



Trinity College Dublin

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

**Trinity Centre
for Ageing and
Intellectual
Disability**

The Care of Older Adults with Intellectual Disabilities and Complex Age-Related Conditions



NDA

Údarás Náisiúnta Míchumais
National Disability Authority

December 2022

Copyright © Fintan Sheerin, Mary McCarron, Philip McCallion, Peter May, Maureen D'Eath, Georgia Lalor, Sandra Fleming. 2022

Funded and published by National Disability Authority, Dublin.

The authors are solely responsible for the content and the views expressed. The views and opinions expressed in this publication remain those of the authors and do not represent the views or opinions of the National Disability Authority

Acknowledgements

The authors would like to thank all the participants in this study who took the time to share their experiences in the focus groups, interviews and surveys. The information they provided and stories they shared are critical in making recommendations for changes within services for older people with intellectual disabilities.

We would also like to acknowledge the assistance of the service managers and facilitators who acted as gatekeepers for the data collection.

Finally, we would like to extend our gratitude to National Disability Authority (NDA) for funding this research and for their patience in allowing it to be completed during a challenging period.

About the authors

Dr Fintan Sheerin is an Associate Professor in Intellectual Disability Nursing at the School of Nursing and Midwifery, Trinity College Dublin.

Dr Sandra Fleming is an Assistant Professor in Intellectual Disability Nursing at the School of Nursing and Midwifery, Trinity College Dublin.

Prof Mary McCarron is Professor of Ageing and Intellectual Disabilities at the School of Nursing and Midwifery, Trinity College Dublin.

Prof Philip McCallion is Professor/Director at the School of Social Welfare, Temple School of Social Work, Temple University, Philadelphia.

Dr Peter May is a Research Assistant Professor at Trinity Centre for Health Policy and Management, Trinity College Dublin.

Georgia Lalor is a Researcher at the School of Nursing and Midwifery, Trinity College Dublin.

Dr Maureen D'Eath is a Postdoctoral Research Fellow at the School of Nursing and Midwifery, Trinity College Dublin.

Dr Amara Naseer and Eadaoin Foden also contributed to this research. Their work is gratefully acknowledged.

This report may be cited as: Sheerin F., Fleming, S., McCarron, M., McCallion, P., May, P., Lalor, G. and D'Eath, M. (2022). *The Care of Older Adults with Intellectual Disabilities and Complex Age-Related Conditions*. Funded by National Disability Authority. Dublin: Trinity College Dublin, School of Nursing and Midwifery.

Table of Contents

Acknowledgements.....	2
Table of Contents	3
List of Tables	5
List of Figures	5
Abbreviations	6
Executive summary.....	7
Introduction	7
Methods	9
Findings.....	11
Discussion	16
Recommendations.....	20
Introduction.....	26
Project aims	26
Objectives.....	26
Background	26
Chapter 1: Current State of Evidence	28
Models of care.....	28
Complex age-related issues.....	40
Measuring outcomes of service	51
Challenges to service provision.....	56
Conclusion	60
Chapter 2: Overview of Fieldwork.....	62
Introduction	62
Study aim and objectives	62
Research design	62
Data collection: phase 1	62
Data collection: phase 2	65
Data analysis	67

Ethical considerations.....	68
Sample profile.....	69
Chapter 3: Findings: Approaches to services.....	71
Introduction.....	71
Specialist service approach.....	73
Nurse-led approaches.....	74
Health and social care approaches.....	76
Flexibility across service approaches.....	78
Key principles of service provision.....	79
Chapter 4: Findings: Providing services to meet older individuals' needs	88
Changing needs of the population as they age.....	88
Dementia.....	88
Retirement.....	90
End of life.....	92
Chapter 5: Findings: Responding to individuals' needs.....	96
Listening to the older person and their family.....	96
The service environment.....	99
Standards and regulations.....	104
Resources.....	105
Outcomes and quality of life.....	111
Chapter 6: Discussion and recommendations.....	116
Service approaches.....	116
Current and future needs.....	121
Meeting future need.....	123
Conclusions.....	126
Limitations.....	127
Recommendations.....	129
References.....	134
Appendix.....	155
Survey findings.....	155

List of Tables

Table 1: Housing types	43
Table 2: Details of participants/respondents across the study	69
Table 3: Service approaches identified across survey respondent settings	71
Table 4: Congregated setting types identified by survey respondents	73
Table 5: Significant age-related concerns for older adults in services	88

List of Figures

Figure 1: Components of a model of care for older people with intellectual disabilities and age-related complex needs	29
Figure 2: South Australian Intellectual Disability Health Service Model of Care 2020	37
Figure 3: Scope of age-related needs of older people with intellectual disabilities	120

Abbreviations

COVID-19	Coronavirus Disease 19
DPER	Department of Public Expenditure and Reform
GS	Generic Services
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
IDS-TILDA	Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing
NDA	National Disability Authority
OTH	Other
PCC	Person-centred Care
PCP	Person-centred Planning
RNID	Registered Nurse in Intellectual Disability
SS	Specialist services
TCAID	Trinity Centre for Ageing and Intellectual Disability
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Executive summary

Introduction

People with intellectual disabilities are living longer with increasing numbers advancing into older age (Egan et al., 2022). This is directly related to improvements in health care and supports but it carries with it challenges, for the growth of services in Ireland was predicated on meeting the needs of a population who would have a shorter lifespan. Recent decades have seen a movement from a relatively predictable demographic to one that is increasingly diverse and with needs that are varied and complex (McCausland et al., 2021a; Hatzidimitriadou & Milne, 2005). The absence of a concomitant change in the national approach to service provision and the funding model therein, has meant that, as people with intellectual disabilities have aged, services have found it difficult to respond to their needs and wishes. It is in this context that, in 2019, the National Disability Authority commissioned the Trinity Centre for Ageing and Intellectual Disability (TCAID) to carry out research on the care of older adults with complex age-related conditions.

The aim of this research was to examine the care and service options for older adults with intellectual disabilities and complex age-related conditions across a number of service settings: intellectual disability services which provided specific ageing pathways; intellectual disability services that offered a generic pathway; and nursing homes. For the purposes of this study, an older adult with intellectual disabilities is defined as a person who is 40 years of age or older. This is in line with the definition employed for the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (McCarron et al., 2017b)

The occurrence of COVID-19 at the initial stage of this research, and the effect of that on nursing homes led to an ethically-based decision being made not to burden those settings with the demands of this study. The result is that their voices are not present in this study.

This research presents a detailed review of the evidence base pertaining to the care and support of older adults with intellectual disabilities and complex age-related conditions. It considerably adds to that through the generation of evidence on the models of care that are currently guiding services and the identification of key shortcomings in the resourcing of services as they look to meeting individuals' needs in the future.

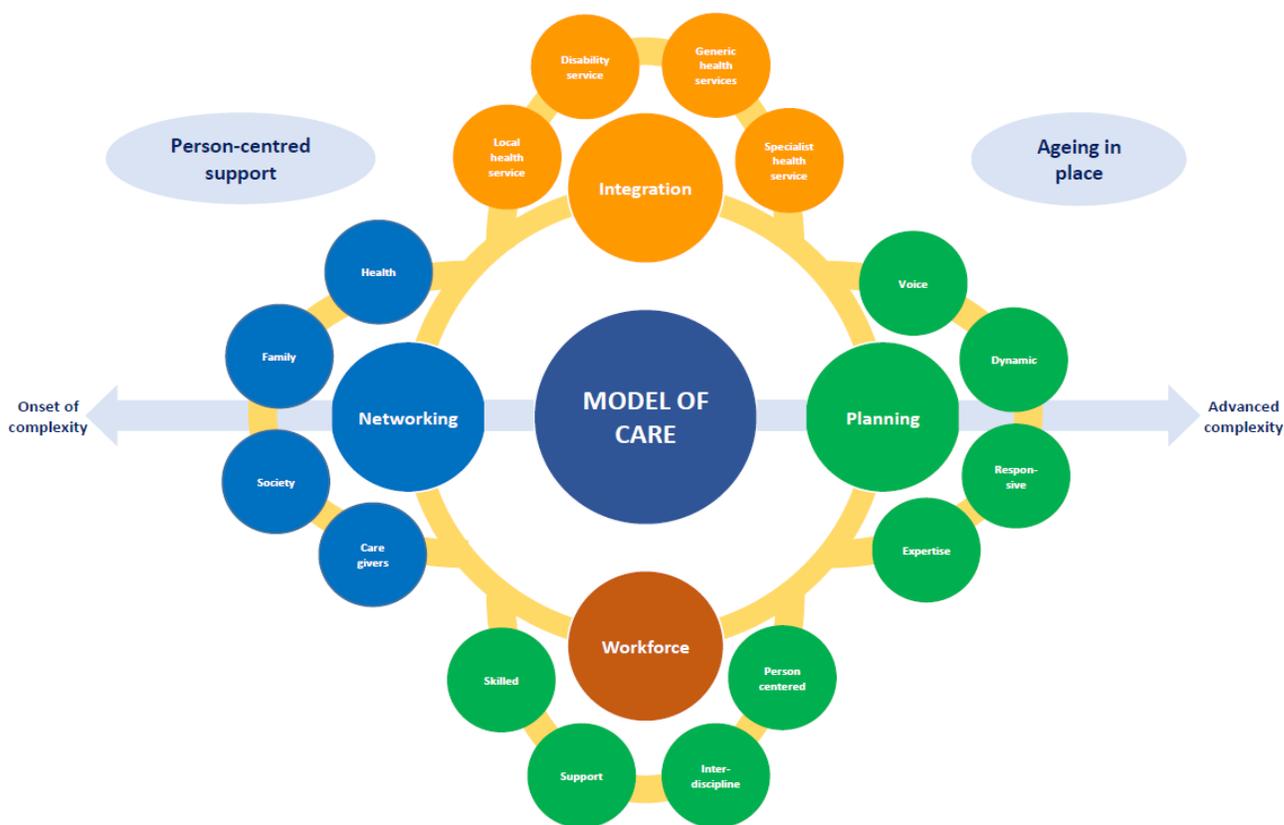
The findings are intended to guide policymakers and service providers in relation to various models of service and supports, including, in particular, the HSE, the

Department of Health and the Department of Public Expenditure and Reform (DPER).

The report is divided into six chapters; the first sets the context by presenting the key literature on the care of older adults with intellectual disabilities and complex age-related needs and the second details the methodology and profile of participants. The following three chapters each examine a particular theme derived from topics addressed across the various datasets whilst the final chapter discusses the findings in relation to existing literature, making recommendations based on these findings.

As noted in the figure below, based upon a systematic review (Sheerin et al., 2021a), several recurrent concepts seen as central to the provision of service and care for older people with intellectual disabilities were identified, including integration, planning, workforce, and networking, all underpinned by principles of ageing in place and person-centred planning (PCP).

Components of a model of care for older people with intellectual disabilities and age-related complex needs



Source: (Sheerin 2021, based on HSE, 2016; Genio, 2016)

The systematic review and other literature reviews undertaken by the team established that the main issues affecting older people with intellectual disabilities were physical, psychological, and social issues, as well as the challenges to providing care. Responding to the complex needs of older people with intellectual disabilities was established as a challenge, with the current response to care characterised by a lack of future planning, limited resources and funding and a care system that is fragmented, with ageing, intellectual disability and dementia services often working in silos. To address these gaps in service provision, an argument is made that there is an urgent need for a comprehensive and integrated approach to care. An integrated care model requires proactive planning, connected services, a multidisciplinary workforce, and support for familial and social networks.

Methods

This was a descriptive mixed methods design study, using two phases of data collection. Phase 1 of data collection sought to explore the perspectives of senior staff and managers in intellectual disability services and nursing homes on:

- Current models of care in specialist and non-specialist settings
- Factors influencing decision-making on care needs
- Expected future need
- Experiences of supporting 'transitions' (i.e., geographical, social, health and activity or work),
- Current outcomes and how these outcomes affect quality of life in the different settings.

Data was collected using focus groups, interviews, and a survey questionnaire.

Phase 2 explored the experiences and outcomes for support staff, older people with intellectual disabilities, and family members when faced with age-related challenges including their experiences of navigating health care transitions, in tandem with social, geographical, and activity or work transitions. Data were collected during this phase using focus groups and interviews.

The audio recordings from focus groups and interviews were transcribed verbatim by a professional company, and the researchers reviewed these written transcripts for accuracy. The qualitative data was analysed using the reflexive thematic analysis approach proposed by Braun and Clarke (2006) whereby data was coded, and over-arching themes were identified. The research team discussed how the themes fit with theoretical perspectives and current policy as identified in the literature review regarding current practice and the processes which drive it, current and planned provision for ageing, and perceived future need. Themes were also considered in the context of the IDS-TILDA dataset.

The main overarching themes identified in the qualitative data were:

- Approaches to service
- Providing service to meet individuals needs
- Responding to individuals' needs

Analysis of quantitative data, obtained through the two online questionnaires, was conducted using SPSS Version 21 (IBM Corporation 2012). Statistical tests were performed to establish whether statistically significant differences between two overarching categories of service approaches (those with specific ageing pathways and those without) were present in the data. These were explored using Fisher's Exact Test but no statistically significant differences ($p < 0.005$) were identified in respect of a range of complex ageing conditions. Services falling within each category described a mix of effective and limited or non-existent pathways. Thus, for example, 66.7% ($n=10$) of 'specialist' services indicated that they had an effective pathway for dementia care, with 33.3% ($n=5$) stating that they did not. Amongst 'non-specialist' services, 40% ($n=4$) indicated that they had an effective dementia pathway and 60% ($n=6$) did not. As no significant differences were identified, descriptive statistics were generated first to describe the demographic profile of individuals residing in intellectual disability care services for older people intellectual and to develop an overall picture of current service approaches and models of care for older people with intellectual disabilities and complex age-related needs, including the financial implications of complex age-related care needs for services. Qualitative data within the surveys were coded thematically to identify themes that would help to uncover valuable insights and to support the interpretation of the quantitative data.

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin. All researchers involved in the study were bound by and adhered to the national and international codes of good practice in research, and by professional standards within their disciplines. All participants received information sheets that outlined the study procedures, the risks and benefits associated with participating, and the protocols regarding confidentiality and voluntary participation. For the online survey, participants were asked to read information on the study and give informed consent before starting the survey. Before each focus group and interview, written or verbal consent was obtained from participants. Where verbal consent was given, this formed part of the audio recording. To protect the confidentiality of participants, focus group and interview audio files were uploaded onto a password protected folder on a double-encrypted, password-protected TCAID computer and deleted from the audio recorders. The audio files were transcribed by a professional transcription company that had signed a Data Processing Agreement with the Data Controller for this study. Once transcribed, the audio recordings were deleted, and the transcripts were stored on the double encrypted TCAID computer available only to the researchers. During transcription, all identifying information was removed, and participant names were pseudonymised.

Details of participants/respondents across the study

Mode of Data Collection	Participants	No. of Participants
Focus groups (n=8)	Service managers	
	<i>Specialist service (SS)</i>	8
	<i>Generalist service (GS)</i>	8
	Direct care staff	
	<i>Specialist service (SS)</i>	5
	<i>Generalist service (GS)</i>	4
Individual interviews (n=13)	Service manager (SS)	1
	Older person with intellectual disability	7
	Family of older person receiving services	2
	Family of deceased older person	3
Group interviews (n=3)	Joint older persons with intellectual disability	2
	Joint family (Fam) and or older person (OP) with intellectual disability	3 (Fam) 2 (OP)
Main survey (n=32)	Senior managers from adult intellectual disability services	32
Follow-on costings survey (n=2)	Senior managers from adult intellectual disability services	2
Total No. Participants		79

As noted, the occurrence of the COVID-19 pandemic during the timescale of this research resulted in significant challenges, not least in engaging with the nursing home sector where COVID-19 had a very significant impact. As a result, and despite repeated efforts over a protracted period, it was not possible to access nursing home input in the study. The findings, therefore, represent the perspectives of managers and staff from intellectual disability service providers and of people/family members of people who received care in such services.

Findings

The findings are presented below under the three emergent themes.

Theme 1: Approaches to services

Survey respondents identified their approaches to service provision under the headings which differed in name and number from those identified in the focus groups (the *specialist service approach*, the *nurse-led approach* and the *health and social care approach*), but the details from those discussions suggest that the *medical* and *biopsychosocial models* align with the *nurse-led* and *health and social care*

approaches, respectively, with the *Living Well with Dementia* aligning with the *specialist service* approach. The medical and social models, which have been the focus of much discourse over the past decades have clearly influenced these three approaches.

It is noticeable that, despite their alignment to particular service approaches, all services employed a mix of congregated settings, with people living in individual homes in the community, at home with families, in nursing homes (intellectual disability and mainstream) and in specialised dementia accommodation. The first approach to service, the specialist approach, was described as one that is largely focused on meeting the needs of older individuals with intellectual disabilities with specific age-related complex concerns. Provision of specialist service was also seen to be something that was not location or unit-specific, but which could potentially be put in place, in the older person's current living space. Nurse-led approaches prevailed in intellectual disability services for many decades but were questioned in the light of moves to community living, as the pendulum swung away from a medical model towards a social one. The health-related complexity now being seen early and late in the lives of older people with intellectual disabilities have necessitated approaches combining health and social care. Across all the service types, the social model was most frequently reported in the survey as one used to guide services (all: 75%, n=24; Specialist Services: 81.3%, n=13; Generic Services: 90%, n=9; Other: 33.3%, n=2). Some focus group participants saw nursing as a manifestation of the 'medical model' and, in the case of one service, they made a decision to move away from a nurse-led approach towards one grounded in social care. In an appropriate environmental setting, some social care staff were confidently supporting service users with a myriad of complex conditions to ensure that service users could live in their homes for as long as possible. However, other services brought together a variety of components to create an eclectic approach to care. Despite the conceptualisation of services being categorisable under 'ageing specific' and 'ageing non-specific' labels, it was very apparent that most organisations actually met the needs of their ageing service users in a variety of settings: generic areas without a specific focus on age; homes in the community; campus settings; and specialist areas centred on service older people.

Throughout the focus groups, interviews and main survey, perspectives were obtained on the aspects of components of services that participants considered integral to providing services to older people with intellectual disabilities. In the survey, participants were asked to rank key aspects and it is notable that there was no difference in responses and views across nominally specialist and non-specialist services. All ranked person-centred support, ageing in place, responsiveness to the person's needs and proactive future planning highly. Less highly ranked components were having skilled staff, effective links to generic and specialist health services and family involvement. It is notable that very few ranked the physical environment at

all, which is an interesting point as many focus group and interview participants considered this to be an important factor in meeting service needs.

It was evident that there were no clear service types or approaches manifest in the services that took part in this study. Whilst some services may have had specific older person pathways, often linked to the development of health-related complexities such as dementia, they also had generic paths through which many older people will receive service. Similarly, the other services had some examples of specific older person services and a range of other more generic ones. Participants in all of these aspired to the key older person service principles of ageing in place and person-centred support but these were mediated through service approaches that were often an eclectic mix of health and social care. The ability to realise an individualised service that met the older person's needs and desires was, however, seriously challenged by resource limitations and difficulties in accessing mainstream health and social care services. Despite this, all were committed to ensuring that they could provide the best quality service to meet these older individuals' needs as they developed.

Theme 2: Providing services to meet older individuals' needs.

As people with intellectual disabilities live longer, organisations have had to respond by developing services to meet issues which may arise as a result of this. These may relate to ageing itself or to specific conditions that tend to become more prevalent in older age. The main areas of changing need that were identified in the focus groups and interviews related to dementia and end of life, but a number of others, including behaviour, mental health, frailty, multi-morbidity and polypharmacy were also briefly noted and some of these also arose in the surveys. A majority of respondents noted that there are pathways in place for dementia, mental health concerns and behavioural concerns, with a minority indicating that effective formal pathways are in place to address obesity (22.6%; n=7), cancer (32.3%; n=10), multi-morbidity (32.3%; n=10), frailty (35.5%; n=11) and chronic illness (35.5%; n=11). One key area of particular concern was dementia. It was noted that, as the older person transitioned through different stages of the disease, their needs changed too. Participants highlighted the importance of support needs being tailored to meeting those developing needs. The multidisciplinary approach was considered to be of particular significance in addressing these, as it allowed different skillsets to be called on to respond in a coordinated and individualised manner. The main concerns appeared to be related to the effect on other people living in the house, the need to buy in health services and the presence of non-regular staff in the house setting. This could be managed well, through proper planning. When this was present, the outcomes were reported as invariably positive.

Whereas service managers largely focused on health and structural service issues, such as dementia, end of life care and advanced planning, direct care staff, family members and older people themselves also identified the importance of retirement in the lives of older people with intellectual disabilities. It was noted that the traditional service structure meant that older people usually had to continue taking part in day services, requiring them to rise early in the morning.

Ageing, irrespective of longevity, leads inevitably towards death at some point, so it is not surprising that advanced planning and end of life support were identified as important in any discussion of service provision for older people with intellectual disabilities. Most survey respondents (83.3%; n=25) reported that their services engaged in bereavement and end of life preparations, to some degree, with the family, friends and housemates of older people, as well as engaging in end of life (85.7%; n=24) and advanced care planning (78.5%; n=25) conversations with some or all older adults in their service. It was noted that there is a need for staff and others to be comfortable talking about death and decisions around end of life.

Theme 3: Responding to individuals' needs

Participants spoke of a number of key issues that impacted on their ability to enact an appropriate approach to service for older people with intellectual disabilities. Adherence to a given service model was noted to be determined by a number of factors, including the environment, standards and regulations and resources. As previously noted, services need to be agile if they are to be able to respond to the changing needs of the older person. This presented a challenge to identifying the care pathway for the individual and the location in which that service could be provided. Funding was central to these factors, and the rigid nature of funding models was particularly problematic. Capital funding was noted to be crucial as it determined whether the environment could be adapted to respond to both individuals' needs and safety and standards.

It was clear that, in planning for the journey through old age, associated illness and onwards towards death, participants placed a significant emphasis on listening to the voices of the older people and of those around them. Their input was considered crucial to building a service that responded, not just to need but also to personal wishes.

The service environment was reported as particularly important when seeking to meet the changing needs of older people with intellectual disabilities and with a requirement to be modifiable in order to be able to adequately support the individual needs of the older person. This raised questions regarding the potential for reasonable modifications or retrofitting to be carried out. Thus, the pragmatic and financial realities of the service environment may be a determinant in where

the older person may be accommodated. It is clear that, while ageing in place is the 'gold standard', it may not be achievable, and service may sometimes have to be provided in a non-optimal environment.

It was noted that funding is provided at a defined and static level which does not take account of changing complexity, new compliance needs, or individuals' wishes. The cost of providing a service for those older people living in a particular environment is met by *congregating* the monies provided for those people's service. This seriously limited the possibility of individualised services responses.

Although participants were positive about the move to community living over recent decades, it was noted that the closure of larger or campus-based accommodation has reduced the options available to services as their service users age with complex needs. Some considered that the ultimate answer for some people may need to be in some form of congregated setting and some considered these to be more modifiable than community house settings. The uncertainty surrounding accommodation and service locations may contribute to increasing the number of transitions that older people with intellectual disabilities experience.

The development of national standards for disability services, overseen by the Health Information and Quality Authority (HIQA) in 2013, was an important milestone in service provision and these standards have had a significant influence on the lives of people with intellectual disabilities. The requirement to meet standards has resulted in environmental modifications being mandated by HIQA though these have not always been completed as the funding required for those modifications was significant. The result was that in such cases, the older people had to leave their homes. In the absence of extra funding to meet these needs, there is often a 'balancing game' between meeting regulatory standards-related requirements and funding-driven policy requirements.

Throughout this study, respondents and participants repeatedly referred to the difficulties of achieving individually determined, person-focused supports for people with intellectual disabilities as they aged, and needs became more complex. Whilst the fundamental issue was often identified as being one of funding, particularly the challenge of accessing responsive funding from the Health Service Executive, this was usually manifested in the availability of the practical resources required to run a service, particularly accommodation, staffing, healthcare and health or supportive equipment. A consequence of inadequate staffing may be that a person cannot continue to be cared for in their own home and may need to be transferred to other generic locations, such as nursing homes.

Just over 70% (70.4%, n=19) of survey respondents reported that they had encountered examples of not having the staffing skill mix in place appropriate to meet a person's need. Whereas there is a need for an appropriate configuration of staff and staff skill mix to support the person as they age, the associated cost of such resources was a concern for some participants. Education and upskilling opportunities for all staff was seen as being essential.

The issue of quality, as an outcome of care, arose in a number of the sibling interviews. These family members repeatedly spoke of the relationship between certain factors and quality of care, namely, staffing levels, staff knowledge and skills in respect of intellectual disability and the stability and continuity of the workforce in living environments. Family members, more generally, wanted the service given to their family member to reflect the changes which they may experience as they age including attendance at day service and participation in activities. Likewise, the vast majority (93.1%; n=27) of respondents reported that quality of life (QOL) outcomes change as older people with intellectual disabilities and complex age-related needs develop. Such changes, it was said, should be seen as a normal part of ageing.

Discussion

The proportion of older people in the services is increasing, with the older age cohort already presenting as the dominant one in 28% of services surveyed or being expected to be so within the next 5 years. The expectation is that it will rise rapidly over the next five years in other services too. Furthermore, almost 40% indicated that they expected that the share of service users in this age group will rise rapidly within the next 5 years and, although just over half the services were reported to have the resources "to some extent" to meet the needs of older people with intellectual disabilities as they age, less than 10% reported being able to fully meet these needs. Respondents overwhelmingly reported (93.3%, n=28) that complex age-related issues have implications for provision of service to older people with intellectual disabilities in their service

It is, therefore, not surprising that respondents highlighted the relevance of age-related issues to services. The increase in life expectancy has brought a new focus on transitions in later life (Egan et al., 2022) and the need for services to be reconfigured accordingly. The National Positive Ageing Strategy (Department of Health, 2013) provided a framework for addressing age-related policy and service at a national level, but the impact of this in the lives of older people with intellectual disabilities has progressed more slowly. The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (McCarron et al., 2017b) and the identification of Positive Ageing Indicators for people with intellectual

disabilities (Healthy and Positive Ageing Initiative, 2018) have been important milestones in redressing this. Furthermore, the recent Disability Capacity Review to 2032 (Department of Health, 2021a), may provide an important platform for the resourcing service supports for people with intellectual disabilities as they age. Such developments have increased awareness of the need to support healthy ageing for people with intellectual disabilities, and to embed the principles of positive ageing in intellectual disability services. It is not surprising, therefore, that key concepts such as ageing in place, person-centred support, responsiveness to older persons' needs and proactive future planning were highlighted by participants in this study. There was also widespread consensus that quality of life outcomes change as people with intellectual disabilities age, just as they do for those in the general population, and these require a level of agility on the part of services to facilitate individually-determined responses, such as having a slower pace of life and daytime activities that differ from the day centre model that has been the cornerstone of service provision for adults with intellectual disabilities. Whereas social engagement is considered to be a mainstay of service provision under New Directions (HSE, 2015), it should be noted that quality of life for some people, as they age, may actually involve a narrower range of community engagement and that this may, in turn, require more supports.

Whereas a commitment to the provision of an individualised service to meet the needs of people as they age was evident, service managers, direct care staff and family members emphasised the considerable challenges to actually achieving this for those in receipt of service. Central to this is absence of a formal model of service pertaining to ageing and the scarcity of key resources, particularly funding. This hampered the agile response that is often needed to appropriately respond to needs that may change very rapidly. Aspects of staffing were also identified as a constraining challenge, particularly as pertaining to the recruitment and retainment of skilled personnel.

The traditional distinction between the medical and the social model, discussed by the participants, may reflect an emphasis that has not served people with intellectual disabilities well. This emphasis focuses on the professions rather than on the individuals themselves and the people (staff and family) who support the lives of people with intellectual disabilities and on the values that underpin their support, namely person-centredness, ageing in place and self-determination. This has also diverted attention away from what has not yet been achieved in respect of decongregation, namely the challenges of accessing quality healthcare for people with intellectual disabilities as they age, on the same basis as the general population.

It must be acknowledged that, despite the challenges outlined above, participants in this study, concurred that, in line with Article 19 of the UNCRPD (United Nations, 2006), older people with intellectual disabilities should have person-centred support, provided preferably, in their own homes (Department of Health, 2020b; Chapman et al., 2018; Patti et al., 2010). Participants also agreed that such support should be dynamic in nature, and responsive to emerging age-related complexity (HSE, 2021; Schepens et al., 2019; New South Wales Ministry of Health, 2012; McCarron et al., 2010a). Increasing age may add to the complexity of the transitions experienced by older people with intellectual disabilities and person-centred future planning can support and prepare older people with intellectual disabilities for transitions that reflect and respect the preferences of the individual (Strnadová, 2019). Instead, many such transitions are reactive, made in response to a crisis and without the benefit of proactive planning (Strnadová, 2019). It was abundantly clear that there is a need for a more properly structured service model, focused on healthy ageing among people with intellectual disabilities, and with dedicated funding.

A majority of survey respondents identified dementia as the most significant challenge to meeting the needs of older adults with intellectual disabilities in their service. Similar issues were raised by participants and respondents in respect of end of life care. There was unanimity in the view that older people should be supported to die at home whenever possible, but that this could only be achieved with proper planning and flexible resources (Todd et al., 2020). The findings of this study, though, provide examples of extraordinary efforts on the part of individual teams and staff members, to support those in their care to die at home. There were also exemplars of the individual being involved in end of life care decisions and planning. Whilst it is noted that family were involved and supported, a number of family members did not feel supported during times of bereavement. Another area of need that was raised in this study was not one related to health or illness, but focused instead on the patterns of life for older people with intellectual disabilities, particularly their need or desire to step back from day services or intensive activities.

The issue of resources is a repeating theme in the findings and underpins so many aspects of service provision, with key healthy ageing principles largely unachievable in the absence of responsive funding, flexible staffing models, suitable accommodation and access to equipment and other resources. The findings reflect Northway et al. (2017)'s assertion that a strong body of evidence exists to indicate that the key determinants of whether people with intellectual disabilities can age in place are environmental issues and staff training. If decisions regarding support for people with intellectual disabilities are to be person-centred, then they must be

guided by the person's needs and wishes and framed within the rights conferred by the UNCRPD. Such decisions must also take into account the fact that needs will change over time and not always in accordance to a predictable pattern. Forward planning is therefore vital if the person is to experience consistency, responsivity and seamlessness in the service they receive and is best achieved through the use of a structured service model which can facilitate timely funding and resource responses.

If person-centred supports are to be provided for older people with intellectual disabilities, it is imperative that adequate resources are made available. Staffing levels, staff mix, and the timely provision of equipment were all reported to impact on the ability of services to respond to the changing and, often complex, needs of people with intellectual disabilities as they age. Many of the challenges are underpinned by inadequate funding and a funding model that is not sensitive to increased need at the level of the individual. Staffing levels, skill mix and staff willingness (or otherwise) to take on roles that are traditionally beyond one's boundaries may also be a significant barrier to meeting older persons' needs. One solution to recruitment challenges is the upskilling of other staff, such that they will be able to undertake some health-related activities.

A variety of service approaches have been reported in this study, spanning the health-social continuum. The absence of any consistent approach to supporting healthy ageing across or within services suggests that the experience of the older person with intellectual disabilities is predicated, with a certain level of chance, upon the region in which they are located and, consequently, on the service with which they are registered. There is clearly no national model or strategic approach to providing older age intellectual disability service to those who receive service. Despite the *trojan* efforts of services, services staff and families, a quality responsive service cannot be achieved in the absence of a national plan and in the context of an inflexible funding model that did not have its foundation in person-centeredness.

The services systems, the workforce and the funding mechanisms currently available for people who are ageing with intellectual disabilities were all developed at a different time and to achieve different goals. It is important to remember that living to old age for people with intellectual disabilities is still a relatively new phenomenon, and that when community-based options were developed, they were largely focused on moving young adults out of institutions and campuses and into jobs, community engagement and use of public transportation. The view of health and healthcare was grounded in a desire to break away from medical models and to celebrate opportunities to be healthy rather than focused on illness and health needs. Much of this is still true as people age but plans are not in place to resource

ageing needs, work and day programming options have not been preparing for retirement and there is little realisation that older age is often associated with increasing chronic conditions, some of which may be more varied for people with intellectual disabilities and needing at least some specialised supports (McCallion & Jokinen, 2017; Janicki et al., 2005).

This study set out to examine the care/service options for older adults with intellectual disabilities and complex age-related needs. A variety of approaches to providing service were identified, but few of these could be considered to be 'structured or planned approaches. Moreover, none were underpinned by an ageing 'service model' but, rather, represented modifications of individual intellectual disability providers' services, drawing on the standard funding allocation received from the HSE. There was, however, no dedicated funding to support services' responses to the changing needs of their older service recipients. These changing needs, which relate to people with intellectual disabilities living into older age, and the anticipated costs of providing service to meet these were identified by the Irish State as far back as 2012 in the Value for Money and Policy Review of Disability Services (Department of Health, 2012), but this does not appear to have resulted in significant change, with the inadequacy of the current funding model strongly criticised by the National Federation of Voluntary Bodies (NFVB) seven years later (NFVB, 2019). The outcomes of this study support these concerns. That so many positive outcomes are being achieved for many older people is a credit to the services, their staff and family carers. This is, however, a wholly unsustainable approach to meeting the needs of older Irish people with intellectual disabilities.

Recommendations

Based on the findings of this research, and bearing in mind recommendations made by participants and the limitations outlined above, four main strategies are recommended for achieving positive outcomes for older people with intellectual disabilities. These are underpinned by the principles and articles of the UNCRPD. When Ireland ratified the UNCRPD in 2018, the State undertook to ensure the full realisation of the human rights and fundamental freedoms of people with disabilities. This can only be achieved if service outcomes are closely aligned to the commitments made on ratification of the Convention.

Develop a national model of service for healthy ageing among people with intellectual disabilities

Healthy and positive ageing has been a central principle of Irish government policy for the past decade, and has been progressed in mainstream society through the Healthy Ireland initiative. Its realisation has not been seen on an equal basis among older people with intellectual disabilities, as called for in Article 25 of the

Convention, primarily due to the absence of a national model of healthy ageing for this cohort of the population.

- Intellectual disability policy should give full consideration to the needs and desires of people with intellectual disabilities as they age. This is particularly pertinent as we are likely to see increasing numbers of people living into old age and this will bring with it greater demands on services that are unable to meet current need.
- Any new model of service should be enacted consistently across the Irish state such that older people with intellectual disabilities will receive quality services irrespective of location or affiliation to specific service agencies. To be effective, the model of service will require investment and defined funding lines, separate to those which currently are in place. It is recommended that the HSE set up a national steering group to oversee the development of the new model and enactment of this new model of service.
- In keeping with the HSE policy of decongregation that has seen many positive changes in the living situations of people with intellectual disabilities, the new service model should address the historical gap that has developed between intellectual disability agencies and mainstream health and social care providers, to ensure that mainstream services are accessible to older people with intellectual disabilities on an equal basis to others in society.
- The South Australian model, referred to in text, notes the importance of intersectoral collaboration between mainstream ageing and intellectual disability sectors. The new model of service for older people with intellectual disabilities should ensure that there are clear pathways of care and support for older people with intellectual disabilities, with integration and networking across all relevant sectors.
- If a new national model of service for healthy ageing is to be developed, it is imperative that there be a rethinking and restructuring of the current funding model.

Reconfigure intellectual disability services to meet age-related needs

The development of services for people with intellectual disabilities in Ireland has been somewhat fragmented, with the State only becoming directly involved in service provision at a late stage. Thus, voluntary and other services progressed along a generic structure which had residential, day service and some other activational components; HSE-led intellectual disability services adopted this structure too. The funding model that underpinned these services reflected their congregated nature and the fact that most people with intellectual disabilities were not expected to live into older age. Whilst services have responded to the fact that

people are living longer lives and have been innovative in trying to respond to the needs and desires of older people with intellectual disabilities, they have often been stymied by the unavailability of resources.

- Given that some service approaches to meeting older persons' needs have evolved in a piece-meal manner, with no clearly planned approach, efforts are needed to identify and enact evidence-based responses that can optimise positive outcomes.
- Specialist ageing service pathways will need to be developed to support the needs of older people whose complex needs cannot be met in their own home. Pathways should be prospective to ensure that there is advanced planning. Examples of successful pathways have been introduced in some intellectual disability services for people who, for example, need palliative support.
- Resources will need to be invested in supporting retirement opportunities, meeting more specialised health needs, environmental modifications and new staffing patterns to sustain ageing in place opportunities to live one's last days as one wishes (Ferretti et al., 2022).
- Whilst the policy of decongregation has been a positive one which has resulted in quality outcomes for many people with intellectual disabilities, there is a need to consider the potential for developing specialist services for people with complex age-related needs which cannot be met in the person's own home. Thus, a forum should be set up to explore how the foundational principles of Time to Move on from Congregated Settings can be applied to re-congregated service structures such as specialist dementia facilities or generic nursing homes.
- Nursing homes were considered to be a final option by many participants in this study. If, however, nursing homes are to be used, there is a need to resource new models of collaboration between nursing homes, intellectual disability service providers and families to preserve the lives desired by people with intellectual disabilities as they age. Such developments should be supported and informed by further research both on the experiences of nursing homes in caring for people with intellectual disabilities and the experiences of older people with intellectual disabilities and their family members of nursing home care.

Develop clear resource models that can respond in a timely manner to the changing needs of older people with intellectual disabilities

Participants and respondents in this study highlighted how important it is to have a resource model that can respond to the changing needs of people with intellectual

disabilities as they age. These changes may result in a requirement for modifications to the built environment and specialised equipment. The move to community living, whilst positive, has seen services renting or purchasing accommodation that may not be modifiable as the needs of the occupants change. The inability to retrofit or change the living space, due to rental agreements or lack of funding, was a key factor in deciding whether a person with intellectual disabilities could age in place.

- There is a requirement for new funding models that will allow for resources to be made available to older persons, when needed, to provide individualised and person-centred support. Processes should be put in place to ensure that such funding can be built into the person's ageing plan and be accessed when needed. Consideration should also be given to the inclusion of an oversight process that could monitor value for money, *vis à vis*, meaningful outcomes for the older person.
- More rapid introduction of personalised budgets, with a broad purchasing scope could support the configuration of individualised services around older persons' needs and wishes (Benoot et al., 2022).
- In line with recommendations regarding housing and built environment, it is vital that the purchase of community-based accommodation for people with intellectual disabilities should be underpinned by the UNCRPD principle of universal design (United Nations, 2006) and the guidelines provided in the recent NDA (2022b) report on residential care settings. Whilst this will improve the quality of housing, remove the need for relocation and increase opportunities for ageing in place, it will not be achievable in the absence of targeted resources.
- The realisation of the above will require a planned and structured approach. A working group should be set up to make recommendations on new models for resource planning in respect of housing and the built environment. Further research is also required to fully inform the associated policy implications.

Build the knowledge and skills of professionals, formal and informal carers

The provision of a responsive service to meet changing needs is predicated on the availability of knowledgeable and skilled professionals, and caregivers. This study highlights the commitment of staff to achieving the best possible outcomes for older people with intellectual disabilities. This was attested to by many family participants. Deficiencies were identified, however, in respect of the staffing models and the availability of required skills. Particular mention was made to the difficulty in recruiting specialist staff, particularly intellectual disability nurses, to meet complex health-related needs.

- The rostering of staff in intellectual disability settings has traditionally been structured around periods of greatest activity. Thus, greater numbers of staff were assigned to weekdays and less to nights and weekends. Such approaches may have served a pattern of living that was typical in intellectual disability services for younger cohorts of people. Ageing brings different needs and different patterns of living. Complexity, such as dementia, also leads to the need for alternative ways of rostering staff. Consideration should, therefore, be given to the enactment of dynamic staff rostering that can respond to changing needs. This will have a cost implication and will need to be configured within any new model of service for healthy ageing.
- Staffing and skill-mix were identified as challenges to implementing aged care. New staffing models or workforce redesign should be explored, guided by the commitment to meet the needs and wishes of older people. This will likely require reconsideration of the roles of professionals and other formal carers as well as introduction of financially viable patterns of working which ensure the availability of appropriate support when required. This may also be informed by the use of resource allocation modelling.
- The relatively recent increase in the expected lifespan of people with intellectual disabilities has brought with it new and emerging complexity and other issues. There is an urgent need to provide professionals, carers and families with education and training how to best support older people with intellectual disabilities. There is also a need for such education and training to be provided to those who provide services to older people in mainstream health and social care settings. Education and training should include the following content:
 - Person-centred support approaches
 - Health ageing in the context of intellectual disabilities
 - Age-related complexity and evidence-based interventions
 - Health interventions pertinent to prevalent conditions, including dementia, palliative care, mental health, pain, chronic illness, osteoporosis and polypharmacy
 - Advanced planning and end of life care: understanding the wishes of the older person for their last days, the suitability of extraordinary measures (for example, enteral feeds and ventilators); management of the person's last days and death, including grieving and bereavement
- It is clear that many people with intellectual disabilities will continue to avail of disability services as they age. This study has highlighted that, with

increasing numbers of older people, there will, for some people, need to be a focus on related health needs. The role of the RNID was identified as being important in this regard, but challenges in recruiting such nurses were highlighted. Workforce planning should be undertaken to identify prospected staffing needs and strategies should be enacted to increase the number of RNIDs being educated for the Irish intellectual disability services.

Introduction

In 2019, the National Disability Authority commissioned the Trinity Centre for Ageing and Intellectual Disability (TCAID) to carry out research on the care of older adults with complex age-related conditions.

Project aims

This research aims to examine the care and service options for older adults with intellectual disabilities and complex age-related conditions.

Objectives

- To review the existing evidence base regarding the care of older adults with complex age-related conditions
- Generate additional evidence regarding current models of care
- Generate additional evidence regarding expected future needs
- Compare outcomes and quality of life in different care settings

The findings will guide policymakers and service providers in relation to various models of service and supports, including in particular the HSE, the Department of Health and the Department of Public Expenditure and Reform (DPER).

Background

The number of adults with intellectual disabilities reaching older age has increased in recent decades (Dolan et al., 2021) as health and social conditions continue to improve (Bigby & Haveman, 2010). However, despite improvements in the life expectancy of people with intellectual disabilities, mortality rates remain higher for this population compared to persons without intellectual disabilities (Dolan et al., 2021; McCarron et al., 2015; Lauer & McCallion, 2015). Ageing with intellectual disabilities is often associated with premature ageing and an increased risk of age-related health conditions (Alftberg et al., 2021; Haveman et al., 2010; Hatzidimitriadou & Milne, 2005). People with Down Syndrome, for example, have an increased risk of developing Alzheimer's disease at younger ages due to premature ageing (Bigby, 2008a; Janicki & Dalton, 2000). The literature suggests that health and social care systems are largely ill-equipped to meet the complex age-related needs of older adults with intellectual disabilities (García-Domínguez et al., 2020; Burke et al., 2019; McCarron et al., 2018a; McCallion et al., 2013b; Haveman et al., 2011) and as a result, this population face a range of unmet health and social care needs (Bigby, 2014). This highlights the need for community-based integrated care for people with intellectual disabilities and for greater coordination

between age, disability, and healthcare services. While ageing in place is one of the key principles underpinning care for this population and is the preference for most people with intellectual disabilities (Chapman et al., 2018; Patti et al., 2010), it is not always possible to achieve. When age-related conditions become increasingly complex, informal, or formal care in the home may no longer be appropriate in meeting their complex needs, leading to transitions into community residential settings, specialist units within disability services or nursing homes. The aim of this research is to examine these care options and whether they meet the needs of older people with intellectual disabilities in Ireland.

This report is divided into six chapters; the first sets the context by presenting the key literature on the care of older adults with intellectual disabilities and complex age-related needs and the second details the methodology and profile of participants. The following three chapters each examine a particular theme derived from topics addressed across the various datasets whilst the final chapter discusses the findings in relation to existing literature, making recommendations based on these findings.

Chapter 1: Current State of Evidence

A Scopus database search was carried out using key search terms to identify literature related to the care of older adults with intellectual disabilities and complex age-related conditions.

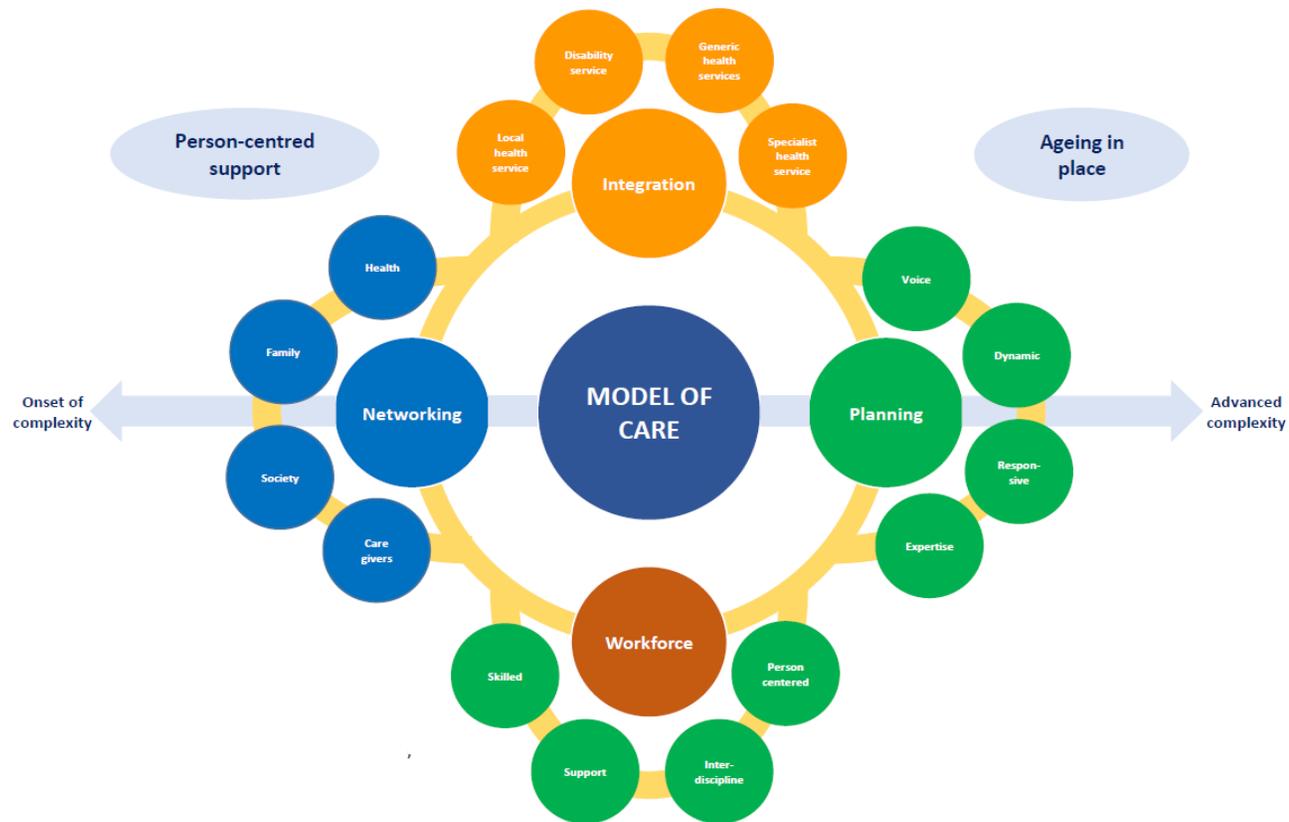
The literature review begins with a description of the key principles and components underpinning a model of care for people ageing with intellectual disabilities. This is followed by an overview of the main issues which affect adults with intellectual disabilities, including physical, mental, and social needs, and the complexity that may accompany them. An overview of outcome measurement will then be presented, including its purpose, the tools currently used for measuring outcomes and the challenges associated with measurement. Finally, the care and support available to older people with intellectual disabilities will be addressed, with consideration given to the provision of care services in Ireland, and the barriers to accessing services.

Models of care

A model of care defines the way health services are organised and provides guidance on how to deliver best-practice care and services for a person or population as they move through the stages of a condition, injury, or event (New South Wales Agency for Clinical Innovation, 2013). It aims to ensure that people receive the “right care, at the right time, by the right team and in the right place” (Ibid, p.3) (New South Wales Agency for Clinical Innovation, 2013, p. 3) and is guided by core components and principles that sit within a structured framework which guides the implementation and evaluation of care (palliAGED, 2021). Any such model of care should also be cognisant of the obligations imposed by the United Nations (2006) Convention on the Rights of Persons with Disabilities (UNCRPD) to ensure that all people with disabilities are treated as people with rights, with the capacity to claim those rights, make decisions for themselves and participate as active members of society. However, to date, there is no universally agreed-upon model of care for older people with intellectual disabilities and complex age-related conditions, and the literature highlights that there is a need for such a model to address the gaps in service provision and the level of fragmented care that is experienced.

The key components and underpinning principles of a model of care for older adults with intellectual disabilities and complex age-related conditions are described in a systematic review by Sheerin et al. (2021a). While the review did not identify a specific model of care, several recurrent concepts seen as central to the provision of service and care for older people with intellectual disabilities were identified. These key components include integration, planning, workforce, and networking (Figure 1).

Figure 1: Components of a model of care for older people with intellectual disabilities and age-related complex needs



Source: (Sheerin 2021, based on HSE, 2016; Genio, 2016)

Furthermore, the authors stated that such a model of care should be underpinned by the principles of ageing in place and person-centred planning (PCP). These key principles are described below, followed by a description of the key components of a model of care.

Key principles underpinning a model of care

Ageing in place

Ageing in place is a key underpinning principle of care for older people with intellectual disabilities in Ireland (Department of Health, 2020b) and internationally (Chapman et al., 2018; Patti et al., 2010). It refers to “the ability to live in one’s own home and community safely, independently and comfortably, regardless of age, income or ability level” (Center for Disease Control and Prevention, 2009, p. 1). Ageing in place encompasses people ageing in a variety of settings, including in a family home, in an independent home in the community (supported living), in a community group home, and in a larger disability-specific residential facility (Hussain et al., 2013; Webber et al., 2010; NDA, 2006). As such, Hussain et al. (2013) recommend using the term ‘Ageing in My Chosen Place’ as it captures the variety of living experiences desired by people with intellectual disabilities.

Supporting ageing in place

While ageing in place is the preference for most people with intellectual disabilities, as well as their family members and support staff, there are a range of factors that impact the ability of people to age in place. An analysis by Bigby (2002) on ageing and disability services identified three common overarching issues in relation to supporting ageing in place. These include a lack of available appropriate services, problems with quality and access to services, and programmatic or funding mechanisms that create obstacles to accessing services and collaboration between service providers. Under these overarching themes, several specific barriers to ageing in place were found in the literature, including the issue of ageing family carers (Chou & Kröger, 2022), staff knowledge and skills in dealing with complex conditions such as dementia (Alftberg et al., 2021), the built environment (Webber et al., 2010) and mobility issues (Schepens et al., 2019).

Parents are often the primary caregivers to people with intellectual disabilities who live in the family home (Heller, 2017). This is often the wish of both parties, however, continued family care in the home is not always possible or desirable (Brennan et al., 2018). Similar to persons without intellectual disabilities, as people with intellectual disabilities age, they often require higher levels of support and care due to functional and cognitive decline associated with biological ageing processes (Egan et al., 2022). This, in turn, increases demand on the primary caregiver, and as parents age they often become unable to provide the level of support required, leading to relocation, such as a move to a residential ageing facility (Chou & Kröger, 2022; Bowers et al., 2014). In one study, the majority (70%) of parents of people with intellectual disabilities felt that the support provided in residential

ageing facilities was not suitable to meet the needs of people ageing with intellectual disabilities (Shaw et al., 2011). A range of factors have been found to predict a move out of the home for people with intellectual disabilities (Ryan et al., 2014). These included increasing level of needs on the part of the person with intellectual disabilities, family carers being aged 75 years and over, stress experienced by the caregiver, both the person with intellectual disabilities and the family caregiver living in unsuitable accommodation, and low socioeconomic status (Ryan et al., 2014). Findings from a review by Ryan et al. (2014) indicate that there is an increased need for appropriate services for older people with intellectual disabilities and for ageing family carers, as well as a need for early future planning. These authors suggest that future planning for the care of older people with intellectual disabilities is an essential process which should begin before the onset of functional and cognitive decline for both the person with intellectual disabilities and their family carer.

Existing literature indicates that the physical home environment is a key factor in enabling a person to age in place (Northway et al., 2017; Webber et al., 2010). In a study by Webber et al (2010), support staff in group homes cited mobility issues, functional decline and unsuitability of the physical home environment as factors contributing to relocation. Support staff strongly advocated for equipment and house modifications or a move to modified or purpose-built homes as people's needs changed and mobility issues developed, to prevent a move to generic care facilities (Webber et al., 2010). The issue of providing care to people with dementia was also identified in studies relating to ageing in place (Alftberg et al., 2021; McCarron et al., 2010b; Bigby, 2008a). When reflecting on ageing in place in group homes, support staff in one study expressed concern around the appropriateness of their service in dealing with complex conditions such as dementia due to a lack of knowledge and skills in this area and that this would necessitate a move to a generic nursing home for older people, while other support staff expressed a wish for those with dementia to age in place, regardless of dementia (Alftberg et al., 2021).

Relocation and social networks

While the relocation of people with intellectual disabilities from an institutional setting to community-based settings has been associated with an improved quality of life, the literature indicates that in some instances, relocation can lead to a range of negative outcomes (McCarron et al., 2018a; McConkey et al., 2016). These include functional decline (Esbensen et al., 2008), emotional and behavioural problems (Hamilton et al., 2005), psychological distress (Hulbert-Williams & Hastings, 2008), and difficulty in developing friendships and maintaining social networks (Bigby, 2008b).

Adults with Down Syndrome may be at higher risk of experiencing relocations than adults with other intellectual disabilities (Woodman et al., 2014; Patti et al., 2010).

Patti et al. (2005) found that 60% of adults with Down Syndrome experienced one or more relocations over 5 years, compared to 21% of adults with non-Down Syndrome-related intellectual disabilities of the same age, and they found that age-related functional decline and the presence of dementia may have been directly related to the prevalence of relocation. The same authors suggest that the incidence of significant life events may influence individuals' overall level of cognitive and adaptive functioning (Patti et al., 2005). In other words, exposure to recurrent relocations may lead to cognitive, emotional, and behavioural problems for people with intellectual disabilities (Woodman et al., 2014). Due to the higher incidence of life events and changes experienced by people with Down Syndrome, they may be at a greater risk of experiencing cognitive and behavioural decline, compared to those with other intellectual disabilities (Patti et al., 2010; Esbensen et al., 2008; Patti et al., 2005).

Person-centred support

The second key principle underpinning a model of care for people ageing with intellectual disabilities identified by Sheerin et al. (2021a), is person-centred care. In recent decades, care for people with intellectual disabilities has progressively shifted from a system-centred, medically dominated, and fragmented approach, toward a person-centred and holistic approach, whereby services are tailored to the individual (Ratti et al., 2016; McCance et al., 2011). Person-centred approaches to care are central to ageing and disability policy and practice in Ireland (HSE, 2013; HIQA, 2012) and internationally (McCormack & McCance, 2016; McCormack et al., 2015). It is increasingly being recognised as a key component of best practice and quality care for the ageing population (Edvardsson et al., 2010) and is widely advocated by both service providers and service users (Gridley et al., 2014).

Definitions of person-centred care have changed over time and there are a range of similar terms used in the literature, such as patient-centred care, person-centred care, and relationship-centred care (de Silva, 2014). Despite a growing body of literature on person-centred care, there is no standard and agreed-upon definition, and there is a lack of consensus around its core elements, best practices, and measures to assess effectiveness (American Geriatrics Society, 2016). Overall, person-centred care can be described as an approach that focuses on the individual's values, needs, and abilities, and is achieved through a collaborative and dynamic relationship among people with intellectual disabilities, their families, support staff, and service providers (American Geriatrics Society, 2016; McCormack et al., 2015; Edvardsson et al., 2010). For example, McCormack et al. (2010, p. 13) define person-centred care as:

An approach to practice established through the formation and fostering of therapeutic relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is

enabled by cultures of empowerment that foster continuous approaches to practice development.

Although definitions of person-centred care vary, they are all underpinned by common principles. Being person-centred means affording people dignity, respect, and compassion, offering coordinated and personalised care, support, and treatment, and enabling person-centredness (Harding et al., 2015). A study by Edvardsson et al. (2010) found that promoting ‘a continuation of self and normality’ (p. 2614) was an important aspect of person-centred care for people with dementia, their family members, and care staff and that this could be achieved through the five key areas of: knowing the person, welcoming family, providing meaningful activities, being in a personalised environment, and experiencing flexibility and continuity.

Several conceptual frameworks have also been developed, such as the Senses Framework (Nolan et al., 2004), the VIPS Framework (Brooker & Latham, 2015), the Authentic Consciousness Framework (McCormack, 2003), and the Person-centred Nursing Framework (McCormack & McCance, 2010; McCormack & McCance, 2006). The Person-Centred Nursing Framework, one of the most cited frameworks in the literature, was derived from research related to person-centred practice for older people and was designed to address nursing practice and education in the care of older people (Ross et al., 2015; McCance et al., 2011). This framework comprises four key constructs – *prerequisites*, which focus on the attributes of the nurse; *the care environment*, which focuses on the context in which care is given; *person-centred processes*, which focus on delivering care through a range of activities; and *outcomes*, which are the results of effective, person-centred nursing (McCance et al., 2011). Although this framework specifically relates to nursing, the principles underpinning the framework are relevant to other care providers (Miller, 2021).

There are a range of person-centred approaches in which people with intellectual disabilities and healthcare professionals engage. These include shared decision-making, self-management support, social prescribing, person-centred outcomes, and person-centred planning approaches, among others (Miller, 2021). The following section describes one of these approaches, person-centred planning, in greater detail.

Person-centred planning

The draft HSE Interim Standards for New Directions (HSE, 2015) requires that each person with a disability has a personal plan that includes the services and supports to be provided to them to achieve a good quality of life and to realise their goals. It states that this approach should be used by service providers to facilitate the personal planning process effectively for each person. In line with these National Standards, the NDA and the HSE developed a National Framework

for person-centred planning (PCP) to provide a more consistent approach to PCP in Ireland and is intended to inform and guide how PCP is implemented across services for people with disability (HSE, 2018b).

Person-centred planning aims to put ‘individuals with intellectual disabilities at the centre of service and support planning, identifying how individuals wish to live their lives and what is needed to make it possible’ (McCausland et al., 2021c, p. 1). Person-centred planning therefore can support people with intellectual disabilities to vindicate their rights under the UNCRPD. PCP requires that all supports be flexible and responsive to the changing needs of the person, that the process involves ongoing listening and learning, that there is a focus on the outcomes that both the person and the service want to achieve, that the planning process is accessible to the person, and that all information is provided in a meaningful format (HSE, 2018b; Sanderson, 2000). Furthermore, PCP is grounded in a social model and strengths-based approach and takes into account the person's wider support networks such as family and friends, which makes this approach particularly appropriate in managing life transitions (NDA, 2006). The core values and beliefs underpinning PCP include individuality, equality, respect, empowerment, choice, inclusion and active citizenship, and independence (HSE, 2018b).

The NDA (2005) outlines six key principles of PCP:

1. Person-centred planning is planning from an individual’s perspective on his or her life
2. Person-centred planning entails a creative approach to planning which asks, ‘what might this mean?’ and ‘what is possible?’ rather than assuming common understandings and limiting itself to what is available
3. Person-centred planning takes into consideration all the resources available to the person – it does not limit itself to what is available within specialist services
4. Person-centred planning requires serious and genuine commitment and cooperation of all participants in the process
5. Person-centred planning is an art – not a science. It is best viewed as an organic, evolving process.
6. The development of a plan is not the objective of person-centred planning. The objective is to make a real, positive difference in someone’s life.

Despite an emphasis on person-centred care in policy and practice, the literature regarding the effectiveness of PCC and PCP is sparse (Claes et al., 2010). However, from this literature, a range of benefits associated with PCP have been identified (McCausland et al., 2021c). It has the potential to improve social networks, contact with family and friends, engagement in group activities, and participation in the community (McCausland et al., 2021c; Claes et al., 2010; Robertson et al., 2007). It

has also been shown to increase choice-making (Ratti et al., 2016; Robertson et al., 2007) and self-determination (Espiner & Hartnett, 2012) and improve self-esteem (Wigham et al., 2008). However, research has shown that PCP may benefit some individuals more than others, and there have been calls for more research on its effectiveness (Ratti et al., 2016; Claes et al., 2010; Robertson et al., 2007).

The implementation of PCP poses challenges, and a range of barriers and facilitators associated with the outcomes of PCP have been identified in the literature. A key barrier to implementation is the personal characteristics of the individual. For example, McCausland et al. (2021c) found that the most common barrier to PCP cited by people with intellectual disabilities was themselves. Participants with intellectual disabilities referred to behaviours that challenge and other individual characteristics such as anxiety and mental health difficulties, as factors that impeded their ability to achieve their goals. Support staff in another study reported that it was harder to use person-centred approaches with older residents due to negative life course experiences related to their disability which result in reduced engagement in decision-making and reduced skills required for self-advocacy (Kählin et al., 2016).

It has been suggested that the environment and approach to providing care are important in enabling person-centredness and that PCP is more likely to be successful when a person lives in an enriching and stimulating environment (HSE, 2018b). Contextual and organisational factors such as living close to one's family and having a care manager have been associated with increased social networks and increased chances of getting PCP (Robertson et al., 2007). McCausland et al. (2021c) suggest that having adequate organisational support for people with severe intellectual disabilities may be the most significant factor in facilitating PCP goals. Factors related to the process of person-centred planning including the personal involvement of the focus person and the commitment of facilitators to PCP have also been associated with increased benefits in the areas of the size of social networks, contact with friends and choice (Robertson et al., 2007).

Key components of a model of care

Integration

The literature indicates that people ageing with intellectual disabilities frequently encounter uncoordinated and fragmented ageing, disability and healthcare systems; and the absence of integration between systems can lead to overlapping or missed services, and a disruption to the continuity of care for service users (Darker, 2014). Integrated care is required to achieve a seamless care pathway for service users and is therefore identified as central to the delivery of best practice care in a number of models of care (HSE, 2021; Government of South Australia, 2020; HSE, 2019a; 2018a).

One such example of an integrated care model is the *South Australia Intellectual Disability Health Service (SAIDHS) Model of Care 2020* – a 3-tiered model of care developed in response to a need for more accessible health services for people with intellectual disabilities and complex health needs (Government of South Australia, 2020) (Figure 2). It adopts a life course approach to care, designed to provide care across a continuum, from early intervention, to mild, moderate, chronic, and complex related care, and it assumes that people will access and move back and forth between these tiers. The model proposes that a liaison team within hospitals or local health networks could act as link between mainstream services and more targeted services for people with complex needs, like the role of liaison nurses in the UK. The model also proposes that intellectual disability health services providing specialist care (i.e., comprehensive assessment; healthcare planning) should link with existing services (e.g., mental health services) to support people with a high level of complex health needs who cannot be supported by mainstream or targeted services.

A review by Giuntoli et al. (2015) identified nine models or approaches to health service delivery for people with intellectual disabilities in the UK and Australia. All of the models emphasised the importance of interagency collaboration and the need for services to be sufficiently resourced to meet the needs of people with intellectual disabilities. The authors reported that co-operation between and integration of specialist and mainstream services was presented as the best approach to care. However, only one model specifically addressing the needs of older people was identified – the Fair Horizons model in the UK. This model was developed by Fear et al. (2012) to address the barriers to service access that are experienced by older people with intellectual disabilities. It is a person-centred, interdisciplinary model of mental healthcare delivery, that aims to implement care tailored to the needs of the individual rather than care that is based on a specific target group. The model proposes one point of entry for the service user, with a number of care pathways that can be followed based on their needs. However, while the Fair Horizons model has been recognised as an innovative model, it has not yet been tested or evaluated and there is uncertainty around the cost implications of the model (Giuntoli et al., 2015; Tyrer, 2012).

Figure 2: South Australian Intellectual Disability Health Service Model of Care 2020



Source: (Government of South Australia, 2020, p. 33)

Service planning

The changing age profile of people with intellectual disabilities has implications for service planning, including for the demand for services designed to meet the needs of older people with intellectual disabilities and for services to support ageing caregivers (Doody et al., 2011). Health service planning refers to the process of “aligning existing health service delivery arrangements with changing patterns of need, to make the most effective use of available and future resources for a population” (Department of Health Queensland, 2015, p. 5). Therefore, service planning is key to supporting an integrated approach to care (Hatzidimitriadou & Milne, 2005) and to providing a seamless care pathway (McCarron et al., 2018b).

In order to achieve a seamless and integrated model of care, there is a need for planning to be proactive and responsive to the changing needs of people as they age, and a need for greater and more meaningful involvement of service users in decision-making and planning processes (HSE, 2021; 2019a; 2016; Hussain et al., 2013). Involving the voice of the service user, their family, and carers, is consistent with the approach of person-centred care and is a key mechanism for ensuring that the person’s changing physical and health needs are met (Bekkema et al., 2015a; Hatzidimitriadou & Milne, 2005). Planning should also be interdisciplinary, whereby health professionals across different sectors work collaboratively, along with the service user (McCarron et al., 2018b), to ensure that care is provided in a timely and efficient manner (Sheerin et al., 2021a; Chapman et al., 2018).

Workforce

As the number of people with intellectual disabilities living into older age continues to increase, and their health and social needs become more complex, it will be necessary for healthcare services and systems to adapt and develop new ways of delivering services that better address the needs of this group (Department of Health, 2021b; Wilson et al., 2020). These demographic changes affect not only the number of people requiring care but also the makeup of the workforce providing care (HSE, 2015). As outlined in this review, research shows that services are unprepared to deal with age-related complexities, with staff often lacking the skills and knowledge required to provide quality care. In particular, staff have expressed concerns over a lack of experience in providing dementia-specific care (Alftberg et al., 2021; Schaap et al., 2018; Cleary & Doody, 2017; Iacono et al., 2014) and end of life care (McCarron et al., 2021; Tuffrey-Wijne & Davidson, 2018; McCarron et al., 2017a) for people with intellectual disabilities and complex needs. This has an impact on the capacity of staff and services to support the individual to age in place and provide person-centred care (Alftberg et al., 2021; Bekkema et al., 2015b; Webber et al., 2010), and may result in individuals with increased care needs moving to a specialist care setting when their needs cannot be met in their current home (Cleary & Doody, 2017; Iacono et al., 2014).

As described by the Health Information and Quality Authority, “a service’s workforce is one of its most important resources in delivering safe, high-quality care and support. It is important that the members of the workforce are skilled and competent to deliver quality care and support and that the workforce is planned, structured and managed to deliver the service’s quality and safety outcomes” (HIQA, 2012, p. 23). Workforce planning and training that focuses on developing a responsive, flexible, multiskilled and collaborative workforce is, therefore, required to address these issues and provide high-quality integrated care (HSE, 2021; 2019a; Department of Health, 2017). Developing the current and future healthcare workforce should involve: proactive recruitment of staff who have the appropriate skills, competencies and experience in the area of intellectual disability and ageing; training and upskilling of staff across ageing, disability and health sectors; support for the development of career pathways; retention of staff; cross-disciplinary training and educational programmes that bring staff together from different sectors; and service specialisation to cater for individuals with more complex needs (Hussain et al., 2021; HSE, 2019a). Supporting and upskilling informal carers such as family, is also an important consideration, as their role and the role of wider social networks in supporting people with intellectual disabilities cannot be underestimated.

Networking

Research highlights the vital role of family involvement and social networks in supporting ageing in place in the community and in mitigating the negative outcomes associated with relocation (Woodman et al., 2014; Jokinen et al., 2012). It also shows the importance of social interaction for positive health, wellbeing, and social inclusion for those ageing with and without intellectual disabilities (Scott & Havercamp, 2018; Johnson et al., 2012). However, older people with intellectual disabilities tend to experience greater levels of social isolation and loneliness, compared to that experienced by persons without intellectual disabilities (MacDonald et al., 2018; Gilmore & Cuskelly, 2014) and have limited opportunities to engage in social activities (McCausland et al., 2021b; Forrester-Jones et al., 2017).

Therefore, to achieve a truly integrated model of care for older people with intellectual disabilities it is important that the social network is supported and fostered (Johansson et al., 2017). There is, however, a consensus that assistance with forming social supports and facilitating people to participate in the community does not necessarily lead to meaningful social contact (Duggan & Linehan, 2013). Duggan and Linehan (2013) proposed 4 key strategies to enhance meaningful social connections including circles of support, peer-based approaches, programmes that enhance social competencies, and befriending strategies. Overall, the literature on models of care indicates that better coordination between ageing, disability and health services (Shaw et al., 2011; NDA, 2006), providing accessible environments and supports (NDA, 2006), and integrated support between familial, social and

health service networks are needed to support older people with intellectual disabilities to age in place. An emphasis should be placed on person-centred planning (Schepens et al., 2019) and enhancing social supports and friendships as the person becomes more disabled over time (Shaw et al., 2011).

Complex age-related issues

Older adults with intellectual disabilities are an increasingly diverse population whose health and social care needs are highly varied and complex (McCausland et al., 2021a; Hatzidimitriadou & Milne, 2005). Although no single definition of complex care needs exists (Gridley et al., 2014), broadly speaking, individuals considered to have complex care needs experience a range of support needs across multiple areas, including psychosocial, behavioural, health, and social needs. This complexity is also influenced by environmental and contextual factors such as the person's socioeconomic status and the health systems and services in place (Dew et al., 2019; Collings et al., 2016). Thus, Brenner et al. (2018, p. 1647) define complex care needs as:

Multidimensional health and social care needs in the presence of a recognized medical condition or where there is no unifying diagnosis. They are individual and contextualized, are continuing and dynamic, and are present across a range of settings, impacted by healthcare structure.

The ageing process and the progressive increase in life expectancy of people with intellectual disabilities further add to the complexity of these needs (Alcedo et al., 2017). The international literature suggests that for some groups of people with intellectual disabilities, ageing is a more complex process than that experienced by persons without intellectual disabilities due to premature ageing and secondary health conditions, or additional age-related health conditions that a person with a disability may experience (Alftberg et al., 2021; Haveman et al., 2010; Hatzidimitriadou & Milne, 2005). For example, Down Syndrome has been associated with premature ageing and an increased risk of developing early-onset dementia (Bigby et al., 2008; Janicki & Dalton, 2000).

While the life expectancy of older people with intellectual disabilities has risen substantially over the last number of decades, it still remains lower than that of persons without intellectual disabilities (Heller, 2019), and although the health and social care needs of ageing people with intellectual disabilities have been the focus of World Health Organization health and social policies (Evenhuis et al., 2001; Hogg et al., 2001), those ageing with intellectual disabilities still face a range of unmet health and social needs, and disparities continue to exist (Bigby, 2014).

Physical and mental health needs

There is widespread consensus that older people with intellectual disabilities are at greater risk of experiencing a range of health issues related to ageing which can

occur at earlier ages and at higher rates than among people who do not have intellectual disabilities. These health issues include cardiovascular diseases, obesity, diabetes, epilepsy, gastrointestinal issues (such as constipation), kidney disease, osteoporosis, frailty, falls and fractures, thyroid disorders, sensory impairment, poor oral health, high levels of medication use and polypharmacy, depression, and dementia (García-Domínguez et al., 2020; Burke et al., 2019; Haveman et al., 2011). The cause of this disparity has been attributed to a range of factors including a person's genetic predisposition to health conditions, socio-economic status, difficulties with accessing and utilising generic health services, a lack of information, poor mobility, poor eating habits, a lack of exercise, accommodation circumstances, and medication use (McCallion et al., 2013b; Haveman et al., 2011).

It is common for the older people without intellectual disabilities to experience multiple conditions at once and the prevalence of such multimorbidity tends to increase with age (Kirchberger et al., 2012). However, multimorbidity is higher in the population of people with intellectual disabilities and occurs at a much earlier age, compared to the population of those without intellectual disabilities (McCarron et al., 2013). For example, in one study, a high rate of multimorbidity (71%) was reported in adults with intellectual disabilities over 40 years of age living in Ireland, a rate that was much higher than the rate found in people who do not have intellectual disabilities (58%), and those aged 65 years or over were 3.4 times more likely to be multimorbid (McCarron et al., 2013). The same study reported that the most common multimorbidity pattern was mental health/neurological disease.

Research shows that older people with intellectual disabilities experience poorer mental health than that experienced by people without intellectual disabilities (McCarron et al., 2017b). The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) is a large-scale multi-wave study of older adults aged 40 years and over with intellectual disabilities in Ireland (McCarron et al., 2014). It is designed to explore the health, social, economic, and environmental circumstances of 753 people as they age and provides data on how their circumstances change over time (McCarron et al., 2014). In 2017, IDS-TILDA reported a high prevalence (52%) of emotional, nervous, and psychiatric conditions in older adults with intellectual disabilities (McCarron et al., 2017b). Depression and anxiety were found to be the main contributors to poor mental health, with the prevalence of depression being significantly higher in older people with intellectual disabilities than in those without intellectual disabilities (McCarron et al., 2017b). Of particular importance was the finding that the prevalence of depression was lower amongst those living independently and with family than those living in other types of accommodation. A range of factors may predispose persons with intellectual disabilities to depression and anxiety, such as the side effects of medications, sensory impairments and associated communication difficulties, ageing-specific disorders, as well as significant life events, such as a

change in a person's living situation or bereavement of a friend or family member (McCallion et al., 2019).

Dementia

Specific cohorts within the older population with intellectual disabilities may experience specific disability-related illnesses, such as the aforementioned link between Down Syndrome and dementia (McCausland et al., 2021a). People with Down Syndrome are prone to developing dementia at earlier ages and more frequently than people with other types of intellectual disabilities and people without intellectual disabilities (Strydom et al., 2013). The average age of onset of dementia is in the early 50s among people with Down Syndrome, compared to the late 60s in people with other types of intellectual disabilities (Strydom et al., 2010). There is, however, no consensus on whether the prevalence of dementia in people with non-Down Syndrome-related intellectual disabilities is higher than of that in people without intellectual disabilities. One study reported that the incidence of dementia in adults with intellectual disabilities aged 65 and older was five times greater than in the population of people without intellectual disabilities (Strydom et al., 2013), whereas another found that there was no difference in the prevalence of dementia between these populations (Zigman et al., 2004). In addition to dementia appearing earlier in people with Down Syndrome, the prevalence of the disease increases with age. One longitudinal study reported that the prevalence increased from under 10% in people aged in their 40s to more than 30% in those aged in their 50s (Strydom et al., 2010).

The additional challenges associated with a dual diagnosis of dementia further add to the complexity of their needs. Such challenges include impairment of activities of daily living, emotional and behavioural issues, including aggressive behaviours, wandering and pacing, apathy, eating and sleeping disturbances and depression (Hatzidimitriadou & Milne, 2005). The behavioural and psychological symptoms of dementia can significantly influence the quality of life of the individuals affected as well as their families and caregivers (Marsack-Topolewski & Samuel, 2020).

Social and environmental needs

In addition to physical and mental health needs, older people with intellectual disabilities face unmet social needs (McCausland et al., 2021a). These include a range of housing needs, such as issues around suitable accommodation, around transitioning from one place of residence to another, and issues related to continued accommodation with older adult caregivers (Gilbert et al., 2008; Hogg et al., 2001). They also include needs around social participation, social networks, and inclusion (McCausland et al., 2021a; McCallion et al., 2013b; Bigby, 2008b), as well as employment and retirement (McCausland et al., 2021a). As older adults are affected by age-related changes and secondary health conditions, these challenges may become more pronounced (Janicki, 2010).

Housing and the Built Environment

According to the 2016 Census, approximately 66,500 people with intellectual disabilities are living in Ireland. These people live in a variety of housing types including in family homes, independent settings in the community, group homes, and in larger residential centres and institutions (Roebuck, 2021; Inclusion Ireland, 2019; Mansell & Beadle-Brown, 2009) (See Table 1 for description of housing types).

Although there has been a significant policy shift in housing to support older people with intellectual disabilities to move from congregated settings toward living independently in the community (HSE, 2011). However as of the end of 2019 1,953 people with intellectual disabilities remained in congregated settings (HSE, 2019b).

Table 1: Housing types

Housing Type	Description
Family home	Person with intellectual disabilities (ID) lives in family home, often with family members including parents and/or siblings.
Independent living in the community	Supported living: Person with ID rents/owns a house of their choosing among the general population, which they may share with people they choose. Staff support provided by agency of their choosing and separate from housing provider.
	Home sharing: People with ID share a home with another person who is paid to provide support as needed.
Community group homes	Dispersed housing: Apartments and houses of the same types and sizes as the majority of the population live in, scattered throughout neighbourhoods among the rest of the population. Typically owned by service providers. House a small number of people with ID and support staff are provided according to assessed needs.
	Clustered housing: More than one home or housing unit on the same site forming a separate community from the surrounding population. House a smaller number of people.
	Clustered supported living: Specially built groupings of houses/apartments on the same site with shared staffing across houses. Up to 15 people may live in the same cluster, either in single-person or shared housing.
Residential centres/institutions	Disability-specific residential facilities: Large group homes or multiple houses on a campus for people with ID, separated from the general population. House a larger number of people (ranging from 8-300) and full-time support is provided.
	Mainstream residential facilities for older people (nursing home).

Source: (Roebuck, 2021; Inclusion Ireland, 2019; Mansell & Beadle-Brown, 2009)

Currently statistics on the housing circumstances of people with intellectual disabilities in Ireland are not published (Inclusion Ireland, 2019). However, the 2017 National Intellectual Disability Database (NIDD) did give an indication of housing statistics for people with intellectual disabilities, but only considers those already engaged with disability services. According to NIDD, in 2017, 55.5% of adults (aged 18 and over) with intellectual disabilities lived in a family home setting; 22.2% lived in community group homes; 10.2% lived in residential centres; and 6.2% lived in an independent setting in the community. In a sample of IDS-TILDA participants, those living at home with family and in the community tended to be younger with a mild or moderate range of intellectual disabilities, and those living in residential type centres tended to be older and with more severe to profound levels of intellectual disabilities (McCallion et al., 2013b). However, a substantial proportion (15%) of those aged 35 years and older, and almost a third of those aged 35 years and older with moderate, severe or profound intellectual disabilities continue to live at home with family (Hourigan et al., 2018). The National Housing Strategy for Disabled People 2022-2027 (Government of Ireland, 2022) noted that over the period 2016-2020, just under 2000 homes were allocated to people with intellectual disabilities at a rate of about 200 per year, despite the fact that they account for 'about 90% of those in disability residential care' (ibid. p. 25).

One of the primary challenges in response to ageing in people with intellectual disabilities is meeting their complex care needs, and supporting them to age in place in their homes or communities when this preference is expressed (Wu et al., 2021). While there has been progress in terms of deinstitutionalisation and moving people into the community, older people still face many barriers to accessing care and report a range of unmet housing and support needs (Wu et al., 2021; Bien et al., 2013). This may be related to the lack of national policy in respect of older with complex needs highlighted by the NDA in their guidelines on enhancing residential care setting (NDA, 2022b). These are grounded in Health Quality and Standards Authority standards and in state regulations, but also draw heavily on the concept of universal design, a key principle of the UNCRPD (United Nations 2006). The guidelines acknowledge the scale of costs that are associated with different levels of design and retrofit, with significant spatial development requiring significant funding. It is clear from the guidelines and from the associated research report (NDA, 2022a) that some voluntary and HSE services have been engaged in new-builds and in retrofitting extant residential accommodation but others may find the costs prohibitive, especially as they highlight the deficits in the funding model (National Federation of Voluntary Bodies, 2019).

Living arrangement

A person's living arrangement plays a key role in respect of meeting their care needs. A recent outcomes evaluation of models of service in the disability sector indicated that quality of life outcomes improved for people with intellectual disabilities after they moved from congregated settings to the community (NDA,

2021a) as reflected in the literature on service users' satisfaction with their living situation. In one study, service users identified the physical features of living arrangements and the provision of activities and staff as the main contributors to satisfaction (O'Rourke et al., 2004). Staff issues such as restrictions on personal independence, staff impatience, and staff shortages, were identified as the primary contributors to dissatisfaction. However, experiences vary according to the type of accommodation, with service users living in their family home more likely to report being happy, but also more likely to report feeling lonely, compared to those living in group homes (ibid., 2004). In contrast, other studies have reported that older people with intellectual disabilities are more likely to want to move out of their family home to gain more independence (McGlaughlin, 2004). Keyworkers and family carers also highlight the need for more accessible accommodation, especially for people with reduced mobility, as well as the requirement for more residential supports (McCausland et al., 2021a; Brennan et al., 2018).

Choice

Article 19 of the UNCRPD affirms the right of people with disability to choose their place of residence and where and with whom they live, however choice, or lack thereof, is a key issue identified in the literature relating to older adults with intellectual disabilities (HSE, 2011; Bowey, 2005; McGlaughlin, 2004). While ageing in place, the option to remain living in one's home of choice with appropriate support, is crucial for people with intellectual disabilities as they age, adults with intellectual disabilities are often given limited choices in relation to their living arrangements (McCallion et al., 2013b; Innes et al., 2012). IDS-TILDA found that three-quarters of adults with intellectual disabilities (75%) reported having no choice in relation to where they lived, 85% had no choice in relation to who they lived with, and nearly half of participants said they had no choice over what time they went to bed (McCallion et al., 2013b). Overall, participants did, however, report having a good level of choice regarding other basic day-to-day activities such as how they spend their free time, the food they eat, and the clothes they wear (McCallion et al., 2013b). Lack of choice and control may be experienced by both older people living at home with family and in residential facilities (10-12 residents) (Eley et al., 2009). However increased choice has been associated with community-based and smaller settings, compared to larger congregated settings such as residential centres (HSE, 2011). Older people with intellectual disabilities, caregivers and staff, have also expressed concern over a lack of choice and information regarding future accommodation (Innes et al., 2012).

Caregiving

Another major concern related to the social care needs of older people with intellectual disabilities identified in the literature is the burden of care experienced by older caregivers living with older people with intellectual disabilities (McCausland et al., 2021a). Caregiving in the family home has many advantages, such as facilitating the desires of older people with intellectual disabilities to age in

place, and has been linked to a greater quality of life and financial benefits (Brennan et al., 2018). In addition, ageing family caregivers may benefit from the mutual caregiving relationship which often develops between themselves and those whom they are caring for (Grant & Ramcharan, 2001; Williams & Robinson, 2001).

Despite these benefits, both older people with intellectual disabilities and their family caregivers have expressed concern about the burden of caregiving, due to the complexity of the health needs of people with intellectual disabilities and the challenges faced by carers to support these needs as they age (Ryan et al., 2014). While some ageing family caregivers may want to continue caring for people with intellectual disabilities as they age, many are concerned about the future of those they are caring for, in particular how their loved ones will be cared for after they pass away (Ryan et al., 2014; Innes et al., 2012; Bowey, 2005). Deterioration in the health of the person with intellectual disabilities and persistent behaviours that challenge, may lead to family carers reluctantly exploring alternative care options as they can no longer provide care (Taggart et al., 2012).

Several explanations have been proposed to account for ageing family carers' reluctance to explore alternative care arrangements including denial about their capacity to provide long-term care, the emotional impact of relinquishing care on all concerned, the absence of future planning, and a lack of support (Garnham et al., 2019; Walker & Hutchinson, 2017; Ryan et al., 2014; Taggart et al., 2012). According to Taggart et al. (2012), carers may find it difficult to accept their own mortality and the realisation that they may not be able to continue to provide care. They may have difficulty letting their loved ones go due to concerns about feeling lonely without them and may also have concerns about how out-of-home placements may impact negatively on their loved ones (Taggart et al., 2012). Family carers report a lack of engagement by service providers to initiate or facilitate future planning, leaving parents without formal support with this sensitive issue (Walker & Hutchinson, 2017). Brennan et al. (2020) reported the potential for very positive outcomes for families who engage in a future planning process while acknowledging the importance of the readiness of families to take action in this regard. However, Garnham et al. (2019) argues that a lack of adequate or ongoing support services, inadequate support and a limited supply of quality community residential provision ensures that the disability sector functions in a context of crisis which neither funds nor supports families to confidently plan for a timely transition from family-based care.

Research emphasises the need for proactive planning and more information on alternative housing in meeting the current and future needs of older people with intellectual disabilities. In one study, early planning was viewed as essential for ageing family carers, who highlighted the long timescales involved in both letting ageing people with intellectual disabilities go from their place of residence and in securing suitable accommodation (Bowey & McGlaughlin, 2007). Family carers in

this study also stated that many moves occur in response to a crisis, resulting in service users being placed in an emergency placement that is not suited to their needs. This further illustrates the need for older people with intellectual disabilities to have more choice and control over their living arrangements and for them to be fully involved in planning processes before the need arises for a change of residence.

Social inclusion and social networks

The quality of life implications of social inclusion and participation are far-reaching for both the general population and older people with intellectual disabilities (McCausland et al., 2021b; Bigby, 2008b). Fundamental to the concepts of social inclusion and participation are informal relationships and friendships, as well as good social networks and connectivity, all of which have been associated with quality of life outcomes for people with intellectual disabilities (McCausland et al., 2021b).

A review highlighting the value of social relationships and interactions (Abdi et al., 2019) found that, for some older people with intellectual disabilities, relationships with family and friends were identified as the most important thing in their lives and that their families and close friends provided companionship and facilitated social and pleasurable activities. In several studies, participants reported experiencing social isolation and feelings of loneliness when the ability to sustain relationships and engage in social activities was lost due to physical impairments such as frailty, a lack of independence, and ill-health (Bunn et al., 2017; Centre for Ageing Better, 2015; Nicholson et al., 2012). Participants also reported being unable to enjoy social activities and hobbies due to these impairments (Nyman et al., 2017; Lawrence et al., 2009).

Recent research by McCausland et al. (2021b), examining the nature and quality of friendship for older people with intellectual disabilities living in Ireland, found that a large majority of participants (92.4%) had friends. However, half of the participants reported not having a close friendship or a 'best friend'. Furthermore, support staff were found to play an important social role in the lives of older people and a carer or service provider was the second most common best friend reported (McCausland et al., 2021b). However, the authors suggest that there is a uniquely precarious nature to the friendships of older people with intellectual disabilities for reasons that include a small social network, a lack of choice about who they interact with, limited opportunity to meet people outside of their family, co-resident peers, and paid support staff and the transfer of staff who they consider to be their friends.

The extent of older people with intellectual disabilities' involvement with their friends and family, and with the community, has been associated with their type of residence, the severity of their disability, the complexity of their needs, and their

age (McCarron et al., 2017b). For example, IDS-TILDA has found that older people with more severe to (McCarron et al., 2017b). Studies have reported that those living in dispersed housing and in smaller community-based group home settings, compared to larger group home settings, had larger social networks and more friendships with those who were not support staff, their family, or co-resident peers (Emerson et al., 2001; Emerson et al., 2000).

Employment and retirement

Employment and participation in meaningful activities have been associated with positive physical and mental health outcomes (McCausland et al., 2020; McGlinchey et al., 2013; Fesko et al., 2012), higher self-esteem, self-determination (Fesko et al., 2012), and a greater sense of quality of life (Burke et al., 2022) in adults with intellectual disabilities. Despite the obligation on States under the UNCRPD to safeguard and promote the realisation of the right of people with disability to work, across all the age groups, people with intellectual disabilities have much lower rates of employment than people without intellectual disabilities and face barriers to engagement in occupation which increases the risk of social exclusion and poverty (King et al., 2022; McCausland et al., 2020). King et al. (2022) found that IDS-TILDA participants who had poor physical health, difficulty getting around their home environment, or older age were less likely to engage in work and leisure activities. Although people with intellectual disabilities have low paid employment rates, many engage in some form of regular structured occupational activity such as a day programme or volunteering, which has been associated with better emotional and mental health (McCausland et al., 2020; Bigby et al., 2015). The study by King et al. (2022) emphasises the importance of increasing resources and opportunities available in the community to promote engagement in meaningful activities. They also argue that occupational therapists working with people with intellectual disabilities may play an important role in supporting ageing in place in the community, facilitating transitions to the community from residential facilities, and supporting meaningful engagement in activities. Similarly, in another study using data from the IDS-TILDA study, McCausland et al. (2020) reported that functional limitations predicted occupational status and that the social support of family and friends was strongly associated with being occupationally active.

The transition from paid employment and engagement in structured occupational activities to retirement poses challenges for older adults with intellectual disabilities (Innes et al., 2012). In studies exploring the experiences and perspectives of staff on ageing and intellectual disability, staff expressed concern about the risks of retirement, such as the potential for emotional distress associated with a change in lifestyle and a loss of access to services (Alftberg et al., 2021; Innes et al., 2012; Bigby et al., 2011). These concerns were echoed by people with intellectual disabilities in another study who expressed anxiety about retirement as they move into the age of retirement, due to the potential loss of continuity and loss of social support (Judge et al., 2010). Adults with disability who retire frequently lose

contact with staff and peers from employment or day programme services and fail to develop new avenues for social connections and community participation (Stancliffe et al., 2015; McDermott & Edwards, 2012; McCarron, 2011; Judge et al., 2010). Further, individuals living in group homes who retire, often require increased support at home, and due the limited availability of staff to provide such care, some older people with intellectual disabilities may stay in employment even beyond the usual retirement age of people without intellectual disabilities (Webber et al., 2010). Studies emphasise the importance of continued engagement in meaningful activity in mitigating these negative effects (Alftberg et al., 2021; Bigby et al., 2011). McCausland et al. (2020) argue that more lifelong learning opportunities for older people with intellectual disabilities is necessary to help them plan for the future and adjust to the transition from adult to older adult, in order to avoid the potential negative consequences of retirement, such as a loss of social support, loneliness and isolation.

End of life needs

The health inequalities experienced by people with intellectual disabilities have been well documented. As previously mentioned, the literature indicates that older adults with intellectual disabilities experience higher levels of multi-morbidity (McCarron et al., 2013), higher mortality rates (Reppermund et al., 2020; McCarron et al., 2013), a higher prevalence of early-onset dementia (McCarron et al., 2017c; McCarron et al., 2014; Strydom et al., 2013), higher rates of avoidable deaths (O'Leary et al., 2018; Heslop et al., 2014) and inequalities in access to and experience of health care services, compared to the general population (McCarron et al., 2018b; McCarron et al., 2017a). It is also reported that these inequalities extend into the provision of end of life and palliative care (McCarron et al., 2017a; Lauer & McCallion, 2015; McCarron et al., 2015). A review in the UK, for example, found that people with intellectual disabilities are at greater risk of poorer quality healthcare at the end of life as some healthcare providers may lack understanding and awareness about how to support the end of life needs of older adults with intellectual disabilities (Care Quality Commission, 2016).

Despite the trend toward an increase in the life expectancy of people with intellectual disabilities and greater awareness surrounding the inadequacy of end of life care (Tuffrey-Wijne & Davidson, 2018; Ryan & McQuillan, 2005), the literature indicates that services and healthcare staff are mostly unprepared to meet the end of life needs of people with intellectual disabilities (Adam et al., 2020). A study by Tuffrey-Wijne and Davidson (2018) highlighted the complexity of providing end of life care to people with intellectual disabilities and outlines the common barriers to providing such care that they identified in the literature. These include: difficulties with communication which affect all aspects of care provision including pain management and assessment; difficulties with patient understanding and insight into their condition; a lack of involvement in end of life decision-making among people with intellectual disabilities; multi-morbidity and polypharmacy; complex social

circumstances; care transitions; a lack of experience among healthcare staff of people with intellectual disabilities; a lack of experience of illnesses, death, and dying; and a lack of knowledge about end of life care among staff (Tuffrey-Wijne & Davidson, 2018).

Similarly, in Ireland, McCarron et al. (2021) identified pain assessment and pain management as particular challenges faced by healthcare staff providing care to people with intellectual disabilities at the end of their lives, with staff describing instances where they were unsure if a person was in pain in the last 3 months of their lives. The findings also highlighted elements of care that appeared to contribute to more positive end of life experiences. These included good collaboration between intellectual disability services and palliative care services, improved communication with general health care services and being supported to die in one's own home. It is the preference of most people to remain living in their homes up to the end of their life and being cared for in a familiar environment may be even more important for people with intellectual disabilities (McCarron et al., 2017a; Bekkema et al., 2015b). While ageing and dying in place is supported by most healthcare staff, providing care in the home is often impacted by insufficient staff knowledge and experience, and a lack of equipment or resources (e.g., assistive mobility devices) (Bekkema et al., 2015b; Webber et al., 2010). McCarron et al. (2021) suggest that earlier planning about end of life care and earlier referral to palliative services is needed to support dying in place.

Advance care planning

Advance care planning (ACP) is one of the main approaches used in managing end of life and palliative care needs (Voss et al., 2020; Detering et al., 2010). It is a process of planning and documenting one's own end of life preferences (McKenzie et al., 2017) and is defined as a "person-centred, ongoing process of communication that facilitates patients' understanding, reflection, and discussion of goals, values, and preferences for future care" (Rogne & McCune, 2013, p. 228). ACP has been shown to improve end of life care and patient and family satisfaction and reduce stress, anxiety and depression in the family members of deceased individuals (Bernacki & Block, 2014; Detering et al., 2010). A systematic review carried out by Martin et al. (2016) among nursing home residents showed that ACP led to a reduction in unwanted medical interventions at the end of life and to more actions that supported the wishes of residents. While ACP could potentially improve end of life care, the tools and methods used are varied and the outcome measures used in existing studies are highly variable (Martin et al., 2016; Detering et al., 2010). Furthermore, the literature indicates that intellectual disability services are largely unprepared to meet the end of life needs of people with intellectual disabilities and that healthcare staff and families are unsure about how and when to approach end of life conversations (McCarron et al., 2017a). In response to this, IDS-TILDA developed the 'Glancing Back, Looking Forward' planning toolkit for health care staff which includes a suite of easy-to-read materials to facilitate end of

life conversations with the individual, and to enable autonomy regarding their own death (McCarron et al., 2017a).

Measuring outcomes of service

The following section provides an overview of outcome measurement in disability services, including the purpose of measuring outcomes, what it encompasses, and the related challenges.

Existing research suggests that care systems do not always adequately meet the needs of people with intellectual disabilities highlighting the need within the intellectual disability service system for more consistent and responsive services that support positive outcomes (Townsend-White et al., 2012). Prior to the development of national standards for disability services (HIQA, 2013) there had been limited formal regulation of disability services in Ireland, with a lack of mandatory standards and no external oversight (National Economic Social Council, 2012). There has also been a lack of focus on outcomes, which 'are the effects on the individual of the services or supports received' (National Economic Social Council, 2012, p. ix) and little accountability in terms of the quality of service delivered in Ireland.

Historically, funding bodies and service providers monitored public services by measuring inputs, which measure resources related to a certain programme (e.g., funding; staffing) and outputs, which measure the results achieved through the provision of services (e.g., number of people supported) (NDA, 2019; Quilliam & Wilson, 2011). However, in recent years, with the shift toward person-centred care, there is increasing emphasis being placed on supporting individuals to achieve personal outcomes and a greater interest in determining the outcomes of services and supports (NDA, 2019). According to the NDA (2016, p. 2):

An outcomes focus shifts the emphasis to achieving outcomes and not only to undertaking activities and delivering services. Outcome indicators seek to measure the impact of disability services on the lives of people with disabilities. This is different from measurement of inputs (such as number of staff) or measurement of activities (such as number of personal assistance hours delivered).

Purpose of outcome measurement

While the overall purpose of outcome measurement in disability services is to ensure that each individual receives the care and support that is needed to meet their personal goals and have a good quality of life, outcomes can be measured at different levels and for different purposes:

- At the individual level, outcome measurement can be used to monitor individual progress towards accomplishing personal goals on the quality of life outcome domains;

- At the service level, standardised outcome measurements or indicators can be used to evaluate service quality and to assess value for money;
- Data from outcome measurement at the individual and service level can be used to support quality improvement systems in disability services by identifying gaps in service provision;
- Outcome measurement can also be used for quality assurance purposes to ensure that services deliver outcomes and demonstrate compliance with policies, standards and regulations. (NDA, 2019)

The 'Value for Money Policy Review' (VFMPR) (Department of Health, 2012) recommends outcome measurement at the personal, organisational and programme levels to improve personal outcomes for people with disability and to improve service quality in Ireland. It is important that disability services are accountable for the care that is being delivered and know what outcomes people are achieving in relation to the public money invested (NDA, 2016; Burgess et al., 2015). As the primary funders of disability services in Ireland, the HSE also needs to know what outcomes are being achieved at both the service and programme levels (NDA, 2016).

Quality of life domains framework

Over the last decades, quality of life has been advocated as an indicator to evaluate public services and is used in service planning and delivery (Rand & Caiels, 2015). In 2016, in line with VFMPR recommendations, and following extensive research and public consultation, the NDA developed a Quality-of-Life Outcomes Domain Framework to assess outcomes for people using disability services in Ireland.

The framework includes nine high-level quality of life domains which propose that persons who use disability services (NDA, 2019):

1. Are living in their own home in the community
2. Are exercising choice and control in their everyday lives
3. Are participating in social and civic life
4. Have meaningful personal relationships
5. Have opportunities for personal development and fulfilment of aspirations
6. Have a job or other valued social roles
7. Are enjoying a good quality of life and well being
8. Are achieving best possible health
9. Are safe, secure and free from abuse

These outcome domains align with the Health Information and Quality Authority (HIQA) Residential Standards, the Interim Standards for New Directions and the United Nations Convention on the Rights of Persons with Disabilities (UNCRC) (NDA, 2019). In addition to the quality of life domain framework, the NDA developed a Quality Framework for the HSE (unpublished) focusing on the predictors of outcomes for people with disability. These predictors include elements of services and supports that facilitate the attainment of personal outcomes (NDA, 2019) such as Active Support (enables people with intellectual disabilities to engage in meaningful activities and relationships), person-centred planning, and access to transport.

Measurement tools

Different tools are used to measure outcomes at the individual level and at the service level, and these tools can be mapped against the Quality of Life Outcomes Domain Framework.

The Personal Outcome Measures Tool

One example of a tool that is used to measure outcomes at the individual level is the Personal Outcome Measures Tool (POMS) developed by the Council on Quality and Leadership (CQL) in the U.S. This tool is used by some services in Ireland, and across other jurisdictions including the U.S., Canada and Australia (NDA, 2019; National Economic Social Council, 2012). The POMS is an individualised outcomes planning and monitoring tool that can be used to guide person-centred planning and assesses quality of life as defined by a person and determines whether the supports provided by a service align with the self-defined goals of the individual (NDA, 2019). It is responsive to the individual's needs, focusing entirely on their perspective and reflects the principles of self-determination. Outcomes are measured against five domains (Council on Quality and Leadership, 2022):

- My Human Security
- My Community
- My Relationships
- My Choices
- My Goals

Within each of these domains are indicators that guide decision making about the presence of outcomes. For example, the following indicators can be found under the domain 'My Choices':

- People choose where and with whom they live
- People choose where they work

- People choose services

National Core Indicators Instrument

Standardised outcome measurement tools are used to assess outcomes at the service level (NDA, 2019). The National Core Indicators (NCI) instrument is an example of such a tool that is widely used across the U.S. to evaluate service quality for people with intellectual and developmental disabilities (IDD), and at the Federal level, is used to benchmark service quality. The NCI includes a range of indicators that are organised across key domains: Individual Outcomes; System Performance; Health, Welfare and Rights. Data is collected through an in-person adult consumer survey, three family surveys and a staff stability survey, which looks at issues such as staff turnover (NCI-IDD, 2020).

With the POMs, people define their own outcomes based on their own experiences and from their own perspective. Whereas the NCI tool is a standardised tool that uses survey questions that are universally relevant (NDA, 2019). Therefore, the type of tool used is dependent on the purpose of outcome measurement.

Challenges in outcome measurement

A number of challenges associated with outcome measurement have been identified in the literature. For example, a literature review by Quilliam and Wilson (2011) on outcome measurement in disability services illustrated that developing tools to effectively measure outcomes such as social and community participation and self-determination is challenging because it is difficult to convert these abstract concepts into measurable outcomes.

Quality of life should ideally be measured using self-report (Rand & Caiels, 2015). Therefore, outcome measurement for people with more severe/profound levels of intellectual disabilities is another key issue, as impaired communication may affect their ability to outline their goals, express their satisfaction with support, and evaluate the impact of services on their quality of life (Nieuwenhuijse et al., 2019; Rand & Caiels, 2015). The measurement tools designed specifically for people with intellectual disabilities require a certain level of cognitive ability, which may lead to evaluators using proxies to assess quality of life, such as conducting interviews with family, friends or other healthcare professionals who answer questions on their behalf (Bigby et al., 2014; Hartnett et al., 2008). However, a number of studies on measuring outcomes in people with intellectual disabilities have reported the use of a proxy as a limitation (Nieuwenhuijse et al., 2019; Verdugo et al., 2014; Petry et al., 2009; Hartnett et al., 2008). The Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities recommend using behavioural observation as an alternate approach to self-report when communication is impaired (NDA, 2019).

Another key challenge in relation to outcome measurement is the issue of attributing any given activity or intervention to an outcome, as attaining outcomes is multifaceted in nature (Cook, 2017). There are multiple interacting factors that can have an impact on a person attaining their goals, such as individual characteristics, support from social networks, financial support, health status, and the changing health and social care needs of a person with intellectual disabilities as they age. Therefore, it is more helpful to assess the contribution of services to attaining outcomes rather than attributing outcomes solely to disability services (NDA, 2019; Cook, 2017). However, many tools used for outcome measurement do not directly assess the contribution of a service to attaining outcomes.

Recommendations for improvement

The NDA (2019) recommends the following approaches to improve outcome measurement in disability services:

- While compliance with policies, standards and regulations is an essential component of service provision, it is crucial that quality assurance and improvement systems include individual assessments of quality of life outcomes to ensure that services deliver the preferred and the intended outcomes. They suggest that HIQA could include an outcomes-focus in their quality assurance processes and could evaluate outcome indicators and predictors in the outcome domains framework.
- Outcome measurement should include evaluation of personal outcomes at the individual level and measuring outcome indicators at the service level
- At the individual level outcomes can be measured using person-centred tools such as the POMs or the Goal Attainment Scaling (GAS) tool. In addition, random checks could be conducted with a number of individuals to assess whether their person-centred plans align with their quality of life outcome goals. Observation should be used for those with severe or profound intellectual disabilities.
- At the service level standardised outcome measurement tools such as the NCI can be used to benchmark quality of disability services. Evaluating the presence of predictors of outcomes should also be considered in terms of outcome measurement at the service level. This can be useful for assessing whether services are providing the supports required for attaining quality of life outcomes. This can be achieved through the use of standardised observation or interviews.

Further to these recommendations, in their report on outcome measurement, the NDA provide an overview of the types of approaches to measurement that can be used for the nine quality of life domains. As an example, the following approaches can be used for Outcome domain 1: 'Living in one's own home in the community':

- Standardised indicator: Did you choose where you live? Do you choose whom you live with? Do you have a key to your accommodation? Are you happy with your accommodation?
- Observation: Assess if person has access to all areas in his/her home and garden and can come and go in home and garden as and when he/she appears to want to. Assess if home is adapted to his/her needs in terms of size, design, location, etc., and if person has his/her own possessions around the home.
- Outcome predictors: Does person have access to transport and to local community facilities and to personal assistants in the community?
- Open-ended interview questions: Do you want to move house? What are your goals? Have services supported you to attain these goals? How have they done this? (NDA, 2019, p. 14)

Challenges to service provision

The provision of services to people with intellectual disabilities in Ireland has shifted from a medical model of care toward a social care model that focuses on choice, social inclusion, and the rights of people with intellectual disabilities (McCarron et al., 2018b). However, despite these positive policy changes, disparities in service provision continue to exist for people with intellectual disabilities and complex care needs. Existing service provision remains largely unprepared to meet the needs of older people with intellectual disabilities and is characterised by a growing demand for disability and age-related services, limited availability of specialist services, health and disability professionals with limited skills and training in ageing and intellectual disabilities, and a lack of coordination between ageing and disability sectors.

The provision of services to people ageing with intellectual disabilities, coordination between ageing and disability services, and the barriers to accessing mainstream health services will be detailed in the following section.

Current and future provision of disability services

In Ireland, people with a disability may be supported through general community health and social services (Department of Health, 2021a). These mainstream services are complemented by specialist community-based services which are delivered to about 9% of people with a disability (Department of Health, 2021a; 2020a), through a range of interventions including adult day care, support for community engagement, disability allowances, multidisciplinary therapies, personal assistant services, respite care to support carers, specialist end of life care, rehabilitation, home help, aids and appliances, and early intervention teams (Department of Health, 2020a; Linehan et al., 2014). As of 2014, the largest staff cohort within these services is support staff (47%), followed by a grouping of nurses, social care staff, and therapists (43%) (Linehan et al., 2014). The majority of

specialist disability services are delivered in the community by voluntary, non-profit organisations, with the remaining services delivered directly via the HSE (Linehan et al., 2014).

In recent years there has been an increased need for the provision of community disability services in Ireland. According to The National Ability Support System (NASS) - a national database of persons in receipt of or who require disability services – 36,649 people were registered as receiving or needing disability services as of December 2020, an increase of 64% from 2019 (Casey et al., 2020). While the proportion of service users with intellectual disabilities registered on the NASS decreased since 2019, intellectual disability was the most reported disability in 2020, followed by neurological disability and autism. Eighteen percent of people on the database were aged 55 years and older. The following data on service use was captured in the NASS 2020 report: 66% of service users accessed at least one specialist support; 63% accessed at least one day service; 21% were in receipt of residential services. The number of people availing of residential services increased from 5,297 in 2019 to 7,535 in 2020. Of these, the majority (93%) had an intellectual disability and were aged 40 years and older (79%). It is important to note, though, that NASS does not capture data about people with intellectual disabilities who are not already in receipt of services but who may be in need of such, particularly as they and their family members age.

The data indicate that a high level of unmet need for disability services continues to exist in Ireland and that this level of unmet need will continue to grow as the disability population ages (Department of Health, 2021a). For example, the Review of Disability and Social Care Demand and Capacity Requirements by the Department of Health in Ireland (2021a), reported that the number of adults with intellectual disabilities needing access to specialist disability supports is projected to increase by a sixth by 2032, with the greatest need predicted for those aged 55 years and over. A public consultation with almost 800 people including people with intellectual disabilities was undertaken to inform the development of a Disability Action Plan (2023 – 2025) ((Department of Health, 2022).(Department of Health, 2022) Participants with a disability prioritised funding for multidisciplinary therapy services for adults, early intervention, personal assistance services, day services, and respite. People with intellectual disabilities who attended face-to-face consultations emphasised flexible support for living at home, involvement in the community, jobs and social networks. On the other hand, carers of adults with disabilities prioritised funding for respite services and short breaks, day services, community supports, home help and supported housing/residential care. Submissions from disability organisations in Ireland argued that current service models were outdated and overly focused on service providers and that a radical overhaul was needed, with a greater focus on person-centred and responsive supports. They cautioned against increasing the capacity of services before transforming the quality and effectiveness of these services. They also argued that

the funding model needed to be overhauled to achieve service transformation and many organisations saw personalised budgets/individual funding as key to reform, and necessary to move away from the provider-led model that currently exists.

Barriers to accessing mainstream health services

It is widely recognised that the prevalence of chronic health conditions in people with intellectual disabilities is higher than in the general population and that their healthcare needs are not being adequately met by general healthcare services (García-Domínguez et al., 2020; Burke et al., 2019; McCarron et al., 2018b; McCallion et al., 2013b; Haveman et al., 2011). In the report, “*Shaping the Future of Intellectual Disability Nursing in Ireland*” (McCarron et al., 2018b), participants in focus groups, including family members and people with intellectual disabilities, outlined key barriers to healthcare, including communication difficulties, difficulties in accessing healthcare, and a reliance on others to support them to access care (McCarron et al., 2018b). Parents described generic adult health services as being unsuitable for people with intellectual disabilities, an issue that was underpinned by a lack of coordinated care and described generic healthcare professionals as lacking in communication skills. This issue was echoed by participants with intellectual disabilities who described health professionals’ lack of communication skills as extremely distressing. Communication issues have also been identified by primary healthcare teams as a barrier to care for older people with intellectual disabilities in other studies (Ziviani et al., 2004; Powrie, 2003). For example, Ziviani et al. (2004) reported that GPs felt they were ill-equipped to meet the needs of people with intellectual disabilities whose needs would be best managed outside of primary care services due to communication issues and a lack of knowledge and skills on the part of the doctors.

Despite other studies suggesting that mainstream healthcare professionals hold positive attitudes toward people with intellectual disabilities (Truesdale-Kennedy et al., 2011), people with intellectual disabilities and their carers have reported experiencing stigmatising attitudes, discrimination, and negative comments in mainstream health services (Gibbs et al., 2008; Mason & Scior, 2004). Stigmatising attitudes may influence healthcare professionals’ ability to provide adequate care and act as a barrier for people with intellectual disabilities in accessing mainstream health services (Pelleboer-Gunnink et al., 2017). A systematic review by Pelleboer-Gunnink et al. (2017), found diagnostic overshadowing to be a key feature of studies, with the tendency of clinicians to overlook symptoms of mental health problems and attribute them to being part of ‘having an intellectual disability’.

In the report by McCarron et al. (2018b) nurses in focus groups suggested that family and service user’s experience of healthcare provision would be enhanced by the assistance of a professional, who could help them navigate and access mainstream healthcare services, as well as social and community services. Literature highlighting the health inequalities experienced by people with

intellectual disabilities emphasises the need for nurses with specialist skills and knowledge to support and enable people with intellectual disabilities to access mainstream healthcare services and receive high-quality health care (Doody et al., 2022; Reppermund et al., 2020; McCarron et al., 2018b; Trollor et al., 2017). In Ireland, the Registered Nurse in Intellectual Disability (RNID) may play an important coordinating or liaising role, forming a central link between services and could be key to supporting person-centred care and health outcomes for older people with intellectual disabilities (McCarron et al., 2018b; Brown et al., 2016). In the UK, such liaison nurses have been shown to improve the care that individuals receive, by preparing patients and staff for hospital admissions or outpatient visits, educating and supporting staff to communicate effectively through role-modelling effective communication and care, advising on questions of capacity to consent to treatment, and linking service users and providers to other specialist intellectual disability services (Gibbs et al., 2008). However, support from RNIDs mainly exists for those living in residential centres, as the majority of RNID's work in these settings, and support from community RNIDs is typically only provided to those who have moved from a residential centre to a community setting, and this structure fails to encapsulate those living at home with family (Doody et al., 2011; Sheerin, 2004). Doody et al. (2011) suggest that a change in service provision and greater collaboration between RNIDs, primary care teams and families is needed to address this issue. The authors also state that the focus should be on ageing and disability services coordinating their resources to achieve optimum outcomes for people with intellectual disabilities.

Uncoordinated ageing and disability services

A key issue in relation to care for older people with intellectual disabilities is that the care pathway is very unclear, with service provision often fragmented and uncoordinated, and as a result, health and social care services may be unprepared to meet their complex and unique needs (Doody et al., 2011). Historically, the provision of care in Ireland has been organised into separate categories including older people, people with physical disabilities and people with sensory disabilities, people with intellectual disabilities, and people with mental health difficulties (NDA, 2006) with the distinction between disability and ageing programmes defined by reference to chronological age (65 and over) (Leahy, 2018). There is little coordination between ageing and disability services, with separate funding mechanisms in place and the responsibility for each group falling on different 'Care Group Managers' (NDA, 2006).

The division between population groups creates challenges for people who may be impacted by both ageing and disability (NDA, 2006). Older people who experience disability for the first time in later life after the age of 65 may only engage with older people's services and may not have access to appropriate disability services. On the other hand, people with intellectual disabilities who have long-term contact with disability services may continue to receive the same services after the age of

65, or there could be a disruption to care if they are transferred to older people's services (Leahy 2018). These mainstream services tend to be ill-equipped to support the specific needs of people with intellectual disabilities (Slevin et al., 2011). In a review by Innes et al. (2012), the main theme that emerged from studies about service provision was the difficulty in identifying the individual's needs. In settings designed for people with intellectual disabilities, changes experienced due to ageing were attributed to old age, while in generic ageing settings such as older people's homes, changes were attributed to the persons' intellectual disability, with authors stating that people were not receiving appropriate care and treatment (Innes et al., 2012).

One group thought to be particularly disadvantaged by the division between services is people with intellectual disabilities who develop dementia before the age of 65. There has been no clear provision within services for this group, as dementia services are largely based within older people's services (Leahy, 2018). People with intellectual disabilities who have dementia may have a differing course and progression of the disease, and as a result, the supports required by people with intellectual disabilities may differ from those required by the general population (McKenzie et al., 2020). Therefore, a key issue that has emerged in relation to service provision in Ireland and other countries has been that of whether older people with intellectual disabilities with a diagnosis of dementia should be cared for by older people's services or whether care should be provided by specialist services under the umbrella of intellectual disability (McCarron & Lawlor, 2003).

In Ireland, a recent response has been the development of specialist services to support people with intellectual disabilities ageing with dementia, including specialist memory clinics (McCarron & Lawlor, 2003). In 2022, the National Intellectual Disability Memory Service (NIDMS) was established in Ireland to provide access to specialist memory assessment, diagnostic and treatment services for people with intellectual disabilities presenting with memory concerns, and is delivered by a nurse-led multidisciplinary team (TCAID, 2022). The service also aims to provide an adaptable model of care that can be incorporated into existing dementia assessment and diagnostic services and will provide regional satellite centres that will work in partnership with these existing services (Dementia Pathways, 2022).

Conclusion

This literature review provides an overview of the care and support needs of older adults with intellectual disabilities and complex-age-related conditions. The main issues affecting older people with intellectual disabilities, including physical, psychological, and social issues, as well as the challenges to providing care and the key features of a model of care for older people with intellectual disabilities are addressed.

Responding to the complex needs of older people with intellectual disabilities is a challenge. The current response to care is characterised by a lack of future planning, limited resources and funding and a care system that is fragmented, with ageing, intellectual disability and dementia services often working in silos. To address these gaps in service provision, there is an urgent need for a comprehensive and integrated approach to care. An integrated care model requires proactive planning, connected services, a multidisciplinary workforce, and support for familial and social networks.

Chapter 2: Overview of Fieldwork

Introduction

The following section provides an overview of the methods used for data collection in the study. The research aims, objectives and design are presented, followed by a description of phase 1 and 2 data collection approaches, and data analysis. A separate technical Annex provides the search terms used in the literature review, the focus group and semi-structured interview schedules, the questionnaire and the follow-on costing survey.

Study aim and objectives

The aim of this study is to examine to the care and with intellectual disabilities and complex age-related conditions. The objectives of the research are to:

- Review the existing evidence base regarding the care of older adults with complex age-related conditions
- Generate additional evidence regarding current models of care
- Generate additional evidence regarding expected future needs
- Compare outcomes and quality of life in different care settings

Research design

The study utilised a descriptive mixed methods design, using two phases of data collection.

Data collection: phase I

Phase I of data collection sought to explore the perspectives of senior staff and managers in intellectual disability services and nursing homes on the following:

- Current models of care in specialist and non-specialist settings
- Factors influencing decision-making on care needs
- Expected future need
- Experiences of supporting 'transitions' (i.e., geographical, social, health and activity/work),
- Current outcomes and how these outcomes affect quality of life in the different settings.

Data was collected using focus groups, interviews, and a survey questionnaire.

Focus groups

Inclusion criteria

The general inclusion criteria for all focus groups were that participants had to be aged 18 years or older and be able to consent to participate. To be considered eligible to participate in phase I focus groups, participants had to have been:

- Senior nursing, social or service managers **and**
- Employed in an intellectual disability service for older adults with intellectual disabilities and offering specialist ageing facilities **or**
- Employed in an intellectual disability service for older adults with intellectual disabilities but not offering specialist ageing facilities

Sampling and recruitment

Intellectual disability services were purposively sampled from the IDS-TILDA service database. These included services that provide specialist ageing facilities for older adults with intellectual disabilities and services that do not provide specialist ageing facilities but do cater for older adults with intellectual disabilities. Service management (i.e., CEOs) from eight services were contacted, four from specialist ageing services, and four providing non-specialist ageing services, requesting their support in recruiting a maximum of four senior staff members to participate in online focus groups and to nominate a gatekeeper who would be responsible for distributing a letter of invitation and information sheets to participants in each service.

Data collection method

Four semi-structured focus groups with a total of 16 participants were conducted online via Zoom between the 2nd and 20th of September 2021. All focus groups were conducted by a moderator and assistant moderator. The focus groups were guided by an interview schedule.

Quality of life themes were considered through the conceptual framework identified by Schalock et al. (2002).

In addition, a one-to-one interview was carried out with another participant from a specialist ageing service who was not available to attend the focus groups.

Survey

Inclusion criteria

The criteria for inclusion in the online survey included the criteria set out for phase I focus group participants.

Sampling and recruitment

Using the Trinity Centre for Ageing and Intellectual Disability's (TCAID) comprehensive mailing list, senior managers from 80 residential adult intellectual

disability services were invited to take part in the online survey questionnaire. A letter of invitation with an embedded link to the online survey and information sheets was sent by email to senior managers on February 14th with an initial deadline of 2 weeks. Due to low response rates, the deadline was extended to March 25th and a reminder email was sent leading up to this deadline.

Data collection method

The online survey was developed using Qualtrics. Questions designed to explore the economic aspects of complex needs were developed by a Health Economist. A draft survey was presented to the NDA for agreement.

The final survey instrument included 38 items consisting of Likert scale questions, multiple-choice questions, lists for rating, and open-ended questions to allow participants to elaborate on their answers. The time of completion was estimated to be approximately 45 minutes, during the piloting phase of the survey.

To address the aims and objectives of the study the survey questions captured information on the following:

- The type of service model/approach used
- The needs of older adults with intellectual disabilities including complex age-related health needs, and housing and accommodation needs
- Responding to health needs
- End of life issues, advance care planning, and bereavement
- Outcomes and quality of life indicators
- Costing

Toward the end of the survey, participants were asked a question about whether they would be interested in receiving a follow-on survey exploring the cost implication of supporting older people with intellectual disabilities and complex age-related needs in greater detail.

The detailed findings from the survey are included in the Technical Annex.

Follow-on costings survey

A second, follow-on survey was developed based on the findings from the first survey and aimed to explore the financial implications of age-related complex care needs for services, including the cost implication of housing modifications, older adults with intellectual disabilities relocating to another home and staffing issues related to their service. The survey was developed in Qualtrics with input from a Health Economist within TCAID.

Participants were asked to identify a specific location/living space within their service that addressed the needs of older people with intellectual disabilities and answer questions with reference to the chosen accommodation. The time of completion of the survey was estimated to be approximately 15 minutes.

Four participants in the main survey agreed to receive the follow-on, costings survey. The online survey, along with an invitation letter and information sheet, was sent by email to participants on June 20th, with a deadline of 2 weeks. The deadline was extended by one week to July 4th, to ensure that all participants were given the chance to complete the survey. Two participants completed the follow-on survey.

Data collection: phase 2

Phase 2 aimed to explore the experiences and outcomes for support staff, older people with intellectual disabilities, and family members when faced with age-related challenges including their experiences of navigating health care transitions, in tandem with social, geographical, and activity/work transitions. Data were collected during this phase using focus groups and interviews.

Focus groups

Inclusion criteria

Inclusion in the phase 2 focus groups was based on the following criteria:

- Nursing, health and social care or key worker staff (not in a senior position) **and**
- Employed in an intellectual disability service for older adults with intellectual disabilities and offering specialist ageing facilities **or**
- Employed in an intellectual disability service for older adults with intellectual disabilities but not offering specialist ageing facilities **or**
- Employed in a nursing home where older adults with intellectual disabilities have been accommodated

Sampling and recruitment

The same recruitment process was carried out for the phase 2 focus groups. Service management in intellectual disability services who were purposively sampled in phase 1 were asked to permit a maximum of four direct care staff per service to take part in focus groups. Letters of invitation and participant information forms were sent to direct care staff, via previously identified gatekeepers. Again, at the time of recruitment, nursing homes were experiencing staffing shortages due to COVID-19 and as a result, it was not possible to recruit nursing home staff to phase 2 of the study.

Data collection method

Four semi-structured focus groups were carried out online between February 16th and March 1st, two with direct care staff in an intellectual disability service providing specialist ageing facilities and two from intellectual disability services without specialist ageing facilities. A total of nine participants took part in the focus groups. Five out of eight of the services contacted responded to the request for participants.

Phase 2 focus groups explored the same subject areas as covered in the phase 1 focus groups:

- Factors influencing decision-making on care needs
- Expected future needs
- Experiences of 'supporting transitions'
- Current outcomes and how these affect the quality of life of service recipients.

Interviews

Inclusion criteria

Participants without intellectual disabilities were required to meet the following criteria:

- Aged 18 years or over
- Immediate family member of living or deceased older adult with intellectual disabilities who is/was accommodated in:
 - An intellectual disability service for older adults with intellectual disabilities and offering specialist ageing facilities or
 - An intellectual disability service for older adults with intellectual disabilities but not offering specialist ageing facilities or
 - A nursing home.
- Participants with intellectual disabilities:
 - Aged 40 years or over
 - Older adult with mild or moderate intellectual disability
 - Self-advocating by self-declaration
 - Have the capacity to consent to take part in this study
 - Consent to inclusion and participation in the study

Sampling and recruitment

Seven intellectual disability services as well as The National Federation of Voluntary Service Providers, Inclusion Ireland, The National Advocacy Service and Citizen Advisory Panellists were contacted and asked to identify potential participants and to pass on a letter of invitation and information about the study.

Data collection method

Fifteen semi-structured interviews were carried out in a place of convenience for interviewees, between April 15th and July 8th, 2022. Two interviews were conducted over the phone, two were online over Zoom, and the remainder were face-to-face either in a day centre, a residential centre, or their home. The duration of interviews varied, ranging from approximately 8 to 55 minutes, with the average length of interviews lasting approximately 22 minutes.

The purpose of these interviews was to explore the perspectives of staff, service users and family members. The interviews were framed by an interview schedule which explored:

- The interviewee's experience and outcomes when faced with age-related challenges
- Experience of health-related and other 'transitions'
- Experience of support during these 'transitions'
- Perspectives on their current outcomes and how these affect their quality of life.

Data analysis

Qualitative analysis

The audio recordings from focus groups and interviews were transcribed verbatim by a professional company, and the researchers reviewed these written transcripts for accuracy. The qualitative data was analysed using the reflexive thematic analysis approach proposed by Braun and Clarke (2006) whereby data was coded, and over-arching themes were identified. The research team discussed how the themes fit with theoretical perspectives and current policy as identified in the literature review regarding current practice and the processes which drive it, current and planned provision for ageing, and perceived future need. Themes were also considered in the context of the IDS-TILDA dataset.

The main overarching themes identified in the qualitative data were:

- Approaches to service
- Providing service to meet individuals needs
- Responding to individuals' needs

Quantitative analysis

The quantitative data, obtained through the two online questionnaires, were analysed using SPSS Version 21 (IBM Corporation 2012). Statistical tests were performed to establish whether statistically significant differences between two overarching categories of service approaches (those with specific ageing pathways and those without) were present in the data. These were explored using Fisher's Exact Test but no statistically significant differences ($p < 0.005$) were identified in respect of a range of complex ageing conditions. Services falling within each category described a mix of effective and limited/non-existent pathways. Thus, for example, 66.7% ($n=10$) of 'specialist' services indicated that they had an effective pathways for dementia care, with 33.3% ($n=5$) stating that they did not. Amongst 'non-specialist' services, 40% ($n=4$) indicated that they had an effective dementia pathway and 60% ($n=6$) did not. As no significant differences were identified, descriptive statistics were generated first to describe the demographic profile of individuals residing in intellectual disability care services for older people intellectual and to develop an overall picture of current service approaches and models of care for older people with intellectual disabilities and complex age-related needs, including the financial implications of complex age-related care needs for services.

Qualitative data within the surveys were coded thematically to identify themes that would help to uncover valuable insights and to support the interpretation of the quantitative data.

Ethical considerations

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Health Sciences in Trinity College Dublin. All researchers involved in the study were bound by and adhered to the national and international codes of good practice in research, and by professional standards within their disciplines. All participants received information sheets that outlined the study procedures, the risks and benefits associated with participating, and the protocols regarding confidentiality and voluntary participation. For the online survey, participants were asked to read information on the study and give informed consent before starting the survey. Before each focus group and interview, written or verbal consent was obtained from participants. Where verbal consent was given this formed part of the audio recording. To protect the confidentiality of participants, focus group and interview audio files were uploaded onto a password protected folder on a double-encrypted, password-protected TCAID computer and deleted from the audio recorders. The audio files were transcribed by a professional transcription company that had signed a Data Processing Agreement with the Data Controller for this study. Once transcribed, the audio recordings were deleted, and the transcripts were stored on the double encrypted TCAID computer available only

to the researchers. During transcription, all identifying information was removed, and participant names were pseudonymised.

Sample profile

In summary, qualitative data collection was undertaken through the conduct of four semi-structured focus groups with managers from services offering specialist ageing services (SS) and from services that offered a generic care pathway (GS). Four further focus groups were conducted with direct staff from both settings. Finally, 16 interviews were conducted, one with a service manager, and the others with older adults with intellectual disabilities, family members of older people who are receiving intellectual disability services and family members of older people with intellectual disabilities who are now deceased. Quantitative data was administered through the use of a survey questionnaire. Thirty-two completed questionnaires were returned (40%). Four participants indicated that they were interested in receiving the follow-on survey exploring costs associated with service provision. Of these, only 2 services completed the follow-up survey offering very limited insights into costing and funding challenges (Table 2).

Table 2: Details of participants/respondents across the study

Mode of Data Collection	Participants	No. of Participants
Focus groups (n=8)	Service managers	
	<i>Specialist service (SS)</i>	8
	<i>Generalist service (GS)</i>	8
	Direct care staff	
	<i>Specialist service (SS)</i>	5
	<i>Generalist service (GS)</i>	4
Individual interviews (n=13)	Service manager (SS)	1
	Older person with intellectual disability	7
	Family of older person receiving services	2
	Family of deceased older person	3
Group interviews (n=3)	Joint older persons with intellectual disability	2
	Joint family (Fam)/older person (OP) with intellectual disability	3 (Fam) 2 (OP)
Main survey (n=32)	Senior managers from adult intellectual disability services	32
Follow-on costings survey (n=2)	Senior managers from adult intellectual disability services	2
Total No. Participants		79

The occurrence of the COVID-19 pandemic during the timescale of this research resulted in significant challenges, not least in engaging with the nursing home sector where COVID-19 had a very significant impact. As a result, and despite repeated efforts over a protracted period, it was not possible to access nursing home input in the study. The findings, therefore, represent the perspectives of managers and staff from intellectual disability service providers and of people/family members of people who received care in such services.

The survey responses demonstrate that issues around ageing are of key relevance to services, with just over 28% of the services reporting that the older age group is already the dominant age group in their service or will be so within the next 5 years. Furthermore, almost 40% indicated that they expected that the share of service users in this age group will rise rapidly within the next 5 years and, although just over half the services were reported to have the resources “to some extent” to meet the needs of older people with intellectual disabilities as they age, less than 10% reported being able to fully meet these needs. Respondents overwhelmingly reported (93.3%, n=28) that complex age-related issues have implications for provision of service to older people with intellectual disabilities in their service.

Chapter 3: Findings: Approaches to services

Introduction

This study sought to explore models and approaches to care and service provision employed across intellectual disability services that provide a specialist age-related approach, those that do not have a specialist age-related approach and nursing homes, and to provide information on future needs. Whilst the delineation of services into the above three approaches appears quite clear, it quickly emerged that none of the participating services could be defined so clearly, with diverse approaches to care being adopted in all of the participating sites. Thus, services have developed formal/informal pathways which incorporated aspects of the aforementioned models. Many services surveyed also noted that the model used to guide the service response changed as complex needs developed (Specialist Services (SS): 75%; Generic Services (GS): 50%; Other (OTH): 83.3%). For the purpose of this section, rather than using the term 'models' we have opted to describe these as 'approaches.' A number of approaches emerged from the data. Three main approaches arose from the focus groups, namely, the *specialist service approach*, the *nurse-led approach* and the *health and social care approach* which appears to operate on a spectrum between conventional social care and an eclectic fusion of social care and nurse-led approaches. These along with a number of more specific approaches (such as *Living Well with Dementia*) were included in the subsequent survey. Respondents identified their approaches under the headings in Table 3 below:

Table 3: Service approaches identified across survey respondent settings

Model	All	SS	GS	OTH
Social model	75% (n=24)	81% (n=13)	90% (n=9)	33% (n=2)
Medical model	31% (n=10)	50% (n=8)	20% (n=2)	0%
Living Well with Dementia	50% (n=15)	75% (n=12)	10% (n=1)	33% (n=2)
Biopsychosocial	50% (n=15)	69% (n=11)	20% (n=2)	33% (n=2)

Whilst these differ in name and number from those identified in the focus groups, the details from those discussions suggest that the *medical* and *biopsychosocial models* align with the *nurse-led* and *health and social care* approaches, respectively, with the *Living Well with Dementia* aligning with the *specialist service* approach.

The medical and social models, which have been the focus of much discourse over the past decades have clearly influenced these three approaches and participants acknowledged those influences over time:

Yeah, I've worked in the service for twenty-five years. And when I first started, I suppose the model of care was very much a traditional approach. And I suppose I feel that we have improved so much since then. (Betty, D¹, SS)

...we would be very much of the social care model, it would have been very much the medical model up until about thirty years ago, but they were very, very progressive... [service name]...was one of the first to open up a community home. (Freda, D, SS)

...we have a combined model between social care and then a nurse led service as well. So there's still a large proportion of nurses working in the service especially in our residential but in day services it's a mixture...some of our services are totally social care led, some of the community homes with the younger age groups. Some of the more complex areas where people have additional needs, a lot of medical needs and are quite vulnerable there would be social care, care staff and registered nurses in intellectual disability. (Geraldine, D, SS)

The extent to which services utilise a combination of approaches is apparent in the survey responses presented in Table 3.

Whilst the social and medical models are often considered to be incompatible, the approaches to service described by participants pointed to a drawing together of aspects of both models. This was borne out in the survey responses: 50% (n=16) of respondents identified their services as having a specialist ageing facility (SS); 31.3% (n=10) reported that their services had no specialist ageing facilities (GS); and 18.6% (n=6) considered that their services were 'a mixture of the two' (OTH) with flexibility to move between both, drawing on internal or external resources. This was also manifested in the fact that there was no significant difference in the types of settings that were employed to meet older people's needs in either SS, GS and other service types. Thus, all three comprised a mix of congregated settings (Table 4):

¹ Participants are identified by pseudonyms, followed by a letters to identify which cohort they are from: D - direct care staff; M – manager; FAM – family member' OP – older person. Survey respondents' narratives are followed by the letter 'S'.

Table 4: Congregated setting types identified by survey respondents

	All	SS	GS	OTH
Congregated setting	37.5% (n=12)	37.5% (n=6)	50% (n=5)	16.7% (n=1)
Individual homes in the community	81.3% (n=26)	93.8% (n=15)	70% (n=7)	66.7% (n=4)
Clusters of homes in the community	18.8% (n=6)	18.8% (n=3)	20% (n=2)	16.7% (n=1)
In a home with family members	34.4% (n=11)	43.8% (n=7)	30% (n=3)	16.7% (n=1)
Nursing home for people with intellectual disability	3.1% (n=1)	0%	0%	16.7% (n=1)
Specialised dementia residence	21.9% (n=7)	25% (n=4)	10% (n=1)	33.3% (n=2)
Mainstream nursing home	21.9% (n=7)	35.7% (n=6)	0%	16.7% (n=1)

Specialist service approach

The first approach to service, the specialist approach, was described as one that is largely focused on meeting the needs of older individuals with intellectual disabilities with specific age-related complex concerns. Provision of specialist service was also seen to be something that was not location or unit-specific, but which could potentially be put in place, in the older person’s current living space:

...specialist services might try and be developed around them where possible.
(Michael, M, SS)

Unit-specific specialist services may cater for a wide range of complex age-related needs up to and including end of life care:

...our service would be classed as the ageing opportunity house. So, within the mid...[county name]...area we are the only house in [town name] and surrounding areas that can cater for people with ageing needs and intellectual disability...we have epilepsy, dementia, and we also have more medical needs like MS, rheumatoid arthritis, we have three people in wheelchairs where they would have been mobile in their life and mobility has now decreased significantly where we are using either steadies or hoists. But more so we are looking at like you know

we have some people that have developed even hemochromatosis, diabetes, cholesterol, high blood pressure...we'd hope that this would be the end of life unit for anybody that we care for. (Ingrid, D, GS)

However, across the three service types, dementia was identified as presenting the most significant challenge to meeting the needs of older adults in the service. The provision of specialist services to people with dementia clearly demands the availability of a multi-disciplinary skillset to meet the older persons' holistic needs:

...we've invested a huge amount of resources into this dementia, this specific house, where the staff are trained...it's a dementia team that's made up of an OT, an ANP, and a behaviour therapist. (Mary, M, SS)

One service reported using the Butterfly Model which focuses on 'delivering emotion-focused care that connects with people in a dignified, human way...[addressing]...the holistic needs of the individuals and supports quality of life for each person living with dementia across the whole of their lived experience' (Primacare Living Solutions, 2022). It is a humanistic and sensitive model without a medical or professional focus which often underpins dementia care in nursing homes. This was the approach which was also employed in some specialist homes for those older people with intellectual disabilities and a diagnosis of dementia, offering a pathway from early through to end-stage of the disease:

One of the homes supports people...at advanced mid stage dementia and there is...[sic]...admission criteria to enter this home setting. And the other home supports people at endstage dementia where they are offered palliative type care. (Sarah, M, SS)

...you must have a diagnosis of dementia to move into this particular home...[for]...everybody who has that diagnosis of dementia, who's living in the community. (Mary, M, SS)

Specialist service approaches tended to be directed primarily towards meeting the older person's needs in the presence of a specific (typically) health-related problem. As such, it drew on the skills and knowledge of specialist practitioners. One other approach that was largely focused on health needs was the nurse-led one.

Nurse-led approaches

Nurses have been at the centre of service provision to people with intellectual disabilities for many years and many approaches have continued to see them as key to service provision, particularly where health is a focus. It was widely acknowledged that nursing care was an important part of service but that this could be offered within intellectual disability services under a nursing-led approach:

...we are talking...[about]...reverting back to more of a nurse led model.
(Michael, M, SS)

...we use the Roper, Logan and Tierney model...we have got nurses on site each day. (Moya, M, SS)

The manifestation of this, in terms of the structuring of care was, in some sites, in the form of a disability service-based nursing home, but geared towards meeting the developing needs of older people with intellectual disabilities:

...it would be very much the nursing home model, because we are a specific retirement home for intellectual disability...people move from their own home into a nursing home... (Michael, M, SS)

...we saw the need of...not having a nursing home but a nursing home type model...we try to get resources into it, the expertise, the skills set in order to support people to age in place. (Claire, M, GS)

A key reason for such developments was the absence of appropriate accommodation within organisations where the ageing person with intellectual disabilities' needs could be met. Whilst nurse-led approaches were described, most participants did not consider generic nursing homes to be the best setting for providing service to older people with intellectual disabilities and some suggested that when this became a 'solution' to meeting the older person's needs, it represented a step backwards, out of tune with the values underpinning intellectual disability service:

...the nursing model in the nursing homes don't...[sic]...accommodate for other needs that a person with intellectual disability needs. (Carol, M, GS)

Indeed, it was considered that this could lead to negative consequences for the older person:

...people who were in a nursing home with...[intellectual and developmental disabilities]...have had significant adverse consequences because they have been misplaced in nursing homes when they are under sixty-five and no residential place.
(Anne, M, SS)

Nurse-led approaches prevailed in intellectual disability services for many decades but were questioned in the light of moves to community living, as the pendulum swung away from a medical model towards a social one. The health-related complexity now being seen early and late in the lives of older people with intellectual disabilities have necessitated approaches combining health and social care.

Health and social care approaches

Across all the service types, the social model was most frequently reported in the survey as one used to guide services (all: 75%, n=24; SS: 81.3%, n=13; GS: 90%, n=9; OTH: 33.3%, n=2). Some focus group participants saw nursing as a manifestation of the 'medical model' and, in the case of one service, they made a decision to move away from a nurse-led approach towards one grounded in social care:

We have tried to move away from the nursing home type scenario...while we have lots of nursing oversight, the people that are providing the hands-on care on a day-to-day basis would come from a social care model. (Jane, M, SS)

The social care approach was seen to be well suited to community-based situations:

...it's mainly a social model within the community...we are trying to keep them within their homes as long as possible. (Carol, M, GS)

...we'd have a lot of focus on our social care model with a person-centred approach and that would be regarding quality of life and how they can enhance a person's participation in the community as much as possible. (Moya, M, SS)

However, the staffing structure of social care houses and the lack of flexibility around resourcing staffing may limit the support that can be given within these settings as described by a survey respondent:

Staffing issues as most social care houses have a sleep over staff only. If a service users' needs change and require a waking night staff due to financial constraints a move of unit/house is proposed. (S)

In an appropriate environmental setting, some social care staff were confidently supporting service users with a myriad of complex conditions to ensure that service users could live in their homes for as long as possible. Many social care staff have become increasingly skilled and confident in dealing with significant health conditions:

Yes, it's social care, we've learnt an awful lot about medical conditions though, very much so. We've had to become kind of quite comfortable with quite serious medical conditions in terms of particularly uncontrolled diabetes, and medical conditions that come along with ageing. (Hannah, D, GS)

However, other services brought together a variety of components to create eclectic approach to care. It was acknowledged that nursing remained involved in some settings, *working collaboratively* (Moya, M, SS), something which was common

across a number of the services represented at the focus groups. Bringing together health and social care was not always easy though:

But because people's needs are changing, we are trying to merge both medical and social and that is causing a lot of difficulties. (Carol, M, GS)

This appears to be linked to the fluidity of the older person's needs and the requirements for service to be able to respond in an agile manner. It may also relate to the lingering perception that the medical and social models are irreconcilable and cannot exist together. Caring for people with complex needs shows that this is not necessarily the case:

Where we are very much a social model but as people age, I suppose there's a huge recognition the need for that nursing model of supports. (Claire, M, GS)

Some of the more complex areas where people have additional needs, a lot of medical needs and are quite vulnerable, there would be social care, care staff and nursing RNIDs. (Geraldine, D, SS)

...we're a social care model so when it comes to the medical, a lot of residents would have moved on to a nursing home, would have been supported with the MDT, with family, myself and the day service, we'd work together. (Kate, M, GS)

This was particularly relevant in the case of conditions such as dementia, the prevalence of which is significant in the ageing intellectual disability population, and especially in those with Down syndrome. Indeed, Alzheimer's dementia was noted by many of the participants:

...the model of care is living well, as people age and that is the key thing that we're trying to come out...living well through the continuum of dementia was hugely important. Making sure that people had all the supports in place to ensure that they have everything that they need to live well, particularly with dementia. (Sarah, M, SS)

...we have set up two high support homes and we are supporting people as they age with complex needs...we have a high incidence of dementia, so they are supported now to remain in their homes surrounded by their friends and their family. We've had to change our model of care from the social model to the biopsychosocial model and that has proven very positive... (Emily, M, GS)

Despite the conceptualisation of services being categorizable under 'ageing specific' and 'ageing non-specific' labels, it was very apparent that most organisations actually met the needs of their ageing service users in a variety of settings: generic areas without a specific focus on age; homes in the community; campus settings; and specialist areas centred on service older people:

On campus we have...people living here and they're all in big bungalows...[and]...two community settings with small bungalows in two different locations...out in the community... (Moya, M, SS)

This was due to the fact that, despite a desire to meet the older person's wishes to...

...remain in their home surrounded by the people that knows them best and surrounded by their friends... (Emily, M, GS)

...this was not always possible due to lack of resources, particularly financial, and so the realisation of an approach to care that could be responsive to the needs of the individual older person was often not achieved. These and other challenges will be considered later in this chapter.

Flexibility across service approaches

The challenge of providing an agile service approach was discussed in the focus groups in terms of how movement across approaches of care might be facilitated. This might involve transitioning from an intellectual disability service to a generic older person setting or an acute setting.

Transitions happened for a number of reasons, but the primary one was that of changing needs. Where a person is supported to live in a social care setting, there may be no nurses available, and this might result in the older person having to move to a nursing home:

...we don't have nurses so when it comes to their medical needs, if it's something that we can't provide then the transition is looked at with nursing homes... (Kate, M, GS)

...once you start looking at severe mobility issues or hoisting and things like that, that would be transition to nursing home. (Hannah, D, GS)

Others addressed this by changing the skill mix of staff:

We were a social model...we are introducing nurses into it because people have had expressed the wish to remain in their homes...we now have the biopsychosocial model where we have nursing involved. (Emily, M, GS)

When internal transfers were required, assessment, planning and collaboration between parts of the intellectual disability service itself were considered vital, particularly between staff and the multi-disciplinary team:

We would have had a transition for a nursing home for one gentleman. And there was a lot of work done between like the day staff...he was supported with staff if

needed. But then again as we are a social care model, it was the medical model that was needed. The transition worked very well. (Kate, M, GS)

Flexibility within the intellectual disability services, however, has certain limits and in some instances, this led to older people no longer being able to receive support there. Despite the widely stated opinion amongst service staff and family members that moving an older person to a nursing home was not a desirable outcome of care, it did happen, and staff tried to make this as positive an experience as possible. It was suggested that consultation with the nursing home was key to the success of this move. One participant spoke of transitioning older people to community nursing homes noting that it required...

...a lot of transitioning planning, introducing the individuals to the nursing homes...[involving]...the nursing home staff. (Katrin, M, GS)

It appears, therefore, that decisions related to transitions and to responding to changing individual needs require a level of agility and flexibility in the service approach that calls for significant resources. These two aspects of service provision will be addressed anon.

Key principles of service provision

Throughout the focus groups, interviews and main survey, perspectives were obtained on the aspects of components of services that participants considered integral to providing services to older people with intellectual disabilities. In the survey, participants were asked to rank key aspects and it is notable that there was no difference in responses and views across nominally specialist and non-specialist services. All ranked person-centred support, ageing in place, responsivity to the person's needs and proactive future planning highly. Less highly ranked components were having skilled staff, effective links to generic and specialist health services and family involvement. It is notable that very few ranked the physical environment at all an interesting point as many focus group and interview participants considered this to be an important factor in meeting service needs.

Person-centred support

The importance of person-centeredness was repeatedly stated by participants whether explicitly or in respect of older persons being valued as individuals who have the right to make informed choices about their lives. It was also inherent in a focus on the core tenets of individuality, equality, dignity and inclusion. Almost 30% (n=8) of survey respondents cited person-centred support as the most important component of a specialist ageing service for older people with intellectual disabilities and complex needs. Likewise, 96.6% (n=28) of respondents reported, in line with Article 3 of the UNCRPD (United Nations, 2006), that exercising choice and control was a very relevant quality of life outcome for older people with intellectual disabilities.

The achievement of person-centred support was not always easy, and participants also identified some of the challenges they faced in implementing and upholding it. A person-centred approach, as identified by participants, focused on the person being central to all aspects of the service they are receiving:

...you're looking at the person as an individual, their needs are done as an individual as well and their choices and getting to know the other voice and being able to speak for themselves or have advocacy for each individual. I think it's vital to a person's quality of life. (Moya, M, SS)

...giving back the decision making to the person, with the support network around them. But the person being...centred rightly at the centre of it. (Emily, M, GS)

Acknowledging the changing needs and wishes of the person, person-centred planning meetings were held annually in some settings to ascertain the person's current needs and their personal goals for the forthcoming year, with plans revisited during the year as required. Reflecting the core principles of person-centredness, individuals were enabled and supported to take an active part in their planning meeting and were afforded the opportunity to invite a person/s of their choice, if they so wished, to advocate on their behalf:

...we do that meeting annual every year just to see what their needs are and what their goals would be and what they would like to achieve within the year...they would invite in who they would like to invite. It would be an ongoing assessment over the year but in terms of person-centred we are trying to tailor the care to suit them. (Noreen, M, SS)

The nature of age-related needs is such that changes can occur rapidly, raising the need for proactive planning and responsivity:

Just, like, it hits you in the face...I was in a house a couple of weeks ago, one of the ladies was walking up the corridor...and only last week she pinched up and now she can't walk at all...So now she needs to use a hoist for everything. (Freda, D, SS)

Thus, whilst an annual review approach may allow for future planning, it is important that this is followed up by more frequent reviews to support the responsivity required to achieve person-centred support. A level of frustration was evident among some direct care staff about an inadequacy of planning and projection describing reactive firefighting rather than a proactive approach to the needs of their service users as they age:

...I suppose that's probably a negative really that we don't have that five-year plan. That that's not something that we have looked at...it's very frustrating in

ways, because a lot of our things are very, are reactive to emergency situations. And that's when things happen...know what I mean. (Betty, D, SS)

I think there's a lot of talk about forward planning, but it doesn't seem to happen until, its nearly always crisis managed. And as I say there's loads and loads of talk, but the resources aren't there to put those ideas and those things in place. As I say to my group, I feel that everything is crisis managed. (Eve, D, GS)

The realisation of person-centred support is vital if older people with intellectual disabilities are to be able to remain supported in their own homes and proper resourcing is key to this happening. Failure to do this will place another key principle of older person service at risk, that of ageing in place.

Ageing in place

Ageing in place is “the ability to live in one’s own home and community safely, independently and comfortably, regardless of age, income or ability level” (Center for Disease Control and Prevention, 2009, p. 1) or, more simply, ‘staying in your own home or community as you age (Grove, 2021, p. 2) with an appropriate level of independence (O’Sullivan et al., 2022). It is recognised as a key component in achieving healthy ageing (WHO, 2007). This was confirmed by survey participants who, overall, ranked the importance of ageing in place second only to person-centred support (22.2%, n=6), though 40% of non-specialist services ranked it as most important. Participants acknowledged its importance in respect of how service should be configured for people with intellectual disabilities, as they age, but noted that whilst some community intellectual disability services currently support the person to age in place, other services have not reached that stage yet with ageing in place something that they aspire to:

...we have people who are getting older who are being supported...[to]...age in place. (Anne, M, SS)

...I'm in a service that is entering into the older ageing adult...our main aim at the moment is to age in place, that's kind of what we're trying to aim for. (Noreen, M, SS)

The aforementioned potential for changes in health status and, consequently, in support needs inevitably requires an ability for service to be reconfigured in terms of staffing and other resources, if ageing in place is to be achieved. Thus, changes brought on by ageing should not necessarily lead to a movement out of one’s home. It was noted, though, that processes related to recruitment and finance may not be timely enough to achieve this:

One lady had dementia and for us to put, say the staffing complement went from one staff to two staff on the day. And then two staff at night...and you're talking about your business cases, and you have paper trails going in. (Ann, D, SS)

...I would have a lot, they are very, I think I heard some number, say of twenty business plans that go...two might be accepted. (Eve, D, GS)

Changing needs and developing complexity in such needs may also negatively impact other service users, challenging the potential for ageing in place:

...I would find a lot of it would be behaviours for a start, it could be being up all night...everybody is in bed by 11, up at 7, and then you have maybe this one person up all night and then the other ladies are disturbed, or gentlemen you know...so it's like a social impact in anybody's houses. (Freda, D, SS)

I think especially for the other people who live with the person; sometimes the person with the illness or the dementia their needs come first and...[other people]...get left behind and they feel they are not getting the support they need. (Geraldine, D, SS)

Acknowledging their belief that ageing in place is a principle that should be aspired to, some participants considered it to be morally wrong that it has been explicitly or implicitly 'promised' by services yet has not been realised for some people:

People are individuals, their needs need to be assessed and a service built around that individual...they are talking about that since I was in college...it has happened for some people, but it hasn't happened for everybody. It's cruel to have to push somebody out of their home where they have lived for whatever number of years and say 'right we can't look after you anymore'... (Eve, D, GS)

However, it was noted that, in the absence of alternatives and when the risk of continuing to care for a person *in situ* becomes too great, some service users may be transferred to generic nursing homes:

So, I don't think much fazes us here, until it comes to a point where you are looking at the risk and where we stand with that...where we are holding a lot of that without the acute support. (Ingrid, D, GS)

Survey responses confirmed this view. Although nearly half of survey respondents (43%; n=13) believed that most people within their service would likely age in place as they developed complex age-related needs, 32% (n=8) believed that some people would likely need to be transferred to a mainstream nursing home due to a lack of available and suitable options within their service. Survey respondents also identified a need for increased medical support for people with a diagnosis of dementia, and that people might need to move to a dementia-specific service as the disease progressed.

Decisions regarding the use of generic nursing homes arose, therefore from a care dilemma and were contextualised by a consideration that the needs of older adults with intellectual disabilities could not be adequately addressed in such settings:

They need so much more time, they need people that know them, they need people that care about them. They do need people that are watching out for them in relation to abuse and everything. But they need so much more care than they'll ever get in a nursing home, and such different care. They cannot be put into a bed, or in a chair and just left there. They need to be stimulated at all times. (Freda, D, SS)

One participant noted that a positive and collaborative relationship had been built between her service and a local generic nursing home to address any potential shortcomings:

Our service users were the first people with intellectual disability that they had dealt with. And we built up a very strong relationship with them initially...for me it was about building up the relationships, an education process for everyone involved really. But the nursing homes yes, it has been positive, our relationship with them are good. (Hannah, D, GS)

The predominating view was, though, that ageing in place was something that should underpin a quality ageing service, but that it needs to be properly resourced and is based on a combined and integrated effort by all parties, drawing from the various strands of service alluded to earlier in this section:

It's really a social care model but with the assistance of nursing. And multidisciplinary team are really invaluable with the OT and physio, speech therapy...we've a very good staff you know very low turnover of staff...and they've got to know them, got to know their families. And they're also in their own communities, they're living out in the community and attending their local ageing you know, active ageing groups. They're known in the community. You know they're looked after I suppose by the people around them as well...they're living in their own little community areas. (Cathy, D, SS)

We would have a very close working relationship with the residential staff. And we would like to kind of have a holistic approach to the service users there where we're all kind of working together. (Katrin, M, GS)

The question of resources led one survey respondent to propose that there should be a...

...review of decongregation policy to reflect the changing needs of older people with an ID...[sic]...and the resource requirements to manage ageing in place. (S)

The above reference to proper resourcing is a repeating thread throughout the findings and one upon which a quality service is premised. This does not mean that there is a need to duplicate supports that are already there, but, perhaps, facilitate increasing use of mainstream community and health resources through developing formal and reliable lines of communication between such services and those working in the intellectual disability sector.

Networking and multidisciplinary support

Participants, therefore, recognised the importance of the networking across members of the multidisciplinary team and their role in identifying supports that the person may require and to ensure continuity of care across the service that the person utilises:

...MDT meetings to see what environmental supports we can put in place...whether it's OT, SLT, whether it's behavioural or it's psychiatric consultations. (Michael, M, SS)

we have an activation team that would link in on those meetings as well to-help them progress their goals from that side of things. We'd have the nursing team and then we'd also have the activation team. (Noreen, M, SS)

The importance of networking extended beyond multidisciplinary interactions within services, and it was noted that linkages between generic and disability services were also vital, allowing for a sharing of knowledge and skills as well as to maximising the potential for the older person to obtain health services whilst remaining in their home setting. One participant described a broad network of such links:

...when it comes to palliative care and that...diabetes and neurology we have a consultant at the end of a mobile phone nearly all the time...We have access now to wound care...advice from mainstream hospitals...a consultant psychiatrist...GP...team of nurse prescribers ... [and]...an Advance Nurse Practitioner who...has her own referral pathways...she will put twenty times more detail than what our own GP would put into a referral letter. (Michael, M, SS)

Many of these links were described as being informal contacts made between someone in the disability service and someone in the other health setting. It was acknowledged that there was a somewhat tenuous nature to these, such that if key personnel changed, they could be lost. It was for this reason that one participant considered such pathways needed to be more formally established:

I see the benefit of having formalised pathways and I think especially with the acute it's an area that we need to progress further, especially in terms of older persons. (Anne, M, SS)

That said, there was a benefit in having informal connections as it helped to access services that might otherwise be difficult to access:

...an ophthalmologist...will do their yearly eye check and things like that. However, we also have like a very good referral system with them, a private ophthalmologist who gets good links then to the primary care hospital as well.
(Noreen, M, SS)

Establishing, and nurturing such links can be particularly crucial where it is difficult to find expertise within the services:

...integration with other services...and referral out is very important and making sure that the person has all of the links with all of the carers that they need.
(Sarah, M, SS)

The ageing profile of service users that has become characteristic in most intellectual disability organisations has led to a greater focus on end of life care and this has required staff to learn new skills. Close links with hospices have been important in this regard:

...we are now trying to train up staff with end of life care. We've built up links with the local hospice...they are coming in and supporting the staff on site to support people right to end of life, offering them day to day support about, you know, skin care, skin integrity, mouth care, medications and so forth... (Sarah, M, SS)

Developing relationships between intellectual disability and non-disability services can support ageing in place, increase inclusion and bring benefits for both partners:

...the nursing home geographically it's just across the road...they would have a music session on a Friday so our service users would go over to join their group and...in turn then we would have different events happening in our day service so we would extend the invitation. (Margaret, M, GS)

They were also considered to have the potential to reduce hospital admissions:

...linking in with individual supports...would help maintain...[older people with intellectual disabilities]...at home and out of hospital and the number of admissions possibly would be reduced into the acute services if we had that ongoing link into the acute services and the gerontology specialists' services. (Anne, M, SS)

Despite these positive accounts, others noted a reticence on the part of some generic services to respond to requests of support, assuming that the presence of health care professionals in the disability service meant that they already had the required expertise:

...there's a presumption that you have...somebody supporting people; they are not inclined to support us because we have nursing support. (Jane, M, SS)

This was echoed in a survey respondent's comment in which s/he noted the assumption in generic services that intellectual disability services have unending resources such that...

...the person is well catered for in the service...[and]...would not benefit from other supports. (S)

Realising specialist ageing service: barriers and facilitators

Participants demonstrated a strong commitment to seeing the central concepts of service delivery enacted in their workplaces. They acknowledged, though, that these were hard to achieve where resources, particularly housing and funding, were not made available:

...if we don't have the resources and the funding it's very challenging for staff to try and apply a person-centred approach for that person and to really realise what their own decisions are and give them the choice and decisions on their day. (Anne, M, SS)

Where resources were unavailable, older people often found themselves moved to settings which were not best suited to their needs or desires, perhaps to a nursing home, or a service house simply because there was a vacancy. These decisions often resulted in a definitive outcome, with a permanent move for the older person ensuing. The idea of setting up step-down facilities to support people with, for example, acute illnesses and injuries was proposed as a way of avoiding permanent moves and supporting the person along a path back to their regular living situation, similar to that provided in mainstream services:

So, I suppose it's the nursing aspects of it then I suppose we were looking at maybe a step-down service, somewhere that people need to be between coming out of hospital and then coming back to their community-based home. (Jane, M, SS)

Whereas, in this case, the step-down was provided within the intellectual disability service, others had sourced such facilities in mainstream health service settings:

So, like people coming out of hospital as well sometimes it can be very difficult for them to go back into their own house...we've had to try and access that through generic services in our area. (Anne, M, SS)

Whenever a person's changing needs required an alteration in the care pathway, and particularly a change in accommodation, it was considered that there was a

need for careful planning and for the person's choice to be central to any decisions that were made:

...we had one lady that moved through choice because a lady she was living with had to go to a nursing home; now hers was an easy transition...her friend, whom she lived with for thirty odd years, wanted to go and live with her best friend. But that was very planned, and we could organise that. (Claire, M, GS)

Two survey respondents noted the importance of 'pre-planning' but highlighted the fact that it often does not take place, leading to reactivity in the face of an approaching crisis. But even with proper planning, such moves could be difficult for all involved:

...families because it is a big change. They trust the staff, and this is the person's home and for them the transition to a nursing home can be quite hard, and for the staff themselves. (Kate, M, GS)

In the review of the data presented in this section of the findings chapter, it is evident that there were no clear service types or approaches manifest in the services that took part in this study. Whilst some services may have had specific older person pathways, often linked to the development of health-related complexities such as dementia, they also had generic paths through which many older people will receive service. Similarly, the other services had some examples of specific older person services and a range of other more generic ones. Participants in all of these aspired to the key older person service principles of ageing in place and person-centred support but these were mediated through service approaches that were often an eclectic mix of health and social care. The ability to realise an individualised service that met the older person's needs and desires was, however, seriously challenged by resource limitations and difficulties in accessing mainstream health and social care services. Despite this, all were committed to ensuring that they could provide the best quality service to meet these older individuals' needs as they developed.

Chapter 4: Findings: Providing services to meet older individuals' needs

Some challenges of matching care models to the changing needs of service users have already been highlighted. Participants explored the potential for addressing these and how services might be modified. They addressed these through consideration of the changing needs of the population, the service environment, the impact of regulatory requirements, end of life care, changing service needs and financial realities.

Changing needs of the population as they age

As people with intellectual disabilities live longer, organisations have had to respond by developing services to meet issues which may arise as a result of this. These may relate to ageing itself or to specific conditions that tend to become more prevalent in older age. The main areas of changing need that were identified in the focus groups and interviews related to dementia and end of life, but a number of others, including behaviour, mental health, frailty, multi-morbidity and polypharmacy were also briefly noted and some of these also arose in the surveys (Table 5).

Table 5: Significant age-related concerns for older adults in services

Issue of Concern	All	SS	GS	OTH
Dementia	55.2% (n=16)	64.3% (n=9)	44.4% (n=4)	50% (n=3)
Mental health	27.6% (n=8)	28.6% (n=4)	33.3% (n=3)	16.7% (n=1)
Behaviours	20.7% (n=6)	14.3% (n=2)	44.4% (n=4)	0%
Frailty	17.2% (n=5)	7.1% (n=1)	44.4% (n=4)	0%
Multi-morbidity	20.7% (n=6)	28.6% (n=4)	22.2% (n=2)	0%

A majority of respondents noted that there are limited or effective pathways in place for dementia, mental health concerns and behavioural concerns, with a minority indicating that there are effective formal pathways to address obesity (22.6%; n=7), cancer (32.3%; n=10), multi-morbidity (32.3%; n=10), frailty (35.5%; n=11) and chronic illness (35.5%; n=11).

Dementia

One key area of particular concern was dementia. It was noted that, as the older person transitioned through different stages of the disease, their needs changed too. Participants highlighted the importance of support needs being tailored to meeting those developing needs. The multidisciplinary approach was considered to be of particular significance in addressing these, as it allowed different skillsets to be

called on to respond in a coordinated and individualised manner. That said, participants reported delays in getting diagnoses for conditions like dementia, perhaps due to diagnostic overshadowing, and this made it difficult for services to respond in a timely manner:

...we would be seeing a lot of people now who are probably waiting for a diagnosis for dementia. (Moya, M, SS)

This was also highlighted by family members who spoke of delayed diagnoses and wrong diagnoses. Epilepsy was the precursor to the dementia diagnosis for three of the family members who noted that health professionals had not made them aware that this might be an indicator of dementia:

I don't think that it was ever mentioned about dementia setting in at a later age. "Oh it's, you know, the seizures" but the seizures were only a symptom. So, I think that information is the name of the game really, informing families what to expect and the, I suppose, the keyworker, I come back to the key worker, monitoring what's going on with each resident. (Nancy, Fam)

The capacity to be able to reach a clear and timely diagnosis was seen to be crucial to planning future service responses, something also highlighted by (Dennehy et al., 2022):

...we are trying to get ahead of that future planning needs as opposed to being in that reactive mode all the time...we have had incidents where somebody gets a diagnosis of dementia and...very rapidly somebody can be living quite a nice lifestyle over here in the service to absolutely not being able to meet their needs and then we are only heading in one direction. (Claire, M, GS)

It was also observed that there can be a lack of connectivity between services, contributing to diagnostic delay. One family member observed that the siloed nature of the health and care services frustrated her attempts to get appropriate care for her sister:

...I was going with all the information and...[sister's name]...was being chopped up into different sections. So I was going for her epilepsy to...[hospital name]...who couldn't care less about the dementia, and then I was going to...[service name]...with the dementia, thinking, you know, does anybody know anything about this...none of the pieces were put together. (Siobhan, Fam)

A number of participants in services without age-specific pathways observed that the complexity of health needs associated with dementia meant that they could not always be met in the person's home setting and that an alternative living setting was often needed:

It is a challenge for our residential service when people become unwell physically and also in terms of dementia because our houses are absolutely community homes. They are the same as anybody else's home in the community and...when people, decisions are being made about whether somebody needs a nursing home, it's usually around the nursing needs because we really almost don't have any nurses in our services at all... (Elizabeth, M, GS)

...we've had a couple of individuals that moved from their family into nursing homes because of dementia. It got to the stage that we couldn't look after them in the best possible way in day services. The environment was just becoming way, way too stressful for them. It was very stressful for families as well. (Katrin, M, GS)

It was noted that meeting those needs in a community house inevitably has an impact on others who are living there:

...we would have a number of individuals living in smaller community houses that are ageing and are showing signs of dementia, one or two would have got a diagnosis. So, it's trying to find a space where we are continuously bringing in different equipment, we are trying to teach the people they live with that there's things changing. (Jane, M, SS)

Notwithstanding any health concerns, the needs of people often change as they age, and this may simply include the need or desire to slow down and to take life at a different pace.

Retirement

Whereas service managers largely focused on health and structural service issues, such as dementia, end of life care and advanced planning, direct care staff, family members and older people themselves also identified the importance of retirement in the lives of older people with intellectual disabilities. It was noted that the traditional service structure meant that older people usually had to continue taking part in day services, requiring them to rise early in the morning. This essentially removed the possibility for a transition from 'work-life' to retirement:

...they are not able to be out and about five days a week, going swimming one day and dancing another...they have done that, they have worn the tee-shirt. They have done work experience, they have had the jobs, they have done the training. And now it's an opportunity for them to take it easy for a little while and enjoy their life for what's left of it...here, they are not under pressure to take part in anything really to be honest. Like, if they come in the morning and they say, 'I just want to sit and do my knitting today'. (Hannah, D, GS)

One survey respondent noted that the day activities for older persons can be quite limited and have not really been adequately addressed:

Day services are now concentrated on New Directions for younger persons. Older persons require a place to meet up, meet friends, have routine and orientation. Older persons like older persons in generic community require active age groups with qualified staff to provide specific activities to specific needs. Integration to community-based active age groups doesn't work for everyone particularly if complex needs, non-verbal and any behavioural or psychological needs. (S)

Quality of life for some people, as they age, may involve less, rather than more community engagement. And although community engagement is a key Health Information and Quality Authority (HIQA) metric, it was suggested that may no longer be of the same relevance for some older persons:

...they want us to be going out twice a week with her...to do community activities. The woman is blind, nearly bed bound...She just wants to listen to Daniel O' Donnell and be warm and comfortable and have long baths and that, not into the chair and up to the leisure centre with the noise deafening. The management are saying because she's in a community house now and this community engagement and community inclusion has to happen, that they have to provide evidence every week that she's had the opportunity to do these things. (Geraldine, D, SS)

This was affirmed by a number of family members who considered that continuing full-time day services was detrimental to their loved ones' health and wellbeing. They, themselves, made decisions to reduce the time their family member spent in such services:

I felt the Monday to Friday, all day, was too much for him, he wasn't able to cope with the noise level and the numbers...So I chose sessions that he would go to, and I would drive him down and pick him up. (Nancy, Fam)

They still have activities here during the day...they go to bowling and they go to music sessions and, you know, little bits and pieces. Which is enough for him...it has worked out extremely well. (Kay, Fam)

The closure of day services during the COVID-19 lockdown, was seen to have provided a welcome reset which also led to more innovation and individualisation:

...I think COVID yes it had its negatives, but I think within our service here we really adapted to that and listened to what the people we support needed. So, whether it was that lie in to 11 o'clock in the day, that they didn't need to get on a bus to go in somewhere for 9 o'clock. We were really listening to their needs. (Ingrid, D, GS)

Slower paced days and increased use of internet-based communication supported a more relaxed lifestyle which had positive effects:

...so, we have been trying to rethink day services as we are calling it...people in some of the community residential houses, didn't want to have the same. They got happy, the pace was slower, and they enjoyed being able to be at home more...the pace seemed a little bit gentler and easier so if they were people who were suffering with anxiety, or where they had transitioning difficulty, they didn't have that anymore. (Geraldine, D, SS)

However, it was noted that maintaining such realities was an option that some services could not implement easily:

But I suppose normally, now when they're all back to day service. There might not be the same opportunities to stay at home, if you don't want to go in because of that. You know it would have to be a bit more planned. (Cathy, D, SS)

This was again linked to funding and the constraints associated with the idea of a congregated funding model. Without individualised funding, it was considered that services would struggle to provide the person-centred service to facilitate retirement and older cohorts of people with intellectual disabilities would be less likely to have specific budgets to meet their needs. Without such specific and reactive budgets, services may face dilemmas in the allocation of resources as described by a survey respondent:

Funding to address increasing needs as people age is the primary issue. Their needs compete with all adults in the service, not just between those are considered older people. (S)

End of life

Ageing, irrespective of longevity, leads inevitably towards death at some point, so it is not surprising that advanced planning and end of life support were identified as important in any discussion of service provision for older people with intellectual disabilities. Most survey respondents (83.3%; n=25) reported that their services engaged in bereavement and end of life preparations, to some degree, with the family, friends and housemates of older people, as well as engaging in end of life (85.7%; n=24) and advanced care planning (78.5%; n=25) conversations with some or all older adults in their service.

It was noted that there is a need for staff and others to be comfortable talking about death and decisions around end of life. Whereas such conversations may have occurred between staff or with family members, there appears to have been a reticence in discussing this with the ageing person:

Before this you didn't discuss those care conversations and end of life planning with the person; it was more with the family and staff who made those decisions. (Emily, M, GS)

When asked about barriers to engaging in these conversations, survey respondents described how staff may avoid advanced care planning and end of life discussions because they are afraid of causing the person or family emotional distress due to the sensitive nature of the topic. They also highlighted how healthcare systems and professionals are unprepared to carry out advanced care planning as “there appears to be a lack of a cohesive approach” to care and that staff lack the appropriate knowledge and skills to have such conversations:

Lack of engagement and planning at strategic level, lack of understanding by stakeholders of the importance of this area, lack of understanding of need for staff education in end of life care. (S)

...lack of knowledge and experience dealing with the subject some staff may feel that they are ill equipped to lead out and engage with the person, family and housemates on this subject. (S)

Most participants expressed a desire for the older person to die at home, wherever possible. As one direct staff member noted:

Because they are living longer...we would love to see them pass away in their own homes, where they have developed over the years. (Ingrid, D, GS)

Developing capacity to engage in such conversations with individuals, particularly when they are well, allows for the older person’s voice to be heard and for it to be the key guide when end of life planning is needed:

...we really try to get out there...to do the end of life...[planning]...with people when they are well, and they are in good form. (Claire, M, GS)

Dying and death has a wider effect within the community of the older person, and it was considered that these conversations needed to extend to those in the older person’s community:

...it’s very important when an individual is ill in the day service that the other individuals are brought along in the process...when you know somebody is terminally ill than the other individuals that individual who is ill is spoken about, that the other individuals are given that opportunity to speak about their favourite memories of that person. That they can make phone calls or Facetime then in the hospital or in the hospice or whatever. (Katrin, M, GS)

Early planning was suggested to give the person the chance to air their choices in respect of:

...where they want to age, what they want in place for their end of life plan. (Sarah, M, SS)

This is advanced planning, and is the basis of the Irish Hospice Foundation's *Think Ahead* (Irish Hospice Foundation, 2022). This tool was considered to provide a space for discussion and listening, bringing together all relevant voices:

The importance of communicating with family members and to get their ideas on board and be proactive in addressing end of life and advanced care planning. (Sarah, M, SS)

...getting their wishes down before they got into a situation where they didn't really understand or know what was going on around them. (Eve, D, GS)

Whilst the challenges of initiating advanced planning were acknowledged, participants made it clear that such planning allowed for discussions on resources and staff skill mix such that these could be addressed in a timely manner, to support a positive end of life experience:

[We]...called a multidisciplinary team meeting and said this man should age in place. And we linked with our palliative care unit in...[city name]...And they came on site and gave us all training on how to, syringe drivers and all that and he aged in place, and he passed away here. And it was lovely. (Noreen, M, SS)

The importance of resources in achieving outcomes like this cannot be underestimated. Thus, it was noted that services need to be flexible and modifiable to meet the ageing persons' changing needs. As with dementia care, this was seen to be a challenge, particularly in respect of staffing and philosophy:

For one lady whose request was to die here...we got an independent advocate involved...The barriers! Oh, the barriers! First of all, they said the cost, staffing, and the effect it this may have on the other service users living in the house to have somebody so ill in the house. But I believe it was finance and staffing. (Eve, D, GS)

The main concerns appear to have related to the effect on other people living in the house, the need to buy in health services and the presence of non-regular staff in the house setting. This could be managed well, through proper planning. When this was present, the outcomes were invariably positive. The commitment of service, managers, direct care staff and family to support an older person's wishes was evident from the following account:

We had a huge meeting with the family, myself, my manager and the GP and a whole package was put in place. She was to go on an antibiotic if she had a UTI or something like that. But otherwise, when it got to the end it was to stop. And I have to say the end was just amazing, a staff team of twelve and one of her favourite staff and her other favourite staff got out of her bed and came in. She said at half three that day 'I'm going to sleep now. I'll miss you all'. She died twelve

hours later; they were her last words. But there was, there was so much planning, so much had to go into it, it had to be signed by the director of nursing. (Freda, D, SS)

The process of dying at home was seen to be a positive experience for other residents, supporting them to understand how unwell an individual is and therefore to prepare them for the fact of death:

Not at all, no, from my experience it was, it was good. Because the others could see and understand that she was unwell...we had palliative care coming to the house they could see how she was being taken care of and they were prepared for her passing. It wasn't such a major shock when she did pass, they would have been living with her for a long period of time. So yeah, they were part of her everyday life. (Eve, D, GS)

An open, honest and explicit approach to illness, dying and death was contrasted with a previous, more paternalistic and, maybe, more patronising approach:

...with our older population here for years and years and years they just weren't told anything. Someone was gone on holidays until they were going to their funeral. Because 'oh we don't want to upset them; we don't want this', you know that sort of way. (Hannah, D, GS)

In an organic way, service users were helped to prepare for the inevitability of their own deaths and supported to articulate their own wishes:

...we do it in a very natural and slow way, end of life plans aren't complete but it's picking up the opportunities, if they are in mass they'll say 'oh that song is nice'. Or if we are at a funeral you know with a lady that loved daffodils and the street was lined with daffodils and she was brought to the church. So, it was about having those conversations with the people we support here. It's a slow burner but it's being done. (Ingrid, D, GS)

Retirement and end of life represent key milestones in the lifespan of each individual. However, people do not experience these homogenously and across the discussions, participants stressed the importance of consultations with, and the involvement of, the older person themselves and their family.

Chapter 5: Findings: Responding to individuals' needs

Participants spoke of a number of key issues that impacted on their ability to enact an appropriate approach to service for older people with intellectual disabilities. Adherence to a given service model was noted to be determined by a number of factors, including the environment, standards/regulations and resources. As previously noted, services need to be agile if they are to be able to respond to the changing needs of the older person. This presented a challenge to identifying the care pathway for the individual and the location in which that service could be provided. Funding was central to these factors, and the rigid nature of funding models was particularly problematic:

...our funding comes as a big group you know it's very hard to develop individual supports. For...the older age group it came in under the umbrella of the budget...you wouldn't have had individualised funding, so you are part of a bigger group. (Geraldine, D, SS)

Capital funding, though, was noted to be crucial as it determined whether the environment could be adapted to respond to both individuals' needs and safety/standards. The scale of the challenge was described in respect of one service:

We don't have the staffing, we don't have the houses and we don't have the beds, that's where the biggest challenge is coming from. As I said for...[county name]...we have three services that have an ageing profile and each with six beds. So that's eighteen beds and service that has nearly seven hundred...so you are talking a very big service for very little beds. (Ingrid, D, GS)

The need for equipment also posed a concern in community group settings where it became a hindrance to the lives of others living in the house. Among the other issues impacting on providing appropriate service was staffing levels. The ability to match staffing and skill mix to the needs of the person is a central tenet of older person care provision, but this is difficult where there is high staff turnover.

Listening to the older person and their family

It is clear that, in planning for the journey through old age, associated illness and onwards towards death, participants placed a significant emphasis on listening to the voices of the older people and of those around them. Their input was considered crucial to building a service that responded, not just to need but also, to personal wishes. This was borne out in the comments of focus group and interviewee participants as well as in the survey. Respondents were asked to rank 12 issues in order of importance on a five-point scale; 57.1% (n=8) of those in SS ranked consultation with the older person as being of highest importance compared to 22.2% (n=2) of those in GS.

There are various ways in which such consultation can be approached. One service, for example, conducted interviews with those over 50 years of age who were availing of their services, to identify what they would like for their future, thus allowing additional supports to be put in place to fulfil those wishes:

...we ran interviews with the older cohort, anybody over 50, and asked them personal questions. Where would they like to live when they're older? What would they like as they get older? What would they not like as they get older? And this has influenced and has had very positive outcomes in supporting people to age in place as well. (Sarah, M, SS)

...we were getting much more individualised, much more person-centred, involving the services users in any decision element of decision making what, where they want to go, what they'd like to do, what activities, what time they want to come in, what time they want to go home. (Katrin, M, GS)

In order to build a 'package' of such individualised supports, it was often necessary to move beyond the boundaries of the service and to leverage input from others:

His wish is to go to day service every day...He wants to live at home. So, we've had a lot of team meetings with family and himself in making decisions. So, he wanted to stay at home...so we had to get referrals to the community OT, community physio, adaptations to the house. Currently the family are needing more support. (Margaret, M, GS)

Whilst it was acknowledged that meeting the wishes of the person is central to decision making, it is not always possible for them to stay in their current home, and some compromises may have to be made and again, the question of resources was identified:

...it's difficult when you're trying to do everything person-centred with the person, to focus on listening to them and really want them, because it was people's preferences to stay at home, you know, to be in their own home and not have to move. But that's not reality I guess at times. So sometimes you have to try and reach a compromise. (Sarah, M, SS)

...the person has accepted the fact that they need to change for health...[she]... had lived independent with very minimal support now finds herself needing more support. So, she is advocating that she wants to be in the same town, and I find myself having nowhere to offer for her in this town...I don't have a funded available space for her right now. (Mary, M, SS)

It was suggested, though, that some services were not always driven by the wishes of the person and their family:

...the residential services are actually provided by external residential services and almost all of them are for profit. You're in a completely different ballgame...there is no discussion around actually what the person wants. (Elizabeth, M, GS)

...the general decision was made against family wishes that she would stay where she is now. (Michael, M, SS)

Interestingly, whilst focus group participants noted the importance of education for family members, such support and education were not scored highly by the survey respondents. Some family members, themselves, noted that services were not always attuned to their needs, particularly in the area of bereavement support. As people with intellectual disabilities age, it is inevitable that they will experience the death of friends and, most significantly, of parents. These can be traumatic times for families as siblings manage their own grief whilst trying to support their brother or sister with intellectual disabilities.

Whilst family members spoke highly of the care provided to their loved ones and staff/managers recounted examples of excellence in supporting older people with intellectual disabilities to die at home (see previous chapter), those family members who discussed bereavement, all considered that there was a lack of grief counselling for people with intellectual disabilities who had experienced loss and for family members themselves. Two sisters, who had taken on the role of being primary carers for their sibling after the death of their parent, reported that, in the absence of support, they struggled with both their loss and with the change in circumstances:

... [older person's name] was lost, lost, I thought, and didn't know life without Mum as her support ... So, yeah, it was very hard, a minefield, and you were also dealing with the fact that, you were aware of her demise...you were grieving for her, and you were looking for answers and you were looking for help and you were looking for a path and you weren't getting any of those things. (Siobhan, Fam)

Lack of bereavement support for one brother, following the death of his mother, was reported to have led to him developing behavioural challenges and being admitted to a psychiatric inpatient facility, a location that his sister felt was not appropriate:

Bereavement counselling was just not available...the plan was that he would go into that house respite permanently; it broke down because he just was behaviourally all over the place and it wasn't fair on the other residents...he went to hell and back, and there was no counselling and there was no behavioural therapy and there was, there was nothing really. I don't think I even got him a social worker during those years. (Nancy, Fam)

This sense of being alone and unsupported was also described by siblings whose family member with intellectual disabilities had shown signs of dementia. One sister described the extra strain she experienced because she was fighting for advice and support at the same time as caring for her sister who was suffering dementia and epilepsy:

...we knew we were coming to the end of what we could do for her, we were worried for her because she would get up in the middle of the night and have her coat on and go out the front door. So you never slept, you were constantly awake thinking, is she up now, what's she thinking, where is she going...I asked her for help...we were on our hands and knees...it was like falling off a cliff...if it was just the dementia and the epilepsy...you're on your knees and then you might be pointed towards a nursing home system that doesn't want her, that doesn't want someone with an intellectual disability. (Siobhan, Fam)

Another family member spoke of an underlying fear about the permanence of her sister's accommodation and service, despite the fact that her sister, now in her 60s, had been in the same residential service since she was four years old:

...it's an unfounded worry as such I suppose, because it hasn't been threatened in any way but if, say [service name]...was just to go with lack of funding or...where would [sibling name] go...maybe it's unfounded but nobody has really clarified that to families...or given that guarantee. (Louise, Fam)

The unsurety belied a concern that decisions could be made that would affect her sister, perhaps a distrust grounded in the absence of clear communication. It should be noted that, as in all qualitative research, these accounts represent the experiences and perspectives of those who shared them and cannot be seen to describe any broader reality.

It has been seen that the needs of older people with intellectual disabilities have become more complex as they increasingly live longer lives. Drawing on the principles of quality service provision, there has been an increasing realisation that supports should not solely follow the needs that are perceived to follow particular age-related challenges but should also take strong account of the desires of the older persons themselves. In considering how services might best respond to those needs and desires, it became clear that changes were required across services but that these were being challenged by other factors, not least funding.

The service environment

The service environment is particularly important when seeking to meet the changing needs of older people with intellectual disabilities, and needs to be modifiable in order to be able to adequately support the individual needs of the

older person. This raises questions regarding the potential for reasonable modifications or retrofitting to be carried out:

...there's only so much you can do to certain houses, only so many hoists can be put in place. There's only so many ramps can be put in place. (Anne, M, SS)

Thus, the pragmatic and financial realities of the service environment may be a determinant in where the older person may be accommodated. It is clear that, while ageing in place is the 'gold standard', it may not be achievable, and service may sometimes have to be provided in a non-optimal environment. Whilst it was previously noted that many participants considered nursing homes to not be the location of choice, it was noted that some of the facilities offered by such homes may need to be provided in specialist age-related locations in intellectual disability services:

...because of the level of equipment people require when they suffer from dementia in the long term and the requirement to have such a significant amount of equipment and resources in their environment. (Anne, M, SS)

...one of the houses has a hoist...that's taking up space. A bedroom might have different chairs, there's a comfy chair, there's a wheelchair. There's the oxygen concentrator, requires oxygen. She would've been on sub-cut fluids. So that would, it would've been I suppose an apparatus that you'd put that hanging off...it really was nearly like the acute setting in one of the rooms...but the storage is a huge issue, huge, huge issue. (Ann, D, SS)

It was noted that such specialist facilities may be particularly difficult to facilitate in the community, and that space needs may be a particular problem:

...you need to have a big location because...there's a lot of equipment and a lot of maybe storage space needed in terms of incontinence wear and all that...There also needs to be pockets of the private space within the house because you know obviously everyone always needs their own personal space. (Claire, M, GS)

...most of our community houses don't lend themselves to having this structural environment in place to support somebody to age in place when they get to a particular stage whether it's dementia up to mid-stage and late stage. (Anne, M, SS)

Another dilemma is whether to set up such specialist services and move people out of social and home settings that they are familiar with:

...do we open another dementia specific location, or do we try to support people to age in place for the last twenty years with the people they have been growing old with? It's trying to find that balance. (Jane, M, SS)

...you are trying to ascertain where the person's needs are best met in the home or in a specialist unit, which are the predominant needs, is it the physical needs or the social and psychological needs and the need to be in the community and to be with their friends and family. (Anne, M, SS)

It was noted that the service environment needs go beyond specialist age-related facilities and requires spaces for other things, such as activities and relaxation (multisensory). The challenge for facilitating this in the community is sometimes compounded by the fact that services may not actually own the community houses, but rather have them on lease from landlords who, understandably, may be reluctant to have significant structural changes made:

...we have a good few rental properties, and there may be resistance from a landlord to do adaptations. And so we can find ourselves, even though we have a contract, we have maybe a...[20 year]...lease. (Mary, M, SS)

This participant further explained that pressurising the landlord for such changes could lead to the lease being broken and this would affect all of the people living there. So, there is clearly a balance to be achieved in managing care in a space that has environmental limitations and social consequences:

...trying to provide for somebody who needs medical support, and you know, a huge amount of equipment, a huge amount of hoisting, all that...it's that extra into a house and the impact it has on all the residents in the house. (Elizabeth, M, GS)

Attempts to source more suitable accommodation in both urban and rural areas, either to rent or to purchase, was identified as a key issue with housing, in general, described as being in very short supply. Services find that they are competing in the open market for housing and may have the increased expense of adapting properties to be suitable for their needs and compliant with the prevailing regulations:

We are looking for the last ten years for another house, or a site and we can't get one. We are in a high tourist area...there was one house on the market there. We were outbid but it was like maybe three hundred and fifty thousand...we would need another three hundred and fifty thousand to make it, to comply with regulations you know. (Ann, D, SS)

Lack of availability may have stymied the expansion of services' housing stock in recent years; however, participants also implicated the competitive funding model as a reason why services may be unable to open new houses. It was suggested that the funding model favoured private sector providers who are using investment funding to open houses for people with intellectual disabilities. However, a participant noted that providing accommodation alone may not meet the service needs of an individual:

...when a person gets into crisis no matter what age or cannot live at home any longer or needs a very specific type of service that we don't provide they are being referred back to the HSE and whoever tenders for the funding gets it. So, it's usually some of the new service providers which are private organisations with big funding behind them. They are purchasing houses and opening community houses which hopefully will be successful and work well, and hopefully the transitions, we've done a lot of work transitioning them but you just wonder where the future lies...But it seems that anyone who has needed housing in the recent past has had to go to a new service provider...but out of their local area, their family home, they've already ended up in crisis and moved to our respite type services and then out of that be totally abandoned and moved to a whole new county and not get a service let alone a day service from it. (Geraldine, D, SS)

The difficulties in getting modifiable accommodation have also driven some services to sourcing houses in rural, rather than urban areas:

They would've, in the past bought houses in...estates and semi-detached houses. But I think they're thinking now a bit more in the future, trying to future-proof the houses, and going for bungalows a little bit more out in the country. (Betty, D, SS)

The possible social effect of such a move was noted, with the potential for older people to experience isolation and loss of independence. Such a move could also have negative impacts on service users' access to community resources and transport links:

They won't be able to walk to the shops...it impacts on their independence and...you have to think about that as well...and the isolation. (Betty, D, SS)

These challenges are often further complicated by a situation whereby an older person is being discharged from another location and a 'bed' needs to be found due to pressure from the discharging site:

...hospitals when they are trying to discharge someone, they really don't have an understanding at all, they see 'oh well you have a vacant bed here so why can't that person go there?' But it's different when you are dealing with a person's home rather than just oh here's you know a bed. (Carol, M, GS)

One participant noted that a safeguarding issue might determine who moves into accommodation, rather than choice or compatibility:

...if there's a safeguarding issue in the home then that person gets bumped up the list. Now we are very well aware of the vulnerability issues, but if you only have one house in an area and you've got twelve different people looking for a space there you are not going to, they are not going to be all there. (Eve, D, GS)

Although participants were positive about the move to community living over recent decades, it was noted that the closure of larger or campus-based accommodation has reduced the options available to services as their service users age with complex needs. Some considered that the ultimate answer for some people may need to be in some form of congregated setting and some considered these to be more modifiable than community house settings:

...when I first started there was people coming from community into residential. And that was all stopped...I suppose there are some homes where you know you won't be able to support the person for one reason or another. And I don't know what's going to happen to here, because we're the last residential campus here. (Betty, D, SS)

...when their needs now have deteriorated, we're finding that a lot of people need to come back in on campus as well. (Moya, M, SS)

...they're all bungalows, they've all wide corridors...we have the walk-in showers, like as in from an equipment point of view...we would be equipped for the ageing process. We may need to install equipment going forward in some of the houses such as overhead hoists and things like that. But as for the facilities, floor plans size we're well equipped for it. (Noreen, M, SS)

Such congregated solutions included the potential of moving people to nursing homes, something that was also driven by cost:

So it's a very, very costly model of service...sometimes it can be seen that maybe the nursing home is the cheaper model. But it's not the quality model we want. (Claire, M, GS)

The uncertainty surrounding accommodation and service locations may contribute to increasing the number of transitions that older people with intellectual disabilities experience. All the older people participating in this study had experienced at least one change of accommodation in the past. They did acknowledge that they had been consulted about moving to a different setting, but no one considered that they had any option but to accept the proposed move:

The people in the house...[decided that I would move]...they did...we still had to move... (Nicola, OP)

No, she didn't really want to move like, but it was just I suppose that ...this big change was happening you know. (Mags, Fam)

However, notwithstanding the concerns of staff and managers, it was notable that older people with intellectual disabilities and siblings alike were very satisfied with the current accommodation being provided. Most older participants reported that

they hoped to stay in their current accommodation and were confident that they would do so:

I want to stay in this apartment. (Rose, OP)

One lady who lives with her parents expected that she would move in the future and stated that her preference was to move to the house in which she currently receives respite:

...and I'm over 70...I know you have to think ahead now. (Sue, OP)

Although some siblings had been anxious about the prospect of their family member's change of accommodation, they spoke very highly about the sensitive way in which this transition was supported by services and staff:

We were very, very, very worried about it...because he had such a relationship with the staff over there and the other clients. But the transition was made so easy for him...they just eased it so much for him transferring. You know they brought him down for short periods and for tea and helped, got him to help with the design of the room and the colours of the room. (Kay, Fam)

Such accounts highlighted the very positive supports that were being provided in many services, in the face of significant challenges. These challenges in creating living environments that can meet the needs of older people with intellectual disabilities are not solely related to availability of accommodation but must also be seen in the context of standards and regulations.

Standards and regulations

The development of national standards for disability services, overseen by the Health Information and Quality Authority (HIQA) in 2013, was an important milestone in service provision and these standards have had a significant influence on the lives of people with intellectual disabilities. The requirement to meet standards has resulted in environmental modifications being mandated by HIQA though these have not always been completed as the funding required for those modifications was significant. The result was that in such cases, the older people had to leave their homes:

...particularly in relation to fire...we would struggle with our older age population in getting people out within the three minutes that is specified by HIQA...so we've had to try and put in infrastructure within houses to put in extra fire doors in bedrooms, move people downstairs. Unfortunately, sometimes people have to leave their homes because HIQA have said that we can't provide the environmental infrastructure or the nursing infrastructure to support their needs. (Anne, M, SS)

In the absence of extra funding to meet these needs, there is often a 'balancing game' between meeting regulatory standards-related requirements and funding-driven policy requirements:

...in terms of the funding and the cost element of that and the resources required to be able to amend this without the balance of funding as well. As well as the regulations with HIQA you also have the New Directions, Infection in Congregated Settings and all those different legislations and policies coming out as well. (Carol, M, GS)

Some participants did note that limited funding was sometimes obtained to meet requirements and that the HIQA inspection and report process could be instrumental in this being realised:

...we didn't have enough staff on board...and it was certainly highlighted at a HIQA inspection, and we went through a very difficult time...that's where we had to go to get the funding that we needed...it's absolutely crucial that you have enough staff on your roster to be able to run your service. (Claire, M, GS)

These contributions demonstrate the reality that services are often having to carefully balance their desire to provide a service that meets the best practice principles (for example, ageing in place) against the environmental and regulatory requirements. They are also doing so in the reality of limited resources, an issue that underpins many of the themes in this report.

Resources

Throughout this study, respondents and participants repeatedly referred to the difficulties of achieving individually determined, person-focused supports for people with intellectual disabilities as they aged, and needs became more complex. Whilst the fundamental issue was often identified as being one of funding, particularly the challenge of accessing responsive funding from the Health Service Executive, this was usually manifested in the availability of the practical resources required to run a service, particularly accommodation, staffing, healthcare and health/supportive equipment. The findings in these regards will now be presented.

Staffing

There are many factors that impact on how services for people with intellectual disabilities are staffed but one principal factor is the changing and complex care needs of persons as they age. In order to meet changing/escalating needs, there is a concurrent requirement to titrate the staffing resource against those needs. Three quarters (75%, n=21) of survey respondents reported that they had experiences of staffing levels being insufficient to meet need. To respond to such need, it was observed that services might have to provide additional staff during both day and night-time. It was noted that, even where there was a will and the resources to

obtain extra staff, there was frequently difficulties in getting suitably qualified people. Recruiting Registered Intellectual Disability Nurses (RNIDs) was highlighted, in this regard, as a specific, significant difficulty for service:

In the last three months, I don't know how many advertisements we've put out for nursing staff and nothing, nothing! We've never even got to interview...you get a few after the graduation...and that's probably short term...I suppose the most difficult part would be when someone has palliative care. And they're actively dying. (Ann, D, SS)

...the shortage of nurses... it's really hampering a lot of planning and a lot of de-congregating and a lot of proposed transiting. (Michael, M, SS)

As a response in some services, the RNID coordinated the care across more than one site with the direct care being delivered by social care staff:

...it's being staffed solely by social care people, and they are doing a phenomenal job, it's overseen by nursing staff...that are carrying out the role from an external basis... So while we have lots of nursing oversight the people that are providing the hands-on care on a day-to-day basis would come from a social care model. (Jane, M, SS)

Services also looked to staff flexibility as a way of accommodating the changing needs of the person:

...a lot of staff doing split shifts to try and cover high support times and balance that out...a lot of flexibility for staff, in order to accommodate what the quality of support people are receiving. (Carol, M, GS)

This flexibility allowed service houses to maintain the current staff cohort, in acknowledgement of the fact that changes in staff can be a significant source of stress for older people with intellectual disabilities (McCarron et al., 2017b). Participants spoke of the dedication and commitment of staff to the those receiving their service:

...since 2015 I have the same staff for both my teams. In one house I'm so proud of nobody has done no relief, no agency has done a sleep-over in over two years. The other house I've had...I might have the agency do the day shift but never had to have an agency do the sleep over in that house. That's because the staff and the level of commitment...the level of care they have for the service users, it is brilliant! (Freda, D, SS)

Forced dependency on agency staff was an issue of concern; not only did lead to discontinuity for the older person, but few agency nurses have training in, or experience of, working with people with intellectual disabilities:

Yea, I suppose at the moment here where I'm working our complement is eight staff nurses, but we've only got four at the minute...you might have one familiar nurse on and then the second nurse would be agency staff...there could be different agency staff every day...and you don't know what background they have got...And recently we had a recruitment drive and there was no nurses you know interviewed that day. So yeah. it's going to be a huge challenge. (Betty, D, SS)

A consequence of inadequate staffing may be that a person cannot continue to be cared for in their own home and may need to be transferred to other generic locations, such as nursing homes. This issue was also highlighted in the narrative comments of survey respondents, one of whom noted that their 'service is totally under-resourced to meet the changing needs of our elderly population, particularly those living in single staff houses with stairs in the community'. Another suggested that staffing issues 'impact negatively on the person's ability to age in place'.

However, services and family members may continue to deploy significant resources to support individuals who have transferred to a community nursing home. Two siblings were adamant that such supplementary support was essential to ensure that their family member received an adequate service:

And the plan was, when the staff were trained up and able and ready and have assigned people to look after... [person's name]... [service name]... would become more of "we'll drop in and visit." Or they were to take a step back. But it ended up with... [service name]... looking after... [person's name] from 10 o'clock in the morning till 6 o'clock in the evening and them taking over for the night-time. (Fiona, Fam)

The staffing level was very low, I would say minimal, but it was a very good nursing home... we trusted the matron there and the staff; it was very well run, but for example, they wouldn't have somebody to sit with... [person's name]... at night, they'd just look in. So, I did the night duty, I sat with him during the night... and one of the service provider staff, came in during the day then for me. (Nancy, Fam)

A further issue noted by service managers was the difficulty in getting staff to take on positions of responsibility; this also impacted on service delivery. It was also acknowledged, though, that it is not only about filling these posts but there is also a need to support staff in such positions:

...trying to encourage people to step up to the likes of... certified nursing assistant, CNM1, CNM2 positions... I think even if you had the number of nurses it's trying to make sure that the organisation has supports in place that for those positions in a good way. (Michael, M, SS)

One result of the such shortages has been that care assistants are increasingly carrying out traditionally nursing-related duties:

I would prefer to have a nurse on site overseeing some of the interventions. But...nurses are just not out there. (Jane, M, SS)

This raises the topic of skill mix, not just in respect of the various staff/carer groups but also of the skills that are available within the staffing complement to meet the older person's needs. Just over 70% (70.4%, n=19) of survey respondents reported that they had encountered examples of not having the staffing skill mix in place appropriate to meet a person's need. Whereas there is a need for an appropriate configuration of staff and staff skill mix to support the person as they age, the associated cost of such resources was a concern for some participants:

...funding is massive...we still don't have enough nursing...that nursing model of service as the person ages it's absolutely essentially. (Claire, M, GS)

The importance of supporting social care workers in their roles was also identified and participants noted that they may need to take on new roles to support the person as they age:

...there's a huge need to upskill health care assistants in that as well. (Michael, M, SS)

This change in job description may require a certain amount of buy-in or good-will from staff:

...we can support the social care workers however they need to be open to taking on the roles and we need buy-in from the staff group that they are going to take on these key roles within their current pay scale and current grade...if you have buy-in from the staff and the willingness of the staff and good culture they will row in with you in terms of trying to support people at home. (Anne, M, SS)

The need for education and upskilling opportunities for all staff was seen as being essential. Some of this education is provide by nurses/nurse specialists and in other areas, the education opportunities may be provided by the services' onsite training department. Another approach is the use of tertiary continuing education opportunities:

...staff training is critically important and having a good, trained staff...is critically important to support this group. (Sarah, M, SS)

We have our own onsite training...there's like six or seven training officers that are specifically employed for that area...well for people to access further education from colleges. (Carol, M, GS)

The CNE...(Centre for Nurse Education)...is a great resource tool as well, we have used a lot of the training resources from there. (Claire, M, GS)

For some services staff and family education has been around specific areas such as dementia care and ageing in place:

Ageing in place, we need good staff training behind it so we would be very involved in supporting staff to help the person to age in place. We're very heavily involved with staff and the person's family members to help them to continue to age in the house of their choice. (Sarah, M, SS)

...over the last few years, we have done a lot of training with staff in the area of dementia. (Claire, M, GS)

Notwithstanding the need for staff upskilling as identified by participants, some participants spoke about some of the challenges associated with staff upskilling such as the need for more upskilling, some reluctance by staff to avail of and implement the skills training and challenges associated with the nature of the subject being discussed, for example, end of life care:

So, at first there was a little bit of reluctance...but I think then as people seen first-hand the impact that it could make on somebody's life, or end of life, the buy in was a lot greater. (Moya, M, SS)

We have done longitudinal training with people around end of life and using the end of life planning tool which is I think probably one of the most difficult trainings for staff because a lot of people struggle with that piece, with individuals talking about end of life. (Claire, M, GS)

Some services also offered training opportunities to personnel that don't provide direct care but who do come into contact with the person over the course of their work such as transport drivers and maintenance staff:

...our transport drivers and maintenance...if they have any interaction with any of the residents. (Carol, M, GS)

Other services have invited nursing home staff to their education and training session to enable them to support the person who was transitioning from their current service to their nursing home:

...we would have invited in nursing home staff to the training, and we would have gone out and provided training to nursing home team of staff just as part of a transition. (Claire, M, GS)

The issue of staffing and ensuring an appropriate staff mix is one of great pertinence to services. The speed at which an older person's care needs may change requires a timely and flexible response however services experience particular challenges in the recruitment of RNIDs, and the reluctance of some staff to upskill or take positions of responsibility. The absence of such skill mix and shortfalls in staffing

levels may result in an untimely relocation of an older person from their current home.

Funding

It has already been noted that the provision of a quality service, and one that is responsive to the older persons' needs and wishes, is premised on the availability of resources, and particularly funding. Thus, if there is no flexibility in financial resourcing, this will result in a service that will be unable to address individual's needs and wishes. Some participants noted that where staffing and environmental adaptations were possible, there was often a difficulty in getting this funded:

...we have not been able to care for them within their own home and that was probably due to funding issues, whether they needed increasing staff. Some of it was environmental. (Sarah, M, SS)

This view was also aired by one survey respondent:

...funding not available for change related needs in a proactive manner. (S)

It was noted that this inability to get funds was also leading to non-optimal service outcomes for the older persons:

...the majority of our people have gone to nursing homes for the very reason; it's not that we didn't have skills, or we didn't have the expertise, or we didn't have the experience...we are finding it more and more difficult to get any funding for anybody's changing needs. (Claire, M, GS)

Even where there was potential for funding, the process was often quite unwieldy, and this led to delays such that the older person's needs had changed and the funded service response possible was one that was no longer aligned to those needs:

We had to apply to our funders through our business case process...and we had a long wait. (Emily, M, GS)

Nor could the service be aligned to the older person's stated wishes, making person-centeredness impossible to apply:

...if we don't have the resources and the funding, it's very challenging for staff to try and apply a person-centred approach for that person and to really realise what their own decisions are and give them the choice and decisions. (Anne, M, SS)

It was noted that funding is provided at a defined and static level which does not take account of changing complexity, new compliance needs, or individuals' wishes. The cost of providing a service for those older people living in a particular

environment is met by *congregating* the monies provided for those people's service. This seriously limited the possibility of individualised services responses:

We still only get €12,000 and €15,000 euro for them. But the staffing needs are higher, the transport, the equipment, the facilities both for the houses and for the services. Being able to give time to people means you need more staff because if you have ten people and you need to give somebody...a really respectful time in the bathroom, then somebody else has to be with the other people. (Elizabeth, M, GS)

This problem transferred to the provision of equipment to meet older person's needs. The challenges in respect of managing such equipment in a setting that has limited capability of being expanded or structurally changed, has been identified already. The purchase of equipment and provision of space is, again, subject to availability of funding:

it's never just about the person because there's always so many influencing factors...do we have the equipment? Is there space to put in what they need in the house they are living in...but finance isn't always there to do it. So, you are always, it comes back to resources and finance a lot (Jane, M, SS)

For some services, it was possible to achieve a compromise, due to the creativity and of in-service occupational therapists and physiotherapists to source equipment as needed via personal contacts:

Well, I have to say in our situation over the years. that has improved greatly...we'd have an OT and physiotherapists...their workload is massive, but they were able to get all of the equipment and things and appliances that were required in the last few months. We had them really quickly, within a couple of days sometimes and a week for a wheelchair it was fantastic. (Eve, D, GS)

Adequate resources are the key prerequisite to the provision of person-centred supports for older people with intellectual disabilities. Staffing levels, staff mix, and the timely provision of equipment were all reported to impact on the ability of services to respond to the changing and, often complex, needs of people with intellectual disabilities as they age. Many of the challenges are underpinned by inadequate funding and a funding model that is not sensitive to increased need at the level of the individual.

Outcomes and quality of life

Survey respondents most frequently reported using person-centred support plans (78.1%; n=25) or person-centred care plans (68.8%; n=22) to measure outcomes of care and support for older adults in their services. Almost 60% (59.4%; n=19) used their advocacy process or a complaints process (59.4%; n=19) and more than half

reported using HIQA standards measures (56.3%; n=18). Other reported tools included satisfaction surveys (46.9%; n=15), and the DisDAT (Disability Distress Assessment Tool) (Regnard et al., 2007) (43.8%; n=14). Apart from satisfaction surveys and the HIQA measures, specialist services reported using these tools more than non-specialist services. However, overall, these tools were used more frequently by 'other' services compared to specialist and non-specialist services.

Focus group participants, too, reported the use of those and other measurement tools including I Plan, Glancing Back Planning Forward tool (Burke et al., 2017), as well as qualitative interviews and satisfaction surveys:

...we have a system called 'I Plan', so we can go in and monitor are we meeting the outcomes for people. We're using the live outcomes; we're looking at them. They're constantly being looked at and changed and monitored with the individual. (Elizabeth, M, GS)

...the tool that we used...for supporting the care conversations...[is]...the 'Glancing Back, Planning Forward' tool, and we analyse that...we say well, did we meet all the person's wishes? Did we tick the boxes of what they wanted to do? And if we did, that's where the positive outcome is for the person. (Emily, M, GS)

...we do what we call 'reliable interviews' with people. And I suppose we come back, and we score it; we determine what outcome is present in a person's life or what isn't. (Claire, M, GS)

We have our questionnaires that we would provide to the residents, and then we just kind of educate people on their rights and the complaints process. And the more that people are aware of what they're entitled to, and their likes and their choices, the more that we find that people speak if they want change or if they're not happy with something or if they'd like something else. (Moya, M, SS)

For others, the measurement of outcomes is work that is only being commenced, and specifically in relation to those who have been diagnosed with dementia or who are likely to be:

...in terms of measuring, it...[the process]...is really starting now...trying to figure out you know how many people and looking at how many people are fifty years of age or forty years of age now, and we will be going through the screening for dementia, especially if they are presenting with Down syndrome. (Claire, M, GS)

In relation to measuring outcomes of care for people with dementia, participants spoke about the need to review the person's care on a more frequent basis:

...people with dementia, their goal planning is very different...so their goal planning, definitely the timelines, are shorter. So, we might do that every three months, but you might just focus on one goal as opposed to maybe two or three. So, it's very individualised...everything is always captured on kind of like your action plan page...there's a timeline on it and we'd always have one person with the key responsibility to ensure that that goal...and make sure that the person is getting what they would have liked. And that's really how we measure. (Mary, M, SS)

The potential limitations of some outcome of care measurement tools arose as a discussion point in a number of focus groups. It was argued that there was a lack of clarity as to what the indicators of quality might be, and participants spoke about the challenges of documenting the evidence to show that the outcomes identified for the person had been met:

I suppose measuring it, you know it's kind of a bit, it's thrown me a little bit to be honest because if somebody asked me to prove that somebody is living a good life...I can show you documentation and speak to the person and they could tell you themselves once they are verbal. But on paper to give evidence of it, I don't know...but as a measurable tool I don't know what you would use really to determine how good somebody's life is. (Jane, M, SS)

Outcome measurement in a situation whereby the older person could not communicate verbally was identified by some of the participants as potentially challenging and this highlighted the need for the task to be conducted by someone who knew the individual very well:

...[communication]...can be measured in several ways. Even if it's vocalisation around whether they are happy or not, it's really down to the person knowing the person very well and knowing how they express that they are happy. And how they express that they are not...that ability is a tool to use to gauge what the person's experience is, how they are expressing themselves. (Anne, M, SS)

Likewise, it was queried whether responses to surveys reflected the perspective of the person themselves or the staff member who completes the survey:

...the service user satisfaction survey that we would do annually or more often...sometimes I do feel a lot of the times are filled in by staff. So, are you getting the staff's perspective of what the person's life is like or are you getting the true reflection of how the person's lived experience would be? (Jane, M, SS)

The issue of quality, as an outcome of care, arose in a number of the sibling interviews. These family members repeatedly spoke of the relationship between certain factors and quality of care, namely, staffing levels, staff knowledge and skills

in respect of intellectual disability and the stability and continuity of the workforce in living environments:

She knows everybody here, and the staff is a huge thing. (Mags, Fam)

Some spoke of the deep affection between the older person with intellectual disabilities and staff members:

...he was very happy those last two years of his life even though he was in a wheelchair and was basically non-verbal; he was just loved by the staff. You could see, there were one or two, one particular man there, one of his carers, as soon as he walked into the room, his face would just light up, they had an amazing relationship. (Nancy, Fam)

His manager in the last house was so amazing. Oh, they had been together for twenty-six years. And they were like a couple, they got on so well. So, she made sure that everything was done for the right reasons. (Kay, Fam)

As previously described, family members wanted the service given to their family member to reflect the changes which they may experience as they age including attendance at day service and participation in activities. Likewise, the vast majority (93.1%; n=27) of respondents reported that quality of life (QOL) outcomes change as older people with intellectual disabilities and complex age-related needs develop. Such changes, it was said, should be seen as a normal part of ageing:

QOL outcomes change as the person gets older. This is a natural process and one that is not necessarily a worsening of outcomes. (S)

As with all people as they age, the outcomes of life do change, but this does not have to be a negative change, it means living as well as you can, engaging as much as you can but staying safe also. (S)

Persons, as they get older, may have different quality of life outcomes. Going out to concerts etc. may not be their priority, but meeting friends in a quiet environment may now be their quality of life outcome. (S)

These approaches to outcomes measurement are more akin to ongoing person-centred planning and may be considered 'bespoke' in nature. This idea of planning for the future care needs of individuals was further discussed by some participants who identified the benefit of having short and long-term plans to accommodate the person as their needs changed:

...we are updating everybody's need assessments in terms of our five-year planning as well. Individuals are being interviewed as well as their family members to try and plan for their future and try to accommodate everyone's needs so that we know what, in five years' time or even in two months' time, life for someone is

going to look like, even if their health does deteriorate. That okay we have planned actions in place and that we have put in business plans for everybody, as accurately as we can. (Carol, M, GS)

A wide range of tools are used by services to measure outcomes for, and the quality of life of, older people with complex needs. However, measuring outcomes was perceived not to be straightforward and the process is often one of ongoing care and support planning, rather than outcome measurement. There was unanimity across the data sources that the components of a good quality of life change with age and ensuring a good quality of life requires careful attention to individual needs.

This chapter drew together data from older people with intellectual disabilities, family members, intellectual disability service managers and direct care staff. It is notable that despite the initial aim of the study to explore models of care employed by specialist age-related services and those that do not have a specialist age-related service, this clear delineation does not exist. Rather services employ diverse approaches to care that incorporate various living settings (home, community, campus, specialist units) grounded in diverse, and often eclectic models, underpinned by nursing, health, and social care.

Chapter 6: Discussion and recommendations

The proportion of older people in the services is increasing, with the older age cohort already presenting as the dominant one in 28% of services surveyed. The expectation is that it will rise rapidly over the next five years in other services too. It is, therefore, not surprising that respondents highlighted the relevance of age-related issues to services. This increase in life expectancy has brought a new focus on transitions in later life (Egan et al., 2022) and the need for services to be reconfigured accordingly. The National Positive Ageing Strategy (Department of Health, 2013) provided a framework for addressing age-related policy and service at a national level, but the impact of this in the lives of older people with intellectual disabilities has progressed more slowly. The Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (McCarron et al., 2017b) and the identification of Positive Ageing Indicators for people with intellectual disabilities (Healthy and Positive Ageing Initiative, 2018) have been important milestones in redressing this. Furthermore, the recent Disability Capacity Review to 2032 (Department of Health, 2021a), may provide an important platform for the resourcing service supports for people with intellectual disabilities as they age. Such developments have increased awareness of the need to support healthy ageing for people with intellectual disabilities, and to embed the principles of positive ageing in intellectual disability services. It is not surprising, therefore, that key concepts such as ageing in place, person-centred support, responsiveness to older persons' needs and proactive future planning were highlighted by participants in this study. There was also widespread consensus that quality of life outcomes change as people with intellectual disabilities age, just as they do for those in the general population, and these require a level of agility on the part of services to facilitate individually-determined responses, such as having a slower pace of life and daytime activities that differ from the day centre model that has been the cornerstone of service provision for adults with intellectual disabilities.

Service approaches

Whereas a commitment to the provision of an individualised service to meet the needs of people as they age was evident, service managers, direct care staff and family members emphasised the considerable challenges to actually achieving this for those in receipt of service. Central to this is absence of a formal model of service pertaining to ageing and the scarcity of key resources, particularly funding. This hampered the agile response that is often needed to appropriately respond to needs that may change very rapidly. Aspects of staffing were also identified as a constraining challenge, particularly as pertaining to the recruitment and retainment of skilled personnel.

This study set out to examine the care and service options for older adults with intellectual disabilities and complex age-related conditions. It did so from a premise that there are clearly delineable approaches to providing service and that these can be generalised as intellectual disability services with specific ageing pathways, services without such pathways and mainstream nursing homes. Drawing from this, the study further sought to garner new evidence on current models/approaches to care, to compare outcomes and quality of life in care settings and to provide additional information on expected future needs of older adults with intellectual disabilities and complex age-related conditions. Whilst nothing can, at this point, be concluded in respect of nursing homes (due to their non-inclusion in this study), the findings suggest, however, that there is in fact no clear delineation within intellectual disability services *vis a vis* models or approaches for this cohort. This is also borne out by the dearth of literature identified in this regard (Sheerin et al., 2021a). In the absence of a dedicated, structured approach, intellectual disability services, staff and family members have had to develop alternative possibilities, often an eclectic mix of health and social care provision often cobbled from adjustments to services for other age groups, to provide the support required for people with intellectual disabilities to achieve healthy ageing.

The reason for the lack of structured approaches may also lie with the fact that intellectual disability service in Ireland was never properly underpinned by a service model but developed in a somewhat fragmented manner, through the growth of largely voluntary bodies, funded by the state. Furthermore, the historical financial and physical separation of the intellectual disability service from other mainstream services has resulted in a service structure that does not easily support the application of national strategies on ageing to people with intellectual disabilities. The funding model for such services was for many years a largely congregated one, which facilitated group rather than individual activity, making person-centred outcomes difficult to achieve (Bigby, 2002). Furthermore, as noted by the NDA (2006), the siloing of funding between ageing and disability services has resulted in a lack of coordination between them in addressing older persons' care needs. These issues have likely limited the realisation of general population healthy ageing policies in the lives of many older people with intellectual disabilities. The Department of Health (2022) highlighted the need for a complete overhaul of the services funding model, noting that this was crucial if service transformation is to be achieved. Attempts to roll out alternative, and agile, funding models, such as personalised budgets, has been slow despite the establishment of the task force in 2016. The absence of such funding models, and the reported delays associated with the business case process means that person-centred supports are often unavailable, or delayed at best, leading to an inability to meet older persons' needs.

These issues may have contributed to the evolution of service approaches described by participants. The move towards a social model of disability, while welcome, saw a concomitant move away from the health-oriented perspectives

that had historically predominated service provision, something manifested in the policy on decongregation (HSE, 2011) which saw the flourishing of community-based accommodation provided largely by social care staff with the assumption, as in other countries, that healthcare services in the community would be accessed similar to the general population (McCallion et al., 2017). The roll-out of such settings has, however, occurred in the absence of comprehensive, quality community-based healthcare and at a time when ageing demographics have changed, and health complexity in particular has increased. The commitment to the social model without required levels of community delivered healthcare, as obligated by the UNCRPD, has resulted in a dilemma as to whether older adults with developing complexity can or should remain in settings that no longer have health personnel. The prioritisation of social inclusion and decongregation may have also led to the reduction of residential places within intellectual disability services thereby inadvertently increasing the transition of people with developing complex needs into other long-term care (Egan et al., 2022).

The traditional distinction between the medical and the social model, discussed by the participants, may reflect an emphasis that has not served people with intellectual disabilities well. This emphasis focuses on the professions rather than on the individuals themselves and the people (staff and family) who support the lives of people with intellectual disabilities and on the values that underpin their support, namely person-centredness, ageing in place and self-determination. This has also diverted attention away from what has not yet been achieved in respect of decongregation, namely the challenges of accessing quality healthcare for people with intellectual disabilities as they age, on the same basis as the general population.

A growing tendency for older adults with intellectual disabilities to be moved to new congregated settings has been highlighted by a number of authors (Todd et al., 2020; Taggart & Hanna-Trainor, 2017). In order to redress this, many agencies have had to create their own aged-care pathways, bringing together various services and creating informal networks to better access mainstream health and social services. It was noted, though, that many of these networks were not built on the formalised relationships that are recommended as part of an integrated service model (Sheerin et al., 2021a). There has also been recognition that there may be a need for the creation of new roles to support such networks and ensure that community-based healthcare delivery for example in hospitals be supported through the creation of liaison and other specialised roles (McCarron et al., 2016).

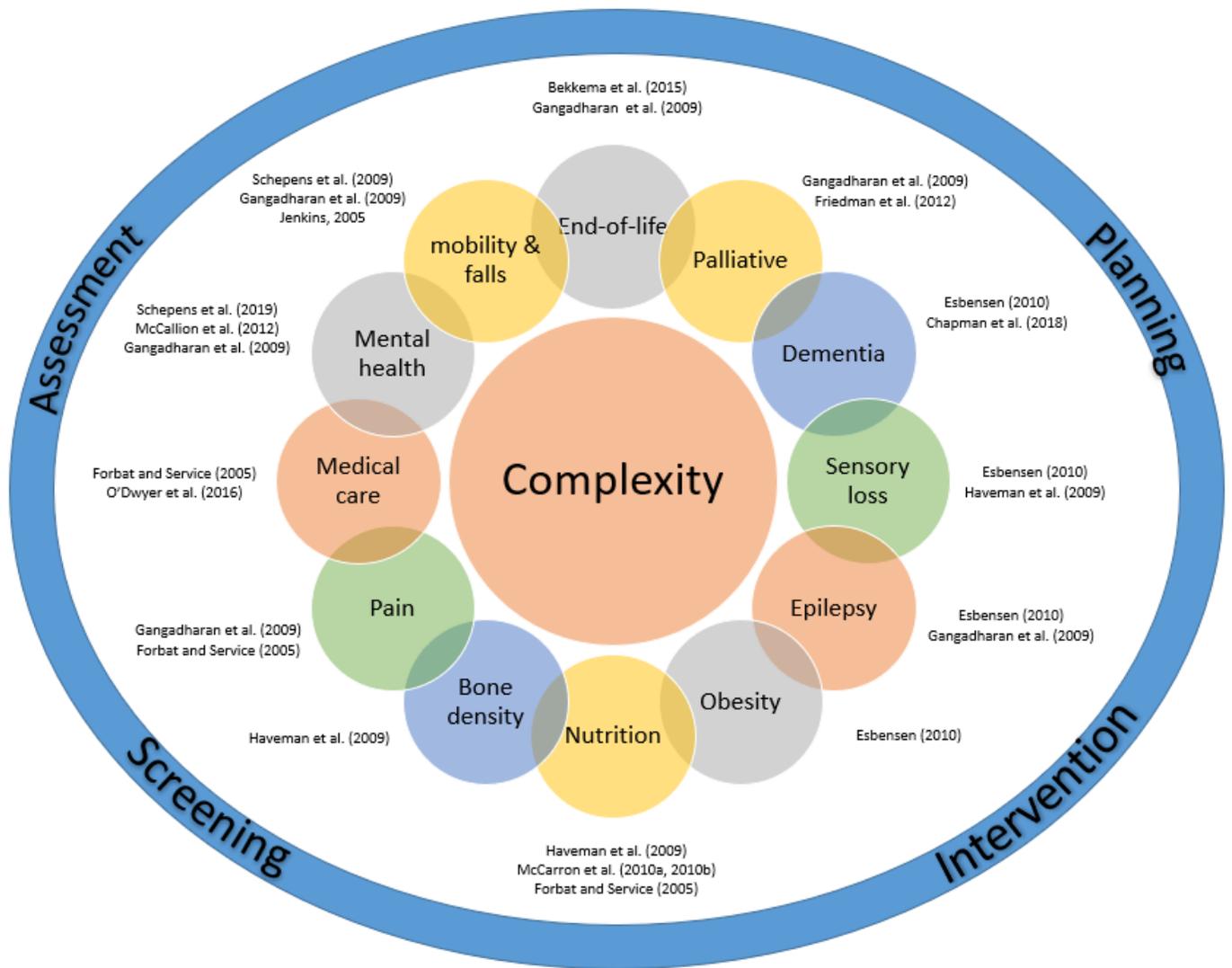
It must be acknowledged that, despite the challenges outlined above, participants in this study, concurred that, in line with Article 19 of the UNCRPD (United Nations, 2006), older people with intellectual disabilities should have person-centred support, provided preferably, in their own homes (Department of Health, 2020b; Chapman et al., 2018; Patti et al., 2010). Participants also agreed that such support should be dynamic in nature, and responsive to emerging age-related complexity

(HSE, 2021; Schepens et al., 2019; New South Wales Ministry of Health, 2012; McCarron et al., 2010a). Increasing age may add to the complexity of the transitions experienced by older people with intellectual disabilities and person-centred future planning can support and prepare older people with intellectual disabilities for transitions that reflect and respect the preferences of the individual (Strnadová, 2019). Instead, many such transitions are reactive, made in response to a crisis and without the benefit of proactive planning (Strnadová, 2019).

Such planning has not been easy, though, with many participants pointing to the challenge of providing a responsive service in the context of an inflexible funding system. Indeed, several participants recounted stories whereby services could not be provided, resulting in older people being transferred to non-optimal accommodation. This reality was highlighted previously by Ryan et al. (2014), who noted the risk of nursing homes and residential placements becoming the default answer for such older people. It is important, though, to move beyond acknowledging this as it is occurring in the absence of optimal care pathways, and the focus must move to ensuring that such pathways are put in place.

It is abundantly clear that there is a need for a more properly structured service model, focused on healthy ageing among people with intellectual disabilities, and with dedicated funding. Such a model must be informed by the needs, complex and otherwise of this group of people. The literature review has identified many health-related issues. Many of these are presented in Figure 3, and describe impairments (sensory loss), disease processes (dementia, osteoporosis, epilepsy), metabolic concerns (nutrition, obesity), chronicity (pain), accidents (mobility and falls), mental health, life transitions (end of life) and intensive interventions (medical and palliative care). Others identified in this study, include problematic behaviours and frailty. Multimorbidity and, at times, different presentations of symptoms were also noted to be a significant health concern and this may underly some of the complexity that often characterises ageing amongst people with intellectual disabilities, as a number of the above issues may present simultaneously and interact with each other (Mann et al., 2022; Hussain et al., 2020; McCarron et al., 2013). This may bring with it the need for complex interventions, such as those identified by O'Dwyer et al. (2016).

Figure 3: Scope of age-related needs of older people with intellectual disabilities



Source: (Sheerin et al., 2021a)

Current and future needs

A majority of survey respondents identified dementia as the most significant challenge to meeting the needs of older adults with intellectual disabilities in their service. This was also reflected in the comments of managers, direct care staff and family members across focus groups and interviews, with a particular emphasis on the significantly negative impact on the older persons' quality of life (Marsack-Topolewski & Samuel, 2020). Dementia is a progressive disease which brings a myriad of complex challenges across health, social and other domains (Sheerin et al., 2020). It is typically characterised as having three stages (early, mid and late) during which health, functional, psychological and cognitive changes become increasingly pronounced, leading to associated changes in support and care needs (*ibid.*). It is support-intensive, with constant supervision often needed to reduce risk of injury (Jokinen et al., 2013; Janicki et al., 2003). Many participants related their experiences of attempting to address these needs but noted that staffing issues and inflexible funding seriously limited their ability to do so. They were often not in a position to reconfigure services around those needs and this impacted on their ability to support the older person to age in place, as recommended (Janicki et al., 2005; Janicki et al., 1996). This also restricted the team's and families' potential to plan the support and care of the person as they moved through the disease's trajectory. Some services have managed to set up purpose-built dementia units which follow best practice guidelines but this is often supported through private and charitable funding. They are, however, in a position to provide a home environment where specialised care can be provided and where there is appropriate space, skill mix and equipment. Other services have used existing resources to provide high-standard, homely care, often bringing in nurses and other health professionals from other parts of the services. Still absent, however, is evidence of collaboration between intellectual disability service agencies and Alzheimer's care providers to create a more shared rather than intellectual disability specific model. The absence of dedicated resources for planning and service provision is something that must be addressed and is a key principle in the Irish National Dementia Strategy (Department of Health, 2014, p. 13):

Available resources should be deployed on the basis of need and as effectively as possible to provide services for all people with dementia, including those with early-onset dementia and/or an intellectual disability, and should be delivered in a culturally appropriate way.

Dementia was also of particular concern to family members, who reported a lack of information being available to them, even where their sibling had Down Syndrome. Indeed, some families felt unsupported by both intellectual disability and by generic health service, something which is likely amplified by the disjuncture between disability and geriatric services. The growing reality is that there are people with intellectual disabilities and dementia who have always lived with family

and who would particularly benefit from a more joined up approach between disability and geriatric services. The literature identifies family involvement as an important aspect of specialist dementia services particularly as part of a palliative care approach (Voss et al., 2020; Wiese et al., 2014). Any shortcoming in this respect may relate to the absence of a structured dementia pathway, noted by the survey respondents, in general (33.3%) and specialised services (60%).

Similar issues were raised by participants and respondents in respect of end of life care. There was unanimity in the view that older people should be supported to die at home whenever possible, but that this could only be achieved with proper planning and flexible resources (Todd et al., 2020). The findings of this study, though, provide examples of extraordinary efforts on the part of individual teams and staff members, to support those in their care to die at home. There were also exemplars of the individual being involved in end of life care decisions and planning. Whilst it is noted that family were involved and supported, a number of family members did not feel supported during times of bereavement.

Whilst end of life care needs may be considered to be generic, there are specific needs that arise with differing illness processes. The profile of diseases and conditions leading to death in older people with intellectual disabilities may differ to that in the general older population (Heslop & Glover, 2015), leading to the suggestion that there is less understanding of the end of life care needs of people with intellectual disabilities, than there is for other older adults. (Todd et al., 2020). There is a need for staff training and education in relation to end of life planning and care, something that has previously been highlighted in the literature (McCallion et al., 2017; Ryan et al., 2011; Ryan et al., 2010). Some services reported good engagement with palliative care teams. In the context of increasing longevity and the complex needs that may be associated with this, timely engagement with palliative care teams and advanced planning, grounded in the Irish Hospice Foundation's *Think Ahead* (Irish Hospice Foundation, 2022) may provide a good basis for an inclusive and respectful approach. Planning is not always possible, however. A recent UK study has reported that unexpected or less-expected deaths are more commonly experienced by people with intellectual disabilities than in the general population, making delivery of desired end of life care more difficult if it can only be instigated late in a terminal diagnosis (Bernal et al., 2021).

Another area of need that was raised in this study was not one related to health or illness, but focused instead on the patterns of life for older people with intellectual disabilities, particularly their need or desire to step back from day services or intensive activities. IDS-TILDA (McCarron et al., 2014) reported that more than 70% of respondents were still attending a day service in older age with only 6.7% being retired, compared to 40% in the same age groups in the general population (Hudson et al., 2014). McCallion et al. (2013a) notes that retirement in the general population is supported by a number of factors, including financial resources. There

was widespread consensus that quality of life outcomes change as people with intellectual disabilities age just as is the case with general population and that older people may require or desire a slower pace of life than that which they had in earlier years. However, supporting individuals to withdraw from day centres may have prohibitive financial implications for services if they have to staff houses which were previously unoccupied during day service hours.

Meeting future need

The issue of resources is a repeating theme in the findings and underpins so many aspects of service provision, with key healthy ageing principles largely unachievable in the absence of responsive funding, flexible staffing models, suitable accommodation and access to equipment and other resources. The findings reflect Northway et al. (2017)'s assertion that a strong body of evidence exists to indicate that the key determinants of whether people with intellectual disabilities can age in place are environmental issues and staff training. The policy on decongregation has enabled many people to live in their own homes in the community. However, a sizeable proportion of these homes are proving to be unsuitable for individuals with complex needs as they lack downstairs bathrooms, space required for healthcare equipment and/or the extra staff that might be required. Managers and direct care staff participants suggested that this was due to a lack of investment in purchasing or modifying accommodation in recent years and reported the difficulty of competing in the housing market. Whilst ageing in place is presented as the optimal option for most older people with intellectual disabilities, and some successful examples of such were described in the focus groups, unsuitable accommodation, increased support or medical needs, as well as an inadequate staff mix, present insurmountable obstacles, in some instances leading to movement to alternative settings including community nursing homes. Although some examples of positive collaborations between nursing homes and intellectual disability services were described, nursing homes were unanimously considered a setting of last resort for the family member participants in this study, and one which was not adjudged to be optimal due to the negative impacts of relocation (Egan et al., 2022), potential lack of acceptance (Webber et al., 2014), social exclusion (Egan et al., 2022) and an inadequate understanding of the social and other needs of older people with intellectual disabilities (Buys et al., 2012). Furthermore, people with intellectual disabilities may enter generic long-term care settings at a younger age than the general population. Nursing homes were also considered to be unsuitable placements for the older person due to perceived inadequate staffing levels, lack of training to work with people with intellectual disabilities and also because the depth of caring relationships between staff and the older person, so highly valued by family members, was often absent. It is to be established if these represent fears as opposed to experiences, if those fears are justified and whether there are steps to be taken and supported to alleviate such concerns

Availability and management of resources are of central importance to the provision of a quality ageing service. If decisions regarding support for people with intellectual disabilities are to be person-centred, then they must be guided by the person's needs and wishes and framed within the rights conferred by the UNCRPD. Such decisions must also take into account the fact that needs will change over time and not always in accordance to a predictable pattern. Forward planning is therefore vital if the person is to experience consistency, responsiveness and seamlessness in the service they receive and is best achieved through the use of a structured service model which can facilitate timely funding and resource responses. The service approaches described by participants in this study clearly sought to achieve positive outcomes but could often not respond to the older person's needs. Some accounts clearly did represent quality support and care but these were successful due to the innovation and determination of managers, staff and family carers, but such outcomes were 'case-specific' and were not necessarily achieved in all cases. Similarly, some services with age-related pathways or, for example, specialised dementia-friendly accommodation, could not offer this to all older people in the service, due to limited availability. The lack of consistency in provision for older persons has implications for services' ability to meet age-related needs, whether complex or not.

The findings of this study identified particular shortcomings regarding staffing and accommodation. Staffing levels, skill mix and staff willingness (or otherwise) to take on roles that are traditionally beyond one's boundaries may be a significant barrier to meeting older persons' needs. Challenges in these respects were identified by survey respondents, with three quarters (75%; n=21) reporting that they had experienced staffing levels being insufficient to meet need and 70.4% (n=19), reporting examples of not having the staffing skill mix in place appropriate to meet a person's need. Some of the problem may relate to a shortage of and difficulty in recruiting experienced RNIDs. Indeed, registration figures indicate that over the period 2016 to 2022 the number of RNIDs has fallen by nearly 1000. Current attempts to meet acute hospital and SláinteCare workforce needs, through the planned commencement of post-registration general nurse programmes targeting intellectual disability and mental health nurses, will result in further difficulties in accessing RNIDs. Participants suggested that RNIDs were an important part of the service response, particularly in the health domain. The role of the RNID has been an ambiguous one for some decades. It was developed during the institutional period of service provision and was strongly located in the medical model. As paradigms changed, the RNID bridged medical and social realms. The role became less definitive, leading participants in the report, *Shaping the Future of Intellectual Disability Nursing in Ireland*, to suggest that the role was difficult to differentiate from that of the social care assistant or of general nurses working in intellectual disability services (McCarron et al., 2018b). That strategy report, however, proposed a

refocusing of intellectual disability nursing on roles pertaining to health, including nurse specialist, advanced practitioner and liaison ones. The enactment of recommendations from McCarron et al.'s report may explain participants' assertion that RNIDs may play an essential role in supporting older people to age in place and that lack of their health-focussed skillset may precipitate the transfer of older people to settings other than their own homes. This may also be contributed to by the difficulties in funding 'twilight' staff to accommodate 'waking nights' (staff on active night duty), something that is often required in situations of acute and chronic illness including dementia. Such staffing models are more expensive and the process of getting funding was reported by participants to be slow and not responsive to immediate need.

One solution to recruitment challenges is the upskilling of other staff, such that they will be able to undertake some health-related activities. This recommendation is frequently aired in the literature (Johansson et al., 2017; Tuffrey-Wijne et al., 2007; Janicki et al., 2005) and is an important aspect of age-related care as it supports the consistency of relationships, something that family members noted to be important in the lives of their loved ones. There appears, however, to be a reluctance among some staff to upskill or take positions of responsibility. This is an interesting finding as previous studies (for example, Olsson & Gustafsson, 2020) have reported staff to be positively disposed to such education and training. The reason for such reticence is unclear but may be rooted in social care staff seeking to adhere to a social (not medical) model and nursing seeking to protect its role in the health domain. Related findings, though not in respect of medical tasks, were found in a recent NDA (2021b) study. It is recognised, though, that upskilling of staff increases the confidence of staff to support people with intellectual disabilities with complex needs to age in place (Webber et al., 2016; Bigby, 2010). The inability to fill posts and the adherence of staff groups to bounded roles may contribute to dependency of some services on agency staff who do not know the person, something that makes it difficult to achieve person-centred support (Edvardsson et al., 2010).

A variety of service approaches have been reported in this study, spanning the health-social continuum. The absence of any consistent approach to supporting healthy ageing across or within services suggests that the experience of the older person with intellectual disabilities is predicated, with a certain level of chance, upon the region in which they are located and, consequently, on the service with which they are registered. There is clearly no national model or strategic approach to providing older age intellectual disability service to those who receive service. Service providers in the state came into being, initially through the activities of religious congregations, then of parent and family groups and finally private agencies. Whilst the Irish state funded the work of many of these organisations, the state only became active providers of intellectual disability services in the later 20th

century. The work of voluntary agencies cannot be underestimated and they have responded to the needs of people with intellectual disabilities of all ages and supported families. They have also sought to enact service changes in line with international best practice. They have done this, however, in the absence of any national plan and in the context of an inflexible funding model, mediated largely via the Health Service Executive, that was not created or grounded in person-centeredness. The HSE has also set in train policies that have sought to fundamentally alter aspects of the service agencies' approaches, most notably *Time to Move on from Congregated Settings* (HSE, 2011). This rightly progressed decongregation and community living but the staffing profile for new living units was, to a certain degree, influenced by that which had been in the congregated model: some new units became social care led while others maintained a nurse-led approach, with health-related complexity more likely to be met in the latter rather than in the former. This is borne out by the findings of this study. The continuing lack of consistency in terms of a service model is problematic and is contributing to a situation whereby the care and support of older people with intellectual disabilities, in Ireland, cannot be guaranteed to be able to respond to their needs.

Conclusions

The services systems, the workforce and the funding mechanisms currently available for people who are ageing with intellectual disabilities were all developed at a different time and to achieve different goals. It is important to remember that living to old age for people with intellectual disabilities is still a relatively new phenomenon, and that when community-based options were developed, they were largely focused on moving young adults out of institutions and campuses and into jobs, community engagement and use of public transportation. The view of health and healthcare was grounded in a desire to break away from medical models and to celebrate opportunities to be healthy rather than focused on illness and health needs. Much of this is still true as people age but plans are not in place to resource ageing needs, work and day programming options have not been preparing for retirement and there is little realisation that older age is often associated with increasing chronic conditions, some of which may be more varied for people with intellectual disabilities and needing at least some specialised supports (McCallion & Jokinen, 2017; Janicki et al., 2005).

Contrasts in the experiences and needs of people with intellectual disabilities when growing older (as compared to in the younger years) were substantiated in the findings here as well as an absence of needed dedicated resources and preparedness, particularly in the healthcare sector and the intellectual disabilities workforce generally. There were also exemplar models identified in the findings that should be considered further and more widely resourced. One example is the work initiated by the HSE as a result of the report *Shaping the Future of Intellectual*

Disability Nursing in Ireland (McCarron et al., 2018b) which has resulted in new roles for nurses as intellectual disability liaisons in general hospitals and a re-vamp of intellectual disability nursing curricula. There are also calls for a similar workforce redesign for other workforce groups (Sheerin et al., 2021b). The establishment and tracking of indicators of positive ageing for people with intellectual disabilities (McGlinchey et al., 2018) is another important step. Needs assessments, evaluation, and redesigned training and roles will, however, only achieve so much.

Finally, many of the respondents raised concerns about placements in nursing homes occurring. There are models for challenging such placements by objectively assessing whether such a level of care is optimal and whether there are alternatives that may be provided at similar or less cost that preserve ageing in place (New York State Area Agencies on Aging, 2013). However, if nursing homes are to be used there is also a need to resource new models of collaboration between nursing homes, intellectual disability service providers and families to preserve the lives desired by people with intellectual disabilities as they age.

This study set out to examine the care and service options for older adults with intellectual disabilities and complex age-related needs. A variety of approaches to providing service were identified, but few of these could be considered to be structured or planned approaches. Moreover, none were underpinned by an ageing 'service model' but, rather, represented modifications of individual intellectual disability providers' services, drawing on the standard funding allocation received from the HSE. There was, however, no dedicated funding to support services' responses to the changing needs of their older service recipients. These changing needs, which relate to people with intellectual disabilities living into older age, and the anticipated costs of providing service to meet these were identified by the Irish State as far back as 2012 in the Value for Money and Policy Review of Disability Services (Department of Health, 2012), but this does not appear to have resulted in significant change, with the inadequacy of the current funding model strongly criticised by the National Federation of Voluntary Bodies (NFVB) seven years later (NFVB, 2019). The outcomes of this study support these concerns. That so many positive outcomes are being achieved for many older people is a credit to the services, their staff and family carers. This is, however, a wholly unsustainable approach to meeting the needs of older Irish people with intellectual disabilities.

Limitations

At the outset of this study, it had been envisaged that the research would have been completed and reported on in a twelve month period. The arrival of COVID-19 coincided with the initial approaches to service and nursing home gatekeepers. The project team, in collaboration with the NDA, made a decision to stall the project, as it was clear that health and social care agencies had to prioritise the

safety and wellbeing of their staff and service recipients at that time. Sampling of services and of participants was a very slow process and there may have been a reticence among some about taking part, brought on by the ongoing effects of the pandemic. Thus, there may be a limitation as to the representativeness of services that took part in the focus groups and interviews. It is worth noting, though, that there was a consistency in the issues that were raised in both qualitative and quantitative data sets.

The pandemic meant that no in-person data collection could be conducted, leading to the use of secure online platforms. This may have affected the ability to achieve the depth of discussion that might otherwise have been possible in a face-to-face meeting. The effect of COVID-19 on mainstream nursing homes was very significant and many were managing difficult staffing and care realities. Despite repeated attempts, it was concluded that it would not be possible for the input from this sector to be included in this study. Whilst understandable, it is unfortunate as their perspectives would have added significantly to those of intellectual disability service participants and family members. The main survey achieved a very high response rate, though very little could be gleaned in respect of costings as so few services volunteered to participate in the follow-up survey. This very much reduced the extent to which it is possible to draw any conclusions in these regards.

Recommendations

Based on the findings of this research, and bearing in mind recommendations made by participants and the limitations outlined above, four main strategies are recommended for achieving positive outcomes for older people with intellectual disabilities. These are underpinned by the principles and articles of the UNCRPD. When Ireland ratified the UNCRPD in 2018, the State undertook to ensure the full realisation of the human rights and fundamental freedoms of people with disabilities. This can only be achieved if service outcomes are closely aligned to the commitments made on ratification of the Convention.

Develop a national model of service for healthy ageing among people with intellectual disabilities

Healthy and positive ageing has been a central principle of Irish government policy for the past decade, and has been progressed in mainstream society through the Healthy Ireland initiative. Its realisation has not been seen on an equal basis among older people with intellectual disabilities, as called for in Article 25 of the Convention, primarily due to the absence of a national model of healthy ageing for this cohort of the population.

- Intellectual disability policy should give full consideration to the needs and desires of people with intellectual disabilities as they age. This is particularly pertinent as we are likely to see increasing numbers of people living into old age and this will bring with it greater demands on services that are unable to meet current need.
- Any new model of service should be enacted consistently across the Irish state such that older people with intellectual disabilities will receive quality services irrespective of location or affiliation to specific service agencies. To be effective, the model of service will require investment and defined funding lines, separate to those which currently are in place. It is recommended that the HSE set up a national steering group to oversee the development of the new model and enactment of this new model of service.
- In keeping with the HSE policy of decongregation that has seen many positive changes in the living situations of people with intellectual disabilities, the new service model should address the historical gap that has developed between intellectual disability agencies and mainstream health and social care providers, to ensure that mainstream services are accessible to older people with intellectual disabilities on an equal basis to others in society.
- The South Australian model, referred to in text, notes the importance of intersectoral collaboration between mainstream ageing and intellectual disability sectors. The new model of service for older people with

intellectual disabilities should ensure that there are clear pathways of care and support for older people with intellectual disabilities, with integration and networking across all relevant sectors.

- If a new national model of service for healthy ageing is to be developed, it is imperative that there be a rethinking and restructuring of the current funding model.

Reconfigure intellectual disability services to meet age-related needs

The development of services for people with intellectual disabilities in Ireland has been somewhat fragmented, with the State only becoming directly involved in service provision at a late stage. Thus, voluntary and other services progressed along a generic structure which had residential, day service and some other activational components; HSE-led intellectual disability services adopted this structure too. The funding model that underpinned these services reflected their congregated nature and the fact that most people with intellectual disabilities were not expected to live into older age. Whilst services have responded to the fact that people are living longer lives and have been innovative in trying to respond to the needs and desires of older people with intellectual disabilities, they have often been stymied by the unavailability of resources.

- Given that some service approaches to meeting older persons' needs have evolved in a piece-meal manner, with no clearly planned approach, efforts are needed to identify and enact evidence-based responses that can optimise positive outcomes.
- Specialist ageing service pathways will need to be developed to support the needs of older people whose complex needs cannot be met in their own home. Pathways should be prospective to ensure that there is advanced planning. Examples of successful pathways have been introduced in some intellectual disability services for people who, for example, need palliative support.
- Resources will need to be invested in supporting retirement opportunities, meeting more specialised health needs, environmental modifications and new staffing patterns to sustain ageing in place opportunities to live one's last days as one wishes (Ferretti et al., 2022).
- Whilst the policy of decongregation has been a positive one which has resulted in quality outcomes for many people with intellectual disabilities, there is a need to consider the potential for developing specialist services for people with complex age-related needs which cannot be met in the person's own home. Thus, a forum should be set up to explore how the foundational principles of Time to Move on from Congregated Settings can

be applied to re-congregated service structures such as specialist dementia facilities or generic nursing homes.

- Nursing homes were considered to be a final option by many participants in this study. If, however, nursing homes are to be used, there is a need to resource new models of collaboration between nursing homes, intellectual disability service providers and families to preserve the lives desired by people with intellectual disabilities as they age. Such developments should be supported and informed by further research both on the experiences of nursing homes in caring for people with intellectual disabilities and the experiences of older people with intellectual disabilities and their family members of nursing home care.

Develop clear resource models that can respond in a timely manner to the changing needs of older people with intellectual disabilities

Participants and respondents in this study highlighted how important it is to have a resource model that can respond to the changing needs of people with intellectual disabilities as they age. These changes may result in a requirement for modifications to the built environment and specialised equipment. The move to community living, whilst positive, has seen services renting or purchasing accommodation that may not be modifiable as the needs of the occupants change. The inability to retrofit or change the living space, due to rental agreements or lack of funding, was a key factor in deciding whether a person with intellectual disabilities could age in place.

- There is a requirement for new funding models that will allow for resources to be made available to older persons, when needed, to provide individualised and person-centred support. Processes should be put in place to ensure that such funding can be built into the person's ageing plan and be accessed when needed. Consideration should also be given to the inclusion of an oversight process that could monitor value for money, *vis à vis*, meaningful outcomes for the older person.
- More rapid introduction of personalised budgets, with a broad purchasing scope could support the configuration of individualised services around older persons' needs and wishes (Benoot et al., 2022).
- In line with recommendations regarding housing and built environment, it is vital that the purchase of community-based accommodation for people with intellectual disabilities should be underpinned by the UNCRPD principle of universal design (United Nations, 2006) and the guidelines provided in the recent NDA (2022b) report on residential care settings. Whilst this will improve the quality of housing, remove the need for relocation and increase opportunities for ageing in place, it will not be achievable in the absence of targeted resources.

- The realisation of the above will require a planned and structured approach. A working group should be set up to make recommendations on new models for resource planning in respect of housing and the built environment. Further research is also required to fully inform the associated policy implications.

Build the knowledge and skills of professionals, formal and informal carers

The provision of a responsive service to meet changing needs is predicated on the availability of knowledgeable and skilled professionals, and caregivers. This study highlights the commitment of staff to achieving the best possible outcomes for older people with intellectual disabilities. This was attested to by many family participants. Deficiencies were identified, however, in respect of the staffing models and the availability of required skills. Particular mention was made to the difficulty in recruiting specialist staff, particularly intellectual disability nurses, to meet complex health-related needs.

- The rostering of staff in intellectual disability settings has traditionally been structured around periods of greatest activity. Thus, greater numbers of staff were assigned to weekdays and less to nights and weekends. Such approaches may have served a pattern of living that was typical in intellectual disability services for younger cohorts of people. Ageing brings different needs and different patterns of living. Complexity, such as dementia, also leads to the need for alternative ways of rostering staff. Consideration should, therefore, be given to the enactment of dynamic staff rostering that can respond to changing needs. This will have a cost implication and will need to be configured within any new model of service for healthy ageing.
- Staffing and skill-mix were identified as challenges to implementing aged care. New staffing models or workforce redesign should be explored, guided by the commitment to meet the needs and wishes of older people. This will likely require reconsideration of the roles of professionals and other formal carers as well as introduction of financially viable patterns of working which ensure the availability of appropriate support when required. This may also be informed by the use of resource allocation modelling.
- The relatively recent increase in the expected lifespan of people with intellectual disabilities has brought with it new and emerging complexity and other issues. There is an urgent need to provide professionals, carers and families with education and training how to best support older people with intellectual disabilities. There is also a need for such education and training to be provided to those who provide services to older people in mainstream health and social care settings. Education and training should include the following content:

- Person-centred support approaches
 - Health ageing in the context of intellectual disabilities
 - Age-related complexity and evidence-based interventions
 - Health interventions pertinent to prevalent conditions, including dementia, palliative care, mental health, pain, chronic illness, osteoporosis and polypharmacy
 - Advanced planning and end of life care: understanding the wishes of the older person for their last days, the suitability of extraordinary measures (for example, enteral feeds and ventilators); management of the person's last days and death, including grieving and bereavement
- It is clear that many people with intellectual disabilities will continue to avail of disability services as they age. This study has highlighted that, with increasing numbers of older people, there will, for some people, need to be a focus on related health needs. The role of the RNID was identified as being important in this regard, but challenges in recruiting such nurses were highlighted. Workforce planning should be undertaken to identify prospected staffing needs and strategies should be enacted to increase the number of RNIDs being educated for the Irish intellectual disability services.

References

- Abdi, S., Spann, A., Borilovic, J., De Witte, L., & Hawley, M. (2019), 'Understanding the care and support needs of older people: a scoping review and categorisation using the WHO international classification of functioning, disability and health framework (ICF)'. **BMC Geriatrics**, 19(1).
- Adam, E., Sleeman, K. E., Brearley, S., Hunt, K., & Tuffrey-Wijne, I. (2020), 'The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review'. **Palliative medicine**, 34(8), 1006-1018.
- Alcedo, M. Á., Fontanil, Y., Solís, P., Pedrosa, I., & Aguado, A. L. (2017), 'People with intellectual disability who are ageing: Perceived needs assessment'. **International Journal of Clinical and Health Psychology**, 17(1).
- Alftberg, Å., Johansson, M., & Ahlström, G. (2021), 'Ambivalence among staff regarding ageing with intellectual disabilities: Experiences and reflections'. **Journal of Intellectual Disabilities**, 25(2).
- American Geriatrics Society (2016), 'Person-Centered Care: A Definition and Essential Elements'. **Journal of the American Geriatrics Society**, 64(1), 15-18.
- Bekkema, N., De Veer, A. J. E., Hertogh, C. M. P. M., & Francke, A. L. (2015a), "From activating towards caring': shifts in care approaches at the end of life of people with intellectual disabilities; a qualitative study of the perspectives of relatives, care-staff and physicians'. **BMC Palliative Care**, 14(1).
- Bekkema, N., De Veer, A. J. E., Wagemans, A. M. A., Hertogh, C. M. P. M., & Francke, A. L. (2015b), "To move or not to move': a national survey among professionals on beliefs and considerations about the place of end-of-life care for people with intellectual disabilities'. **Journal of Intellectual Disability Research**, 59(3), 226-237.
- Benoot, T., Roose, R., Dursin, W., Verschuere, B., & McKenzie, J. (2022), 'Aspirations of People With Intellectual Disabilities Living in a Care Organization'. **Journal of Social Work**, 22(4), 1105-1122.
- Bernacki, R. E., & Block, S. D. (2014), 'Communication about serious illness care goals: a review and synthesis of best practices'. **JAMA internal medicine**, 174(12), 1994-2003.
- Bernal, J., Hunt, K., Worth, R., Shearn, J., Jones, E., Lowe, K., & Todd, S. (2021), 'Expecting the unexpected: measures, outcomes and dying trajectories for expected and unexpected death in adults with intellectual disabilities in social care settings in the UK'. **Journal of Applied Research in Intellectual Disabilities**, 34(2), 594-605.
- Bien, B., McKee, K. J., Dohner, H., Triantafyllou, J., Lamura, G., Doroszkiewicz, H., Krevers, B., & Kofahl, C. (2013), 'Disabled older people's use of health and social care services and their unmet care needs in six European countries'. **The European Journal of Public Health**, 23(6), 1032-1038.

- Bigby, C. (2002), 'Ageing people with a lifelong disability: Challenges for the aged care and disability sectors'. **Journal of Intellectual and Developmental Disability**, 27(4).
- Bigby, C. (2008a), 'Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability'. **Journal of Intellectual and Developmental Disability**, 33.
- Bigby, C. (2008b), 'Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community'. **Journal of Intellectual and Developmental Disability**, 33(2).
- Bigby, C. (2010), 'A five-country comparative review of accommodation support policies for older people with intellectual disability'. **Journal of Policy and Practice in Intellectual Disabilities**, 7(1), 3-15.
- Bigby, C., Bould, E., & Beadle-Brown, J. (2015), '**Not as connected with people as they want to be**'-Optimising outcomes for people with intellectual disabilities in supported living arrangements. New South Wales: Living with Disability Research Centre, La Trobe University.
- Bigby, C., & Haveman, M. (2010), 'Aging. A Continuing Challenge'. **Journal of Policy and Practice in Intellectual Disabilities**, 7(1), 1-2.
- Bigby, C., Knox, M., Beadle-Brown, J., & Bould, E. (2014), 'Identifying good group homes: Qualitative indicators using a quality of life framework'. **Intellectual and Developmental Disabilities**, 52(5), 348-366.
- Bigby, C., McCallion, P., McCarron, M. (2014), Serving an Elderly Population *In: M. Agran, Brown, F., Hughes, C., Quirk, C., Ryndak, D. (ed.) Equality & Full Participation for Individuals with Severe Disabilities: A Vision for the Future*. Paul H. Brookes
- Bigby, C., Webber, R., Bowers, B., & McKenzie-Green, B. (2008), 'A survey of people with intellectual disabilities living in residential aged care facilities in Victoria'. **Journal of Intellectual Disability Research**, 52(5), 404-414.
- Bigby, C., Wilson, N. J., Balandin, S., & Stancliffe, R. J. (2011), 'Disconnected expectations: Staff, family, and supported employee perspectives about retirement'. **Journal of Intellectual & Developmental Disability**, 36(3), 167-174.
- Bowers, B., Webber, R., & Bigby, C. (2014), 'Health issues of older people with intellectual disability in group homes'. **Journal of Intellectual and Developmental Disability**, 39(3).
- Bowey, L. (2005), 'Adults with a Learning Disability Living with Elderly Carers Talk about Planning for the Future: Aspirations and Concerns'. **British Journal of Social Work**, 35(8), 1377-1392.
- Bowey, L., & McGlaughlin, A. (2007), 'Older carers of adults with a learning disability confront the future: Issues and preferences in planning'. **British Journal of Social Work**, 37(1), 39-54.
- Braun, V., & Clarke, V. (2006), 'Using thematic analysis in psychology'. **Qualitative research in psychology**, 3(2), 77-101.

- Brennan, D., McCausland, D., O'Donovan, M. A., Eustace-Cook, J., McCallion, P., & McCarron, M. (2020), 'Approaches to and outcomes of future planning for family carers of adults with an intellectual disability: a systematic review'. **Journal of Applied Research in Intellectual Disabilities**, 33(6), 1221-1233.
- Brennan, D., Murphy, R., McCallion, P., & McCarron, M. (2018), "'What's going to happen when we're gone?' Family caregiving capacity for older people with an intellectual disability in Ireland'. **Journal of Applied Research in Intellectual Disabilities**, 31(2).
- Brenner, M., Kidston, C., Hilliard, C., Coyne, I., Eustace-Cook, J., Doyle, C., Begley, T., & Barrett, M. J. (2018), 'Children's complex care needs: a systematic concept analysis of multidisciplinary language'. **European Journal of Pediatrics**, 177(11), 1647.
- Brooker, D., & Latham, I. (2015), **Person-centred dementia care: Making services better with the VIPS framework**. London and Philadelphia: Jessica Kingsley Publishers.
- Brown, M., Chouliara, Z., MacArthur, J., McKechnie, A., Mack, S., Hayes, M., & Fletcher, J. (2016), 'The perspectives of stakeholders of intellectual disability liaison nurses: a model of compassionate, person-centred care'. **Journal of Clinical Nursing**, 25(7-8), 972-982.
- Bunn, F., Burn, A.-M., Robinson, L., Poole, M., Rait, G., Brayne, C., Schoeman, J., Norton, S., & Goodman, C. (2017), 'Healthcare organisation and delivery for people with dementia and comorbidity: a qualitative study exploring the views of patients, carers and professionals'. **BMJ open**, 7(1), e013067.
- Burgess, P., Pirkis, J., & Coombs, T. (2015), 'Routine outcome measurement in Australia'. **International Review of Psychiatry**, 27(4), 264-275.
- Burke, É., O'Dwyer, C., Ryan, K., McCallion, P., & McCarron, M. (2017), **Glancing Back, Planning Forward, A guide for planning end of life care with people with intellectual disability**. Dublin: Trinity Centre for Ageing and Intellectual Disabilities, Trinity College Dublin.
- Burke, É., O'Dwyer, M., McGlinchey, E., Foran, S., Phadraig, C. M., Carroll, R., McCallion, P., & McCarron, M. (2019), Overview of the Important Physical Health Concerns *In*: V. P. Prasher & M. Janicki (eds.). **Physical Health of Adults with Intellectual and Developmental Disabilities**. Switzerland: Springer
- Burke, T., Deffew, A., Stafford, O., Docherty, C., Burke, S., Mostert, R., Van Loon, J., Lombardi, M., Vaughan, M., & Brickell, R. (2022), 'Quality of Life outcomes in a community cohort of adults with an intellectual disability using the Personal Outcome Scale'. **Frontiers in Rehabilitation Sciences**, 33.
- Buys, L., Aird, R., & Miller, E. (2012), 'Service providers' perceptions of active ageing among older adults with lifelong intellectual disabilities'. **Journal of Intellectual Disability Research**, 56(12).
- Care Quality Commission (2016), **A different ending: addressing inequalities in end of life care**. Newcastle upon Tyne: CQC.

- Casey, C., O’Sullivan, M., Flanagan, N., & Fanagan, S. (2020), **Annual Report of the National Ability Supports System (NASS) 2020**. Dublin: Health Research Board.
- Center for Disease Control and Prevention. (2009). **Healthy Places Terminology**. Available at: <https://www.cdc.gov/healthyplaces/terminology.htm>. Accessed: 18/02/2022.
- Centre for Ageing Better (2015), **Later life in 2015: An analysis of the views and experiences of people aged 50 and over**.
- Chapman, M., Lacey, H., & Jervis, N. (2018), 'Improving services for people with learning disabilities and dementia: Findings from a service evaluation exploring the perspectives of health and social care professionals'. **British Journal of Learning Disabilities**, 46(1), 33-44.
- Chou, Y.-C., & Kröger, T. (2022), 'Ageing in place together: older parents and ageing offspring with intellectual disability'. **Ageing & Society**, 42(2), 480-494.
- Claes, C., Van Hove, G., Vandeveld, S., van Loon, J., & Schalock, R. L. (2010), 'Person-centered planning: Analysis of research and effectiveness'. **Intellectual and Developmental Disabilities**, 48(6), 432-453.
- Cleary, J., & Doody, O. (2017), 'Nurses' experience of caring for people with intellectual disability and dementia'. **Journal of Clinical Nursing**, 26(5-6).
- Collings, S., Dew, A., & Dowse, L. (2016), 'Support planning with people with intellectual disability and complex support needs in the Australian National Disability Insurance Scheme'. **Journal of Intellectual and Developmental Disability**, 41(3).
- Cook, A. (2017), **Outcomes based approaches in public service reform**. Edinburgh: What Works Scotland Edinburgh.
- Council on Quality and Leadership. (2022). **Personal Outcome Measures**. Available at: <https://www.c-q-l.org/tools/personal-outcome-measures/>. Accessed: 02/11/22.
- Darker, C. (2014), 'Integrated healthcare in Ireland—a critical analysis and a way forward'. **Adelaide Health Foundation**.
- de Silva, D. (2014), **Helping measure person-centred care: a review of evidence about commonly used approaches and tools used to help measure person-centred care**. London: The Health Foundation.
- Dementia Pathways. (2022). **The National Intellectual Disability Memory Service**. Available at: <https://dementiaphways.ie/care-pathways/dementia-in-people-with-an-intellectual-disability/the-national-intellectual-disability-memory-service>. Accessed: 05/05/2022.
- Dennehy, H., Allen, A. P., McGlinchey, E., BATTERY, N., García-Domínguez, L., Chansler, R., Corr, C., Dunne, P., Kennelly, S., & Daly, L. (2022), 'A scoping review of post-diagnostic dementia supports for people with intellectual disability'. **Ageing & mental health**, 1-10.
- Department of Health (2012), **Value for Money and Policy Review of Disability Services in Ireland**. Dublin: Department of Health.

- Department of Health (2013), **The National Positive Ageing Strategy**. Dublin: Department of Health.
- Department of Health (2014), **The Irish National Dementia Strategy**. Dublin: Department of Health.
- Department of Health (2017), **Working together for health: The national strategic framework for health and social care workforce planning**. Dublin: Department of Health.
- Department of Health (2020a), **Disability Action Plan Framework**. Dublin: Department of Health.
- Department of Health (2020b), **Housing Options for Our Ageing Population Policy Statement**. Dublin: Department of Health.
- Department of Health (2021a), **Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032**. Dublin: Department of Health.
- Department of Health (2021b), **Transforming Lives - Working Group I Report on Future Needs for Disability Services**. Dublin: Department of Health.
- Department of Health (2022), **Disability Action Plan 2022 - 2025 Report on the Public Consultation**. Dublin: Department of Health.
- Department of Health Queensland (2015), **Guide to health service planning (Version 3)**. Queensland: State of Queensland (Queensland Health).
- Detering, K. M., Hancock, A. D., Reade, M. C., & Silvester, W. (2010), 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial'. **Bmj**, 340.
- Dew, A., Collings, S., Dillon Savage, I., Gentle, E., & Dowse, L. (2019), "'Living the life I want": A framework for planning engagement with people with intellectual disability and complex support needs'. **Journal of Applied Research in Intellectual Disabilities**, 32(2).
- Dolan, E., Lane, J., Hillis, G., & Delanty, N. (2021), 'Changing trends in life expectancy in intellectual disability over time'. **Irish Medical Journal**, 112(9), 1006.
- Doody, C. M., Markey, K., & Doody, O. (2011), 'Future need of ageing people with an intellectual disability in the Republic of Ireland: lessons learned from the literature'. **British Journal of Learning Disabilities**, 41(1), 13-21.
- Doody, O., Hennessy, T., Moloney, M., Lyons, R., & Bright, A. M. (2022), 'The value and contribution of intellectual disability nurses/nurses caring for people with intellectual disability in intellectual disability settings: A scoping review'. **Journal of Clinical Nursing**(00), 1-48.
- Duggan, C., & Linehan, C. (2013), 'The role of 'natural supports' in promoting independent living for people with disabilities; a review of existing literature'. **British Journal of Learning Disabilities**, 41(3), 199-207.
- Edvardsson, D., Fetherstonhaugh, D., & Nay, R. (2010), 'Promoting a continuation of self and normality: person-centred care as described by people with

- dementia, their family members and aged care staff'. **Journal of Clinical Nursing**, 19(17-18), 2611-2618.
- Egan, C., Mulcahy, H., & Naughton, C. (2022), 'Transitioning to long-term care for older adults with intellectual disabilities: A concept analysis'. **Journal of Intellectual Disabilities**, 26(4), 1015-1032.
- Eley, D. S., Boyes, J., Young, L., & Hegney, D. G. (2009), 'Accommodation needs for carers of and adults with intellectual disability in regional Australia: their hopes for and perceptions of the future'. **Rural and remote health**, 9(3), 1-13.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Järbrink, K., Knapp, M., Netten, A., & Noonan Walsh, P. (2001), 'Quality and costs of supported living residences and group homes in the United Kingdom'. **American Journal on Mental Retardation**, 106(5), 401-415.
- Emerson, E., Robertson, J., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., Walsh, P. N., & Netten, A. (2000), 'Quality and costs of community-based residential supports, village communities, and residential campuses in the United Kingdom'. **American Journal on Mental Retardation**, 105(2), 81-102.
- Esbensen, A. J., Seltzer, M. M., & Krauss, M. W. (2008), 'Stability and change in health, functional abilities, and behavior problems among adults with and without Down syndrome'. **American Journal on Mental Retardation**, 113(4), 263-277.
- Espiner, D., & Hartnett, F. M. (2012), 'I felt I was in control of the meeting': facilitating planning with adults with an intellectual disability'. **British Journal of Learning Disabilities**, 40(1), 62-70.
- Evenhuis, H., Henderson, C. M., Beange, H., Lennox, N., & Chicoine, B. (2001), 'Healthy ageing—adults with intellectual disabilities: physical health issues'. **Journal of Applied Research in Intellectual Disabilities**, 14(3), 175-194.
- Fear, C., Scheepers, M., Ansell, M., Richards, R., & Winterbottom, P. (2012), 'Fair Horizons': a person-centred, non-discriminatory model of mental healthcare delivery'. **The Psychiatrist**, 36(1), 25-30.
- Ferretti, L., McCarron, M., & McCallion, P. (2022), Building Shared End-of-Life Supports and Cross-Training for Hospice/Palliative and Intellectual Disability Services Providers *In*: R. J. Stancliffe, M. Wiese, P. McCallion, & M. McCarron (eds.). **End of Life and People with Intellectual and Developmental Disability**. Switzerland: Springer
- Fesko, S. L., Hall, A. C., Quinlan, J., & Jockell, C. (2012), 'Active aging for individuals with intellectual disability: Meaningful community participation through employment, retirement, service, and volunteerism'. **American Journal on Intellectual and Developmental Disabilities**, 117(6), 497-508.
- Forrester-Jones, R., Beecham, J. K., Barnoux, M., Oliver, D., Couch, E., & Bates, C. (2017), 'People with intellectual disabilities at the end of their lives: The case

- for specialist care?'. **Journal of Applied Research in Intellectual Disabilities**, 30(6), 1138-1150.
- García-Domínguez, L., Navas, P., Verdugo, M. Á., & Arias, V. B. (2020), 'Chronic Health Conditions in Aging Individuals with Intellectual Disabilities'. **International Journal of Environmental Research and Public Health**, 17(9), 3126.
- Garnham, B., Bryant, L., Ramcharan, P., Yu, N., & Adams, V. (2019), 'Policy, plans and pathways: the 'crisis' transition to post-parental care for people ageing with intellectual disabilities in rural Australian carescapes'. **Ageing and Society**, 39(4), 836-850.
- Genio (2016), **COMMUNITY SUPPORTS MODEL FOR PEOPLE WITH DEMENTIA**. Ireland: Genio and Health Service Executive.
- Gibbs, S. M., Brown, M. J., & Muir, W. J. (2008), 'The experiences of adults with intellectual disabilities and their carers in general hospitals: a focus group study'. **Journal of Intellectual Disability Research**, 52(12), 1061-1077.
- Gilbert, A., Lankshear, G., & Petersen, A. (2008), 'Older family-carers' views on the future accommodation needs of relatives who have an intellectual disability'. **International Journal of Social Welfare**, 17(1), 54-64.
- Gilmore, L., & Cuskelly, M. (2014), 'Vulnerability to Loneliness in People with Intellectual Disability: An Explanatory Model'. **Journal of Policy and Practice in Intellectual Disabilities**, 11(3), 192-199.
- Giuntoli, G., Newton, B., & R, F. K. (2015), **Current models of health service delivery for people with intellectual disability: Literature review**. Australia: Social Policy Research Centre, The University of New South Wales.
- Government of Ireland (2022), **The National Housing Strategy for Disabled People 2022-2027**. Dublin: Government of Ireland.
- Government of South Australia (2020), **SA Intellectual Disability Health Service - Model of Care**. South Australia: Government of South Australia.
- Grant, G., & Ramcharan, P. (2001), 'Views and experiences of people with intellectual disabilities and their families.(2) The family perspective'. **Journal of Applied Research in Intellectual Disabilities**, 14(4), 364-380.
- Gridley, K., Brooks, J., & Glendinning, C. (2014), 'Good practice in social care for disabled adults and older people with severe and complex needs: evidence from a scoping review'. **Health & Social Care in the Community**, 22(3), 234-248.
- Grove, H. (2021), 'Ageing as well as you can in place: Applying a geographical lens to the capability approach'. **Social science & medicine**, 288, 1-10.
- Hamilton, D., Sutherland, G., & Iacono, T. (2005), 'Further examination of relationships between life events and psychiatric symptoms in adults with intellectual disability'. **Journal of Intellectual Disability Research**, 49(11), 839-844.
- Harding, E., Wait, S., & Scrutton, J. (2015), **The state of play in person-centred care**. London, UK: The Health Policy Partnership.

- Hartnett, E., Gallagher, P., Kiernan, G., Poulsen, C., Gilligan, E., & Reynolds, M. (2008), 'Day service programmes for people with a severe intellectual disability and quality of life: Parent and staff perspectives'. **Journal of Intellectual Disabilities**, 12(2), 153-172.
- Hatzidimitriadou, E., & Milne, A. (2005), 'Planning ahead: Meeting the needs of older people with intellectual disabilities in the United Kingdom'. **Dementia**, 4(3), 341-359.
- Haveman, M., Heller, T., Lee, L., Maaskant, M., Shooshtari, S., & Strydom, A. (2010), 'Major Health Risks in Aging Persons With Intellectual Disabilities: An Overview of Recent Studies'. **Journal of Policy and Practice in Intellectual Disabilities**, 7(1), 59-69.
- Haveman, M., Perry, J., Salvador-Carulla, L., Walsh, P. N., Kerr, M., Van Schrojenstein Lantman-De Valk, H., Van Hove, G., Berger, D. M., Azema, B., Buono, S., Cara, A. C., Germanavicius, A., Linehan, C., Määttä, T., Tossebro, J., & Weber, G. (2011), 'Ageing and health status in adults with intellectual disabilities: Results of the European POMONA II study'. **Journal of Intellectual and Developmental Disability**, 36(1), 49-60.
- Healthy and Positive Ageing Initiative (2018), **Positive Ageing Indicators**. Dublin: Department of Health.
- Heller, T. (2017), **Service and support needs of adults aging with intellectual/developmental disabilities**. Illinois, Chicago: Institute on Disability and Human Development, Institute on Disability and Human Development.
- Heller, T. (2019), 'Bridging Aging and Intellectual/Developmental Disabilities in Research, Policy, and Practice'. **Journal of Policy and Practice in Intellectual Disabilities**, 16(1), 53-57.
- Heslop, P., Blair, P. S., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2014), 'The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study'. **The Lancet**, 383(9920), 889-895.
- Heslop, P., & Glover, G. (2015), 'Mortality of people with intellectual disabilities in England: a comparison of data from existing sources'. **Journal of Applied Research in Intellectual Disabilities**, 28(5), 414-422.
- HIQA (2012), **A Guide to the National Standards for Safer Better Healthcare**. Dublin: Health Information and Quality Authority.
- Hogg, J., Lucchino, R., Wang, K., Janicki, M., & Saxena, S. (2001), 'Healthy Ageing - Adults with Intellectual Disabilities: Ageing and Social Policy'. **Journal of Applied Research in Intellectual Disabilities**, 14(3).
- Hourigan, S., Fanagan, S., & Kelly, C. (2018), **Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings**. Dublin: Health Research Board
- HSE (2011), **Time to Move on from Congregated Settings, A strategy for Community Inclusion**. Dublin: Health Service Executive.

- HSE (2013), **Quality assessment and improvement: person centred care and support**. Dublin: Quality and Patient Safety Directorate (HSE).
- HSE (2015), **New Directions. Interim Standards for New Directions, Services and Supports for Adults with Disabilities**. Dublin: Health Service Executive.
- HSE (2016), **A National Model of Care for Paediatric Healthcare Services in Ireland**. Dublin: Health Service Executive.
- HSE (2018a), **Model of Care for Transition from Paediatric to Adult Healthcare Providers in Rare Diseases**. Dublin: Health Service Executive.
- HSE (2018b), **A National Framework for PersonCentred Planning in Services for Persons with a Disability**. Dublin: Health Service Executive.
- HSE (2019a), **ADULT PALLIATIVE CARE SERVICES MODEL OF CARE FOR IRELAND**. Dublin: Health Service Executive,.
- HSE (2019b), **Time to Move on from Congregated Settings: annual progress report 2019**. Dublin: Health Service Executive.
- HSE (2021), **Mental Health Services for Adults with Intellectual Disabilities: National Model of Service**. Dublin: Health Service Executive.
- Hudson, E., Mosca, I., & O'Sullivan, V. (2014), **The Economic Wellbeing of Over 50's and their Children**. Dublin: The Irish Longitudinal Study of Ageing.
- Hulbert-Williams, L., & Hastings, R. P. (2008), 'Life events as a risk factor for psychological problems in individuals with intellectual disabilities: a critical review'. **Journal of Intellectual Disability Research**, 52(11), 883-895.
- Hussain, R., Parmenter, T., Knox, M., Janicki, M., & Wark, S. (2013), **Keeping my place in the community: Achieving successful ageing-in-place for people with intellectual disabilities**. Australia: Australian Research Council (ARC) Linkage Project.
- Hussain, R., Parmenter, T., Wark, S., Janicki, M., Knox, M., & Hayhoe, N. (2021), 'Mitigating the impact of the 'silos' between the disability and aged-care sectors in Australia: Development of a Best Practice Framework'. **Journal of Applied Research in Intellectual Disabilities**, 34(6).
- Hussain, R., Wark, S., Janicki, M. P., Parmenter, T., & Knox, M. (2020), 'Multimorbidity in older people with intellectual disability'. **Journal of Applied Research in Intellectual Disabilities**, 33(6), 1234-1244.
- Iacono, T., Bigby, C., Carling-Jenkins, R., & Torr, J. (2014), 'Taking each day as it comes: staff experiences of supporting people with D own syndrome and A lzheimer's disease in group homes'. **Journal of Intellectual Disability Research**, 58(6), 521-533.
- Inclusion Ireland (2019), **Housing for people with intellectual disabilities**. Dublin: Inclusion Ireland.
- Innes, A., McCabe, L., & Watchman, K. (2012), 'Caring for older people with an intellectual disability: A systematic review'. **Maturitas**, 72(4), 286-295.

- Irish Hospice Foundation. (2022). **I want to Think Ahead**. Available at: <https://hospicefoundation.ie/i-need-help/i-want-to-think-ahead/> Accessed: 18/10/2022.
- Janicki, M., Heller, T., Seltzer, G., & Hogg, J. (1996), 'Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability'. **Journal of Intellectual Disability Research**, 40(4), 374-382.
- Janicki, M. P. (2010), 'Aging adults with intellectual disabilities: Perspectives on emerging service concerns'. **Journal of Special Education and Rehabilitation**, 11(1-2), 114-129.
- Janicki, M. P., & Dalton, A. J. (2000), 'Prevalence of dementia and impact on intellectual disability services'. **Mental retardation**, 38(3), 276-288.
- Janicki, M. P., Dalton, A. J., McCallion, P., Baxley, D. D., & Zendell, A. (2005), 'Group home care for adults with intellectual disabilities and Alzheimer's disease'. **Dementia**, 4(3), 361-385.
- Janicki, M. P., McCallion, P., & Dalton, A. J. (2003), 'Dementia-Related care Decision-Making in group homes for persons with intellectual disabilities'. **Journal of Gerontological Social Work**, 38(1-2), 179-195.
- Johansson, M., Björne, P., Runesson, I., & Ahlström, G. (2017), 'Healthy ageing in people with intellectual disabilities from managers' perspective: A qualitative study'. **Healthcare (Switzerland)**, 5(3).
- Johnson, H., Douglas, J., Bigby, C., & Iacono, T. (2012), 'Social interaction with adults with severe intellectual disability: Having fun and hanging out'. **Journal of Applied Research in Intellectual Disabilities**, 25(4), 329-341.
- Jokinen, N., Janicki, M. P., Keller, S. M., McCallion, P., Force, L. T., Disabilities, N. T. G. o. I., & Practices, D. (2013), 'Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia'. **Journal of Policy and Practice in Intellectual Disabilities**, 10(1), 1-24.
- Jokinen, N. S., Janicki, M. P., Hogan, M., & Force, L. T. (2012), 'The middle years and beyond: Transitions and families of adults with Down syndrome'. **Journal on Developmental Disabilities**, 18(2), 59.
- Judge, J., Walley, R., Anderson, B., & Young, R. (2010), 'Activity, Aging, and Retirement: The Views of a Group of Scottish People With Intellectual Disabilities'. **Journal of Policy and Practice in Intellectual Disabilities**, 7(4), 295-301.
- Kåhlin, I., Kjellberg, A., & Hagberg, J. E. (2016), 'Choice and control for people ageing with intellectual disability in group homes'. **Scandinavian Journal of Occupational Therapy**, 23(2), 127-137.
- King, E., Brangan, J., McCarron, M., McCallion, P., Bavussantakath, F. R., & O'Donovan, M.-A. (2022), 'Predictors of Productivity and Leisure for People Aging with Intellectual Disability'. **Canadian Journal of Occupational Therapy**, 89(2), 135-146.
- Kirchberger, I., Meisinger, C., Heier, M., Zimmermann, A.-K., Thorand, B., Autenrieth, C. S., Peters, A., Ladwig, K.-H., & Döring, A. (2012), 'Patterns of

- Multimorbidity in the Aged Population. Results from the KORA-Age Study'. **PLoS ONE**, 7(1), e30556.
- Lauer, E., & McCallion, P. (2015), 'Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data'. **Journal of Applied Research in Intellectual Disabilities**, 28(5), 394-405.
- Lawrence, V., Murray, J., & Banerjee, S. (2009), "'Out of sight, out of mind": a qualitative study of visual impairment and dementia from three perspectives'. **International psychogeriatrics**, 21(3), 511-518.
- Leahy, A. (2018), 'Too many 'false dichotomies'? Investigating the division between ageing and disability in social care services in Ireland: A study with statutory and non-statutory organisations'. **Journal of Aging Studies**, 44, 34-44.
- Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., McConkey, R., & Staines, A. (2014), **Moving Ahead: Mapping the Policy Landscape**. Dublin: School of Social Work and Social Policy, Trinity College.
- MacDonald, S. J., Deacon, L., Nixon, J., Akintola, A., Gillingham, A., Kent, J., Ellis, G., Mathews, D., Ismail, A., & Sullivan, S. (2018), 'The invisible enemy': disability, loneliness and isolation'. **Disability & Society**, 33(7), 1138-1159.
- Mann, C., Jun, G. T., Tyrer, F., Kiani, R., Lewin, G., & Gangadharan, S. K. (2022), 'A scoping review of clusters of multiple long-term conditions in people with intellectual disabilities and factors impacting on outcomes for this patient group'. **Journal of Intellectual Disabilities**, 0(0), 1-17.
- Mansell, J., & Beadle-Brown, J. (2009), 'Dispersed or clustered housing for adults with intellectual disability: A systematic review'. **Journal of Intellectual & Developmental Disability**, 34(4), 313-323.
- Marsack-Topolewski, C. N., & Samuel, P. S. (2020), 'Caregivers' Perceptions of Family Quality of Life of Individuals with Developmental Disabilities Comorbid with Dementia: A Pilot Study'. **Journal for ReAttach Therapy and Developmental Diversities**, 3(2), 56-70.
- Martin, R. S., Hayes, B., Gregorevic, K., & Lim, W. K. (2016), 'The effects of advance care planning interventions on nursing home residents: a systematic review'. **Journal of the American Medical Directors Association**, 17(4), 284-293.
- Mason, J., & Scior, K. (2004), "Diagnostic overshadowing' amongst clinicians working with people with intellectual disabilities in the UK'. **Journal of Applied Research in Intellectual Disabilities**, 17(2), 85-90.
- McCallion, P., Ferretti, L., & Park, J. (2013a), Financial issues and an aging population: Responding to an increased potential for financial abuse and exploitation *In*: J. Birkenmaier, J. Curley, & M. Sherraden (eds.). **Financial education & capability: Research, education, policy and practice**. Oxford: University Press
- McCallion, P., Ferretti, L. A., Beange, H., & McCarron, M. (2019), Epidemiological issues in intellectual disability and aging research *In*: V. P. Prasher & M. Janicki

- (eds.). **Physical health of adults with intellectual and developmental disabilities**. Switzerland: Springer
- McCallion, P., Hogan, M., Santos, F. H., McCarron, M., Service, K., Stemp, S., Keller, S., Fortea, J., Bishop, K., & Watchman, K. (2017), 'Consensus statement of the International Summit on Intellectual Disability and Dementia related to end-of-life care in advanced dementia'. **Journal of Applied Research in Intellectual Disabilities**, 30(6), 1160-1164.
- McCallion, P., & Jokinen, N. (2017), *Aging In*: M. L. Wehmeyer, I. Brown, M. Percey, K. Shogren, & M. Fung (eds.). **A Comprehensive Guide to Intellectual and Developmental Disabilities**. Baltimore, MD: Paul Brookes Press
- McCallion, P., Swinburne, J., Burke, E., McGlinchey, E., & McCarron, M. (2013b), Understanding the similarities and differences in aging with an intellectual disability: linking Irish general population and intellectual disability datasets *In*: R. Urbano (ed.) **International Review of Research in Developmental Disabilities**. Elsevier
- McCance, T., McCormack, B., & Dewing, J. (2011), 'An exploration of person-centredness in practice'. **Online Journal of Issues in Nursing**, 16(2), 1-9.
- McCarron, M. (2011), **Growing older with an intellectual disability in Ireland 2011: First results from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)**. Dublin: Trinity College Dublin.
- McCarron, M., Burke, E., White, P., O Dwyer, C., Ryan, K., O Farrell, & McCallion, P. (2017a), **“He’d mind you, you mind him” Experiences of end of life care for people with an intellectual disability as perceived by staff carers**. Dublin: Trinity College Dublin.
- McCarron, M., Carroll, R., Kelly, C., & McCallion, P. (2015), 'Mortality rates in the general Irish population compared to those with an intellectual disability from 2003 to 2012'. **Journal of Applied Research in Intellectual Disabilities**, 28(5), 406-413.
- McCarron, M., Haigh, M., McCallion, P., McCallion, P., Carroll, R., Burke, E., McGlinchey, E., O'Donovan, M.-A., McCausland, D., & Sheerin, F. (2017b), **Health, wellbeing and social inclusion: Ageing with an intellectual disability in Ireland: Evidence from the first ten years of The Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)**. Dublin: Trinity College Dublin.
- McCarron, M., & Lawlor, B. A. (2003), 'Responding to the challenges of ageing and dementia in intellectual disability in Ireland'. **Aging and Mental Health**, 7(6), 413-417.
- McCarron, M., Lombard-Vance, R., Murphy, E., O'Donovan, M.-A., Webb, N., Sheaf, G., McCallion, P., Stancliffe, R., Normand, C., Smith, V., & May, P. (2018a), **Quality of life outcomes and costs associated with moving from congregated settings to community living arrangements for people with intellectual disability**. Dublin: Health Research Board.

- McCarron, M., McCallion, P., Burke, E., & Timmins, F. (2021), **End of Life Care for People with an Intellectual Disability a Qualitative Exploration of Staff Carers' Experiences**. Research Square.
- McCarron, M., McCallion, P., Carroll, R., Burke, E., Cleary, E., McCausland, D., McGlinchy, E., O'Donovan, M.-A., Mulryan, N., & Shivers, C. (2014), **Advancing years, Different challenges: Wave 2 IDS-TILDA: Findings on the ageing of people with an Intellectual Disability**. Dublin: Trinity College Dublin.
- McCarron, M., McCallion, P., Fahey-McCarthy, E., & Connaire, K. (2010a), 'Staff Perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia'. **Journal of Policy and Practice in Intellectual Disabilities**, 7(2).
- McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K., & Dunn-Lane, J. (2010b), 'Supporting persons with down syndrome and advanced dementia: Challenges and care concerns'. **Dementia**, 9(2), 285–298.
- McCarron, M., McCallion, P., Reilly, E., Dunne, P., Carroll, R., & Mulryan, N. (2017c), 'A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome'. **Journal of Intellectual Disability Research**, 61(9), 843-852.
- McCarron, M., Sheerin, F., Roche, L., Ryan, A., Griffiths, C., Keenan, P., Doody, O., D'Eath, M., Burke, E., & McCallion, P. (2018b), **Shaping the future of intellectual disability nursing in Ireland: Supporting people with an intellectual disability to live ordinary lives in ordinary places**. Ireland: Health Services Executive.
- McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Carroll, R., & McCallion, P. (2013), 'Patterns of multimorbidity in an older population of persons with an intellectual disability: Results from the intellectual disability supplement to the Irish longitudinal study on aging (IDS-TILDA)'. **Research in Developmental Disabilities**, 34(1), 521-527.
- McCausland, D., Guerin, S., Tyrrell, J., Donohoe, C., O'Donoghue, I., & Dodd, P. (2021a), 'A qualitative study of the needs of older adults with intellectual disabilities'. **Journal of Applied Research in Intellectual Disabilities**, 34(6), 1560-1568.
- McCausland, D., McCallion, P., Brennan, D., & McCarron, M. (2020), 'In pursuit of meaningful occupation: Employment and occupational outcomes for older Irish adults with an intellectual disability'. **Journal of Applied Research in Intellectual Disabilities**, 33(3), 386-397.
- McCausland, D., McCallion, P., Carroll, R., & McCarron, M. (2021b), 'The nature and quality of friendship for older adults with an intellectual disability in Ireland'. **Journal of Applied Research in Intellectual Disabilities**, 34(3), 763-776.
- McCausland, D., Murphy, E., McCarron, M., & McCallion, P. (2021c), 'The potential for person-centred planning to support the community participation of

- adults with an intellectual disability'. **Journal of Intellectual Disabilities**, 26(3), 603-623.
- McConkey, R., Keogh, F., Bunting, B., Garcia Iriarte, E., & Watson, S. F. (2016), 'Relocating people with intellectual disability to new accommodation and support settings: Contrasts between personalized arrangements and group home placements'. **Journal of Intellectual Disabilities**, 20(2), 109-120.
- McCormack, B. (2003), 'A conceptual framework for person-centred practice with older people'. **International journal of nursing practice**, 9(3), 202-209.
- McCormack, B., Borg, M., Cardiff, S., Dewing, J., Jacobs, G., Janes, N., Karlsson, B., McCance, T., Mekki, T. E., & Porock, D. (2015), 'Person-centredness - the 'state' of the art'. **International Practice Development Journal**, 5, 1-15.
- McCormack, B., Elizabeth, B., Jan, D., Catherine, T., Mary, M., Ann, C.-N., Kate, K., & Lorna, P.-K. (2010), **The implementation of a model of person-centred practice in older person settings final report**. Dublin: Health Service Executive.
- McCormack, B., & McCance, T. (2010), **Person-centred nursing: theory, models and methods**. UK: Wiley-Blackwell.
- McCormack, B., & McCance, T. (2016), **Person-centred practice in nursing and health care: theory and practice** John Wiley & Sons.
- McCormack, B., & McCance, T. V. (2006), 'Development of a framework for person-centred nursing'. **Journal of advanced nursing**, 56(5), 472-479.
- McDermott, S., & Edwards, R. (2012), 'Enabling self-determination for older workers with intellectual disabilities in supported employment in Australia'. **Journal of Applied Research in Intellectual Disabilities**, 25(5), 423-432.
- McGlaughlin, A. (2004), 'Enabling Adults with Learning Disabilities to Articulate their Housing Needs'. **British Journal of Social Work**, 34(5), 709-726.
- McGlinchey, E., McCallion, P., Burke, E., Carroll, R., & McCarron, M. (2013), 'Exploring the Issue of Employment for Adults with an Intellectual Disability in Ireland'. **Journal of Applied Research in Intellectual Disabilities**, 26(4), 335-343.
- McGlinchey, E., McCallion, P., McDermott, S., Foley, M., Burke, E. A., O'Donovan, M.-A., McCausland, D., Gibney, S., & McCarron, M. (2018), **Positive Ageing Indicators for People with an Intellectual Disability**. Dublin: Trinity Centre for Ageing and Intellectual Disability.
- McKenzie, K., Metcalfe, D., Michie, A., & Murray, G. (2020), 'Service provision in Scotland for people with an intellectual disability who have, or are at risk of developing, dementia'. **Dementia**, 19(3), 736-749.
- McKenzie, N., Mirfin-Veitch, B., Conder, J., & Brandford, S. (2017), "'I'm still here": Exploring what matters to people with intellectual disability during advance care planning'. **Journal of Applied Research in Intellectual Disabilities**, 30(6), 1089-1098.

- Miller, E. (2021), **How is person-centred care understood and implemented in practice? A literature review.** Scotland: Healthcare Improvement Scotland.
- National Economic Social Council (2012), **Quality and standards in human services in Ireland: Disability services.** Ireland: National Economic Social Council.
- National Federation of Voluntary Bodies. (2019). **Funding Crisis in Disability Services.** Available at: http://www.fedvol.ie/fileupload/Publications/NFVSP%20Drivers%20and%20Deficits%20in%20ID%20Services%20June_2019.pdf. Accessed: 04/11/2022.
- NCI-IIDD (2020), **National Core Indicators®-Intellectual and Developmental Disabilities: 2020-21 In-Person Survey (IPS)** United States: National Core Indicators—Intellectual and Developmental Disabilities.
- NDA (2005), **Guidelines on Person Centred Planning in the Provision of Services for People with Disabilities in Ireland.** Dublin: National Disability Authority.
- NDA (2006), **Ageing & Disability: A Discussion Paper.** Dublin: National Disability Authority.
- NDA (2016), **Outcomes for Disability Services.** Dublin: National Disability Authority.
- NDA (2019), **Outcome Measurement in evaluating the Quality of Disability Services.** Dublin: National Disability Authority.
- NDA (2021a), **Moving In, Moving On. An evaluation of the outcomes and costs of congregated and community models of service in the disability sector.** Dublin: National Disability Authority.
- NDA (2021b), **Staff and Change Management: Good Practice in the Transition to Community Residential Disability Services.** . Dublin: National Disability Authority.
- NDA (2022a), **Improving Quality of Life and Enhancing COVID-19 Infection Control in Existing Residential Care Settings for Older People: Research Report.** Dublin: National Disability Authority.
- NDA (2022b), **Improving Quality of Life and Enhancing COVID-19 Infection Control in Existing Residential Care Settings for Older People: Universal Design Guidelines.** Dublin: National Disability Authority.
- New South Wales Agency for Clinical Innovation (2013), **Understanding the process to develop a Model of Care An ACI Framework.** New South Wales: NSW Agency for Clinical Innovation.
- New South Wales Ministry of Health (2012), **Service Framework to Improve the Health Care of People with Intellectual Disability.** New South Wales: NSW Ministry of Health.
- New York State Area Agencies on Aging. (2013). **Older New Yorkers and the NYS Olmstead Plan.** Available at:

- https://www.agingny.org/uploads/1/2/3/0/123049588/older_new_yorkers_and_the_nys_olmstead_plan_final_3_oct_2013.pdf. Accessed: 05/11/2022.
- Nicholson, C., Meyer, J., Flatley, M., Holman, C., & Lowton, K. (2012), 'Living on the margin: understanding the experience of living and dying with frailty in old age'. **Social science & medicine**, 75(8), 1426-1432.
- Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., Echteld, M. A., & Olsman, E. (2019), 'Quality of life of persons with profound intellectual and multiple disabilities: A narrative literature review of concepts, assessment methods and assessors'. **Journal of Intellectual & Developmental Disability**, 44(3), 261-271.
- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004), 'Beyond 'person-centred' care: a new vision for gerontological nursing'. **Journal of Clinical Nursing**, 13, 45-53.
- Northway, R., Holland-Hart, D., & Jenkins, R. (2017), 'Meeting the health needs of older people with intellectual disabilities: exploring the experiences of residential social care staff'. **Health and Social Care in the Community**, 25(3), 923-931.
- Nyman, S. R., Innes, A., & Heward, M. (2017), 'Social care and support needs of community-dwelling people with dementia and concurrent visual impairment'. **Aging & mental health**, 21(9), 961-967.
- O'Dwyer, M., Peklar, J., McCallion, P., McCarron, M., & Henman, M. C. (2016), 'Factors associated with polypharmacy and excessive polypharmacy in older people with intellectual disability differ from the general population: a cross-sectional observational nationwide study'. **BMJ open**, 6(4), e010505.
- O'Leary, L., Cooper, S. A., & Hughes-McCormack, L. (2018), 'Early death and causes of death of people with intellectual disabilities: A systematic review'. **Journal of Applied Research in Intellectual Disabilities**, 31(3), 325-342.
- O'Rourke, A., Grey, I. M., Fuller, R., & McClean, B. (2004), 'Satisfaction with living arrangements of older adults with intellectual disability: Service users' and carers' views'. **Journal of Learning Disabilities**, 8(1), 12-29.
- O'Sullivan, S., Buckley, M., Desmond, E., Bantry-White, E., & Cassarino, M. (2022), **Agency and Ageing in Place in Rural Ireland**. Ireland: University College Cork and Age Action.
- Olsson, S., & Gustafsson, C. (2020), 'Employees' experiences of education and knowledge in intellectual disability practice'. **Journal of Policy and Practice in Intellectual Disabilities**, 17(3), 219-231.
- palliAGED. (2021, 30 June 2021). **Models of Care**. Available at: <https://www.palliaged.com.au/tabid/4501/Default.aspx>. Accessed: 13/07/2022.
- Patti, P., Amble, K., & Flory, M. (2010), 'Placement, relocation and end of life issues in aging adults with and without Down's syndrome: a retrospective study'. **Journal of Intellectual Disability Research**, 54(6), 538-546.
- Patti, P. J., Amble, K. B., & Flory, M. J. (2005), 'Life events in older adults with intellectual disabilities: Differences between adults with and without Down

- syndrome'. **Journal of Policy and Practice in Intellectual Disabilities**, 2(2), 149-155.
- Pelleboer-Gunnink, H. A., Van Oorsouw, W. M. W. J., Van Weeghel, J., & Embregts, P. J. C. M. (2017), 'Mainstream health professionals' stigmatising attitudes towards people with intellectual disabilities: a systematic review'. **Journal of Intellectual Disability Research**, 61(5), 411-434.
- Petry, K., Maes, B., & Vlaskamp, C. (2009), 'Measuring the quality of life of people with profound multiple disabilities using the QOL-PMD: First results'. **Research in Developmental Disabilities**, 30(6), 1394-1405.
- Powrie, E. (2003), 'Primary health care provision for adults with a learning disability'. **Journal of advanced nursing**, 42(4), 413-423.
- Primacare Living Solutions. (2022). **Innovations in Care**. Available at: <https://www.primacareliving.com/butterfly-model-of-care>. Accessed: 16/08/2022.
- Quilliam, C., & Wilson, E. (2011), **Literature Review Outcomes Measurement in Disability Services: A review of policy contexts, measurement approaches and selected measurement tools**. Melbourne: Deakin University.
- Rand, S., & Caiels, J. (2015), **Using Proxies to assess Quality of Life: A Review of the Issues and Challenges. Discussion Paper**. U.K: Quality and Outcomes of person-centred care policy Research Unit (QORU), Univeristy of Kent.
- Ratti, V., Hassiotis, A., Crabtree, J., Deb, S., Gallagher, P., & Unwin, G. (2016), 'The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review'. **Research in Developmental Disabilities**, 57, 63-84.
- Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C. (2007), 'Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT)'. **Journal of Intellectual Disability Research**, 51(4), 277-292.
- Reppermund, S., Srasuebku, P., Dean, K., & Trollor, J. N. (2020), 'Factors associated with death in people with intellectual disability'. **Journal of Applied Research in Intellectual Disabilities**, 33(3), 420-429.
- Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., & Knapp, M. (2007), 'Person-centred planning: factors associated with successful outcomes for people with intellectual disabilities'. **Journal of Intellectual Disability Research**, 51(3), 232-243.
- Roebuck, M. (2021), 'Housing for People with Intellectual Disabilities: A Scoping Review'. **Journal on Developmental Disabilities**, 26(2), 1-25.
- Rogne, L., & McCune, S. L. (2013), **Advance care planning: Communicating about matters of life and death**. New York: Springer Publishing Company.

- Ross, H., Tod, A. M., & Clarke, A. (2015), 'Understanding and achieving person-centred care: the nurse perspective'. **Journal of Clinical Nursing**, 24(9-10), 1223-1233.
- Ryan, A., Taggart, L., Truesdale-Kennedy, M., & Slevin, E. (2014), 'Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary'. **International Journal of Older People Nursing**, 9(3), 217-226.
- Ryan, K., Guerin, S., Dodd, P., & McEvoy, J. (2011), 'End-of-life care for people with intellectual disabilities: paid carer perspectives'. **Journal of Applied Research in Intellectual Disabilities**, 24(3), 199-207.
- Ryan, K., McEvoy, J., Guerin, S., & Dodd, P. (2010), 'An exploration of the experience, confidence and attitudes of staff to the provision of palliative care to people with intellectual disabilities'. **Palliative medicine**, 24(6), 566-572.
- Ryan, K. R., & McQuillan, R. (2005), 'Palliative care for disadvantaged groups: people with intellectual disabilities'. **Progress in Palliative Care**, 13(2), 70-74.
- Sanderson, H. (2000), **Person-centred planning: Key features and approaches**. York: Joseph Rowntree Foundation.
- Schaap, F. D., Fokkens, A. S., Dijkstra, G. J., Reijneveld, S. A., & Finnema, E. J. (2018), 'Dementia care mapping to support staff in the care of people with intellectual disability and dementia: a feasibility study'. **Journal of Applied Research in Intellectual Disabilities**, 31(6), 1071-1082.
- Schepens, H. R. M. M., Van Puyenbroeck, J., & Maes, B. (2019), 'How to improve the quality of life of elderly people with intellectual disability: A systematic literature review of support strategies'. **Journal of Applied Research in Intellectual Disabilities**, 32, 483-521.
- Scott, H. M., & Haverkamp, S. M. (2018), 'Promoting wellness in people with intellectual and developmental disabilities through relationships'. **Current Developmental Disorders Reports**, 5(3), 150-156.
- Shaw, K., Cartwright, C., & Craig, J. (2011), 'The housing and support needs of people with an intellectual disability into older age'. **Journal of Intellectual Disability Research**, 55(9), 895-903.
- Sheerin, F. (2004), 'Identifying the foci of interest to nurses in Irish intellectual disability services'. **Journal of Learning Disabilities**, 8(2), 159-174.
- Sheerin, F., Fleming, S., Naseer, A., Foden, E., McCallion, P., & McCarron, M. (2021a), **Care of Older Adults with Intellectual Disabilities and Complex Age-Related Conditions: A Systematic Review Final Report [Unpublished Manuscript]**. Trinity Centre for Ageing and Intellectual Disability.
- Sheerin, F., McCallion, P., & McCarron, M. (2021b), Responding to Changing Workforce Realities: One Profession's Experience *In*: M. Putman & C. Bigby (eds.). **Handbook on Ageing with Disability**. Routledge

- Sheerin, F., McCallion, P., McGlinchey, E., O'Dwyer, M., Reilly, E., & McCarron, M. (2020), Aging with Intellectual Disability: Dementia and Cognitive Decline *In*: E. Matson (ed.) **Handbook of Dual Diagnosis**. Switzerland: Springer
- Slevin, E., Taggart, L., McConkey, R., Cousins, W., Truesdale-Kennedy, M., & Dowling, S. (2011), **Supporting people with Intellectual Disabilities who challenge or who are ageing: A rapid review of evidence**. Belfast: Univeristy of Ulster.
- Stancliffe, R. J., Bigby, C., Balandin, S., Wilson, N. J., & Craig, D. (2015), 'Transition to retirement and participation in mainstream community groups using active mentoring: A feasibility and outcomes evaluation with a matched comparison group'. **Journal of Intellectual Disability Research**, 59(8), 703-718.
- Strnadová, I. (2019), 'Transitions in the lives of older adults with intellectual disabilities: "Having a sense of dignity and independence"'. **Journal of Policy and Practice in Intellectual Disabilities**, 16(1), 58-66.
- Strydom, A., Chan, T., King, M., Hassiotis, A., & Livingston, G. (2013), 'Incidence of dementia in older adults with intellectual disabilities'. **Research in Developmental Disabilities**, 34(6), 1881-1885.
- Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., Jokinen, N., Courtenay, K., Bass, N., & Sinnema, M. (2010), 'Dementia in older adults with intellectual disabilities—epidemiology, presentation, and diagnosis'. **Journal of Policy and Practice in Intellectual Disabilities**, 7(2), 96-110.
- Taggart, L., & Hanna-Trainor, L. (2017), **Supporting older adults with a learning disability and their ageing family carers: A family and community support model (FULL REPORT)**.
- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012), 'Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability'. **Journal of Intellectual Disabilities**, 16(3), 217-234.
- Todd, S., Bernal, J., Shearn, J., Worth, R., Jones, E., Lowe, K., Madden, P., Barr, O., Forrester Jones, R., & Jarvis, P. (2020), 'Last months of life of people with intellectual disabilities: A UK population-based study of death and dying in intellectual disability community services'. **Journal of Applied Research in Intellectual Disabilities**, 33(6), 1245-1258.
- Townsend-White, C., Pham, A., & Vassos, M. (2012), 'A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours'. **Journal of Intellectual Disability Research**, 56(3), 270-284.
- Trinity Centre for Ageing and Intellectual Disability. (2022, 25/04/2022). **The National Intellectual Disability Memory Service**. Available at: <https://www.tcd.ie/tcaid/research/NIDMS.php>. Accessed: 05/07/2022.
- Trollor, J., Srasuebku, P., Xu, H., & Howlett, S. (2017), 'Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data'. **BMJ open**, 7(2), e013489.

- Truesdale-Kennedy, M., Taggart, L., & McIlfratrick, S. (2011), 'Breast cancer knowledge among women with intellectual disabilities and their experiences of receiving breast mammography'. **Journal of advanced nursing**, 67(6), 1294-1304.
- Tuffrey-Wijne, I., & Davidson, J. (2018), 'Excellence in palliative and end-of-life care provision for people with intellectual disability'. **International Journal of Palliative Nursing**, 24(12), 598-610.
- Tuffrey-Wijne, I., Hogg, J., & Curfs, L. (2007), 'End-of-life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: a review of the literature and available resources'. **Journal of Applied Research in Intellectual Disabilities**, 20(4), 331-344.
- Tyrer, S. P. (2012), 'An innovative service but will it work in practice? Commentary on ... Fair Horizons'. **The Psychiatrist**, 36(1), 30-31.
- United Nations (2006), **United Nations Convention on the Rights of Persons with Disabilities**. . Geneva: United Nations.
- Verdugo, M. A., Gómez, L. E., Arias, B., Navas, P., & Schalock, R. L. (2014), 'Measuring quality of life in people with intellectual and multiple disabilities: Validation of the San Martín scale'. **Research in Developmental Disabilities**, 35(1), 75-86.
- Voss, H., Vogel, A., Wagemans, A. M., Francke, A. L., Metsemakers, J. F., Courtens, A. M., & de Veer, A. J. (2020), 'What is important for advance care planning in the palliative phase of people with intellectual disabilities? A multi-perspective interview study'. **Journal of Applied Research in Intellectual Disabilities**, 33(2), 160-171.
- Walker, R., & Hutchinson, C. (2017), 'Planning for the future among older parents of adult offspring with intellectual disability living at home and in the community: A systematic review of qualitative studies'. **Journal of Intellectual & Developmental Disability**, 43(4), 453-462.
- Webber, R., Bowers, B., & Bigby, C. (2014), 'Residential aged care for people with intellectual disability: A matter of perspective'. **Australasian Journal on Ageing**, 33(4), E36-E40.
- Webber, R., Bowers, B., & Bigby, C. (2016), 'Confidence of group home staff in supporting the health needs of older residents with intellectual disability'. **Journal of Intellectual and Developmental Disability**, 41(2), 107-114.
- Webber, R., Bowers, B., & McKenzie-Green, B. (2010), 'Staff responses to age-related health changes in people with an intellectual disability in group homes'. **Disability and Society**, 25(6), 657-671.
- WHO (2007), **Global age-friendly cities: A guide**. Switzerland: World Health Organization.
- Wiese, M., Stancliffe, R. J., Dew, A., Balandin, S., & Howarth, G. (2014), 'What is talked about? Community living staff experiences of talking with older people with intellectual disability about dying and death'. **Journal of Intellectual Disability Research**, 58(7), 679-690.

- Wigham, S., Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., & Romeo, R. (2008), 'Reported goal setting and benefits of person centred planning for people with intellectual disabilities'. **Journal of Intellectual Disabilities**, 12(2), 143-152.
- Williams, V., & Robinson, C. (2001), 'He will finish up caring for me': people with learning disabilities and mutual care'. **British Journal of Learning Disabilities**, 29(2), 56-62.
- Wilson, N. J., Riches, V. C., Riches, T., Durvasula, S., Rodrigues, R., & Pinto, S. (2020), 'Complex support needs profile of an adult cohort with intellectual disability transitioning from state-based service provision to NDIS-funded residential support'. **Journal of Intellectual and Developmental Disability**, 45(4), 355-364.
- Woodman, A. C., Mailick, M. R., Anderson, K. A., & Esbensen, A. J. (2014), 'Residential transitions among adults with intellectual disability across 20 years'. **American Journal on Intellectual and Developmental Disabilities**, 119(6), 496-515.
- Wu, D., Gao, X., Xie, Z., & Xu, Z. (2021), 'Understanding the unmet needs among community-dwelling disabled older people from a linkage perspective'. **International Journal of Environmental Research and Public Health**, 18(2), 389.
- Zigman, W. B., Schupf, N., Devenny, D. A., Mizejeski, C., Ryan, R., Urv, T. K., Schubert, R., & Silverman, W. (2004), 'Incidence and prevalence of dementia in elderly adults with mental retardation without down syndrome'. **Am J Ment Retard**, 109(2), 126-141.
- Ziviani, J., Lennox, N., Allison, H., Lyons, M., & Del Mar, C. (2004), 'Meeting in the middle: improving communication in primary health care consultations with people with an intellectual disability'. **Journal of Intellectual and Developmental Disability**, 29(3), 211-225.

Appendix

Survey findings

A. Type of residential setting for service users

Type of residential setting	Percent & number
Congregated setting	
All	37.5% (n=12)
Specialist	37.5% (n=6)
Non specialist	50% (n=5)
Other	16.7% (n=1)
Individual homes in the community	
All	81.3% (n=26)
Specialist	93.8% (n=15)
Non specialist	70% (n=7)
Other	66.7% (n=4)
Clusters of homes in the community	
All	18.8% (n=6)
Specialist	18.8% (n=3)
Non specialist	20% (n=2)
Other	16.7% (n=1)
In a home with family members	
All	34.4% (n=11)
Specialist	43.8% (n=7)
Non specialist	30% (n=3)
Other	16.7% (n=1)
Nursing home for people with intellectual disability	
All	3.1% (n=1)
Specialist	0
Non specialist	0
Other	16.7% (n=1)
Specialised dementia residence	
All	21.9% (n=7)
Specialist	25% (n=4)
Non specialist	10% (n=1)
Other	33.3% (n=2)
Mainstream nursing home	
All	21.9% (n=7)
Specialist	35.7% (n=6)

Non specialist	0%
Other	16.7% (n=1)
Other	
All	9.4% (n=3)
Specialist	0%
Non specialist	10% (n=1) “day services”
Other responses: 33.3% (n=2) “Homes in the community/ bungalows on a campus setting” “Residential type bungalows with 6 residents with ID”	

B. Most important components of specialist ageing service

The most important components of a specialist ageing service for older people with intellectual disability and complex needs ranked in order of importance with 1 being the most important.

Ranking %	1	2	3	4	5	6	7	8	9
Ageing in Place									
All	22.2% (n=6)	14.8 (n=4)	3.7 (n=1)	14.8 (n=4)	3.7 (n=1)	14.8 (n=4)	7.4 (n=2)	7.4 (n=2)	11.1 (n=3)
Specialist	38.5% (n=5)	7.7% (n=1)	7.7 (n=1)	7.7 (n=1)	0%	15.4 (n=2)	7.7 (n=1)	7.7 (n=1)	7.7 (n=1)
Non specialist	0%	25% (n=2)	0%	25 (n=2)	12.5 (n=1)	25 (n=2)	12.5 (n=1)	0%	0%
Other	16.7% (n=1)	16.7% (n=1)	0%	16.7% (n=1)	0%	0%	0%	16.7% (n=1)	33.3 (n=2)
Person-centred support									
All	29.6% (n=8)	18.5% (n=5)	25.9% (n=7)	11.1% (n=3)	7.4% (n=2)	3.7% (n=1)	3.7% (n=1)	0%	0%
Specialist	23.1% (n=3)	15.4% (n=2)	23.1% (n=3)	15.4% (n=2)	7.7% (n=1)	3.7% (n=1)	3.7% (n=1)	0%	0%
Non specialist	25% (n=2)	25% (n=2)	37.3% (n=3)	12.5 (n=1)	0%	0%	0%	0%	0%
Other	50% (n=3)	16.7% (n=1)	16.7% (n=1)	0%	16.7% (n=1)	0%	0%	0%	0%
Responsive to needs									
All	11.1% (n=3)	18.5% (n=5)	22.2% (n=6)	22.2% (n=6)	7.4% (n=2)	14.8% (n=4)	0%	0%	3.7% (n=1)
Specialist	0%	30.8% (n=4)	7.7% (n=1)	30.8% (n=4)	15.4% (n=2)	15.4% (n=2)	0%	0%	0%
Non specialist	20% (n=2)	12.5% (n=1)	25% (n=2)	25% (n=2)	0%	0%	0%	0%	12.5% (n=1)

Other	16.7% (n=1)	0%	50% (n=3)	0%	0%	33.3% (n=2)	0%	0%	0%
Social involvement / networking									
All	0%	0%	3.7% (n=1)	0%	14.8% (n=4)	3.7% (n=1)	29.6% (n=8)	25.9% (n=7)	22.2% (n=6)
Specialist	0%	0%	7.7% (n=1)	0%	7.7% (n=1)	0%	23.1% (n=3)	30.8% (n=4)	30.8% (n=4)
Non specialist	0%	0%	0%	0%	12.5% (n=1)	0%	50% (n=4)	37.5% (n=3)	3.3% (n=2)
Other	0%	0%	0%	0%	33.3% (n=2)	16.7% (n=1)	16.7% (n=1)	0%	0%
Proactive future planning									
All	18.5% (n=5)	22.2% (n=6)	0%	7.4% (n=2)	14.8% (n=4)	22.2% (n=6)	11.1% (n=3)	3.7% (n=1)	0%
Specialist	23.1% (n=3)	15.4% (n=2)	0%	0%	15.4% (n=2)	23.1% (n=3)	15.4% (n=2)	7.7% (n=1)	0%
Non specialist	25% (n=2)	12.5% (n=1)	0%	12.5% (n=1)	12.5% (n=1)	37.5% (n=3)	0%	0%	0%
Other	0%	50% (n=3)	0%	16.7% (n=1)	16.7% (n=1)	0%	16.7% (n=1)	0%	0%
Family involvement / networking									
All	0%	3.7% (n=1)	0%	7.4% (n=2)	7.4% (n=2)	7.4% (n=2)	37% (10)	22.2% (n=6)	14.8% (n=4)
Specialist	0%	0%	0%	7.7% (n=1)	0%	7.7% (n=1)	38.5% (n=5)	30.8% (n=4)	15.4% (n=2)
Non specialist	0%	0%	0%	12.5% (n=1)	25% (n=2)	0%	25% (n=2)	12.5% (n=1)	25% (n=2)
Other	0%	16.7% (n=1)	0%	0%	0%	50% (n=3)	25% (n=2)	12.5% (n=1)	0%
Effective links to general and specialist services									
All	0%	0%	11.1% (n=3)	11.1% (n=3)	25.9% (n=7)	7.4% (n=2)	3.7% (n=1)	22.2% (n=6)	18.6% (n=5)
Specialist	0%	0%	7.7% (n=1)	15.4% (n=2)	38.5% (n=5)	15.4% (n=2)	0%	0%	23.1% (n=3)
Non specialist	0%	0%	25% (n=2)	0%	12.5% (n=1)	0%	12.5% (n=1)	37.5% (n=3)	12.5% (n=1)
Other	0%	0%	0%	16.7% (n=1)	16.7% (n=1)	0%	0%	50% (n=3)	16.7% (n=1)
Skilled staff									
All	3.7% (n=1)	11.1% (n=3)	22.2% (n=6)	14.8% (n=4)	11.1% (n=3)	18.5% (n=5)	7.4% (n=2)	7.4% (n=2)	3.7% (n=1)
Specialist	0%	15.4% (n=2)	38.4% (n=5)	15.4% (n=2)	7.7% (n=1)	7.7% (n=1)	7.7% (n=1)	7.7% (n=1)	0%

Non specialist	0%	12.5% (n=1)	12.5% (n=1)	0%	12.5% (n=1)	37.5% (n=3)	0%	12.5% (n=1)	12.5% (n=1)
Other	16.7% (n=1)	0%	0%	33.3% (n=2)	16.7% (n=1)	16.7% (n=1)	16.7% (n=1)	0%	0%
Physical / built environment									
All	11.1% (n=3)	11.1% (n=3)	11.1% (n=3)	11.1% (n=3)	7.4% (n=2)	7.4% (n=2)	0%	11.1% (n=3)	25.9% (n=7)
Specialist	7.7% (n=1)	15.4% (n=2)	7.7% (n=1)	7.7% (n=1)	7.7% (n=1)	7.7% (n=1)	0%	15.4% (n=2)	23.1% (n=3)
Non specialist	0%	0%	0%	12.5% (n=1)	0%	0%	0%	0%	37.5% (n=3)
Other	25% (n=2)	12.5% (n=1)	33.3% (n=2)	16.7% (n=1)	0%	16.7% (n=1)	0%	16.7% (n=1)	16.7% (n=1)

C. Presence of service pathways for specified health issues

Extent of formal pathway through which services can support adults with health issues by service type.

Condition	Non-existent pathway	Limited pathway	Effective pathway
Dementia			
All	6.2% (n=2)	38.7% (n=12)	54.8% (n=17)
Specialist	0%	33.3% (n=5)	66.7% (n=10)
Non-specialist	20% (n=2)	40% (n=4)	40% (n=4)
Other	0%	50% (n=3)	50% (n=3)
Mental health			
All	6.5% (n=2)	29% (n=9)	64.5% (n=20)
Specialist	0%	40% (n=6)	60% (n=9)
Non-specialist	10% (n=1)	30% (n=3)	60% (n=6)
Other	16.7% (n=1)	0%	83.5% (n=5)
Behaviours			
All	0%	32.3% (n=10)	67.7% (n=21)
Specialist	0%	40% (n=6)	60% (n=9)
Non-specialist	0%	40% (n=4)	60% (n=6)
Other	0%	0%	100% (n=6)
Frailty			
All	16.7% (n=5)	50% (n=15)	33.3% (n=10)
Specialist	7.1% (n=1)	64.3% (n=9)	28.6% (n=4)
Non-specialist	40% (n=4)	40% (n=4)	20% (n=2)
Other	0%	20% (n=2)	66.7% (n=4)
Multi-morbidities			
All	16.7% (n=5)	51.6% (n=16)	32.3% (n=10)
Specialist	13.3% (n=2)	60% (n=9)	26.7% (n=4)
Non-specialist	30% (n=3)	40% (n=4)	30% (n=3)
Other	0%	50% (n=3)	50% (n=3)

D. Most important components for meeting needs

Participants were asked to rank the most important issues for meeting the needs of older people with intellectual disabilities as they age, in order of importance from 1 to 12. The table below presents the scores 1 to 5 on each item.

	1	2	3	4	5
Appropriate staff skills					
All	13.8% (n=4)	20.7% (n=6)	13.8% (n=4)	3.4% (n=1)	17.2% (n=5)
Specialist	21.4% (n=3)	14.3% (n=2)	0%	0%	14.3% (n=2)
Non-specialist	0%	22.2% (2)	33.3% (3)	0%	22.2% (n=2)
Other	16.7% (n=1)	33.3% (n=2)	16.7% (n=1)	16.7% (n=1)	16.7% (n=1)
Adequate staff mix					
All	0%	17.2% (n=5)	17.2% (n=5)	24.1% (n=7)	10.3% (n=3)
Specialist	0%	28.6% (n=4)	7.1% (n=1)	21.4% (n=3)	0%
Non-specialist	0%	0%	33.3% (n=3)	22.2% (n=2)	22.2% (n=2)
Other	0%	16.7% (n=1)	16.7% (n=1)	33.3% (n=3)	16.7% (n=1)
Staff education / training					
All	3.4% (n=1)	3.4% (n=1)	3.4% (n=1)	17.2% (n=5)	13.8% (n=4)
Specialist	0%	7.1% (n=1)	7.1% (n=1)	14.3% (n=2)	7.1% (n=1)
Non-specialist	0%	0%	0%	22.2% (n=2)	11.1% (n=1)
Other	16.7% (n=1)	0%	0%	16.7% (n=1)	33.3% (n=2)
Access to timely screening, diagnostic and interventional care					
All	17.2% (n=5)	10.3% (n=3)	6.9% (n=2)	17.2% (n=5)	13.8% (n=4)
Specialist	14.3% (n=2)	14.3% (n=2)	7.1% (n=1)	21.4% (n=3)	21.4% (n=3)
Non-specialist	22.2% (n=2)	11.1% (n=1)	0%	22.2% (n=2)	11.1% (n=1)
Other	16.7% (n=1)	0%	16.7% (n=1)	0%	0%
Responsive resource model					
All	0%	6.9% (n=2)	20.7% (n=6)	6.9% (n=2)	6.9% (n=2)
Specialist	0%	7.1% (n=1)			14.3 (n=2)
Non-specialist	0%	0%	11.1% (n=1)	0%	0%
Other	0%	11.1% (n=1)	16.7% (n=1)	11.1% (n=1)	0%
Responsiveness of funders to changed / increased client needs					

All	17.2% (n=5)	20.7% (n=6)	17.2% (n=5)	6.9% (n=2)	3.4% (n=1)
Specialist	7.1% (1)	21.4% (n=3)	21.4% (n=3)	7.1% (n=1)	7.1% (n=1)
Non-specialist	33.3% (n=3)	22.2% (n=2)	11.1% (n=1)	11.1% (n=1)	0%
Other	16.7% (n=1)	16.7% (n=1)	16.7% (n=1)	0%	0%
HIQA regulation					
All	0%	0%	3.4% (n=1)	0%	0%
Specialist	0%	0%	7.1% (n=1)	0%	0%
Non-specialist	0%	0%	0%	0%	0%
Other	0%	0%	0%	0%	0%
Staff buy-in					
All	0%	0%	0%	10.3% (n=3)	3.4% (n=1)
Specialist	0%	0%	0%	14.3% (n=2)	7.1% (n=1)
Non-specialist	0%	0%	0%	11.1% (n=1)	0%
Other	0%	0%	0%	0%	0%
Appropriate physical environment					
All	10.3% (n=3)	10.3% (n=3)	6.9% (n=2)	3.4% (n=1)	3.4% (n=1)
Specialist	0%	0%	7.1% (n=1)	7.1% (n=1)	0%
Non-specialist	22.2% (n=2)	22.2% (n=2)	0%	0%	11.1% (n=1)
Other	16.7% (n=1)	16.7% (n=1)	16.7% (n=1)	0%	0%
Good inter-professional staff working relationships					
All	0%	0%	0%	0%	6.9% (n=2)
Specialist	0%	0%	0%	0%	7.1% (n=1)
Non-specialist	0%	0%	0%	0%	0%
Other	0%	0%	0%	0%	16.7% (n=1)
Support and education for family members					
All	0%	0%	3.4% (n=1)	0%	3.4% (n=1)
Specialist	0%	0%	7.1% (n=1)	0%	7.1% (n=1)
Non-specialist	0%	0%	0%	0%	0%
Other	0%	0%	0%	0%	0%
Consultation with the older person					
All	37.9% (n=11)	10.3% (n=3)	6.9% (n=2)	6.9% (n=2)	13.8% (n=4)

Specialist	57.1% (n=8)	7.1% (n=1)	7.1% (n=1)	0%	7.1% (n=1)
Non-specialist	22.2% (n=2)	11.1% (n=1)	11.1% (n=1)	0%	22.2% (n=2)
Other	16.7% (n=1)	16.7% (n=1)	0%	33.3% (n=2)	16.7% (n=1)

E. Most likely outcomes for service users who develop complex aged related needs

Outcome	Most people	Some people	A minority of people
They will age in place			
All	43.3% (n=13)	40% (n=12)	16.7% (n=5)
Specialist	50% (n=7)	35.7% (n=5)	14.3% (n=2)
Non-specialist	40% (n=4)	40% (n=4)	20% (n=2)
Other	33.3% (n=2)	50% (n=3)	16.7% (n=1)
They will transfer to a specialist ageing facility within the service			
All	3.7% (n=1)	55.6% (n=15)	40.7% (n=11)
Specialist	0%	61.5% (8)	38.5% (5)
Non-specialist	0%	37.5% (3)	62.5% (5)
Other	16.7% (n=1)	66.7% (4)	16.7% (n=1)
They will transfer to another residential house, in the service, that has more support			
All	13.3% (n=4)	46.7% (n=14)	40% (n=12)
Specialist	21.4% (n=3)	50% (n=7)	28.6% (n=4)
Non-specialist	10% (n=1)	40% (n=4)	50% (n=5)
Other	0%	50% (3)	50% (n=3)
They will transfer to a mainstream nursing home, outside the service			
All	16% (n=4)	32% (n=8)	52% (n=13)
Specialist	16.7% (n=2)	33.3% (n=4)	50% (n=6)
Non-specialist	14.3% (n=1)	28.6% (n=2)	57.1% (n=4)
Other	16.7% (n=1)	33.3% (n=2)	50% (n=3)

F. Use of outcome measurement approaches

Person-centred support plan	
All	78.1% (n=25)
Specialist	87.5% (n=14)
Non-specialist	60% (n=6)
Other	83.3% (n=5)
Person-centred care plan	
All	68.8% (n=22)
Specialist	75% (n=12)
Non-specialist	50% (n=5)
Other	83.3% (n=5)

Satisfaction surveys	
All	46.9% (n=15)
Specialist	37.5% (n=6)
Non-specialist	50% (n=5)
Other	66.7% (n=4)
Complaint process	
All	59.4% (n=19)
Specialist	56.3% (n=9)
Non-specialist	50% (n=5)
Other	83.3% (n=5)
HIQA standards measures	
All	56.3% (n=18)
Specialist	43.8% (n=7)
Non-specialist	60% (n=6)
Other	83.3% (n=5)
DisDAT (Disability Distress Assessment Tool)	
All	43.8% (n=14)
Specialist	50% (n=8)
Non-specialist	50% (n=5)
Other	16.7% (n=1)
I Plan	
All	0%
Specialist	0%
Non-specialist	0%
Other	0%
Glancing Back, Looking Forward	
All	21.9% (n=7)
Specialist	25% (n=4)
Non-specialist	20% (n=2)
Other	16.7% (n=1)
Advocacy Process	
All	59.4% (n=19)
Specialist	62.5% (n=10)
Non-specialist	40% (n=4)
Other	83.3% (n=5)
Other elaboration:	
All about me, Assessment of Need (S); Planning Ahead Document (S)	mdt/restrictive strategy reviews (NS) day service new directions (NS)