



Challenges in care and service provision for older adults with intellectual disabilities and complex age-related conditions in Ireland

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Abstract

Background: People with intellectual disabilities are living longer and are increasingly diverse, with health and care needs that are varied and complex. Without changes to funding, services have found it difficult to respond to needs and wishes.

Method: A descriptive mixed methods design study, data were collected through questionnaire, focus groups and individual interviews from intellectual disability service managers, direct care staff and older people with intellectual disabilities and family members.

Results: Continued reticence on the part of some community healthcare providers to treat people with intellectual disability was noted. Although some service innovations were noted, housing, staffing levels, staff mix and the timely provision of equipment were all reported to impact the ability of services to respond to changing needs. Current per-capita funding practices were reported as unresponsive to growing age-related complexity and fundamentally unsustainable.

Conclusions: The health inequalities experienced by people with intellectual disabilities are compounded as they age with complex age-related health needs. There is an urgent need for revision of the service model in Ireland and instigation of flexible and responsive approaches to funding.

KEYWORDS

health, intellectual disability, research

Accessible summary

- More people with intellectual disabilities are living into old age and may experience age related ill health.
- In this study, we interviewed older people with intellectual disability, family members and staff and managers in intellectual disability services. We also surveyed staff from the services.

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- We found that there is a concern that as people with intellectual disability age and have different health and social needs, the way that services are provided and staffed may no longer suit the needs of the individuals.
- Most intellectual disability services are now based in the community and most staff are social care rather than healthcare staff and may not have the skills and experience to provide care to older adults with healthcare needs. Accommodation in the community may not be suitable for older adults with healthcare needs.
- A new model of care and different model of funding intellectual disability services is needed to meet the needs of older people with intellectual disability.

1 | 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 have continued to improve (Bigby & Haveman, 2010; McCallion & Jokinen, 2017). Despite these changes, however, mortality rates remain higher for this population compared to people without intellectual disabilities (Dolan et al., 2021; Lauer & McCallion, 2015; McCarron et al., 2015). Ageing with intellectual disabilities is often associated with premature ageing and increased risk of age-related health conditions (Alftberg et al., 2021; Gensous, et al., 2020); people with Down Syndrome, for example, have an increased risk of developing Alzheimer's disease at younger ages (Gensous et al., 2020; Iulita et al., 2022; Janicki & Dalton, 2000). Few healthy ageing interventions are aimed at people with intellectual disabilities (Santos et al., 2020). Thus, people with intellectual disability may experience health inequalities throughout their lives and these inequalities may be compounded by conditions experienced by all people as they age (Northway et al., 2017). Healthcare inequalities have been implicated in avoidable excess mortality among people with intellectual disability; furthermore, inequality of access to palliative care for people with intellectual disabilities has been described as 'an urgent international priority' (Adam et al., 2020, p. 1007).

Historically, the needs of people with intellectual disabilities in Ireland were met in institutions and on segregated campuses (Murphy & Bantry-White, 2021). The drive for community-based services has been the dominant paradigm in Ireland over recent decades and the move towards a social model of disability has resulted in a concomitant move away from the health-oriented perspectives that had previously predominated service provision, and further driven the policy on decongregation (HSE, 2011).

This resulted in the flourishing of community-based accommodation staffed largely by social care staff with the assumption that healthcare services in the community would be accessed in a similar way to the general population (McCallion & Jokinen, 2017). The roll-out of such decongregation has, however, occurred in the absence of initiatives to ensure comprehensive, quality community-based healthcare even as the numbers ageing, and related health complexity has increased. Instead, as

in other countries, such as the United States and United Kingdom, the growth of services in Ireland was predicated on meeting the needs of a relatively predictable population who would have a shorter lifespan to one that is increasingly older, diverse and with needs that are varied and complex (McCallion & Jokinen, 2017; McCausland et al., 2021). 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 changing needs and wishes. The prioritization of social inclusion and decongregation 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 community services (Egan et al., 2022). The literature suggests that health and social care systems are ill-equipped to meet the complex age-related needs of older adults with intellectual disabilities (Burke et al., 2019; García-Domínguez et al., 2020; McCarron et al., 2018; Sheerin et al., 2023) and, as a result, this population faces a range of unmet health and social care needs (Albuquerque & Carvalho, 2020; Bigby et al., 2014; Rinaldi et al., 2022). The commitment to the social model without required levels of community-delivered healthcare, as obligated by the Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006), has resulted in a dilemma as to whether older adults with developing complexity can or should remain in settings that no longer have healthcare personnel. There is a need for community-based integrated care for people with intellectual disabilities with greater coordination of health and social care services.

A systematic review was undertaken as an integrated component of a National Disability Authority-funded study, '*The care of older adults with intellectual disabilities and complex age-related conditions*' (Sheerin et al., 2023). This review sought to identify models of care to support older people with intellectual disabilities and complex age-related conditions. The inclusion criteria were people aged 40 and older, an intellectual disability, approaches to care and models of care. Peer-reviewed descriptive research papers were included along with policies from grey literature. A complex age-related condition was defined as a combination of physical, intellectual, health, behavioural, emotional and welfare needs along a continuum of complexity which often challenges the social, educational and health structures available to support them (Whitehurst, 2010). The review revealed the absence of any explicit

model of care for this group of people, thus increasing the vulnerability of older adults to health inequalities and to inadequate and inappropriate care. It did, however, point to several recurrent concepts central to the provision of service and care that are apparent. These key components include integration, planning, workforce and networking with service provision underpinned by the principles of ageing in place and person-centred planning (Sheerin et al., 2023).

This paper provides insight into the care and service options for older adults with intellectual disabilities and complex care needs in Ireland and identifies the challenges to meeting individuals' needs as they age.

2 | METHODS

The study utilized a descriptive mixed methods design, incorporating two phases of data collection to achieve the study aim of examining the care and service options for older adults with intellectual disabilities and complex age-related conditions. The sampling strategy sought to involve all key stakeholders to achieve a multiperspectival exploration of current service approaches and models of care for older people with intellectual disabilities and complex age-related needs. Thus, service managers and direct care staff were purposively sampled from throughout Ireland to garner their experiences of providing care to this growing cohort of people with intellectual disabilities; likewise, the qualitative interviews with the older people themselves and their family members were designed to provide insights from their perspectives. The survey was developed to examine the characteristics of current Irish services, user needs, the availability and effectiveness of current resources and to identify current and anticipated challenges to services.

Data collection in Phase 1 included online focus groups, interviews, and an online survey questionnaire. Individuals, defined by their roles as senior staff members, were recruited to the interviews and focus groups via the Chief Executive Officers of eight intellectual disability services purposively sampled from a national database of intellectual disability services.

The focus groups and interviews, which took place between the 2 and 20 September 2021, were guided by a semistructured interview schedule and sought to explore the perspectives of senior staff and managers in intellectual disability services on:

- Current models of care in specialist and nonspecialist settings.
- Factors influencing decision-making on care needs.
- Expected needs.
- Experiences of supporting 'transitions' (e.g., geographical, social, health and activity or work).

Current outcomes and how these outcomes affect quality of life in different settings.

The questionnaire was created and distributed using the Qualtrics XM system. The development was informed by the aim of the study, the literature and by the data generated in the Phase 1

interviews. It was piloted by two senior managers after which a small number of changes to phrasing were made. The 38 survey items consisted of Likert-type scale questions, multiple-choice questions, lists for rating, and open-ended questions to allow participants to elaborate on their answers. The questions were designed to capture the following information: type of service models/approaches; the needs of older adults with intellectual disabilities including age-related health needs, housing and accommodation needs; responding to health needs; end of life issues; advance care planning and bereavement; outcomes and quality of life indicators and costings.

Senior managers from all 80 residential adult intellectual disability services in Ireland were invited to take part in the online questionnaire. A letter of invitation with an embedded link to the online survey and information sheet was sent by email on 14 February 2022, with an initial deadline of 2 weeks, which was extended to 25 March 2022, with a reminder email sent leading up to this final deadline. Thirty-two completed questionnaires were received, representing a response rate of 40%.

Phase 2 explored the experiences and outcomes for support staff, older people with intellectual disabilities and family members, when faced with age-related challenges and included 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 between the February and July 2022.

The support staff participants in Phase 2 comprised nursing, health and social care staff employed to provide direct care to older people with intellectual disability. Letters of invitation and participant information were forwarded to direct care staff by the service managers who had been purposively sampled to participate in phase 1. The online focus groups were scheduled for a time convenient to the participants.

The older people and the family members participants were recruited via voluntary advocacy and support organizations, and through contact with intellectual disability services. The interviews were framed by an interview schedule that explored: experiences and outcomes when faced with age-related challenges; experience of health-related and other 'transitions'; and experience of support during these 'transitions' and perspectives on their current outcomes and how these affect their quality of life. The interviews were carried out in a place of convenience for the interviewees. Two interviews were conducted over the phone, two were online over Zoom and the remainder were face-to-face in either a day centre, a residential centre or in the interviewee's home.

The audio recordings from focus groups and interviews were transcribed verbatim by a professional company and the researchers reviewed written transcripts for accuracy. The analysis was data driven and inductive, and a priori codes were not used. The analysis was guided by Braun and Clarke's reflexive thematic approach recursively following the six phases of data familiarization; systematic data coding; initial themes generation from coded and collated data; developing and reviewing themes; refining, defining and naming themes; and report writing (Braun & Clarke, 2006, 2021).

As the process progressed, the research team discussed how the themes fit with theoretical perspectives and current policy, as identified in the literature reviewed, regarding current practice, the

processes that drive it, current and planned provision for ageing, and perceived future need.

Analysis of quantitative data, obtained through the online questionnaire, was conducted using SPSS Version 27 (IBM Corporation, 2020). Descriptive statistics were generated first to describe the demographic profile of individuals residing in intellectual disability care services for older people 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. Narrative data within the survey 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 at Trinity College Dublin. 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. These were also available in accessible formats, as required. 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. Participants names were pseudonymized and all data stored in a password protected folder on a double-encrypted, password-protected computer.

3 | DETAILS OF PARTICIPANTS

The services that participated in the study included those located in Dublin, in other cities and towns and in rural areas. Dublin City and county accounted for almost 40% (38.7%, $n = 12$) of the services represented in the survey. Over one-third (35.5%, $n = 11$) are based in rural areas and just over one quarter are in cities and counties other than Dublin (25.8%, $n = 8$). Details of participants/respondents are presented in Table 1 below.

4 | FINDINGS

The findings from the research are organized under three key themes developed from the data: approaches to care, challenges and consequences.

4.1 | Approaches to care

Services were recruited for the study as either having an overall specialist (SS) or generalist (GS) approach to service provision. 'Specialist', in this context, refers to an approach largely focused on meeting the needs of older individuals with intellectual disabilities and specific age-related complex concerns and 'generalist' refers to approaches without a specific

TABLE 1 Details of participants/respondents across the study.

Mode of data collection	Participants	No. of participants
Focus groups ($n = 8$)	SM	
	SS	8
	GS	8
	D	
	SS	5
	GS	4
Individual interviews ($n = 13$)	SS	1
	OP with intellectual disability	7
	Fam of OP receiving services	2
	Fam of deceased OP	3
Group interviews ($n = 3$)	OPs with intellectual disability and support person	2
	Joint Fam and or OP with intellectual disability	3 (Fam) 2 (OP)
Survey ($n = 32$)	Senior managers from adult intellectual disability services	32
Total number of participants		77

Abbreviations: D, direct care staff; Fam, family; GS, generalist service; OP, older person; SM, service manager; SS, specialist service.

focus on age. However, although some services may have had specific older person pathways linked, for example, to the development of health-related complexities such as dementia, they also had generalist paths through which many older people received service. Similarly, the generalist services had some examples of specific older person services and a range of other more generalist ones. 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. Services employed a mix of settings, with people living in individual homes in the community, at home with families, in nursing homes (intellectual disability and mainstream) and in specialized dementia accommodation.

Across all the service types, the social model was most frequently reported in the survey as guiding services (75%, $n = 24$). Some focus group participants saw nursing as a manifestation of the 'medical model' and reported that their service had moved to one grounded in social care, with social care staff supporting service users with a myriad of complex conditions to remain in their homes for as long as possible:

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)

Other service providers brought together a variety of components to create an eclectic approach to care as health-related complexity, now being seen at all stages in the lives of older people with intellectual disabilities, has necessitated approaches combining health and social care. Such health-related complexities were reported as relating to ageing itself, to specific conditions that tend to become more prevalent in older age, to an individual's need to change their pace of life and to end of life needs. However, dementia arose repeatedly in the interviews and focus groups, with more than half of survey respondents (55.2%, $n = 16$) identifying this as an issue of concern. Other issues of concern included end of life, mental health, behaviours, frailty and multimorbidity. The speed at which the age-related needs of an older person can change, presented challenges for services to plan proactively and respond agilely:

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).

Notwithstanding the service approach, participants in all settings aspired to the key older person service principles of ageing in place and person-centred support despite a range of significant challenges.

4.2 | Challenges to supportive positive ageing

Although there were many challenges identified, three main problematic areas were evident: (1) difficulties in accessing mainstream health and social services; (2) lack of adequate and available resources for accommodation; and (3) difficulties in addressing staffing and skill mix. In addition, a level of frustration was evident among some direct care staff respondents about an inadequacy of planning and projection as they described themselves as reactively firefighting issues rather than proactively addressing the needs of service users as they aged:

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).

4.2.1 | Accessing mainstream health and social services

Despite the prevalence of health issues such as dementia, mental health concerns and behavioural challenges, most respondents reported that there were limited or effective pathways in place to address these. Furthermore, only a minority indicated that there were

effective formal pathways to addressing multimorbidity (32.3%; $n = 10$) and frailty (35.5%; $n = 11$). Whereas some examples of positive interaction with the general health services were described, other respondents noted a reticence on the part of some community-based services to respond to requests of support, assuming that the presence of health care professionals in the disability service meant that they already had both the required expertise and unending resources:

...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).

The long waiting lists and general lack of resources in the Irish health services were also cited as barriers to access as was the fragmentation and siloing of services.

A multidisciplinary approach was considered by many to be particularly important in addressing developing needs, as it allowed different skillsets to be called on to respond in a coordinated and individualized manner. Developing relationships between intellectual disability and non-disability services can support ageing in place, increase inclusion and bring benefits for both partners. However, participants reported delays in getting diagnoses for conditions like dementia, perhaps due to diagnostic overshadowing, making it difficult for services to respond in a timely manner.

This was also highlighted by family members who spoke of delayed diagnoses and incorrect diagnoses with a lack of connectivity leading to diagnostic delay. 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. 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).

4.2.2 | Accommodation

Although participants were positive about the move to community living over recent decades, it was highlighted that the closure of larger or campus-based accommodation has reduced the options available to services as their service users age with complex needs. Several participants considered that the ultimate answer

for some people may need to be in some form of congregated setting, however 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).

Houses based in the community were reported as becoming highly problematic in providing appropriate care when people developed complex care needs. In Ireland, many community-based houses are rented, and landlords may not permit structural alterations. Moreover, houses may not be modifiable or amenable to retrofitting. The need for equipment and storage can also present challenges to ageing in place:

...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).

The need for health-related equipment also becomes challenging where its space, operation and energy needs poses a hindrance to the lives of others living in the house.

The welcome development of national standards for disability services by the Health Information and Quality Authority (HIQA, 2013) have had a considerable influence on the lives of people with intellectual disabilities. However, the modifications necessary to bring some accommodation up to the required standards were reported to have been prohibitively expensive, resulting in older people having to leave their existing and desired 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).

4.2.3 | Staffing and skills mix

The ability to meet changing/escalating age-related needs, requires a concurrent ability to titrate the staffing resource against those needs. Three quarters ($n = 21$) of survey respondents reported that they had experiences of staffing levels being insufficient to meet need, and just over 70% ($n = 19$) reported that they had encountered examples of not having the appropriate staffing skill mix in place to meet a person's need. It was noted that, even where there was a will and the resources to obtain extra staff, there were frequently difficulties in recruiting suitably qualified people. Recruiting Registered Intellectual Disability Nurses (RNIDs) was highlighted, in this regard, as a specific, significant difficulty for services:

In the last three months, I don't know how many advertisements we've put out for...[intellectual disability]...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).

In response to this challenge, some services employed an RNID to coordinate the care across more than one site with daily care being delivered by social care staff and care assistants who were increasingly carrying out what was traditionally seen as nursing-related duties. The importance of supporting social care workers in their roles was 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).

Services also looked to staff scheduling 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 approach allowed the homes where people cared to live to maintain the current staff cohort, recognizing that changes in staff can be a significant source of stress for older people with intellectual disabilities. Forced dependency on agency staff was an issue of concern; not only did it lead to discontinuity for the older person, but it was noted that few agency nurses have training in, or experience of, working with people with intellectual disabilities:

...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 were no nurses you know interviewed that day. So yeah, it's going to be a huge challenge. (Betty, D, SS).

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).

4.2.4 | Supporting retirement

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. Quality of life for some people, as they age, may involve less, rather than more community engagement; although community engagement is a key HIQA metric, it was suggested that it may need to be conceptualized differently 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 (Irish singer) 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).

Traditionally, many services have been structured around adults with intellectual disabilities attending days services, 5 days per week. This necessitates a routine that requires rising early in the morning, essentially removing the possibility for a transition from 'work-life' to retirement:

...they are not able to be out and about 5 days a week, going swimming 1 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... (Hannah, D, GS).

The need or desire to retire from day services may, however, be constrained by staffing issues in community houses that typically close during the day. That said, it is useful to note that the enforced closure of day services during the Covid-19 restrictions provided the opportunity to innovate for greater individualization of the daytime routine:

...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

To the extent that their resources allowed, some services continue to try to implement more flexible options post Covid:

...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 also noted that maintaining such realities was an option that some services could not easily implement.

4.2.5 | End of life

Ageing, irrespective of longevity, inevitably leads to 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. They also engaged 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. Most participants expressed a desire for the older person to die at home, wherever possible. Positive experiences of fulfilling an older person's end of life wishes were discussed in the focus groups, however challenges were also identified 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).

4.2.6 | Funding

The key challenge identified by the respondents, and the one which underpinned the other challenges, was that of funding. The funding provided to services was perceived to be inadequate and is provided at a defined and static level which does not take account of changing

complexity, new compliance needs, or individuals' wishes. Often money is "congregated" to address the overall costs of providing a service for older people living in a particular environment, limiting the possibility of individualized 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).

...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 individualized funding, so you are part of a bigger group. (Geraldine, D, SS).

Respondents reported that complex health-related needs often progressed rapidly and unpredictably, requiring a speedy response. However, the process through which increased funding may be achieved to meet these needs was described as slow, rigid, and often unsuccessful:

... say of twenty business plans that go in, I think two might be accepted. (Eve, D, GS).

Respondents described efforts to overcome the challenges to the provision of quality, person-centred care, but it was clear that inadequate resources inevitably may result in services being unable to continue to provide the required care to older people with intellectual disabilities.

4.3 | Consequences

Despite a strong commitment to seeing the central concepts of quality service delivery enacted in their workplaces, respondents acknowledged 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 realize what their own decisions are and give them the choice and decisions on their day. (Anne, M, SS).

Notwithstanding the importance that respondents attributed to the service principles of person-centred services and ageing in place, the changes brought about by ageing can make individuals vulnerable to transitioning out of their home unless services are able to

reconfigure the necessary support. 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 due to funding limitations:

...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).

The increased needs of an individual may require an immediate response, however the process of applying for extra resources may not be timely enough to provide sufficient support to enable ageing in place:

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).

Changing needs and developing complexity in such needs was also reported to negatively impact other service users, challenging the potential to maintain 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).

Where resources were unavailable, older people often found themselves moved to settings that were not best suited to their needs or desires, perhaps to a nursing home, or to another service house simply because there was a vacancy. These decisions often result in a permanent move ensuing for the older person. Decisions regarding the use of generic nursing homes were reported as presenting a care dilemma given a view 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).

Ironically, it was also reported that although individuals may be transferred to generic nursing homes because of inadequate staffing, disability services and family members may continue to deploy significant resources to support their care. Two siblings were adamant that such supplementary support was essential to ensure that their family member received an adequate service. One reported:

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).

It was suggested that step-down facilities should be developed to support people with, for example, acute illnesses and injuries 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).

5 | DISCUSSION

The proportion of older people receiving intellectual disability services in Ireland is increasing. The older age cohort is already presenting as the dominant one in 28% of services surveyed or is expected to be so within the next 5 years. Furthermore, almost 40% of the respondents in this study 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. Similar to other European countries (Cooper et al., 2015; De Leeuw et al., 2022; García-Domínguez et al., 2020), older people with intellectual disabilities in Ireland are likely to experience complex and chronic health conditions. This has been confirmed by findings from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing, which show older people with intellectual disability in Ireland to have an increased prevalence of chronic health conditions

compared to the general population (Burke et al., 2017). Respondents in this study overwhelmingly reported (93.3%, $n = 28$) that complex age-related issues have implications for provision of care to older people with intellectual disabilities in their service. The reported lack of effective care pathways for many of the conditions that may challenge older people with intellectual disability as they age and the reported continued reticence on the part of some community healthcare providers to treat people with intellectual disability contravenes the right to equal access to general and specialized care asserted under Article 25 of the UNCRPD (United Nations, 2006) and compounds the health inequalities experienced by this section of the population. The concern is not unique to Ireland (McCallion & Jokinen, 2017) and Redley (2019) has highlighted the need for thoughtful planning to avoid these outcomes.

The development of services for people with intellectual disabilities in Ireland has been fragmented, with the state only becoming directly involved in service provision at a late stage. Services progressed along a generalist structure that had residential, day service and other activational components, with funding models reflecting their congregated nature and that most people with intellectual disabilities were not expected to live into older age. The move towards a social model of disability, moved away from the medical/health-oriented perspectives that had historically predominated service provision, to a flourishing of community-based accommodation provided largely by social care staff. As in other countries, such as the United States, the United Kingdom and Australia, there were assumptions that healthcare services in the community would be accessed similar to the general population (McCallion & Jokinen, 2017), but the consequences of an absence of comprehensive, quality community-based healthcare are now compounded by increased health complexity and growing numbers of older adults.

The prioritization of social inclusion and decongregation has in some cases inadvertently increased the transition of people with developing complex needs into other long-term care (Egan et al., 2022). Although services are responding to people living longer lives and are being 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 with potentially poorer outcomes experienced (Todd et al., 2020). Housing, staffing levels, staff mix and the timely provision of equipment were all reported to impact on the ability of services to respond. Key healthy ageing principles are proving largely unachievable in the absence of responsive funding, flexible staffing models, suitable accommodation and access to equipment and other resources. The current practice of per capita funding takes no account of growing age-related complexity and that this has not only created the conditions that we report on in this paper but also holds providers hostage to inexorable trends; the system as is, is fundamentally unsustainable. Furthermore, it has led to a reality whereby the inability to support ageing in place has fuelled a trend for older adults with intellectual disabilities to be moved to new congregated settings, something also noted in the United Kingdom (Taggart & Hanna-Trainor, 2017; Todd et al., 2020).

Support for people with intellectual disabilities should be person-centred, guided by the person's needs and wishes, framed within the rights conferred by the UNCRPD and responsive when needs change over time. 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 (Innes et al., 2012). This can be assisted by upskilling staff to create an agile workforce, ready to respond 'in place' as needs become more complex, something also iterated widely in the literature (Janicki et al., 2005; Johansson et al., 2017; Tuffrey-Wijne et al., 2007).

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 realization will not, however, be on an equal basis among older people with intellectual disabilities as called for in Article 25 of the Convention, in the absence of a national model of healthy ageing for this cohort, flexible funding and a foundation in person-centredness. In keeping with the HSE policy of decongregation that has seen many positive changes in the living situations of people with intellectual disabilities, such a new service model should ensure that mainstream services are accessible to older people with intellectual disabilities on an equal basis to others in society.

6 | LIMITATIONS AND FURTHER RESEARCH

The Covid-19 pandemic impacted this study in a number of ways. Sampling and recruitment of services and participants was deferred for 18 months and progressed very slowly thereafter, possibly because of the ongoing effects of the pandemic and may have affected the representativeness of the participating services. However there was consistency in the issues raised in both the quantitative and qualitative data sets including a widespread consensus that complex age-related issues have implications for provision of service to older people with intellectual disabilities in their service, a commitment by all stakeholders to the importance of person-centred support and a conviction that the current model of funding services is inappropriate and inadequate to meet the emerging challenges to the provision of care.

The pandemic also precluded face-to-face interviews and some depth of discussion may have been lost in the online medium. Due to ongoing Covid-related difficulties experienced by the sector, it proved impossible to recruit nursing homes respondents to the study and, therefore, their valuable perspective could not be included.

Neither geography nor transport were identified as barriers to accessing health services, which is noteworthy in light of other studies that identified disparities in access to healthcare across

regions in Ireland (Smith et al., 2019). Further research focussed on this issue is warranted.

Further research is required to explore and document the experiences of nursing homes in caring for people with intellectual disabilities and the experiences of nursing home care among older people with intellectual disabilities and their family members. Such research will inform the potential development of a model of collaboration between nursing homes, intellectual disability service providers and families to preserve the lives desired by people with intellectual disabilities as they age.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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