

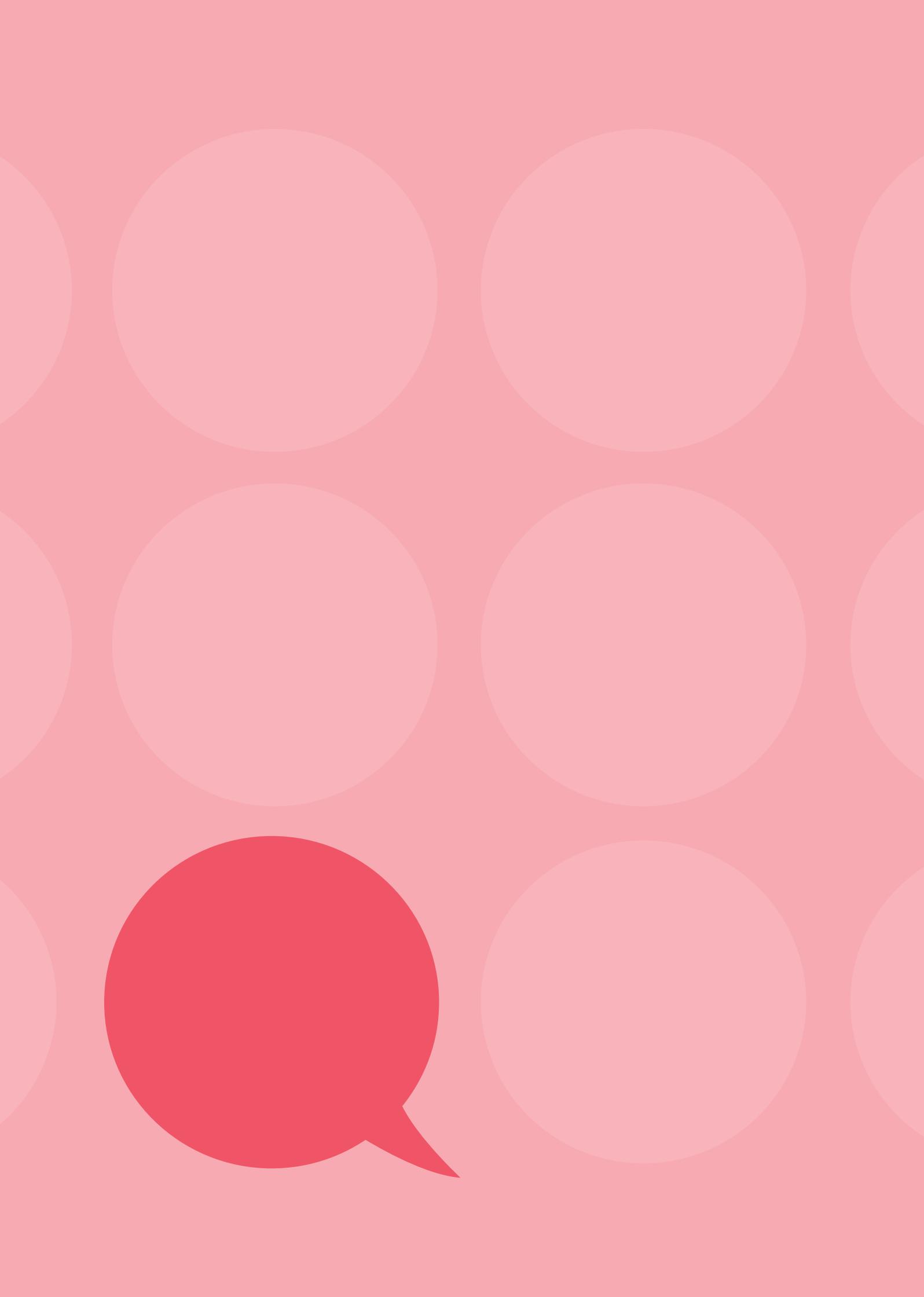
Service Demand Forecasting

Report 2021



seirbhís tacaíochta
cinn-teoireachta
decision support service





Executive Summary

The Decision Support Service (DSS) is a new service established by the Assisted Decision-Making (Capacity) Act 2015 (the Act) to promote the rights and interests of adults who may require support to make decisions about their personal welfare, property, and affairs. To design and implement a service that meets the needs of its service users, the DSS needs to understand the likely demand for the range of supports provided for under the Act.

This report sets out the approach and results of a two-phase demand-forecasting project undertaken by the Decision Support Service (DSS). The project was undertaken to inform operational, organisational and service design considerations for the establishment of the DSS. As a completely new service in Ireland, the aim of this project was to gain insights and understanding of the number and needs of potential users of this service.

Phase 1

The aim of Phase 1 was to identify and establish a baseline population of adults within existing datasets likely to benefit from supports and services provided by the DSS. It is important to state that there is no presumption that any person or group of persons will become service-users of the DSS. The need to access the supports available under the Act will always depend on a person's individual circumstances and the particular decisions that they need to take. In Phase 2, the established baseline population is further analysed and matched to specific DSS supports and services.

Previous estimates have primarily used a disability/ diagnosis approach in identifying population groups likely to benefit from DSS services. A broader, more comprehensive approach was taken herein to include all persons within identified population cohorts who may have difficulties with one or more of the four elements of a functional capacity assessment in respect of a relevant decision (see Section 1.3.1). As well as identifying potential users of the DSS on commencement of the Act, this approach facilitates identifying populations who may benefit from the service in the future. Commencing with an examination of the whole population, the broadest possible definition of disability was applied to include relevant difficulties such as those that are self-perceived as well as medically diagnosed difficulties and conditions.

Consideration was also given to population cohorts who may benefit from the support framework under the Act - particularly those who may experience decision-making challenges due to specific diagnoses, specific residential or institutional settings and/or safeguarding needs.

The rationale for the selection of these criteria is that the DSS will be available to the entire adult population in Ireland. Any adult who needs decision-making support, whether occasionally or frequently, will be able to access the service. There is no prerequisite to have a diagnosed condition or illness. Anyone - at any point in their life - may, for any number of reasons, require some decision-making support.

In order to establish a total baseline population of likely service users of the DSS, data was examined across several data types and data sources to identify potentially relevant cohorts. A hierarchical framework was applied to the data sources in order to establish a baseline dataset that was both comprehensive and minimised the risk of double counting. The most robust, reliable and/or nationally representative data sit at the top of the hierarchy. Data gathered with less robust and reliable methodologies and/or less relevant/applicable data sources are at the bottom of the hierarchy. The Census provided a national, whole population dataset that enabled delineation of the adult population in terms of age, geography, residential status, and long-term health condition.

There was an initial focus on a single permutation within the Census, i.e., adults with a difficulty with learning, remembering, or concentrating. However, through applying the hierarchical framework, additional permutations within the Census were explored to broaden the potential range as much as possible.

Census 2016 was identified as being the most comprehensive source as it counts every person present in Ireland on Census night and contains relevant data to estimate a baseline range. Comparison with historical data is possible as the Census is repeated every five years, enabling comparison between Census 2016 and earlier years to establish patterns of change in terms of growth and/or decline.

Nationally representative surveys examined such as TILDA, the National Disability Survey and Irish Health Survey asked more in-depth questions which allowed for cross analysis e.g., of specific needs relating to decision-making capacity, against specific cohorts including age and diagnoses. This provided a mechanism to validate the data from Census 2016.

A range of data from sources further down the hierarchical framework were identified and examined based on particular relevance to the DSS e.g., specific data on Wards of Court; and disability registers and individuals accessing specific services, including financial and housing supports. These data sources provide insight into cohorts with specific conditions as identified in the census.

Following a review of all identified data sources, data on adults with difficulty learning, remembering, or concentrating from Census 2016 was identified as the most robust single dataset of persons who may need or benefit from the services of the DSS, once operational. This dataset was identified as it is most closely aligned to three out of the four elements of a functional assessment of capacity as set out in the 2015 Act: ability to understand information; ability to retain information; and ability to weigh up information and make a decision. This dataset has the benefit of taking a non-diagnostic approach and of being self-reported i.e., people identify themselves as having these needs.

This dataset taken in isolation is limited as it is unlikely to be exhaustive of all adults who may have difficulties with one of the elements of a functional assessment and therefore benefit from the services of the DSS, in particular persons who might have difficulties due to a transient or changeable condition, or those who fail to meet the fourth element: the ability to communicate a decision made.

As such, further datasets were examined within the same data source (Census 2016), to potentially expand this baseline number, and look instead at a baseline 'range' of likely users. Data on persons with intellectual disability, and with a psychological or emotional condition were identified as relevant datasets within the same Census category of 'long-term conditions or difficulties'.

The benefit of these datasets is that they could be directly compared against the persons with a difficulty learning, remembering, or concentrating dataset to avoid double counting. Both identified datasets include characteristics which may affect a person's decision-making capacity, but this cannot be assumed for the whole cohort. It was concluded that the most likely DSS users within the cohorts of persons with intellectual disability or a psychological or emotional condition would also identify as having a difficulty learning, remembering, or concentrating.

Data on persons with deafness or serious hearing impairment was also considered within the Census category of long-term conditions or difficulties. By reason of a deafness or serious hearing impairment a person may experience difficulties with the fourth element of a functional capacity assessment - namely communicating a decision. However, this cannot be assumed for the whole cohort and the Act is very clear that appropriate tools to support communication must be available.

Speech disability was not recorded within the Census, however, data on speech disability was gathered by the CSO in the 2006 National Disability Survey. Speech disability may also be relevant to the fourth element of a functional assessment; the ability to communicate a decision made. The figure presented for speech disability herein is the 2006 figure of 25,270 adjusted to 2016 population.

Finding: Using these datasets, the baseline population of potential users of the DSS can be stated as ranging between 116,811 to 187,265, at 2016 population levels.

Based on the data examined, this range can be disaggregated by age and by geography, which provides useful insights into DSS operational service distribution.

Within the baseline population range, there are identifiable cohorts who may be more likely to need the services of the DSS. These are identified as persons with a disability or condition, for example intellectual disability or psychological or emotional condition who identify as having a difficulty with learning, remembering, or concentrating.

Conversely, within the baseline population, those identified for the reason of having difficulty communicating only are unlikely to need certain services from the DSS.

Other data sources provide insight into cohorts who are likely to benefit from DSS services as well as those with existing decision-making arrangements in place. For example, approximately 2,300 adults are currently Wards of Court, of whom over a quarter have the General Solicitor acting as their Committee. Approximately 1,000 Enduring Powers of Attorney (EPAs) are currently registered annually. These are EPAs made under the Powers of Attorney Act 1996.

Other cohorts examined that may be likely to need the services of the DSS include those in residential care facilities. This is due to the increased incidence of a third party requiring various consents, both in respect of treatment, and in relation to contracts for service. There are up to 44,000 adults in residential care facilities in Ireland. Not all adults in residential care will require the supports available under the Act. Equally, those adults in residential care who have specific needs in relation to their decision-making capacity will already be included within the baseline population range.

Finding: The baseline population range as identified was adjusted to 2021 population levels providing a baseline population range of 125,406 to 201,064. This represents 3.3% to 5.2% of the adult population (1 in every 20 adults)

The lower baseline population can be disaggregated by age and by geography, providing useful insights for DSS operational service distribution: 24% are aged 65 years and older; 28% live in one of the four Dublin administrative areas; 14% reside in nursing homes.

Phase 2

The purpose of Phase 2 of the research was to further analyse this baseline population and match it with potential DSS supports and services, specifically the estimated number of decision-making assistant agreements (DMAAs), co-decision-making agreements (CDMAs) and decision-making representative orders (DMROs) likely to be commenced in the first five years of operation.

Finding: The baseline population is estimated to be 204,171 in 2022 rising to 216,767 in 2026.

Using National Disability Survey data on levels of need, a distribution of need for services within the baseline population was established. From there, levels of need were converted into support arrangement tiers. This was further adjusted to take account of individuals that may move from requiring a CDMA to requiring a DMRO due to lack of a suitable person to act as CDMA.

Finding: After adjustment, the distribution of need was set at 72% for DMAAs, 19% for CDMAs, and 9% for DMROs.

The baseline population does not represent the actual numbers likely to seek DSS services. To calculate annualised figures, a review of comparable jurisdictions was undertaken together with data from Wards of Court in Ireland.

Finding: At 100% take up level, the number of individuals seeking the services of the DSS range from 22,861 in 2022 to 24,271 in 2026.

A range of alternative take-up scenarios were considered – 25%; 50% and 75% take up levels with DMRO uptake remaining at 75% throughout all scenario testing.

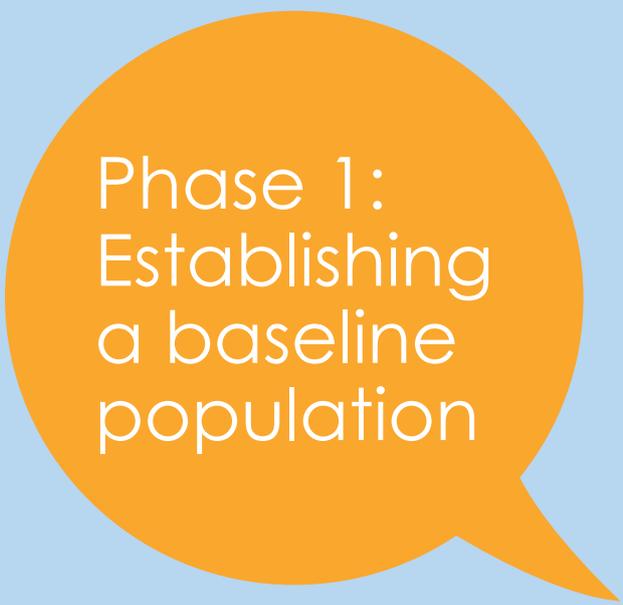
At the 25% update levels for DMMA and CDMA and 75% DMRO, an estimated 7,408 individuals are expected to access the DSS in its first year of service, rising to 7,942 in 2026. However, bearing in mind current indications that the service will commence in mid-2022, the total number of arrangements may therefore be reduced by half, to 3,704. At the same time, if pent-up demand for lower levels of services is factored in to the initial six months of operation, total arrangements may increase to mid-way between the six month and 12-month figures.

Finding: A reasonable estimate for the first six months of operations (July to December 2022) would be 5,556 decision-support arrangements.

Panel member DMRs will be available for those who do not have a suitable person to act in this capacity. A review of comparable service usage in three other jurisdictions and in the wards of court system in Ireland established that the average public/private split was 33% for public (panel member) DMROs and 67% for private DMROs.

Finding: Of the 1,695 estimated number of DMRs appointed for the first year of service, 1,136 would be private while 559 would be public (requiring a panel member).

In terms of geographical breakdown for service need, it is unsurprising that larger urban centres of population have the highest numbers in terms of DSS service need. This includes the four administrative areas of Dublin - Dublin City, Dún Laoghaire Rathdown, Fingal and South County Dublin - and Cork County and City, Galway and Limerick.



Phase 1:
Establishing
a baseline
population

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Key findings

- There is no single data source in Ireland of adults who require support to make decisions. However, there are a range of data sources that include people with capacity difficulties as well as specific diagnoses and conditions associated with an increased likelihood of capacity difficulties.
- The Decision Support Service (DSS) is a new service established by the Assisted Decision-Making (Capacity) Act 2015 (the Act) to promote the rights and interests of adults who may require support to make decisions about their personal welfare, property and affairs.
- To design and implement a service that meets the needs of its service users, the DSS needs to understand the likely cohort of users that need, or would benefit from, supported decision-making.
- Since the Act stipulates that incapacity cannot be presumed based on diagnosis, the approach taken to service demand forecasting should, where possible, reflect a functional assessment of capacity. This is based on a person's ability to understand, at the time that a decision is to be made, the nature and consequences of that decision, and be able to communicate that decision.
- A baseline population of likely DSS users has been established using a non-diagnostic data source (Census 2016), supported by three nationally representative surveys which asked more in-depth questions allowing for cross-analysis and providing a mechanism to validate Census data.
- The baseline population should be seen as a broad group of adults who may benefit from the supports and services of the DSS due to their likelihood of failing to meet one or more of the pillars of a functional assessment of capacity.
- The baseline population ranges from 116,811 to 187,265 with the lower figure including only those reporting difficulties in learning, remembering, or concentrating and the upper figure extended to also include those with communication difficulties.
- When population projections are applied, the baseline population in 2021 ranges from 125,406 to 201,064.
- This represents 3.3% to 5.2% of the adult population (1 in every 20 adults).
- The lower baseline population can be disaggregated by age and by geography, providing useful insights for DSS operational service distribution:
 - 24% are aged 65 years and older
 - 28% live in one of the four Dublin administrative areas
 - 14% reside in nursing homes
- Other data sources provide insight into cohorts with specific conditions or other vulnerabilities placing them at higher likelihood of benefiting from DSS services as well as those with existing decision-making arrangements in place. For example:
 - Approximately 2,300 adults are currently Wards of Court, of whom over a quarter have the General Solicitor acting as their Committee.
 - Approximately 1,000 Enduring Powers of Attorney (EPAs) are currently registered annually. These are EPAs made under the Powers of Attorney Act 1996.
 - There are approximately 44,000 adults living in long term care settings across nursing homes, disability services and mental health services.
 - Many people living with neurological and mental health conditions that can adversely affect decision-making capacity live in the community, included an estimated 20,000 to 35,000 people with dementia.

Chapter 1

1.1 Introduction

This report sets out the approach and results of the first of two phases in a service demand forecasting project undertaken by the Decision Support Service (DSS). The project was undertaken to inform operational, organisational and service design considerations for the establishment of the DSS. As a completely new service in Ireland, the aim of this project was to gain insights and understanding of the number and needs of potential users of this service.

The aim of Phase 1 is to identify and establish a baseline population of adults within existing datasets likely to benefit from supports and services provided by the DSS. In Phase 2, this baseline population will be further analysed and matched to specific DSS supports and services.

1.2 Background

The DSS is a new statutory service established by the Assisted Decision-Making (Capacity) Act 2015 (the Act). It is part of the Mental Health Commission (MHC) but has a new and separate role. While the Act is not yet fully commenced, work to establish the DSS is under way. The Act is an important piece of reforming human rights law that establishes a tiered system of legally recognised supports for people who require help with making decisions about their personal welfare or property and affairs. It also sets out guiding principles for anyone interacting with a person who has difficulties with their decision-making capacity. This may include, for example, people with an intellectual disability, mental illness, dementia, acquired brain injury or other neurological condition. The Act also provides for people who wish to plan ahead for a time when they might lose their capacity, by way of an advance healthcare directive or an enduring power of attorney.

The Act abolishes the current wardship system and requires all current Wards of Court to be reviewed and discharged from wardship within three years following commencement. The courts will consider whether a current ward requires a decision support arrangement.

When operational, the DSS will:

- (a) Regulate and register decision support arrangements
- (b) Supervise the actions of decision supporters appointed under a decision support arrangement
- (c) Investigate complaints under the Act
- (d) Maintain a panel of experts who will assist the DSS in its functions
- (e) Maintain searchable registers of decision support arrangements
- (f) Promote awareness and provide information about the Act.

The DSS will act as the central authority for matters relating to the Hague Convention on the International Protection of Adults. Full commencement of the Act and the operationalisation of the DSS also play a key role in the State's compliance with the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), which was ratified in 2018.

Article 12 of the UNCPRD acknowledges the right of persons with disabilities to enjoy legal capacity on an equal basis with others in all aspects of life. It also affirms their right to have equal access to own or inherit property and to control their own financial affairs, all of which is subject to safeguards which are proportional and tailored to personal circumstances and applied over the shortest possible period. In line with this principle, supported decision-making represents an alternative to guardianship or other types of substituted decision-making.¹

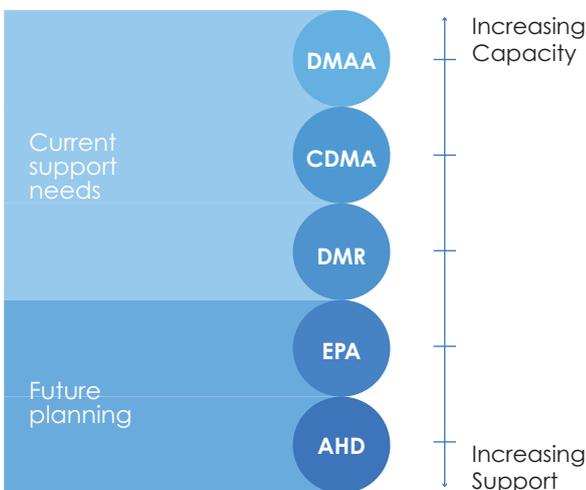
On commencement of the Act, there will be five decision support arrangements available for people who have challenges with their capacity and who may need support to make certain decisions. These arrangements are based on the various levels of support that a person requires to make a specific decision at a specific time.

¹ European Association of Service providers for Persons with Disabilities (EASPD) 2018. I-DECIDE, A report on the global situation of supported decision making and the role of support services

- Decision-making assistance agreement (DMAA)
- Co-decision-making agreement (CDMA)
- Decision-making representation order (DMRO)
- Enduring power of attorney (EPA)
- Advance healthcare directive (AHD)

Figure 1 illustrates how these five arrangements may be understood in terms of increasing capacity compared with increasing support and whether the arrangements reflect current support needs or future planning.

Figure 1: Tiered decision support arrangements



Under these arrangements, people can be appointed as decision supporters. A decision supporter has the authority to help with certain decisions about a person's personal welfare, property and money matters. The type of support they can provide depends on the decision support arrangement in place.

The relevant person (the person who has a decision support arrangement) is the key stakeholder and primary future user of the DSS. Original analysis from the Department of Justice and Equality estimated that over 220,000 adults in Ireland could have an arrangement with the DSS. This analysis looked at the sum of persons across groups of likely users using key diagnostic/condition-based indicators i.e., intellectual disability, mental illness, acquired brain injury and age-related conditions, such as dementia.

1.3 Methodology

This section sets out the approach used to identify potential service users of the DSS. While in practice this was an iterative process it is described here in a logical sequence. The focus of Phase 1 is on persons with current capacity challenges who may benefit from decision-making support services such as DMAAs, CDMAAs and DMROs to exercise their decision-making capacity. Advance planning (through AHDs and EPAs) will also be supported through the DSS. However, as these arrangements are made by persons who currently have capacity, demand forecasting for these services is explored separately.

1.3.1 Defining capacity

The DSS will be a service for adults who may face challenges exercising their decision-making capacity, now or in the future. To identify all potential adults that may require or benefit from the services of the DSS, it is necessary to understand the definition of capacity as set out in the Act. This states that a person's capacity will be functionally assessed, based on their ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made.²

The fact that a person lacks capacity in respect of a decision on a particular matter at a particular time does not prevent them from being regarded as having capacity to make decisions on the same matter at another time. In addition, lacking capacity in respect of a decision on a particular matter does not permit presumption of incapacity to make decisions on other matters.

Decision-making capacity is not based on a specific diagnosis or medical condition and is instead determined by examining a person's ability to:

- Understand³ information relevant to a specific decision
- Retain that information long enough to make a voluntary choice
- Use or weigh that information as part of the process of making the decision
- Communicate⁴ their decision.

These are referred to in this report as the four pillars of a functional assessment of capacity.

² Part 1, Section 3(1), Assisted Decision-Making (Capacity) Act 2015.

³ With regard to understanding the information, this is to be interpreted as ability to understand an explanation given in a way that is appropriate to the person's circumstances, whether using clear language, visual aids or any other means.

⁴ With regard to communicating a decision, this is to be interpreted as through talking, writing, using sign language, assistive technology or any other means.

Because of the functional approach to capacity as set out in the Act, it was determined that a diagnoses-based, or solely diagnoses-based approach, to this project would be inappropriate. The approach therefore required the identification of population groups who may be more likely than the general population to benefit from decision-making supports by reason of failing to meet one or more of the four pillars of a functional assessment of capacity.

1.3.2 Approach to identifying population groups

Previous estimates have primarily used a disability/diagnosis approach in identifying population groups likely to benefit from DSS services. However, several constraints were identified in such an approach in an Irish context:

- It excludes population groups without a diagnosed disability (and others receiving disability supports and services) who may benefit from supported decision-making
- It relies on national disability databases and registers as a comprehensive reflection of the actual number of people with cognitive and/or intellectual disabilities
- It presumes that all persons with specific diagnoses (such as intellectual disability or dementia) require decision-making support. This is inconsistent with the Act, which specifies that individual capacity should be assessed functionally and must not be pre-determined by reference to a medical condition or diagnosis.

Within this project, a broad approach was taken, to include all population cohorts that fail or are likely to fail to meet one or more of the four pillars of functional capacity as set out in Section 1.3.1. As well as identifying potential users of the DSS on commencement of the Act, this approach facilitates identifying populations who may benefit from the service in the future. In addition, it would potentially yield more comprehensive and inclusive data that could help to determine the extent to which the baseline population of potential DSS users may utilise supported decision-making services when available and which services they may be likely to avail of. Within this broader approach, the following criteria were agreed to assist in identifying relevant cohorts and subsequently, appropriate data sources:

- Begin with the whole adult population
- Where required, use the broadest possible definition of disability to also include relevant difficulties⁵
- Include relevant self-perceived as well as medically diagnosed difficulties and conditions

- Consider at-risk population cohorts particularly those groups at increased risk of vulnerability due to ageing, specific diagnoses, specific residential or institutional settings and/or safeguarding needs.

The rationale for the selection of these criteria is that the DSS will be available to the entire adult population in Ireland. Any adult that needs decision-making support or assistance, whether occasionally or frequently, will be able to access the service irrespective of general ability or age. There is no prerequisite to have a diagnosed condition or illness. Anyone at any point in their life may for any number of reasons require some decision-making support.

Widening the scope beyond diagnosed disability is more inclusive of the potential needs of those who may experience difficulties in areas relevant to decision-making but have not been formally diagnosed with a disability, due to not meeting the diagnostic criteria or other reasons. It also recognises that persons with a diagnosed disability should not be assumed as lacking capacity or requiring decision-making supports solely based on their diagnosis.

Including self-assessed as well as medically diagnosed data broadens the potential population. Furthermore, individuals with a high level of awareness of their difficulties and challenges may be more likely to access decision-making support or assistance when available.

Finally, acknowledging that some populations have a higher risk of vulnerability, risk factors including ageing, certain diagnoses and specific settings are reviewed to ensure consideration of these cohorts even where they are not captured through other mechanisms.

1.3.3 Approach to identifying data on relevant populations

There is no single overarching database in Ireland of all population cohorts likely to benefit from decision-making supports across all levels. Data on populations supported through existing decision-making arrangements, such as Wards of Court and registered Enduring Powers of Attorney, is available but this relates only to those deemed to require the highest level of decision-making support. In order to ensure those who may benefit from lower levels of support were included, the approach taken was to assemble an amalgam of data sources and extract appropriate data.

⁵ This is consistent with the approach and definitions set out in UNCRPD, which defines persons with disabilities under Article 1 as including 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.'

A preliminary list of data sources was compiled comprising organisations (and divisions within larger organisations) with relevant data based on criteria as set out in Sections 1.3.1 and 1.3.2. To facilitate a comprehensive exploration of the data, a multi-level approach was taken. This encompassed national level population counts, nationally representative surveys, disability and diagnosis specific services and registers, disability and diagnosis specific financial supports, existing decision-making arrangements, as well as other relevant data sources. Table 71 in Section 4.1.1 provides summary data on these data sources.

Data was initially retrieved from websites, published reports and publicly available datasets. Where necessary, this was followed up through engaging with key personnel within organisations to find out if the information sought was held by that organisation or available elsewhere and/or to access more detailed information.

All data retrieved was scanned for relevance by examining whether it correlated either directly or indirectly with one or more of the four functional pillars of capacity. The list of potential sources of data was then re-categorised as:

- Data is available and relevant
- No data is available (or unavailable in a centralised/ useable format)
- Data is available but not relevant.

Data sources identified as 'available and relevant' are described in Sections 2.2 to 2.8 while their detailed findings and analysis is presented in Sections 3.2 to 3.12. The issue of non-availability of data is further explored in Section 4.1.3.

Chapter 2

2.1 Overview of data sources

This chapter gives a brief introduction to each of the data sources identified as available and relevant to provide context for presentation of their analysis in Chapter 3. Each data source is described and the rationale for choosing it outlined. Table 1 provides an overview of data types and sources.

Table 1: Overview of data sources

Data type	Data source
National level population counts	Census
Nationally representative surveys	National Disability Survey
	The Irish Longitudinal Study on Ageing
	Irish Health Survey
Disability databases	National Ability Support System
	National Intellectual Disability Database
	National Physical and Sensory Disability Database
Diagnosis based databases and other estimates of specific conditions	Acquired brain injury
	Dementia and other neurological conditions
	Mental health conditions
Disability and diagnosis specific financial supports	Social housing for people with disabilities
	Disability allowance
	Long-term illness scheme
Care settings	Nursing homes
	Residential centres for people with disabilities
	Residential centres for people with mental health conditions
Existing decision-making arrangements	Wards of Court
	Enduring Power of Attorneys

2.2 National level population counts

The census of population is the only source of data that counts the whole population of Ireland at national level. Censuses 2006, 2011 and 2016 were identified as relevant.

2.2.1 Census

A census of population is carried out every five years by the Central Statistics Office (CSO) and counts every person present in Ireland on a particular date. It provides detailed demographic information, including age and residence, at state and county level making it particularly relevant for forecasting demand on services across a range of geographical levels.

Census data on disability is derived from answers to Questions 16 and 17. Question 16 is a seven-part question that asks about the existence of the following long-lasting conditions:

- Blindness or a serious vision impairment
- Deafness or a severe hearing impairment
- A difficulty with basic physical activities such as walking, climbing stairs, reaching, lifting or carrying
- An intellectual disability
- A difficulty with learning, remembering or concentrating
- A psychological or emotional condition
- A difficulty with pain, breathing or any other chronic illness or condition

If a person answers 'yes' to any of the parts of Question 16, they are then asked to answer Question 17. This question is a four-part question that asks whether an individual has a difficulty doing any of the following activities:

- Dressing, bathing or getting around inside the home (self-care disability)
- Going outside the home alone to shop or visit a doctor's surgery (going outside the home disability)
- Working at a job or business or attending school or college (employment disability)
- Participating in other activities, such as leisure or using transport.

Individuals are counted as having a disability⁶ if they answer 'yes' to any part of the above two questions, including, if they ticked 'yes' to any of the parts of Question 17 even though they may not have ticked 'yes' to any of the parts of Question 16.

2.3 Nationally representative surveys

Nationally representative surveys were identified as potentially adding insight to selected cohorts and issues and providing data that may be extrapolated to a national level. Three surveys were identified as relevant: The National Disability Survey (2006), The Irish Longitudinal Study on Ageing (2009-2016), and the Irish Health Survey (2019).

2.3.1 National Disability Survey

The National Disability Survey (NDS) was conducted by the CSO in Autumn 2006 using a sample based on responses to two questions on disability asked in Census 2006. The purpose of the NDS was to provide a detailed profile of people with a disability in Ireland. Data was collected through personal interviews using paper-based questionnaires. Three separate samples were selected for the NDS:

- Individuals residing in private households who had not reported any disability in Census 2006
- Individuals residing in private households who had reported one or more disabilities in Census 2006
- Individuals residing in a nursing home, hospital or children's home who had reported one or more disabilities in Census 2006.

The NDS questionnaires were based on the social model of disability which defines disability as 'the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers s/he may face'. Section 1 of the questionnaire collected a range of data on nine specific disability types including the level of difficulty experienced by respondents in carrying out their daily activities. Of these nine disability types, four were excluded from this analysis as less relevant to the four pillars of functional capacity (Mobility and dexterity, Pain, Breathing and Sight). The remaining five disabilities were considered relevant to this project namely:

- Hearing
- Speech
- Remembering and concentrating
- Intellectual and learning
- Emotional, psychological and mental health.

The NDS provides insight into how these disabilities impact on a person's ability to engage in everyday activities and, for those disabilities related to communication, how the disability impacts on communicating with specified groups of people. Findings were published in two volumes, the first of which was accessed for this report together with supporting datasets. The NDS was the only identified source of data

⁶ It should be noted that the Census refers to these long-lasting conditions/difficulties as disabilities when reporting findings, yet the Census questions do not ask individuals if they have a disability.

on speech disability among all data sources examined in this project.

2.3.2 The Irish Longitudinal Study on Ageing

The Irish Longitudinal Study on Ageing (TILDA) is a large-scale, nationally representative study of adults aged 50 and over. Its purpose is to provide an evidence-base for addressing current and emerging issues associated with population ageing in Ireland across health, economic and social systems. The first wave of the study was conducted in 2009 and has been repeated at two-to-three-year intervals with the same cohort, with the most recent wave conducted in 2018 (Wave 5). Data is collected through interview administered tests and questions as well as self-completed questionnaires. In addition, Waves 1 and 3 included a health assessment.

Comprehensive results, including published reports and anonymised microdata files, were available for the first four waves of the study and a limited number of bespoke reports were available for Wave 5. Anonymised microdata files for waves one to four were accessed through the Irish Social Science Data Archive (ISSDA).

TILDA has generated extensive data on older adults in Ireland, facilitating an in-depth examination of their experience of difficulties and disabilities relevant to decision-making. Data related to cognitive functioning, hearing, and mental health was identified as being particularly relevant. Other variables related to level and type of dependency, advance care planning and internet usage may be considered in a later stage of this project and are not reported here.

Learning and memory were investigated within TILDA using three separate measures: verbal memory, prospective memory and self-rated memory. Executive function was assessed using a verbal fluency task, while global cognitive function was assessed using the Mini-Mental State Examination (MMSE).

Wave 4 was conducted in 2016 providing an opportunity to access and analyse data on this cohort at a point in time comparable to Census 2016 data. In addition, longitudinal data was identified as being potentially useful in documenting age-related changes across a range of relevant variables.

2.3.3 The Irish Health Survey

The second Irish Health Survey (IHS) was conducted in 2019/20 and published by the CSO in December 2020. It forms part of a European Union wide health survey providing data and insights on various aspects of health in Ireland. The survey is based on self-reported data from people aged 15 years and over and outlines their view of their health status, from how well they are feeling, to the extent to which they suffer from long-standing health conditions, as well as other factors. Survey results are used here to provide further insight on the health experience of persons with disabilities and their carers,

particularly in relation to individuals reporting difficulty learning remembering or concentrating.

2.4 Disability and diagnosis specific databases

Data on disability services usage and need in Ireland is collected and managed by the Health Research Board (HRB). In 2019 the National Ability Support Scheme (NASS) replaced two earlier databases: The National Intellectual Disability Database (NIDD) and the National Physical and Sensory Disability Database (NPSDD). Reports on all three databases were identified as relevant and examined and the HRB provided further data on request.

2.4.1 National Ability Support System (NASS)

The National Ability Supports System (NASS) is a national database that records information about disability-funded services. NASS is managed by the HSE and the HRB. NASS collects and stores data on disability funded services such as residential services, respite care, day services, personal assistants and specialists supports such as occupational therapy or physiotherapy.

NASS began collecting data in September 2019 and replaced the NIDD and NPSDD, which were decommissioned in January 2018. NASS differs from the earlier in several ways. Firstly, NASS has expanded the types of disability that can be recorded to include autism, developmental delay and mental health. Secondly, the NPSDD registration criteria only covered individuals up to the age of 65; on NASS there is no upper age limit for registration. Furthermore, NASS provides the facility to record diagnosis which was not previously captured on NIDD.

There are 11 disability categories that NASS records data on with an additional category termed 'Not verified'. The disabilities are:

- Intellectual
- Autism Spectrum Disorder (ASD)
- Deafblind – dual Sensory
- Hearing loss and/or deafness
- Developmental delay (under 10 years only)
- Neurological
- Physical
- Specific learning disorder (other than intellectual)
- Speech and/or language
- Visual
- Mental health.

A description of the disabilities is contained in the Appendix (Table 75).

2.4.2 National Intellectual Disability Database (NIDD)

Established in 1995, the National Intellectual Disability Database (NIDD) was a service planning tool designed to capture data on the usage of and the need for specialist disability services among people with intellectual disability. The database informed the regional and national planning of these services by providing information on trends in demographics, current service use and future service need. Reports were published annually. These reports together with data accessed from the HRB by request were identified as relevant to this project.

2.4.3 National Physical and Sensory Disability Database (NPSDD)

The National Physical and Sensory Disability Database (NPSDD) was a service planning tool designed to capture data on the usage of and need for specialist disability services among people with physical and sensory disability. Registration was limited to individuals aged less than 66 years with a physical/sensory disability that availed of, or who required, a specialised health or personal social service and who consented to register on the database. Disabilities were required to be persistent physical, sensory, neurological, speech or language disability arising from disease, disorder or trauma.

The data within the three datasets NASS, NIDD and NPSDD were identified as relevant for providing potential insight into the level of need, the types of services being accessed and whether individuals are residing in a supported/institutional setting or within a private residence.

2.5 Diagnosis based databases and other estimates of specific conditions

While the Act makes clear that incapacity must not be assumed because of a pre-existing medical condition, certain neurological and mental health conditions can affect aspects of cognitive functioning needed to make decisions, such as perception, attention and memory. Neurological disorders encompass developmental disorders, acquired brain injury and neurodegenerative disorders.

Data on adults with neurological conditions and mental health disorders was accessed through a broad range of sources including registers, surveys and reports published by government bodies, academic institutes and other non-government organisations.

2.6 Disability and diagnosis specific financial supports

Relevant data on disability and diagnosis specific financial supports was identified and accessed from two sources: data held by the Housing Agency on social housing support for people with disabilities and the HSE's Primary Care Reimbursement Service, specifically the long-term illness scheme.

2.6.1 Social housing support for people with disabilities

Social housing support is housing provided to people who are assessed as being unable to afford housing from their own resources. Local authorities assess, allocate and are the main providers of social housing support in Ireland. Some housing is also provided by approved housing bodies, but applications are still made through the local authority. While all applicants for social housing support must fall below net income limits set by the local authority,⁷ priority can thereafter be given based on other needs. A special area of consideration identified as relevant for the purposes of this project was housing for people with disabilities, including physical, intellectual, mental health and sensory disabilities.

Three of these disabilities are relevant to decision-making. Physical disability, while not directly relevant, is also included, as an applicant is assessed on their primary disability from a housing need perspective. A limited amount of data on social housing support for people with disabilities was available through reports published by the Housing Agency and further data was provided directly by the Housing Agency on request.

2.6.2 Disability Allowance

The Disability Allowance is a weekly allowance paid to people with a disability. To qualify for Disability Allowance the person must:

- Have an injury, disease or physical or mental disability that has continued, or may be expected to continue, for at least one year; and
- As a result of this disability be substantially restricted in undertaking work that would otherwise be suitable for a person of that age, experience and qualifications.

Data was requested from the Department of Social Protection (DSP) in relation to adults in receipt of a Disability Allowance. Since 2017, the DSP has recorded data on the types of disability according to ICD10 (International Statistical Classification of Diseases and Related Health Problems). Prior to 2017, General Practitioners were not obliged to categorise disabilities.

⁷ Affordability is assessed according to maximum net income thresholds which vary depending on location and whether the application is for a single person or a family.

The following ICD10 codes were identified as potentially relevant since they correspond to both the census disabilities and the four pillars of functional capacity:

- F60 - 69: Disorders of adult personality and behaviour
- F70: Mental retardation
- F80 - 89: Disorders of psychological development
- I60 - 69 Cerebro vascular diseases
- C71: Malignant neoplasm of brain
- D43: Neoplasm of uncertain or unknown behaviour of brain and central nervous system
- D33: Benign neoplasm of brain and other parts of central nervous system.

2.6.3 Long-Term Illness Scheme

The Long-Term Illness Scheme enables people with eligible conditions to receive free medicines and approved appliances from their community pharmacist, irrespective of their income or other circumstances, for the treatment of that condition. The scheme is administered by the HSE, and records are held by the HSE Primary Care Reimbursement Service (PCRS). The scheme covers 16 long-term conditions.

There is limited data available in Ireland on people diagnosed with neurological conditions. Data from the long-term illness scheme was identified as potentially contributing to this data deficit as seven of the 16 conditions covered by the scheme may affect neurological functioning. Moreover, as eligibility for the scheme is not income dependent, this data source is inclusive of all persons requiring medicines/appliances to manage one of these conditions or more of these long-term illnesses.

A limited amount of published data was accessed. Further data was provided on request from the PCRS on the number of unique beneficiaries of the long-term illness scheme aged 18 and over, where activity had been recorded over the previous 12 months, with one or more of the following illnesses:

- Epilepsy
- Parkinsonism
- Multiple sclerosis
- Intellectual disability
- Cerebral palsy
- Muscular dystrophies
- Hydrocephalus.

2.7 Care settings

Care settings were identified as potentially including a high proportion of people with capacity difficulties by the nature of the services provided and level of dependency of residents requiring such care. In addition, it was recognised that entry into and residing in care settings can trigger the need for financial arrangements, care agreements and other personal welfare decisions to be made.

There are three main types of long-term residential care facilities for adults in Ireland: older persons, disability, and mental health services. Those living in such facilities were identified as warranting special consideration since a requirement for this level of care indicates a high level of dependency. In addition, anecdotal evidence suggests that staff members may be involved in assisting residents with decision-making where no alternative legal arrangements are in place.

The Health Information and Quality Authority (HIQA) is responsible for the monitoring, inspection and registration of designated centres for people with disabilities and for older people (such as nursing homes) while the Mental Health Commission (MHC) has a similar function regarding approved centres for people with mental health conditions requiring residential care. Both HIQA and the MHC maintain registers of these centres and publish inspection and annual activity reports. Data on residential centres is also collected by the Mental Health and Social Care divisions of the HSE.

2.8 Existing decision-making arrangements

Data relating to Wardship, the current scheme for substitute decision-making pursuant to the Lunacy Regulation (Ireland) Act 1871, was accessed through the Office of the Wards of Court, within the Courts Service of Ireland. The Office of the Wards of Court is also responsible for maintaining the register of Enduring Powers of Attorney (EPAs) made under the Powers of Attorney Act 1996.

Data on Wards of Court (WOC) and EPAs were accessed on request through the Office of Wards of Court. Data on WOC was obtained at individual record level. This detailed the date of declaration, an indication as to whether the ward has a private committee or general solicitor and the category of the ward's illness/condition. In addition to this, data was accessed, on request, pertaining to residence type for each ward. Residence types include private home, psychiatric unit, assisted living and nursing homes.

Chapter 3

3.1 Overview of data findings and analysis

This chapter focuses on findings and analysis of the data sources set out in Chapter 2.

3.1.1 Common themes across datasets

Data was often presented thematically in the data source examined. Common thematic categories emerged including challenges with learning, memory, concentration, hearing, speech, psychological health and emotional health. While not aligned in all aspects, these thematic categories were considered relevant to the functional pillars of capacity, and this shapes how data is presented in Chapter 3 as illustrated in Table 2.

Table 2: Presentation of themes from data by functional pillars of decision-making capacity

Capacity pillar			
Understand information	Retain information	Use or weigh up information	Communicate decision
Learning	Memory	Learning	Hearing
Concentration	Concentration	Memory	Speech
Psychological health	Psychological health	Concentration	
Emotional health	Emotional health	Psychological health	
Hearing		Emotional health	

3.1.2 Terms and language used

Data reported here reflects the language used in each survey or database, for example issues relating to memory are reported as remembering disability in the National Disability Survey and as cognitive function in The Irish Longitudinal Study on Ageing.

3.2 Census

3.2.1 Method of filtering Census data

The most recent Census figures pertain to 2016. As the 2021 Census has been postponed until 2022, with publication of data not expected until 2023, the 2016 Census forms the most recent whole population database upon which a set of baseline figures can be drawn. Given that the data is five years old, both the 2011 and 2006 Census were examined to gain further understanding of growth and/or decline, as well as patterns of development within certain cohorts, i.e., age groups and counties.

In 2016 the population of the state was 4,761,865. Of this, the adult population (18+) amounted to 3,571,363. While the entire adult population is eligible to seek the services of the DSS, only those whose current decision-making capacity is in question are likely to do so in the immediate term. This prompted the question: How many of the 3.5 million adult population might potentially benefit from decision-support services in the immediate term?

This process commenced with an examination of the population that self-identified in Census 2016, as having a difficulty or long-lasting condition. Question 16 of Census 2016 set out seven 'difficulties or long-lasting conditions' as described in section 2.2.1. A total of 567,168 adults indicated having one or more of these conditions.

A second question was then posed: How many of these 567,168 adults might potentially benefit from decision-support services in the immediate term?

In answering this, the four pillars of a functional assessment of capacity were applied to this population, i.e., How many of the 567,168 adults would likely fail to meet one or more of these four pillars? Of those surveyed within

Census 2016, the condition that best reflects the pillars of functional capacity was identified as difficulty learning remembering or concentrating. This condition ties in with the first three pillars of understanding, retaining and weighing up, and using information to make a decision. For this reason, adults with a difficulty learning remembering and concentrating' are the primary focus. Within this condition there is no emphasis on a diagnosis or requiring the adult accessing services for them to self-identify as having the condition. While this can be viewed as advantageous in terms of capturing a wider portion of the population it should be noted that the number reported is reliant on self-declaration and it is possible that not every adult with a difficulty learning, remembering or concentrating will self-identify as having any difficulty in this regard.

Two further conditions within this cohort were identified as relevant, namely adults with an intellectual disability and those with a psychological or emotional condition, as they also relate directly to three out of the four pillars referred to above. In relation to psychological and emotional conditions, it is important to note that this may only be in a temporary manner. It is also important to note that not everyone with an intellectual disability or psychological or emotional condition will experience capacity difficulties; this will be considered in more detail in Sections 3.2.3 to 3.2.6.

A final potentially relevant category was identified as 'deafness or a serious hearing impairment.' Adults with this impairment may experience challenges in exercising their decision-making capacity, due to difficulty with hearing information and/or difficulty in fully engaging with communicating their decision. As with the other conditions examined, this cohort cannot be assumed to lack capacity by virtue of their condition.

Table 3 shows each of the difficulties and long-lasting conditions and those identified as relevant to the four pillars of the functional capacity assessment.

Table 3: Difficulties or long-lasting conditions recorded in Census 2016

Difficulty or long-lasting condition	Relevant to decision-making capacity?
Blindness or a serious vision impairment	No
Deafness or a serious hearing impairment	Yes
A condition that substantially limits one or more basic physical activities	No
An intellectual disability	Yes
Difficulty learning remembering or concentrating	Yes
Psychological or emotional condition	Yes
Other disability including chronic illness	No

3.2.2 Census findings: Difficulty learning, remembering or concentrating

Table 4 shows that there are **116,811** adult persons with difficulty learning remembering and concentrating; this represents 3.3% of the total adult population in the state. The proportion of total population that persons with difficulty learning, remembering or concentrating accounts for has been steadily increasing since 2006.

Table 4: Total adult population and those with difficulty learning remembering or concentrating in 2006, 2011 and 2016

Year	2006	2011	2016
Adult population with DLRC in state	86,986	104,342	116,811 ⁸
Total adult population in state	3,203,814	3,439,565	3,571,363
Percentage of total adult population with DLRC	2.7%	3%	3.3%

Table 5 details the composition of DLRC by age group and shows that a higher proportion of the adult population over the age of 65 reported a difficulty learning, remembering or concentrating, with 7.4% (47,413) compared with 2.4% of those adults aged 18-64.

⁸ 34,290 of 116,811 have DLRC only and no other condition.

Table 5: Total adult population and those with difficulty learning remembering or concentrating by age

2016	18-64	65+
Population with DLRC in state	69,398	47,413
Total adult population in state	2,933,796	637,567
Percentage of total adult population with DLRC	2.4%	7.4%

The number of adults with difficulty learning, remembering or concentrating resident in communal settings, and specifically nursing homes, is presented in Table 6. Of the **47,413** adults over the age of 65 with a difficulty learning, remembering or concentrating, 16,237 reside in communal settings, of which 27% (12,801) are resident in nursing homes. In the 18-64 age group, 5,360 reside in communal settings, of which 4.4% (3,062) reside in nursing homes.

The total number of adults with a difficulty learning, remembering or concentrating in nursing homes in the 65+ age group has increased from 9,129 in 2006 to 12,801 in 2016. However, as a percentage of the population with a difficulty learning, remembering or concentrating this has remained steady at around 27%. The number of adults with a difficulty learning, remembering or concentrating aged 18-64 residing in nursing homes has been in decline since 2006 both in percentage terms and absolute numbers. In 2006 this accounted for 6.7% (3,469), falling to 4.4% (3,062) in 2016.

Table 6: Adult population with difficulty learning remembering or concentrating in 2006, 2011 and 2016 by age group, residence in communal settings (all), and residence in a nursing home

Adult population	2006		2011		2016	
Population in of adults with DLRC	86,986		104,342		116,811	
Age groups	18-64	65+	18-64	65+	18-64	65+
Number with condition	52,044	34,942	61,958	42,384	69,398	47,413
Total residing in communal setting ⁹	7,024	15,065	6,063	15,695	5,360	16,237
Nursing home residents	3,469	9,129	3,408	11,515	3,062	12,801
Percentage in nursing homes	6.7%	26.1%	5.5%	27.2%	4.4%	27%

Table 7 presents the numbers of adults at county level that reported a difficulty learning, remembering or concentrating in 2016. Figures for 2011 and 2006, included in the table, highlight the change, in absolute terms, in all counties. To understand these figures further they have been contextualised in terms of the total adult population per county. General population growth and population growth among adults with a difficulty learning, remembering or concentrating in the period 2006 to 2016 is also highlighted. While the total adult population grew by 131,798 (3.8%) in the period 2011 to 2016 the adult population with a difficulty learning, remembering or concentrating grew by **12,469** (12%). County Carlow experienced the largest proportionate growth in the period 2011 to 2016 with a 326 (26.3%) increase. Counties Sligo and Donegal experienced general population decline in the period 2011 to 2016 yet experienced growth in their population with a difficulty learning, remembering or concentrating, increasing by 108 (5.9%) and 281 (7.1%) respectively.

In absolute terms Dublin City was the county/administrative area with the highest number reporting a difficulty learning, remembering or concentrating in the State with 15,693. Cork county was the next highest with 8,932. When the four administrative areas of Dublin are combined there was a population of 32,627. Monaghan was the only county to have experienced a decline in population with a difficulty learning, remembering or concentrating, less 53 (-3.7%), while at the same time experiencing marginal growth in its general population (0.8%).

⁹ CSO classifies communal setting as hospital, nursing home/children's home; educational establishment; religious community; defence establishment; prison; shelter or refuge (including homeless) hotel, boarding house, guest house or B&B; Tourist/youth hostel or campsite; civilian ship, boat or barge.

Table 7: Total adult population and those with difficulty learning, remembering or concentrating by county in 2006, 2011 & 2016, and percentage change 2006 to 2016

Year	Adult population 18+ with DLRC			Percentage change in population with DLRC		Total Adult population 18+			Population growth	
	2006	2011	2016	2006-2011	2011-2016	2006	2011	2016	2006-2011	2011-2016
State	86,986	104,342	116,811	20%	12%	3,203,814	3,439,565	3,571,363	7.4%	3.9%
Carlow	1,104	1,242	1,568	12.5%	26.3%	37,681	40,473	42,080	7.4%	4%
Cavan	1,276	1,540	1,742	20.7%	13.1%	46,876	52,989	55,153	13%	4.1%
Clare	2,230	2,491	2,745	11.7%	10.2%	82,385	86,530	88,192	5%	1.9%
Cork City	3,407	3,871	4,447	13.6%	14.9%	96,916	98,035	104,067	1.2%	6.2%
Cork County	6,353	7,770	8,932	22.3%	15%	268,138	292,549	304,786	9.1%	4.2%
Donegal	3,264	3,953	4,234	21.1%	7.1%	106,976	117,405	117,150	9.8%	-0.2%
Dublin City	12,155	14,243	15,693	17.2%	10.2%	414,716	432,317	455,883	4.2%	5.5%
Dún Laoghaire Rathdown	3,809	4,551	5,194	19.5%	14.1%	150,843	161,301	170,224	6.9%	5.5%
Fingal	3,709	4,923	5,480	32.7%	11.3%	177,770	198,196	212,405	11.5%	7.2%
Galway City	1,427	1,669	1,833	17%	9.8%	59,061	60,922	63,145	3.2%	3.7%
Galway County	3,224	3,751	4,217	16.4%	12.4%	117,303	128,537	131,306	9.6%	2.2%
Kerry	2,980	3,327	3,504	11.64	5.3%	106,799	110,562	113,180	3.5%	2.4%
Kildare	3,317	4,257	4,989	28.3%	17.2%	135,998	150,863	159,590	10.9%	5.8%
Kilkenny	1,884	2,107	2,526	11.8%	19.89%	64,676	70,404	73,288	8.9%	4.1%
Laois	1,258	1,694	2,019	34.7%	19.2%	49,046	57,627	60,433	17.5%	4.9%
Leitrim	674	708	797	5%	12.6%	21,817	23,747	23,856	8.9%	0.5%
Limerick City & County	4,253	4,697	5,531	10.4%	17.8%	140,548	145,742	147,809	3.7%	1.4%
Longford	704	987	1,050	40.2%	6.4%	25,461	28,407	29,655	11.6%	4.4%
Louth	2,157	2,862	3,185	32.7%	11.3%	82,034	89,605	93,838	9.2%	4.7%
Mayo	3,010	3,419	3,510	13.6%	2.7%	92,870	98,124	98,539	5.7%	0.4%
Meath	2,342	3,137	3,768	34%	20.1%	118,210	130,735	137,910	10.6%	5.5%
Monaghan	1,235	1,417	1,364	14.7%	-3.7%	41,542	44,452	44,822	7%	0.8%
Offaly	1,279	1,662	1,983	30%	19.31%	51,699	55,538	56,834	7.43%	2.3%
Roscommon	1,354	1,553	1,644	14.7%	5.86%	44,265	47,989	48,239	8.4%	0.5%
Sligo	1,478	1,845	1,953	24.8%	5.85%	46,284	49,852	49,574	7.7%	-0.6%
South Dublin	4,546	5,627	6,260	23.8%	11.25%	182,746	193,997	203,661	6.2%	5%
Tipperary	3,438	3,921	4,256	14.1%	8.54%	111,313	117,994	118,789	6%	0.7%
Waterford City & County	2,184	2,577	2,828	18%	9.74%	80,952	84,887	86,829	4.9%	2.3%
Westmeath	1,848	2,013	2,197	8.9%	9.14%	58,222	63,112	65,186	8.4%	3.3%
Wexford	2,569	3,440	4,040	33.9%	17.44%	96,898	106,478	110,556	9.9%	3.8%
Wicklow	2,518	3,088	3,322	22.6%	7.58%	93,769	100,196	104,384	6.9%	4.2%

To assist in establishing levels of need within the population of 116,811 adults with a difficulty learning, remembering and concentrating, further investigation and analysis of the composition of this cohort was undertaken, regarding permutations of population with other conditions considered relevant to decision-making capacity i.e., intellectual disability, psychological or emotional conditions, and deafness or serious hearing impairment. Table 8 presents these permutations and further analysis is presented in Sections 3.2.3 to 3.2.5.

Table 8: Permutations of the population with difficulty learning, remembering or concentrating 2016

Permutation	Number of adults
Difficulty Learning, Remembering or Concentrating with Intellectual Disability and Psychological or Emotional Condition	13,968
Difficulty Learning, Remembering or Concentrating with Intellectual Disability	30,138
Difficulty Learning, Remembering or Concentrating with Psychological or Emotional Condition	35,841
Difficulty Learning, Remembering or Concentrating only	34,290
Deafness or a Serious Hearing Impairment only	42,287

3.2.3 Census findings: Intellectual disability

Census 2016 shows that there were **44,864** adults in the state who reported having an intellectual disability. This represents 1.3% of the total adult population in the state. In 2011 there were 41,266 individuals identifying with an intellectual disability. This represents an increase of 3,418 (8.7%) in the period 2011 to 2016. The number with an intellectual disability in the 2006 Census cannot be used as a direct comparison as it included learning disability.

Table 9: Adults population with an intellectual disability in 2006, 2011 & 2016

Year:	2006	2011	2016
Adult population with an intellectual disability in state	45,266 ¹⁰	41,266	44,864
Total adult population in state	3,203,814	3,439,565	3,571,363
Percentage of adult population with an intellectual disability	1.4%	1.2%	1.3%

Data on intellectual disability was examined to identify adults who also identified as having a difficulty learning, remembering or concentrating. To avoid double counting, those with a difficulty learning, remembering or concentrating were removed from this cohort, hence arriving at a figure of 14,726 for an adult population with intellectual disability but without a difficulty learning, remembering or concentrating. Table 10 presents these three categories by age group.

Table 10: Adult population in 2016 with intellectual disability and with/without difficulty learning, remembering or concentrating by age group

Age group	18-64	65+	Total adults
Total number with an intellectual disability	35,957	8,907	44,864
Number with intellectual disability with a difficulty learning, remembering, or concentrating	23,558	6,580	30,138
Number with intellectual disability without a difficulty learning, remembering, or concentrating	12,399	2,327	14,726

3.2.4 Census findings: Psychological or emotional condition

In 2016 the number of adults in the State with a psychological or emotional condition amounted to **106,743**. This represents 5.5% of the adult population. Table 11 shows an increase in absolute numbers since 2006 with 60,519 identifying with a psychological or emotional condition in that year. In the period 2006 to 2011 there was a 44%

¹⁰The 2006 Census asked if individuals had a "Learning or Intellectual disability" This accounts for the higher figure than 2011 and 2016. In these years individuals were asked if they had an intellectual disability only.

increase while in the period 2011 to 2016 there was a 23%. These increases are considerably more than the 7% and 4% increases that were experienced in the general population for the same periods.

Table 11: Adult population with a psychological or emotional condition in 2006, 2011 & 2016

Year	2006	2011	2016
Adult population with psychological or emotional condition in state	60,519	86,948	106,743
Total adult population in state	3,203,814	3,439,565	3,571,363
Percentage of adult population with psychological or emotional condition	1.9%	2.5%	5.5%

Data on adults with a psychological or emotional condition was examined to again, avoid any double counting the population with a difficulty learning, remembering or concentrating. Adults with a difficulty learning, remembering or concentrating within this cohort were identified and removed. The total number with a psychological or emotional condition in 2016 amounts to 106,743. When the number with a difficulty learning, remembering or concentrating (35,841) was subtracted, the number with the condition amounted to **70,902**.

Table 12: Adult population in 2016 with psychological or emotional condition and with/without difficulty learning, remembering or concentrating by age group

Age group	18-64	65+	Total adults
Total number with psychological or emotional condition	86,599	20,144	106,743
Number with psychological or emotional condition and a difficulty learning, remembering, or concentrating	24,045	11,796	35,841
Number with psychological or emotional condition less a difficulty learning, remembering, or concentrating	62,554	8,348	70,902

3.2.5 Census findings: Deafness or serious hearing impairment

The number of adults with deafness or serious hearing impairment in 2016 amounted to **99,150** as shown in Table 13. This represents 2.78% of the population and an increase of 12% on the 2011 number of adults identifying with the condition. It is not possible to show the number of adults with deafness or serious hearing impairment in 2006 as this condition was enumerated together with blindness in that census.

Table 13: Adult population with deafness or serious hearing impairment in 2006, 2011 & 2016

Year	2006	2011	2016
Adult population with deafness or serious hearing impairment in state	71,710 ¹¹	88,393	99,150
Adult population in state	3,203,814	3,439,565	3,571,363
Percentage of adult population with deafness or serious hearing impairment	-	2.6%	2.8%

Data on adults with deafness or serious hearing impairment was also further disaggregated to identify those with and without a difficulty learning, remembering or concentrating. Table 14 shows that in 2016, of the 99,150 individuals with deafness or serious hearing impairment, 17,263 have a difficulty learning, remembering or concentrating. The number of adults with deafness or serious hearing impairment that do not have a difficulty learning, remembering or concentrating amounts to **81,887**.

¹¹ This figure has been excluded because in 2006 DHI was not a condition that data was gathered on. Instead, it was collected with a group of conditions: Blindness, deafness or a severe vision or hearing impairment.

Table 14: Adult population in 2016 with deafness or serious hearing impairment and with/without difficulty learning, remembering or concentrating by age group

Age group	18-64	65+	Total adults
Total number with deafness or serious hearing impairment	36,166	62,984	99,150
Number with deafness or serious hearing impairment and a difficulty learning, remembering or concentrating	5,206	12,057	17,263
Number with deafness or serious hearing impairment less a difficulty learning, remembering or concentrating	30,960	50,927	81,887

3.2.6 Census findings: Summary

Data from Census 2016, as well as Census 2011 and 2006 was relevant in identifying populations with conditions that reflect the four pillars of functional capacity, namely individuals with difficulty learning, remembering or concentrating with or without a further three conditions: intellectual disability, psychological or emotional conditions, and deafness or serious hearing impairment. Table 15 summarises the data examined in Sections 3.2.2 to 3.2.5. The population of note in determining a cohort of potential DSS service users is adults with a difficulty learning, remembering amounting to **116,811**. Of these, **34,290** adults have a difficulty learning, remembering or concentrating only. In addition, there are a further:

- **14,726** adults with an intellectual disability without a difficulty learning, remembering or concentrating
- **70,902** adults with a psychological or emotional condition without a difficulty learning, remembering and concentrating
- **81,887** adults with deafness or serious hearing impairment without a difficulty learning, remembering and concentrating.

Table 15: Adult population in 2016 with intellectual disability, psychological or emotional condition, deafness or serious hearing impairment with/without difficulty learning, remembering or concentrating

Number of adults	Intellectual Disability	Psychological or emotional condition	Deafness or serious hearing impairment
With condition	44,864	106,743	99,150
With condition and a difficulty learning, remembering or concentrating	30,138	35,841	17,263
With condition and no difficulty learning, remembering or concentrating	14,726	70,902	81,887

3.3 National Disability Survey

As set out in Chapter Two, the National Disability Survey (NDS) surveyed nine disability categories. Five of the nine disabilities included in the NDS are examined here, namely:

- Remembering and concentrating,
- Intellectual and learning,
- Speech,
- Hearing, and
- Emotional, psychological and mental health.

Respondents were asked to include only difficulties that had lasted, or were expected to last six months or more, or that regularly re-occur. Three levels of difficulty (moderate, a lot, can't do at all) were included for those reporting remembering and concentrating, speech and hearing disabilities. A fourth level (just a little difficulty) was included for those respondents reporting intellectual and learning, and emotional, psychological and mental health disabilities. Where available, data is displayed in both percentages and numbers of individuals. For a more detailed description of the NDS, please see Section 2.3.1.

Table 16 presents an overview of each of the five disabilities among adults (18+) and children (0-17 years) for context. Data is presented in both percentages and numbers (in thousands). Remembering and concentrating disability was reported by the highest number of individuals (113,000) closely followed by emotional, psychological and mental health disability (110,600). However, a higher number of adults reported emotional, psychological and mental health disability (100,700) compared with remembering and concentrating disability (95,200). The least reported disability was speech, for the whole cohort (35,300) and for adults only (25,200). Age breakdown varied considerably according to disability type: those aged 0-17 years accounted for 37.6% of all intellectual and learning disability, 28.6% of speech disability, 15.8% of remembering and concentrating disability, 9% of emotional, psychological and mental health disability, and 5.7% of hearing disability.

Table 16: Number and proportion of adults and children reporting five types of disability

Disability type	Remembering & concentrating		Intellectual & learning		Speech		Hearing		Emotional, psychological & mental health	
	%	Number	%	Number	%	Number	%	Number	%	Number
Total	100%	113,000	100%	71,600	100%	35,300	100%	57,600	100%	110,600
0-17	15.8%	17,800	37.6%	26,900	28.6%	10,100	5.7%	3,300	9%	9,900
Total adults	84.2%	95,200	62.4%	44,700	71.4%	25,200	94.3%	54,300	91%	100,700

3.3.1 Remembering and concentrating disability

Table 17 presents data on individuals with a remembering and concentrating disability by level of difficulty and age group. Respondents were asked to report if they experienced a moderate level of difficulty, a lot of difficulty or could not do the activity at all due to their disability. Just under half (49.7%) of adults with a remembering and concentrating disability reported a moderate level of difficulty while a further 37.1% reported a lot of difficulty. 13.2% reported not being able to carry out everyday activities at all due to this disability. Among older adults (age 65+) this increased to 19% (7,676 individuals).

Table 17: Level of difficulty by age group among individuals with a remembering and concentrating disability

Difficulty	A moderate level		A lot of difficulty		Cannot do at all		Total	
	%	Number	%	Number	%	Number	%	Number
Total	48.6%	54,900	38.8%	43,800	12.7%	14,300	100%	113,000
0-17	42.8%	7,631	47.4%	8,453	9.9%	1,766	100%	17,850
18-64	53.8%	29,426	37.3%	20,411	8.9%	4,858	100%	54,695
65+	44.1%	17,843	36.9%	14,936	19%	7,676	100%	40,455
Total adults	49.7%	47,269	37.1%	35,347	13.2%	12,534	100%	95,150

Tables 18 and 19 present findings on three types of activities associated with a remembering and concentrating disability: remembering to do important things, forgetting where I put things, and concentrating for 10 minutes. As individuals could report difficulty with more than one type of activity, the sum of the three types of activity reported in Table 18 is greater than the total number of individuals reporting a remembering and concentrating disability.

A higher number of individuals reported difficulty due to forgetting where they put important things (85,800) compared with remembering to do important things (77,600) or concentrating for 10 minutes (77,900). Overall a broadly similar pattern was seen in the proportions experiencing different levels of difficulty across the three activity types with close to half (45% to 52%) experiencing a moderate level of difficulty, more than a third (35.4% to 38.3%) experiencing a lot of difficulty and the remainder (12.6% to 16.7%) reporting not being able to do the activity at all.

Table 18: Specific activity by level of difficulty among individuals with a remembering and concentrating disability

Activity	A moderate level		A lot of difficulty		Cannot do at all		Total	
Remembering to do important things	50.4%	39,100	35.6%	27,600	14.1%	10,900	100%	77,600
Forgetting where I put things	52%	44,600	35.4%	30,400	12.6%	10,800	100%	85,800
Concentrating for 10 mins	45%	35,000	38.3%	29,800	16.7%	13,100	100%	77,900

Table 19 shows the breakdown by age group of these three activities associated with a remembering and concentrating disability. Remembering to do important things followed a similar age pattern to the overall remembering and concentrating disability as shown in Table 16 (84.8% & 84.2% for adults and 15.1% & 15.8% for children respectively). Difficulty with forgetting where I put things was more prevalent among adults than the overall disability (88.6% compared with 84.2%) and concentrating for 10 mins was less prevalent (80.1%).

Table 19: Specific activity by age group among individuals with a remembering and concentrating disability

Activity	0-17		18-64		65+		Total adults	
Remembering to do important things	15.1%	11,700	45.3%	35,200	39.5%	30,600	84.8%	65,800
Forgetting where I put things	11.5%	9,900	46.9%	40,100	41.7%	35,700	88.6%	75,800
Concentrating for 10 mins	19.8%	15,500	47.1%	36,700	33.0%	25,700	80.1%	62,400

3.3.2 Intellectual and learning disabilities

Table 20 presents data on individuals with an intellectual and learning disability by level of difficulty and age group. Under a fifth (18.6%) of adults with intellectual and learning disabilities reported experiencing just a little difficulty in carrying out everyday activities while 33% reported a moderate level of difficulty. A similar percentage (31.9%) reported a lot of difficulty and the remaining 16.4% reported not being able to carry out everyday activities at all due to this disability. Among older adults (age 65+) this increased to 21.6% (1,495 individuals).

Table 20: Level of difficulty by age group among individuals with an intellectual and learning disability

Difficulty	Just a little		A moderate level		A lot of difficulty		Cannot do at all		Total	
Total	16.7%	12,000	36.2%	25,900	34.7%	24,800	12.5%	8,900	100%	71,600
0-17	13.7%	3,684	41.4%	11,163	39.1%	10,540	5.8%	1,566	100%	26,953
18-64	17.7%	6,672	34.6%	13,054	32.3%	12,177	15.5%	5,838	100%	37,741
65+	23.8%	1,644	24.4%	1,684	30.2%	2,083	21.6%	1,495	100%	6,906
Total adults	18.6%	8,316	33.0%	14,737	31.9%	14,260	16.4%	7,334	100%	44,647

Tables 21 and 22 present findings on specific issues associated with intellectual and learning disabilities: intellectual functions, interpersonal skills and learning everyday skills as well as the number of individuals diagnosed with intellectual disability. Table 21 shows that, of the 71,600 individuals reporting intellectual and learning disabilities, 50,400 had been diagnosed with an intellectual disability. Among those with a diagnosis of intellectual disability, 27.8% reported just a little difficulty in carrying out everyday activities, 48.1% reported a moderate level of difficulty, 17.8% a lot of difficulty and the remaining 6.4% reported not being able to carry out everyday activities at all. The other three issues reported in Table 21 are not categorised according to diagnosis so represent both those with and without a diagnosis of intellectual disability. A higher number of individuals (55,000) reported difficulty learning everyday skills compared with difficulty with intellectual functions (27,700) or interpersonal skills (22,300). The proportions experiencing the highest level of difficulty in each of these three issues ranged from 12.2% for learning everyday skills to 15.5% for intellectual functions.

Table 21: Level of difficulty by specific issue among individuals with an intellectual and learning disability

Activity/Diagnosis	Just a little		A moderate level		A lot of difficulty		Cannot do at all		Total	
	%	Count	%	Count	%	Count	%	Count	%	Count
Intellectual functions	14.5%	4,000	32.7%	9,100	37.3%	10,300	15.5%	4,300	100%	27,700
Interpersonal skills	20.4%	4,600	32.2%	7,200	32.4%	7,200	15.0%	3,400	100%	22,300
Learning everyday skills	18.5%	10,200	35.4%	19,500	33.9%	18,700	12.2%	6,700	100%	55,000
Diagnosed with intellectual disability	27.8%	14,000	48.1%	25,200	17.8%	9,000	6.4%	3,200	100%	50,400

Table 22 shows the breakdown by age group of activities associated with an intellectual and learning disability and those with and without an intellectual disability diagnosis. Of those with a diagnosis of intellectual disability, more than half (51.5%) were aged 18-64 with a further 42.4% aged 0-17. Only 6.1% were aged 65 and older.

Table 22: Specific issue by age group among individuals with an intellectual and learning disability

Level/Issue	0-17		18-64		65+		Total adults	
	%	Count	%	Count	%	Count	%	Count
Intellectual functions	26.3%	7,300	61.7%	17,100	11.9%	3,300	73.6%	20,400
Interpersonal skills	38.5%	8,600	51.7%	11,600	9.9%	2,200	61.6%	13,800
Learning everyday skills	40.4%	22,200	50.5%	27,700	9.2%	5,000	59.7%	32,700
Diagnosed with intellectual disability	42.4%	21,400	51.5%	26,000	6.1%	3,100	57.6%	29,100

3.3.3 Speech disability

Table 23 presents data on the level of difficulty in carrying out everyday activities by individuals with a speech disability by age group. 46.1% of adults with a speech disability reported a moderate level of difficulty while a further 34.8% reported a lot of difficulty. 19.1% reported not being able to carry out everyday activities at all due to this disability. A higher proportion of adults aged 18-64 reported the highest level of difficulty compared with adults aged 65 and older (22.5% and 13.5% respectively).

Table 23: Level of difficulty in everyday activities among individuals with a speech disability

Difficulty	A moderate level		A lot of difficulty		Cannot do at all		Total	
	%	Count	%	Count	%	Count	%	Count
Total	47.6%	16,800	34.4%	12,200	18.0%	6,400	100%	35,400
0-17	50.8%	5,146	33.7%	3,416	15.5%	1,568	100%	10,130
18-64	47.4%	7,467	30.1%	4,734	22.5%	3,546	100%	15,747
65+	44.0%	4,187	42.5%	4,050	13.5%	1,286	100%	9,523
Total adults	46.1%	11,654	34.8%	8,784	19.1%	4,832	100%	25,270

Table 24 presents findings on the level of difficulty in being understood by different groups by respondents with a speech disability, including family members, friends, people providing everyday services, health care professionals, and other people. These findings are not disaggregated by age therefore reflect both adults and children. As indicated in Table 16, adults accounted for 71.4% of those reporting a speech disability. Level of difficulty is categorised differently here compared to previous tables: no difficulty, some difficulty or a lot/can't communicate at all. Among those reporting a speech disability, the proportion reporting no difficulty varied according to the audience. 37.2% reported no difficulty being understood by family members while a smaller percentage (15.5%) reported no difficulty being understood by people providing everyday services. Conversely, half (50.2%) of those with a speech disability reported a lot of difficulty or not being able to communicate at all with people providing everyday services while 21.9% reported this level of difficulty communicating with family members.

Table 24: Level of difficulty being understood by others by group type among individuals with a speech disability

Group type/Difficulty	None	Some	A lot/can't do
Family members	37.2%	40.9%	21.9%
Friends	24.1%	41.0%	35.0%
People providing everyday services	15.5%	34.2%	50.2%
Health care professionals	23.2%	40.5%	36.3%
Other people	12.8%	36.7%	50.5%

3.3.4 Hearing disability

Table 25 presents data on the level of difficulty in carrying out everyday activities by individuals with a hearing disability by age group. 60.1% of adults with a hearing disability reported a moderate level of difficulty while a further 36.8% reported a lot of difficulty. 3.1% reported not being able to carry out everyday activities at all due to this disability. A higher proportion of adults aged 18-64 reported the highest level of difficulty compared with adults aged 65 and older (5% and 1.6% respectively).

Table 25: Level of difficulty in everyday activities among individuals with a hearing disability

Difficulty	A moderate level		A lot of difficulty		Cannot do at all		Total	
Total	61.1%	35,200	35.7%	20,600	3.2%	1,800	100%	57,600
0-17	77.7%	2,531	18.3%	595	4%	131	100%	3,257
18-64	62.0%	14,207	33%	7,573	5%	1,151	100%	22,931
65+	58.8%	18,462	39.6%	12,432	1.6%	518	100%	31,412
Total adults	60.1%	32,669	36.8%	20,005	3.1%	1,669	100%	54,343

Table 26 presents findings on the level of difficulty in being understood by specified groups by people with a hearing disability: family members, friends, people providing everyday services, health care professionals, and other people. These findings are not disaggregated by age therefore reflect both adults and children. As previously indicated in Table 16, adults accounted for 94.3% of those reporting a hearing disability. Among those reporting a hearing disability, the proportion reporting no difficulty varied according to the audience. 57.6% reported no difficulty being understood by family members while a smaller percentage (36.4%) reported no difficulty being understood by people providing everyday services. Conversely, 19.4% of those with a hearing disability reported a lot of difficulty or not being able to communicate at all with people providing everyday services while 7.1% reported this level of difficulty communicating with family members.

Table 26: Level of difficulty being understood by others by group type among individuals with a hearing disability

Group type/Difficulty	None	Some	A lot/can't do
Family members	57.6%	35.3%	7.1%
Friends	48.4%	42.0%	9.7%
People providing everyday services	36.4%	44.2%	19.4%
Health care professionals	52.2%	37%	10.9%
Other people	36.6%	45.3%	18.1%

3.3.5 Psychological, emotional, and mental health disabilities

Table 27 presents data on the level of difficulty in carrying out everyday activities by individuals with psychological, emotional and mental health disabilities by age group. 22.2% of adults with psychological, emotional and mental health disabilities reported experiencing just a little difficulty in carrying out everyday activities while 42% reported a moderate level of difficulty. 32.9% reported a lot of difficulty and the remaining 3.7% reported not being able to carry out everyday activities at all due to this disability. Among older adults (age 65+) this increased to 7.3% (1,904 individuals).

Table 27: Level of difficulty in everyday activities among individuals with a psychological, emotional and mental health disabilities

Difficulty	Just a little		A moderate level		A lot of difficulty		Cannot do at all		Total	
Total	22.8%	25,300	41.9%	46,300	31.7%	35,100	3.6%	4,000	100%	110,700
0-17	29.9%	2,982	39.9%	3,982	27.1%	2,706	3%	300	100%	9,970
18-64	20.5%	15,317	43.3%	32,364	33.8%	25,297	2.4%	1,796	100%	74,774
65+	27%	7,001	38.4%	9,955	27.3%	7,097	7.3%	1,904	100%	25,957
Total adults	22.2%	22,318	42%	42,318	32.2%	32,394	3.7%	3,700	100%	100,730

Table 28 presents findings on the frequency with which difficulties associated with psychological, emotional and mental health disabilities occurred: occasionally, often, and most of the time. These findings are not disaggregated by age therefore reflect both adults and children. As indicated in Table 28, adults accounted for 91% of those reporting psychological, emotional and mental health disabilities. Among those reporting occasional occurrence, half (49.7%) reported just a little difficulty while a further 42.7% reported a moderate level of difficulty. 7.8% reported a lot of difficulty and the remaining 0.3% reported not being able to carry out activities at all. Among those reporting occurrences most of the time, a much higher proportion reported a lot of difficulty (52.4%) or not being able to do at all (8.7%).

Table 28: Level of difficulty with everyday activities by frequency among individuals with a psychological, emotional, or mental disability

Frequency	Just a little	Moderate	A lot	Can't do at all
Occasionally	49.7%	42.3%	7.8%	0.3%
Often	14.1%	54.1%	31.1%	0.7%
Most of the time	6.5%	32.4%	52.4%	8.7%

3.3.6 Summary of NDS findings

The data presented above describes the extent to which certain disabilities impact on everyday activities. In doing so they help validate assumptions that individuals across all five of the disability types surveyed may experience difficulties and barriers relevant to their ability to exercise their decision-making capacity. This is likely to be through their reported level of difficulty with everyday activities, as well as against specific tasks such as remembering to do important things and concentrating for 10 minutes. These difficulties are closely aligned to the first three capacity pillars.

Also relevant is the reported level of difficulty being understood by others. This closely aligns to the fourth capacity pillar; communicating the decision. However, it is notable that the range of difficulties experienced ranges significantly within the cohorts, which will be explored further in Phase 2 of this project.

Data relating to speech and hearing is particularly insightful. Ability to communicate a decision is one of the four pillars of a functional assessment of capacity according to the 2015 Act. Speech and hearing disabilities may impact a person's ability to communicate, depending on the level of severity and the extent to which appropriate aids are available and utilised. While hearing disability is reported in more recent surveys including Census 2016, the information reported in the National Disability Survey 2006 is the only data source identified that specifically asks about how the hearing impairment impacts communication with a range of people. Data on speech disability is limited in Ireland and was only identified as having been reported in the National Disability Survey 2006.

3.4 The Irish Longitudinal Study on Ageing

Three variables from the Irish Longitudinal Study of Ageing (TILDA) were identified as relevant and examined here: cognitive functioning, hearing, and mental and emotional health. Data is presented for Waves 1 to 4 where available, however not all questions were asked consistently across all waves. Where a question was asked in that wave but not included in the anonymised microdata files (AMF), this is recorded as not available. Where a question was not asked in that wave, this is recorded as not asked. Data from Wave 4 is further presented by age categories. Data is presented in percentages and the total number of participants in each wave is noted for reference in each table. For a more detailed description of TILDA, please see Section 2.3.2.

3.4.1 Cognitive functioning

Table 29 presents self-rated day-to-day memory across four waves of the study. Respondents were asked to rate their memory on a five-point scale from excellent to poor. 45.8% of respondents reported excellent or very good memory in Wave 1 compared to 38.8% in Wave 2, 36.6% in Wave 3 and 33.6% in Wave 4. Conversely, a higher proportion reported fair or poor day-to-day memory at Wave 4 compared to Wave 1 (18.4% and 15.9% respectively).

Table 29: Self-rated day-to-day memory by level of difficulty in Waves 1 to 4

Rating	Excellent	Very good	Good	Fair	Poor	Total
Wave 4	7%	27.6%	46.9%	16.3%	2.1%	5,715
Wave 3	7.8%	28.8%	45%	15.9%	2.5%	6,572
Wave 2	9.1%	29.7%	41.9%	16.6%	2.7%	7,207
Wave 1	13.6%	32.2%	38.2%	13.1%	2.8%	8,504

Frequency of absent mindedness, shown in Table 30, was only asked in waves 1 and 4 with broadly comparable results. In both waves, most respondents reported being absent minded some of the time (70.7% in Wave 1 and 73.9% in Wave 4).

Table 30: Self-rated frequency of absent mindedness in Waves 1 and 4

Frequency	None of the time	Some of the time	Most of the time	All of the time	Total
Wave 4	17.5%	73.9%	6.5%	2%	5,715
Wave 3	Not asked				
Wave 2	Not asked				
Wave 1	20.4%	70.7%	6.7%	2.2%	8,504

Table 31 shows data on difficulty concentrating in Wave 4 as this was the only wave in which respondents were asked this question. Furthermore, as the question was asked in the context of stressful life events it may not reflect difficulty concentrating more generally. Almost half of the respondents (46.8%) indicated they had no difficulty while a further 36.9% reported a little difficulty.

Table 31: Self-rated difficulty concentrating by level of difficulty in Wave 4

Difficulty	None at all	A little bit	Moderate	Quite a bit	Extreme	Total
Wave 4	46.8%	36.9%	8.7%	4.8%	0.9%	5,715
Wave 3	Not asked					
Wave 2	Not asked					
Wave 1	Not asked					

Table 32 shows data from Wave 4 by age breakdown. A higher proportion of adults aged 75+ reported poor day-to-day memory compared with those aged 50-64 (3.4% and 1.3% respectively). Similar patterns were seen for absent-mindedness with around twice as many respondents age 75+ reporting this all the time compared with younger cohorts (3.1% and 1.4% respectively) and for those reporting extreme difficulty concentrating (1.5% for those age 75+ compared to 0.8% for those age 50-64).

Table 32: Difficulty with memory, absent mindedness and concentrating by age group in Wave 4

Difficulty	Poor day to day memory	Absent minded all the time	Extreme difficulty concentrating
50-64	1.3%	1.4%	0.8%
65-74	2.1%	2.1%	0.7%
75+	3.4%	3.1%	1.5%
Total aged 50+	2.1%	2.0%	0.9%

3.4.2 Hearing

Hearing ability was surveyed using eight self-reported measures and two further questions regarding accessing hearing services. Three of the hearing ability questions were asked across all four waves. Of these, summary findings are reported for two (use of a hearing aid was excluded). In addition, one question which was asked at three waves (ability to follow a conversation with one person) is reported here. Table 33 shows data on self-rated hearing (with or without a hearing aid). 58.6% of respondents reported excellent or very good hearing in Wave 1 compared to 50.2% in Wave 2, 51% in Wave 3 and 49.4% in Wave 4. There was a smaller difference in Wave 1 compared to Wave 4 in the percentage reporting fair or poor hearing (13.8% and 14.4% respectively).

Table 33: Self-rated hearing (with or without a hearing aid) by level of difficulty in Waves 1 to 4

Rating	Excellent	Very good	Good	Fair	Poor	Total
Wave 4	15.7%	33.7%	36%	12.8%	1.6%	5,715
Wave 3	19.2%	31.8%	33.7%	13.2%	2.1%	6,572
Wave 2	19.5%	30.7%	34.3%	13.0%	2.4%	7,207
Wave 1	28.2%	30.4%	27.6%	11.5%	2.3%	8,504

As shown in Table 34, three-quarters of respondents (72.2% in Wave 3 to 73.8% in Wave 4) reported being able to follow a conversation with four people (in a quiet environment such as the person's home) across the three waves for which data was available. However, more than a quarter reported some difficulty in doing so, of which 5.6% in Wave 3 and 5.1% in Wave 4 reported much difficulty or not able to do so at all.

Table 34: Ability to follow a conversation with four people (with or without a hearing aid) by level of difficulty in Waves 2 to 4

Ability	No difficulty	Some difficulty	Much difficulty	Can't do	Total
Wave 4	73.8%	21%	4.2%	0.9%	5,715
Wave 3	72.2%	22.1%	5%	0.6%	6,572
Wave 2	73.1%	26.8%			7,207
Wave 1	Not available				8,504

Table 35 shows data on ability to follow a conversation with one person. A higher percentage of people were able to follow a conversation with just one other person (93.6% in Wave 1 to 95.3% in Wave 2). A small minority reported much difficulty or unable to do so at all (0.5% in Wave 3 and 0.8% in Wave 1).

Table 35: Ability to follow a conversation with one person (with or without a hearing aid) by level of difficulty in Waves 1 to 3

Ability	No difficulty	Some difficulty	Much difficulty	Can't do	Total
Wave 4	Not asked				5,715
Wave 3	95%	4.6%		0.5%	6,572
Wave 2	95.3%		4.7%		7,207
Wave 1	93.6%	5.6%		0.8%	8,504

Table 36 shows data from Wave 4 by age breakdown. A much higher proportion of adults age 75+ reported poor hearing compared with those aged 50-64 (3.5% and 0.4% respectively). The proportion of respondents age 75+ reporting at least much difficulty following a conversation with four or more people was twice as high as among respondents aged 50-64 (1.2% and 2.7% respectively).

Table 36: Difficulty with hearing by age group in Wave 4

Age group	Poor hearing	Can't follow a conversation with four or more people
50-64	0.4%	0.6%
65-74	1.8%	1%
75+	3.5%	1.2%
Total aged 50+	1.6%	0.9%

3.4.3 Mental and emotional health

Table 37 shows data on self-rated emotional or mental health. 60.9% of respondents reported excellent or very good emotional or mental health in Wave 1 compared to 55.7% in Wave 2, 55.5% in Wave 3 and 53.6% in Wave 4. There was a smaller difference in Wave 1 compared to Wave 4 in the percentage reporting fair or poor emotional or mental health (9.9% and 10.1% respectively).

Table 37: Self-rated emotional or mental health by level of difficulty in Waves 1 to 4

	Excellent	Very good	Good	Fair	Poor	Total
Wave 4	16.9%	36.7%	36.3%	8.9%	1.2%	5,715
Wave 3	19.3%	36.2%	35%	8.3%	1.2%	6,400
Wave 2	20.8%	34.9%	34%	8.9%	1.4%	7,207
Wave 1	26.5%	34.4%	29.1%	8.5%	1.4%	8,504

Table 38 shows data on the percentage of participants reporting any medically diagnosed emotional, nervous or psychiatric condition, including but not limited to anxiety, depression, psychosis and schizophrenia. Responses remained quite consistent across the three waves for which data is available, ranging from 8.5% in Wave 1 to 7.5% in Wave 4 of respondents indicating they had received a medical diagnosis for one or more of these conditions.

Table 38: Medically diagnosed emotional, nervous or psychiatric condition in Waves 1,3 and 4

	Yes	No/Don't know
Wave 4	7.5%	92.5%
Wave 3	7.6%	92.4%
Wave 2	Not available	
Wave 1	8.5%	91.5%

Several questions were asked regarding depression. The two reported in Table 39 are medically diagnosed depression and the percentage of participants reporting having had a major depressive episode in the past 12 months. Responses ranged from 5.4% in Wave 1 to 5% in Wave 4. A similar pattern was seen amongst those reporting a major depressive episode, with a lower percentage in Wave 4 compared to Wave 2 (4.6% and 6.1% respectively).

Table 39: Measures of depression reported in Waves 1 to 4

	Medically diagnosed	Major depressive episode last 12 months
Wave 4	5%	4.6%
Wave 3	5.2%	5%
Wave 2	Not available	6.1%
Wave 1	5.4%	Not available

Comparable questions were asked regarding anxiety as shown in Table 40. Medically diagnosed anxiety ranged from 4.8% in Wave 1 to 4.3% in Wave 4 while the range for generalised anxiety disorder between Waves 4 and 2 was 2.7% and 3.3% respectively.

Table 40: Measures of depression reported in Waves 1 to 4

	Medically diagnosed	Generalised anxiety disorder last 12 months
Wave 4	4.3%	2.7%
Wave 3	4.8%	3.4%
Wave 2	Not available	3.3%
Wave 1	4.8%	Not available

Table 41 shows data from Wave 4 by age breakdown. While a proportion of adults age 75+ reported poor mental health compared with those aged 50-64, the difference is smaller than for either cognitive functioning or hearing (1.6% and 1.2% respectively). Medically diagnosed anxiety and depression were highest in those aged 50-64, with the proportion of those in the youngest age cohort reporting around twice the rate of those aged 75+ for anxiety (5.2% compared with 2.7%) and depression (6.7% compared with 3%).

Table 41: Poor emotional/mental health and medically diagnosed anxiety or depression by age group in Wave 4

Age group	Poor emotional/mental health	Medically diagnosed anxiety	Medically diagnosed depression
50-64	1.2%	5.2%	6.7%
65-74	1%	4.3%	14.4
75+	1.6%	2.7%	3%
Total aged 50+	1.2%	4.3%	5%

3.4.4 Summary of TILDA findings

Data from TILDA provides further insight into the experiences of community dwelling older people in Ireland across a range of issues relevant to this project, relating to their decision-making capacity, namely their cognitive functioning, hearing, and mental and emotional health. A particular strength is its ability to illustrate differences between age groups over 50 years. A consistent pattern seen throughout each wave was a higher proportion reporting excellent or good than those reporting fair or poor overall, however these proportions varied considerably between age cohorts with those aged 75 and older reporting a significantly higher proportion of fair or poor ability across cognitive functioning and hearing compared to younger age groups with almost a complete reversal in this pattern for mental and emotional health.

Adequate cognitive functioning is required to manage complex tasks and plays a role in decision-making. Changes in cognitive function are common in ageing and occur across a person's lifespan. Cognitive decline is characterised by impairments in memory and decision-making ability including planning, organisation and mental flexibility. As well as day-to-day decisions, important decisions about retirement, health, housing and finances may also require additional supports in cognitively impaired older adults.¹²¹³

Data from each subsequent wave of TILDA shows some decline in cognitive functioning over time however changes are minimal as may be expected, given that the time frame between Waves 1 and 4 is only six years on average. Stronger evidence of an association between cognitive decline and ageing is seen in the analysis of Wave 4 data by age groups. While only self-rated measures of cognitive function are reported here, research has shown an association between objective cognitive function and self-rated cognitive function.¹⁴ Table 42 shows the potential number of people aged over 50 with poor cognitive functioning if the rate seen in TILDA Wave 4 is applied to the Census 2016 population.

Table 42: Potential number at population level by age group with poor cognitive functioning when TILDA rate (Wave 4) applied to Census 2016 population

Age group	Census 2016	Poor day to day memory	Absent minded all the time	Extreme difficulty concentrating
50-64	808,893	10,516	11,325	6,471
65-74	373,508	7,844	7,844	2,615
75+	264,059	8,978	8,186	3,961
50+	1,446,460	27,337	27,334	13,047

Sensory decline is a widespread problem in older persons and is associated with a variety of negative outcomes including increased dependency.¹⁵ Data from each subsequent wave of TILDA shows a significant decline in self-rated hearing ability but a slight improvement in ability to follow a conversation with both one and four people. Older age groups were less likely to report high ability to hear well. Table 43 shows the potential number of people aged over 50 with poor hearing if the rate seen in TILDA Wave 4 is applied to the Census 2016 population.

Table 43: Potential number at population level by age group with poor hearing ability when TILDA rate (Wave 4) applied to Census 2016 population

Age group	Census 2016	Poor hearing with or without a hearing aid	Can't follow a conversation with four or more people
50-64	808,893	3,236	4,853
65-74	373,508	6,723	3,735
75+	264,059	9,242	3,169
50+	1,446,460	19,201	11,757

Increasing attention is being paid to mental and emotional health among older adults.¹⁶¹⁷ Measures of mental health in TILDA include self-rated emotional health, diagnosed mental illness and measures of symptomatic anxiety and depression, the most common mental health disorders affecting older people. However, unlike other variables, anxiety and depression had a higher prevalence among 50-64 year olds compared to those aged over 75.

Table 44 shows the potential number of people aged over 50 with poor mental and emotional health if the rate seen in TILDA Wave 4 is applied to the Census 2016 population.

¹²Mental health and cognitive function (p170). In Fifty Plus in Ireland, First results from The Irish Longitudinal study on Ageing, 2011.
¹³Glisky EL. Changes in Cognitive Function in Human Aging. In: Riddle DR, editor. Brain Aging: Models, Methods, and Mechanisms. Boca Raton (FL): CRC Press/Taylor & Francis; 2007. Chapter 1. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK3885/>
¹⁴Cognitive changes over time – chapter 8 (TILDA)
¹⁵Sensory impairment (p82). In Fifty Plus in Ireland, First results from The Irish Longitudinal study on Ageing, 2011.
¹⁶Department of Health 2020. Sharing the Vision: A mental health policy for everyone
¹⁷Department of Health 2013. The National Positive Ageing Strategy.

Table 44: Potential number at population level by age group with poor mental and emotional health when TILDA rate (Wave 4) applied to Census 2016 population

Age group	Census 2016	Poor mental/emotional health	Medically diagnosed anxiety	Medically diagnosed depression
50-64	808,893	9,707	42,062	54,196
65-74	373,508	3,735	16,061	16,434
75+	264,059	4,225	7,130	7,922
50+	1,446,460	17,667	65,253	78,552

3.5 Irish Health Survey

The Irish Health Survey published in 2020 reports on data from 2019-2020 on persons with difficulty remembering or concentrating. Unlike the Census, it does not include persons with a difficulty with learning. The survey findings outlined an estimated prevalence rate of 1.3% of the population aged 15 years and over for persons with difficulty remembering or concentrating. When this prevalence rate was applied to the estimated population of the state aged 15 years and over as of April 2020 (CSO, 2020) the population of persons with a difficulty remembering or concentrating was calculated to be 64,706.

A noteworthy finding from the survey is that 31% of those who self-reported to have a lot of difficulty remembering or concentrating, also reported that they have moderately severe or severe depression. The survey suggests a correlation between individuals with a difficulty remembering or concentrating and those with psychological and emotional issues, in particular depression. The survey provides a more up to date number of individuals with difficulty remembering or concentrating than Census 2016. This estimate does not take account of those that experience a difficulty learning, so it does not provide a direct comparison.

3.6 Disability services databases

As outlined in Chapter 2 there are three databases that provide detail on persons registered with or accessing disability services in Ireland. Although NASS has replaced both NIDD and NPSDD it was deemed appropriate to include data from these two decommissioned databases as they pertain to 2016, which provides a useful comparison to the census year examined.

3.6.1 National Ability Support System (NASS)

Table 45 shows data on the total number of persons registered with NASS in 2019 including breakdown by age group. In 2019, there were **15,982** adults registered with NASS as accessing disability services.

Although the NIDD and the NPSDD were decommissioned in January 2018, NASS was not available to users until September 2019. The data in Table 45 show updated information migrated from the NIDD and NPSDD as well as any new registrations recorded in 2019.

Table 45: Individuals registered with NASS 2019

Age	Total number registered ¹⁸
0-17 years	6,452
18-65 years	14,616
66 years+	1,366
Total	22,434
Total adults	15,982

¹⁸Total number of records reviewed in 2019

NASS data is recorded at HSE CHO (Community Healthcare Organisation) area. Table 46 shows the age breakdown by CHO. The table shows that a greater number of those in receipt of disability services are in the 18-65 age group, 14,616 (91%) while the 66+ age group only accounts for 1,366 (9%). Among all the CHO areas CHO 4 has the highest total number of 18–65-year-olds with a total of 2,596. This area also accounts for the highest number of 66+ year olds with 278. CHOs 7 and 9 account for the 2nd and 3rd highest in terms of service user registrations.

Table 46: Adults registered with NASS by HSE Community Healthcare Organisation (CHO) area 2019, by age group

CHO area/Age group	18-65	66+
CHO 1: Donegal, Sligo/Leitrim, West Cavan, Cavan/Monaghan	1,680	144
CHO 2: Galway, Roscommon, Mayo	1,439	117
CHO 3: Clare, Limerick, North Tipperary/East Limerick	769	71
CHO 4: Kerry, North Cork, North Lee, South Lee, West Cork	2,596	278
CHO 5: South Tipperary, Carlow/Kilkenny, Waterford, Wexford	1,204	101
CHO 6: Wicklow, Dún Laoghaire, Dublin South East	1,064	62
CHO 7: Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West	2,152	217
CHO 8: Laois/Offaly, Longford/Westmeath, Louth, Meath	1,699	128
CHO 9: Dublin North, Dublin North Central, Dublin North West	2,013	248
Total	14,616	1,366

3.6.2 National Intellectual Disability Database (NIDD)

Table 47 shows data on the number of individuals registered with NIDD in 2016 and in 2011 for context. There were 19,357 adults registered with NIDD in 2016. This was an increase of 885 (4.8%) from 2011 when 18,472 adults were registered.

Table 47: Individuals registered on NIDD 2016 & 2011

Age	2016	2011
0-17	8,918	8,852
18-64	17,947	17,387
65+	1,410	1,085
Total	28,275	27,324
Total adults	19,357	18,472

The number of the adults registered with NIDD in 2016 is considerably lower than the number self-reporting an intellectual disability on the Census 2016. The former amounting to 19,357 and the latter amounting to 44,864. This may be an indication of the threshold required for diagnosis and/or the number of persons actually accessing formalised services.

Table 48 below shows the residential status of individuals availing of day services. It also indicates the degree of disability i.e., mild, moderate, severe or profound as well as not verified. Distinction is made between residents and day attenders. Adults with moderate, severe or profound intellectual disability represented 66% of the total number availing of day services.

Table 48: Residential status of adults availing of day services, by level of intellectual disability and by age group, NIDD 2016

	Not verified	Mild	Moderate, severe or profound	All levels
Residents	25	1,275	6,204	7,504
Day attenders ¹⁹	198	4,858	6,363	11,419
Total	223	6,133	12,567	18,923

3.6.3 National Physical and Sensory Disability Database (NPSDD)

Table 49 shows that there was a total of 16,157 adults registered with the NPSDD in 2016. These individuals had a range of disabilities from neurological, multiple, physical, speech and/or language, hearing loss/deafness and visual. This was a decrease of 979 (5.7%) from 2011 when 17,136 adults were registered.

Table 49: Individuals registered on NPSDD 2016 & 2011

Age	2016	2011
0-17	5,606	8,034
18-66	16,157	17,136
Total	21,763	25,170
All adults	16,157	17,136

3.6.4 National disability databases summary

Data examined from the national disability databases NASS, NIDD and NPSDD provided data on the number of adults accessing disability services in the state. While it cannot be assumed that a person with an intellectual disability requires support to exercise their decision-making capacity, the benefit of this data is that persons registered with and/or accessing services may be more likely to have higher levels of need and therefore more likely to also benefit from future DSS services and supports.

These data sources provide limited insight into an overall national population of likely DSS users as they are focused solely on persons with an intellectual disability. In addition, due to the process of data transfer and gathering underway within NASS, only a partial dataset is available at this time.

These data sources provide insights into the proportion of persons who self-report having an intellectual disability and those diagnosed with an intellectual disability and/or accessing services. In Census 2016 there were 44,864 adults who self-reported having an intellectual disability. This compares with 19,357 (43.1%) registered with NIDD in the same year. This appears to support the idea that not all persons with an intellectual disability will require supports and services. This would further support a non-diagnostic approach to identifying potential cohorts of DSS users.

3.7 Diagnosis based databases and other estimates of specific conditions

Data on adults with neurological conditions and mental health disorders was accessed through a broad range of sources including registers, surveys and reports published by government bodies, academic institutes and other non-government organisations. Section 2.5 provides further information on the rationale for inclusion of these conditions.

3.7.1 Acquired brain injuries

Acquired brain injuries (ABI) are injuries that happen after birth excluding hereditary, congenital or degenerative causes. They include traumatic brain injuries, such as those caused by falls, road traffic crashes and assaults, and non-traumatic brain injuries, such as those caused by stroke, brain tumours and brain infections. The three most common causes of ABI are: stroke (39%), falls (14%) and road traffic crashes (14%).²⁰

¹⁹Day attendees are those that reside outside of the supported residential communities

²⁰Acquired Brain Injury Ireland. www.abiireland.ie Accessed 16/2/2021

Prior to 2019, the National Stroke Register published annual reports from 2012 to 2018. In 2018, analysis was conducted on 3,602 hospital admissions with a primary diagnosis of stroke, with similar numbers reported in 2017 and 2016.²¹ Tables 50 and 51 summarise data from the first Irish National Audit of Stroke, published in 2020, on individuals admitted to hospital with a diagnosis of stroke in 2019. Table 50 shows post-stroke outcomes in terms of survival and disability. Less than one-fifth of patients (17.9%) had no disability following their stroke while 32.8% had a mild disability and 37.6% had a moderate or severe disability.

Table 50: Post-stroke outcomes in 2019

Post-stroke disability						Death		Total counted		Total strokes	
None		Mild		Mod-Severe		%	No.	%	No.	%	No.
%	No.	%	No.	%	No.						
17.9	655	32.8	1202	37.6	1377	11.7	427	100	3661	100	4275

Further analysis as shown in Table 51 below shows that only some of this disability can be attributed to the stroke event in 2019. A considerable proportion of all patients admitted had either a known pre-existing disability (31.6%) or their disability status was unknown (12.4%). From an age perspective, the likelihood of pre-existing disability increased with age: 78.4% of those aged between 17 and 64 years had no pre-existing disability compared with 34.1% of those aged 80 and older. Similarly, total known disability amongst the youngest and oldest cohorts was 12.9% and 51.6% respectively.

Table 51: Pre-stroke disability by age group

	17-64		65-79		80+		Total	
	%	No.	%	No.	%	No.	%	No.
None	78.4	819	60.6	1079	34.1	495	56	2393
Mild	8.7	91	15.9	284	22.6	327	16.4	702
Moderate-Severe	4.2	44	10.3	184	29	421	15.2	649
Unknown	8.6	90	13.1	234	14.3	531	12.4	531
Total known disability	12.9	135	26.2	468	51.6	748	31.6	1351
Total	100	1044	100	1781	100	1450	100	4275

Stroke incidence and outcomes have improved significantly in recent years. National stroke audits conducted in 2008 and 2015 reported stroke hospitalisation rates of 10,000 and 7,500 respectively and mortality rates of 19% and 14%. In addition, the proportion of post-stroke patients being newly admitted to residential care fell from 15% in 2008 to 8% in 2015.²²

However, given ageing demographics together with higher survival rates, it is likely that the previously estimate of 30,000 adults living with post-stroke disability in Ireland is an under-representation.²³ The Irish National Audit of Stroke (INAS) has over 45,000 cases on its database.²⁴

Head injuries account for around one fifth of all major trauma injuries receiving hospital care in Ireland (and who fulfil length of stay criteria). Table 52 shows data since 2014 when the first major trauma audit was conducted.²⁵ Most head injuries included in the audit (around 85%) are classified as severe head injury which is further categorised as mild, moderate or severe traumatic brain injury. Over the five years for which data is available, 3,434 mild traumatic brain injuries have been recorded as well as 513 moderate and 780 severe injuries.

²¹HSE (2019). National Stroke Register Report 2018.

²²Irish Heart Foundation/HSE National Stroke Audit 2015; Irish Heart Foundation/HSE National Stroke Audit 2008.

²³HSE (2020). National Stroke Strategy 2020-2025.

²⁴National Office of Clinical Audit.

²⁵24 trauma receiving hospitals participated in the audit in 2014-15. Since 2016 all 26 trauma receiving hospitals have participated.

Table 52: Number and severity of people with head injuries receiving care in Irish hospitals

Year	All head injuries	All severe head injuries ²⁶	Mild TBI	Mod TBI	Severe TBI
2018	1418	1222 (1175)	887	109	179
2017	1357	1155 (1130)	814	136	180
2016	1161	1022 (1000)	748	97	155
2015	745	644 (633)	452	62	119
2014	929	797 (789)	533	109	147

The annual major trauma audits do not include disability outcomes following head injury. Analysis conducted as part of the 'National policy and strategy for the provision of neurorehabilitation services in Ireland 2011-2015' estimated a prevalence of between 50,878 and 80,260 people in Ireland living with TBI-related moderate or severe disability. The same report estimated that 150,000 people in Ireland need neuro-rehabilitative services on an ongoing basis.²⁷

3.7.2 Dementia and other neurological conditions

Neurodegenerative conditions are incurable and debilitating conditions that result in progressive degeneration of nerve cells, causing problems with movement (ataxias) and/or cognitive functioning. Three of the most common neurodegenerative conditions are included here: dementias, Parkinson's disease, and multiple sclerosis.

Neurodevelopmental conditions, such as autism spectrum disorders (ASD) and intellectual disability (ID) are usually present from birth and encompass a range of developmental deficits varying from mild limitations of executive functioning to global impairments of social and learning skills. Epilepsy is also included here as a common neurological condition that may be developmental in nature or caused by brain injury.

Dementia

While there is no register or database of people living with dementia in Ireland, estimates have been calculated by applying European Collaboration on Dementia (EuroCoDe) prevalence rates to the Irish population as shown in Table 53. An alternative prevalence rate has been calculated for 2016 only by applying the UK Cognitive Functioning Assessment Scale II (CFAS II) to the Irish population,

Table 53: Estimated prevalence of dementia in Ireland

	2016	2021	2026
EuroCoDe ²⁸	55,266	65,641	79,021
CFAS II ²⁹	39,272	N/A	N/A

Estimates of the residential status of people with dementia in Ireland have also drawn on various sources. The most frequently cited in recent Irish reports include an estimate, based on analysis of available Irish data, that 63% of people with dementia are living in the community³⁰ and an estimated prevalence rate, based on findings from the CFAS II study, that 72% of nursing home residents have dementia.³¹

²⁶The number in brackets refers to those with sufficient assessment data available (Glasgow Coma Scale) to enable further categorisation: the sum of the last three columns (mild, mod, severe TBI) equals the number in brackets.

²⁷HSE, 2011.

²⁸O'Shea, E. et al. Developing and implementing dementia policy in Ireland, 2017.

²⁹Pierse, T. et al. Estimates of the prevalence, incidence and severity of dementia in Ireland, 2019.

³⁰Cahill, S. et al. Creating excellence in dementia care, 2012.

³¹Pierse, T. et al. Estimates of the prevalence, incidence and severity of dementia in Ireland, 2019.

Table 54: Estimated residential status of people with dementia in Ireland

	Community	Residential care
63% of people with dementia living in the community assumption applied to EuroCoDe prevalence ³²	34,818	20,448
72% of nursing home residents have dementia assumption applied to EuroCoDe prevalence ³³	35,736	19,530
72% of nursing home residents have dementia assumption applied to CFAS II prevalence ³⁴	19,742	19,530

Parkinson's Disease

An estimated 12,000 people in Ireland have Parkinson's Disease. As it is more common in older people, prevalence is expected to rise as the population ages.³⁵

Multiple Sclerosis

An estimated 10,000 people in Ireland have Multiple Sclerosis.³⁶

Epilepsy

A review of Irish data estimated a prevalence of 37,000 people in Ireland with epilepsy in 2009 including 31,000 people aged 18 and older.³⁷

Autism spectrum disorder

A review of Irish data estimated a prevalence rate of 1 to 1.5% of autism spectrum disorder in Ireland in 2018.³⁸ A separate report has estimated the number of adults in Ireland aged 18-64 without a concurrent intellectual disability to be between 16,379 and 23,079.³⁹

Intellectual disability

Data on intellectual disability is available from the Census. As reported in Section 3.2.4, 44,864 adults reported having an intellectual disability in Census 2016 representing 1.26% of the total adult population. In addition, 21,747 children were reported as having an intellectual disability in Census 2016.

3.7.3 Mental health conditions

Mental health conditions comprise a wide range of disorders that affect mood, thinking and behaviour including depression, mania, bipolar disorder, anxiety disorders, schizophrenia, eating disorders and addictive behaviours. Approximately 90% of mental health needs are managed at primary care level with 10% referred to community-based specialist mental health services. Of these, 10% are admitted for in-patient treatment.⁴⁰ The Mental Health Commission maintains a register of approved in-patient centres for mental health services. In April 2021, there were 60 approved centres for adult services, including general adult, psychiatry of later life and continuing care, with a total of 2,546 places.

The national psychiatric inpatient reporting system (NPIRS), managed by the Health Research Board, gathers data on admissions to and discharges from all Mental Health Commission approved centres in Ireland. The most recent year for which data is available is 2019. The data provided refers to service activity not people, so the same person admitted twice will be counted as two admissions.

³²O'Shea, E. et al. Developing and implementing dementia policy in Ireland, 2017.

³³Pierse, T. et al. Estimates of the prevalence, incidence and severity of dementia in Ireland, 2019.

³⁴Pierse, T. et al. Estimates of the prevalence, incidence and severity of dementia in Ireland, 2019.

³⁵Parkinson's Association of Ireland.

³⁶The Multiple Sclerosis Society of Ireland.

³⁷Linehan, C. et al. Examining the prevalence of epilepsy and delivery of epilepsy care in Ireland. *Epilepsia*, 51(5):845–852, 2010.

³⁸Department of Health. Estimating prevalence of Autism Spectrum Disorders in the Irish population, 2018.

³⁹National Disability Authority. Models of good practice in effectively supporting the needs of adults with autism, without a concurrent intellectual disability, living in the community, 2017.

⁴⁰HSE 2020_Delivering specialist mental health services 2019

Table 55 provides data on admissions to Irish psychiatric units and hospitals. There were 16,710 admissions in 2019 of which 5,277 (32%) were first admissions. Depressive disorders accounted for a quarter (24.5%) of all admissions, followed by schizophrenia at 21.2%. In 2019, involuntary admissions (covered by the Mental Health Act 2001) accounted for 14.1% of all admissions. There was a much higher proportion of involuntary status among those admitted for treatment of schizophrenia and mania (29.2% and 23.7% respectively) compared with admissions for treatment of depressive disorders and neuroses (5.2% and 3.2% respectively).

Table 55: Admissions in 2019 by diagnosis, order of admission and legal status

	Admissions			Legal status		
	First	Total	% of all admissions	Voluntary	Involuntary	% Involuntary
Depressive disorders	1,274	4,088	24.5%	3,876	212	5.2%
Schizophrenia	892	3,540	21.2%	2,508	1,032	29.2%
Mania	435	1,689	10.1%	1,288	401	23.7%
Neuroses	602	1,686	10.1%	1,632	54	3.2%
Personality & behavioural disorders	359	1,406	8.4%	1,299	107	7.6%
Alcoholic disorders	301	1,090	6.5%	1,049	41	3.8%
Other drug disorders	440	1,090	6.5%	928	162	14.9%
All other diagnoses	1,727	3,684	22.1%	3,084	600	16.3%
Total	5,277	16,710	100%	14,359	2,351	14.1%

There were 16,735 discharges (including deaths) in 2019. 190 (1%) of these had been admitted more than one year before discharge. Table 56 shows length of stay of in-patients discharged within one year of admission. The average length of stay was 27.7 days while those with a diagnosis of schizophrenia had the highest average length of stay at 35.1 days. However, the difference between average and median length of stay indicates a considerable range in lengths of stay for those with a diagnosis of schizophrenia and across all diagnoses.

Table 56: Discharges in 2019 by diagnosis and length of stay

	All	Length of stay	
		Average days	Median days
Total	16,545	27.7	15
Depressive disorder	4,073	28.8	16
Schizophrenia	3,477	35.1	19
Mania	1,753	31.3	21
Neuroses	1,695	20.6	12
Personality & behavioural disorders	1,545	17.6	7
Alcoholic disorders	1,169	19.8	12
Other drug disorders	1,158	14.7	7

3.7.4 Summary

A range of diagnosis-based databases and other estimates of specific conditions allow for an approximation of the number of people in Ireland living with an increased risk of cognitive impairment due to a specific diagnosis. However, given that some individuals have two or more diagnoses, it is not possible to estimate the total number of people at risk. Furthermore, insufficient data is available to calculate the proportion of people likely to experience cognitive impairment impacting on their decision-making ability.

Despite this, it is likely that persons with mental health and/or neurological conditions, in particular dementias, stroke and other acquired brain injuries would be likely to benefit from the supports and services of the DSS. It is considered that a functional, needs based approach will capture persons with such conditions that have specific needs through national needs-focused data, e.g., Census data.

3.8 Social housing support for people with disabilities

Two key data sources from the Housing Agency relating to social housing are examined below: social housing assessment and social housing allocation.

Four types of disability are included in social housing assessments for people with disabilities: physical, intellectual, mental health and sensory disabilities. While physical disability is not usually correlated with decision-making capacity, it is included here in recognition of the assessment process used whereby a person with two or more disabilities will be allocated based on the higher priority and only this higher priority is recorded. For a more detailed description of social housing support for people with disabilities, please see Section 2.6.1.

3.8.1 Social housing assessment (waiting list)

A summary of social housing assessments is published annually. The most recent publication provides information on people on social housing waiting lists by local authority in 2019 and 2018. A total of **5,319** households on waiting lists in 2019 and 5,095 in 2018 had a primary need of disability. Table 57 shows data on the type of disability recorded as the primary need. Physical, mental health and intellectual disability were the three main types of disability in both years with a smaller number of applications due to sensory disability. It should be noted that these are households as opposed to individuals so as such may include households where it is a person under the age of 18 that has the disability.

Table 57: Number of households on social housing waiting list due to a main need of disability (and below income threshold)

Year	Type of disability					Total
	Sensory	Mental health	Intellectual	Other	Physical	
2019	380	1,603	1,550	55	1,731	5,319
2018	361	1,522	1,474	42	1,696	5,095

3.8.2 Social housing allocations

Data was made available by the Housing Agency on housing allocations made to people with disabilities for the years 2016-2019. Table 58 below shows data on the total number of households allocated social housing per year due to a primary need of disability as well as breakdown by disability type. Physical disability accounted for around half of all houses allocated due to a primary need of disability in each year between 2016 and 2019.

Table 58: Number of households allocated social housing due to a main need of disability (and below income threshold)

Year	Type of disability				Total
	Sensory	Mental health	Intellectual	Physical	
2019	239	263	296	1,231	2,389
2018	155	318	167	761	1,457
2017	118	365	199	833	1,579
2016	88	194	215	682	1,206

3.8.3 Summary of social housing support findings

Access to social housing supports for people with disabilities may be indicative of a level of support required by this cohort however this cannot be presumed from the data currently available. Since access to social housing support for people with disabilities is income dependent, the data here excludes all those with disabilities who fall outside of the maximum income thresholds set by local authorities. In addition, data is not availability for this cohort on the age

of the applicant therefore it is not known what percentage of assessments relate to those under the age of 18. Data is not currently available on the severity of disability or the number and type of disabilities where the applicant has more than one. Conclusions cannot be drawn on the number of adults within this cohort that may benefit from or need the supports or services of the DSS. In 2019, the Housing Agency undertook a review of how data is collected across local authorities regarding the awarding of a medical/disability priority in the allocation of social housing. The purpose of the review was to streamline and standardise across local authorities, both information collected and how it is processed. Thus, further relevant data may be available in the future.

3.9 Disability allowance

Tables 59 and 60 below show the numbers in receipt of disability allowance in September 2019 and September 2018 respectively. The data shows a considerable increase across all disability types in September 2019. This difference may be at least partly explained by administrative changes in reporting as described in Section 2.6.2.

Table 59: Number of adults in the state in September 2019 in receipt of Disability Allowance according to Disability Type

Disability type	Number of recipients
C71/D43/D33 Neoplasm	79
F60-69 Disorders of adult personality and behaviour	278
F70-79 Mental retardation	518
F80-89 Disorders of psychological development	2,728
I60-69 Cerebro vascular diseases	470
Total	4,073

Table 60: Number of adults in the state in September 2018 in receipt of Disability Allowance according to Disability Type

Disability type	Number of recipients
C71/D43/D33 Neoplasm	49
F60-69 Disorders of adult personality and behaviour	158
F70-79 Mental retardation	315
F80-89 Disorders of psychological development	1,460
I60-69 Cerebro vascular diseases	279
Total	2,261

3.10 Long term illness scheme

Seven of the 16 conditions covered by the long-term illness (LTI) scheme administered by the Primary Care Reimbursement Service (PCRS) were examined here:

- Epilepsy
- Parkinsonism
- Multiple Sclerosis
- Intellectual Disability
- Cerebral Palsy
- Muscular Dystrophy
- Hydrocephalus.

For a more detailed description of the long-term illness scheme, please see Section 2.6.2.

3.10.1 Recipients of scheme due to long-term illness

Data was provided for each of these conditions by age group and geographical location. The youngest age group provided was 16-24 years thus data in the table below begins from this age and not 18 years. Table 61 shows data on recipients of the LTI scheme by age group. In the past 12 months, a total of 33,632 individuals aged 16 and older with a primary diagnosis of one of the seven conditions listed accessed the LTI scheme at least once. Two-thirds of the total (21,864) had a primary diagnosis of epilepsy, while 4,451 had a primary diagnosis of Parkinsonism. Around a quarter (8,220) of recipients aged over 16 years were 65 or older.

Table 61: Recipients of long-term illness scheme Nov 2019 to October 2020 by illness and age group

Long term illness	16-64	65+	Age not known	Total
Epilepsy	17,756	3,606	502	21,864
Parkinsonism	1,043	3,394	14	4,451
Multiple Sclerosis	3,027	799	25	3,851
Intellectual Disability	2,155	325	41	2,521
Cerebral Palsy	562	51	23	636
Muscular Dystrophy	149	33	2	184
Hydrocephalus	109	12	4	125
All illnesses	24,801	8,220	611	33,632

3.10.2 Summary

The seven conditions examined were selected due to their potential impact on neurological functioning and subsequent increased likelihood of benefitting from supports and services offered by the DSS. Both residents of long-term care and community-dwelling individuals can be beneficiaries of the LTI; this data is useful as it is not limited to a care or residential setting. In addition, since eligibility is not income dependent, this data source is inclusive of all persons requiring medicines or appliances to manage one or more of these long-term conditions.

However, it should be noted that the information provided by the PCRS does not capture items purchased outside of community drug schemes so may not comprehensively reflect all medicines required by a person to treat the selected condition.

There is limited data available in Ireland on people diagnosed with neurological conditions and data from the long-term illness scheme was identified as potentially contributing to this data deficit. It does not represent a count of all individuals in Ireland with these conditions, for example in the case of Intellectual Disability, multiple other sources show a much higher prevalence than the 2,521 individuals identified through this source.

3.11 Care settings

Data from three types of residential care facilities is examined here: older persons services, mental health services, and other disability services. Geographical data is available across all three types of care facilities, this may be used in Phase 2 of the project. For a more detailed description of residential care facilities in Ireland, please see Section 2.7.

3.11.1 Residential care services for older people

A Register of Designated Centres for Older People's Services is maintained by the Health and Information Quality Authority (HIQA). In April 2021, there were 571 designated centres for older people (nursing homes), providing a total of 32,104 places. Of these, 113 centres with 5,592 places were run by the Health Service Executive with the remaining 458 centres and 26,512 places being operated by other providers.

Census data records place of residence which includes nursing homes and other communal settings. As described in Section 3.2.2, Census 2016 found that 27% of adults aged 65 and older and 4.4% of those aged 18-64 reporting a difficulty learning, remembering or concentrating were resident in nursing homes. The proportion of nursing home residents reporting a difficulty learning, remembering or concentrating in Census 2016 is shown in Table 62. More than half of all nursing home residents aged 18 and older (55.2%) reported a difficulty in learning, remembering or concentrating compared to 3.3% of the adult population overall (see Table 4).

Table 62: Proportion of nursing home residents reporting a difficulty learning, remembering or concentrating in Census 2016

	18-64	65+	Total 18+
Number of nursing home residents	5,154	23,580	28,734
Number of nursing home residents with a difficulty learning, remembering or concentrating	3,062	12,801	15,863
Proportion of nursing home residents with a difficulty learning, remembering or concentrating	59.4%	54.3%	55.2%

3.11.2 Residential care services for people with disabilities

HIQA also maintains a Register of Designated Centres for Disability Services for adults and children. In April 2021, there were 1,360 designated centres providing a maximum of 9,187 places. Of these, 138 centres with 1,140 places were run by the Health Service Executive with the remaining 1,222 centres and 8,047 places being operated by other providers. 238 centres had 10 or more residents, 42 of which had more than 20 residents.

Outcomes of the 'Moving on from congregated settings' policy 2012-2019

A report published by the HSE in 2011 recommended that people who live in congregated settings should move to their own homes in the community with the support they need. Congregated settings are where 10 or more people with a disability live together in a single living unit or are placed in accommodation that is campus based.

At the start of 2012 there were 3,401 residents in congregated settings, reducing to 1,953 by the end of 2019. During this time, a total of 942 residents transitioned out of congregated settings either in line with the policy or to other appropriate arrangements while a further 783 residents passed away and 278 residents were admitted or re-admitted to congregated settings. Data is available on the number and profile of residents who have transitioned in line with the policy as well as those who remain in a congregated setting, a summary of which is presented in Table 63.

Table 63: Profile of residents who have transitioned and who remain in congregated settings

Severity of disability	Transitioned	Remained in congregated setting	Level of support required	Transitioned	Remained in congregated setting
Not known	17	2	NK	NK	NK
Borderline	3	1	NK	NK	NK
Intellectual disability & mental health	26	47	Intensive	66	150
Physical & Sensory	39	108	High	537	1289
Profound	109	293	Moderate	226	403
Severe	356	772	Low	75	81
Moderate	313	613	Minimum	9	30
Mild	79	117	Not known	28	0
Total	942	1,953	Total	942	1,953

3.11.3 Residential care services for people with mental health illness

Data relevant to residential centres for people with mental health illness is collected by the Mental Health Commission (MHC), the Health Service Executive (HSE) and the Health Research Board (HRB).

Section 3.7.3 described acute admissions to and discharges from approved centres in 2019 for in-patient adult psychiatric services. It also highlighted the existence of patients who had been admitted more than one year previously. Among this cohort, 69 had been admitted more than 5 years previously with 21 of these admitted more than 25 years previously. Further information on long-stay patients in approved centres is available through a census of the in-patient population conducted by the MHC. In November 2018, 42% of patients (923) across 90% of all centres (54) had been admitted more than 6 months previously. Table 64 provides further detail on length of time since admission.

Table 64: Length of time since admission to MHC approved centre (November 2018)

Time since admission	6-12 months	1-5 years	5-10 years	10 years+	Total > 6 months
Number of in-patients	129	403	198	233	963

The MHC also inspects and monitors all 24-hour nurse staffed community residences. In January 2021 there were 119 residential units providing a maximum a total of 1,340 beds.

The HSE Mental Health Division is responsible for delivery of HSE and HSE funded mental health services at community and in-patient levels. Data on residential care services that do not have nursing staff in place 24 hours per day (for example low, medium and high support hostels) was retrieved from a published register. In January 2021 there were 213 residential units but data on the number of beds was not available. An estimate of 1,340 beds is based on applying the proportions reported in a survey of high, medium and low support community residences.⁴¹

3.11.4 Summary of residential care facilities

These data sources provide an approximation of the number of people in residential care facilities in Ireland. However, while there is limited risk of double counting as these data sources count beds, not people, this data does not account for occupancy levels within services.

Table 65: Summary of beds available in residential care facilities

Cohort	Centre Type	Centres	Beds
Older persons services	Designated centre	571	32,104
Disability services	Designated centre	1,360	9,187
Mental health inpatients > 6 months	Approved centre	54	963
Mental health community residences (24 hr staffed)	Other residential	119	1,340
Mental health community residences (non 24 hr staffed)	Other residential	213	1,340
Total		2,317	44,934

It is likely that a considerable number of persons in residential care settings may benefit from the supports and services of the DSS. It is also a cohort of persons that may be more likely to access legal frameworks due to inherent and ongoing consent requirements. However, specific needs for DSS services cannot be assumed based on a person's residential setting and this will be explored further in Phase 2 of this project.

3.12 Existing decision-making arrangements

3.12.1 Wards of Court

Given that there will be a transfer to the supports of the DSS of some individuals who would have previously fallen within the remit of the Office of the Wards of Court, data was sought on the current numbers of wards of court and the rate at which wards are declared.

There were 2,287 Wards of Court registered with the Office of the Wards of Court as of October 2020⁴². Of these, 1,680 (73% of total wards) had a private committee appointed to manage their affairs while 607 (27% of total wards) had the General Solicitor appointed.

⁴¹ 'Happy living here' (2007). Mental Health Commission and Health Research Board.

⁴² Unpublished data, Office of the Wards of Court, 2020

Table 66 shows data on the number of Wards of Court, their primary condition, and the number which have a private committee or the General Solicitor for each. The split between private committee and General Solicitor is of note to the DSS, as it may be indicative of persons that could require a decision-making representative from the DSS panel.

Table 66: Numbers of Wards of Court by category of condition and numbers that have Private Committee and General Solicitor, 2020

Category	Total	Private Committee	General Solicitor
Anorexia	10	5	5
Brain Damage	435	366	69
Dementia	713	536	177
Intellectual disability	303	212	91
Learning Disability	265	173	92
Other	50	32	18
Psychiatric	218	107	111
(Not Categorized)	293	249	44
Total	2,287	1,680	607

The rate at which wards are declared is of note to the DSS in terms of demand forecasting. Table 67 below outlines the number of wards declared on an annual basis between 2015 and 2019. This ranges from between 219 wards declared (at its lowest rate) in 2015 and 385 wards (at its highest rate) in 2019. It is likely that more people could be the subject of a decision-making representation order as it is a lower threshold than wardship, for example, an order may be put in place for a single issue and/or a single decision. Conversely, this number may be lessened as people will also be able to avail of less intrusive supports such as a decision-making assistance agreement or a co-decision-making agreement.

Table 67: Number of Wards of Court declared annually from 2015 to October 2020

Year	Number
2020 to date	269
2019	385
2018	327
2017	325
2016	290
2015	219

Table 68 below shows the breakdown in terms of where wards aged between 18 and 65 were residing. Given the age parameters for this data the number accounted for is lower than the total number of Wards of Court.⁴³

Table 68: Place of residence for Wards of court, 18–65-year-olds

Residence of Wards of Court	Number
Hospital	33
Assisted Living	225
Discharged	3
Hostel	6
Nua Healthcare	3
Nursing Home	117
Other	77
Prison	1
Private Residence	531
Private Residence (Outside of Ireland)	5
Psychiatric Unit	73
St Andrews UK	2
St Michael's House	1
Unknown	3

3.12.2 Enduring Powers of Attorney

Anyone planning for their future can make an enduring power of attorney (EPA). This arrangement enables an individual (referred to as the donor) to give authority to a known and trusted person, to act on the individual's behalf should they lose the capacity to make certain decisions in the future.

The Office of the Wards of Court currently maintains a register of EPAs made under the Powers of Attorney Act 1996. All new EPAs executed following commencement of the 2015 Act will be registered with the DSS. Current numbers of EPAs registered are likely to be indicative of numbers that will be registered with the DSS.

Table 69: Numbers of Enduring Power of Attorney registered annually from 2015 to October 2020

Year	Number
2020 to date	981
2019	1,031
2018	990
2017	750
2016	738
2015	661

The Office of the Wards of Court provided, on request, the location of EPA donors for 2019. Dublin had the highest number of registrations at 538, accounting for 52% of all registered EPAs in the state. Table 70 shows data on the number of EPAs by county/location.

⁴³Analysis of data from the Office of the Wards of Court

Table 70: Number of EPAs registered by County/location, 2019

County/Location	Number of EPAs registered
Dublin	538
Limerick	25
Mayo	16
Kerry	28
Galway	31
Cork	103
Kerry	28
Tipperary	21
Wexford	23
Louth	17
Cavan	6
Offaly	8
Sligo	13
Waterford	13
Kilkenny	12
Monaghan	6
Clare	7
Donegal	17
Leitrim	4
Meath	28
Westmeath	9
Wicklow	28
Kildare	25
Laois	6
Carlow	8
Longford	2
Roscommon	6
USA	1
England	1
Not Supplied	1
Total	1,031

3.12.3 Summary of current decision-making arrangements

Data on Wards of Court and registered EPAs provides detail on a cohort of the population that is known to currently access legal decision-making arrangements in the state. There are low total numbers across wardship and registered EPAs on an annual basis representing persons who have lost capacity in one or more area and require decision supports.

This data suggests a high level of unmet need and/or use of informal arrangements in the state to deal with situations where an adult does not have the legal capacity to make a certain decision or provide consent.

Importantly, this data shows that of those adults in wardship, 27% had the General Solicitor appointed as Committee. This data is relevant to forecasting the number of adults that may require the services of a decision-making representative from the panel maintained by the DSS.

Chapter 4

4.1 Summary of key findings

4.1.1 Summary data from each data source

In order to establish a total baseline population of likely service users of the DSS, data was examined across several data types and data sources to identify potentially relevant cohorts. Table 71 shows summary data on the total maximum number within a specific cohort that can be taken from each data source. Data refers to adults aged 18+ unless otherwise stated.

Table 71: Maximum number per cohort by data source, type and year

Data source	Data type	Year	Cohort	Number
Census	National level population count	2016	Difficulty learning, remembering or concentrating	116,811
			Intellectual disability	44,864
			Psychological or emotional condition	106,743
			Deafness or serious hearing impairment	99,150
National Disability Survey	Nationally representative survey	2006	Remembering and concentrating	95,200
			Intellectual and learning	44,700
			Speech	25,200
			Hearing	54,300
			Emotional, psychological and mental health	100,700
The Irish Longitudinal Study on Ageing	Nationally representative survey	2016	Poor day to day memory (age 50+ only)	27,337
			Absent minded all off the time (age 50+ only)	27,334
			Extreme difficulty concentrating (age 50+ only)	13,047
			Can't follow a conversation with four or more people due to hearing impairment (age 50+ only)	11,757
			Poor mental or emotional health	17,667
Irish Health Survey	Nationally representative survey	2020	Difficulty remembering or concentrating	64,706
National Ability Support System	Diagnosis based database	2019	Registered with a disability service	15,982
National Intellectual Disability Database	Diagnosis based database	2016	Diagnosed intellectual disability	19,357
National Physical and Sensory Disability Database	Diagnosis based database	2016	Disability registered with NPSDD	16,157

Data source	Data type	Year	Cohort	Number
National Office of Clinical Audit	Diagnosis based database	2020	Stroke	45,000
Health Service Executive	Policy estimate	2011	Traumatic brain injury	80,260
Health Service Executive	Policy estimate	2011	All acquired brain injury requiring neuro-rehabilitative services	150,000
Academic journal	Research/Forecasting	2021	Dementia	65,641
Parkinson's Association of Ireland	NGO estimate	NK	Parkinson's disease	12,000
Multiple Sclerosis Society of Ireland	NGO estimate	NK	Multiple sclerosis	10,000
Academic journal	Research	2009	Epilepsy	31,000
National Disability Authority	Research	2017	Autism	23,079
National Psychiatric In-Patient Reporting System	Service database	2019	Admissions to in-patient mental health services	16,710
Housing Agency	Service database	2019	Social housing assessment for people with disabilities (waiting list)	5,319
	Service database	2019	Social housing allocation for people with disabilities	2,389
Department of Social Protection	Service database	2019	Disability allowance (selected conditions)	4,073
Primary Care Reimbursement Service	Service database	2020	Long term illness scheme (selected conditions)	33,632
Health Information and Quality Authority	Service register	2021	Older persons services	32,104
	Service register	2021	Disability services	9,187
Mental Health Commission	Service register	2021	Mental health community residences (with 24hr staff)	1,340
	Census	2018	Long-term (>6 months) inpatients in mental health services	963
Health Service Executive	Service register	2021	Mental health community residences (without 24hr staff)	1,340
Office of Wards of Court	Service database	2020	Wards of Court	2,287
	Service register	2019	Registered Enduring Powers of Attorney	1,031

4.1.2 Data limitations

There are several limitations to the data described in this report, in particular relating to comparability of data, data coverage, contradictory data sources and ability to reconcile data sources.

Data comparability

The variety of different data sources and data types identified in this report do not allow direct comparison of data sources. This includes a mixture of needs-based and condition-based data sources, as well as self-reported and diagnosis-based data sources. Some data sources identified, in particular those reported by service type, disability database or estimates from advocacy bodies provide a total number within a cohort, whereas housing supports, financial supports and Enduring Powers of Attorney provide annualised access-based data.

In addition, service-based data i.e., persons in residential care facilities, are counted based on bed availability and therefore do not provide a count of actual persons.

Data use for national level forecasting

Many of the data sources identified are specific to certain cohorts, i.e. access to specific services, specific diagnoses or specific needs and are not able to be scaled to a national level forecast of DSS users.

Data coverage and inclusivity

Within the data sources examined, issues were identified relating to data coverage. This included limited or one-off data collection, incomplete records, registers and databases, and limited breakdowns with data i.e., by geographic location or age group.

It is acknowledged that certain population groups are likely to be excluded from routine data collection methods, i.e., homeless or transient populations. It is also noted that transient or progressive needs or conditions relating to a person's decision-making capacity may be difficult to capture within most data sources.

It is also likely that service-based data and diagnosis-based data may be affected by general accessibility and availability of services and does not take into account the prevalence of unmet needs.

Contradictory data

Data identified across different data sources was at times contradictory. This was identified between Census data and diagnosis-based databases. This was also notable between records on databases and academic prevalence studies.

Data reconciliation

It is noted that there is a high risk of double counting between data sources identified. For example, a person who has self-reported as having a difficulty with learning, remembering or concentrating in Census 2016, may be captured on a disability database and may also be residing in a residential care facility. Similarly, a person with a dual diagnosis of, for example, intellectual disability and mental illness with certain difficulties or needs relating to their decision-making capacity may be counted twice or not at all depending on if and how relevant data is captured.

4.1.3 Non-availability of data

As described in Section 1.3.3, all data retrieved was scanned for relevance by examining whether it correlated either directly or indirectly with one or more of the four functional pillars of capacity. This process flagged up an issue of data not being available at all or in a useable format. This is further explored here.

Data may be unavailable for several reasons, but these can be broadly grouped as:

- Data not collected
- Administrative limitations in how data was recorded and shared.

Data not collected

Areas relevant to this project in which no routine national data collection exists include:

- Neurological conditions, specifically the number of unique individuals accessing neuro rehabilitative services
- Psychiatric/mental health conditions, specifically the number of unique individuals accessing mental health services, or accessing non-specialised services e.g., through their GP
- Speech difficulties or disabilities, specifically the number of unique individuals accessing specialised services relating to their ability to communicate.

Administrative issues in how data is recorded and shared

Throughout the identification and analysis of data sources it was noted that there was a lack of standardised data collection systems including non-standardised data collection and non-standardised data recording. This included non-centralised data i.e., collection recorded at local level and/or recorded in a non-standardised manner at local level. It also included data collected in a manner that does not allow for easy collation or comparison i.e., free text answers within surveys.

It was also noted that there is still a reliance on paper-based records, particularly within health services, where relevant data may be collected in relation to a person's decision-making capacity, or a relevant condition, but not collated into an accessible database.

4.2 Establishing a hierarchical framework

There is no single overarching database for adults in Ireland who face capacity challenges and may require support to exercise their decision-making capacity. There is data available on populations in the state currently supported through existing legal arrangements such as Wards of Court and people with Enduring Powers of Attorney. Such data may be transferable in terms of potential users of the DSS. However, there are difficulties associated with identifying new populations that would access lower tiers of support (i.e., Decision-Making Assistance Agreements and Co-Decision-Making Agreements) given that this is a novel service.

A range of data sources including relevant databases (condition-based services, medical conditions, financial supports) were therefore examined with the aim of identifying and isolating the most reliable national estimate of likely future users of the DSS.

A hierarchical framework was applied to the data sources in order to establish a baseline dataset that was both comprehensive and cognisant of the risk associated with double counting. The most robust, reliable and/or nationally representative data sit at the top of the hierarchy. Data gathered with less robust and reliable methodologies and/or less relevant/applicable data sources are at the bottom of the hierarchy.

It was recognised that using more than one source of data in estimating a baseline range would carry a high risk of double counting. If figures from a range of data sources were added together, for example, they may take account of an individual with a dual diagnosis or condition. Furthermore, as data sources break down the population in different ways, e.g., by condition/difficulty, by access to a service, by residential setting or demographic indicator (i.e., age) adding sources together would not account for instances where persons cross all data sources, or only one.

Figure 2: Hierarchy of data sources



This hierarchy identifies total population count survey data as the most reliable, relevant and robust Irish data. Single source data (for example, all adults reporting as having a difficulty learning, remembering, or concentrating) is recognised as the preferable data source, particularly when disaggregating data, adjusting data to population change and using data to project forward. However, using only one data source to identify likely DSS users presents obvious limitations in its ability to exhaustively capture all likely or potential cohorts. As such, additional permutations within the same national population count data source (i.e., aggregated data across different responses in the Census) are considered next on the hierarchy.

Nationally representative surveys were classified as the next most reliable, relevant and robust data source for the purposes of this project. By design, nationally representative surveys are intended to allow the results for their sample population to be extrapolated on a proportionate basis to the wider population.

Diagnosis and service-based databases and registers are next on the hierarchy. These data sources often provide more detailed information on certain populations and provide counts of real people, not estimates based on prevalence. At a national population level, these databases are less useful as they present a high risk of double

counting. They can be useful in validating specific permutations in national datasets, e.g., persons self-reporting an intellectual disability in Census 2016, compared to persons registered with an intellectual disability in NIDD in 2016.

Academic studies and prevalence studies are included lower down the hierarchy, depending on their specific methodology and relevance. Many commonly cited cohorts cited by Irish NGOs and advocacy bodies are based on UK studies. While such studies are relevant to an Irish context, they can be problematic to extrapolate to a national estimate.

Application of hierarchical framework to data sources identified

The Census provided a national, whole population dataset that enabled delineation of the adult population in terms of age, geography, residential status, and long-term health condition. There was an initial focus on a single permutation within the Census, i.e., adults with a difficulty with learning, remembering, or concentrating. However, through applying the hierarchical framework, additional permutations within the Census were explored to broaden the potential range as much as possible.

Census 2016 was identified as being the most comprehensive source as it counts every person present in Ireland on Census night and contains relevant data to estimate a baseline range. Comparison with historical data is possible as the Census is repeated every five years, enabling comparison between Census 2016 and earlier years to establish patterns of change in terms of growth and/or decline.

Nationally representative surveys examined such as TILDA, the National Disability Survey and Irish Health Survey asked more in-depth questions which allowed for cross analysis e.g., of specific needs relating to decision-making capacity, against specific cohorts including age and diagnoses. This provided a mechanism to validate the data from Census 2016.

A range of data from sources further down the hierarchical framework were identified and examined based on particular relevance to the DSS e.g., specific data on Wards of Court; disability registers and individuals accessing specific services, including financial and housing supports. These data sources provide insight into cohorts with specific conditions as identified in the census. While some of the data sources across the hierarchical framework provided limited insight in relation to the overall baseline population of likely DSS users, they will be examined further when analysing the distribution of need within this population in Phase 2 of this project.

4.3 Baseline population

Following a review of all identified data sources, data on adults with difficulty learning, remembering, or concentrating from Census 2016 was identified as the most robust single dataset of persons who may need or benefit from the services of the DSS, once operational. This dataset was identified as it is most closely aligned to three out of the four pillars of a functional assessment of capacity as set out in the 2015 Act:

- Ability to understand information
- Ability to retain information and
- Ability to weigh up information and make a decision.

This dataset has the benefit of taking a non-diagnostic approach and of being self-reported i.e., people identify themselves as have these needs.

This dataset taken in isolation is limited as it is unlikely to be exhaustive of all adults who may fail to meet one of the capacity pillars and therefore benefit from the services of the DSS, in particular people that might sometimes fail to meet one of the grounds due to a transient or changeable condition, or those who fail to meet the fourth pillar: The ability to communicate a decision made.

As such, further datasets were examined within the same data source (Census 2016), to potentially expand this baseline number, and instead look at a baseline 'range' of likely users. Data on persons with intellectual disability, and with a psychological or emotional condition were identified as relevant datasets within the same Census category of 'Long-term conditions or difficulties.'

The benefit of these datasets is that they could be directly compared against the persons with a difficulty learning, remembering, or concentrating dataset to avoid double counting. Both datasets identified include characteristics which may affect a person's decision-making capacity, but this cannot be assumed for the whole cohort. It was concluded that the most likely DSS users within the cohorts of persons with intellectual disability or a psychological or emotional condition, would also identify as having a difficulty learning, remembering, or concentrating.

Data on persons with deafness or serious hearing impairment, was also identified within the Census category of Long-term conditions or difficulties. The benefit of this dataset is that it aligns to the fourth pillar of a functional assessment of capacity, not otherwise captured within the persons with a difficulty learning, remembering, or concentrating cohort: The ability to communicate a decision made. While people may experience difficulties exercising their decision-making capacity by reason of a deafness or serious hearing impairment, again, this cannot be assumed for the whole cohort.

Speech disability was not recorded within the census, however, data on speech disability was gathered by the CSO in the 2006 National Disability Survey. Speech disability also aligns to the fourth pillar of a functional assessment of capacity; the ability to communicate a decision made. The figure presented for speech disability below in Table 72 is the 2006 figure of 25,270 adjusted to 2016 population.

Using these datasets, the baseline population of potential users of the DSS can be stated as ranging between 116,811 to 187,265, at 2016 population levels. Based on the data examined, this range can be disaggregated by age and by geography, which provides useful insights into DSS operational service distribution.

Data examined from other sources including was reviewed and used to validate the baseline population range identified from Census data. Data across representative groups and specific cohorts enhanced understanding of the specific needs and attributes of certain cohorts but was not directly comparable or transferrable to census data and was therefore not used to expand or contract the range. This data will be examined further within Phase 2 of the project.

Table 72 provides a final baseline population upon which service demand forecasting in Phase 2 is based. The adult population with a difficulty learning, remembering, or concentrating is broken down into its constituent parts detailing the various permutations of combined conditions. This will assist in establishing level of need within this cohort:

- Difficulty learning, remembering, or concentrating with intellectual disability and psychological or emotional conditions
- Difficulty learning, remembering or concentrating with intellectual disability
- Difficulty learning, remembering, or concentrating with psychological or emotional conditions
- Difficulty learning, remembering, or concentrating only and
- Difficulty learning, remembering, or concentrating with other conditions (not included above).

When the difficulty learning, remembering, or concentrating population is combined with adults that have deafness or serious hearing impairment only and adults with a speech disability we arrive at a baseline population of 187,265.

Table 72: Baseline population range based on Census 2016 and NDS 2006⁴⁴

Type of difficulty	Number
Difficulty learning, remembering, or concentrating	116,811
Difficulty learning, remembering, or concentrating with intellectual disability and psychological or emotional conditions	13,968
Difficulty learning, remembering, or concentrating with intellectual disability	30,138
Difficulty learning, remembering, or concentrating with psychological or emotional conditions	35,841
Difficulty learning, remembering, or concentrating only	34,290
Difficulty learning, remembering, or concentrating with other conditions	2,574
Deafness or serious hearing impairment*	42,287
Speech disability	28,167
Total	187,265

⁴⁴With no difficulty learning, remembering, or concentrating, intellectual disability or psychological or emotional condition

Within the baseline population range, there are identifiable cohorts who may be more likely to need the services of the DSS. These are identified as persons with a disability or condition, for example intellectual disability or psychological or emotional condition who identify as having a difficulty with learning, remembering, or concentrating.

Conversely, within the baseline population, those identified for the reason of having difficulty communicating only, are unlikely to need certain services from the DSS, for example, they are unlikely to need a decision-making representative, but may benefit from one of the lower supports that provide assistance with obtaining information and communicating their decision. This will be explored further in Phase 2 of this project.

Other cohorts examined that may be likely to need the services of the DSS includes those in residential care facilities. This is due to the increased incidence of a third party requiring various consents, both in respect of treatment, and in relation to contracts for service. There are up to 44,000 adults in residential care facilities in Ireland. It is noted however, that those with specific needs in relation to their decision-making capacity will already put them within the baseline population range.

The baseline population range as identified can be adjusted to 2021 population levels. This provides a baseline population range of **125,406** to **201,064**. This is based on CSO population projections and assumes a similar proportion of the population continues to experience the same difficulties. Given the previous trends within Census data, this is likely to provide a conservative estimate of the current population.

Table 73: Baseline population adjusted to 2021 population

Cohort	Population		
Difficulty learning, remembering or concentrating with intellectual disability and psychological or emotional conditions	14,996		
Difficulty learning, remembering or concentrating with intellectual disability	32,356		
Difficulty learning, remembering or concentrating with psychological or emotional conditions	38,478		
Difficulty learning, remembering or concentrating only	36,813		
Difficulty learning, remembering or concentrating with other conditions	2,763		
Deafness or other serious hearing impairment		45,409	
Speech disability			30,249
Sub-Total	125,406	45,409	30,249
Total		201,064	

4.4 Advance planning

The baseline population considers those who may benefit from decision-making support in the immediate term. The Act additionally makes provision for adults who wish to plan ahead for a time when they might lose their capacity in the future. Advance planning is widely acknowledged as a way to respect autonomy and allow individuals to be self-determining. Two decision support arrangements that facilitate advance planning are:

- Enduring Power of Attorney (EPA) - EPAs may already be created under the Powers of Attorney Act 1996. The scope of an EPA is extended under the 2015 Act so that an attorney may now be appointed to take decisions in healthcare matters. Attorneys under the 2015 Act will be subject to supervision by the DSS.
- Advance Healthcare Directives (AHD) - AHDs are placed on a statutory basis under Part 8 of the Act, the part of the Act which is the responsibility of the Department of Health. The purpose of an AHD is to allow a person to be treated according to their will and preferences and to provide healthcare professionals with information about a persons' treatment choices. A person may also appoint an agent, known as a designated healthcare representative in the AHD, to ensure that his or her AHD is complied with. Part 8 further states that the Minister for Health may make regulations to provide for the notification of a making of an advance healthcare directive to the Director of the Decision Support Service and for the Director to maintain a register of advance healthcare directives.

While EPAs have been considered in Sections 2.8 and 3.12.2, these sections refer to EPAs that are registered; this step occurs only in situations where the donor becomes mentally incapacitated, for the EPA to take effect. In other words, it does not capture the EPAs that have been created but not registered since the donor has retained capacity to manage their own affairs. No centralised record exists in Ireland of EPAs that have been created but not registered. Anecdotal evidence suggests that many EPAs in Ireland are only created at a time when a person's capacity to make decisions independently may first be called into question.

Until such time as the Act is commenced, there is no legal framework for AHDs in Ireland. However, the 'Think Ahead' initiative by the Irish Hospice Foundation offers a framework to help people think about, discuss and record what their preferences are with regard to healthcare treatment in the event of emergency, serious illness or death.

As outlined above, there is limited data on evidence of current advance planning in Ireland. Relevant data from two sources, a survey conducted on behalf of Safeguarding Ireland in 2020 and The Irish Longitudinal Study on Ageing in 2016 (Wave 4) is presented in the Appendix (Tables 76 and 77).

Appendix

Table 74: Difficulty learning remembering or concentrating by age and setting 2006, 2011 and 2016

Adult population 18+	2006		2011		2016	
State	86,986		104,342		116,811	
Age groups	18-64	65+	18-64	65+	18-64	65+
	52,044	34,942	61,958	42,384	69,398	47,413
Nursing home residents	3,469	9,129	3,408	11,515	3,062	12,801
Carlow	1,104		1,242		1,568	
Age groups	18-64	65+	18-64	65+	18-64	65+
	713	931	797	445	1,048	520
Nursing home residents	30	94	28	95	35	91
Dublin City	12,155		14,243		15,693	
Age groups	18-64	65+	18-64	65+	18-64	65+
	7,235	4,920	8,339	5,904	9,144	6,549
Nursing home residents	305	972	265	1,242	256	1,498
South Dublin	4,546		4,551		5,194	
Age groups	18-64	65+	18-64	65+	18-64	65+
	3,249	1,297	3,820	1,807	4,011	2,249
Nursing home residents	123	231	182	445	228	478
Fingal	3,709		4,923		5,480	
Age groups	18-64	65+	18-64	65+	18-64	65+
	2,586	1,123	3,171	1,752	3,469	2,011
Nursing home residents	180	379	228	666	217	723
Dún Laoghaire-Rathdown	3,809		5,627		6,260	
Age groups	18-64	65+	18-64	65+	18-64	65+
	2,163	1,646	2,342	2,209	2,645	2,549
Nursing home residents	105	419	75	705	107	798
Kildare	3,317		4,257		4,989	
Age groups	18-64	65+	18-64	65+	18-64	65+
	2,169	1,148	2,692	1,565	3,087	1,902
Nursing home residents	329	442	305	670	234	816

Adult population 18+	2006		2011		2016	
Kilkenny	1,884		2,107		2,526	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,131	753	1,226	881	1,405	1,121
Nursing home residents	205	210	191	232	106	333
Laois	1,258		1,694		2,019	
Age groups	18-64	65+	18-64	65+	18-64	65+
	728	530	1,109	585	1,333	686
Nursing home residents	44	59	48	63	43	163
Longford	704		987		1,050	
Age groups	18-64	65+	18-64	65+	18-64	65+
	436	268	603	384	640	410
Nursing home residents	24	46	28	135	36	126
Louth	2,157		2,862		3,185	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,452	705	1,787	1,075	1,963	1,222
Nursing home residents	62	107	57	241	170	283
Meath	2,342		3,137		3,768	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,434	908	1,892	1,245	2,221	1,547
Nursing home residents	69	325	130	455	77	559
Offaly	1,279		1,662		1,983	
Age groups	18-64	65+	18-64	65+	18-64	65+
	731	548	963	699	1,168	815
Nursing home residents	14	194	23	224	31	229
Westmeath	1,848		2,013		2,197	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,047	801	1,217	796	1,404	793
Nursing home residents	104	264	100	253	28	183
Wexford	2,569		3,440		4,040	
Age groups	18-64	65+	18-64	65+	18-64	65+
	94	153	2,123	1,317	2,454	1,586
Nursing home residents	1,593	976	91	258	110	397
Wicklow	2,518		3,088		3,322	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,559	959	1,837	1,251	2,019	1,303
Nursing home residents	152	273	115	451	83	424

Adult population 18+	2006		2011		2016	
Clare	2,230		2,491		2,745	
Age groups	18-64	65+	18-64	65+	18-64	65+
	79	300	1,432	1,059	1,638	1,107
Nursing home residents	1,174	1,056	50	253	30	239
Cork City	3,407		3,871		4,447	
Age groups	18-64	65+	18-64	65+	18-64	65+
	2,196	1,211	2,514	1,357	2,825	1,622
Nursing home residents	180	115	225		175	300
Cork County	6,353		7,770		8,932	
Age groups	18-64	65+	18-64	65+	18-64	65+
	3,602	2,751	4,492	3,278	5,232	3,700
Nursing home residents	122	746	201	987	252	1,173
Kerry	2,980		3,327		3,504	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,696	1,284	1,946	1,381	2,092	1,412
Nursing home residents	166	386	144	302	88	284
Limerick City and County	4,253		4,697		5,531	
Age groups	18-64	65+	18-64	65+	18-64	65+
	2,614	1,639	2,837	1,860	3,419	2,112
Nursing home residents	335	435	208	480	130	496
Tipperary	3,438		3,921		4,256	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,969	1,469	2,328	1,593	2,543	1,713
Nursing home residents	80	527	83	456	100	415
Waterford City and County	2,184		2,577		2,828	
Age groups	18-64	65+	18-64	65+	18-64	65+
	79	150	1,475	1,102	1,678	1,150
Nursing home residents	1,285	899	31	273	52	236
Galway City	1,427		1,669		1,833	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,007	420	1,209	460	1,338	495
Nursing home residents	78	61	36	63	21	58
Galway County	3,224		3,751		4,217	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,646	1,578	1,983	1,768	2,251	1,966
Nursing home residents	74	585	113	670	83	715

Adult population 18+	2006		2011		2016	
Leitrim	674		708		797	
Age groups	18-64	65+	18-64	65+	18-64	65+
	314	360	7	120	406	391
Nursing home residents	11	83	360	348	5	109
Mayo	3,010		3,419		3,510	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,568	1,442	1,775	1,644	1,841	1,669
Nursing home residents	89	427	70	400	84	554
Roscommon	1,354		1,553		1,644	
Age groups	18-64	65+	18-64	65+	18-64	65+
	622	732	826	727	809	835
Nursing home residents	60	325	43	275	15	289
Sligo	1,478		1,845		1,953	
Age groups	18-64	65+	18-64	65+	18-64	65+
	968	510	1,104	741	1,168	785
Nursing home residents	89	90	141	118	92	109
Cavan	1,276		1,540		1,742	
Age groups	18-64	65+	18-64	65+	18-64	65+
	645	631	824	716	987	755
Nursing home residents	32	205	30	243	27	210
Donegal	3,264		3,953		4,234	
Age groups	18-64	65+	18-64	65+	18-64	65+
	1,875	1,389	2,186	1,767	2,359	1,875
Nursing home residents	119	307	101	321	110	363
Monaghan	1,235		1,417		1,364	
Age groups	18-64	65+	18-64	65+	18-64	65+
	637	598	749	668	771	593
Nursing home residents	54	219	59	234	39	154

*Figures in red are estimated numbers. CSO reports figures as < to protect identification of a nursing home/individuals when the numbers are low. For example, where a number is reported as 89 above it would have appeared in census figures as <90.

Table 75: Definition of disability types recorded on NASS

Disability type	Definition
Intellectual	Conditions appearing in the developmental period (age 0–18 years) associated with impairments of mental functions, difficulties in learning and performing certain daily life skills and limitations of adaptive skills in the context of community environments compared to others of the same age. Includes: Down syndrome, Prader-Willi syndrome, Fragile X syndrome, Klinefelter syndrome.
Autism Spectrum Disorder (ASD)	Autism (including Asperger's syndrome) is used to describe developmental disorders involving disturbances in cognition, interpersonal communication, social interactions and behaviour (in particular obsessive, ritualistic, stereotyped and rigid behaviours).
Deafblind – dual sensory	Deafblind (dual sensory) – refers to dual sensory impairments associated with severe restrictions in communication, and participation in community life. Deaf blindness is not just vision impairment with a hearing loss, or a hearing loss with vision impairment. Deaf blindness is a unique disability requiring distinct communication and teaching practices.
Developmental delay (under 10 years only)	Applies to children aged 0–5 where conditions have appeared in the early developmental period, but no specific diagnosis has been made and the specific disability group is not yet known. For the purposes of NASS only, the age restriction has been broadened to less than 10 years.
Hearing loss and/or Deafness	Encompasses Deafness, hearing impairment, hearing loss.
Neurological	Including epilepsy, spina bifida, Alzheimer's disease and conditions such as multiple sclerosis, acquired brain injury and Parkinson's disease, applies to impairments of the nervous system.
Physical	Conditions that are attributable to a physical cause or impact on the ability to perform physical activities, such as mobility. Physical disability examples include absence or deformities of limbs, arthritis, back disorders, bone formation or degeneration.
Specific learning disorder (other than intellectual)	Learning disorder is a general term referring to a group of disabilities, presumed due to central nervous system dysfunction rather than an intellectual disability, covering significant difficulties in the acquisition and use of organizational skills, listening, speaking, reading, writing, reasoning or mathematical skills, includes ADHD.
Speech and/or language	Encompasses speech loss, impairment and/or difficulty in being understood.
Visual	Encompasses blindness and vision impairment (not corrected by glasses or contact lenses), which can cause severe restriction in communication and mobility, and in the ability to participate in community life.
Mental health	Mental health related disability includes recognizable symptoms and behaviour patterns, frequently associated with distress, which may impair personal functioning in normal social activity. For a mental health related disability, one would normally expect that there be a relevant diagnosis. General issues with behaviour (where there is no specific diagnosis) should be reflected in the 'Level of support' information rather than here in 'Disability type'.
N 20ot verified	Use this option where the type of disability has not been verified for the individual. Also this option may be used for all reported instances of developmental delay above the age of 10.

Table 75: Geographical breakdown of projected 2021 baseline population and service level need

		DMAA	CDMA	DMRO	Panel DMR	Private DMR	Total
Carlow	1.2%	1,706	450	213	70	143	2,369
Dublin City	12.8%	18,479	4,876	2,310	762	1,548	25,666
Dún Laoghaire-Rathdown	4.8%	6,900	1,821	863	285	578	9,583
Fingal	6%	8,610	2,272	1,076	355	721	11,958
South Dublin	5.7%	8,255	2,179	1,032	341	691	11,466
Kildare	4.5%	6,469	1,707	809	267	542	8,985
Kilkenny	2%	2,971	784	371	123	249	4,126
Laois	1.7%	2,450	646	306	101	205	3,402
Longford	0.8%	1,202	317	150	50	101	1,670
Louth	2.6%	3,804	1,004	475	157	319	5,283
Meath	3.9%	5,590	1,475	699	231	468	7,764
Offaly	1.6%	2,304	608	288	95	193	3,200
Westmeath	1.8%	2,642	697	330	109	221	3,670
Wexford	3.1%	4,481	1,183	560	185	375	6,224
Wicklow	2.9%	4,231	1,117	529	175	354	5,877
Clare	2.5%	3,575	943	447	147	299	4,965
Cork City	2.9%	4,218	1,113	527	174	353	5,859
Cork County	8.5%	12,355	3,260	1,544	510	1,035	17,159
Kerry	3.2%	4,588	1,211	573	189	384	6,372
Limerick City and County	4.1%	5,991	1,581	749	247	502	8,321
Tipperary	3.33%	4,815	1,271	602	199	403	6,688
Waterford City and County	2.4%	3,520	929	440	145	295	4,888
Galway City	1.8%	2,560	675	320	106	214	3,555
Galway County	3.7%	5,323	1,405	665	220	446	7,392
Leitrim	0.7%	967	255	121	40	81	1,343
Mayo	2.8%	3,994	1,054	499	165	335	5,548
Roscommon	1.4%	1,955	516	244	81	164	2,716
Sligo	1.4%	2,009	530	251	83	168	2,791
Cavan	1.54%	2,236	590	279	92	187	3,105
Donegal	3.3%	4,749	1,253	594	196	398	6,595
Monaghan	1.3%	1,817	479	227	75	152	2,523
TOTAL		144,766	38,202	18,096	5,972	12,124	201,064

Advance planning

Table 76 presents findings from a public opinion survey conducted by Red C on behalf of Safeguarding Ireland in May 2020. The purpose of the survey was to better understand attitudes towards planning ahead for future decisions regarding healthcare and finances by asking respondents if they had taken specific actions and if so, what barriers had they encountered with regard to advance healthcare planning. Quota controls were used to ensure a nationally representative sample of adults in the Republic of Ireland aged 18+ and data was weighted across gender, age, region and social class in accordance with CSO population data.

While 30% of respondents had made a will, only 6% had created a will and 4% had created advance care plans. When those considering action were combined with those who had taken action, more than half (58%) indicated some action in will-making compared with 27% in advance financial planning decisions and 24-33% in advance healthcare planning decisions. Further analysis (not presented here) showed that younger age groups, single people, men, those in social classes C2DE, and those living in urban areas were less likely to undertake advance planning; of these, age was the biggest determinant.

Table 76: Actions undertaken or considered in planning ahead for future care

Have you done any of the following?			
	Not done, not considering	Considering	Done
Made a Will	42%	28%	30%
Created an EPA	73%	21%	6%
Created an AHD	76%	20%	4%
Created a Think Ahead Form	67%	29%	4%
Undertaken other actions for future healthcare wishes	68%	26%	6%
Total	33%	67%	

Among those who had taken action or considered taking action on advance planning for healthcare decisions, only 5% reported encountering difficulties with putting plans in place. The main barriers cited were:

- concerns/reluctance to discuss planning ahead and death with family members
- the financial cost associated with planning ahead
- lack of awareness of the process and what forms need to be completed.

Table 77 presents data from questions related to advance care planning in The Irish Longitudinal Study on Ageing (TILDA) in 2016 which included 5,715 adults aged 50 and older. This was the first wave of the study in which questions on advance care planning were asked. Further information on TILDA is available in Sections 2.3.2 and 3.4.

Almost three-quarters of respondents (73.7%) had not undertaken any type of advance care planning. Among those who had, by far the most common type of action taken was informal conversations with relatives (23.6%). Very few respondents had formally documented wishes in writing (2.5%) and even fewer (0.6%) had engaged in informal conversations with medical professionals. When analysed by age cohorts, older age was positively correlated with increased likelihood of undertaking any type of advance care planning with the biggest increase consistently seen between those aged 65-74 and those aged 75+.

Table 77: Types of advance care planning undertaken by age group

Age	Informal conversations with relatives		Informal conversations with medical professional		Formally by documenting in writing		None of these	
	Number	% age group	Number	% age group	Number	% age group	Number	% age group
50-64	460	22.4%	3	0.2%	31	1.5%	1567	76.2%
65-74	465	22.7%	12	0.6%	47	2.3%	1528	74.7%
75+	375	27%	16	1.2%	64	4.6%	941	67.8%
Total 50+	1346	23.6%	33	0.6%	145	2.5%	4212	73.7%



Phase 2:
Estimating
service
demand
2022-2026

Introduction

This report sets out the approach and results of the second phase in a service demand forecasting project conducted by the Decision Support Service (DSS). This project was undertaken to inform operational, organisational and service design considerations for the establishment of the DSS. As a completely new service in Ireland, the aim of the project was to gain insights and understanding of the number and needs of potential users of the DSS. In Phase 1, a baseline population was established of adults likely to benefit from supports and services provided by the DSS. Key findings from Phase 1 are listed in Appendix 1. The purpose of Phase 2 was to further analyse this baseline population and match it with potential DSS supports and services, specifically the estimated number of decision-making assistant agreements (DMAAs), co-decision-making agreements (CDMAs) and decision-making representative orders (DMROs) likely to be commenced in the first five years of operation.

The following sections describe:

- Baseline population in 2022
- Categorising the baseline population into support arrangements tiers
- Estimated baseline population through to 2026
- Estimated annualised figures through to 2026
- Alternative scenarios base on 25%, 50% and 75% uptake
- Estimated distribution of public (panel member) and private DMROs
- Estimated distribution of services by geographical location

Baseline population in 2022

An estimated 2021 baseline population was established in Phase 1 by applying the projected adult population in 2021 to the baseline population figures derived from Census 2016, and in the case of speech disability, from the National Disability Survey 2006. This assumed the 2016/2006 proportionate relationship of baseline population to state population remained unchanged in 2021 and that there was no growth in the numbers with conditions other than those associated with population growth.

Table 1 presents the estimates updated to 2022 which is the expected first year of operations.⁴⁵ These estimates use the same proportionate relationship linked to population growth only as described above. The baseline population for 2022 comprises a total of 204,171 adults (aged 18+), including 127,313 adults with difficulty learning remembering and concentrating (DLRC), 46,100 adults with deafness or serious hearing impairment only (DSHI), i.e., without any other conditions and 30,758 adults with speech disability.

To understand the population reporting DLRC better, sub-populations within this group were established, namely: DLRC with Intellectual Disability (ID) AND Psychological and Emotional Conditions (PEC); DLRC with ID; DLRC with PEC; DLRC with other conditions (not PEC or ID); and DLRC only. This breakdown of the DLRC population facilitated a more comprehensive application of a distribution of need which is explored in the next section. In addition, DSHI (without DLRC) and Speech disability are included in the baseline population to represent the communication pillar of functional capacity. The four pillars of functional capacity as referred to in the Decision Making (Capacity) Act 2015 are described in Section 1.3.1 of the Phase 1 report.

⁴⁵A mid-year commencement of services has been agreed

Table 1: Baseline population in 2022

Cohort	Population		
	DLRC	DSHI	Speech
Difficulty learning, remembering or concentrating with intellectual disability and psychological or emotional conditions (DLRC + ID + PEC)	15,224		
Difficulty learning, remembering or concentrating with intellectual disability (DLRC + ID)	32,848		
Difficulty learning, remembering or concentrating with psychological or emotional conditions (DLRC + PEC)	39,063		
Difficulty learning, remembering or concentrating only (DLRC only)	37,373		
Difficulty learning, remembering or concentrating with other conditions (DLRC + other conditions)	2,805		
Deafness or other serious hearing impairment (DSHI)		46,100	30,758
Speech disability (Speech)			
Sub-total	127,313	46,100	30,758
Total	204,171		

Categorising the baseline population into support arrangement tiers

Since Census 2016 does not indicate severity of disability, findings from the National Disability Survey (NDS) 2006 were applied to the baseline population to better understand the likely distribution of support needs among this cohort. In this nationally representative survey, respondents who reported having selected disabilities were asked to describe the level of difficulty they experienced in carrying out everyday activities due to their disability. Three of the nine disabilities reported were selected due to their proximity with DLRC: Remembering and Concentrating (R&C); Psychological, Emotional or Mental Health (PEMH); and Intellectual and Learning (I&L). In addition, hearing and speech disability were included. All respondents were asked to grade their level of difficulty as 'moderate', 'a lot' or 'can't do at all' while those reporting PEMH and I&L disabilities were offered an additional level of difficulty of 'just a little'. Further information on how the NDS helped inform the baseline population is available in Sections 2.3.1 and 3.3 of the Phase 1 report. Table 2 shows, for each disability, the distribution of difficulty experienced. For example, only 3.1% of those with hearing disability reported not being able to carry out everyday activities while just under half (49.7%) of respondents with a remembering and concentrating disability reported a moderate level of difficulty with carrying out everyday activities.

Table 2: Level of difficulty with everyday activities by disability (NDS 2006)

Disability	Level of difficulty				Total
	Just a little	Moderate	A lot	Can't do at all	
I&L	18.6%	33.1%	31.9%	16.4%	100%
PEMH	22.2%	42%	32.2%	3.6%	100%
R&C	N/A	49.7%	37.1%	13.2%	100%
Hearing	N/A	60.1%	36.8%	3.1%	100%
Speech	N/A	46.1%	34.8%	19.1%	100%

These percentages were then applied to the breakdown of the baseline population shown in Table 1 as follows:

- I&L levels of difficulty applied to DLRC + ID +PEC. The rationale is that ID outweighs the other conditions in terms of need.
- I&L levels of difficulty applied to DLRC + ID.
- PEMH levels of difficulty applied to DLRC + PEC.

- R&C levels of difficulty applied to DLRC only.
- R&C levels of difficulty applied to DLRC + other conditions.
- While hearing levels of difficulty correspond with DSHI, it was agreed that this cohort would be categorised entirely at moderate level of difficulty.
- Similarly, speech disability was categorised entirely at moderate level of difficulty.

Table 3 shows the distribution of need within the baseline population (in numbers) when the percentages in Table 2 have been applied.

Table 3: Categorisation of the baseline population according to level of difficulty

Cohort	Level of difficulty				Total
	Just a little	Moderate	A lot	Can't do at all	
DLRC + ID + PEC	2,832	5,039	4,856	2,497	15,224
DLRC + ID	6,110	10,873	10,479	5,387	32,848
DLRC + PEC	8,672	16,406	12,578	1,406	39,063
DLRC only	0	18,574	13,865	4,933	37,373
DLRC + other conditions	0	1,394	1,041	370	2,805
DSHI	0	46,100	0	0	46,100
Speech	0	30,758	0	0	30,758
Total	17,613	129,145	42,819	14,594	204,171

The next step involved converting this distribution of need to support arrangements. It was agreed that the lowest two levels of difficulty, i.e., 'just a little' and 'moderate', corresponded with the category of DMAA, while 'a lot of difficulty' corresponded with the category of CDMA and 'can't do at all' with DMRO. The proportion in each category was then calculated and rounded up to the nearest whole number. The final numbers and proportions for each category are shown in Table 4.

Table 4: Converting baseline population to support arrangement tiers

	DMAA	CDMA	DMRO	Total
Number	147,003	42,876	14,292	204,171
Proportion	72%	21%	7%	100%

It was recognised that an adjustment would need to be made to these support arrangements to account for individuals requiring a higher level of support that their level of difficulty would indicate, due to the lack of a suitable person to act as co-decision maker. Since panel members will only be available at DMRO level, relevant persons who may have been eligible for CDMA based on their level of difficulty only, would now require a DMRO. It was determined that this would apply to 10% of those categorised as CDMA in Table 4.

Table 5 shows the effect that a 10% movement from CDMA to DMRO has on the overall proportionate breakdown in service need. After the adjustment, the distribution stands at 72% for DMAAs, 19% for CDMA and 9% for DMROs.

Table 5: Support arrangements after adjusting for lack of suitable person in 10% of CDMA

	DMAA	CDMA	DMRO	Total
Number	147,003	38,792	18,375	204,171
Proportion	72%	19%	9%	100%

Estimated baseline population through to 2026

Table 6 shows the estimated baseline population from 2022 to 2026. As described previously, these estimates are based on population growth only. The distribution across support arrangements is based on the 72: 19: 9 spread as described in Table 5.

Table 6: Estimated baseline population across support arrangement tiers 2022 to 2026

	DMAA	CDMA	DMRO	Total
2022	147,003	38,792	18,375	204,171
2023	149,183	39,368	18,648	207,198
2024	151,379	39,947	18,922	210,249
2025	153,646	40,545	19,206	213,397
2026	156,072	41,186	19,509	216,767

Estimated annualised figures through to 2026

The baseline population does not represent the actual numbers likely to seek DSS services. To calculate annualised figures, a review of comparable jurisdictions was undertaken together with utilising data from Wards of Court in Ireland as described in Section 3.12.1 of the Phase 1 report. A figure of 11% was agreed, based on data from the Alberta Office of Public Guardians and Trusteeship between 2015 and 2020 and the number of Wards of Court registered in Ireland in 2020 as a percentage of all Wards. To maintain the proportionate breakdown of 72:19:9 for services, 11% was applied across the each of the three tiers of service. Table 7 shows the annualised figures after the application of 11%.

Table 7: Annualised figures across support arrangement tiers 2022 to 2026

	DMAA	CDMA	DMRO	Total
2022	16,460	4,344	2,057	22,861
2023	16,704	4,408	2,088	23,200
2024	16,950	4,473	2,119	23,541
2025	17,204	4,540	2,150	23,894
2026	17,475	4,612	2,184	24,271

Alternative scenarios to reflect 25%, 50% and 75% uptake

The annualised figures presented in Table 7 assume a 100% uptake level of services. Alternative scenarios are presented in Tables 8 (75% uptake), Table 9 (50% uptake) and Table 10 (25% uptake). In addition, a yearly growth of 10% is factored into the numbers shown in the three tables. However only CDMA and DMAA arrangement tiers are adjusted to 50% and 25% in the respective tables. It is assumed that uptake of DMRO will not fall below 75% due to a higher level of need and less scope for opting out of decision support arrangements. Since the service is expected to commence in mid-2022, adjusted figures for 2022 are presented in Table 11. A summary of further investigation into validating assumptions in uptake levels and potential facilitators and barriers to uptake is provided in Appendix 2.

Table 8: Annualised figures at 75% uptake across all support arrangement tiers 2022 to 2026

	DMAA	CDMA	DMRO	Total
2022	13,561	3,578	1,695	18,834
2023	13,884	3,664	1,735	19,283
2024	14,100	3,721	1,763	19,584
2025	14,313	3,777	1,789	19,879
2026	14,538	3,836	1,817	20,191

Table 9: Annualised figures at 50% uptake for DMAA & CDMA and 75% for DMRO

	DMAA	CDMA	DMRO	Total
2022	9,040	2,386	1,695	13,121
2023	9,256	2,443	1,735	13,434
2024	9,401	2,481	1,763	13,644
2025	9,542	2,518	1,789	13,849
2026	9,692	2,558	1,817	14,066

Table 10: Annualised figures at 25% uptake for DMAA & CDMA and 75% for DMRO

	DMAA	CDMA	DMRO	Total
2022	4,520	1,193	1,695	7,408
2023	4,628	1,221	1,735	7,585
2024	4,700	1,240	1,763	7,703
2025	4,771	1,259	1,789	7,819
2026	4,846	1,279	1,817	7,942

Table 11: Adjusted figures for July to December 2022

	DMAA	CDMA	DMRO	Total
50%	2,260	597	847	3,704
75%	3,390	895	1,271	5,556

Estimated distribution of public (panel member) and private DMROs

Panel member DMROs will be available for those who do not have a suitable person to act in this capacity. A review of comparable service usage in three other jurisdictions and in the wards of court system in Ireland established that the average public/private split was 33% for public DMROs and 67% for private DMROs. Applying these percentages, Table 12 shows the distribution of public and private DMROs from 2022 to 2026.

Table 12: Estimated distribution of public and private DMROs at 75% uptake 2022 to 2026

	Public DMRO	Private DMRO	Total
2022	559	1,136	1,695
2023	573	1,163	1,735
2024	582	1,181	1,763
2025	590	1,199	1,789
2026	600	1,217	1,817

Estimated distribution of services by geographical location

The geographical breakdown of estimated service requirements for 2022 is shown in Table 13. This is based on a 25% uptake level for DMAA and CDMA and a 75% uptake for DMROs (see Table 10). The percentage population for each county was calculated, based on 2016 county and state populations and the assumption that this relationship remains unchanged for 2022. The county percentage was then applied to the annualised figures for DMAAs, CDMAAs and DMROs to arrive at a county level figure for each level of support. The split between requirements for public (panel member) and private DMROs is also indicated.

Table 13: Estimated distribution by administrative county in 2022

County	% state population	DMAA	CDMA	DMRO	Total	Public DMRO	Private DMRO
Carlow	1.18%	53	14	20	87	7	13
Dublin City	12.76%	577	152	216	946	71	145
Dún Laoghaire-Rathdown	4.77%	215	57	81	353	27	54
Fingal	5.95%	269	71	101	441	33	68
South Dublin	5.70%	258	68	97	422	32	65
Kildare	4.47%	202	53	76	331	25	51
Kilkenny	2.05%	93	24	35	152	11	23
Laois	1.69%	76	20	29	125	9	19
Longford	0.83%	38	10	14	62	5	9
Louth	2.63%	119	31	45	195	15	30
Meath	3.86%	175	46	65	286	22	44
Offaly	1.59%	72	22	27	121	9	18
Westmeath	1.83%	83	22	31	135	10	21
Wexford	3.10%	140	37	52	229	17	35
Wicklow	2.92%	132	35	50	217	16	33
Clare	2.47%	112	29	42	183	14	28
Cork City	2.91%	132	35	49	216	16	33
Cork County	8.53%	386	102	145	632	48	97
Kerry	3.17%	143	38	54	235	18	36
Limerick City and County	4.14%	187	49	70	307	23	47
Tipperary	3.33%	150	40	56	246	19	38
Waterford City and County	2.43%	110	29	41	180	14	28
Galway City	1.77%	80	21	30	131	10	20
Galway County	3.68%	166	44	62	272	21	42
Leitrim	0.67%	30	8	11	49	4	8
Mayo	2.76%	125	33	47	204	15	31
Roscommon	1.35%	61	16	23	100	8	15
Sligo	1.39%	63	17	24	103	8	16
Cavan	1.54%	70	18	26	114	9	18
Donegal	3.28%	148	39	56	243	18	37
Monaghan	1.26%	57	15	21	93	7	14
Total	100%	4,520	1,196	1,695	7,411	559	1,136

Summary

The baseline population for 2022 is estimated to be 204,171 rising to 216,767 by 2026. Using National Disability Service data on levels of need, a distribution of need for services within the baseline population was established. This was adjusted to take account of individuals that may move from requiring a CDMA to requiring a DMRO due to lack of a suitable person to act as CDMA. After adjustment, the distribution of need was set at 72% for DMAAs, 19% for CDMAAs, and 9% for DMROs.

Annualised figures for the DSS were arrived at by applying a rate based on comparable service usage. At 100% take up level, a combined total of 22,861 DMAAs, CDMAAs and DMROs would be registered with the service in the first year of service (2022). Given that this is a new service in Ireland and that no comparable service has previously existed at DMAA and CDMA levels, it is assumed that a 25% uptake at the lower levels and a 75% uptake of DMROs is the most likely scenario. At these uptake levels, a total of 7,408 arrangements would be made in 2022 rising to 7,942 by 2026. However, current indications are that the service will commence mid-2022 therefore the total number of arrangements may be reduced by half, to 3,704. At the same time, if pent-up demand for lower levels of services is factored in to the initial six months of operation, total arrangements may increase to mid-way between the six month and 12-month figures. Thus, a reasonable estimate for the first six months of operations (July to December 2022) would be 5,556 arrangements.

For DMROs, it is estimated that 33% will require a public (panel member) DMR while 67% will have a suitable person/family member to act on their behalf.

In terms of geographical breakdown for service need it is unsurprising that centres of population have the highest numbers in terms of DSS service need. This includes the four administrative areas of Dublin, Dublin City, Dún Laoghaire Rathdown, Fingal and South County Dublin, and Cork County and City, Galway and Limerick.

Appendix 1: Key findings from Phase 1

- There is no single data source in Ireland of adults who require support to make decisions. However, there are a range of data sources that include people with capacity difficulties as well as specific diagnoses and conditions associated with an increased likelihood of capacity difficulties.
- The Decision Support Service (DSS) is a new service established by the Assisted Decision-Making (Capacity) Act 2015 (the Act) to promote the rights and interests of adults who may require support to make decisions about their personal welfare, property and affairs.
- To design and implement a service that meets the needs of its service users, the DSS needs to understand the likely cohort of users that need, or would benefit from, supported decision-making.
- Since the Act stipulates that incapacity cannot be presumed based on diagnosis, the approach taken to service demand forecasting should, where possible, reflect a functional assessment of capacity. This is based on a person's ability to understand, at the time that a decision is to be made, the nature and consequences of that decision, and be able to communicate that decision.
- A baseline population of likely DSS users has been established using a non-diagnostic data source (Census 2016), supported by three nationally representative surveys which asked more in-depth questions allowing for cross-analysis and providing a mechanism to validate Census data.
- The baseline population should be seen as a broad group of adults who may benefit from the supports and services of the DSS due to their likelihood of failing to meet one or more of the pillars of a functional assessment of capacity.
- The baseline population ranges from 116,811 to 187,265 with the lower figure including only those reporting difficulties in learning, remembering, or concentrating and the upper figure extended to also include those with communication difficulties.
- When population projections are applied, the baseline population in 2021 ranges from 125,406 to 201,064.
- This represents 3.3% to 5.2% of the adult population (1 in every 20 adults).
- The lower baseline population can be disaggregated by age and by geography, providing useful insights for DSS operational service distribution:
 - 24% are aged 65 years and older
 - 28% live in one of the four Dublin administrative areas
 - 14% reside in nursing homes
- Other data sources provide insight into cohorts with specific conditions or other vulnerabilities placing them at higher likelihood of benefiting from DSS services as well as those with existing decision-making arrangements in place. For example:
 - Approximately 2,300 adults are currently Wards of Court, of whom over a quarter have the General Solicitor acting as their Committee.
 - Approximately 1,000 Enduring Powers of Attorney (EPAs) are currently registered annually. These are EPAs made under the Powers of Attorney Act 1996.
 - There are approximately 44,000 adults living in long term care settings across nursing homes, disability services and mental health services.
 - Many people living with neurological and mental health conditions that can adversely affect decision-making capacity live in the community, included an estimated 20,000 to 35,000 people with dementia.

Appendix 2: Factors affecting uptake of decision support services in Ireland: Rapid review of evidence

Introduction

Anecdotal evidence, from seminars and presentations as well as informal discussions between Decision Support Service (DSS) staff and key stakeholders has identified a number of potential barriers to uptake when the service commences in mid-2022. These include lack of awareness of the service, misperceptions about its relevance, cost, and ease of access, particularly in relation to the Digital First approach being taken by the DSS. The aim of this rapid review was to gather available evidence to corroborate or revise the estimates used in the scenario modelling in the second phase of a demand forecasting project, by examining the likely impact of potential barriers and to learn from the experiences of other similar services elsewhere.

Overview of findings

Only a few resources were found which reference uptake of decision-support services; their summarised findings are presented in the next section with further detail provided in the Appendix. These resources encompass a broad range of perspectives including literature reviews, site visits as well as research conducted with service users and their supporters. None of the reviewed resources explicitly focused on the issue of uptake of services nor did they specifically address key concerns around cost of the service or ease of use from a digital first perspective. Awareness of and perceived relevance of the service were alluded to however much of the reference to awareness of the service focused on difficulties encountered with third parties' acceptance of agreements due to their lack of knowledge as opposed to awareness among potential users and supporters. Findings are presented in the next section from the experience of two European jurisdictions (one country and one semi-autonomous region) and four Canadian provinces.

Overall, research that has explored how decision-making is supported in a context that legally recognises supported decision-making is very limited.[1] This is perhaps understandable given that relatively few jurisdictions have a legal framework in place for supported decision-making.

Key findings on service uptake and barriers to uptake

The first two examples are taken from a compendium of existing supported decision-making models and practices in Europe undertaken by the European Network of National Human Rights Institutions (ENNHRI) and Mental Health Europe (MHE) in consultation with their members. Published in 2020, it was written from the perspective of compliance with Article 12 of the United Nations Convention on Rights of People with Disabilities (UNCRPD). Eight members provided information on legal frameworks of which two are presented below due to their reference to uptake of services.

The Czech Republic's reformed Civil Code entered into force in January 2014, abolishing full guardianship, setting time limits on limited guardianship, and recognising supported decision-making as the preferred alternative. Supported decision-making measures include assistance in decision-making for adults with "mental disabilities".

During the first three years of operation, 155 assistance agreements were concluded. Barriers to uptake include a lack of comprehensive information provided by the state about the objectives and use of the new legislation, delays in adopting necessary follow-up legislation and lack of clarity regarding the role of the assistant in specific legal transactions. In addition, many people with disabilities (particularly those living in large institutions) do not have a close person who could provide them with appropriate assistance. Assistance can alternatively be provided by an organisation.

In Spain, reform of the Catalan Civil Code (CCC) in 2010 comprised an integral reform and reconceptualization of legal mechanisms available to support individuals with disabilities or complex needs. This includes the assistance mechanism - a modular and flexible instrument which can range from supporting persons in one aspect of their life (for example, healthcare) to a combination of several aspects (healthcare and financial management as well as bureaucratic, administrative or legal proceedings). Assistance is not linked to the previous absence or limitation of a person's legal capacity and can be provided by a family member, friend or carer or by an approved organisation.

Since 2016, the number of assistances has overtaken the number of court-appointed guardians. No public data is available regarding the number of individuals who have formally requested an assistance but, as of 30 June 2019, 124 active assistances are accounted from which 70 are provided by one non-governmental organisation.

Several studies were identified that examined the situation in Canada, in particular British Columbia which has had Representation Agreements (RAs) in place since 1996. These agreements include a standard section 7 agreement (for use when the relevant person lacks capacity) and a section 9 agreement (used for pre-planning). Presented below are findings from site visits undertaken in 2010 across several Canadian provinces and a literature review in 2018 by the same researcher, to inform development of Australian services.

The literature review found only four studies exploring use of RAs despite being in place for 17 years, all of which were found to be small, conducted over short periods and with limited scope. Moreover, the author noted a focus on pre-planning (section 9 agreements) across the studies together with a bias towards ascertaining the experiences of representatives and service providers with less focus on the lived experience of those making decisions with support. However, some potentially useful findings for the purpose of this review emerged including, for the perspective of the decision-making supporter that this role can be “a challenging and pressure filled responsibility”. Creating an agreement was cited as being difficult and expensive and the perception was that social services and health care staff often had limited understanding of their use. There also seemed to be a lack of clarity in practice between supported and substituted decision-making with representatives perceived to be engaged in both practices while using the same representation agreement, yet strongly characterising their relationship as supportive. Overall, participants in the research wanted greater clarification of what supported decision-making was and how to do it. They expressed there was a lack of education and resources available for practitioners, lawyers and the community more broadly on supported decision-making.

An earlier report in 2010 based on site visits concluded that there had not been a large uptake of RAs in either British Columbia or Yukon. It was concluded that this was often because the people who would benefit from these agreements did not have a close, trusting relationships with a person who could perform this role. It was further noted that lack of a register of supported decision-making authorisations in Alberta made it difficult to determine the prevalence and success of this tool. In Saskatchewan, it was noted that in the initial seven-year period following the introduction of the Adult Guardianship and Co-decision-making Act 2001, 446 cases were filed of which only 7% applied to have a co-decision-maker with the remainder asked for a guardian

to be appointed to help with decisions regarding person or property.

Application of findings to the Demand Forecasting project

Some issues particularly pertinent to this review which include addressing both supply and demand sides are listed below:

- The need for support services to be adequately resourced
- Recognising and overcoming challenges in support for people who are isolated
- Addressing persistent low cultural expectations of people with cognitive disabilities as decision makers
- Ensuring data is collected and incorporating indicators to enable ongoing monitoring and evaluation of services including effectiveness and factors influencing outcomes
- The need for education and training.

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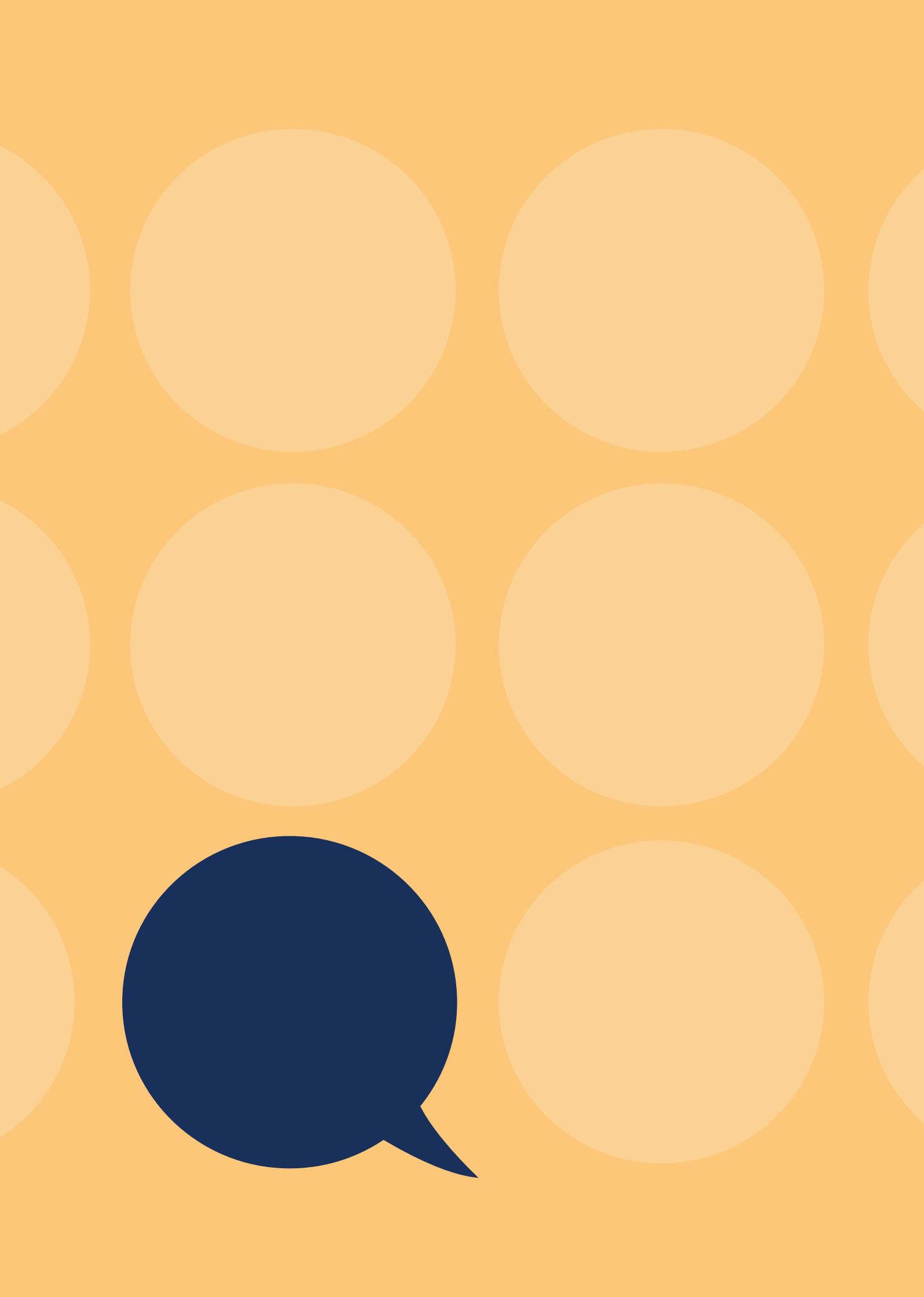
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