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



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Funded and published by National Disability Authority, Dublin.

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# 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.

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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.

# Abbreviations

COVID-19 Coronavirus Disease 19

DPER Department of Public Expenditure and Reform

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

PCC Person-centred Care

PCP Person-centred Planning

RNID Registered Nurse in Intellectual Disability

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)

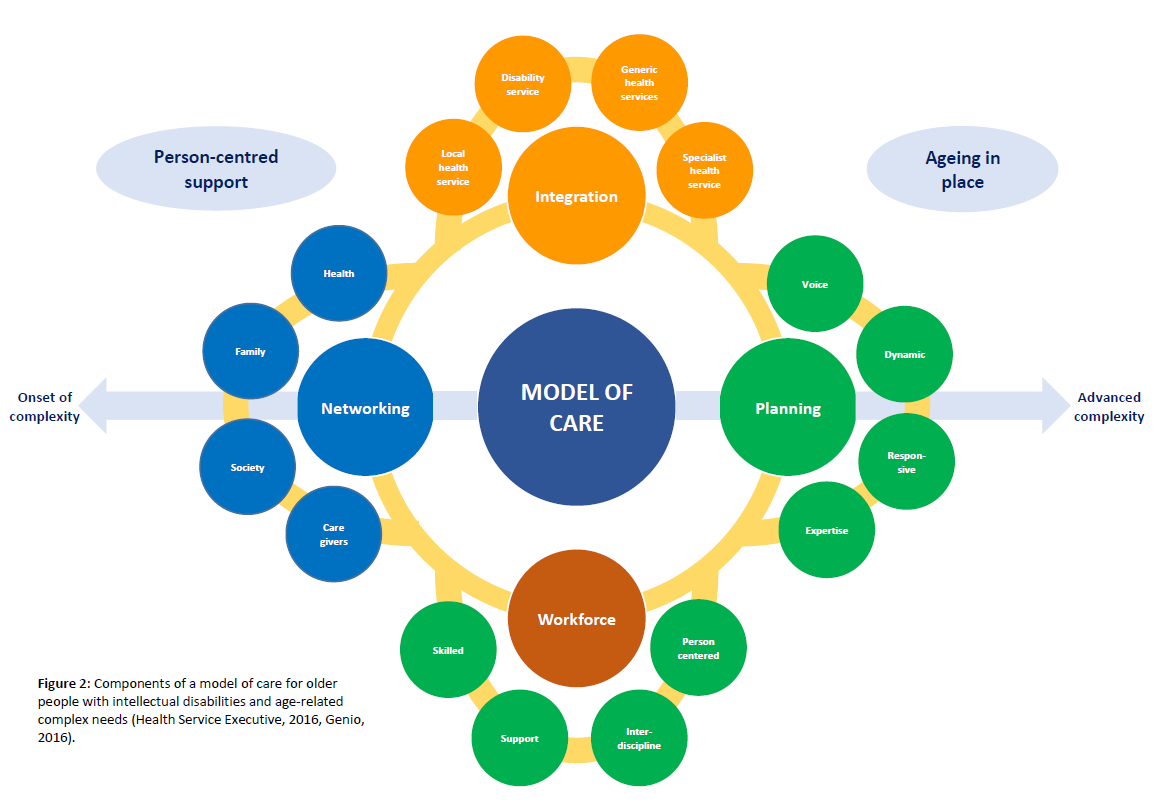
The occurrence of COVID-19 at the initial stage of this research, and the effect of that on nursing homes led to an ethically-based decision being made not to burden those settings with the demands of this study. The result is that their voices are not present in this study.

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/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/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/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**

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| **Mode of Data Collection** | **Participants** | **No. of Participants** |
| **Focus groups (n=8)** | Service managers |  |
| *Specialist service* (SS) | 8 |
| *Generalist service* (GS) | 8 |
| Direct care staff |  |
| *Specialist service* (SS) | 5 |
| *Generalist service* (GS) | 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*** |

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; 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. 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 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, 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, 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/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, responsivity 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 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 build 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.