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Report on current and future older adult services for people with sight loss in Ireland: National Council for the Blind of Ireland

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THE LONDON SCHOOL
OF ECONOMICS AND
POLITICAL SCIENCE ■

Centre for the Philosophy of
Natural and Social Science

Report on Current and Future Older Adult Services for People with Sight Loss in Ireland

National Council for the
Blind of Ireland

Simon Hayhoe and Danny Cahill

Abstract

Research was conducted after issues needing research in the Republic of Ireland (Ireland) for Older Adults who developed sight loss were identified by the National Council for the Blind of Ireland. The research was conducted using grounded methodology in three phases. The first phase found NCBI's Current Services for older adults relate to five elements of what is referred to as inclusive capital. According to the 2016 Irish Census, physical impairments and a large number of cognitive impairments increase in old age, and the likelihood of becoming disabled rises exponentially after the age of 80. The second phase found larger jurisdictions and jurisdictions with older associations have multiple overlapping agencies, leading to confusion in service provision. Services for all jurisdictions are related to what are felt to be traditional demographics, however most jurisdictions surveyed had specialist services based on unique political or cultural backgrounds. The third phase studied academic literature on services for older adults, and found literature fell into categories mostly reflecting the five elements of inclusive capital. The study concludes there is a need to consider physical and mental health, multiple impairments, Significantly Older Adults' social needs and end-of-life care.

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Context

Issues needing research in the Republic of Ireland (Ireland) for Older Adults (OA) – i.e. people over the age of 65 years - who developed sight loss were identified by the National Council for the Blind of Ireland (NCBI). Three prominent examples of these issues are: Current provision is mostly a workforce model; OA`QA are not in need of career development; Training to provide inclusion and domestic skills is needed, and should be prioritised.

Methodology

The project was conducted using grounded methodology. The research was a three-phase, qualitative survey of documentation on demographics, the provision of older adult services in similar jurisdictions and academic literature.

Findings

- *First Phase of Research:* NCBI's Current Services for older adults relate to five elements of what is referred to as inclusive capital. According to the 2016 Irish Census, physical impairments and a large number of cognitive impairments increase in old age, and the likelihood of becoming disabled rises exponentially after the age of 80. The number of OA is also continuing to increase, as a greater number of people are surviving into old age. Heat maps show a correlation between disability and age. The Irish census also shows a strong correlation between average age and disability, and shows proportionately more disability and a higher average age in rural areas. Carers are also more likely to only support people with disabilities for <14 hours per week or >43 hours per week - it is assumed that unpaid carers working >43 hours a week live with the person being cared for and are more likely to be family members, as this figure correlates with unpaid carer hours.
- *Second Phase of Research:* Larger jurisdictions and jurisdictions with older associations have multiple overlapping agencies, leading to confusion in service provision. Services for all jurisdictions are related to what are felt to be traditional demographics, however most jurisdictions

surveyed had specialist services based on unique political or cultural backgrounds. However, there were services common to most of these jurisdictions, including: advocacy services, although this advocacy often focused on younger people's services or employment; health care, although this did not appear to cover issues related to OA – e.g. dementia; IT services, although none of these IT services appeared to specialize in OAs; independent living skills, which was the strongest focus for OA services, although transition training often specialized in younger adults; mobility services, although again these services rarely advertised specialist services for older adults. These observations led to the following hypothesis:

Apart from independent living skills, few small jurisdictions appear to have specialist services for OA, which largely ignores the changing demographics of a growing need for discrete OAS. In addition, services too often appear to be based on institutional tradition rather than targeted needs.

- *Third Phase of Research:* Academic literature on services for older adults fell into categories mostly reflecting the five elements of inclusive capital: networking – well-being, mental health and remaining parts of the community; learning – re-education to be able to remain independent; Information – provision of information on services; space & place – related to independent living in home and community; mobility – transport in, around and outside houses. However, there were complicating issues identified in the literature that need to be addressed, these include: older people are surviving and developing sight loss and multiple impairments; issues of general health and psychological well-being are becoming more important; adults over 80 years (what are termed in the main report as SOA) will increasingly have other health issues related to old age.

Conclusions and Recommendations

Much of the hypothesis stands, and there is a need to consider physical and mental health, multiple impairments, SOA's social needs and end-of-life care. There is also a need for services to emphasise practical issues of independent living and re-education, a need for joined up services, and for associated services supporting other conditions to work together – e.g. services related to hearing loss and dementia. NCBI and other smaller jurisdictions' services have the advantage they are closer to their clients and are the one-stop-shop for SOA.

1 Introduction & Context

1.1 Terms Used Throughout

Terms used throughout the report include:

- The National Council for the Blind of Ireland, referred to as NCBI
- The Republic of Ireland, referred to as Ireland
- Older Adult Services, referred to as OAS and defined as services which are either designed for, or are of greatest use by people who are over 65 years of age
 - Two distinct types of OAS are identified, each of which provides a unique set of issues:
 - the first group is OAS for Older Adults from 65-80 years of age, who are referred to as OA
 - the second group is OAS for Significantly Older Adults over 80 years of age, who are referred to as SOA

1.2 The Nature and Aims of the Study

This report discusses a study of current and potential future OAS by NCBI. The aims of the study are to: develop inclusive service provision by NCBI for OA and SOA, leading to fuller inclusion of people with low or no vision before during and after being referred to NCBI; examine why some OA and SOA do not fully engage with NCBI's services; and to examine the effects of NCBI's services on health and well-being, particularly mental health. In order to achieve these aims, the study examines three forms of data, which inform the development of training and policy:

- Demographic information from the Irish Census, NCBI and academic literature, which could identify vulnerable populations, the concentration of OA and SOA and the geographical distribution of OA
- Services by associations in similar jurisdictions to Ireland (these jurisdictions included countries, states, provinces, etc.), based on a number of variables and cultural and political similarity
- Academic literature on the nature, need and effectiveness of OAS, with special reference to the jurisdictions with similar state systems of social services

During the study, electronic and paper documents were investigated through three phases of analysis: the study of Irish Census data was conducted using data available on its website; the study of similar institutions was conducted through a survey of associations in similar jurisdictions, conducted through services advertised on their websites; academic literature was identified through a search of academic databases, in either academic libraries or Web based academic databases - documents published within the last five years were prioritised during the search of academic literature, although important older documents were also included in the survey as they provided a more detailed landscape of evidence.

In addition to reviewing documentation, the analysis in this study was also designed to develop a model of inclusive capital¹ as an instrument of supporting OA and SOA. This model had been developed during an earlier study of cultural inclusion, and identified issues that were of particular relevance to individuals with disabilities.

“Services by associations in similar jurisdictions to Ireland (these jurisdictions included countries, states, provinces, etc.), based on a number of variables and cultural and political similarity.”

2 Context of, and Model Used During, the Study

2.1 NCBI

NCBI has recently committed to move from a generic geographic patch model of service provision to a life cycle model with separate focus and delivery elements specific to different age groups. In moving to a life cycle model of service provision, NCBI are wary of the assumption that existing services for older people are acceptable as they are and do not need further innovation or development.

Particular areas of focus for future development include:

- Digitalisation – the integration of digital technologies into everyday life is changing the way services are provided around the activities of daily living. This digitalisation needs to be structured into the basic service offer rather than being a referral to a specialist IT trainer.
- Peer support – the correct model of peer support for older people with vision loss needs further definition
- Support for older people who are in long term residential care
- Further integration with OAS e.g. the falls prevention programmes
- Further support models for active participation – e.g. the development of a volunteer support programme

2.2 The Problem Investigated in this Report

NCBI have identified eight issues with its OAS that need development:

- Current provision is mostly based on the support of the workforce with low or no vision – i.e. providing training and support for people of working age who need ICT skills to support their day-to-day work and career. This raises three separate issues: 1) people with low or no vision are mostly over retirement age, and not in need of career development; 2) it is unknown what form of training should be specialised for professionals working with people over the age of retirement – e.g. training to reduce social isolation? Training to perform

particular tasks? 3) whether IT training is needed for people after they leave work, and if it is needed what training should be delivered?

- Although NCBI is a national organisation, much of their training needs to be on a regional level. This raises its own unique issues: 1) many people have to travel to large urban areas sometimes outside their own counties to get training – although public transport is often available, access and time of travel provide further issues; 2) there are a relatively small number of consultants who can provide ICT training, and these consultants are also based in large urban areas
- Travelling for professionals from NCBI raises further issues, as these specialist staff are spread thin
- Clients are referred to NCBI largely because low or no vision is seen to be their most significant impairment, however many clients have additional needs related to old age and other impairments
- Training at the moment is largely generic – e.g. the use of word processing software – rather than specialised – e.g. the use of technologies within shopping or cultural heritage environments
- Many clients have supporters – often family members – who could also be involved in training and provide information about training needs. However, during training sessions the supporters leave those with low or no vision to be trained alone, as this provides time for them to have a break
- Large parts of Ireland are rural, with many of the urban areas being distributed near the coastline, making the provision of OAS particularly challenging

The model of data analysis was conducted using a model of inclusive capital. This model was designed to facilitate social and cultural inclusion of people with disabilities, such as vision loss¹. This is outlined in the section below.

¹ Hayhoe, S., Tonin, C. & Lunardi, G. (2017). 'A Model of Inclusive Capital for Analysis of Non-Economic Human

Capital' Decent Work, Equity and Inclusion, Padova, Italy, 5/10/17 - 7/10/17

2.3 Inclusive Capital

Material philosophies of human value, which see people as having biological, psychological and social needs, have evolved chronologically since the Enlightenment through to present². Human value, referred to as intangible habits and skills and unspoken knowledge, is an effective way of understanding our personal needs. Human values also shape our individual identity and behavior, and our ways of thinking about motives and desires that can drive service provision for OA and SOA.

Previous philosophies of human values have a common theme: they value a *sense of inclusion* as part of our human condition to feel part of a network. That is, they hypothesise the value of family, friends, social class, religion or ethnicity as a community. Therefore, these philosophies agree it is important, if not instinctive, for people to network and learn through others – i.e. although there are better and worse ways of networking and learning and we might be encouraged to use one way over another, we all network and learn, and networking and learning are part of our human condition. Through public services we also seek out inclusion as a value to feel our sense of inclusion, and this inclusion fosters our sense of value. Consequently, to develop inclusive capital can also provide us with a sense of value. Previously, it has been argued that acquiring inclusive capital is especially important for those who are disabled or older, because older people or those with disabilities are more likely to find barriers to accessing the first steps of inclusive capital³. These barriers lead to a lessening of a sense of inclusion in mainstream society, and to a growing sense of social exclusion and isolation. For instance, people with disabilities often find it harder to access technologies they can interact with, or to access the environments of cultural institutions. People with disabilities are also less likely to have their needs understood, or be thought of as

needing access to the learning of people without disabilities. They are often thought to want services that separate them from the community they were raised in.

The physical nature of some disabilities or infirmities caused by old age can also lessen access to acquiring inclusive capital. For instance, developing sight loss later in life can make it harder to join group discussions that are an essential part of networking for gaining information. More particularly, some people who have late disabilities often do not learn Braille or identify themselves as being disabled⁴. Physical disabilities may also make it harder to find transport or access cultural institutions or physical networks. Late acquired learning disabilities can similarly be thought to restrict access to mainstream learning, and the spaces and places of cultural institutions that people once enjoyed. Institutions consequently need to understand this sense of inclusion.

Practically, institutions must also understand ways in which they can adapt spaces and places – both their physical and virtual environments. These institutions and teachers also need to adapt their own behaviour to develop habits and practices that recognize a sense of inclusion in others. Subsequently, to provide a context for the use of inclusive capital as a means of analysing NCBI's OAS, five stages of developing inclusive capital that were used to filter the focus the search of OAS are discussed.

2.4 Five Stages of Providing Inclusive Capital Through OAS

The first stage in providing services is providing *connections and bonds* within a group of people. These groups are largely family or a group of friends, workmates or, as Yardi⁵ observes, connecting and bonding through social media. Without connecting and bonding to a social or cultural network, there is no sense of inclusion. Consequently, creating a service with a sense of inclusion must be premised on a social and cultural process of

² Hayhoe, S. (in press). Cultural Heritage, Ageing, Disability & Identity. Abbingdon, Oxford: Routledge.

³ Ibid.

⁴ Hayhoe, S. (2017). Blind Visitor Experiences at Art Museums. New York: Rowman & Littlefield.

⁵ Yardi, S. (2010). A Theory of Technical Capital. Paper delivered to the TMSP Workshop, Georgia Institute of Technology, Georgia, 11–12 February 2010.

Yardi, S. (2009). Social Learning and Technical Capital on the Social Web. ACM Crossroads. 162: 9–11.

making a client feel valued in these bonds and connections.

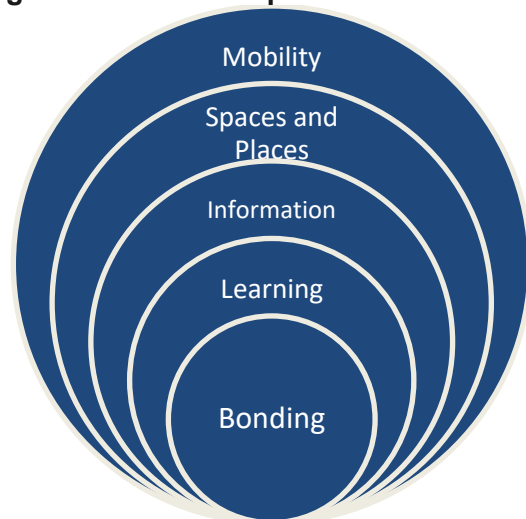
The second stage in providing services is to provide a *means of learning* inclusive capital through networks – that is to say, to use our families, friends and peers to learn and acquire inclusive capital. Consequently, learning inclusive capital consists of acquiring habits, knowledge and practices that can lead to a sense of inclusion. Part of this learning of inclusive capital is also a matter of seeing ourselves as being equally included. However, through this form of learning we also develop a further sense, the moral sense of justice, which can also be described as a form of moral knowledge – i.e. people have refused services previously if they feel they are unjust to their needs or teach skills they don't feel are right.⁶

The third stage of service provision is helping clients *collect information* that points to or later leads to knowledge. This collection of information can include finding out about our surroundings, making judgements about their worth or planning to travel within our surroundings. For example, this information could be providing accessible maps. Such forms of information can also be acquired through the use of technology for gaining information. In the modern era, this third stage can also mean accessing digital networks or learning. Information is consequently a vital part of planning and designing inclusive capital, and its subsequent habits and practice. It can be described as the raw material or the atomic level of inclusive capital. The fourth stage is providing services that allow for *physical or virtual access to spaces and places*, such as visiting or attending spaces in communities, such as shops, churches, pubs, cafes or other social and cultural places. These institutions can include places such as schools, parks, universities, museums or, as Yardi⁷ suggests, surfing websites.

The fifth stage in service provision is providing *physical and virtual mobility*, which allows for navigation through spaces and places, networks, information and learning. For instance, this mobility can be skills needed to

surf the Web for information, move around or between institutional environments, or dexterously navigate technologies like telephones. Conversely, lacking mobility can lead to exclusion, to being unable to attend an institution as a place, to being unable to find information, or to being unable to move between networks. Subsequently, mobility is the essential catalyst of inclusive capital. These five stages are illustrated in the diagram in Figure 1.

Figure 1: The development of inclusive capital and a sense of inclusion: [verbal image] an image of five increasingly sized circles one within the other, with the five stages of inclusive capital in each circle.



The five-stage model of inclusive capital was used in this study as a filter for service provision during the search for data. Although not only surveying services that fit the model was carried out, the survey focused on services that fit into the five stages of developing inclusive capital as a measurement of relevance. The model was also used to identify demographic data for the first stage of data analysis.

For instance, during early analysis OAS emphasising work with existing communities or founding new communities, such as groups of OA or SOA in their local communities, were compared; OAS providing information, including association websites, were examined and compared in different

⁶ Hayhoe, 2017 Op. Cit.

⁷ Yardi, 2009, 2010, Op. Cit.

jurisdictions, and data on the human geography and isolation of transportation in Ireland was searched and analysed through the Irish census, NCBI service information and other secondary source data in academic literature; OAS related to learning were investigated, especially as it related to learning new skills in relation to developing sight loss.

Similarly, in later forms of analysis academic literature relating to transportation, networking, the effects of communal well-being and physical isolation, information, learning and being part of the physical space of the community were emphasised in the analysis.

“The five-stage model of inclusive capital was used in this study as a filter for service provision during the search for data. Although not only surveying services that fit the model was carried out, the survey focused on services that fit into the five stages of developing inclusive capital as a measurement of relevance.”

The following report of the study is broken into the following five sections: 1) the grounded methodology used to analyse and categorise the surveys included in the study; 2) the findings from the first stage of analysis, focusing on the demographic data from the Irish Census and NCBI; 3) the findings from the second stage of analysis, focusing on an analysis of the categories of services discussed in the survey of similar jurisdictions, and the development of an initial hypothesis; 4) the findings from the third stage of analysis, which analysed the hypothesis through the survey of academic literature; 5) conclusions drawn from the study.

3 Research Methodology

3.1 Grounded Methodology

The research methodology used in the study was an adaptation of grounded theory⁸, termed grounded methodology⁹. Like grounded theory, the research was conducted using three phases of data coding – in traditional grounded theory and more formal grounded methodology these are referred to as open (first), axial (second) and selective (third) phases, although these terms were not relevant in this study.

Also like grounded theory, during the three phases of analysis data was analysed in a progressively more focussed way and all forms of data were treated as being equally important. This system of data analysis suited the reflexive, problem solving approach to this novel cultural context and topic, and kept the formal structure of triangulating different forms of data, data analysis and collection methods. However, unlike grounded theory this method encouraged the evolution of culturally constructed theories in the style of Geertz's¹⁰ cultural anthropologies, and collected and analysed the data largely asynchronously – the data was pre-defined, as was the nature of the study in the original proposal - and used deductive rather than inductive logic¹¹. In addition, in this grounded methodology a mixture of qualitative primary and secondary source data was collected, as it was appropriate to the analysis. Although, like traditional grounded theories, all primary data was analysed qualitatively and secondary source statistics were only used to support qualitative analysis.

3.2 System of Search

As stated above, the data for this study was:
a) academic literature on OAS in culturally similar jurisdictions; b) public websites of

associations and institutions for people developing sight loss in jurisdictions similar to Ireland; c) publicly available data on the demographics of Ireland, similar jurisdictions and existing NCBI OAS. The method of searching this documentation was conducted in parallel and asynchronously from September 2018 to late December 2018 – i.e. the searches for academic literature, websites and data sets were conducted at the same time, as was practicable during the time afforded for the study.

The search of the Irish Census, NCBI services and data and demographic data from academic literature was based on: a) the website of Ireland's Central Statistical Service (<https://www.cso.ie>), which contained data and the means for simple analysis of census data – for example, it allowed for the comparison of two or three variables in conventional tables and graphs; b) the NCBI's website (<https://www.ncbi.ie>); c) searches of academic literature through online and library databases – see below on academic literature.

On accessing demographic data on the various websites, searches for specific data based on the five phases of inclusive capital were used, looking in particular for data and services for those over 65 years. However, general demographic data on sight loss and disability – particularly multiple disabilities that were thought to provide an overlap with sight loss and other forms of impairment – were also sought.

The search for jurisdictions that were adjudged to be similar to Ireland were eventually restricted to the most similar jurisdictions, as it was felt that there were too many to survey in the given time. Eventually, three methods were used to identify these similar jurisdictions: the first was subjective knowledge of similar associations, councils and institutions, based on the researcher's

⁸ Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Publishing Company.

⁹ Hayhoe, S. (2012). *Grounded theory and disability studies*. Amherst, New York: Cambria Press.

¹⁰ Geertz, C. (1989). *Works and lives: The anthropologist as author*. Palo Alto, CA: Stanford University Press.

¹¹ Popper, K. (1959). *The logic of scientific discovery*. London: Hutchinson & Co.

Popper, K. (1979). *Objective knowledge: An evolutionary approach* (Rev. ed.). Oxford: Clarendon Press.

and NCBI's experience; the second was the identification of associations, councils or institutions that bore a similarity to NCBI in terms of size, closeness to government and service provision; the third was the following variables to filter jurisdictions:

- Population size - i.e. populations between 1,000,000> and <10,000,000 (approx.), as Ireland has a population of just over 4,200,000
- High-Income – the jurisdictions had to feature in the top quartile of countries by income per capita
- History and culture of service provision / social services – the jurisdictions had to have a mature welfare state, preferably developed over the course of a century or more
- Similar governments and democratically elected ministers
- Similar service provision by government and charitable sectors
- Similar spending on services – taken as a percentage of the jurisdiction's income

From this process, the following jurisdictions were identified:

- Denmark
- Finland
- Massachusetts (US)
- New South Wales (Australia)
- New Zealand
- Norway
- Scotland
- Sweden

“The search for jurisdictions that were adjudged to be similar to Ireland were eventually restricted to the most similar jurisdictions, as it was felt that there were too many to survey in the given time.”

After identifying jurisdictions, data was collected from the publicly available websites of their largest national or large regional OAS provider websites available to the public. These searches were made using regular Google search engine, the website menus and the internal search engines on the websites.

The search of academic literature on OAS in institutional settings gave preference, although not exclusively, to documents published within five years of the search of databases. These documents were searched for using the following research databases: the US National Library of Medicine National Institutes of Health's PubMed database, Scopus, Web of Science, and Google Scholar. Other than Scopus and Google Scholar, the two other academic databases were chosen as they recognised OAS in journals and conference proceedings and access was available to them. Google Scholar was chosen as it is a general database of documents and identified journals and proceedings from other disciplines not recognised in specialised databases.

During both searches, combinations of the following keywords or key phrases in two different categories relating to OAS for people with sight loss were used: CATEGORY A KEYWORDS: visual impairment, blindness, blind, reading impairment, reading disability, visual disability (*these were traditional identifiers of sight loss*); CATEGORY B KEYWORDS: adult services, social services, older adult services, models of service, service provision (*these were identifiers of services pertaining to OAS*). The keywords in CATEGORY A were adapted from previous literature searches in related fields of study¹². Each keyword from CATEGORY A was combined with each keyword from CATEGORY B and separated by a Boolean “AND,” meaning documents had to contain at least a keyword from each category.

There were restrictions to this method of sampling documentation and data sets that made it an imperfect science. For example, it was observed that some databases used

¹² Hayhoe, S. (2018). Epistemological Trends in the Literature on Mobile Devices, Mobile Learning, and Learners with Visual Impairments. *Optometry and*

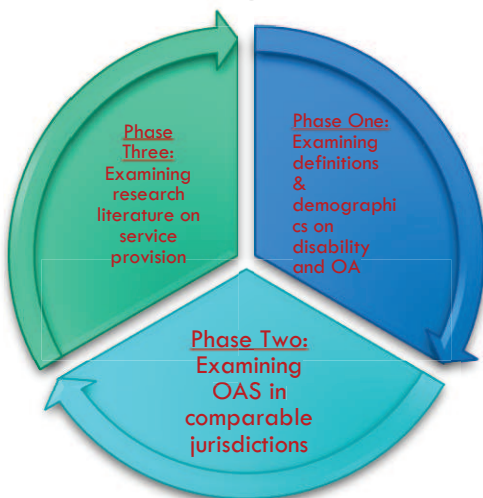
different search algorithms. This provided potential inconsistencies in keyword searches. It was also observed there is no definitive database of all service literature. Therefore, it was assumed that some lesser known journals, conferences and publishers were potentially missed.

There were exceptions to this issue of inconsistency. For instance, although generalist journals on sight loss, such as the British Journal of Visual Impairment and the Journal of Visual Impairment and Blindness, were possibly not covered by specialised databases, they were covered by Google Scholar and Scopus. This said, journals with articles including articles on OAS in general or for clients with multiple disabilities – such as occupational therapy journals - were rarely discovered in the search.

3.3 Implementing the Three Phases of Data Analysis

The three phases of data analysis are outlined in Figure 2, and were initially conducted informally as the data was collected and sifted more formally according to its three stages after the data had all been collected.

Figure 2: Outline of the Stages of Analysis Used During the Study: [verbal image] an image of a circle split into three parts, with arrows showing the direction of the study in each part. The last arrow points to the beginning of phase one, making the process never-ending.



During the first phase, NCBI's existing services were analysed against inclusive capital's five stages. This information was then compared to demographic information from the 2016 Irish Census, and the initial search of the eight top jurisdictions which were adjudged to be similar to Ireland. As this was not a statistical study, only processed data from the Irish Census 2016 was considered, as it was felt that introducing other data sets gathered using different methodologies would lead to inconsistencies. From this data, heat maps and graphs were also referred to, and combinations of variables that arose in the categories of service were identified. From this information, categories of analysis were made for the second phase.

During the second phase, the categories identified in the first phase had further analysis, with links being made between different jurisdictions and their cultural context. In this phase of analysis only qualitative data was considered, along with descriptions of services relevant to OA and SOA. In this meta-analysis, trends in overlapping services were observed and further searches of the services were conducted through their webpages. In addition, and in consultation with NCBI, the management of volunteers was identified as an area that needed extra attention in this analysis. It was at the end of this section of the research that a tentative hypothesis was formed, which became a focus of the third phase of research.

During the third phase, the hypothesis was tested using the literature from the search of academic literature and, after consultation with NCBI, the low uptake of OAS internationally was also considered. Through this analysis, the hypothesis was refined and made more robust and allowed conclusions to be drawn.

4 Analysis of the First Phase

4.1 Initial Observations: An Overview of Demographics, the NCBI and OAS in Similar Jurisdictions

According to the Irish Central Statistics Office (CSO), in 2016 Ireland had a population of over 4,700,000 people and an increased average age of 81.6 years – NB this figure does not take account of gender. Within this general population, 643,000 people were identified as having at least one form of disability, and over 54,800 people were identified as having sight loss.¹³ A full breakdown of those forms of disability in 2016 identified by CSO is identified in Table 1.

Table 1: Persons with a Disability (Number) by Disability Type and Census Year – NB OA may have one or more impairment.

| | |
|---|---------|
| Total persons with a disability | |
| Blindness or a serious vision impairment | 54,810 |
| Deafness or a serious hearing impairment | 103,676 |
| A condition that substantially limits one or more basic physical activities | 262,818 |
| An intellectual disability | 66,611 |
| Difficulty in learning, remembering or concentrating | 156,968 |
| Psychological or emotional condition | 123,515 |
| Other disability, including chronic illness | 296,783 |
| Difficulty in dressing, bathing or getting around inside the home | 140,366 |
| Difficulty in going outside home alone | 184,945 |

¹³ Central Statistics Office (2019) Census 2016 Summary Results (Summary Results). Downloaded from <https://www.cso.ie/en/media/csoie/newsevents/docu>

| | |
|---|---------|
| Difficulty in working or attending school/college | 210,639 |
|---|---------|

| | |
|---|---------|
| Difficulty in participating in other activities | 229,397 |
|---|---------|

The NCBI is the main association for the well-being and support of people who develop sight loss in Ireland. It adheres to the United Nations' Sustainable Development Goal 3, which ensures healthy lives for all people and aims to promote both physical and psychological well-being for its clients. In addition, NCBI is guided by the Irish Government's 2005 Disability Act, which promotes equality for all Irish people with disabilities and legislates against all forms of exclusion in the social sphere.

Apart from services supporting education and supporting Irish people either entering employment or supporting people in long term employment, the NCBI's current services can be mapped to the needs of OA or SOA. Furthermore, the services that were found to be consistent with OAS mapped to the five elements of inclusive capital, with services relating to information and learning being particularly well represented. These services are:

- Bonding and networking: these services included providing emotional support, groups for others with sight loss and counselling mapped with the need of clients
- Learning: these services included those related to raising awareness of the needs of people developing sight loss and conducting public education on low vision solutions mapped to learning – although it was noted that the low service take-up suggested there were other elements of this service that needed investigation
- Information: these services related to the provision of advice and information, the provision of accessible and assistive technologies, the NCBI's library and advocacy for those who need extra support

[ments/pressreleases/2017/prCensussummarypart1.pdf](https://www.ncbi.ie/pressreleases/2017/prCensussummarypart1.pdf) on the 12th December 2018.

- Space & place: These services were activity centres run by the council and the NCBI shop in Dublin, practical solutions, where people not only bought specialised products but also got to meet others with sight loss and see a point of reference for the NCBI
- Mobility: These services were related to rehabilitation and mobility training

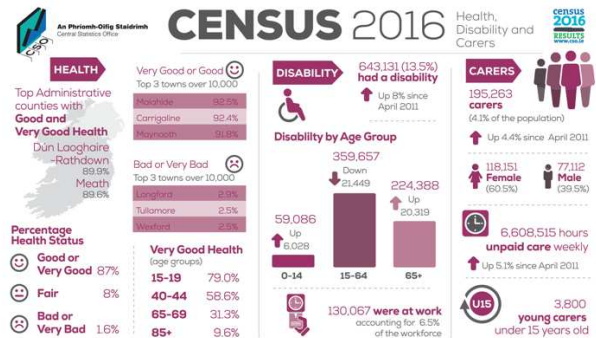
Although the NCBI provides broad categories of OAS already, CSO demographic data indicates that there is an increasing need for social and support services in Ireland, such as those provided by the NCBI. This could potentially present and extra stress on the current systems of providing OAS, when moving to a life-course model. For example, CSO observe the number of carers has increased 4.4 % in the period 2011-2016 – there are now more than 195,000 carers in Ireland, with 3,800 being under the age of 15, and 6,608,500 hours a week of caring being unpaid hours. This data is reflected in the infographic displayed in Figure 3.¹⁴ The initial census data shows the number of people with at least one disability who were identified as being disabled in Ireland also increased since the last census in 2011 - in 2016, 13 ½ % of the population had a disability, a figure that was up approximately 8 % from 2011. Importantly, disability has significantly increased in childhood and adults over retirement age, with the biggest group of people with disabilities – working age adults – decreasing. This finding is partly reflected in the measurements of “good health” scores in the census, where people of working age were exponentially more likely to have very good health than people over retirement age. Importantly, people:

- of working age under the age of twenty were significantly more than twice as likely to have very good health than those over the age of retirement (79 % between 15-19 years versus 31.3 % of people between 65-69 years)
- of working age from 40-44 years were almost twice as likely as people just over the age of retirement to have very good

health (58 % of people from 40-44 years versus 31.3 % of people from 65-69 years)

- over the age of 85 were over eight times less likely to have very good health than people from 15-19 years (79 % between 15-19 years versus 9.6 % over the age of 85 years).

Figure 3: Republic of Ireland Census – Infographic Showing a Broad Demographic Breakdown of All Disabilities in Ireland: [verbal image] showing a large number of carers, an increase in disabled communities who are very young and very old and an increasing health problem amongst the older population.

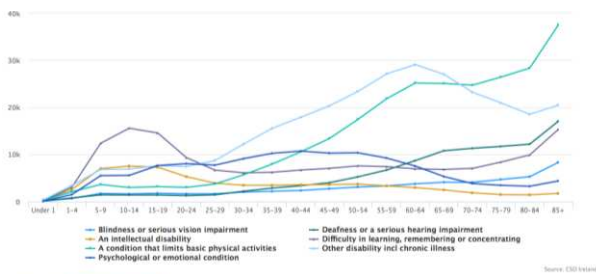


Although there is not enough data to show why there is an increase in these figures, it is likely there is no single cause for the increased number of people with disabilities in Ireland. For example, the increase in disability among children is not reflected in the health outcomes of much younger people, whereas it is reflected in the rapidly deteriorating health of people over the age of retirement. Furthermore, there is a mixed demographic picture of age-related impairment within the census data. For example, census data shows sight loss increases steadily throughout life course until just after the age of 80 years, and then decreases rapidly thereafter until around the age of 98. By contrast, psychological or emotional conditions peak between the ages of 10-14 years, and continues decreasing into adulthood with no significant discernible

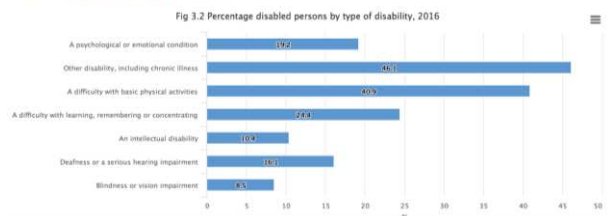
¹⁴ Central Statistics Office (2019) Census 2016 Summary Results [Infograph]. Downloaded from <https://www.cso.ie/en/media/csoie/visualisationtools/>

pattern.¹⁵ These demographic trends are illustrated in Figures 4 and 5. However, as only 8.5 % of people with disabilities have sight loss and other physically disabled populations with much greater populations also increase in old age, there is an increased likelihood people will have more than one disability.

Figure 4: Line Diagram Representing the Populations of Disability by Age in Ireland, 2016: [verbal image] line diagram showing that sight loss increases rapidly with age alongside other physical impairments, whereas learning disabilities relatively decrease with age.



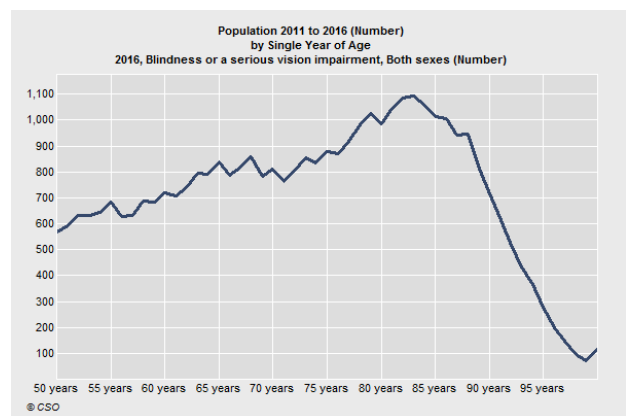
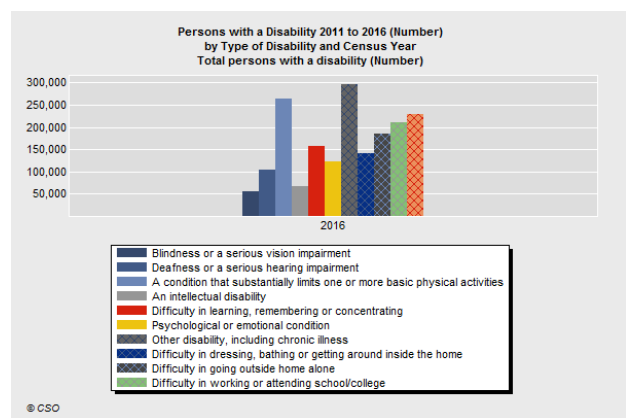
Interactive table: [StatBank Link, ERO06](#)



“The NCBI is the main association for the well-being and support of people who develop sight loss in Ireland. It adheres to the United Nations’ Sustainable Development Goal 3 ...”

¹⁵ Central Statistics Office (2019) Census 2016 Summary Results [Tables]. Downloaded from <http://www.cso.ie/px/pxeirestat/Database/eirestat/Su>

Figure 5: (a) Number of People with Sight Loss in Comparison to Other Disabilities: [verbal image] bar chart showing a relatively small number of people with sight loss compared to other impairments (b) Number of OA and SOA with Sight Loss by Number in Population, showing the increasing number of older people climbing with age until the years between 80-85, when the population rapidly decreases until the ages of 95-100 when the number grows again.



Geographically, in 2016 there was a larger concentration of OA and SOA in the west of Ireland, particularly on the Atlantic coast and some regions close to the border with the North of Ireland. Notably, these communities were more likely to be rural than those areas that had lower concentrations of OA and SOA. In particular, and as illustrated in Figure 6, large urban areas in Ireland, such as Dublin,

Summary%20Results%20Part%201/Summary%20Results%20Part%201_statbank.asp?SP=Summary%20Results%20Part%201&Planguage=0 on the 12th December 2018.

Galway, Limerick and Cork, appear to have dramatically younger populations in their cities.

“CSO graphs from the 2016 Irish census also appear to show a concentration of OA below the age of 81 located at home in rural areas in particular.”

Given the increasing correlation between physical and sensory disability and old age, there is also a discernible pattern of average age and people with disabilities being supported in their own home, with greater concentrations more likely to exist in rural communities towards the Atlantic coast and the border with the North of Ireland. These heat maps are featured in figures 6 and 7.

Figure 6: A Demographic Heat Map of Average Age Distribution in Ireland: [verbal image] the heat map shows a density of older people along the west coast or Ireland and to the south of the border with the North of Ireland.

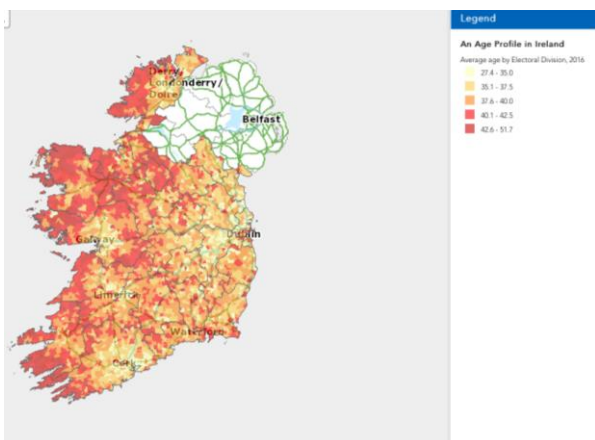
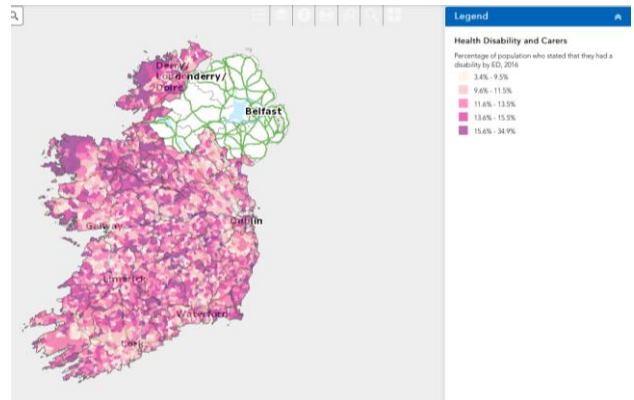
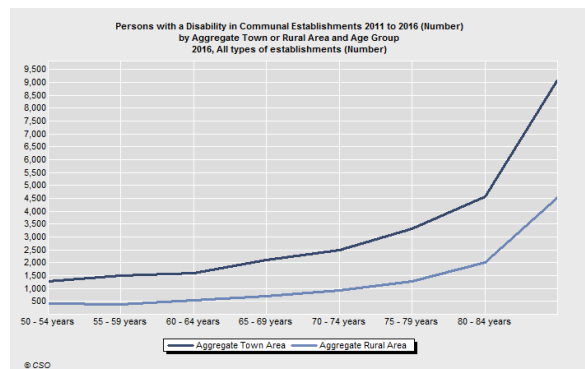


Figure 7: A Demographic Heat Map of Disability & Carer Distribution in Ireland: [verbal image] the heat map shows a more mixed distribution of carers, however there is a particularly strong density along the north west coast.



CSO graphs from the 2016 Irish census also appear to show a concentration of OA below the age of 81 located at home in rural areas in particular. However, despite this concentration there appears to be a higher concentration of OA and SOA in residential care homes in city communities, although the pattern of age groups moving into care homes seems significantly similar. In addition, there seems to be an exponential rise in SOA living in residential care homes. This is illustrated in Figure 8.

Figure 8: A Line Diagram Showing Numbers of People in Residential Care Homes in Ireland: [verbal image] the line grows slowly but steadily from birth, but then grows exponentially after the age of 80 years of age.



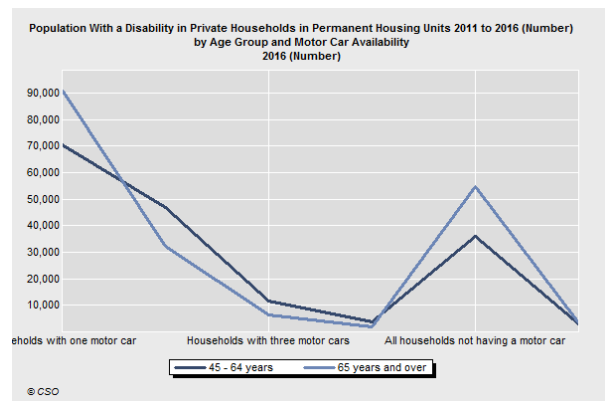
The number of people living in residential care homes in cities could be explained by the greater number of care homes being located in large urban areas. However, it could also at least in part be explained by 2016 Irish Census heat map showing that single adults are concentrated in large urban areas, with the inference that people without spouses or children at home are more likely to be in residential care-homes. This concentration of single people is illustrated in Figure 9.

Figure 9: A Demographic Heat Map Showing Concentration of Numbers of Single People: [verbal image] the heat map shows most of the country light, but stark, deep colours in the cities of Dublin, Cork, Galway, Limerick and Waterford.



Access to private transportation also appears to be problematic for OA and particularly SOA in Ireland. Although most households with OA and SOA will have access to at least one car, with most other households having access to anything between 2–4 cars, there are also a significant number of households without private transportation – there is an assumption that households with carers may generally have access to a car. This issue is illustrated in Figure 10.

Figure 10: A Line Diagram Showing Numbers of Cars by Age Group in Ireland: [verbal image] the line diagram shows the highest number of cars per household is one, with the next highest number not having a car and the numbers declining from two car onwards.



Despite a dearth of evidence on studies of the global population¹⁶, influential systematic reviews find the international context of disability and sight loss internationally is relatively similar to that of Ireland. For example, a study of the amount and nature of sight loss in high-income countries in Europe from 1990-2010¹⁷, shows macular degeneration, a form of eye condition associated with OA and more particularly with SOA, is now the most significant form of sight loss. These figures also show a gendered element to this condition, with more women developing sight loss than men, reflecting the likelihood of more women surviving to older age than men.

¹⁶ Ramke J., Zwi A.B., Palagyi A., Blignault I., & Gilbert C.E. (2015). Equity and blindness: closing evidence gaps to support universal eye health. *Ophthalmic Epidemiology*, 22(5):297–307. <http://dx.doi.org/10.3109/09286586.2015.1077977>

¹⁷ Bourne R.R.A, et al. (2014). Prevalence and causes of vision loss in high-income countries and in Eastern and Central Europe: 1990–2010. *British Journal of Ophthalmology*, 98:629–638. doi:10.1136/bjophthalmol-2013-304033

“According to the 2016 Irish Census, all physical impairments and a large number of cognitive impairments are increasing due to old age, representing an increase from the previous census in 2011.”

Similarly, the global picture of sight loss also shows a strong growth in the OA and SOA population developing sight loss.¹⁸ Currently, of the more than 1,000,000,000 people over 35 years affected by “near” sight loss, 668,000,000 people are over 50 years. Figures for blindness are also increasing, with it estimated that this population will increase to 38,500,000 by 2020, and reach 115,000,000 by 2050. This population growth also shows little sign of diminishing, as ageing is estimated to triple OA and SOA overall in the long term.

4.2 Discussion

According to the 2016 Irish Census, all physical impairments and a large number of cognitive impairments are increasing due to old age, representing an increase from the previous census in 2011. In particular, heat maps of average age and disability show a strong graphical correlation between disability and aging. Similarly, the number of older adults is increasing greatly, as a greater number of people are surviving to old age – i.e. the age lived to is increasing significantly. This is not just an Irish issue, but one experienced by many jurisdictions, particularly those in the developed world. However, it is likely that older adults will not only identify sight loss as their only or most significant impairment, as there are larger populations of people with disabilities whose communities are also increasing – e.g. deafness and people with mobility issues. This also suggests there is an increasing

population of OA and SOA who are more likely to find it difficult to conduct daily tasks or leave their homes.

The growing SOA population is also becoming a significant issue in the provision of OAS, with the likelihood of becoming disabled – including sight loss and dual or multiple disabilities – rising exponentially after the age of 80 years. Significantly, the same heat maps showing a strong correlation between average age and disability, also show proportionately more disability, a dramatically higher average age and instances of disability outside the main urban areas of Ireland, where there are fewer hospitals and communal facilities – i.e. there are high concentrations of older and more disabled people along most of the West Coast of Ireland, and close to the border. Graphing of the Irish Census also shows access to unpaid carers is non-linear – i.e. there is no discernible pattern of proving support for people with disabilities as a whole, OA or SOA. However, there are factors that may have an effect on service provision for OA and SOA that have no significant evidence to support them as of yet.

For example, census data suggests that as carers are more likely to only support people with disabilities for less than 14 hours per week, or care for people over 43 hours per week, it is assumed that unpaid carers working more than 43 hours per week live with the “caree.” Furthermore, as these carers live-in, it is assumed they are more likely to be relatives of the person they support.

This assumption about live-in carers is supported by a strong inverse correlation between single people being largely located in city centres and the increased likelihood of being a person with a live-in carer, such as a spouse. Therefore, there is an indication that there is proportionately more need for OAS, especially for SOA in rural areas, particularly western coastal and border areas and those with low or no car ownership – although data correlating these different factors is as of yet unavailable or unreported, and so this can only remain an inference.

From this research, the following issues

¹⁸ Bourne R.R.A., et al. (2017). Vision Loss Expert Group. Magnitude, temporal trends, and projections of the global prevalence of blindness and distance and near

vision impairment: a systematic review and meta-analysis. *Lancet Glob Health*. Sep;5(9):e888–97. [http://dx.doi.org/10.1016/S2214-109X\(17\)30293-0](http://dx.doi.org/10.1016/S2214-109X(17)30293-0)

considered in the second phase were:

- the need for different OAS for OA and SOA
- the different needs of OA and SOA in rural and urban populations
- OA and SOA who live alone, people who live with carers and people who live in residential accommodation
- OA and SOA who develop a sight loss versus those with dual disabilities

5 Analysis of the Second Phase

5.1 Initial observations

What follows is a review of the jurisdictions, associations and services relating to inclusive capital:

- **Denmark** has a population of over 5,750,000, and their main association is the Danish Association of the Blind — Dansk Blindesamfund¹⁹ (DB), founded in 1911. The main services that DB advertise are: providing telephone consultation for support and guidance; provision of guide dogs; Danish Blind Society consultants, all of whom develop sight loss; Danish blind community housing; clubs, particularly cozy club nights, professional debates, lectures, excursions and trips; Fuglsangcenteret, an accessible hotel for breaks; courses and activities; a traffic companion accompaniment scheme, which allows people to traverse their local communities. In addition, Denmark has a Danish National Library for Persons with Print Disabilities²⁰ (Nota) and the Danish National Library for The Blind²¹ (DBB).
- **Finland** has a population of over 5,500,000, and their main association is the Finnish Federation of the Visually Impaired²² (FFVI), founded in 1928. The main services the FFVI advertise are: advocacy for the blind and partially sighted, including health advocacy; specialist rehabilitation services for those who are losing their sight or have other physical access needs; provision of trained guide dogs; creating networks with international contacts to develop projects and cooperation; provision and training in IT; training and guidance for independent living; the import, sales and lending of technical aids; the production of braille, large-print and audio materials; the transmission of newspapers, magazines and other publications through the web and other digital channels.
- **Massachusetts (US)** has a population of more than 6,800,000, and its main association is Massachusetts Commission for the Blind²³ (MCB), founded in 1906. The main services MCB advertises are: social rehabilitation of people as they develop sight loss; a specialist service providing support for people who are deaf-blind, through the Deaf Blind Extended Supports Unit (DBES); an MCB Resource Library, which provides Braille, large print and audio reading materials; online reporting for eye care providers. Although MCB is the official state provider of services in Massachusetts, there are also charities providing their own services, the main of which is the American Federation of the Blind²⁴ (AFB). AFB is largely focused on the support and education of younger people. In addition, the National Federation of the Blind²⁵, Mass. Branch (NFB Mass.) largely provides advocacy, American Printing House [for the Blind]²⁶ (APH) provides a Braille Library (although there is also a large library at Perkins School, Boston, Mass.), and Guiding Eyes for the Blind (GEFB) which trains and provides guide dogs.
- **New South Wales (Australia)** has a population over 7,500,000 people, and its main association for the blind is Blind Citizens NSW²⁷ (BCNSW), founded in 1910. The advertised services of BCNSW include: individual and systemic advocacy for its clients; technology training on its premises (this requires clients travel to its main centres to receive training); Braille of literature and tuition in Braille (the latter is largely for younger people and children who are blind); a voluntary sewing service for those in need of clothes repairs or minor alterations; peer support and social day social support for participating in external activities; referrals to other

¹⁹ <https://blind.dk/dab>

²⁰ <https://nota.dk/om-nota/English>

²¹ <https://joinup.ec.europa.eu/document/danish-digital-library-service-blind-dls>

²² <https://www.nkl.fi/en>

²³ <https://www.mass.gov/orgs/massachusetts-commission-for-the-blind>

²⁴ <https://www.afb.org/>

²⁵ <https://www.nfb.org/>

²⁶ <https://www.aph.org/>

²⁷ www.bcnsw.org.au/

specialist services, including assistance training and support, independent travel, daily living and sport and recreation. As with Massachusetts, New South Wales also had recourse to national institutions which were represented in the state, including: Vision Australia²⁸, which was founded in 2004 and advertises emotional support, practical advice and strategies; The Vision Australia Library, which provides largely digital access to literature; the Royal Society for the Blind²⁹ (RSB), which dates back to 1884, and provides vision health and measurement services and guide dogs.

“In aggregating these services, it was observed that two outstanding service categories were provided by all jurisdictions, and where they were advertised on the websites of associations they were given prominence.”

- **New Zealand** has a population of more than 4,000,000 people, and its main association is the Blind Foundation³⁰ (BF), founded in 1890. The BF’s advertised services include: the Blind Foundation Library, which has a service called BookLink Digital, providing lending and reading services; help with mobility in the community, including training in and the provision of canes; training and providing guide dogs; help with public or private transportation; counselling and training for those adjusting to sight loss and loss of independence; the use of technology, particularly assistive technologies; cultural support for Māori and Pacific clients,

- Whanau, family and friends; specialist services for those who are deaf-blind.
- **Norway** has a population of more than 5,300,000, and its main association is the Norwegian Association of the Blind and Partially Sighted³¹ (NABPS), founded in 1900. The services it advertises include: rehabilitation for those adjusting to early sight loss and habilitation; magazines for the general public advocating for people who develop sight loss; advise and support for universal design and companies using universal design; providing aids and products; recording and distributing podcasts; providing aids and other technologies for the home; providing enhanced lighting for people with low vision; providing home visits to support clients in their homes; advise and treatment of eye health; providing audio books, guides, electronic reading aids, Braille and read TV; providing white canes and guide dogs and help with mobility; training, general courses and events and providing digital technologies; the association’s Vision and Mastering Centre to provide training and advise; developing physical exercises for clients; running a radio station; providing legal advice and aid for clients.
- **Scotland** has a population around 5,300,000, with its largest organization being the Royal National Institute for the Blind Scotland³² (RNIBS), founded in 1868. The services RNIBS advertises include: a helpline for clients and people who have been diagnosed as having sight loss; reading services, providing audio recorded books for clients; services for people with learning disabilities with low vision; residential care homes. In addition, Scotland also has other institutions including Royal Blind³³ (RB), one of the oldest associations in the world and founded in 1793 as the Edinburgh asylum, and Scottish National Federation of Institutions and Societies for the Blind,

²⁸ <https://www.visionaustralia.org/>

²⁹ www.rsb.org.au/

³⁰ <https://blindfoundation.org.nz/>

³¹ <https://nbfu.no/norwegian-association-blind-and-partially-sighted-youth-nabpy>

³² <https://www.rnib.org.uk/Scotland>

³³ <https://www.royalblind.org/>

found as an advocacy organization alone in 1917. Royal Blind advertises services focused, although not exclusively, on young people's needs, including: advise on eye health; nursing care; residential care homes (Braeside House and Jenny's Well); the Scottish Braille Press, which transcribes documents on demand, provides mostly digital accessible media and books in large print and audio formats, and many magazines and books in Braille. In addition, Scotland has representation from British organisations, such as Guide Dogs, whose focus is on training and providing guide dogs.

- **Sweden** has a population in excess of 10,000,000, with its largest association being the Swedish Association of the Visually Impaired³⁴ (SAVI), founded in 1889. This association advertises the following services: advocacy, both personal and larger political advocacy, for people who are blind; guarding against discrimination of people with sight loss; changing societal attitudes towards people with sight loss; politically and socially defending a general welfare system; providing legal advice for people who develop sight loss; providing social information for people who develop sight loss; producing Perspective, a newspaper for the National Social Security Council; providing Radio SRF for people who develop sight loss; providing an audio archive of documents; support for people who are newly arrived in Sweden and who develop sight loss; various language services for people who develop sight loss and who are from different language groups; "The Cultural Project", Konstvärka, providing education on accessible culture; the provision of rehabilitation training for people who have recent sight loss; Synskadade Riksförbundet's, which is a travel agency specifically for people who develop sight loss; education for and about people who develop sight loss. In addition, Sweden also has other, smaller

associations, such as Guide Dogs Stockholm³⁵ (GDS)/Assistance Dogs International³⁶, which trains and provides guide dogs for people inside and outside Sweden, the Swedish Library of Talking Books and Braille³⁷ (SLTBB), which provides Braille and audio books.

5.2 Discussion

In aggregating these services, it was observed that two outstanding service categories were provided by all jurisdictions, and where they were advertised on the websites of associations they were given prominence.

For example, health care, particularly those related to eye care, was emphasised - all associations considered eye healthcare to be particularly important, and general healthcare advice is given by most associations. Some associations provided support for promoting mental health, general learning disabilities and dual sensory loss – although in this respect, there was an emphasis on deaf-blindness, as a single category of impairment.

Some associations were also linked to government-run national health agencies through their website. However, no association in the survey provided medical treatment, initial assessments or diagnosis for their clients.

Similarly, all jurisdictions surveyed also had at least one association that provided IT and specialist library services, support, help or training in the use of IT, and most associations provided assistive technologies for their clients – either paid for or free.

Taking the observations from the first phase of research and categories of inclusive capital into account, initial observations of this survey showed jurisdictions often have multiple agencies which have their own specialist services. Most of these services relate to the provision of information (talking libraries, Braille, etc.) and education (rehabilitation), with mobility and access to the community spaces and places (including centres for meeting and travelling) playing a lesser role, and activities that allowed for networking

³⁴ <http://www.srf.nu/om-oss/in-english/>

³⁵ http://guidedogs.se/?page_id=491&lang=en

³⁶ <https://www.assistancedogsinternational.org/location/sweden/>

³⁷ <https://www.mtm.se/english/products-and-services/braille/>

taking arguably the lesser role (including the chance to be with or learn with family and friends) – although admittedly the opportunity to live in your own home and being supported as such would provide an opportunity to continue being around family.

These jurisdictions, however, rarely discussed or took account of the geographical distribution or increasing age of its population – one notable exception to this issue was New Zealand's BF, which had a specific service for its indigenous populations and populations on smaller islands.

In addition, it was found that where there was more than one association for people who developed sight loss, these associations' services often overlapped. This suggested that there was competition between service providers and possibly a lack of joined-up provision of services.

Furthermore, as jurisdictions with older associations were found to be more likely to have overlapping services, it was inferred that associations often stuck to traditional roles rather than investigated the need to develop new roles. The inference that many traditional associations stuck with their traditional services was also supported by the observation that some of these services appeared to be confused.

It was also observed that smaller jurisdictions by population tended to have single associations and services, and these services tend to overlap with similar jurisdictions' services. For example, almost all associations provided Braille of existing documents and almost all services provided traditional mobility and rehabilitation training.

Where they did divert, jurisdictions only tended to deviate because their specialist services tended to be influenced by unique political or cultural backgrounds – such as New Zealand's services for indigenous populations. Similarly, Sweden emphasized political advocacy almost at the expense of more practical issues, as it attempted to promote its open, social democratic society. In relation to services specifically targeted at a growing population of OA or SOA, it was noticeable that few associations, or combined associations in the same jurisdiction, accounted for differentiated needs. For example, very few associations specialized in

assistive technology help or training for OA or SOA – most IT training was vocational.

In addition, although libraries existed in almost all jurisdictions, they were often Braille based and therefore were of little use to the majority of OA and SOA who do not read Braille. Few associations also supported transport and independent mobility, or advertised cultural services to promote well-being – and where cultural services existed, these tended to be for younger people, both adults and children. Similarly, although all associations had websites or other sources of information available there was very rarely any specialist service for older adults or an OAS “tab,” “hyperlink” or “button” - where there was a separate page for OA or SOA, there was rarely a specialized information source for older people.

Furthermore, where there was emphasis on services that could be especially helpful to OA and SOA, these services again tended to still be advertised as a means of supporting younger adults. For example:

advocacy was highly represented in many jurisdictions' services, however where advocacy was promoted it often focused on younger people's services or advocacy for the equal employment of those of working age. services related to health care tended to be advertised in a way that was general to all age groups, and did not appear to cover health issues specifically related to OA or SOA, such as dementia.

IT services were advertised in almost all jurisdictions, although none appeared to specialize in OAs, and the greater majority of IT support was designed for those in work or full-time education – although admittedly the largest demographic developing sight loss at present is working age adults. For instance, adverts and information pages on training in adaptive technologies around the house did not specialize in the needs of OA or SOA. services related to independent living skills were found to occasionally have an emphasis on OA, although again not exclusively and with little mention of SOA – a number of associations tended to deemphasise independent living for OA and SOA, and focused instead on residential care homes. mobility training and rehabilitation training still seemed to focus on the transition of people

losing their sight in working-age adult life training, younger adults and children. few associations advertised counselling, low vision or mental health services, and none could be found to mention specialized services for OA or SOA in these fields. although many associations provided information on benefits and state entitlements, these again tended to focus on benefits for those of working age or those in education. Little mention was made of pensions or other entitlements that OA and SOA would particularly need.

The hypothesis we tested in the third second based on these findings was as follows:

Apart from independent living skills, few small jurisdictions appear to have specialist services for OA, which largely ignores the changing demographics of a growing need for discrete OAS. In addition, services too often appear to be based on institutional tradition rather than targeted needs.

6 Analysis of the Third Phase

6.1 Analysis of the Unrefined Hypothesis

Academic literature analysed in the third phase attempted to reflect the jurisdictions sampled in the second phase, in order to maintain consistency of analysis. This data suggested that the hypothesis was largely supported by the academic literature. For instance, it was observed that studies of OA and SOA were relatively rare in *Western* jurisdictions – this classification includes Australia and New Zealand – as these jurisdictions tended to examine OA and SOA as a whole group no matter what their impairment. It was also observed the greater number of studies of sight loss were based in the Far East and the Indian Subcontinent, and were linked to the medical treatment of eye conditions.

In literature relating to the eight jurisdictions, the need for services specialising in the needs of OA and SOA as a distinct community tend not to differentiate according to traditional understandings of impairment. For example, a design-for-all Nordic liberal approach is advocated in Denmark³⁸. This approach recognises the particular issues OA and SOA often face, including falls and problems with memory, however the needs of low vision are

not discussed separately.

Where academic literature on OAS for people developing sight loss existed, however, it often identified a potential need for separate OAS for those developing sight losses. This literature also appeared to fall into categories mostly reflecting the five elements of inclusive capital: networking – this identified particular issues of well-being and mental health that were particular to people who develop sight loss³⁹; learning – re-education to be able to remain independent, especially through bonding in community spaces⁴⁰; Information – provision of information on services⁴¹, particularly technology^{42,43,44,45,46} were perhaps the most identified OAS in the literature, and showed how specialist information and technology services were needed; space & place – related to independent living in home and community and favoured the support of clients for issues relating to physical and mental health in old

³⁸ Bendixen, K. (2010). Perspective from Denmark: Design for All–Point of No Return!. In 3rd International Conference for Universal Design in Hamamatsu, Japan.

³⁹ Hong, T., Mitchell, P., Burlutsky, G., et. al. (2015). Visual impairment and depressive symptoms in an older Australian cohort: longitudinal findings from the blue mountains eye study. *British Journal of Ophthalmology*, 99(8), 1017-1021.

⁴⁰ Orellana, K., Manthorpe, J., & Tinker, A. (2018). Day centres for older people: a systematically conducted scoping review of literature about their benefits, purposes and how they are perceived. *Ageing & Society*, 1-32.

⁴¹ Bundgaard, C., Ekstrand, C., Hännikäinen, T., et. al. (January 2018). *Braille Teaching and Literacy: A Report for the European Blind Union and European Commission*. Copenhagen: Danish Association of the Blind and the International Council for Education of People with Visual Impairment

⁴² Scientific Foresight Unit. (January 2018). *Assistive technologies for people with disabilities*. Brussels: European Parliamentary Research Service.

⁴³ Leonard, V.K., Jacko, J.A., & Pizzimenti, J.J. (2005, October). An exploratory investigation of handheld computer interaction for older adults with visual impairments. In *Proceedings of the 7th international ACM SIGACCESS conference on Computers and accessibility* (pp. 12-19). ACM.

⁴⁴ Hodge, H., Carson, D., Carson, D., Newman, L., & Garrett, J. (2017). Using Internet technologies in rural communities to access services: The views of older people and service providers. *Journal of rural studies*, 54, 469-478.

⁴⁵ Keränen, N.S., Kangas, M., Immonen, M., et. al. (2017). Use of information and communication technologies among older people with and without frailty: a population-based survey. *Journal of medical Internet research*, 19(2).

⁴⁶ Okonji, P.E. (2018). Use of computer assistive technologies by older people with sight impairment: Perceived state of access and considerations for adoption. *British Journal of Visual Impairment*, 36(2), 128-142.

age^{47,48,49}; mobility – the importance of transport in, around and outside houses was similarly linked to health and well-being in OAS^{50,51,52}.

“These findings suggest a greater need for examining more robust specialist OAS in the areas of health screening, independent living, mental health and social/public transportation.”

However, there were complicating issues in the literature that need to be addressed, which included: older people surviving longer into old

age and developing sight loss and multiple impairments, suggesting a greater need for joined up services⁵³; issues of general health and psychological well-being are becoming more important, and the particular mental and physical issues related to OAS, sight loss needs greater appreciation^{54,55,56,57}; SOA will increasingly have other health issues related to their extended age that need addressing through joined-up services^{58,59}.

These findings suggest a greater need for examining more robust specialist OAS in the areas of health screening, independent living, mental health and social/public transportation.

⁴⁷ Mastroianni, J. C., Wray, M. A., Loomis, T. E., & Semple, V. A. (2016). Assessing Self-Rehabilitation Strategies for the Visually Impaired in Denmark. Worcester, Mass.: Worcester Polytechnic Institute.

⁴⁸ Crews, J. E. (2016). Falls among persons aged ≥ 65 years with and without severe vision impairment—United States, 2014. MMWR. Morbidity and mortality weekly report, 65.

⁴⁹ Barnett, A., Cerin, E., Zhang, C. J., et. al. (2016). Associations between the neighbourhood environment characteristics and physical activity in older adults with specific types of chronic conditions: the ALECS cross-sectional study. International Journal of Behavioral Nutrition and Physical Activity, 13(1), 53.

⁵⁰ Shrestha, B. P., Millonig, A., Hounsell, N. B., & McDonald, M. (2017). Review of public transport needs of older people in European context. Journal of population ageing, 10(4), 343-361.

⁵¹ Yeung, P., Towers, A., La Grow, S., Philipp, M., Alpass, F., & Stephens, C. (2015). Mobility, satisfaction with functional capacity and perceived quality of life (PQOL) in older persons with self-reported visual impairment: the pathway between ability to get around and PQOL. Disability and rehabilitation, 37(2), 113-120.

⁵² Turano, K. A., Broman, A. T., Bandeen-Roche, K., et. al. (2004). Association of visual field loss and mobility performance in older adults: Salisbury Eye Evaluation Study. Optometry and Vision Science, 81(5), 298-307.

⁵³ Pollock, A., Hazelton, C., Henderson, C. A., et. al. (2012). Interventions for age-related visual problems in

patients with stroke. Cochrane Database of Systematic Reviews, (3).

⁵⁴ Hong, T., Mitchell, P., Burlutsky, G., Samarawickrama, C., & Wang, J. J. (2014). Visual impairment and the incidence of falls and fractures among older people: longitudinal findings from the Blue Mountains Eye Study. Investigative ophthalmology & visual science, 55(11), 7589-7593.

⁵⁵ Menz, H. B., Lord, S. R., & Fitzpatrick, R. C. (2003). Age-related differences in walking stability. Age and ageing, 32(2), 137-142.

⁵⁶ Phoenix, C., Griffin, M., & Smith, B. (2015). Physical activity among older people with sight loss: a qualitative research study to inform policy and practice. Public health, 129(2), 124-130.

⁵⁷ Ribeiro, M. V. M. R., Júnior, H. R., Nogueira, H., et. al. (2015). Association between visual impairment and depression in the elderly: a systematic review. Arquivos brasileiros de oftalmologia, 78(3), 197-201.

⁵⁸ SenseAge. (no date). Stakeholders and policies having an impact at EU & National level on ageing persons with sensory impairments. European Association of Service Providers for Persons with Disabilities.

⁵⁹ Frost, H., Haw S. & Frank J. (2010). Promoting Health and Wellbeing in Later Life. Interventions in Primary Care and Community Settings. Edinburgh: Scottish Collaboration for Public Health Research and Policy.

7 Main Discussion and Recommendations

NB: In this final discussion, where I refer to OA alone, I am using this term to refer to both OA and SOA.

7.1 Discussion

In this final analysis, the hypothesis at the end of phase two is reintroduced, and discussed:

Apart from independent living skills, few small jurisdictions appear to have specialist services for OA, which largely ignores the changing demographics of a growing need for discrete OAS. In addition, services too often appear to be based on institutional tradition rather than targeted needs.

This hypothesis largely stands true.

Firstly, in order to understand these services, we also need to understand how associations have evolved, and how this evolution is slow to react to changing events in broader society. Many of the services that could be considered OAS – but are rarely labelled as expressly so – have largely evolved out of traditional services; services these associations have provided for decades if not centuries, and services that were suited to the social conditions of the twentieth century⁶⁰ – and in some cases the nineteenth century. These associations have done little to take into consideration modern social support and social services and the changing role of families.

Consequently, a model of service provision often still exists that assumes a family caregiver for older people gaining sight loss is constantly present, and an image of younger people with sight loss needing specialized educational and vocational support. Moreover, this service provision is still designed primarily to relieve financial poverty, and provide separate services for people who live in traditional extended or nuclear families. For example, Scotland has numerous associations, providing services for different elements of the community with sight loss: RB

evolved out of the Edinburgh Asylum, and specializes in support for adults with sight loss, as its original role was to support poorer children with sight loss in separate institutions where they could learn a trade; RNIBS provides support for adults and runs care homes, based on a model that evolved from the middle of the nineteenth century and the First World War, where people required separate literacy or were “blinded” service personnel; Guide Dogs primarily provides service animals and support services for adults with early sight loss, based on their history of similar support founded in the 1930s.

In this respect, OAS in the jurisdictions surveyed were not “nimble” enough to evolve to an increasingly older population who frequently spurn institutionalized service provision. Instead, OAS provision often overlaps and becomes confused, associations compete for clients and resources, and OA and their families often do not know who to turn to when they lose their sight.

Conversely, it can be argued that NCBI and other smaller jurisdictions with a single association have the advantage that they are closer to their clients and are a one-stop-shop for OAS. However, this advantage should not be taken for granted as there is still a need for joined-up services for those who do not fit other traditional models of OAS, and need to respond to the changing demographics of OA both nationally and regionally.

Secondly, the survey of associations shows these associations are largely unable to differentiate between different communities of people with vision loss, and the notion of multiple or dual impairment. For instance, many associations were developed on an understanding that service provision should be focused on people with early sight loss or whose main impairment was sight loss, and should receive lifelong institutional support for sight loss.

Subsequently, associations seem to find it harder to come to terms with the needs of sudden sight loss, multiple or dual

⁶⁰ Hayhoe, S. (2016). The epistemological model of disability, and its role in understanding passive exclusion in eighteenth & nineteenth century protestant

educational asylums. *International Journal of Christianity and Education*, 20(1), 49–66.; Hayhoe, S. (2015). *Philosophy as disability & exclusion*. Charlotte, NC: Information Age Publishing.

impairments – particularly where sight loss is the “lesser” impairment – sight loss in much later life and the mental health issues that arise as a result of sight loss. In these circumstances, it simply appears from the information provided by associations on their websites that OA are referred in this instance to the association of their “strongest” impairment. Given the increasing likelihood of OA having more than one impairment, the chance of OA not having all their needs supported is thus increased.

In addition, associations appear to find it hard to adjust to the changing nature of families’ and governments’ provision of support, and the changing model of nuclear and extended families decreasingly looking after relatives with sight loss; or, the needs of the remaining carer as the only care provider and needing support that could traditionally be provided by an extended family. For instance, a number of associations had little provision for single people who lived alone and could not travel to centres, or in some circumstances – although admittedly less frequently – associations relied on residential homes to support single OA with vision loss.

Thirdly, technological, information and literary provision in OAS often still referred to an older model of separate assistive technologies rather than inclusive technologies⁶¹, and Brailled/audio rather than largely electronic libraries. For instance, almost all associations had libraries whose core collections were recorded by sighted people or Braille. Very little of this literature was in digital format, although admittedly this proportion was growing.

Furthermore, it was found that services too often promoted technologies and well-being that were too often insensitive to the needs of OA, and particularly SOA who frequently did not take up services. Furthermore, in terms of well-being – both physical and mental – the consideration of specialist physical and mental health issues around multiple impairments and SOA’s social and cultural needs often seem to be unconsidered. Subsequently, there is also little emphasis on OAS that relate to practical

issues of independent living and re-education, as the SOA population increases and there is an emphasis on issues of general health and well-being.

“Firstly, in order to understand these services, we also need to understand how associations have evolved, and how this evolution is slow to react to changing events in broader society.”

Fourthly, local needs are very different from the needs of whole jurisdictions, and the need to differentiate services according to urban and rural populations in particular is rarely considered by associations. This was illustrated most clearly in the survey of associations who all but OAS for New Zealand’s first-nations population provided largely generic services, with little advertised consideration for mobility or care within the home. Admittedly, families were mentioned in the information provided by associations, however there was also little consideration given to the isolation of family members in geographically isolated areas.

Fifthly, there is little consideration given by associations or the academic literature to adults who do not fit the model of OA, and fall within a “gray area” of not working before retirement age or working after retirement age. For instance, with increasing numbers of OA undertaking paid and unpaid work there is little consideration given to supporting these adults after they pass the age of retirement. Similarly, associations infrequently considered adults who have been institutionalized or who left the labour market early because of ill health or early-retirement and may need OAS before they become OA.

⁶¹ Hayhoe, S. (2014). The need for inclusive accessible technologies for students with disabilities and learning difficulties. In, Burke, L., (ed.) Learning in a Digitalized

Age: Plugged in, Turned on, Totally Engaged? Melton, UK: John Catt Educational Publishing, pp. 257-274.

7.2 Recommendations for Future Action

Given these general findings, it appears that as NCBI moves into a life-course model its OAS providers need to consider moving beyond simply adapting its current services to considering future plans. In particular, it is advised that six issues need to be addressed in the mid to long term future:

1. There is a greater need for joined up services, and NCBI needs to consider formalizing its relationship with associations and agencies that provide parallel services for OA with more than one disability and health-care providers. NCBI and similar Irish agencies must also consider that clients' sight loss may not be their most significant impairment, and that the social debilitation from more pernicious impairments may have a greater effect on their well-being.
2. NCBI needs to re-consider how it provides OAS in rural areas, particularly those on its western coast and close to its border areas, where its clients' ability to travel independently are reduced. The social and cultural isolation that can exist in such areas is a particular threat to well-being and also effects the family life of the potential carers as well as the clients themselves.
3. NCBI needs to consider having a flexible age for OAS, that exists within a "gray area" of chronological age. As noted in the discussion, people may age or need OAS later or earlier than 65 years – and some people may also remain in the labour force after the age of retirement. Having too rigid an approach to OAS or working age adult services may exclude people who could otherwise benefit from such services.
4. NCBI will need to take account of the mental health issues of its increasing OA population. In particular, it needs to be understood there will be areas of stress that require more support, such as: the transition from being a sighted person to being a person with sight loss in older age, suffering ill physical health in older age, coming to terms with retirement and the social networks this provides or being largely alone in geographically isolated communities.
5. NCBI needs to investigate the lack of service take-up by older adults. As of yet, little literature from jurisdictions similar to Ireland highlight this lack OAS take-up. However, there appears to be a disparity between people recorded as having sight loss in the Irish Census data, and people who regularly take up services by NCBI. Considering some OA may not want services, it is possible some OA are not being referred to NCBI or are not aware of the services available. Therefore, information provision about OAS needs to be considered further.
6. Finally, a system of continual monitoring of the demographic changes in the OA population should be considered. At the moment, there is a "broad brush" approach to OAS, meaning that the same services are provided in large urban areas and rural areas, and inefficiencies are more likely. NCBI many need to consider providing differentiated services based on consistent and reliable data, and make its services evidence based.

“Given these general findings, it appears that as NCBI moves into a life-course model its OAS providers need to consider moving beyond simply adapting its current services to considering future plans.”



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