such centres in only four localities between Malta and Gozo significantly reduces accessibility to this service.
- 3.1.18. In addition, and similar to concerns already highlighted in section 2.1.7, NAO once again reiterates that projections on future demand for a service cannot be solely based on the prevalence of a waiting list or otherwise, as other factors (such as sufficient awareness of the service's existence) play a part in future demand.

## NAO Recommendation

- 3.1.19. This Office recommends that PCDC is refurbished and upgraded to meet the necessary standards that high quality dementia care and management entails, including the provision of dementia friendly design.
- 3.1.20. While NAO once again commends the recent efforts for two additional dementia activity centres to become operational, it still urges AACC to continue exploring additional locations in which such centres could be established and conduct strong projection exercises on future demand for such services. This with the aim of reaching as much of the dementia client base as possible and mitigating challenges, particularly those related to transportation. Notwithstanding, NAO acknowledges the significant difficulties that could be faced in finding adequate human resources, in sufficient numbers, to man additional centres.
- 3.1.21. As NAO's questionnaire was administered at a time in which the two new centres were still not operational, and consequently no feedback on their service delivery was available, it encourages AACC to ensure that the good quality of service as was made apparent from the

positive feedback received on PCDC and Dar Padova, also extends to the Mtarfa and Safi centres.

### **3.2. Strategy Objective Delivery 6.3.4 (b) - Extend the operating hours of the Day Centre at SVP thereby increasing flexibility for individuals with dementia and their caregivers.**

#### *Implemented*

3.2.1. SVP informed the audit team that the opening hours of the PCDC have been extended. Specifically, as at time of writing, opening hours were set between 6.30am till 6pm, as opposed to the previous schedule which was between 6.30am and 4.30pm. PCDC staff explained that attendance by service users varies as it depends on the respective client's and caregiver's needs.

3.2.2. Even though this strategy objective focuses solely on the operating hours of SVP's dementia day centre, the audit team still enquired on what is the situation with regard to Dar Padova in Gozo and the new dementia activity centres in Safi and Mtarfa. However, replies from DIT and AACC to what NAO considers a straightforward request, resulted in three different sets of opening hours being cited to this Office, neither of which corresponded to what is published on AACC's own website. Specifically, these time schedules ranged from 6.30am to 7.30am as opening times in the morning, and from 5.30pm to 6.30pm closing times in the afternoon. While NAO acknowledges that these closing times extend later than 4.30pm as was the original PCDC closing time, it notes that opening times range from equalling that of the original PCDC time or later.

#### **NAO Observation**

3.2.3. This Office positively notes that the operational hours of PCDC were extended as per strategy objective and are now better suited particularly for caregivers who work on regular office hours.

3.2.4. Despite receiving inconsistent information on operational hours of the other three dementia day centres, NAO acknowledges that closing times have apparently been extended when compared to PCDC's original schedule, even if the same could not be ascertained with respect to opening times.

#### **NAO Recommendation**

3.2.5. NAO acknowledges that the opening hours of PCDC were extended in fulfilment of strategy objective delivery 6.3.4 (b). As inconsistent information on the operational hours of the other

three centres was received by NAO, however, it could not ascertain which of these schedules is the correct one. To this end, it urges AACC to make sure that these are sufficient to afford caregivers with enough time to tend to their work and other exigencies. The same consideration should be applied for any subsequent centres which may open in the future.

### **3.3. Strategy Objective Delivery 6.3.4 (c) - Make appropriate transport service available for individuals with dementia making use of the Day Centres.**

#### *Partly Implemented*

- 3.3.1. During meetings with CEO SVP, the audit team was informed that that there is no transportation service available to and from the PCDC and therefore, service users and their caregivers have to make their own arrangements. Both CEO SVP and PC acknowledged that typically and as a consequence of this, people who opt to make use of the PCDC reside in the vicinity, with those living further away not finding the centre's location practical. Similarly, DIT also confirmed that no transport is currently being offered to clients attending the Mtarfa and Safi dementia activity centres.
- 3.3.2. On the other hand, DIT informed the audit team that transportation to and from Dar Padova in Gozo is available and it is used by the large majority of the centre's clients. This service operates on a fixed schedule, with one trip to and one trip from the centre being offered every day. Given the relatively small size of the region in question, this Office was informed that commutes are generally completed in a short timeframe.
- 3.3.3. As already mentioned in point 3.1.9, PC confirmed that long commutes may present difficulties for individuals with advanced symptoms of dementia (who are target clients to such dementia activity centres) as these may experience confusion and/or agitation during a long trip. NAO notes that this consideration ties in with the success of the transportation service as registered in Gozo, given the short trips that are required in this region. In view of this, the audit team notes that the need for additional dedicated dementia activity centres as per point 6.3.4 (a) of this strategy becomes even more apparent, and that it is with the opening of additional centres, covering all local regions, that the strategic objective of providing transport becomes feasible.
- 3.3.4. To this end, DIT informed NAO that it will be carrying out a survey with clients attending the Mtarfa and Safi dementia activity centres to gather overall feedback, including on whether the need is felt, or otherwise, for a transportation service. This notwithstanding, DIT further expressed with NAO that, in its opinion, most informal carers would prefer to have flexible times when to drop off and pick up the persons with dementia from the centres, and any organised transport service would be very limited in this respect. However, this exercise would nonetheless serve to formally assess feasibility in this regard.

## NAO Observation

- 3.3.5. While this Office understands that providing transportation service to and from dementia activity centres carries significant logistical challenges, it still perceives it as an important service particularly for those clients whose caregivers cannot provide them with transportation. This notwithstanding, NAO understands that the success of this strategy objective is closely tied to the availability of dementia activity centres in different localities (section 3.1 refers) to mitigate the long commute concern. This Office additionally notes that the success this service is registering in Gozo (which features short commutes) further reinforces this observation.

## NAO Recommendation

- 3.3.6. With respect to the provision of transportation service to and from dementia activity centres, NAO recommends that DIT expedites the earmarked survey with its clients so that it may better gauge the need for this service and act accordingly. This Office once again draws attention to the success of this service to and from Dar Padova in Gozo, as it feels that due account of this should be taken when considering the eventual implementation or otherwise of such a service in Malta.

- 3.4. Strategy Objective Delivery 6.3.4 (d) - Provide training to staff working in community Day Centres in order to be able to deal with behavioural and physical needs of individuals with dementia as well as creating an activity program suitable for these patients.**

## *Implemented*

- 3.4.1. While this strategy objective calls for staff working within the community Day Centres (which term is generally used to refer to mainstream Active Ageing Centres around Malta), both PC and AACC indicated that this objective is specifically aimed to staff deployed at dementia activity centres. The audit team therefore enquired whether training as cited in this strategy objective has been delivered to the personnel deployed in these centres. In reply, SVP informed this Office that, out of the 20 personnel that are deployed at PCDC, 10 have already underwent specialised training in dementia care, and an additional six are enrolled to attend such training in the first quarter of 2022.

- 3.4.2. With respect to the Mtarfa and Safi dementia activity centres, CEO AACC informed the audit team that it delivered a course entitled 'Introduction to Dementia Care' in September and November 2021 respectively to each day centre. The audit team was also forwarded with an excel sheet which showed that nine members of staff deployed at Mtarfa attended this training, while a signed attendance sheet showed that 13 personnel deployed at Safi also attended this training. A programme of this training was also forwarded to NAO.

- 3.4.3. The audit team was also informed that the staff deployed at Dar Padova have been provided with an introductory course in Dementia Care in 2015, as well as a Certificate in Reminiscence Arts in Dementia Care in 2017. This notwithstanding, DIT additionally indicated that, later this year, these personnel will be invited to participate in the updated dementia care course which has been delivered to the Mtarfa and Safi personnel.
- 3.4.4. With respect to the activity programmes as cited in this strategy objective, PCDC explained that such a programme is in place, and structured in a manner which is sensitive to the requirements of people with dementia. Apart from daily routines, such as breakfast, lunch and mass, PCDC also prepares activities of varying natures, including those specifically intended to cater for memory loss. Such activities were explained to the audit team during their site visit.
- 3.4.5. Insofar as the dementia activity centres at Dar Padova, Mtarfa and Safi are concerned, DIT forwarded NAO with an activity programme that is to be used in these centres. The audit team was additionally informed that activities could change from one day to the next, according to the specific requirements or preferences of the service users in attendance, while also incorporating seasonal themes as applicable. This Office was also forwarded with a template form which is completed at the start of a client's attendance to one of these dementia activity centres, which form, amongst others, records the clients' backgrounds, likes and dislikes. These forms are used so that activities at the dementia activity centres are made more relevant to the service users

### NAO Observation

- 3.4.6. This Office positively notes that the majority of staff deployed in dementia activity centres have been provided with training on dementia care. Additionally, NAO commends the design of activity programmes intended to be used in these centres which take in consideration the needs of dementia clients. This ties in with the generally positive feedback received in NAO's questionnaire on the quality of service being provided at PCDC and Dar Padova.
- 3.5. Strategy Objective Delivery 6.3.4 (g) - Provide outreach support programmes that include both specialised home help for individuals with dementia as well as respite service in the community. This will require training of a team of certified care-workers and coordinated by the Dementia Intervention Team. Different forms of respite care will become available to accommodate patients' needs.**

### Domiciliary Caring

#### *Significant Progress*

- 3.5.1. When enquiring with the DIT on which services the Unit feels constitute help at home as indicated in this strategy objective, the audit team was directed to the domiciliary caring service. This service, NAO notes, entails the provision of a carer at the client's own residence

to carry out specific duties as would be required by the latter, such as assistance with bathing or nappy changing. Table 4 below shows the number of people with dementia who have availed of the domiciliary caring service since 2019.

**Table 4: Number of Dementia Clients making use of the Domiciliary Caring Service**

Year	Number of dementia clients
2019	274
2020	267
2021 (up to September)	113

Source - DIT

**3.5.2.** While taking note of DIT's opinion that the domiciliary caring service is the one addressing the help at home requirement of this strategy objective, NAO however notes that there are additional services which may be contributing to the fulfilment of this requirement. Specifically, this Office draws attention to the following services being offered by the AACC:

- Home Help – offers assistance to older people and persons with special needs in performing light domestic chores and shopping.
- Handyman – offers a range of different repair jobs, which include the service of a carpenter; painter; plumber; electrician; railings installation and transportation of items from one room to another.
- Meals on Wheels – offers the service of delivering one chilled meal per day, to be heated and consumed by the client.
- Domiciliary Nursing – to provide a nursing service at the client's home.
- Carer at Home – the provision of financial support (up to €6,000 per annum in 2021, which will be eventually increased to €7,000 per annum in 2022) to clients who employ a carer of their choice to assist them in their daily needs.

**3.5.3.** In reply to NAO's request to be forwarded with statistics on the uptake of the above-mentioned services by dementia clients, DIT could only forward information related to the domiciliary nursing service, which showed 75 beneficiaries as persons having dementia as their main diagnosis. With respect to the other services, however, DIT replied that it cannot forward such data as record of the diagnoses of beneficiaries is not a requirement and is therefore not kept. This does not make it possible to identify the number of those who are diagnosed with dementia and availing of such services.

**3.5.4.** It is important to highlight however that the abovementioned services are technically generic in nature and not specifically designed for people with dementia. This notwithstanding, while NAO perceives that specialised services would be of more benefit to dementia clients, it nonetheless understands that these services are still of benefit to this cohort of users.

## NAO Observation

3.5.5. This Office feels that the domiciliary caring service, together with the other mentioned services, do fulfil the requirement of providing home help as per this strategy objective. This notwithstanding, while NAO does not contend the benefits which can still be reaped from a generic service, it still believes that dementia clients may have exigencies which would be best addressed through a specialised service and delivered through individuals who have been provided with related training.

## NAO Recommendation

3.5.6. While NAO understands that generic services such as that of domiciliary caring and others which may provide home help are very beneficial to dementia clients, it still encourages AACC to ensure that the manner by which such services are provided to such clients is done so in a way which is sensitive to their particular needs.

## Respite at home

### *Significant Progress*

3.5.7. NAO notes that, as already mentioned in this report, AACC provides a respite at home service to its clients. This service is outsourced, but is administered by the AACC, and involves the provision of a qualified carer to assist the person with dementia in one’s own residence for a specified period of time.

3.5.8. From information forwarded by DIT, NAO noted that in 2020, 138 persons with dementia availed of the respite at home service. As can be seen in Table 5 below, six care packages are offered through this service, with AACC indicating that the most popular option being that of a carer assisting the client for two half days every week.

**Table 5: Respite at Home Care Packages**

Type of Respite at Home Care Package
Care package i (for one whole week: from Monday to Sunday – 24 hours)
Care package ii (for one whole week: from Monday to Sunday - 8am - 5pm)
Care package iii (twice per week, for only seven weeks)
Care package iv (3 days per year)
Care package v (twice a week throughout the entire year, with 4.5 hours each day)
Care package vi (one day per week throughout the entire year, with 9.5 hours each day)

Source: AACC

3.5.9. During meetings with NAO, DIT however explained that the respite at home service, though rendered by qualified carers, is a generic one and is not specialised for people with dementia. The role of the DIT in this case is to facilitate and co-ordinate the service according to the clients' needs, and to guide the respective carer (through communication with the respective service manager) to follow the client's care plan.

3.5.10. To obtain an insight on the client satisfaction level of the respite at home service, NAO sought feedback in this respect through the administered questionnaire. To this question, 12 replies were received with mixed feedback. Specifically, five respondents gave a 5 out of 5 rating, two a 4 out of 5, an additional two assigned a 3 out of 5, and remaining three participants voting a 2 out of 5 rating.

### NAO Observation

3.5.11. NAO acknowledges that dementia clients benefit from the respite at home service even though this is generic in nature. However, the mixed feedback received from the administered questionnaire leads this Office to question whether better quality could be secured overall and whether a specialised service for dementia clients would have a materially positive impact on the registered feedback.

### NAO Recommendation

3.5.12. Insofar as respite at home is concerned, NAO encourages AACC to assess whether the current service could be better fine-tuned so that the specific needs of dementia clients are better catered for.

**3.6. Strategy Objective Delivery 6.3.4 (h) - Increase the number of beds dedicated to institutional community respite for persons with dementia thereby increasing availability.**

### *Implemented*

3.6.1. A number of private community residential homes have entered into a public service agreement with the Government, also called a PPP, to accommodate elderly people, including those with dementia, for a period of three consecutive weeks. This service can be availed of up to three times per year. Table 6 below shows the homes offering this service and number of available respite beds:

3.6.2. In addition to the above, SVP also offers residential respite, particularly to those individuals with severe forms of dementia, including clients who exhibit wandering behaviour. This service can be provided to around 20 clients at any one point. CEO SVP specified that while the residence



is responsible to man the premises in which this service is delivered, it is not involved in its management or planning, as this falls under AACC’s responsibility. CEO SVP further indicated that while this service at SVP was suspended during the height of COVID-19 restrictions, the number of applications received for this service during normal operations is very few. In fact, information forwarded to NAO showed that during the year 2019 (that is before the onset of the pandemic), this service was only availed of for a total of 33 instances.

**Table 6: PPPs offering residential respite**

Name of Home	No. of respite beds
Casa San Paolo, Roseville, Casa Arkati, Villa Messina	5
Casa Francesco	5
Casa Paola	5
Casa Pinto	5
Curia Homes	14
Golden Care	5
Residenza San Ġużepp	5
St. Elizabeth	5
St. Thomas Community Living	5
Dar I-Annunzjata	5
Ghigo Community Residence	5
Casa Serena	5
Central Home	5

Source: DIT

- 3.6.3.** When NAO enquired with DIT on the number of persons with dementia who avail of the residential respite service (that is, not necessarily at SVP), the latter redirected the audit team to CSA for this information. However, when contacted, CSA forwarded the audit team with the number of total applications received for this service, but could not specifically identify the segment of these which relate to people with dementia.
- 3.6.4.** While NAO could not determine the level of uptake of residential respite through the aforementioned PPPs, it enquired with SVP on what may be reason for such a low usage of this service. To this, the latter highlighted that it could be more likely that informal caregivers prefer to look after the person with dementia themselves if the situation is still considered to be manageable at home. This is more so if the person with dementia would exhibit elevated anxiety at the prospect of being transferred to a residential home, even if for a short period of time. CEO SVP further argued that caregivers could generally only ask for services such as that of residential respite when the condition would be presenting considerable challenges.
- 3.6.5.** The above assertions were also expressed by the DIT, agreeing that persons with dementia tend to prefer opting for the respite at home service rather than residential respite. DIT echoed SVP’s observation that making use of residential respite may subject the client to elevated anxiety due to the change in environment. In such instances it would therefore be more beneficial for

the client to remain in one's own residence. Notwithstanding, DIT officials expressed with NAO that respite services should ideally not be used as a last resort when there is already a crisis situation, but that informal caregivers should make use of them periodically to mitigate the possibility of such situation from materialising.

- 3.6.6. The low uptake of the residential respite service was also reflected in the replies in NAO's questionnaire, whereby out of 73 respondents only 8 persons indicated that they have made use of the residential respite service. NAO also notes that feedback on the level of satisfaction from respondents who use the residential respite service was generally positive.

### NAO Observation

- 3.6.7. While this Office acknowledges that the availability of this service is essential and of significant help to anyone who would require it, it however appreciates that the cohort of individuals who may be in need of this service is relatively not numerous. NAO understands that caregivers would be in a position to cope well with daily living, and therefore not requiring this particular service, if the person with dementia would be exhibiting mild symptoms. This is particularly true especially if the clients would be availing of other services which would provide other forms of respite to the caregiver. On the other hand, this Office acknowledges that in cases in which clients would be exhibiting severe symptoms, while such a service would be very helpful to the care givers, it could expose the client to unacceptable elevated anxiety, thereby making the situation worse. To this end, while NAO acknowledges the need of having beds available to offer this service, it remains cautious in expressing concern or otherwise on the low usage. This notwithstanding, NAO agrees with DIT that this service should not be used as a last resort in cases in which challenges to daily life would become unsurmountable, but rather as a pressure valve to mitigate the possibility of such a situation materialising.

### NAO Recommendation

- 3.6.8. Insofar as residential respite is concerned, NAO urges DIT to ensure that, as far as possible, sufficient investment is made in information and educational campaigns so that individuals who are in real need of this service would be made aware of its existence and adequately encouraged to make use of it.
- 3.7. Strategy Objective Delivery 6.3.4 (i) - Develop night-time shelters in a number of localities that specifically cater for individuals with dementia and their caregivers.**

### *Partly Implemented*

- 3.7.1. During the fieldwork stage of this audit exercise, NAO enquired with DIT whether there are night shelters in Malta which are specifically intended to accommodate persons with dementia,

to which query the Unit had replied that there was no such service. This notwithstanding, DIT also highlighted that the new Mtarfa and Safi dementia activity centres (which commenced operations in the latter part of this exercise) are also intended to offer night shelter services to six and five people with dementia accordingly. It is important to highlight that these night shelters are also meant to provide activities for individuals with dementia during the night, as some people with dementia tend to find it difficult to sleep at night. It is planned that these shelters are to be manned by one carer and one nurse during the provision of this service.

- 3.7.2. As these dementia activity centres became operational during the latter parts of this audit assignment, NAO enquired whether the night shelters within these centres have also become operational as at time of writing and whether any clients have started to make use of them. In reply, DIT informed this Office that night shelters in these two centres are operational but have as yet not received any applications for use. NAO was also informed that, while Dar Padova and SVP have had night shelters respectively for some time, these are not intended to be used by people with dementia.

### NAO Observation

- 3.7.3. While NAO is concerned that up till recently no night shelters for people with dementia were operated or outsourced by the AACC, it positively notes the initiation of operations of the Mtarfa and Safi night shelter services during the latter parts of 2021. While this obviously is a positive development, this Office however feels that the number of available beds through these two centres is very limited when compared to the projected number of people with dementia living in the community. This notwithstanding, it is also acknowledged that as at time of writing, this was a relatively new concept and, in fact, there were no clients making use of these night shelters.

### NAO Recommendation

- 3.7.4. As the Mtarfa and Safi Dementia Centres are the first initiatives which offer night shelter for people with dementia, and given that as at time of writing they were not attracting any clients, NAO encourages the AACC and/or the DIT to ensure that extensive exposure of this service is given to the general public so that anyone who would be in need of it would be made aware of its existence. However, as the number of available beds for this service between these two centres is very limited, this Office further urges AACC to increase these (either by further capital investment or through PPPs) should demand eventually prove higher than the available supply.

**3.8. Strategy Objective Delivery 6.3.4 (j) - “Ensure that existing community services (and the development of new ones) housing individuals with dementia adequately cater for their needs. This includes trained staff and a dementia-friendly approach both in service delivery and design.”**

3.8.1. *NAO feels that the attainment of this objective or otherwise is in part determined through the implementation of other strategy points within the dementia strategy, particularly points A (section 3.1), D (section 3.4), H (section 3.6) and I (section 3.7). As these cited objectives all relate to initiatives which are intended to provide a service specifically to people with dementia, this Office understands that there could be other, more generic community services which house people with dementia, and which consequently fall under this objective. It was however not possible for NAO to assess all such entities for their conformance with this strategy objective and it scoped its work to the already mentioned sections.*

**3.9. Strategy Objective Delivery 6.3.4 (k) - “Assist in the setting up a voluntary service for older adults in the community with the aim of providing companionship to individuals with dementia as well as the elderly in general and providing some respite to caregivers. This service can also be operated in collaboration with the private sector.”**

*Not Yet Implemented*

3.9.1. During meetings with NAO, PC and AACC both indicated that this strategy objective has not been implemented. Both AACC and PC asserted that in order for such an initiative to be successful, prospective volunteers must be given specific training on dementia, particularly on how to communicate with such clients. AACC further expressed that the implementation of this strategy objective would require the building of a framework within which such volunteers would need to operate.

3.9.2. AACC however also asserted that the companionship element outlined in the strategy, albeit not through a volunteering set-up, is also offered through the residential respite and the respite at home services. AACC specifically explained that these services do not only provide a caring element to the persons with dementia, but can also be important in providing companionship. It was also highlighted that the Dementia Helpline can also contribute in this respect.

**NAO Observation**

3.9.3. While NAO acknowledges that companionship can be provided through services such as the residential respite and the respite a home, it still believes that a structured initiative in this respect is of benefit. Though this Office understands AACC’s expressed concern that such

an initiative requires a framework within which such volunteers would need to operate, it is however of the opinion that it is the AACC itself which is responsible to formulate such a structure.

### NAO Recommendation

3.9.4. Though this Office acknowledges that services such as the residential respite and respite at home do offer companionship to people with dementia, it still encourages AACC to give due attention to the setting up of a voluntary service with the aim of providing companionship. As suggested by AACC itself, NAO believes that this service needs to be guided by a framework, designed by the former, within which such volunteers would need to operate, thereby securing a desired level of service.

**3.10. Strategy Objective Delivery 6.3.4 (I) - “Assist in the creation of a network to help individuals with dementia and their caregivers in having peer support. This may be achieved by boosting non-government organisations working in this field, possibly through service level agreements.”**

#### *Partly Implemented*

3.10.1. The Malta Dementia Society (MDS) is the only Non-Governmental Organisation (NGO) in Malta which is specifically intended for persons with dementia and their caregivers, with a total of 336 registered members and close to 900 members on its Facebook page as at time of writing. In view of this, the audit team enquired with Chairperson MDS whether it has secured a service level agreement with Government such as that cited in this strategy objective or otherwise. To this, Chairperson MDS replied that no such agreements were, as yet, signed.

3.10.2. CEO AACC however highlighted that AACC collaborates closely with MDS to plan and organise a number of projects and initiatives. In order to achieve this, CEO affirmed that AACC communicates regularly with the chairperson of MDS so as to ensure that such initiatives are successful. An example of such collaboration was the Alzheimer’s Disease Awareness week which was held in September 2021 where AACC and MDS manned an information stand at Valletta City Gate to create awareness on dementia.

3.10.3. CEO AACC further informed the audit team that, before the onset of the COVID-19 pandemic, Dementia Cafes were regularly organised jointly by the AACC and the MDS. Specifically, three such activities were organised in 2018, one was held in 2019, one in 2020, and one which was planned to be held in December 2021. These Dementia Cafes were organised with the aim of providing an informal setting to the informal caregivers and people with dementia to meet and discuss experiences and challenges that they encounter daily. During these meetings, talks by professionals and discussions with these professionals were also held. When NAO enquired

on the events' uptake, CEO AACC affirmed that since it was an open invitation there are no records of the number of attendees, with the number of people varying from one venue to another according to the space available.

3.10.4. This Office was further informed that, given that the pandemic disrupted the continuation of these Dementia Cafes, online support groups were created. Two online sessions were organised in 2020, and a further 10 held during 2021. These sessions are intended for persons with dementia and their caregivers and are planned to be held on a bi-monthly basis with a small group of not more than 10 caregivers. Although no formal application process exists for these groups, the DIT identifies caregivers from its client case who are in need of support and directs them towards attending these groups. The audit team was further informed that discussions are ongoing between the AACC and the MDS so that monthly online support groups currently being facilitated by the AACC, are organised on a more frequent basis, with the support of the MDS.

3.10.5. In addition, during meetings with the audit team, AACC affirmed that clients are encouraged to approach MDS so that they may benefit from the latter's initiatives. This notwithstanding, through its questionnaire NAO noted that, from the 73 respondents, only five indicated that they were MDS members. The audit team further noted that 23 respondents not only indicated that they were not part of this NGO, but further stated that they are not aware of it.

### NAO Observation

3.10.6. While this Office acknowledges that collaboration exists between MDS and AACC in organising activities for individuals with dementia and their informal caregivers as well as organising awareness campaigns intended for the general public, it notes that a formal service level agreement between AACC and MDS, as called for in this strategy objective, is still not in place yet.

### NAO Recommendation

3.10.7. NAO recommends that the working relationship between AACC and MDS is formalised through a service level agreement. This should be intended to commit both entities to a seamless approach in their initiatives thereby providing a better overall service to their clients.

**3.11. Strategy Objective Delivery 6.3.4 (m) - “Provide financial assistance to purchase/rent new assistive/information technology with the aim of increasing autonomy and quality of life” and Strategy Objective Delivery 6.3.4 (n) - “Provide financial assistance for infrastructural modifications that may be necessary within the patient’s residence with the aim of enhancing safety and quality of life of the individual with dementia, their caregivers and family members.”**

*Implemented*

3.11.1. During meetings with AACC, the audit team was informed that in 2021 the former launched the “Telecare on the Move” scheme, intended to provide a subsidised assistive device for persons with dementia. Amongst other functions, this device offers two-way communication between the client and their caregivers and/or a call centre (operating on a 24/7 basis), as well as detecting if the client suffers a fall. It is important to note that this device is designed to operate even outside of the client’s residence thereby increasing the possibility of a client extending his/her independence in a safer manner. Information forwarded by the DIT showed that, as at time of writing, 64 people with dementia were availing of this service.

3.11.2. Both AACC and DIT also directed the audit team to the Housing Authority’s (HA) Scheme for Persons with Disability, which offers financial assistance for infrastructural modifications such as lifts, stair lifts and adaptation works in the residence of the person with dementia. Through this scheme, an applicant may be awarded a maximum grant of €26,000. This grant is means-tested and features sub-thresholds as follows:

- Adaptation works, up to €6,000;
- Stair-lifts, up to €5,000;
- Lifts in private blocks of apartments where assistance is based on the share of the applicant, up to a maximum of €7,000.
- Lifts in private houses, up to a maximum of €20,000.

3.11.3. HA explained that a panel of experts from AACC and the Commission for the Rights for Persons with Disability (CRPD) work together with HA to assess these cases and recommend which works are needed to render the property accessible according to the needs of the clients. When enquiring with HA on the uptake of this scheme by people with dementia, the audit team was however informed that the Authority is not in a position to provide such information since no data is centrally kept on the medical condition of the applicant, even though medical certificates are submitted with the application.



3.11.4. AACC further directed the audit team to the Empowerment Scheme which is operated by Aġenzija Sapport. This scheme aims to provide financial support and guidance to persons with disability (including people with dementia) to purchase equipment which helps them lead a more independent life. This scheme entitles successful applicants to be awarded up to 50% (excluding VAT) of the total cost of the purchased equipment (with a maximum capping of €1,800, even if this amount may be exceeded in exceptional circumstances). In order to apply for the purchase of this equipment, the applicant has to present a report prepared by a professional (such as an occupational therapist, physiotherapist or audiologist) together with the application. When queried by NAO, Aġenzija Sapport indicated that this scheme was availed of by 19 and 21 persons in the years 2020 and 2021 respectively, whose applications cited dementia as the primary diagnoses.

### NAO Observation

3.11.5. This Office acknowledges the mentioned schemes as being in fulfilment of the two strategy objectives in question. NAO feels that these contribute to independent living thereby assisting dementia clients to live in their own residence for longer and delaying institutionalisation.

**3.12. Strategy Objective Delivery 6.3.4 (o) - “Provide support to caregivers to continue working whilst providing care. The caregiver pension should also reflect the specific and significant financial needs of dementia care.”**

### Implemented

3.12.1. With respect to this strategy objective, NAO notes that the services as reviewed throughout this report all, in part and to varying extents, contribute to the provision of support so that the informal caregivers may lead as normal a life as possible including the continuation of work. This notwithstanding, situations may arise in which the caregiver would deem it necessary to desist work to better support the person with dementia. In such instances, NAO understands that this strategy objective is calling for compensation in the form of an allowance to the care giver.

3.12.2. When enquiring on this with the DIT, the audit team was directed to the Income Support and Compliance Division (ISCD) within the Ministry for Social Justice and Solidarity, the Family and Children’s Rights (MFSC), and specifically to the carers’ allowance scheme. Through communication with NAO, ISCD explained that in order for an applicant to be entitled for a carers allowance, the caregiver has to be out of employment and living permanently with the person with dementia. Should these conditions be satisfied, a carer’s allowance, as stipulated in the Social Security Act, Cap. 318, would be awarded to the caregiver at a rate commensurate to the client’s level of dependency. Specifically as at August 2021, this carer’s allowance was categorised in two, namely the ‘increased carer’s allowance’ of €149.32 per week which is



granted to caregivers of clients who are highly dependent, and a 'carer's allowance' of €96.22 per week, which is granted to caregivers of clients with medium dependency requirements.

- 3.12.3. The audit team enquired with DIT whether it deems the current carer's pension as sufficient and adequately reflecting the needs of the informal caregiver when providing the care for the person with dementia. To this, DIT however replied that such an estimate is very difficult to arrive to, as calculating the cost of caring, especially for care afforded to a person with dementia, is not a straightforward process. The Unit further explained that the level of care required in this sector varies significantly throughout the disease's progression and is highly dependent on the type of dementia. As a consequence, determining whether the cited carer's pension rates are sufficient or otherwise is not possible.
- 3.12.4. When enquiring with the ISCD about the uptake of this scheme by caregivers who take care of individuals with dementia, the audit team was informed that such statistics are not available as information kept does not differentiate between different conditions.

### NAO Observation

- 3.12.5. Though NAO acknowledges that determining whether pension rates are sufficient for dementia informal caregivers or otherwise is very difficult, it feels that generally speaking the carers' pension as provided by the ISCD is in fulfilment of this strategy objective. Such a scheme alleviates some of the financial burdens which may be faced by informal care givers who would have opted to stop working to take care of an individual with dementia.
- 3.13. Strategy Objective Delivery 6.3.4 (p) - "Community support services offered by the government should take into consideration the special needs of individuals with dementia and those who care for them in the community. This includes housing options."**

### *Partly Implemented*

- 3.13.1. In its review the audit team observed that, most of the community services which are offered to people with dementia (Table 2 in Section 2.3.2 refers) are generic in nature. Particularly, during this exercise, NAO noted that the only services which are specifically tailored for the needs of individuals with dementia were the DIT, the Dementia Helpline, the Dementia Activity Centres and the Telecare on the move (already discussed in previous parts of the report). As already mentioned, this Office also noted that two Dementia Night Shelters commenced operations during the latter stages of this audit exercise.
- 3.13.2. This notwithstanding and as already mentioned, NAO appreciates that generic services may nonetheless assist people with dementia. In this respect, NAO was informed that AACC is

requesting training on dementia during the tendering process for contracted community services which have a caring component. As an example, NAO was furnished with a copy of the “tender for the provision of care worker services for care homes for older persons and dementia activity centres falling within the active ageing and community care (AACC)”, which featured the above-mentioned training requirement.

## NAO Observation

- 3.13.3. This Office acknowledges that persons with dementia still benefit from the generic services, particularly if these are offered together with other services which are specifically tailored for people with dementia. NAO further commends the inclusion of a training component specifically on dementia in AACC’s related outsourcing tenders, so that staff providing the aforementioned services, and who would therefore be interacting with individuals with dementia, would have adequate knowledge on how to best communicate and deal with these clients.

## NAO Recommendation

- 3.13.4. While NAO once again acknowledges that generic services are still be of benefit to dementia clients, it recommends that AACC endeavours to assess whether significant added benefit could be reaped if some of these could be better tailored for people with dementia. If it is found that that is the case, NAO urges AACC to invest the necessary effort and resources to make these services more focused on the dementia clients’ needs.

- 3.14. Strategy Objective Delivery 6.3.4 (q) - “Develop a basic dementia training programme for first-contact community support personnel (local council workers, the police force, the army, transport staff, the church etc.) in order to better assists individuals with dementia in the community”**

## *Partly Implemented*

- 3.14.1. During meetings with AACC and DIT, the audit team observed that, till time of writing, such training as called-for in this strategy objective has not been delivered on a wide scale.
- 3.14.2. Specifically, while such training was delivered in Safi (which was earmarked to be a dementia friendly village) the audit team however noted that training provided at Safi attracted the participation of only 25 residents. DIT further highlighted that attendance to this training by local services and businesses was so poor, that it was postponed to a later date. Similar talks were intended to be held at the other designated dementia friendly village of Mtarfa within the first quarter of 2022.

- 3.14.3. Enquiring with DIT whether there is the intention of widening the spread of this training to other localities in the country, NAO was informed that there are plans to eventually invite all local councils to engage in similar dementia-friendly initiatives.
- 3.14.4. In addition and in response to this strategy objective, PC indicated that as at time of writing, communication is being held with WHO to invest in a much wider initiative that targets all the Maltese audience who would be interested in getting extensive training on how to manage individuals with dementia. As at time of publishing of this report, NAO was informed by AACC that this initiative, named 'iSupport for Dementia' was launched in Malta in mid-February 2022 and is targeted to all dementia caregivers.

### NAO Observation

- 3.14.5. Although this Office acknowledges the effort made by the DIT to provide training programmes to the stakeholders and the residents in Safi, as well as the Unit's intention to provide similar training in Mtarfa in the first quarter of 2022, it still perceives that the spread of this initiative is too limited. In addition, NAO remains concerned on the lack of participation and interest shown in attending these training courses.
- 3.14.6. This notwithstanding, NAO positively acknowledges the launch of the 'iSupport for Dementia' which will undoubtedly prove to be of assistance to dementia caregivers in managing the condition better.

### NAO Recommendation

- 3.14.7. This Office urges AACC and DIT to invest the necessary effort to ensure that training to community stakeholders and residents is much more widespread and not limited to two localities. It further recommends that new avenues on how to attract more participation are explored, so that any organised training would be better attended.
- 3.15. Strategy Objective Delivery 6.3.4 (r) - "Introduce the Dementia Caregiver Card in order to (i) facilitate caregivers of individuals with dementia to accompany their relative requiring the use of out-patient services at Mater Dei Hospital, and (ii) offer the possibility of extended visiting hours for caregivers of individuals with dementia staying at Mater Dei Hospital."**

### *Not Yet Implemented*

- 3.15.1. When enquiring with AACC on this objective, the latter asserted that this card has not been implemented due to concerns with its adoption. As a start, AACC contends that such a card would label the person with dementia, opening avenues for abuse from third parties. Secondly,

AACC also stated that it perceives the possibility that the benefits that are intended to be afforded to caregivers through this card, could be abused of, principally by having some caregivers using them for reasons other than those strictly associated with the needs of the person with dementia. AACC also asserted that dementia is a condition which causes disability, and therefore one can apply to receive the EU disability card (which was launched by the CRPD) and be eligible for its benefits.

- 3.15.2. The audit team sought PC's opinion on this, to which he replied that, in his view, the dementia caregiver card is still needed as, the EU disability card does not sufficiently substitute the purpose of the proposed "Caregiver card", principally as the latter is intended to afford caregivers the right to accompany their relatives with dementia in hospital and have extended visiting hours, while the disability card provides different benefits.

### NAO Observation

- 3.15.3. NAO disagrees with AACC's reasoning on why the dementia care giver card was not introduced. As a start, this card is not meant for the person with dementia, but rather for the caregiver and its scope is limited to benefits within the hospital. In NAO's view of these considerations, AACC's argument of the person with dementia being labelled is rendered questionable. Secondly, this Office cannot agree that a valid initiative is not implemented due to risks of abuse. NAO contends that such risks should be adequately managed and addressed rather than impeding the implementation of an initiative. Finally, this Office is also concerned by the fact that, as stated by PC, the caregiver card is intended to offer benefits which are not covered by the EU disability card, and therefore the lack of introduction of this initiative is withholding the intended benefits to its target clients.

### NAO Recommendation

- 3.15.4. NAO recommends the expeditious launch of the Dementia Caregiver Card so that its benefits are reaped at the earliest by its intended users.

## Chapter 4 | Strategy Implementation

**This Chapter presents other salient findings on dementia community services which have emerged from the questionnaire administered by NAO. Besides feedback, which was specifically solicited through NAO's queries, this chapter also highlights a number of recommendations which were put forward by the respondents themselves.**

**Note:** When administering its questionnaire, NAO took the opportunity to enquire with respondents on general aspects of community services as provided by AACC. This meant that such feedback did not fall under specific dementia strategy objectives and is therefore being presented separately here.

### 4.1. General Perceptions on Community Care and Services

4.1.1. As part of its effort to understand the general perception of service users, NAO asked the 73 participants to indicate whether they are in agreement or otherwise with a list of statements regarding the Community Care and Services which are currently being provided by AACC. Table 7 below presents the feedback received based on a five-point Likert Scale.

**Table 7: Feedback received on Community Care and Services**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not answered
I believe that the services offered are of good quality	11	29	9	0	0	24
The services offered are not dementia friendly	1	2	11	17	9	33
Location of service is not feasible	3	7	11	12	6	34
Staff is trained to cater for persons with dementia	16	18	8	2	0	29
Hours of certain services are not feasible	1	10	10	10	3	39
I am frequently asked whether I am satisfied with the service being given	4	10	13	10	1	35

Source: NAO

4.1.2. In addition to the above, NAO also enquired with respondents whether they believe that the services being provided are assisting people with dementia to attain an improved quality of life while still living within the community. In reply, out of the 73 participants, 38 replied in the affirmative, 28 replied somewhat, four replied no and the additional three refrained from answering.

4.1.3. Furthermore, when respondents were asked whether they feel that the services being offered are providing enough support, or otherwise, to them as caregivers, 35 respondents replied that they are satisfied with the level of support, 27 stated that they are somewhat supported, and the remaining 11 replied that they are not receiving enough support.

4.1.4. NAO acknowledges that, despite the provision of services, there still would be a segment of the intended client base who would not avail of these due to particular reservations. In this respect, the audit team listed a number of such potential causes for this and solicited feedback from the participants accordingly. Feedback received is presented in Table 8 below and is classified through a five-point Likert Scale.

**Table 8: Feedback received on the provision of services**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Not answered
I am not aware of certain community services	4	14	10	21	9	15
I do not apply for certain services because dementia client refuses/gets agitated	11	14	7	13	10	18
I refuse/do not see any benefit to seek additional help	1	2	5	23	21	21
I prefer to care for the person with dementia myself/do not trust others	4	20	14	9	8	18
I cannot apply for certain services because I have a problem with transportation	11	8	2	15	10	27

Source: NAO

4.1.5. In view of the above, NAO enquired with respondents (through open ended questions) if they have any thoughts and ideas through which they could be better assisted, as informal caregivers, in providing the necessary care to people with dementia. It must be noted that, in reply to this, 24 respondents highlighted that they are satisfied with the current arrangement to an extent that they do not have any recommendations to put forward. Of those who put forward recommendations, the following were the more prevailing:

- i. the need for more support, both psychological as well as through the enhancement of available services;
- ii. the need for additional financial assistance;
- iii. the need for further information and training on how to deal with the condition itself and on how to better manage the patient;

- iv. the need for more awareness on dementia such as through the use of media exposure;
- v. the need to avoid rotation of carers who provide care services in one own's residence, as such changes may cause undue distress to the person with dementia;
- vi. the need for stakeholders to communicate and liaise more with each other so that the services being rendered are better coordinated.

### NAO Observation

- 4.1.6. This Office acknowledges that in reply to such general queries on the services being provided by AACC, most respondents did not have adverse perceptions, with a significant segment of these rather expressing positive reactions to the presented statements. At the same time, NAO still notes that areas of improvement prevail, which may be impeding existing or potential clients from reaping the full intended benefits of the offered services.

### NAO Recommendation

- 4.1.7. NAO encourages AACC to take due note of the reservations and recommendations expressed by the respondents to NAO's questionnaire and assess whether the provided services could be enhanced to address them.

## Concluding Remark

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This Office believes that when dealing with a sensitive topic such as dementia, the holistic wellbeing of the individual with this condition and his/her care giver must be at the forefront of any consideration. To this end, the services offered to these persons have to be designed and administered in a way that fulfils these needs. In this respect NAO notes that an array of services are locally available, even if most are generic in nature and not specifically targeting dementia clients. While this Office acknowledges that generic services are still beneficial to people with dementia, it still believes that dementia clients may have exigencies which would be best addressed through a specialised service and delivered through individuals who have been provided with related training.

With the DIT being the focal point of this audit exercise, NAO acknowledges the generally positive feedback received on the quality of service being delivered by this Unit, even if certain shortcomings in its operations were identified by this Office. This notwithstanding, NAO remains significantly concerned by the low caseload this Unit has when compared to the projected number of people with dementia who are living in the local community. This Office feels that this important service should be afforded to a much wider client base so that as many people with dementia, as far as possible, are better guided and assisted to manage this condition. As expected, a significant expansion of DIT's operation will undoubtedly require additional duly qualified and competent human resources, which in itself is a significant challenge.

Of pivotal importance is the apparent need for a stronger and more structured communication system between the different stakeholders involved in this field. This Office feels that the current setup may present itself significantly fragmented to the intended client, which surely is not an ideal approach to be taken with a person with dementia or his/her caregiver who could already be under significant distress. In NAO's opinion DIT, being the intended focal point for people with dementia, needs to spearhead initiatives to address this important concern, thereby securing more seamless and easier access to all available and applicable services to its clients.

This Office also notes that, of the objective deliverables cited in the National Dementia Strategy in section 6.3, the majority have been implemented or registered significant progress, even if close to two years remain for the strategy implementation period to expire. In fact, NAO acknowledges that some of this progress occurred during the duration of this audit itself. This notwithstanding, this Office still feels that some of these objectives, though implemented, still need to be expanded and/or be better promoted to cover a wider segment of the intended client base.

NAO also draws attention to the objective deliverables of which progress of implementation is not as advanced as the aforementioned. In this regard, this Office encourages involved stakeholders to invest the necessary time and effort to ascertain the fruition of these before the set 2023 mark and to give due consideration to the recommendations set in this audit report.



## 2021-2022 (to date) Reports issued by the NAO

### NAO Annual Report and Financial Statements

May 2021 National Audit Office Annual Report and Financial Statements 2020

### NAO Audit Reports

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May 2021 Performance Audit: Preliminary review: NAO's role in reviewing Government's measures relating to the COVID-19 pandemic

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December 2021 Report by the Auditor General on the working of Local Government for the year 2020

December 2021 An audit of matters relating to the concession awarded to Vitals Global Healthcare by Government Part 2 | A review of the contractual framework