Integrated Atlas of Dementia Care in the Australian Capital Territory - 2022

UNIVERSITY OF CANBERRA

University of New South Wales

Disclaimer:
This report has been prepared through a consultancy process using specific methods outlined in the Framework section of this report. The Project Team has relied upon the information obtained as being accurate with every reasonable effort made to obtain information from service providers providing services to people with dementia across the region. Information related to utilisation of services has not been included in this report.
The information, statements, statistics and commentary (together the "information") contained in this report have been prepared by the project team from publicly available information as well as information provided by the care service providers as described above across the Australian Capital Territory catchment area.
The language used in some of the service categories mapped in this report (e.g. outpatient, day care, non- acute) reflect the international category nomenclature employed within the Description and Evaluation of Services and DirectoriEs for Long Term Care (DESDE-LTC) classification system rather than a description of services. The consistent application of standardised category labels, which have been used for some years in Europe for health service mapping studies, provides a common language for meaningful comparisons of service across regions (nationally and internationally).

Authors
Hossein Tabatabaei-Jafari
MaryAnne Furst
Nasser Bagheri
Nathan M D'Cunha
Kasia Bail
Perminder Sachdev
Nicole O'Connor
Luis Salvador-Carulla

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Contents

Abbreviations

Abbreviation	Definition
ABS	Australian Bureau of Statistics
ACFI	Aged Care Funding Instrument
ACT	Australian Capital Territory
AN-ACC	Australian National Aged Care Classification
BSIC	Basic Stable Input of Care
CALD	Culturally and Linguistically Diverse
DESDE-LTC	Description and Evaluation of Services and DirectoriEs for Long-Term Care
FTE	Full Time Equivalent
GIS	Geographical Information System
HCP	Home Care Packages
HREC	Human Research Ethics Committee
ICD-10	International Classification of Diseases, Tenth Revision
ICF	International Classification of Functioning, Disability and Health
IRSD	Index of Relative Socio-economic Disadvantage
LGA	Local Government Area
LHD	Local Health District
MH	Mental Health
MTC	Main Type of Care
NDIS	National Disability Insurance Scheme
CHSP	Commonwealth Home Support Program
HCP	Home Care Package
NGO	Non-Government Organisation (or community service provider)
NMHC	National Mental Health Commission
PHIDU	Public Health Information Development Unit
PHN	Primary Health Network
SDCP	Specialist Dementia Care Program
SEIFA	Socio Economic Indexes for Areas

Executive Summary

This study aimed to evaluate and describe the pattern of service provision for people with dementia in the Australian Capital Territory. The aims were detailed as: 1) map the availability, workforce capacity and diversity of services for people living with dementia; 2) investigate connections between services and identify gaps in service provision and usage; and 3) develop Integrated Atlases of Dementia Care to support policy and practice change. A healthcare ecosystem approach has been followed using an internationally standardised service classification instrument--the Description and Evaluation of Services and Directories (DESDE) -- to typify and describe all services for dementia care in the study area.

All organisations specifically designed to provide health and social services to people with dementia (specialised) were eligible to be included in this study. Since many people with dementia usually receive care from general services (those which are not specifically designed for people with dementia), general services with a very high level (more than 50%; 'general-50') or a high (between 20 to 50%; identified in this atlas as 'general-20') or proportion of participants with dementia were also considered. Therefore, all specialised, general-50, and general-20 services, both in public and private, and across social and health sectors have been considered in this study.

After receiving ethics approval (UC HREC 10933), all possible services in the ACT were identified from publicly available data. Seventy-one service providers were available in the ACT which provided support and care for people with dementia at the time of conducting this study. However, based on information from their websites or direct questioning, 24 service providers were excluded because they were not specific and less than 20% of their clients had dementia. Thus, there were 47 service providers were included in this study. Websites of the included service providers were used to collect basic information about services, and they were contacted to arrange an online, or in-person interview for further information. However, arranging interviews was not successful for several services providers and thus those that not interviewed coded only based on the publicly available information on their websites. Of those not interviewed, three service providers were unreachable because either no contact was available, or they did not respond to our requests after making at least three calls. Of those who responded

to our request, two did not agree to interview and the rest did not proceed to our request for interview.

The 47 identified service providers offered 107 services by 107 service teams providing 118 main types of care (MTC): 29 (27%) specialised services, 27 (25%) general-50 services, and 51 (48%) general-20 services. Of these, 46 (43%) were residential services, 41 (38%) were outpatient services, 6 (5%) were day care services, 3 (3%) were information services, 6 (6%) were evaluation services, and 5 (5%) were accessibility services. The target population for most service providers was people aged 65 years old or older, or 50 years or older for Aboriginal and Torres strait Islander (hereafter respectfully termed Indigenous) Australians. There were government supports for most types of care through Medicare, residential subsidy, the Home Care Package, the Commonwealth Home Support Program, the National Disability Insurance Scheme, and some other limited programs.

Except for a few service providers (three) which did not have a phone number available to contact, phone contact was the main way to access service providers. However, many had a national line only for all-purpose contact, including consumer contact, with people needing to go through a complex automated answering system. In addition to phone number, almost all have email address but mostly they have one email for all enquiries and usually there were no reply. This process would be quite difficult for older people and did not allow direct contact at the manager level for other service providers, researchers, or policy makers. Regarding availability, residential care was the dominant type of care for people with dementia, with a notable lack of diversity in types of care available. Most providers believed that the current care capacity for people with dementia in the ACT was not adequate to the needs for care. Although a large number of services were general-50 services, the level of workforce expertise did not differ significantly from that in specialised and general-20 services.

The findings of this study demonstrate the feasibility of applying an international service mapping system to describe the service provision in Australia. It has identified significant challenges even in a region with high resources and capability. This study also indicates the importance of contextualising dementia care with the mapping of aged care services as well as information about service use in the ACT. The mapping of dementia care should be expanded to other Primary Health Networks (PHNs) to conduct gap analysis, equality and accessibility to dementia care across Australia.

1 Introduction

At least 3% of people aged 65-74, 17% of people aged 75-84, and 32% of those aged 85 and older are living with dementia (Mayeux and Stern, 2012). In 2022, it was estimated that between 386,200 and 487,500 Australians were living with dementia (AIHW, 2022). This is equivalent to 15 people with dementia per 1,000 Australians, increasing to 83 people with dementia per 1,000 Australians aged 65 and over. Due to its high prevalence in older populations and the lack of a cure for the disease, dementia is a significant health and aged care issue in Australia with a substantial impact on the health and quality of life of people with the condition, as well as those of their family and friends. This will result in a reliance on care providers in all aspects of daily living as the condition progresses and requires a multisectoral approach involving health, social and disability services, and housing.

Aged care services are the most important resource for both people with dementia and their carers. Services include those provided in the community for people living at home (home support and home care), residential services for those requiring permanent care or short-term respite stays, and hospital services for those who need acute or subacute care. One in three people with dementia in Australia live in care accommodation (AIHW, 2022). In 2019–20, there were over 244,000 people living in permanent residential aged care, and more than half (54% or about 132,000) of these had dementia (AIHW, 2022). It is estimated that almost $3.0 billion of health and aged care spending in 2018–19 was directly attributable to the diagnosis, treatment and care of people with dementia. Residential aged care services accounted for the largest share of expenditure (56% or $1.7 billion), followed by community-based aged care services (20% or $596 million) and hospital services (13% or $383 million) (AIHW, 2022).

Considering the proportion of older people affected and the related expenditure, understanding the availability, capacity, workforce profile, accessibility, and equitability of services providing care to this population: as well as an analysis of any gaps in service provision, are essential for supporting evidence-informed planning, prioritisation, and resource allocation. Unfortunately, to date, there has not been any analysis of service provision and variation of healthcare use in this population group in Australia.

1.1 Context

The Australian Capital Territory is an Australian federal territory with a population of around 429,000. Geographically an enclave within the state boundaries of New South Wales, it is home to Canberra, the territory's only city and the nation's capital. The ACT population is resoundingly urban, with close to 400,000 people, or over 90% of its population, living in one of Canberra's seven districts, and smaller numbers living in rural and semi-rural areas to Canberra's south and west. The ACT also has a strong functional link with the small city of Queanbeyan in New South Wales (population around 65,000) due to its proximity to the territory's eastern border.

1.2 Health system in ACT

1.2.1 ACT Regional Health Hub

The role of ACT Health as a regional hub closely connected with the South Eastern NSW PHN. Canberra's area of influence covers a region of 220,000 km^2, with 1.2 million people living in a diverse geographical region incorporating the ACT, Southern NSW, Murrumbidgee, and Illawarra Shoalhaven Local Health Districts. It includes desert and beachside towns, Indigenous communities, drought-stricken farms, retirement communities, a major population centre (Canberra) and other urban clusters (Wollongong and Wagga Wagga). The ACT health system is an established system of general practitioners (GPs), specialists, nurses, allied health and hospital staff, and emergency/retrieval services in a range of organisational models: from single-doctor general practices to large tertiary hospitals where the region's nurses, doctors and allied health workers are trained (Canberra Health Services, 2020). Canberra Health Services provide all healthcare services in the ACT, including the 672-bed Canberra Hospital, 250-bed Calvary Public Hospital, Centenary Hospital for Women and Children, ACT-based community health services, and the outpatient University of Canberra Hospital. The ACT Health Directorate sets policy, plans health services to meet community needs, and funds a range of Non-Government Organisations (NGOs) to provide services to people in the ACT and surrounding region (Canberra Health Services, 2020).

A salient characteristic of the service region is an entrenched low doctor: patient ratio in primary care, with a patient: GP ratio of 1:1350 in the ACT (compared with 1:982 for metropolitan NSW). The entire region also suffers from specialist workforce shortages in surgery, medicine, obstetrics, and paediatrics, as well as nursing and allied health specialities. Population flow data as well as our study on Multiple Sclerosis services (Tabatabaei-Jafari et al., 2023) indicate

frequent cross-jurisdictional travel to access tertiary health care provided by Canberra Health Services in the ACT, supplemented by specialist outreach services from the ACT to the region. As a result of these factors, the region faces challenges in delivering and sustaining effective and equitable care, including reducing variations in care across the region, ensuring equitable access for all, integration of primary, secondary and tertiary care; effective referral and retrieval practices, workforce recruitment and retention, and service delivery to ageing and marginalised populations (Canberra Health Services, 2020).

1.2.2 The ACT Primary Health Network

Capital Health Network, the ACT Primary Health Network is one of 31 PHNs in Australia and covers the whole territory. It is a rapidly growing and diversifying region, with a relatively young population. Planned infrastructure growth to accommodate the needs of this swelling population includes the building of more schools and housing, with areas in Gungahlin and Molonglo expected to be the fastest growing, and the development of transport links, in particular the expansion of the light rail.

PHNs were established in 2015. Part of their role is to develop and commission new services to meet the needs of people with, or at risk of, chronic illness who can be appropriately managed in the primary care setting. They also have a key role in supporting integration and partnerships between health services (including state and territory funded services, NGOs and private practitioners), education providers and other relevant support services.

The territory is relatively socio-economically advantaged: its SEIFA (Socio-Economic Index for Areas) score at 1075 is the second highest of all Primary Health Network regions in Australia after Northern Sydney, and only 2.4% of its population rely on unemployment benefits for income (compared to 4.6-5.8% in Perth, 6.5% in Adelaide, 4.5-5% in Brisbane, 3-4.9% in Melbourne, 3.7% in Western Sydney). It has the second highest rate in Australia of young people still in fulltime education at age 16 (Public Health Information Development Unit (PHIDU), 2019)

Despite this, it has areas of great disadvantage. Canberra's story has been referred to as "a tale of two cities" (Analysis, 2018), its overall relative affluence and education masking pockets of significant and entrenched disadvantage(Burdon, 2017). For example, a relatively high percentage of people in the ACT live in social housing (6.5% compared to 3-3.6% in Perth metropolitan areas, 3.5-4.2% in Brisbane, 1.8-3.7% in Melbourne, 2-4.7% in Central, Eastern

and Northern Sydney), and this varies significantly across the region: while only 2.2-2.8% of people in Gungahlin live in social housing, in the inner north the figure is 10.6% (Public Health Information Development Unit (PHIDU), 2019). Historically, ACT's "salt and pepper" public housing strategy has been one of dispersal rather than congregation. This strategy locates smaller scale public housing throughout Canberra's suburbs and town centres, in order to support the development of diverse local communities, and to achieve positive social and economic outcomes for tenants and the broader community. However, a change in urban planning policy from a greenfield focus to one of urban renewal has also meant planning for redevelopment of the inner urban infrastructure, including the relocation of some inner area public housing further out into the suburban areas (Treasury). Planning and infrastructure changes such as the development of new public transport corridors and the relocation of public housing to more distant suburbs of the city have implications for population mental health through, for example, changes to people's experiences of social isolation or their accessibility to services.

The ACT PHN has the challenging task of commissioning appropriate and adequate health services to meet the needs of its fast growing, dynamic and diverse population. Coupled with the impact of chronic health diseases, this presents great challenges for service planning to meet current and anticipated community need. Running alongside the challenge of chronic care, PHNs are also having to negotiate the ways in which they and their services will engage with the NDIS. The NDIS is one of Australia's most significant social policy changes, and its roll out has impacted both disability and care service provision. The impact of these two major government policies on PHN service commissioning cannot be underestimated, and is explored in further detail in the respective sections below.

1.3 Access to care and supports by people with dementia

People with dementia and their carers experience major problems with accessibility to the services they need. These problems include inadequate health care services, particularly for culturally and linguistically diverse (CALD) populations and those residing in rural areas. Other accessibility issues include access to transport to health care services, long waiting times for appointments with both general practitioners and medical specialists, and affordability. Other related problems included issues of acceptability centred on the role of the family, feelings of shame when receiving care from a non-family member, traditional practices and gender sensitivity (van Gaans and Dent, 2018).

The majority of people with dementia live in the community (Gibson, 2020), relying mainly on informal care provided by their family members or friends to be able to remain living at home (Michalowsky et al., 2016). Indeed, for some, informal care is the only form of care they receive (Furnival and Cullen, 2022). Although the 2021 Aged Care Commission identified need for support for informal care partners to keep their partners with dementia living at home, this support is currently limited to respite care.

1.3 The standard Mapping of care provision for dementia in Australia: The Integrated Atlases of Care

Identifying the level and range of available services is an important aspect in understanding demand and delivery at a point in time for a specific region. A number of international organisations have called for an integrated model of health care, covering specific interventions for different disorders, and including a complex array of service provision settings including homecare, community, hospital, and other residential settings (World Health Organization, 2016). This will be important to improve the productivity and quality of care services, and in fully integrating the health care and social elements of long-term care provision, especially for people with dementia, in order to boost efficient and equitable care provision (Stansfield et al., 2020). The lack of standards for an effective international comparison of service provision in dementia was identified over 20 years ago (Pierre Moise et al., 2004). However, there are still major challenges for producing standard and valid comparisons of the patterns of care to people with dementia across different jurisdictions. National and international comparisons are hindered by ambiguity and inconsistency in service definition and description; differences in organisational structure; inconsistency in service definition and description; and differences in the definition of the target population. Hence using a common assessment and coding system allows harmonisation of service data, can inform equitable allocation of care resources, programmes, and treatment across different health districts, and facilitate linkages of health networks.

In addition, all health system approaches require a broader perspective of health care ecosystem analysis that takes into account the spatial–temporal variation across regions in the patterns of care and related impacts (Snijder et al., 2018, Dwyer-Lindgren et al., 2018). Understanding the complex intersection of contextual factors is fundamental to the implementation, provision, modelling, and improvement of services (Davidoff, 2019). Therefore, specific approaches to local service coding and mapping are required to address local impacts of service use. Integrated

Atlases provide a demonstrated method of categorising services which recognise contextual factors (World Health Organization, 2018, Salvador-Carulla L et al., 2011). The utility of integrated atlases has been demonstrated in describing single location service systems workforce capacity; visualising variations and gaps in health systems, providing a broader perspective (e.g. multi-sectorial); and showing differences in the availability and diversity of services across geographic locations (Australian Institute of Health and Welfare, 2019).

Geographical variations in health service provision and utilisation were first observed in 1973 by Wennberg and Gittelsohn (Wennberg and Gittelsohn, 1973), and continue to be documented in research articles (Bekelman et al., 2016, Corallo et al., 2014), and in atlases of healthcare such as the Ontario Atlas of Care (Noble, 1994), the Dartmouth Atlas (Cronenwett and Birkmeyer, 2000, Goodman et al., 2013), the WHO Atlas of Neurology, and the Australian Atlas of Healthcare Variation. These Atlases of health provide healthcare information for a region or regions. They are however, susceptible to two major biases that could impact on the translation of healthcare findings into regional and local planning and resource allocation: the ecological fallacy bias, which derives from an assumption that national averages apply directly to individuals or to local area services (Rosen et al., 2020, Saunders et al., 2016); and the terminological unclarity bias, which refers to ambiguity and vagueness in the naming and definition of the services (Salvador-Carulla et al., 2015) and interventions (G et al., 2017). They also focus on the provision of medical services, rather than taking an integrated approach. Information is sourced from experts, in a “top down” model.

In order to avoid these pitfalls in the analysis of service provision in local systems, it is necessary to use a common reference framework (Leginski et al., 1989), a validated glossary of terms (Montagni et al., 2018), and a standard classification system (Salvador-Carulla et al., 2013) for coding and mapping local services. Integrated Atlases such as the Integrated Atlas of Mental Health of ACT (Furst et al., 2021a), the Integrated Chronic Care Atlas of Dubbo and Coonamble (Mendoza et al., 2017), the Integrated Mental Health Atlas of Western Sydney (Salvador-Carulla et al., 2015) and the Integrated Atlas of Multiple Sclerosis in the ACT (Tabatabaei-Jafari et al., 2023) have used an innovative service classification instrument, the Description and Evaluation of Services and DirectoriEs for Long Term Care (DESDE-LTC) in combination with Geographic Information Systems (GIS), to gain detailed local information about service provision and availability from local service managers in a “bottom-up” approach. This data has revealed gaps in service provision and identified differences between what services are expected to do and

what they actually do, as well as problems with the stability of service provision. This is highly relevant information for health policy. Additionally, GIS helps to visualise the pattern of care and support communication of complex data to decision makers by providing visual geographical maps of the data (Parrott et al., 2007).

The DESDE-LTC (Salvador-Carulla et al., 2013) tool is a well-defined classification system that can be used for the standardised description of health services available in a defined area using common units of analysis in service assessment, allowing comparisons across different health districts (Salvador-Carulla et al., 2013, Salvador-Carulla et al., 2006, Salvador-Carulla et al., 2000). DESDE-LTC has previously been used for describing care provision in over 34 countries (Romero-Lopez-Alberca et al., 2019). It uses an international terminology and coding system to overcome the problem of local and national variation in the names of services.

1.3.1 Ecological approach

The modified Thornicroft and Tansella matrix of care delivery (Tansella and Thornicroft, 1998) and related ecological production of care model (Boyd and Krupnick, 2013) provide the main model for research within the area of health care systems. Thornicroft and Tansella combined the model of production of healthcare developed by Avedis Donabedian (Donabedian, 1988) to describe health systems in terms of structure, process, and outcomes with an ecological approach, stratifying the decision-making levels within health services, and describing these as “micro” (between patient and clinician-level); “meso” (community level, including healthcare services) and “macro” (governmental-level) . The Thornicroft and Tansella matrix enabled a more holistic and systemic analysis of integrated care across the different components of the system. The DESDE classification system and its earlier version, the European Service Mapping Schedule (ESMS) (Romero-Lopez-Alberca et al., 2019) added “services” at the “micro” level in the spatial axis (quadrant 3A) and a “nano” level to describe the patient-clinician level (quadrant 4A). In Integrated Atlases, we are looking specifically at the care service delivery system at the meso level (quadrant 2A), and the aggregation of information from the micro level to the meso level (quadrant 2A) and from meso level to macro level (quadrant 1A).

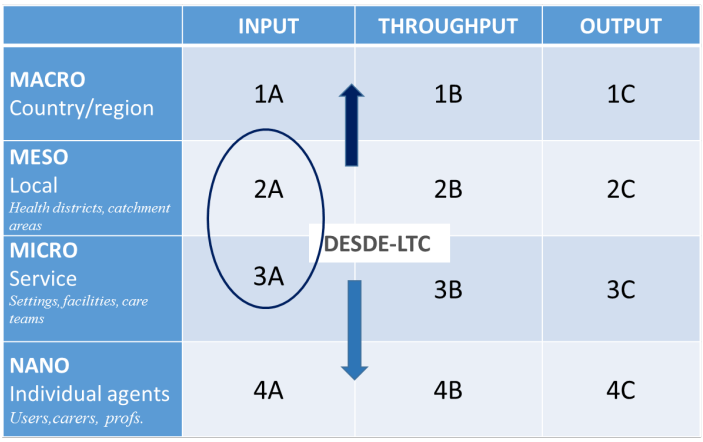

Figure 1-1 Extended Tansella and Thornicroft Care Matrix. Comparison of NMHSPF and DESDE-LTC. Adapted from Tansella & Thornicroft,1998. ***Modified from Thornicroft & Tansella (1999)*** **The Mental Health** ***Matrix, Cambridge Univ. Press***

1.3.2 Layers of services

The complex array of service provision for any given diseases/disorders are provided at different levels of speciality. At the highest level, sub-specialised services are allocated to a specific disease/ disorder. In this level, the service provider targets the specific needs of a particular group of patients. In specialised services, the service provider targets a category of specific diseases/disorders such as neurologic diseases. In the case of very rare diseases, this is the main level of specialised care available to patients. The next layers of care are general services (such as general practitioners, nurse practitioners, and geriatric services) and expanded supply services (such as dietitians, dentists, ophthalmologists, podiatrists and pharmacists). These layers of care are responsible for a large proportion of available services in each health care system.

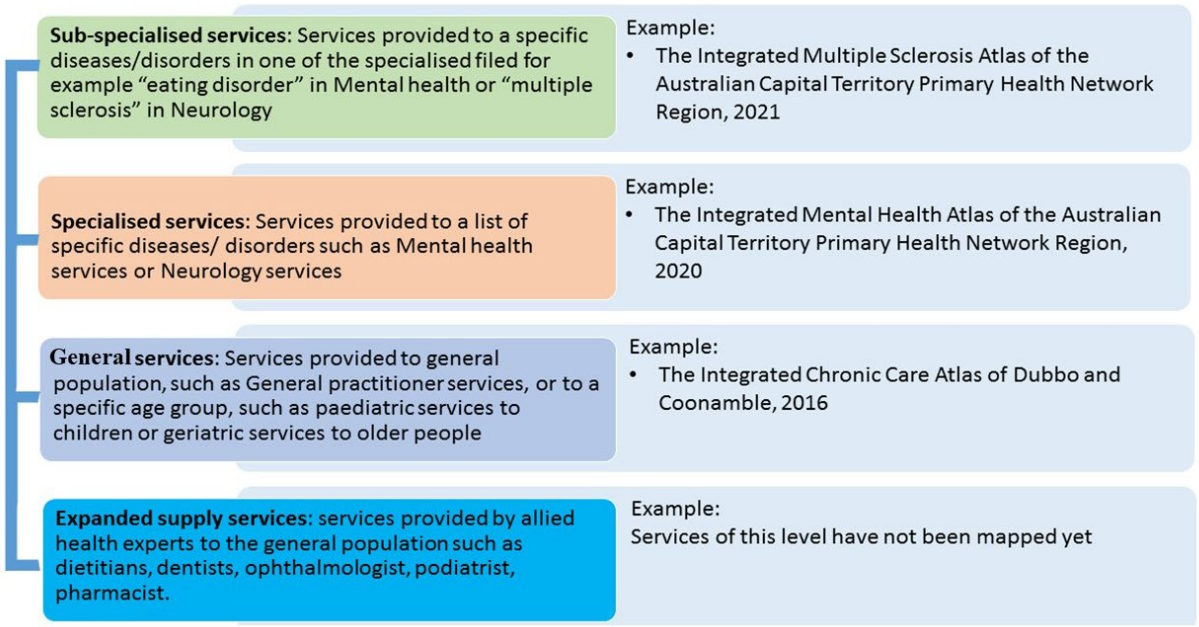

Figure 1-2 layers of health services

1.4 The Atlas of Dementia Care

The Integrated Atlas of Dementia services is an essential tool for planners of dementia service provision in ACT. This Integrated Atlas includes detailed information on social and demographic characteristics and health-related needs, as well as data on service availability and care capacity. The maps and graphics which are used as a main form of presenting the data allow policy planners and decision makers to build bridges between the different sectors. The information in the Atlas enables us to assess strengths and gaps in the health system, and provides the opportunity to assess the impact of policy decisions in the system. This information is vital for future integrated care planning.

The DESDE-LTC was used to code dementia services. The DESDE system classifies services based on actual service activity (i.e. what the service does) rather than on the service's name. The DESDE- LTC system is a classification system which uses a standardised coding methodology based on common terminology and a standardised procedure for data collection. This standardised approach allows service planners and researchers to complete meaningful comparisons of service systems across and within countries. Such comparisons allow for service gap analysis and monitoring of health systems. The use of the DESDE model has allowed comparison of "like for like" services and thus has provided a unique opportunity to assess longitudinal change within a given health system.

In a recent review of the use of the DESDE system it was observed that the DESDE (and the earlier ESMS system) have been used in 585 catchment areas and 34 different countries to describe services at local, regional and national levels. Authors of the review note that the DESDE/ESMS-system's metric properties have been extensively analysed, and the usability of the system has been demonstrated around the world (Romero-Lopez-Alberca et al., 2019).

2 Methodology

Typically, atlases of health are formed through lists or directories of services, and the inclusion of services is based on their official or everyday titles. This is particularly problematic for several reasons:

- the wide variability in the terminology of services and programs, even in the same geographical area
- the lack of relationship between the names of services and their actual functions (e.g. day hospitals, day clinics), as the service name may not reflect the actual activity performed in the setting
- the lack of a common understanding of what a service is. The word 'service' is an umbrella term that is used to describe very different components of the organisation of care. It merges permanent, highly structured services, with clinical units, or even short-term programs and interventions.

2.1 DESDE-LTC

To overcome these limitations, in this project, the DESDE- LTC has been used (Salvador-Carulla et al., 2013). This is an open access, validated, international instrument for the standardised description and classification of services for long term care. It was originally developed for health issues requiring long term care, such as its application in The Integrated Chronic Care Atlas of Dubbo and Coonamble in Australia (Research school of Population Health, 2019), which identifies services across a spectrum of care intensity and duration for people with chronic diseases.

The DESDE-LTC includes a taxonomy tree and coding system that allows the classification of services in a defined catchment area, according to the main care structure/activity offered, as well as to the level of availability and utilisation. It is based on the activities, not the name, of the service provider. The classification of services based on the actual activity of the service therefore reflects the real provision of care in a defined catchment area.

It is important to note that there are typically different units of analysis in research on health and social services, but comparisons should be made across a single and common 'unit of analysis' group. Different units of analysis include macro- organisations (e.g. Local Health Networks), meso-organisations (e.g. Hospitals), and micro- organisations (e.g. Services). They could also include smaller units within a service: main types of care, care modalities, care units, care

intervention programs, care packages, interventions, activities, micro- activities or philosophy of care.

Analysis based on DESDE-LTC is focused on the evaluation of the service delivery teams or Basic Stable Inputs of Care (BSIC).

2.1.1 Basic Stable Inputs of Care

A Basic Stable Input of Care (BSIC) is best described as a team of staff working together to provide care for a group of people. It could also be described as a service delivery or care team. These teams must have time stability (typically, they have been funded for more than three years or have funding secured for three years) and structural stability. Structural stability means that they have administrative support, and two of the following: their own space (which can be in a shared office); their own finances (for instance a specific cost centre); and their own forms of documentation (i.e., they collect data and produce reports on their service activities). There are several criteria that help to define a BSIC (Table 2-1).

Table 1-1 Basic Stable Input of Care Criteria

Criterion	
A	Has its own professional staff
B	All activities are used by the same clients
C	Time continuity
D	Organisational stability
D.1	The service is registered as an independent legal organisation (with its own company tax code or an official register). If NOT:
D.2	The service has its own administrative unit and/or secretary's office and fulfils two additional descriptors (see below). If NOT:
D.3	The service fulfils three additional descriptors
D3.1	It has its own premises and not as part of other facility (e.g. a hospital)
D3.2	It has separate financing and specific accountability (e.g. the unit has its own cost centre)

D3.3	It has separated documentation when in a meso-organisation (e.g. end of year reports)

2.1.2 Classification of BSIC

Once BSIC are identified using the above criteria, the Main Types of Care (MTC) they provide are examined and classified.

Each BSIC is classified by using one or more codes based on the MTC they deliver. Some services might include a principal structure or activity (for example, a 'Residential' code) and an additional one (for example, a 'Day Care' code).

There are seven main classifications of care within the DESDE-LTC, as described below (Figure 2-1).

Residential Care - Used to classify facilities which provide beds overnight for clients for a purpose related to the clinical and social management of their health condition. These include inpatient hospital wards, crisis shelters, residential rehabilitation services and inpatient withdrawal units. Residential Care is divided into Acute and Non- Acute branches (Figure 2-2).

Day Care - Used to classify facilities which: (i) are normally available to several clients at a time (rather than delivering services to individuals one at a time); (ii) provide some combination of treatment for problems related to long-term care needs (e.g. providing structured activities or social contact/and or support); (iii) have regular opening hours during which they are normally available; and (iv) expect clients to stay at the facility beyond the periods during which they have face to face contact with staff: these include the more traditional long-stay day programs (Figure 2-3).

Outpatient Care - Used to code care provided by service delivery teams which: (i) involves contact between staff and clients for some purpose related to the management of their condition and associated clinical and social needs; and (ii) is not provided as a part of delivery of Residential or Day services (Figure 2-4). These include outreach services. Quite often, Outpatient Care also involves the provision of information and support to access other types of care.

Self- Help and Voluntary Care - Used for BSIC which aim to provide clients with support, self- help or contact, with un- paid staff that offer any type of care as described above (i.e. Residential, Day, Outpatient, Accessibility or Information) (Figure 2-5)

Accessibility to Care - Classifies service delivery teams whose **main function** is to facilitate access to care for clients with long- term care needs. These services do not provide any therapeutic care, and include Care Co-ordination services (Figure 2-6).

Guidance including Evaluation (Test and Assessment) and Information:

1. **Evaluation –** Used for service delivery team whose main function is to provide users from the defined target group with "Test and Assessment". **Test:** performing a specific review or examination using a questionnaire or a rating scale or other instrument. **Assessment**: Evaluating a health condition, functioning, behaviour, or need for intervention. (Figure 2-7)
2. **Information for Care** - Used for service delivery teams whose **main function** is to provide clients with information and/or assessment of their needs. Services providing information are not involved in subsequent monitoring/follow- up or direct provision of care. These include many telephones information and triage type services (Figure 2-8).

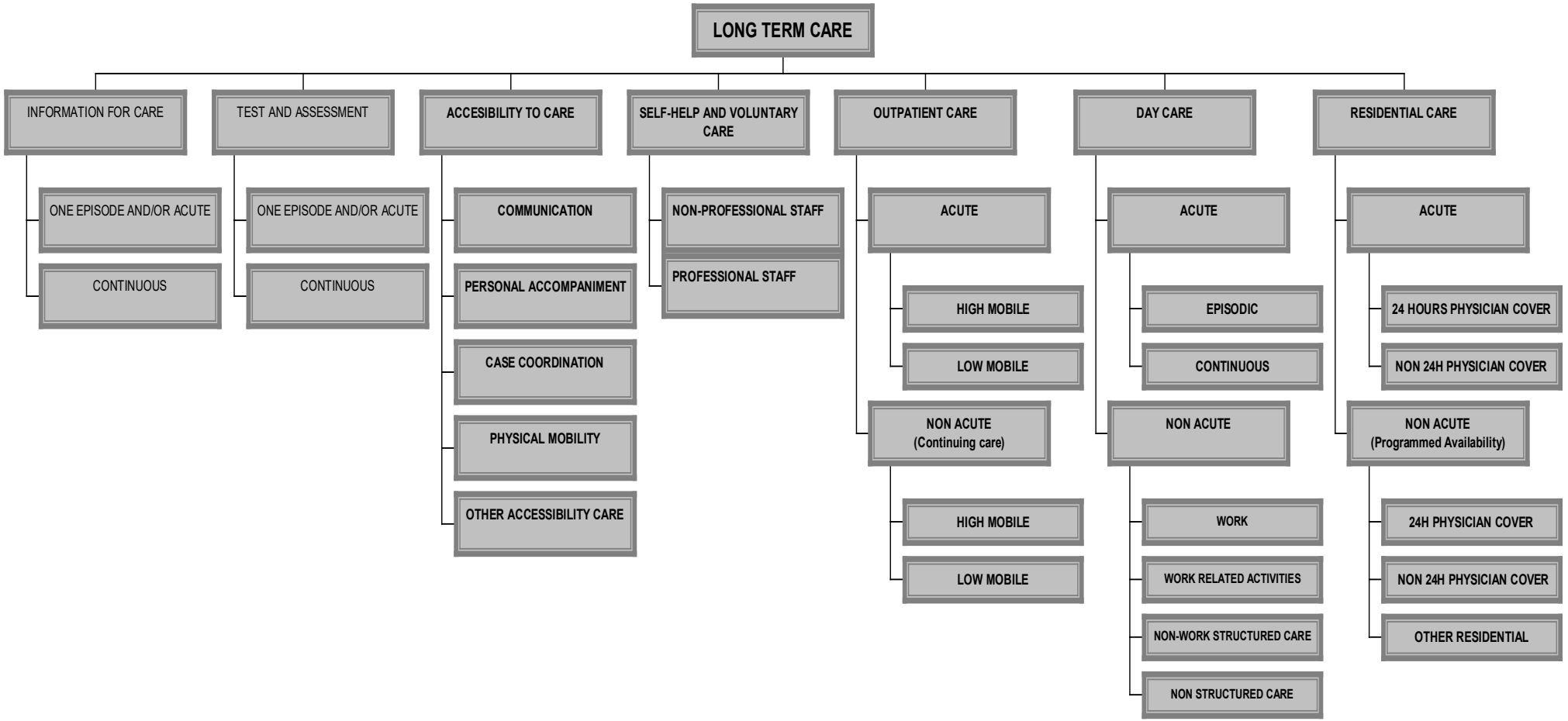

Figure 2-1 Long Term Care Main Branches of Care

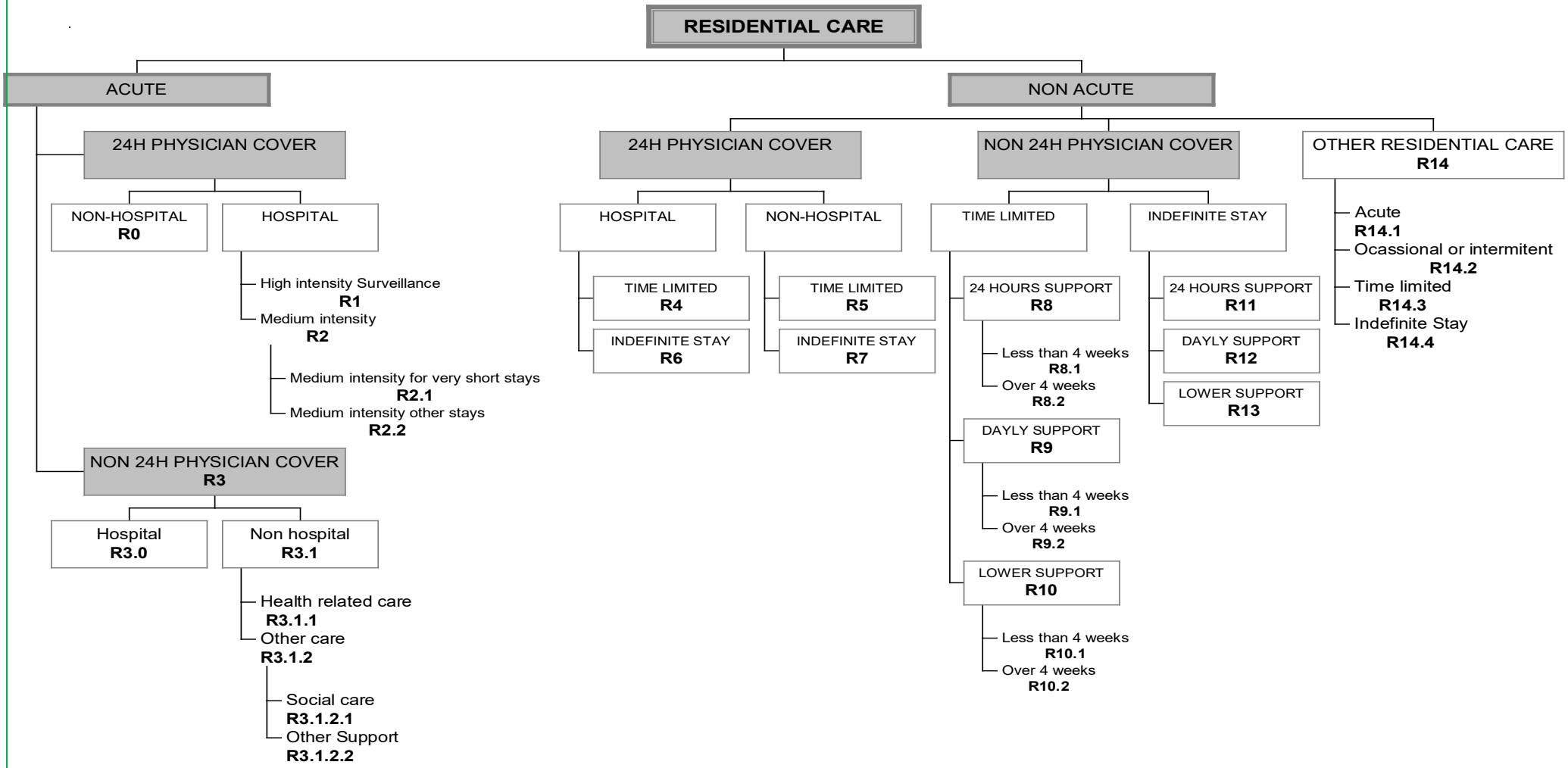

Figure 2-2 Residential Main Branch of Care

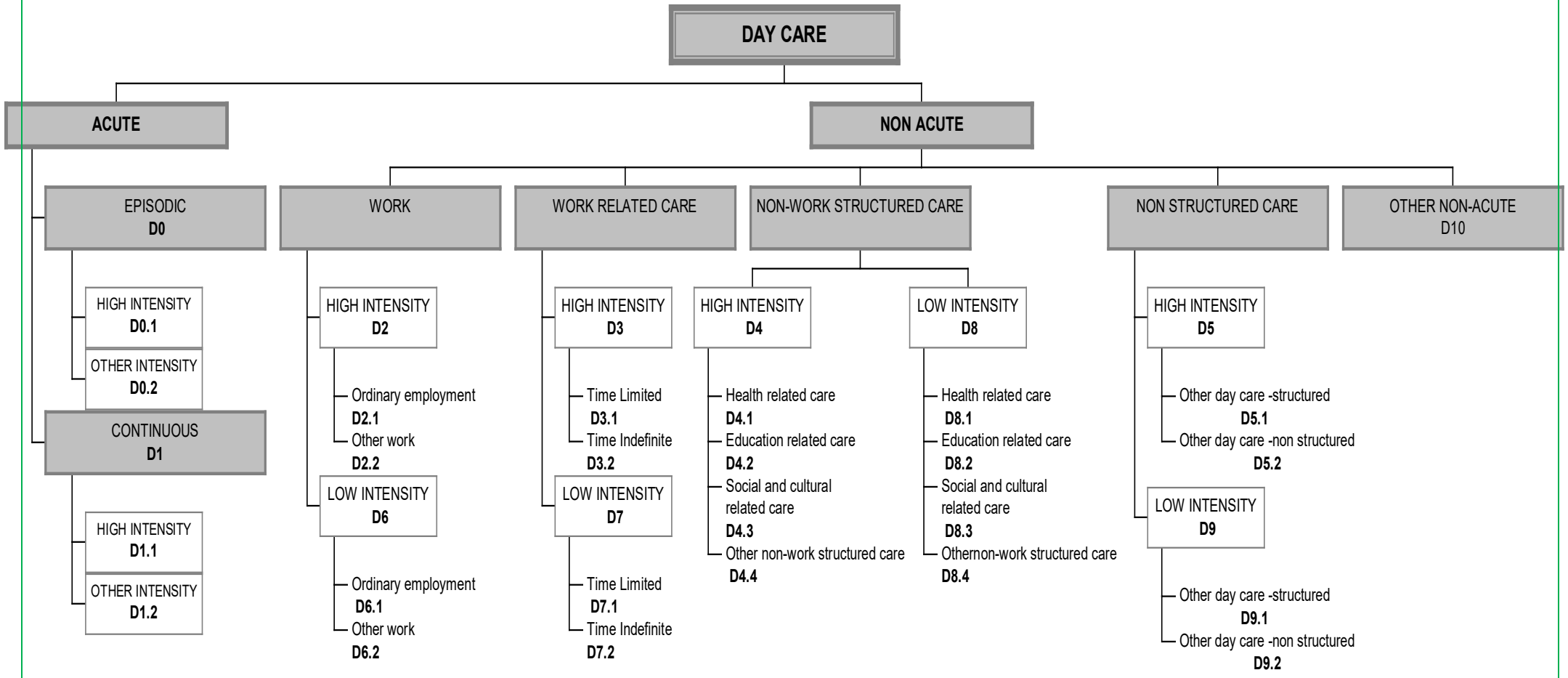

Figure 2-3 Day Care Main Branch of Care

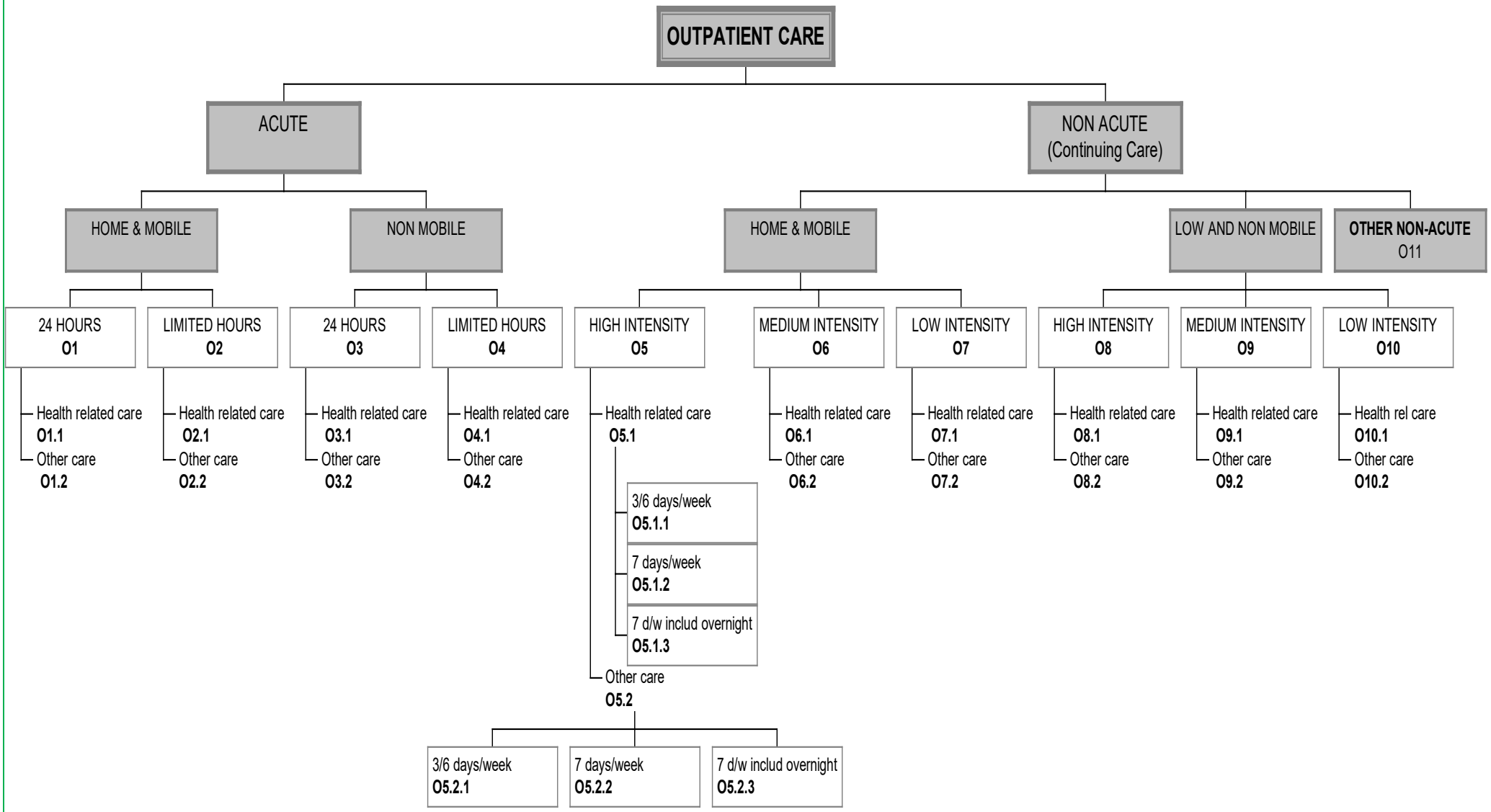

Figure 2-4 Outpatient Main Branch of Care

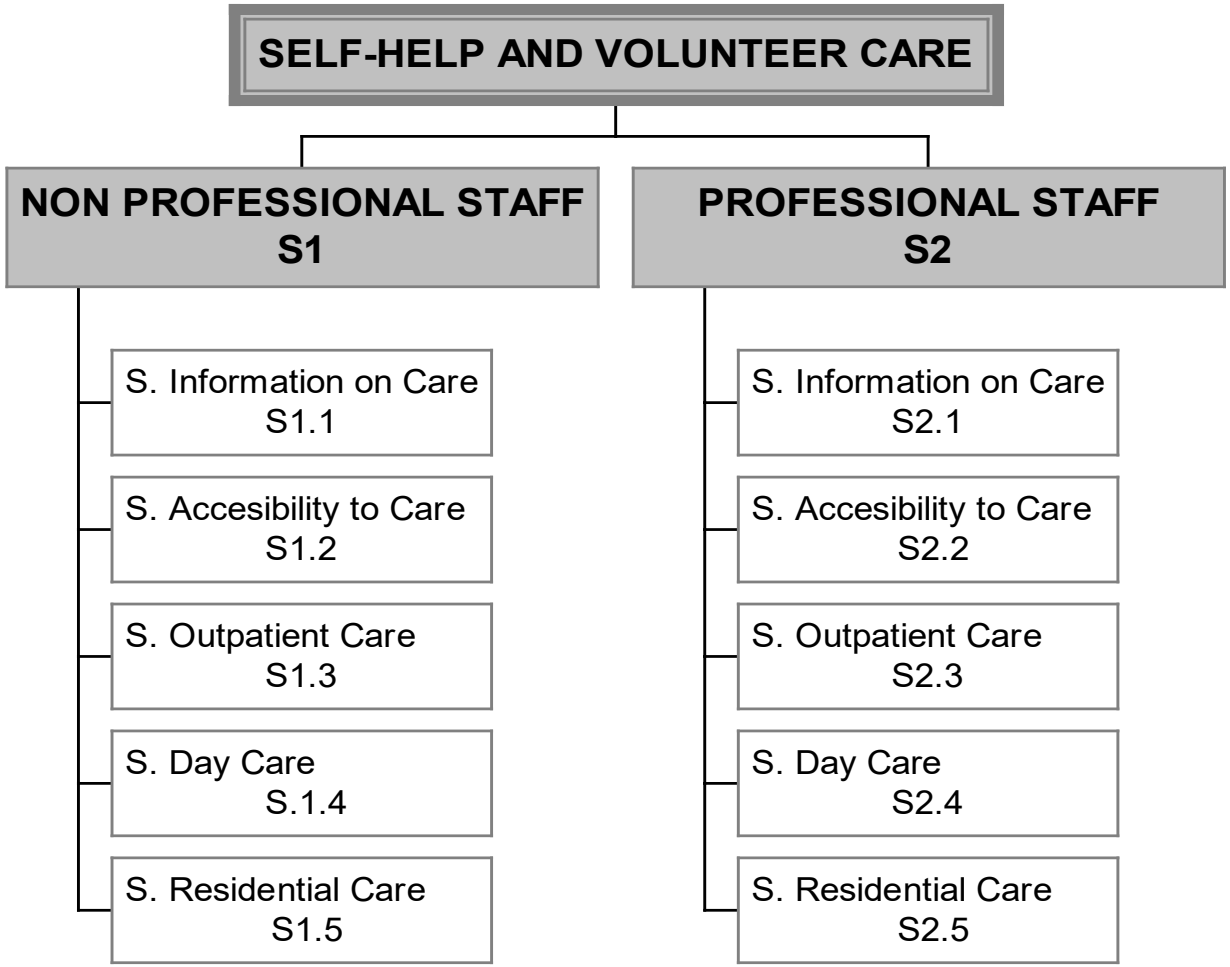

Figure 2-5 Self-help and volunteer Main Branch of Care

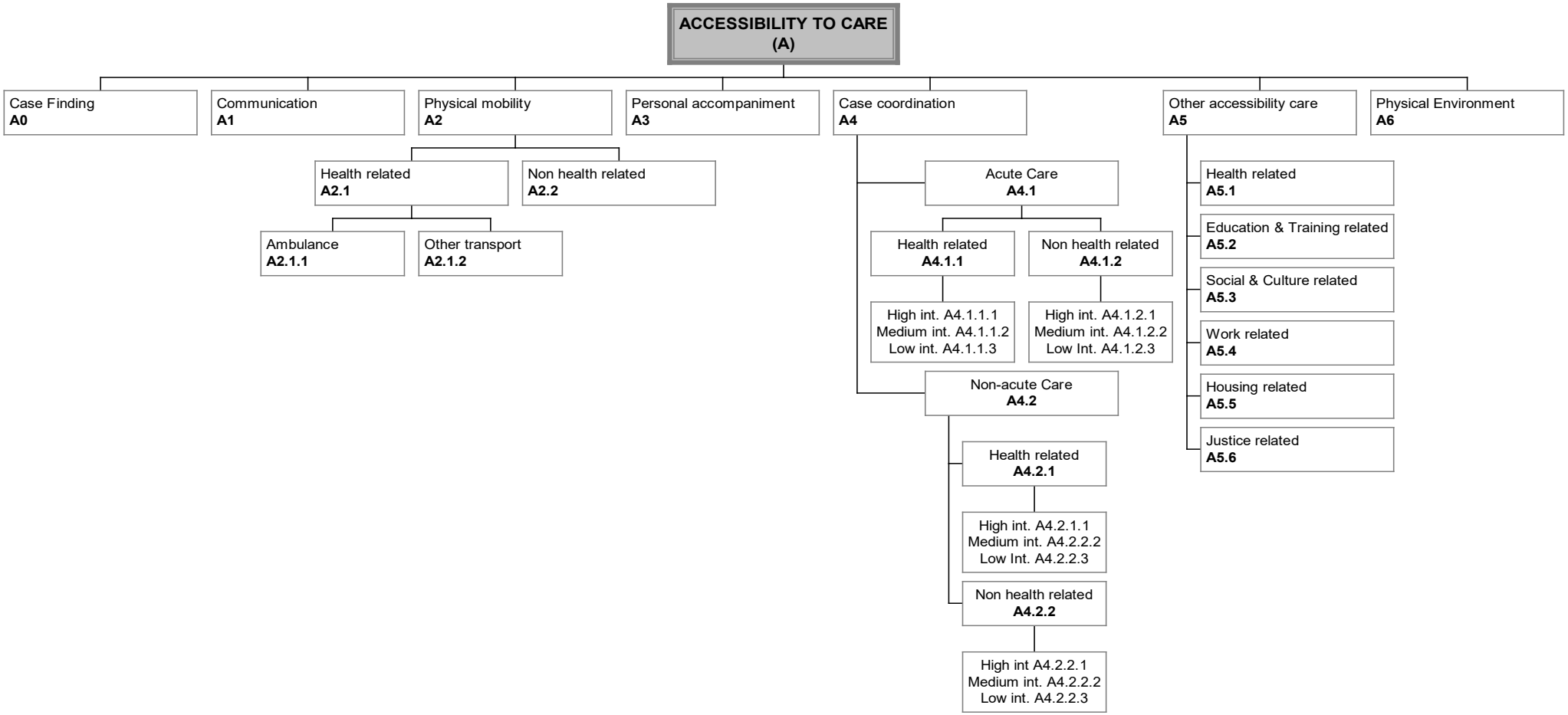

Figure 2-6 Accessibility Main Branch of Care

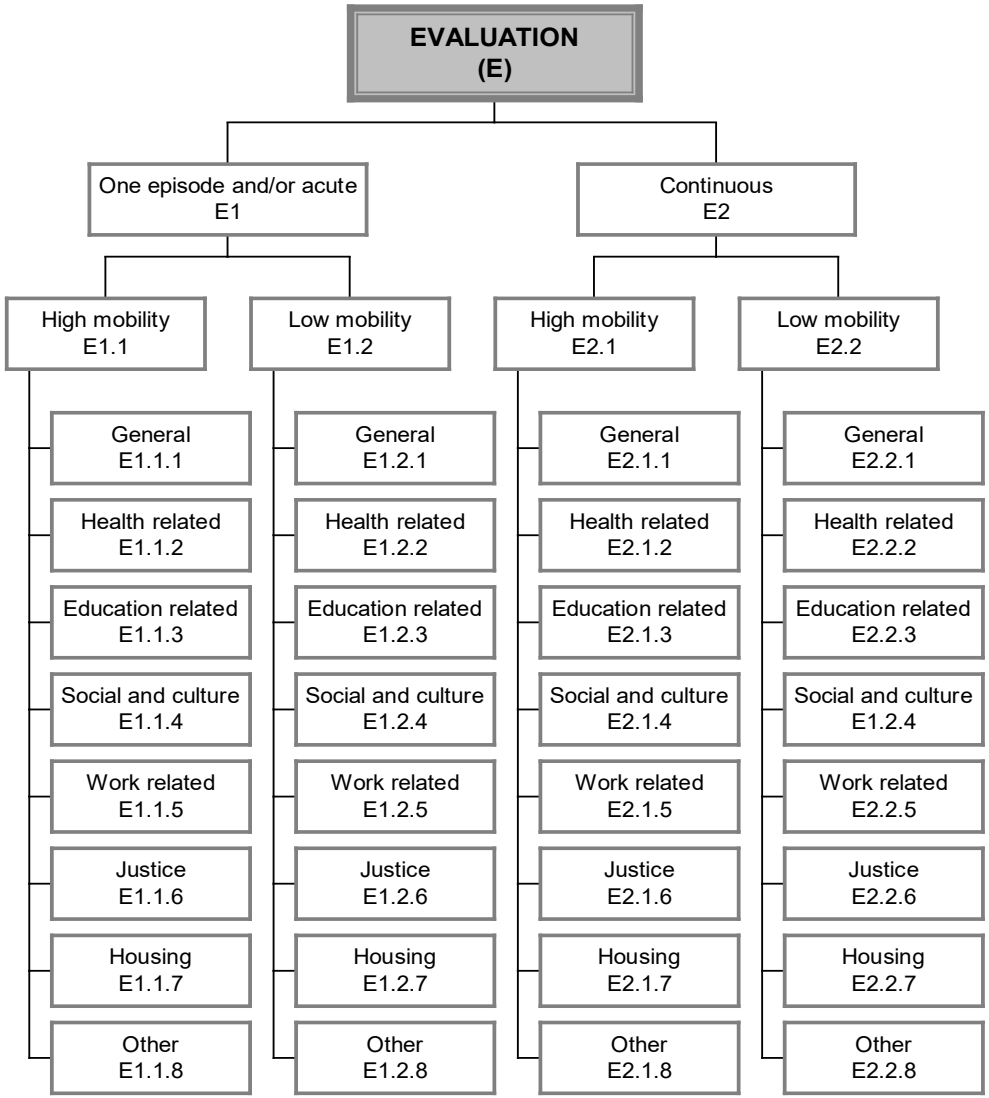

Figure 2-7 Evaluation (test and assessment) Main Branch of Care

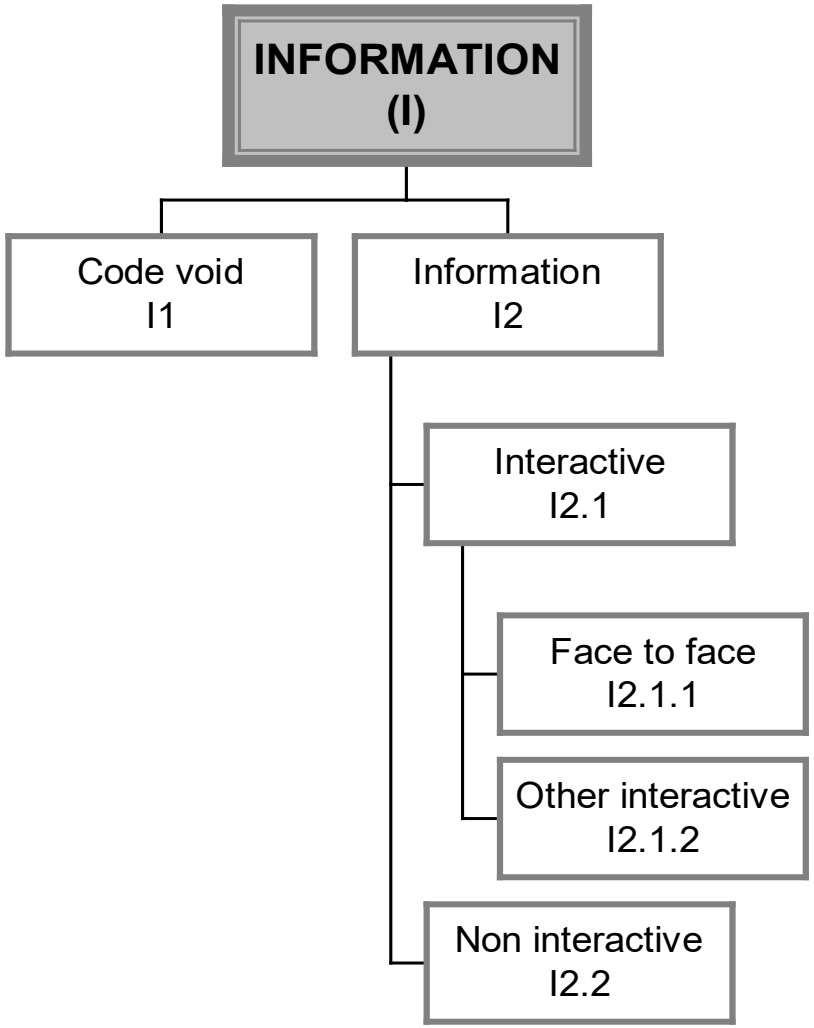

Figure 2-8 Information for Care Main Branch of Care

2.1.3 Other Care Teams (OCT)

These are a minimal set of inputs organised for delivering health-related care characterised by time continuity which do not fulfil the organisational stability criteria or attributes described for a BSIC. An example is a stable clinical unit financed with earmarked funding under a policy provision programme separated from the general financing system of the micro-organisation and using separate documentation due to specific monitoring by the local health agency.

A typical case of OCT is 'clinical units' within 'care teams' of general hospitals or other health-related meso-organisations (e.g. a geriatric program within a broader care unit such as the general ward in a general hospital, or the acute emergency care function provided by the staff of the geriatric care team at the emergency room). These are coded with lower case mtc (d1.1 etc.) to differentiate them from MTCs of BSICs.

2.2 Inclusion Criteria

The Integrated Atlas has clear inclusion criteria to ensure consistency and comparability across Atlases created using the DESDE methodology, both internationally, and across Australia.

To be included in the Atlas a service must meet certain inclusion criteria:

The service must target people with dementia - That is, the primary reason for using the service is for treatment or management of dementia or its complications. This includes specialised services that only provide care to people with dementia, and generalised aged care services that provide geriatric services to older people, including people with dementia. However, from general services, only those services where more than 50% of their clients (general-50) and those where more than 20% and up to 50% (general-20) of their clients have dementia were included in this atlas.

The service is universally accessible - the Atlas focuses on services that are universally accessible, regardless of whether they are publicly or privately funded. Access to most aged care services in Australia requires higher income or savings, or having NDIS, CHSP, HCP support in cases such as people with dementia.

The service is 'stable': that is, it has, or will, receive funding for more than 3 years - the inclusion of stable services guarantees that the mapping reflects the robustness of the system as a basis for evidence- informed planning. As such, services that are pilot projects

or are provided through short term grants are excluded. However, there is an appreciation that the current environment is one where there is significant uncertainty around the continuation of funding streams at both a state and federal level. Thus, an additional qualifier "v" has been added to the classification to identify services that do not have this stability of funding but whose exclusion would skew the information provided.

The service is within the boundaries of ACT- the inclusion of services that are within the boundaries of ACT is essential to have a clear picture of the local availability of resources.

The service provides direct care or support to clients - services that were only concerned with the co-ordination of other services or system improvement, without any type of direct contact with people with a lived experience of mental ill- health, were excluded.

2.3 Atlas Development Process

Phase 1: There were four key steps involved in the creation of the Integrated Atlas of Dementia

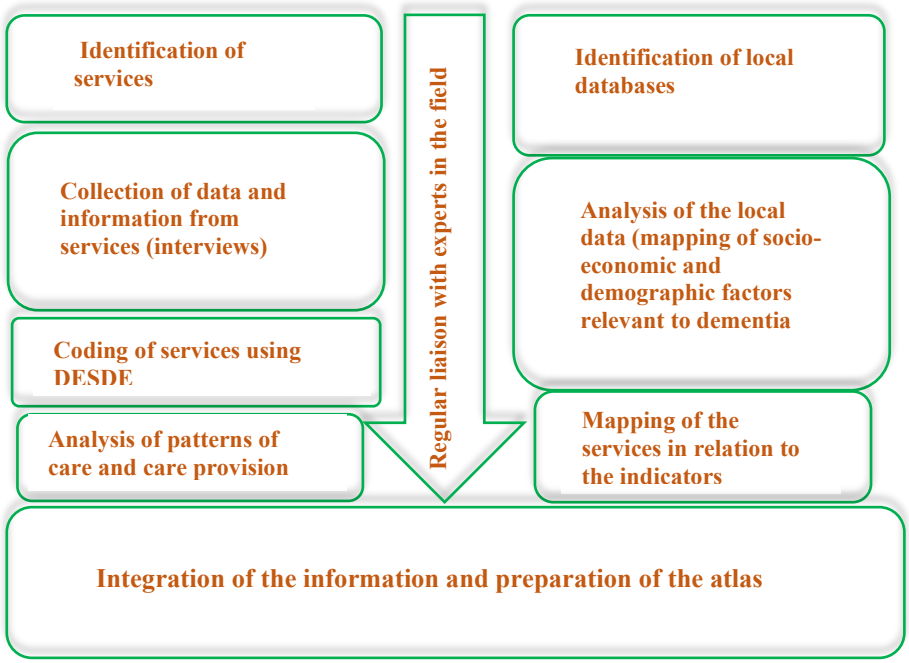

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Figure 2-9 Atlas Development Process

Step 1 – Ethics and Governance Approval

The project obtained ethical approval from the HREC at University of Canberra (ethics protocol 10933).

Step 2 - Data Collection

Initial search identifying eligible services: A preliminary list of organisations was drawn up to verify and pre- qualify where possible their appropriateness for inclusion in the Atlas. Online, telephone directory, and official service directories were searched, and experts in the field were consulted to identify and list eligible services providing dementia care in the ACT reference area (ACT Primary Health Network).

Webpage content extraction: information related to dementia care services were extracted from webpages of identified service providers. The Integrated Atlas methodology provides the framework and template for the information needed. This included:

- basic service information (e.g., name, type of service, description of governance),
- location and geographical information about the service (e.g., service of reference, service area),
- service data (e.g., opening days and hours, staffing, management, economic information, legal system, user profile, number of clients, number of contacts or admissions, number of days in hospital or residential accommodation, number of available beds or places, links with other services), and
- additional information (e.g., name of coder, date, number of observations and problems with data collection).

Contacting organisations and arranging interviews: To collect further information needed but not available on websites, organisations were contacted to arrange interviews with their representatives. A determination was made on how best to contact each organisation for the purposes of gathering the information necessary to create the Atlas.

Interviewing representatives: a representative of each identified organisation was interviewed through face-to-face meeting, via video conference, or through phone connection using the DESDE-LTC service inventory questionnaire. Following the initial interview, additional information was on occasion sought in order to support and verify classification decisions.

At the end of the interview, two open-ended questions were asked An open-ended question was asked from participants provided responses on their views and perceptions on the gaps in dementia services in the ACT region.

1) What do you think are the main gaps in dementia service provision in the region? and

2) What should we know about service gaps for people with dementia or carers, and do you have any examples that demonstrate these gaps?

Interview data were audio-recorded, transcribed verbatim, and then analysed independently by two researchers. Content analysis was conducted to interpret the underlying meaning of the data (Graneheim and Lundman, 2004). The two researchers interrogated the text to understand and characterise its content, and assign meaning units and codes based on their manifest content. Comparisons were then made between the authors interpretations and further sorted into themes based on their similarities until consensus was reached.

Meeting with focus group: An expert panel was established comprising five consumers (people with dementia at an early stage or their carers) and four health service researchers or clinicians and collected data was presented to them to get meaningful feedback and external validation.

Step 3 – Codification

Information gathered in step one was entered into a master spreadsheet, analysed, and allocated a DESDE code (where the service delivery team meets the inclusion criteria). The work of each service delivery team was coded following the criteria defined in the DESDE-LTC, according to the MTC provided. Codes can be split into four different components and follow a standard format.

(i) Client age group: This represents the main target group for which the service is intended or currently accessed by, using capital letters.

GX All age groups

AX Adult (e.g. 18-65)

AO Older adults (e.g., 50 – 65)

Ox Older than 65

TO Period from adult to old (e.g., 55-70)

In this case only services for the Older Adults (AX) and for Older than 65 (OX) have been considered

(ii) ICD-10 Code: ICD-10 codes appear in brackets after the age group code but before DESDE-LTC code in order to describe the main diagnostic group covered by the service. For generalist aged services, the International Classification of Functioning (ICF) code [ICF] is used, which means that the service includes all types of functional disorders rather than a specific disorder. For the specialised services for dementia the code [F01-03] is used.

The key diagnostic codes used in this Atlas are:

Table 1-2 Diagnostic codes used in Integrated Atlas of dementia Care of ACT Region

Diagnostic Code	Diagnosis
F01-03	**All types of dementia**
R41.81	**Age related cognitive decline**
ICF	**Used where the service is for any functional diagnosis**
ICD	**Used where there is not a specific diagnostic group for this service**

(ii) DESDE-LTC code: The third component of the code is the core DESDE-LTC code which is the MTC. As explained above, the services were classified according to their main type of care. This care can be related to: a) Residential care (codes starting with R); b) Day care (codes starting with D); c) Outpatient care (codes starting with O); d) Accessibility to care (codes starting with A); e) Information for care (codes starting with I); and f) Self-help and voluntary care (codes starting with S).

(iv) Qualifiers: In some cases, a fourth component may be incorporated to facilitate a quick appraisal of those characteristics of the services which may be relevant to local policy. Not all available qualifiers have been relevant for use in this Atlas. The qualifiers used in this Atlas are:

Table 2-3 Qualifiers used in Integrated Atlas of multiple sclerosis care in ACT Region

Qualifier	Description
a	**Acute care (complementary):** This qualifier describes acute care which is provided for users in a crisis situation within a non-acute, non-residential setting (branches "O" and "D") but which does not fit criteria for a separate MTC. As an example, this may be relevant to differentiate ambulatory facilities with the capacity to provide acute in working hours care as an ordinary activity from those ambulatory centres that do not provide acute care at all.
b	**Bundled care:** This qualifier describes episode-related care provision, usually provided for non-acute patients within a time limited plan (e.g. three months of brief psychotherapy). The 'b' qualifier is only assigned when at least 80% of the care provided in the facility is short- time limited and episode-related.
c	**Closed care:** This qualifier describes secluded MTCs with high level of security which is provided under locked doors. Usually these units are for crime & justice users or persons with mental illness with high risk for themselves or others. The availability of a single room for seclusion within an acute ward does not qualify the care team as closed care.
d	**Domiciliary care :** This qualifier describes MTCs provided entirely at the home of the user. If a care team provides mobile home care as part of a broader or more general activity it should not be coded as "d".
h	**Hospital (Care provided in a hospital setting):** This qualifier describes non-residential MTCs ("O", "D") provided in a meso-organisation registered as a "hospital" but which is different from acute residential care (e.g. an outpatient unit or a day hospital placed in a general hospital setting in order to differentiate these SCTs from similar units placed in the community). Also describes non-acute residential care normally found in the community (R8-R13) but which in this case is located in a health care campus or cluster and cannot be coded as R4-R6.
l	**Liaison care:** This qualifier describes liaison" MTCs where specific consultation and care is provided for a subgroup of users from a different main target population (e.g., liaison psychiatric care teams for oncology patients) usually located in another area of care (e.g. outpatient consultation on Intellectual Disabilities to a general medical care team or consultation on mental disorders to the general medical care teams of a hospital). A liaison care team provided to inpatients from other wards within the same general hospital will be counted as low mobility outpatient care. This qualifier excludes activities of care which are part of the other care team (e.g. psychology care provided by a psychologist within the oncology unit) and will not be counted as a liaison care team. A special attention should be paid to whether these facilities fulfil criteria for SCT or MTCs and are not care units or care programmes within a care team.

n	**Novel:** This qualifier describes hospital facilities of recent creation in hospital clusters or hospital campuses or community centres with partial residential care that do not fulfil criteria for typical hospitals.
q	**Quite:** This qualifier indicates that the main attribute of the MTC (e.g., mobility, intensity) is significantly higher/greater than for other care teams coded in the same MTC. For example, a "q" qualifier in a "low mobility" MTC indicates that the mobility of the care team is at the higher rank within the "low mobility" group (typically between 20 and 49% of the overall activity performed in the centre). A "q" qualifier in the "high mobility" MTC indicates that the mobility of the care team is higher within the "high mobility" group (typically between 80 and 98% of the overall activity performed in the centre).
s	**Specialised care:** This qualifier describes care teams designed for a specific subgroup within the target population attended by the care system at the local area (e.g. care teams for Elderly persons with Alzheimer's disease within the "E" group, or care teams for Eating Disorders within the "Mental Disorder" group).
u	**Unitary:** This qualifier describes single-handed SCTs where care is typically delivered by a single health care professional (psychiatrist, psychologist, nurse). This descriptor allows differentiating local systems where care is provided mainly by community centres and teams from those where outpatient care is mainly delivered by single professionals in individual practices.
v	This qualifier is used when the code applied at the moment of the interview could vary significantly in the near future (from example from acute outpatient care to non- acute). This depends on the capacity of the service to provide the type of care described by the code due to fluctuations in the demand or the supply capacity. This variability in the pattern of service provision is independent of the time continuity of the service. For example, a continuous service can have a 'v' code due to a health reform while a care program limited to two years may show organisational stability during the period when it is funded.
π	private

Example:

Residential care for adults older than 65 with dementia with behavioural problems will receive the following code: OX [F02.81] – R8s (figure 2-10).

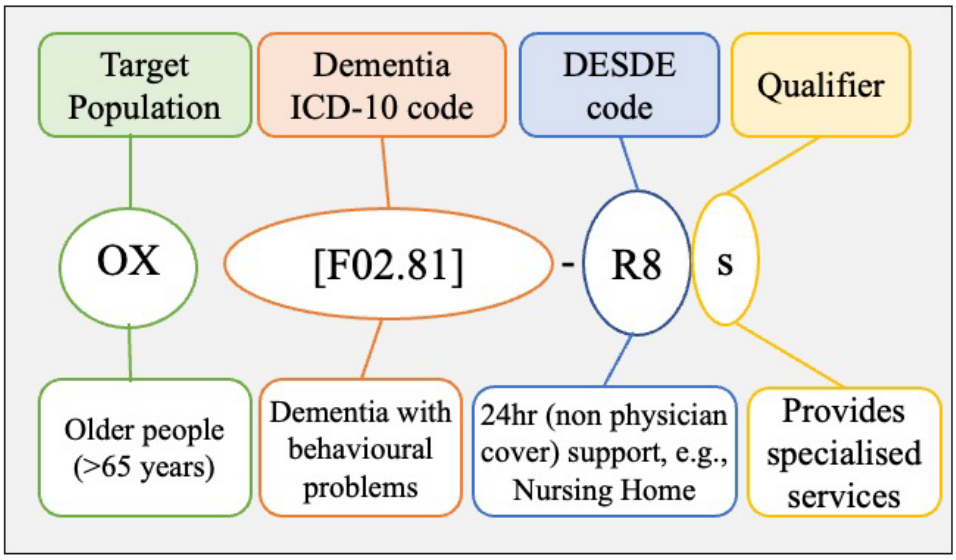

Figure 2-10 Code Components

Step 4 - Mapping the BSIC

The next step in the construction of the Atlas was to map the supply of dementia services in relation to indicators of potential demand within the ACTPHN area. To achieve this step, the BSIC data was exported into a Geographic Information System (GIS) for visualisation.

Step 5 - Description of the Pattern of Care - Service Availability and Capacity

The availability of services was analysed according to their MTC, as well as their capacity.

Availability - defined as the presence, location and readiness for use of service delivery teams in a catchment area at a given time. A service is available when it is operable or useable upon demand to perform its designated or required function. The availability rate for the MTC is calculated per 100,000 of the target population.

Placement Capacity – this is the maximum number of beds in residential care, and places in day care in a care delivery organisation or catchment area at a given time. Rates are also calculated per 100,000 of the target population.

Spider Diagrams – to understand the balance between the different types of care offered in an area, a radar chart tool, also referred to as a spider diagram, is used. The spider diagram is essentially a tool to visually depict the pattern of care in an area. Each of the 21 points on the

radius of the diagram represents the number of MTC for a particular type of care per 100,000 population.

This analysis allows for comparisons of the availability and capacity rates with other areas, and to estimate whether the provision of services is adequate with regard to the population's needs.Following the coding of the services and development of a draft Atlas (Phase 1, or Alpha version), the Atlas is presented to planners in order for them to review and adjust the data and codes presented where necessary (Phase 2, or Beta Version). A Version for Comments is then prepared by the research team for release to stakeholders. Time is allowed for stakeholders to review the service data and coding, and provide any further comment. After further revision based on the received feedback, a Final Version is released to the planners. In the case of ACT, this Atlas represents the results of Phase 2 of the process (Beta Version): that is, the revision of the Alpha version by the planners, and subsequent adjustment to data and codes carried out by the team from the University of Canberra (Figure 2-11).

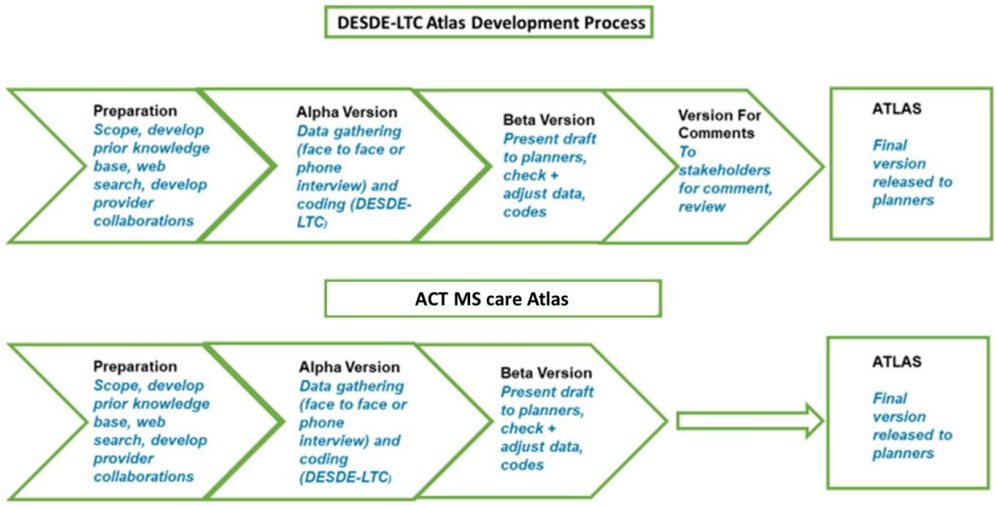

Figure 2-11 Development of the Integrated Atlas of Dementia Care in ACT PHN Region

2.4 Glossary

DESDE Code and Australian Health Care Descriptors

The following table lists the DESDE Main Types of Care shown in the radar or spider diagrams. The variations in terminology for similar types of care in different Australian jurisdictions is a feature of the Australian health care structures. Further complicating the analysis of Australian services, is that within the same state-wide program there may be a great deal of variation in the intensity of care provided. DESDE allows consistent comparisons based on the level of input of care and setting, not localised descriptors.

Table 2-4 Service group for pattern of care analysis

DESDE main Types of Care by Group and sub-type	Examples of Australian Health Care Descriptions
RESIDENTIAL	**Accommodation, Hospital, Residential**
R: ACUTE HOSPITAL	High Dependency Inpatient; Acute Care Unit; Intensive Care Unit; Assessment and Planning Unit
R: NON ACUTE HOSPITAL	Sub-acute; Community Care Units; Extended Care Health Rehabilitation Unit; Extended Treatment
R: ACUTE NON HOSPITAL	Hospital in the Home; Crisis homes (almost complete absent in Australia)
R: NON ACUTE NON HOSPITAL	Aged Care Home
R: OTHER NON HOSPITAL	Aged care residential, Hostel; Group Houses
R: HIGH INTENSITY NON HOSPITAL	Nursing Home
DAY CARE	**Rehabilitation or Recovery**
D: ACUTE HEALTH	Day Hospital services
D: NON ACUTE HEALTH	Some limited, specialist services such as rehabilitation services
D: WORK RELATED	Disability Enterprises; Social firms; Workers Coop
D: OTHER	Social Clubs; Club Houses
OUTPATIENT	**Community or ambulatory care**
O: ACUTE MOBILE HEALTH	Police & Acute Care Response; Crisis and Treatment Team; Assertive Community Treatment
O: ACUTE NON MOBILE HEALTH	Emergency Depts,
O: NON ACUTE MOBILE HEALTH	Mobile Support and Treatment Team; Community Outreach
O: NON ACUTE NON MOBILE HEALTH	Outpatients; Clinic services, Dual Diagnosis; Community Care/Continuing Care
O: NON ACUTE NON MOBILE NON HEALTH	Daily Living
O: NON ACUTE MOBILE NON HEALTH	Personal Helpers and Mentors; Psychosocial support
O: ACUTE NON MOBILE NON HEALTH	Family and violence crisis services (e.g. Yarrow Place, Adelaide)
O: ACUTE MOBILE NON HEALTH	No services identified in Australia
ACCESSIBILITY	
A: OTHER	Advocacy services
A: CARE COORDINATION	Partners in Recovery; Care Navigator; Access and Support
A: EMPLOYMENT	Disability Employment Service or DES; some Partners in Recovery
A: HOUSING	No services identified in Australia
INFORMATION	
I: INFORMATION	Information services
EVALUATION	
E: Evaluation	Telephone triage; Intake & Assessment

3 Description of Services Providing Support for People with Dementia in the ACT Region

3.1 Social Determinant of Health: Socio-demographic and health-related indicators of the Australian Capital Territory Primary Health Area

Health indicators are tools designed to measure the health status of people and the functioning of the health care system through the various factors that influence them (demographic, economic, and social) (System, 2000, M et al., 2008). These factors can be simple or composite factors. Composite synthetic indicators demonstrate a composite score by integrating individual variables using PCA/factor analysis. Researchers and policy planners could investigate the association between composite indices and health care outcomes. For example, social fragmentation is a synthetic indicator representing whether communities are homogenous (high level of cohesion) or fragmented and how the health status of residences in highly fragmented communities is influenced. Therefore, health indicators provide the basic information for contextual analyses and understanding the process in a health care ecosystem, and they help policymakers to quantify context and design interventions in health management. The following maps show the distribution of some dementia related health indicators in ACT.

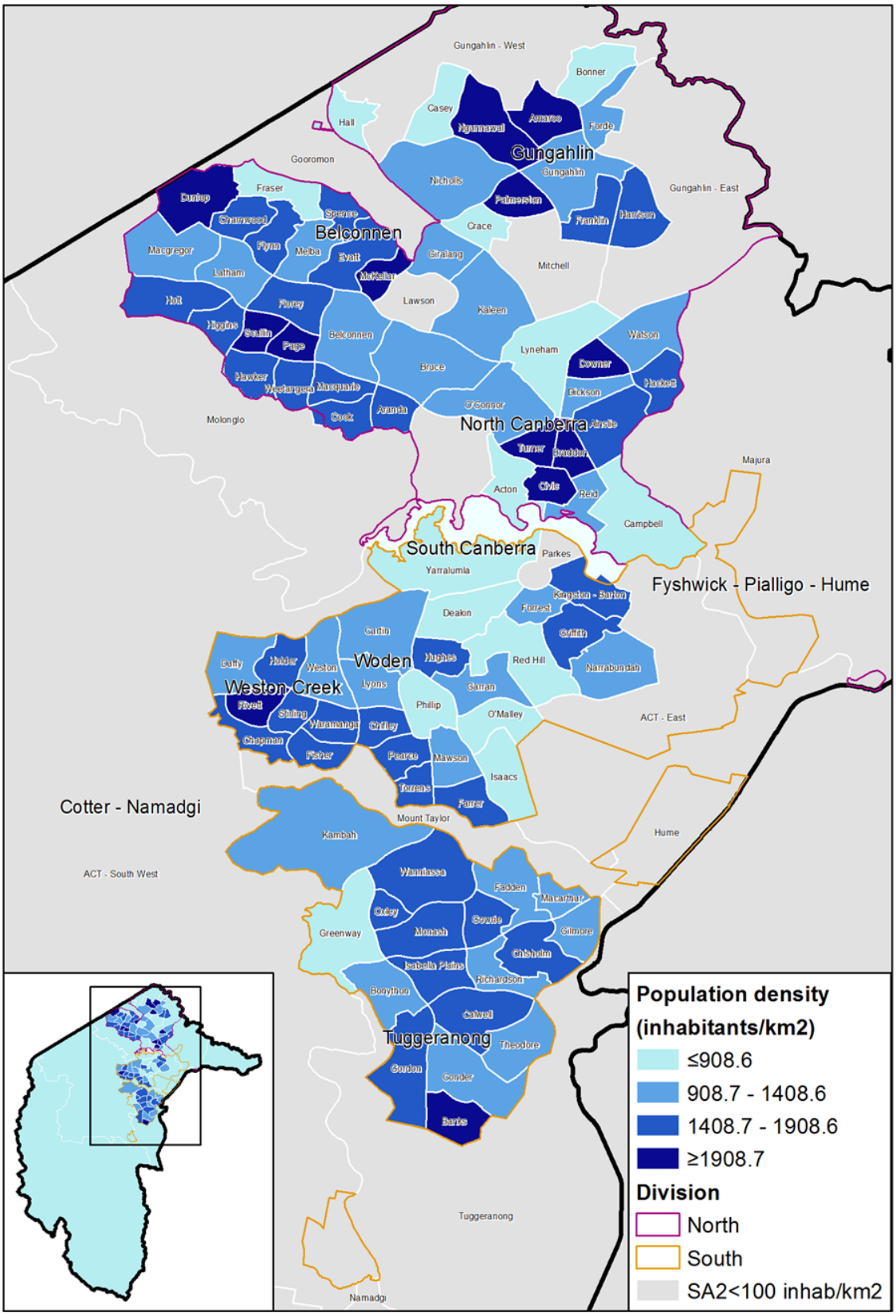

Figure 3-1 Population density in the Australian Capital Territory

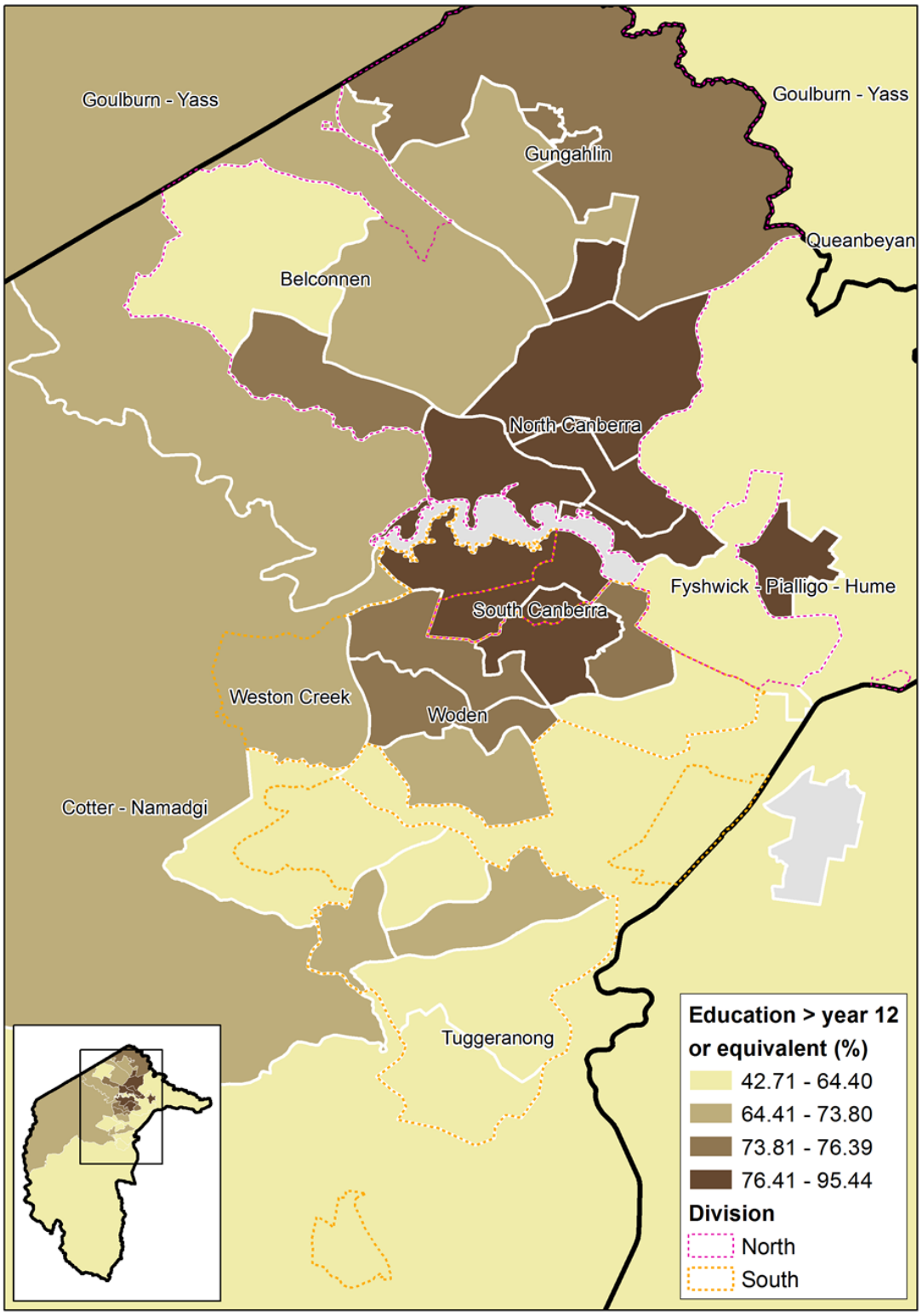

Figure 3-2 Education > year 12 or equivalent in the Australian Capital Territory

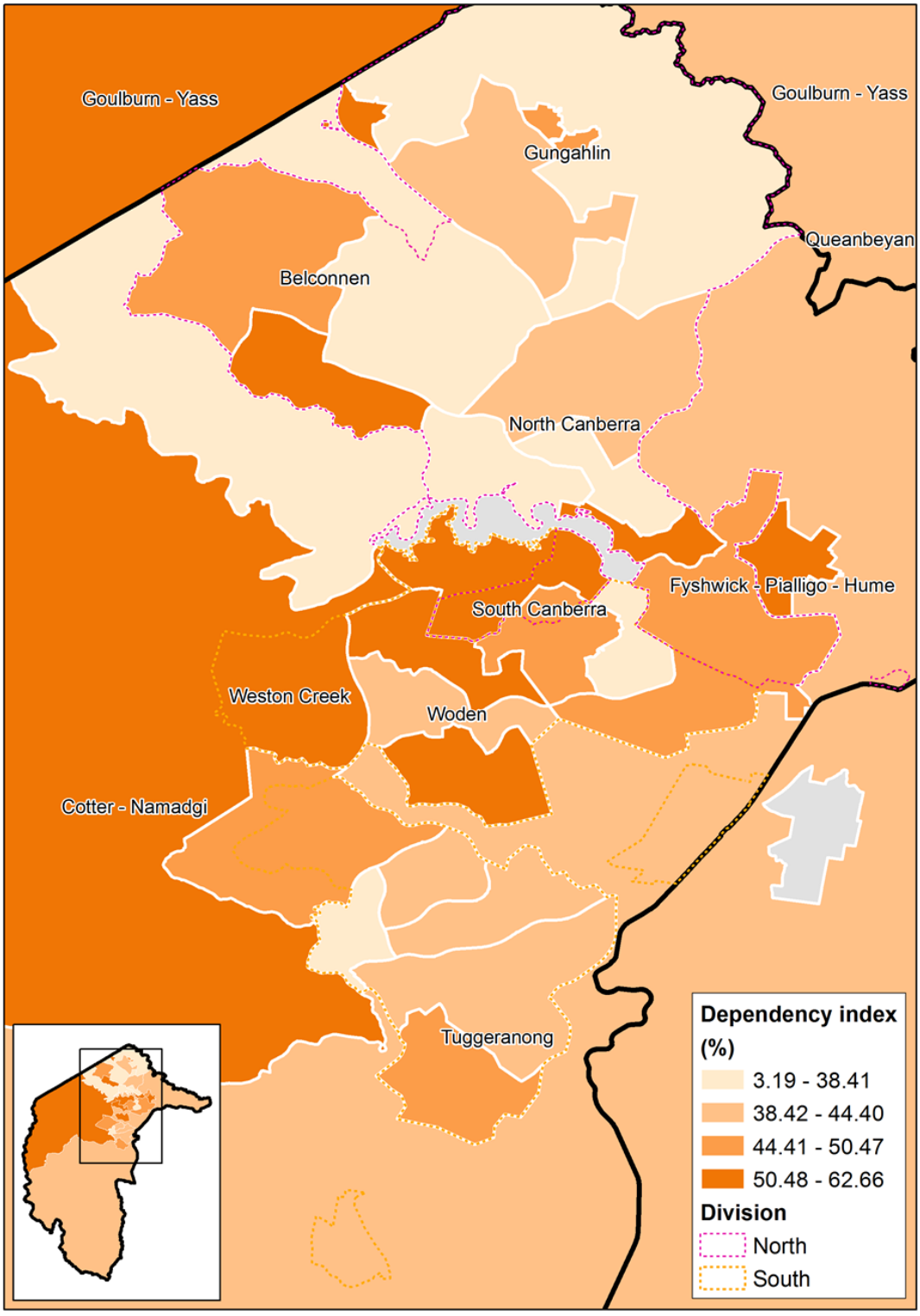

Figure 3-3 Dependency Index (the ratio of youths (ages 0-14) and the elderly (ages 65+) to the number of those in the working-age group (ages 15-64) in the Australian Capital Territory

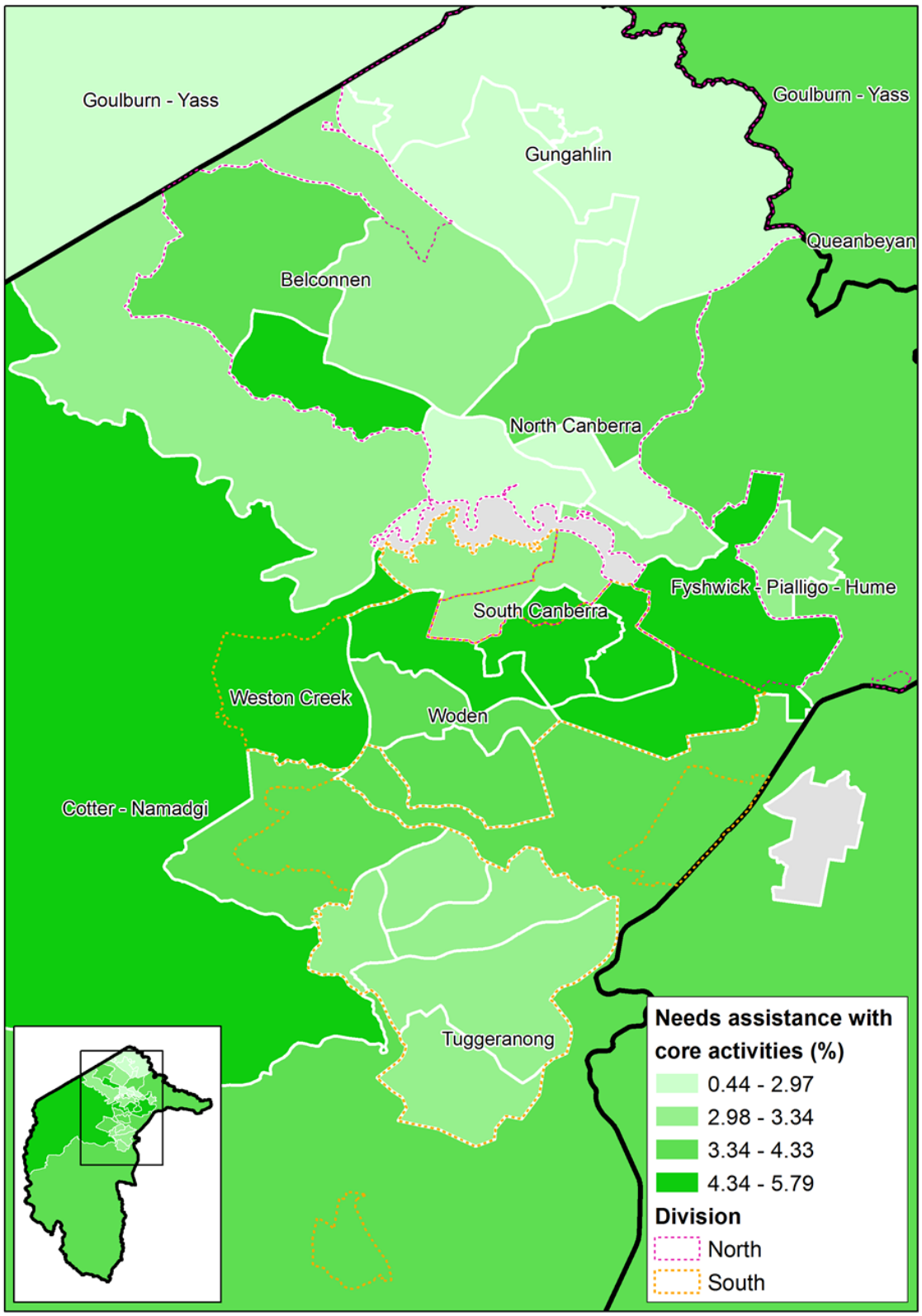

Figure 3-4 Rate of people who need assistance with core activities in the Australian Capital Territory

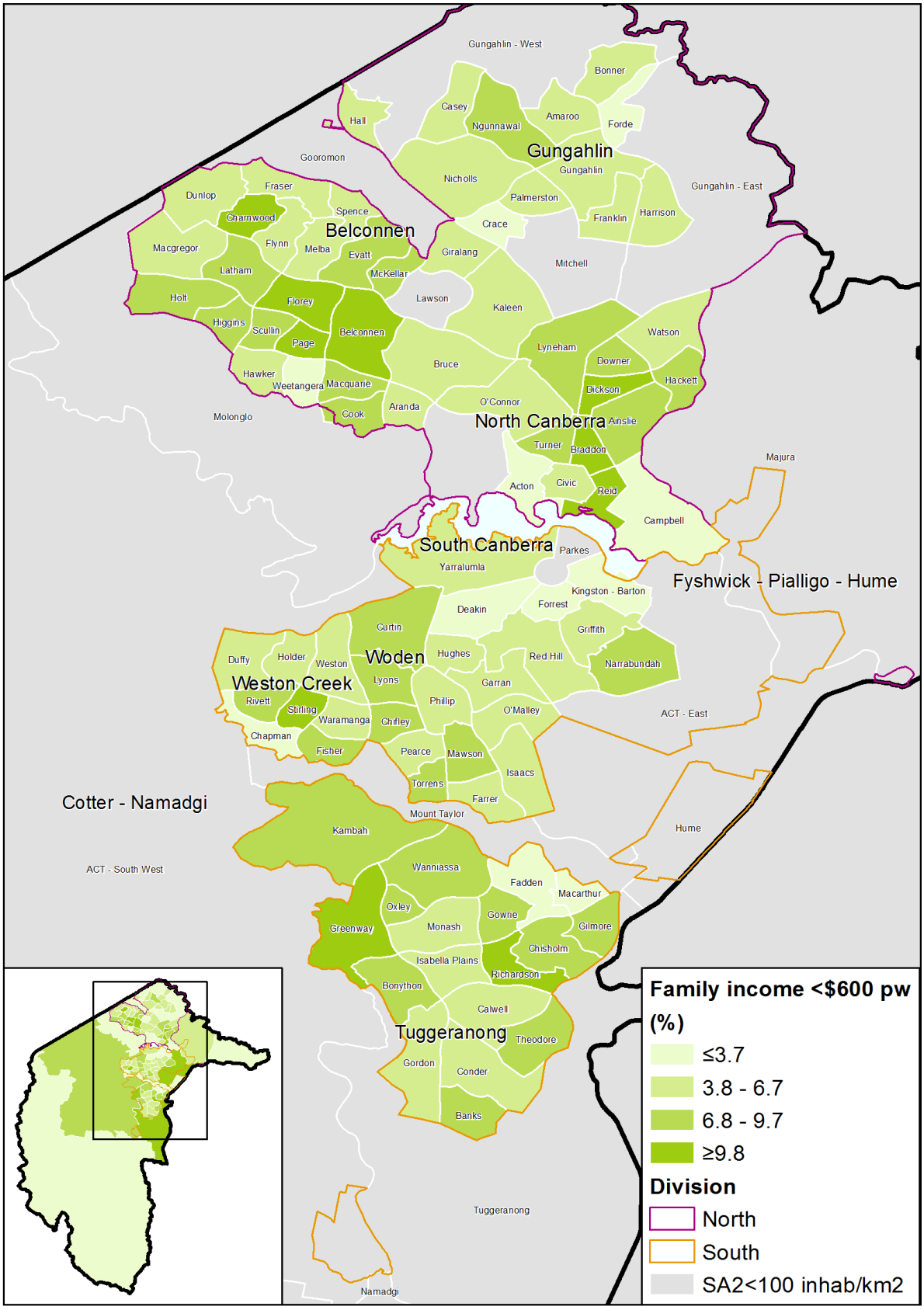

Figure 3-5 Areas of low-income ACT 2018 in the Australian Capital Territory

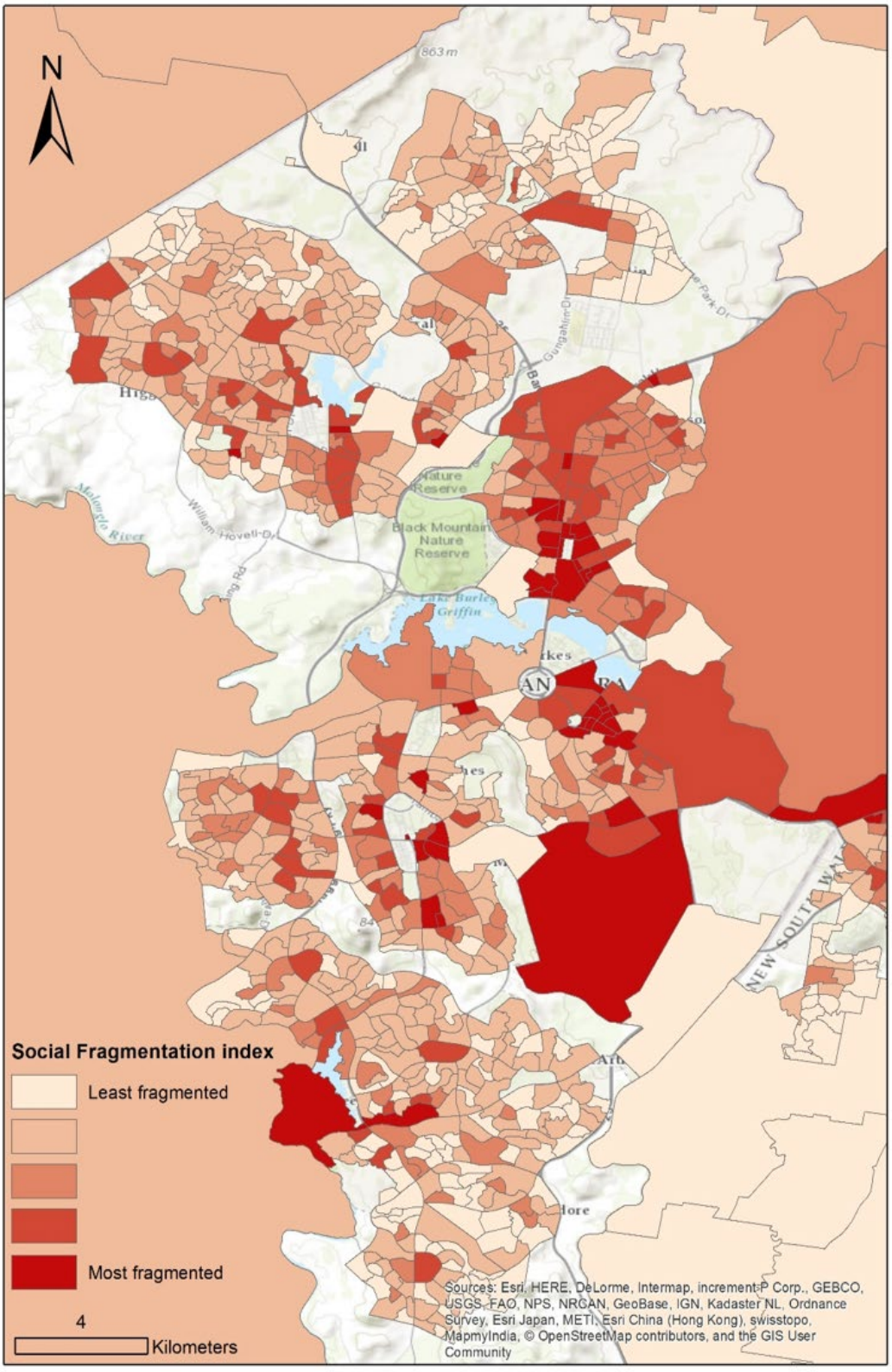

Figure 3-6 Social Fragmentation Index Australian Capital Territory 2018

3.2 General Description

After receiving ethics approval (UC HREC 10933), all possible services that provide health and social services to people with dementia or cognitive impairment in the ACT were identified from publicly available data such as official service directories, telephone directories, Google search, and via consult with experts in the field. Seventy-one service providers had been identified which could potentially be eligible for the study. However, based on basic information from their websites or by directly questioning them, 24 service providers were excluded because less than 20% of their clients had dementia/age-related cognitive impairment. Thus, there were 47 service providers eligible for inclusion in this study.

Information related to care services was extracted from webpages of eligible service providers, including basic service information (e.g., name, type of service, description of governance), location and geographical information about the service, service data (e.g., opening days and hours, staffing, management, economic information, legal system, user profile, number of clients, number of contacts or admissions, number of available beds or places). Furthermore, for additional necessary information, service providers were contacted to arrange interview. Interviews were via face-to-face or online, and they were conducted between the 1st of December 2021 and the 20th of January 2023. However, reaching out to some of services providers for interview were not successful due to the strain on the aged care workforce related to COVID-19. Therefore, the coding of these services was based solely on the information available publicly on their websites. Of those not interviewed, three service providers were not reachable, because either no contact was available, or they didn't respond to our contact after making at least three requests. Of those who responded to our request, two did not agree to interview, and the rest did not proceed to our request for interview. The coding of those who haven't been interviewed is based only on the public information on their website.

A total of 107 services were provided by 107 stable service teams from the included 47 service providers. These teams delivered 118 MTCs. Twenty-eight different MTC codes were applied across these 118 main types of care (figure 3-7). Of the 107 services, 62 services were coded based on face-to-face or online interviews and 45 services coded based on the information on their websites. Only 20 of 107 services reported information about their workforce capacity (e.g., data about total number of employee and their full-time equivalent hours worked), and

thus we were unable to provide an analysis of the workforce capacity of the dementia care system in ACT (Table 3-1, 3-2, 3-3).

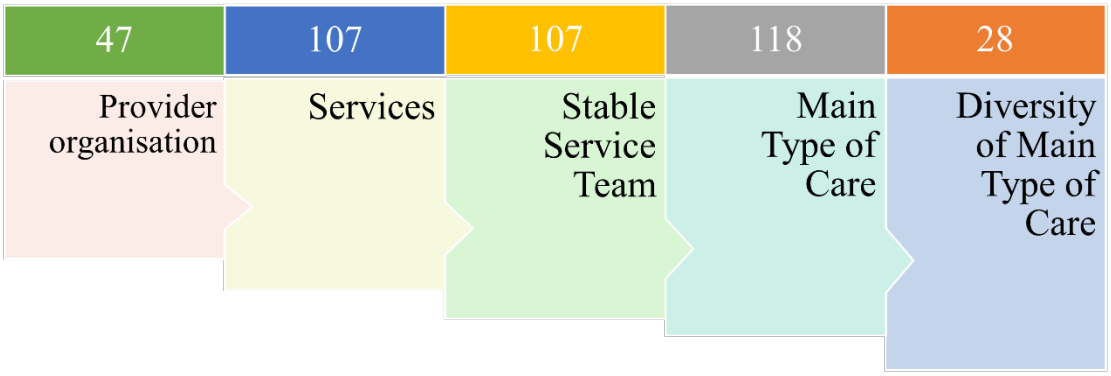

Figure 3-7 Summary of services providing dementia care in the Australian Capital Territory region 2022.

3.3 Specialised vs. general Services

There were 16 organisations comprising 28 BSICs, providing 30 specialised services for people with dementia (Table 3-1). The number of general services was relatively higher than specialised services. There were 17 organisations, comprising 27 BSICs, providing 32 general-50 services (Table 3-2) and 35 organisations with 51 BSICs providing 55 general-20 services (Table 3-3).

3.3.1 Specialised care

The most common type of care was residential care (e.g., dementia units in nursing homes) with 16 of 29 specialised services, and the second most common type of care was outpatient care (e.g., home care) with 7 services (Table 3-1). Day care (2 services), Accessibility to care (2 services), Information care and Evaluation (one service for each) were the rest, and there was no specialised self-help volunteer service.

Table 3-1 Specialised services provided to people with dementia in the Australian Capital Territory

Provider	Service Name	Interviewed	DESDE Code for service team	FTE	Town / Suburb	Area of Coverage
Residential Care						
Adria Care	Special Care for Dementia	Yes	AO, OX[F01-03][ICF 3-4]-R 11 c	Not Available	Stirling	ACT
BaptistCare	Griffith Centre Aged Care Home-Dementia Unit	No	AO, OX[F01-03]-R11 c	Not Available	Griffith	ACT
Calvary	Calvary Haydon -Residential care Memory Support Unit	Yes	AO, OX[F01-03][ICF 3-4]-R 11.1	Not Available	Bruce	ACT
Community Home Australia	Kambera House	Yes	AX, OX[F01-03]-R 11, R8.1	11.0	Gordon	ACT
Goodwin	Goodwin House, Memory Support Unit, Ainslie	Yes	AO, OX[F01-03][ICF 3-4]-R 11.1 s	Not Available	Ainslie	ACT
Goodwin	Residential Care, George Sauttelle House,Memory Support Unit	Yes	AO, OX[F01-03][ICF 3-4]-R 11.1 sv	Not Available	Farrer	ACT
IRT Kangara Water	Residential Care-Discover Unit	Yes	AO, OX[F01-03][ICF 3-4]-R 11 s	Not Available	Belconnen	ACT
RSL LifeCare	Fred Ward Gardens	Yes	AX, OX[F0-F3]-R11.1	Not Available	Curtin	ACT
RSL LifeCare	Bill McKenzie Gardens	Yes	AX, OX[F0-F4]-R11.1	Not Available	Page	ACT
St Andrews	Dementia Specific Unit	Yes	AO, OX[F0-F3]-R 11	Not Available	Hughes	ACT
The Salvation Army Aged Care	Mountain view aged care centre-Dementia unit	No	AO, OX[F0-F3]-R 11	Not Available	Narrabundah	ACT
Uniting care	Uniting Eabrai Weston - Dementia Care Unit	No	AO, OX[F01-03]-R 8.2 c, R8.1	3.0	Weston	ACT
Uniting care	Uniting Mirinjani Weston (LC) Memory Support Unit	No	AO, OX[F0-F3]-R11	Not Available	Weston	ACT
Uniting care	Uniting Amala Gordon Memory Support Unit	No	AO, OX[F0-F3]-R11	Not Available	Gordon	ACT
Villaggio Sant' Antonio	Residential aged care - dementia care	No	AO, OX[F01-03]-R11	Not Available	Page	ACT
Warrigal	Warrigal Residential care-Dementia Specific Wing	Yes	AO, OX[F01-03]-R11.1.2	11.2	Stirling	ACT

Day Care						
Community Home Australia	Club Kalina	Yes	AX, OX[F01-03]-D 5	3.6	Greenway	ACT
Primrose Services	Primrose Caring	No	AX[F0-F3]-D5	Not Available	No Info	ACT
Outpatient Care						
Canberra Hospital (Canberra Health Service)	Memory Assessment Service	Yes	AO, OX[R41.81]-O 9.1 h	0.3	Garran	ACT
Carers ACT	Home care Package Coordination	Yes	AX, OX[Z63.6]|[F0-F3]-O5.2	Not Available	Holt	ACT
Community Home Australia	Acute Inpatient Behavioral Support	Yes	AX, OX[F01-03]-O 5.2	Not Available	Greenway	ACT
Community Home Australia	Home Support	Yes	OX[F01-03]-O 5.2	3.0	Greenway	ACT
Dementia Australia	CHSP (Commonwealth Home Support Program)	Yes	OX[F01-03][e310]-O 6.2	13.0	Griffith	ACT
Dementia Australia	NDSP (National Dementia Support Program)	Yes	OX[F01-03][e310]-O 9.2	2.6	Griffith	ACT
Dementia Australia	CASP (Commonwealth Assistance Support Program)	Yes	AO[F01-03][e310]-O 6.2	1.4	Griffith	ACT
Accessibility to Care						
Carers ACT	NDIS support Co-ordination	Yes	AX[F01-F03]-A4	Not Available	Holt	ACT
HammondCare	Dementia Support Australia-Dementia Management Advisory Services	Yes	AO, OX[F01-03]-A 5.2 a	Not Available	Civic City	ACT
Evaluation						
Canberra Health Service	UCH Memory Clinic	Yes	AX[F01-F03][ICF 3-4]-E2.2.2 h	0.6	Bruce	ACT
Information						
HammondCare	Dementia support Australia-Needs Based Assessment	Yes	AO, OX[F01-04]-I 1.1	Not Available	Civic City	ACT

DESDE codes' description:
Age group: **AO**; older adult (between 50 and 65 years old), **AX**; Adult (18 to 65 years old), **OX**; older people.
Diagnosis: **F01-03**; people diagnosed with dementia, **R41.81**; people with cognitive impairment, **ICF**; International Classification of Functioning, Disability and Health, **Z63.6**; dependent relative needing care at home.

Service: **A 4**.; Accessibility to care-case coordination, **A5.2**; Accessibility to care- education and training related, **D5**; non-acute-non-structured health intensity health related day care, **E2.2.2**; continuous low mobility health related evaluation, **O5.2**; other high intensity non-acute outpatient care, **O9.2**; other medium intensity centre-based non-acute outpatient care, **R8.1**; non-acute non 24 physician cover for less than 4 weeks residential care, **R8.2**; non-acute non 24 physician cover for more than 4 weeks residential care, **R11**; non-acute non24h physician cover identified stay 24 hours support residential care, **R11.1**; non-acute non24h physician cover identified stay 24 hours support residential care (it is non- limited but the purpose is to move-on), R11.2; ; non-acute non24h physician cover identified stay 24 hours support residential care (standard non-limited stay).
Qualifiers: **a**; acute care in a non-acute non-residential care, **c**; secluded care with high level of security, **h**; non-residential care that provided in a hospital, **s**; providing specialised care to specific sub-group of the clients, **v**; the type of provided care could vary over time due to different reason such as financial reasons or system reforming,
FTE: number of fulltime equivalent health professionals allocated to the service

3.3.2 General-50 care

Like specialised services, residential care and outpatient care were the most common type of care with 15 and 8, respectively, of the 32 services in this category (Table 3-2). The contribution of services for evaluation was relatively higher than it was in specialised services, comprising 5 of 32 services. There were four available day care services, but there was no accessibility for care, information services, or self-help and volunteer care in this category of general services, where most consumers are people with dementia or age-related cognitive problems.

Table 3-2 Services which provide general services to older people but more than 50% of their consumers live with dementia

Provider	Service Name	Interviewed	DESDE Code for service team	FTE	Town / Suburb	Area of Coverage
Residential care						
Adria Care	Residential Aged Care Facility	Yes	AO, OX[ICF][ICF]-R 11	24.7	Stirling	ACT
Calvary	Calvary Haydon-Residential Aged Care Unit	Yes	AO, OX[ICF]-R 11.1	Not available	Bruce	ACT
Canberra Aged Care	Canberra Aged Care	No	AO, OX[ICF]-R11.1	Not available	Lyneham	ACT
Canberra Hospital (Canberra Health Service)	Geriatric Acute Ward (2wards)	Yes	AO, OX[ICD]-R 2	14.5	Garran	ACT
Carers ACT	Short-Stay Cottages-Deakin	Yes	AX, OX[Z63.6][ICF]-R8.1, D5.2	Not available	Deakin	ACT
Carers ACT	Short-Stay Cottages-Naraganawali	Yes	AX, OX[Z63.6][ICF]-R8.1, D5.2	Not available	Isaacs	ACT
Goodwin	Residential Care, Ainslie	Yes	AO, OX[R41.81]-R 11.1, R8.1	Not available	Ainslie	ACT
Goodwin	Residential Care, George Sauttelle House	Yes	AO, OX[R41.81]-R 11.1, R8.1	Not available	Farrer	ACT

Goodwin	Residential Care, David Harper House	Yes	AO, OX[R41.81]-R 11.1	Not available	Monash	ACT
IRT Kangara Water	Residential-Serenity Unit	Yes	AO, OX[R41.81]-R 11	Not available	Belconnen	ACT
Pines Living	Pines Living Aged Care Facility	No	AO, OX[ICF]-R11.1	Not available	Farrer	ACT
Southern Cross	Campbell Residential Care	Yes	AX, OX[ICF]-R 11	Not available	Campell	ACT
Southern Cross	Ozanam Residential Care	Yes	AO, OX[ICF]-R 11	Not available	Garran	ACT
Day care						
BaptistCare	BaptistCare Social Club	Yes	AX, OX[ICF]-D5.2	5.0	Red Hill	ACT
Outpatient care						
Calvary	Calvary Public Hospital-Inpatient Geriatric Liaison	Yes	AX, OX[ICD]-O5.1 hl	0.8	Bruce	ACT
Dr Anil Paramadhathil	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
Dr Nyoka Ruberu	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
Just better Care	Aged Care Services-Home care	No	AO, OX[ICF]-O6.1	Not available	Greenway	ACT
LDK	Senior Home Care	Yes	OX[ICF]-O 5.1 dn,, D9 ns	LDK	Senior Home Care	Yes
More Than Medicine	More than Medicine	No	OX[ICD]-O9.1	Not available	Braddon	ACT
RSL LifeCare	Home Care	No	AX, OX[ICF]-O6.2	Not available	Lyneham	ACT
Uniting care	Home and Community Care	Yes	OX[ICF]-O 6.1 aq	17.0	Deakin	ACT
Evaluation						
Calvary	Calvary Public Hospital-Geriatric Rapid Acute Care Evaluation	Yes	AO, OX[ICD][ICF]-E1.1.2	Not available	Bruce	ACT
Calvary	Calvary Public Hospital-Comprehensive Geriatric Assessment	Yes	AO, OX[ICF]-E2.2.2 h	0.2	Bruce	ACT

Canberra Health Service	Aged Care Assessment Team	Yes	AO, OX[ICF]-E1.1.1 d	12.0	Bruce	ACT
Canberra Health Service	UCH Geriatric Clinic	Yes	OX[ICD][ICF]-E2.2.2	1.6	Bruce	ACT
Canberra Hospital (Canberra Health Service)	Rapid Assessment of the Deteriorating Aged at Risk (RADAR)	Yes	AO, OX[R41.81]-E2.2.2 d	7.1	Garran	ACT

DESDE codes' description:
Age group: **AO;** older adult (between 50 and 65 years old), **AX;** Adult (18 to 65 years old), **OX**; older people.
Diagnosis: **F01-03**; people diagnosed with dementia, **R41.81**; people with cognitive impairment, **ICF**; International Classification of Functioning, Disability and Health, **Z63.6**; dependent relative needing care at home.
Service: **D5**; non-acute-non-structured health intensity health related day care, **D9**; non-acute non-structured low intensity day care , **E1.1.1**; one episode high mobility general evaluation, **E1.1.2;** one episode high mobility health related evaluation, **E2.2.2**; continuous low mobility health related evaluation, **O5.1**; high intensity non-acute health related outpatient care, **O 6.1**; non-acute mobile medium intensity health related outpatient care, **O6.2;** non-acute mobile medium intensity other outpatient care, **O9.1**; medium intensity centre-based non-acute health related outpatient care, **R8.1**; non-acute non 24 physician cover for less than 4 weeks residential care, **R11**; non-acute non24h physician cover identified stay 24 hours support residential care, **R11.1**; non-acute non24h physician cover identified stay 24 hours support residential care (it is non- limited but the purpose is to move-on).
Qualifiers: **a;** acute care in a non-acute non-residential care, **b**; when at least 80% of the care provided in the facility is short, time limited, and episode **d**; service provided entirely at the home of the user, **h**; non-residential care that provided in a hospital, **l**; liaison services provided to people admitted to other speciality services, **n**; a novel residential care, **u**; care is typically delivered by a single health professional, **q**; the main attribute of the service is significantly higher/greater than for other service teams coded the same.
FTE: number of fulltime equivalent health professionals allocated to the service

3.3.3 General-20 care

The diversity of care types in general services, in which at least 20% or more (but less than 50%) clients were people living with dementia or age-related cognitive problems, was larger than that in general-50 services (Table 3-3). Outpatient care (e.g., home care) was the most common type of care with 25 of the 55 services in this category, and residential care was the second most common type of care, with 21 services. Day care, accessibility to care, and information services were the other types of care available, with four, three, and two services, respectively. There was no evaluation and self-help and volunteer services available in this category.

Table 3-3 Services which provide general services to older people but where between 20% to 50% of consumers live with dementia

Provider	Service Name	Interviewed	DESDE Code for service team	FTE	Town / Suburb	Area of Coverage
Residential Care						
BaptistCare	Carey Garden Aged Care Centre	No	AO, OX[ICF]-R11	Not available	Red Hill	ACT
BaptistCare	Griffith Centre Aged Care Home	No	AO, OX[ICF]-R11	Not available	Griffith	ACT

IRT Kangara Water	Residential Care- Vitality Unit	Yes	AO, OX[ICF]-R 11	Not available	Belconnen	ACT
Jindalee	Jimdalee Aged Care Residence	No	AO, OX[ICF]-R11	Not available	Narrabundah	ACT
Royal Freemasons' Benevolent Institution	RFBI Holt Masonic Village	No	AX, OX[ICF]-R11.1	Not available	Holt	ACT
RSL LifeCare	Sir Leslie Morshead Manor	Yes	OX[ICF]-R 11	Not available	Lyneham	ACT
RSL LifeCare	Mona Tait Gardens	Yes	OX[ICF]-R 11	Not available	Kaleen	ACT
RSL LifeCare	Fred Ward Gardens	Yes	OX[ICF]-R 11 qc	Not available	Curtin	ACT
RSL LifeCare	Bill McKenzie Gardens	Yes	OX[ICF]-R 11 qc	Not available	Page	ACT
St Andrews	Residential Care	Yes	AO, OX[ICF]-R 11 i	Not available	Hughes	ACT
The Salvation Army Aged Care	Mountain view aged care centre	No	AO, OX[ICF]-R 11	Not available	Narrabundah	ACT
The Salvation Army Aged Care	Burrangiri Aged Care Respite Centre	No	AO, OX[Z63.6]-R8.1, D5	Not available	Rivett	ACT
Uniting care	Uniting Eabrai Weston	No	AO, OX[ICF]-R 11	3.0	Weston	ACT
Uniting care	Uniting Mirinjani Weston (LC)	No	AO, OX[ICF]-R 11, R8.1	3.0	Weston	ACT
Uniting care	Uniting Amala Gordon	No	AO, OX[ICF]-R 11, R8.1	3.0	Gordon	ACT
Villaggio Sant' Antonio	Residential aged care	No	AO, OX[ICF]-R11, R8.1	Not available	Page	ACT
Warrigal	Warrigal residential aged care	Yes	AO, OX[ICF]-R11	1.8	Stirling	ACT
Day Care						
Goodwin	Day Club, Crace	Yes	AO. OX[ICF]-D 5	Not available	Crace	ACT
Goodwin	Day Club, Monash	Yes	AO, OX[ICF]-D 5	Not available	Monash	ACT
Warrigal	Warrigal social	No	AO, OX[ICF]-D5	Not available	Stirling	ACT

Outpatient Care						
Absolute Home care	Absolute Home Care-Nursing Team	No	AO, OX[ICD]-O5.1.3 d	Not available	Lyneham	ACT, Queanbeyan and surrounding areas
Absolute Home Care	Absolute Home Care-Carers Team	No	AO, OX[ICF]-O5.2 d	Not available	Lyneham	ACT, Queanbeyan and surrounding areas
Annecto	Annecto	No	AO, OX[ICF]-O6.2	Not available	Mawson	ACT
BaptistCare	Home Care	Yes	AO, OX[ICF]-O6.2 d	Not available	Symonston	ACT
Calvary	Calvary Community Care	Yes	AO, OX[ICF]-O 5.1	Not available	Bruce	ACT
CarersACT	Counselling	Yes	AX, OX[Z63.6]-O9.2	Not available	Holt	ACT
Disability & aged care Community Services	Disability & aged care Community Services	No	AX, OX[ICF]-O 6.2	Not available	Belconnen	ACT
Geriatrician #1	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Garran	ACT
Geriatrician #2	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
Geriatrician #3	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
Geriatrician #4	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
Geriatrician #5	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
Geriatrician #6	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
Geriatrician #7	Private Geriatric practice	No	AO, OX[ICD]-O9.1 u	Not available	Deakin	ACT
DS1 Aged Care and Disability	DS1 Aged Care and Disability	Yes	GX[ICF]-O5.2.2	Not available	Macquarie	ACT
Enrich living services	Enrich l Living Services	No	AO,OX[ICF]-O6.2	Not available	Page	ACT
Goodwin	Home Care	Yes	AO, OX[ICF]-O 5.1.2 d	Not available	Farrer	ACT

HammondCare	Home Care	Yes	AO, OX[ICF]-O 5.1	Not available	Civic City	ACT
Hender Care	Therapy Team	No	AO, OX[]-O6.1/ O9.1	Not available	Canberra	ACT
HenderCare	Aged care Services	No	AO, OX[ICF]-O6.2	Not available	Canberra	ACT
Life without Barriers	Aged Care Home Services	Yes	OX[ICF]-O6.2.2	Not available	Griffith	ACT
Next Practice GP practice	InReach Team	Yes	OX[ICD]-O 6.1	25.0	Deakin	ACT
R & R Home respite	R & R Home Respite	No	AX, OX[Z63.6]-O5.2.3	Not available	Fraser	ACT
Royal Freemasons' Benevolent Institution	Home care	No	AX, OX[ICF]-O6.2	Not available	Holt	ACT
Warrigal	Warigal Home services-Stirling	No	AO, OX[ICF]-O6.2	Not available	Stirling	ACT
Warrigal	Warigal Home services-Calwell	No	AO, OX[ICF]-O6.2	Not available	Calwell	ACT
Accessibility to Care						
Canberra Health Service	Residential Aged Care Liaison Nurse	Yes	AO, OX[ICF]-A 5.5 hu	1.0	Bruce	ACT
LDK	Aspire Aged Care	Yes	OX[ICF]-A 5.5 cnπ	18.0	Greenway	ACT
Third Age Matters	Aged Care Placement Service	No	OX[ICF]-A5.5	Not available	Narrabundah	ACT
Information						
ACT Chinese Aged Care Information Service	ACT Chinese Aged Care Information Service	No	OX[ICF]-I2	Not available	Canberra	ACT
Advance Care Planning	Advance Care Planning	Yes	AX, OX[ICF]-I2.1.1	Not available	Garran	ACT

DESDE codes' description:
Age group: **AO**; older adult (between 50 and 65 years old), **AX**; Adult (18 to 65 years old), **OX**; older people.
Diagnosis: **F01-03**; people diagnosed with dementia, **R41.81**; people with cognitive impairment, **ICF**; International Classification of Functioning, Disability and Health, **Z63.6**; dependent relative needing care at home.
Service: **A5.2**; Accessibility to care- education and housing related, **D5**; non-acute-non-structured health intensity health related day care, **I 2**; information , **I2.1.1**; interactive face to face information, **O5.1**; high intensity non-acute health related outpatient care, **O5.1.2**; non-acute mobile high intensity 7 days per week outpatient care, **O5.1.3**; non-acute mobile high intensity 7 days per week including overnight outpatient care, **O5.2**; non-acute mobile high intensity other outpatient care, **O5.2.2**; non-acute mobile high intensity 7 days per week other outpatient care, O5.2.3; non-acute mobile high intensity 7 days per week with overnight other outpatient care, **O 6.1**; non-acute mobile medium intensity health related outpatient care, **O6.2**;

non-acute mobile medium intensity other outpatient care, **O6.2.2**; ?, **O9.1**; medium intensity centre-based non-acute health related outpatient care, **O9.2**; medium intensity centre-based non-acute other outpatient care, **R8.1**; non-acute non 24 physician cover for less than 4 weeks residential care, **R11**; non-acute non24h physician cover identified stay 24 hours support residential care, **R11.1**; non-acute non24h physician cover identified stay 24 hours support residential care (it is non- limited but the purpose is to move-on).
Qualifiers: **c**; secluded care with high level of security, **d**; service provided entirely at the home of the user, **h**; non-residential care that provided in a hospital, **n**; a novel residential care, u; care is typically delivered by a single health professional, **q**; the main attribute of the service is significantly higher/greater than for other service teams coded the same, **π**; private
FTE: number of fulltime equivalent health professionals allocated to the service

3.4 The pattern of care across specialised and general services

To understand the balance between the different types of care offered in the area, a radar tool was used to visually depict the mix of service types (pattern of care). Each of the 25 points on the radius of the diagram represents the number of MTC for a particular group of care types per 100,000 target population.

Figure 3-7 compares the pattern of specialised and general care (MTCs per 100,000 of the population) in the ACT region in 2022. The brown line shows the pattern of specialised services specific to people living with dementia, the blue line shows general-50 services where most recipients were people living with dementia, and the grey line shows general-20 services where between 20% and 50% of recipients were people living with dementia.

As the figure shows, the pattern of type of services was relatively similar across specialised and general services. However, the capacity of services per 100,000 population was higher in general-20 when compared with general-50 and specialised services in most types of services. Community residential services (i.e., nursing homes) were the dominant service in all three categories.

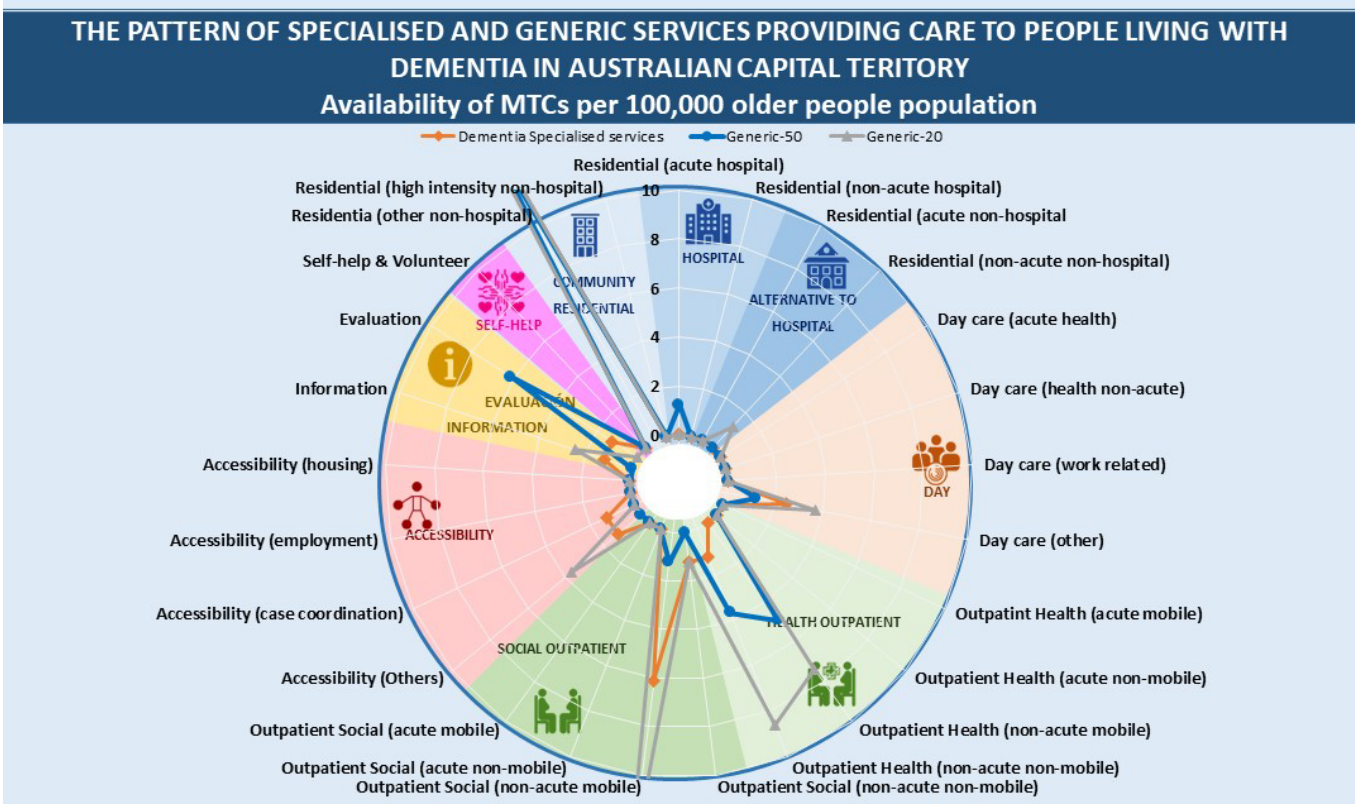

Figure 3-7 Availability of specialised dementia services (brown) and general-50 services (blue) and general-20 services (grey) MTCs per 100,000 adult population

3.7 Qualitative data regarding capacity and gaps in the system

Twenty-nine participants provided responses on their views and perceptions on the gaps in dementia services in the ACT region. The participants were employed in roles in residential aged care (n=12), ACT Health/Canberra Health Services (n=6), Calvary (n=2), COTA (n=2), Carers ACT (n=2), Aged & Community Care Providers Association (n=1), Communities at Work (n=1), Dementia Australia (n=1), a General Practitioner (n=1), and Northside Community Service (n=1). Overall, the analysis revealed that given that older people comprise 20% of the population of ACT and a significant proportion of these may need different types of services, available capacity of the current care system does not seem to be enough. In detailed the identified themes were:

- A lack of dementia-specific services: Participants stated there are not enough day or respite services for people with dementia, placing an increased burden upon informal carers. There is also a considerable need for care options for people with dementia who express behaviours of unmet need, such as agitation, aggression, and depression,

particularly those with younger-onset dementia. For people with these behaviours living in residential aged care, two participants indicated that a lack of an appropriate service and of appropriate staff training has resulted in a cascade of adverse outcomes for the person themselves, other residents, and staff. This has led to aged care providers refusing to accept people with severe dementia, who then remain in the hospital.

- Concern with the quality of existing dementia care: Participants said a primary concern was a poor understanding of how to appropriately care for and treat people with dementia, due to inadequate staff training across services. In addition, workforce supply was considered lacking due to the poor availability of staff with dementia-specific skills and training. Two participants said this gap needed to be addressed before addressing other gaps. The quality of dementia care is also suffering due to current services operating at or near capacity. It was suggested that improved vertical and horizontal integration of services could help reduce strain across service providers.
- Insufficient funding for dementia services: Six participants identified the absence of funding at a local and national level as negatively impacting current service delivery. This factor was suggested to exacerbate staffing issues because the aged care sector is uncompetitive in the job market.
- Poor public awareness of dementia: Six participants said poor knowledge and awareness of dementia is a significant gap, resulting in stigma and a reluctance for people with dementia and their families to identify and access services. This was associated with increased time between the appearance of symptoms and diagnosis, with a shift in culture and mentality required to ensure people receive timely advice and care.

Notably, five participants said the issues described above are not unique to the ACT region, but rather a systemic issue. Moreover, two participants suggested that despite these issues, the ACT is perhaps performing better in dementia care than in other regions of Australia.

4 Discussion

4.1 Overview and the gaps

The main aim of this project was to investigate the availability of dementia care services in the Australian Capital Territory. This included specialised health and social care as well as general services catering to a significant number of clients with dementia or age-related cognitive decline. The findings revealed that only about one-fourth of the services available for people living with dementia are provided by specialised services. The rest of the care available is provided by general services that are not specifically designed to provide care to people with dementia, but who nevertheless often cater to a majority (sometimes up to 80%) of clients with dementia or cognitive difficulties.

It is important to note that even specialised services may not have staff specifically trained to provide care to people with dementia. Rather, the services are designed to cater to people with special needs, but with staff who are not trained for these special needs. These services are specific with regard to the environment, but not to the staff providing care. However, this does not necessarily mean that the staff providing care are underqualified, and in fact, some may be overqualified for their positions. There are several examples of highly qualified professional staff filling positions where the duties required are below their skill level. One example is using a registered nurse as a coordinator in an accessibility to care service.

It is necessary to note that, unfortunately, only a small proportion of available services provided some information about their workforce capacity, thus we do not have a comprehensive picture of workforce to analyse the workforce capacity in dementia care system. Analyse of workforce of dementia services is crucial for better understanding of the quality of services. This is because of poor definition of worker categories, poor consistency of roles between acute, residential and community services (for example a gerontological nurses role is very different from each sector), and the changing state of nurse staffing (ratios or nurse staffing are in effect July 2023, they won't get paid if they don't meet the nursing ratios, and no residential aged care facility in the ACT will meet exemption criteria on this).

Both specialised and general services provide similar patterns of care, with residential care (mostly nursing homes) being the most common type of care available, followed by outpatient care (home care). There are also day care, information and evaluation care, and accessibility to

care services available, although the availability of day care services appears limited in comparison to residential and outpatient care.

Dementia services in ACT are provided at four levels: 1) dementia specialised services dedicated specifically to people living with dementia; 2) general services where the target population is not limited to people with dementia, but majority (more than 50%) of consumers are people living with dementia; 3) general services where the target population is not limited to people with dementia but a moderate proportion (between 20% and 50%) of consumers are people living with dementia; and 4) general services aimed for the general older population, with fewer than 20% of people living with dementia. This project is only focused on the first three categories, and an evaluation of the last category is necessary to have an overview of the aged care system in ACT.

4.2 Access to information

Accessing dementia services information in ACT is considerably more challenging than accessing mental health services (Furst et al., 2018b). Service providers' websites mostly provide general information and for enquiries about details they typically offer information only by phone or email, using a national number that may not be user-friendly for older individuals without the required technological skills. Additionally, there was no capacity for direct contact with manager-level staff for other service providers, researchers, or policymakers. Compared to mental health services, response rates to our interview requests were significantly lower, with about 40% of providers (compare to less than 10% for mental health services) not responding or unable to meet with us (Furst et al., 2018b). Moreover, we found that organisations often failed to provide supplementary information, such as workforce capacity data, in response to our follow-up inquiries, with lower response rates than previously observed among mental health service providers (Furst et al., 2021b).

4.3 Comparing dementia care with psychogeriatric and mental health care in ACT

Comparing the pattern of dementia services with mental health services for older people (Figure 4-1) as well as for adults aged 18 years and older (Figure 4 -2), in the ACT reveals that there is greater variation in the type of services providing support for people living with dementia than for older people (Tabatabaei-Jafari et al., 2020) or adults with mental health issues (Furst et al., 2021a). There are services available (although limited in some categories)

for people living with dementia in five of the six categories of care, while mental health services for older people are limited to only hospital and outpatient types of care. Although the diversity of mental health services for adults is better than mental health services for older people, it is still limited compared with dementia services. This may be due to the better financial support of aged care system than the mental health system. People who use aged care supports usually lose access to other services, including if they had Veterans Health.

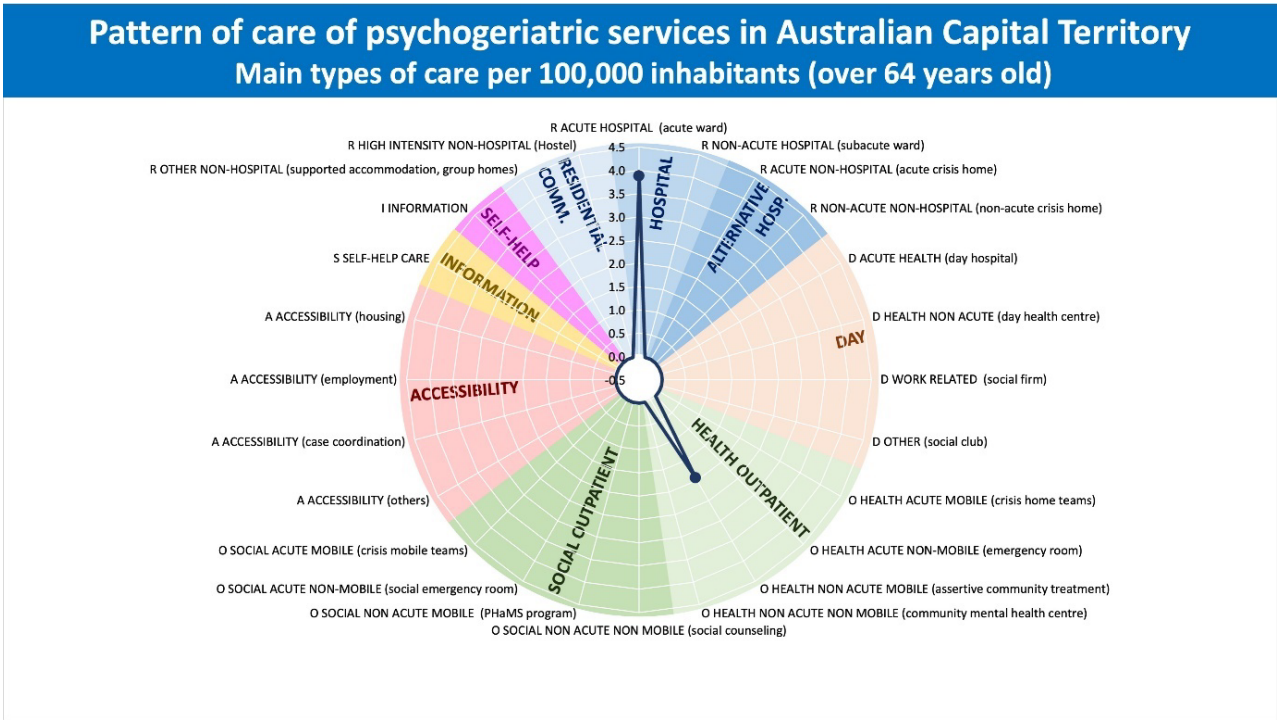

Figure 4-1 Availability of psychogeriatric services MTCs per 100,000 adult population

Figure 4-2 Availability of adult mental health services MTCs per 100,000 adult population

People with dementia receive government subsidised supports through the Aged Care System for both residential and community services. This occurs through the following programs.

4.3.1. Residential supports

The Australian Government subsidises aged care homes across Australia to provide affordable, accessible care. The subsidies (care intervention) and supplements (such as enteral feeding supplement or oxygen supplement) are paid directly to each aged care home. There is a general aged care home subsidy for all aged care residents and a dementia specific subsidy for people with severe dementia symptoms.

Aged Care Funding Instrument (ACFI) and Australian National Aged Care Classification (AN-ACC): These fundings assess the relative care needs of residents and based on the assessment allocated by the government subsidy to aged care providers for delivering residential care. The ACFI funding was for care provided up to 30 September 2022, and since then, AN-ACC funding has replaced. The AN-ACC is intended to better reflect residents' needs with the costs of care delivery.

In the AN-ACC model, providers receive three components: 1) a fixed component; 2) a variable component; and 3) a one-off adjusted payment. Fixed cost is the cost for operating a service, but variable costs will change in proportion to the level of care activity and/or the number of residents a facility manages. The price the industry receives is set and managed through a mechanism referred to as the National Weighted Activity Unit. This is a measure of health service activity which can be expressed as a unit / number against the fixed and variable components. The type and subsidiary amount depend on the place and an assessment of the resident's income and assets. For example, the government will pay the full cost of accommodation if the resident has income less than $30,204.20 and assets less than $55,000.00. The resident should pay the full accommodation cost if they have more than $76,170.12 income or assets above $186,331.20.

Specialist Dementia Care Program (SDCP): The SDCP funds specialist dementia care units in residential aged care homes. The units provide specialised care to people with very severe behavioural and psychological symptoms of dementia. They aim to reduce or stabilise symptoms so that people can move into less intensive care settings. The SDCP provides specialised care for people who live with very severe dementia complicated by physical aggression or other behaviours unable to be managed appropriately by their residential care facility or carers, even with help from other services. The SDCP provides person-centred care from staff with dementia training and specialists via a dementia-friendly living environment. When a person no longer needs specialised care, SDCP providers must plan and support the person's move into a less intensive care setting. Generally, this will be a bed within the provider's facility.

A person is eligible to benefit from this program if they have dementia with very severe behavioural or psychological symptoms which have lasted at least 3 months, and other specialised services have not been able to reduce the behaviours. Approval is based on assessment by an Aged Care Assessment Team.

4.3.2. Home Care Supports

National Disability Insurance Scheme (NDIS): The NDIS launched at trial sites in July 2013, after years of discussion about the need for a major reform of disability services in Australia.

The full NDIS scheme commenced roll out in July 2016, and the ACT was the first state or territory to complete roll out (NDIS, 2021). The NDIS is a new way of funding individualised support for people with severe disability (including psychosocial disability) that involves more choice and control, and a lifetime approach to a person's support needs. To be eligible for the NDIS, people need to meet residence requirements (e.g. hold Australian citizenship, permanent visa or a Special Category Visa) as well as disability or early intervention requirements and they should be between 6 to 65 years of age. This means NDIS is not available for many people with dementia. However, people can keep the NDIS support after 65 if they have entered the NDIS plan before this age. If the eligible person moves into residential aged care or begin receiving home care on a permanent basis after turning 65, this client will cease to be a NDIS participant.

There are unclear roles and responsibilities within the scheme implementation; concerns about planners' understanding of the nature of chronic illness and needs of people with disabilities; issues around funding and appropriately skilled staffing; the downgrading of services, in particular, those providing outreach support to hard to reach populations; and fears for people not eligible for the scheme, or for whom current services may no longer be available (Furst et al., 2018a).

The Disability Support for Older Australians (DSOA): The DSOA program provides support to vulnerable older people with disability who are not eligible for the NDIS. The program replaced the Commonwealth Continuity of Support (CoS) Programme on 1 July 2021, and is only open to its existing clients. To have been eligible, a person must have been an existing client of state-administered specialist disability services at the time the NDIS commenced in their region and either be 65 years and over when the NDIS commenced in their region and assessed as ineligible for the NDIS, or an Aboriginal and Torres Strait Islander person aged 50 to 64 years when the NDIS commenced in their region and assessed as ineligible for the NDIS.

Commonwealth Home Support Programme (CHSP): The CHSP is an entry-level home support program that helps older people to live independently in their homes and communities. CHSP funds a large variety of organisations (called service providers) to deliver care and services. The program aims to build on people's individual strengths and abilities to help them remain living independently and safely at home. It also provides respite services to provide

carers with a break from their caring responsibilities. The program aims to help people live as independently as possible, focus on working with them, rather than doing things for them, and gives a small amount of help to many people. Most people in the CHSP only need 1 or 2 services to help them stay independent.

The CHSP is primarily for frail older Australians who need support to live independently at home and are either: 1) aged 65 years or over (50 or over for Aboriginal or Torres Strait Islander peoples) and have functional limitations and need assistance, or 2) prematurely aged (50 years or older; 45 years or older for Aboriginal and Torres Strait Islander peoples) and are on a low income, homeless, or at risk of being homeless as a result of housing stress or not having secure accommodation. The CHSP also supports carers by providing planned respite services for CHSP recipients. This allows carers to take a break from their caring duties.

Home Care Packages (HCP): The HCP are one of the ways that older Australians can access affordable care services to get some help at home. They are designed for those with more complex care needs beyond what the CHSP can provide. For example, when they need help with many everyday tasks, or complex or intensive tasks at home. Australians are eligible if they are older than 65 years old and need coordinated services to help them stay at home, or are younger than 65 years old and are living with a disability, dementia or other care needs not met through other specialist services.

There are four levels of HCP with different funding amounts: level 1 for basic care needs ($9,179.75), level 2 for low care needs ($16,147.60), level 3 for intermediate care needs ($35,138.55), and level 4 for high care needs ($53,268.10). Recipients work with their chosen provider to identify their care needs and decide how best to spend their package funding. Their service providers coordinate and can manage their services for them on their behalf. Recipients are expected to contribute to the cost of their care if they can afford it. Waiting lists for these programs are a known issue (commonly up to six months), meaning that even though care is identified as needed, it is not delivered, and people with dementia may remain at home with only the informal carer to support them while they wait for package availability in their region. Moreover, for some services, it is not known that people with dementia are on the waiting list until they receive an appointment.

The complexity of different sources of support may indicate the need of an analysis of financing complementary to the analysis of service provision.

4.3 Conclusion

The dementia care system in ACT relies on non-specialised services, leaving little choice for people living with dementia but to use non-specific general aged care services. This is particularly noticeable in day care and respite care. Indeed, in interviews with professionals and meeting with consumers, a considerable need emerged for care options for people with dementia expressing behaviours of unmet needs, particularly those with younger-onset dementia. This is in addition to there being a lack of specialised staff training even in the specialised services that are available. Therefore, there is a need to establish more specialised services, particularly those types currently missing, to help people with dementia to live independently, and stay at home, supported by services such as day and respite care.

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