



An Roinn Sláinte  
Department of Health

# Disability Capacity Review to 2032

A Review of Disability Social  
Care Demand and Capacity  
Requirements up  
to 2032





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# Foreword from Stephen Donnelly TD., Minister for Health



This important Report has been prepared under the Sláintecare Action Plan. This *Review of Disability Social Care Demand and Capacity Requirements* up to 2032 has carefully drawn on best available evidence and information to estimate the scale of current outstanding need for HSE-funded disability services, and how the scale and shape of need is likely to evolve over the years to 2032. This work on the implications of the change in size and age-structure of the disability population complements the *Health Service Capacity Review* published by my Department in 2018.

The primary focus of this Review is on the requirements for social supports to enable people with disabilities live ordinary lives in ordinary places, in line with the Transforming Lives agenda for disability services. But this report, along with its disability population projections, also has implications for the wider health service. People with disabilities, like others, require mainstream primary care, hospital and rehabilitation services, and an ageing population of people with disabilities will mean greater demand in these areas. It will be important to ensure the capability of our health services at community and specialist levels to offer the right clinical support to service users with disabilities, and to deliver services that are accessible to people with disabilities in line with HSE guidance in that regard.

In ratifying the UN Convention on the Rights of Persons with Disabilities, Ireland has committed to the highest attainable standard of health for people with disabilities, and to provision of comprehensive habilitation and rehabilitation services, to enable people with disabilities attain or regain maximum independence. The Review, rightly, emphasises the importance of early intervention services, and of timely rehabilitation following onset of disability, a point also emphasised in my Department's National Neurorehabilitation Strategy. The *Disability Capacity Review* in particular has examined in detail what its projections of current and future needs mean for the development of the workforce in the different therapy disciplines, and my Department will factor this into our future workforce planning.



*Foreword from Stephen Donnelly TD., Minister for Children, Equality, Disability, Integration and Youth*

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Our Programme for Government commits to work towards implementing this *Disability Capacity Review*. I look forward to working with my Ministerial colleagues to make that happen, guided by the wealth of information, data and analysis in this Review.



**Stephen Donnelly T.D.**  
Minister for Health

# Foreword from Roderic O’Gorman TD., Minister for Children, Equality, Disability, Integration and Youth



A key focus of my new Department is promoting the full inclusion of people with disabilities in Irish society and ensuring the continued progressive implementation of the UN Convention on the Rights of Persons with Disabilities.

While these aims are being pursued for most people with disabilities with the support of mainstream public services, a group of our citizens need specialist disability support services to enable them to achieve maximum independence and a fulfilled life in the community. As our population has grown over recent decades, so too has the number of people requiring disability support services funded by the state, be these delivered through the HSE or through our many disability voluntary service providers who are delivery partners.

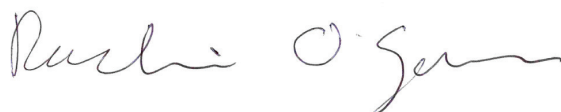
We need to plan ahead for the continued change in the size and age structure of the disability population, and to address gaps in availability of services that have emerged. As the Minister with responsibility for children, I know the particular importance to children with disabilities and their families of having early access to assessments and supports that can help them realise their potential. I understand too how important it is to support our young people, particularly at key transition points in their lives, and to ensure our school-leavers with disabilities are supported to make a successful transition to the adult world.

So I very much welcome the publication of this *Review of Disability Social Care Demand and Capacity Requirements up to 2032* which provides the data and the forecasts to underpin a planned, multi-annual approach to provision of the supports required by our citizens with disabilities. That planned approach is the best basis to ensure services people need will be there, as and when they need them, and reduce the uncertainty and worry that individuals and their families often have. Services which are planned ahead can also offer better value for money, than when they have to be procured in an emergency.

*Foreword from Roderic O’Gorman TD., Minister for Children, Equality, Disability, Integration and Youth*

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Many different Departments have a part to play, be that in education, employment, housing, or community services, to ensure people with disabilities can enjoy a full life as integral members of our communities. The new Department of Children, Disability, Equality and Integration will co-ordinate positive actions on disability across Government. It will also bring a new focus that will locate specialist supports to people with disabilities in the wider disability equality agenda. The data and analysis in this Review will inform that work, and I look forward to progressing it.



**Roderic O’Gorman TD.**

Minister for Children, Equality, Disability, Integration and Youth

## Foreword from Anne Rabbitte TD., Minister of State for Disability



The Programme for Government sets out an ambitious agenda for disability services. Our Ministerial team is committed to improving the lives of people with disabilities and their families through enhancing the quality of services and supports they receive. The *Review of Disability Social Care Demand and Capacity Requirements up to 2032* is an essential tool for that programme of work, documenting the scale of current and future need for services and supports.

The *Review* provides a wealth of data and analyses of the supports and services that are needed and where we need to focus our resources. This will be a key building block for the government's plans for the delivery of health services and supports into the future. It is, of course, one of the many cross-governmental plans needed to support people with a disability living their lives to the fullest and in the way they want to.

It's important we continue all the good work already underway to reframe our disability services around individuals' hopes and needs, delivering genuinely person-centred services and leaving old institutional models behind.

People with disabilities are thankfully living longer. But that means we need to plan ahead and put in place the required services that can assure ageing parents that their loved ones will have the supports they need when the family are no longer in a position to offer support. The next decade will also see a growth in school leavers with disabilities, and we need to plan ahead for their successful transition to the next stage of life.

The analysis in this *Review* has drawn heavily on the Health Research Board's Disability Databases. That Board's new National Ability Supports System which began data collection in 2019 will provide integrated data across intellectual, physical, neurological and sensory disability, and autism. Comprehensive and accurate data across the range of disabilities are critical to give a sound basis for forecasting and for planning future services. It is intended that the forecasts in this *Review* would be updated periodically in the light of new data becoming available, and of progress being made.

## *Foreword from Anne Rabbitte TD., Minister of State for Disability*

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The *Transforming Lives* reform programme encompasses changes in how we deliver children's therapy services, day services for adults, and community-based models of residential services. The pilot programme of Personalised Budgets is testing new models that give individuals with disabilities more choice and control around the supports to live their lives.

We want to be in a position to deliver the right supports in the right place at the right time for people with disabilities. I am pleased that we have the foundation in this Review to take that work forward.



**Anne Rabbitte TD.**

Minister of State for Disability

This Capacity Review was prepared by the Department of Health's Disability Advisor, Eithne Fitzgerald. It updates and extends a similar paper from Working Group 1 of the Transforming Lives disability reform programme, **Report on Future Needs for Disability Services (2018)**, published by the Department of Health.

The preparation of the Disability Capacity Review benefited greatly from the assistance and input from the Health Research Board disability database team, the National Disability Authority, the Economic and Social Research Institute, and the HSE Disability Operations, and Disability Strategy and Planning teams. It has been reviewed by Dr Sarah Craig, Health Research Board; Dr Gráinne Collins, Senior Research Officer, National Disability Authority; Dr Aoife Brick, Economic and Social Research Institute; and Dr Teresa Maguire, Department of Health. Useful feedback was also received from the HSE, and the Department of Public Expenditure and Reform.

Department of Health 2021

# Glossary

## Abbreviation Meaning

<b>ADLs</b>	Activities of daily living e.g. the ability to wash and dress oneself
<b>ASD</b>	Autism Spectrum Disorder
<b>AT</b>	Assistive technology
<b>CAMHS</b>	Child and Adolescent Mental Health Service
<b>CHO</b>	Community Healthcare Organisation – HSE geographical units for community services
<b>Congregated Settings</b>	Residential centres such as institutions, residential campuses or large group homes where ten or more people with disabilities live together
<b>CSO</b>	Central Statistics Office
<b>HIQA</b>	Health Information and Quality Authority
<b>HRB</b>	Health Research Board
<b>HSE</b>	Health Service Executive
<b>ID</b>	Intellectual disability
<b>M1F1</b>	CSO population forecast with high net inward migration, constant fertility
<b>M2F2</b>	CSO population forecast with moderate net inward migration, declining fertility
<b>M3F2</b>	CSO population forecast with low net inward migration, declining fertility
<b>n.a.</b>	Not available
<b>NASS</b>	National Ability Supports System
<b>NDIS</b>	National Disability Inclusion Strategy
<b>NIDD</b>	National Intellectual Disability Database
<b>NPSDD</b>	National Physical and Sensory Disability Database
<b>PA</b>	Personal Assistant
<b>P&amp;S</b>	Physical, sensory or neurological disability
<b>RT</b>	Rehabilitative training
<b>SNA</b>	Special Needs Assistant
<b>UNCRPD</b>	UN Convention on the Rights of Persons with Disabilities
<b>WG1</b>	Report on Future Needs for Disability Services (2018) prepared by Working Group 1, Transforming Lives





# Chapter 1

## Introduction to Disability Services

# Introduction to Disability Services

Ireland is committed to a whole-of-government approach to improving the reach and quality of services for people with a disability. In recognition of the cross-departmental nature of the supports required by people with disabilities, the Department of Justice and Equality published the National Disability Inclusion Strategy 2017-2021 in 2017. The Strategy contains eight themes - equality and choice, joined-up policies and public services, education, employment, health and wellbeing, person-centred disability services, living in the community and transport and access to places. In 2018, Ireland ratified the UN Convention on the Rights of Persons with Disabilities.

About one in seven people in Ireland, or around 643,000, has a disability or long-term condition. Over 90% of those with a disability are supported through general community health and social services. This is in line with the 'mainstream first' approach, underpinned through the Disability Act 2005, which places a legal requirement for public bodies like the HSE to include people with disabilities in their mainstream services.

General health services are complemented by specialist community-based disability services, delivered to about 9% of those with a disability (circa 56,000 people), through a suite of interventions including early intervention, multi-disciplinary therapies, habilitation, rehabilitation and behaviour support, staffed supported housing, specialist end of life care, respite/short breaks to support carers, day services and support for community engagement, personal assistance, home help and assistive technology. Access to disability support services is based on need, not on a specific diagnosis.

This report presents estimates of current and future requirements for these community-based disability services and supports, based on projections of the future size and age-structure of the future disability population out to 2032, and on estimates of the scale of unmet needs.

## 1.1 Disability Policy – Health and Social Care Services

*The Transforming Lives* programme (2014), is a national collaborative effort to build

## *Introduction to Disability Services (continued)*

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better services for people with disabilities. A key priority is to continue to deliver on the strategic aims and recommendations of the significant work and research of the *Value for Money and Policy Review of Disability Services (2012)*. The priority objective is to address the need for a better service model for people with a disability where greater flexibility, choice and control from the service user perspective is central. Under *Transforming Lives*, the focus is on developing individualised person-centred supports to enable people with disabilities participate to their full potential in economic and social life in the community and be enabled to live ordinary lives in ordinary places.

It involves fundamentally changing how we deliver services; delivering on this level of change is a challenge and significant progress is already underway to achieve integration rather than segregation in line with the following policies.

- Residential Care (64% of budget): About 8,300 people with disabilities, 90% being people with an intellectual disability (ID), live in residential care. The most common form this takes is a group home, an ordinary house in the community shared ideally by no more than four people, along with support staff. Demographic change is adding a requirement for about 90 additional residential places a year – in the absence to date of addressing this factor, a considerable volume of unmet need has also emerged. A planned response is required to anticipate need and meet it in a cost-effective manner, rather than high-cost placements in an emergency. In addition, about 2,100 people live in ‘congregated settings’, which are institutions, residential campuses or other living arrangements where ten or more people with a disability live together. *Time to Move on from Congregated Settings (2011)* sets out the current policy to move people from large institutional settings to ordinary houses in the community. This is rooted in evidence around better quality of life, and in Article 19 of the UN Convention on the Rights of Persons with Disabilities.
- The provision of Day Services (21% of budget): *New Directions – Report of the National Working Group for the Review of Health Service Funded Adult Day Services (2012)* aims to improve day services by focusing on empowering people to make their own decisions about how they spend their day and to access activities in their own community. Day services offer support during the weekday, with about three quarters of service users having an intellectual disability.

## Introduction to Disability Services (continued)

- **Respite (3% of budget):** About 6,300 people with disabilities get respite or short breaks. Respite care has a dual focus on helping family carers, and on supporting the individual with a disability. It offers family carers a break, giving them some time for themselves and maintaining resilience. It provides people with disabilities new experiences they can enjoy, and that support achievement of greater independence.
- **Progressing Disability Services for Children and Young People (2009):** Is focused on improving therapy services for children by reorganising children’s services into multi-disciplinary Children’s Disability Network Teams providing for all children with disabilities based on need, regardless of diagnosis, where they live or where they go to school.

The wider suite of actions by Government Departments under the National Disability Inclusion Strategy, for example on employment, housing, and transport, have a critical role to play in supporting effective delivery of disability support services and of the reforms underway in how services are delivered.

### 1.2 Disability Service Providers

With a budget close to €2 billion for 2019, over 27% of specialist disability services are provided directly by the HSE, almost 70% of services are provided by voluntary organisations funded under Section 38 or Section 39 of the Health Act 2004 and the remaining 4% provided by private sector bodies. Disability service providers vary significantly in terms of size, geographical coverage and the range of services provided.

Disability service providers are expected to provide HSE-funded services in line with policy direction, focused on a social model of care complying with both governance and regulatory requirements. The social model of care involves the provision of a range of services and programmes throughout the lifecycle which promote the physical and social wellbeing of people with a disability and includes preventative services, early intervention and community and intensive home supports to moderate the risk factors that result in high-cost care.

Residential services must be registered with HIQA and HIQA standards stipulate that service providers carry out their functions in line with relevant legislation,

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## Introduction to Disability Services (continued)

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regulations, national policies and standards. Organisations are required to show that they are providing a service in accordance with their stated purpose and function and are deploying resources effectively and efficiently in the interests of providing high-quality, person-centred care. It was notable in 2018 that for the first time all disability residential services were registered by HIQA as designated centres meaning that each of these centres has met the required regulatory standards or have time-bound improvement plans in place to achieve full compliance.

### 1.3 Identifying Future Need for Disability Services

Sláintecare Action 1.3 for 2019 committed to identifying the level of future need for disability services. This *Disability Capacity Review* examines service and expenditure requirements for:

- residential care
- adult day services
- personal assistance and home support
- multidisciplinary therapies
- respite, and
- other community services and supports.

While residential services and adult day services together constitute 85% of overall spending, other supports like respite, therapies, personal assistance and community supports can be critical in maximising people's capacity, independence and quality of life.

All indicators throughout this report are that demand is greater than service capacity and this demand is projected to continue to grow in light of both demographic growth and of current unmet need, as evidenced through the demand for emergency places and waiting lists for other services.

Meeting anticipated needs with the current service mix has significant cost implications. Residential care services currently account for around two thirds of the specialist disability budget, serving around 8,300 people at an annual unit cost of around €144,000.<sup>1</sup>

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<sup>1</sup> This is based on dividing net expenditure on disability residential services by the overall number of residents.

## *Introduction to Disability Services (continued)*

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Earlier intervention and improved access to supports for children born with a disability or for those experiencing onset of a disability can help maximise achievement of and retention of capacity. Effective therapy and mental health supports may help moderate challenging behaviours that may otherwise require long-term intensive support levels.

Structured assessment and guidance, particularly for school leavers, along with supports to engage in mainstream education and employment, can enable more young people with disabilities pursue these options rather than lifetime participation in day services.

Better supports to families, including respite, can enhance resilience and capacity to care, and facilitate delayed entry into long-term residential care. Better access to home support and personal assistance services could maximise people's independence and their ability to live at home for longer.

### **1.4 Planning for Future Services**

Sláintecare envisages a model where the majority of healthcare is provided in the community through integrated primary and social care. Where appropriate, care should be provided at home. Where people require residential care, supported housing or supported community living, as far as possible this should be in the community and close to home. This shift to more care provision in the community aligns with international trends for healthcare provision and the World Health Organisation health and well-being goals.

In line with Sláintecare it is essential, that over the next number of years, the State moves to a population-based planning approach, based on demographic and geographic considerations, that reflects both the health and social care needs of those within our population, including those who require specialist disability services. This approach provides an opportunity to prioritise and design the health and social care services that need to be developed for each region, so the population can get the right care, in the right place, at the right time in line with HIQA standards and available resources.

Early progress on a standardised single assessment tool to build a picture of population needs for those with a disability is integral to population-based health and

## *Introduction to Disability Services (continued)*

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social care planning. Work has already been progressed to modernise the allocation of disability funding, which will involve a transition towards personalised resource allocation, including the option of a personal budget.

An important development is the Health Research Board's integrated information system, the National Ability Supports System (NASS), which replaces the HRB's two separate national disability databases. 2019 saw the first round of data collection under the new system, albeit it was incomplete. The NASS is intended to provide a comprehensive system of data collection encompassing people with intellectual, physical, sensory or neurological disabilities, or autism, who are receiving or awaiting specialist disability services and supports. It is to encompass services provided by the HSE, s38 and s39 voluntary bodies, and private sector providers. When complete coverage is achieved, it will provide service providers, HSE management and government with full oversight of disability service provision, and will be an indispensable planning tool in assessing requirements for services and supports.

The *Health Service Capacity Review* published in January 2018 outlined in very clear terms the unsustainability of the Irish health service as currently organised and the imperative for a change from the reliance on hospital services to integrated community services. The *Health Service Capacity Review* deemed as unsustainable the continuation of the status quo. However, it did not encompass the need for specialist disability support services. Under the 2019 Sláintecare Action Plan commitments, this *Disability Capacity Review* provides important evidence and projections for planning future disability services.

The *Disability Capacity Review* builds on and updates the *Report on Future Needs for Disability Services (2018)* prepared by Working Group 1 of the Transforming Lives disability reform programme, which had made estimates of future service needs out to 2025/6 based on anticipated population change and an assessment of current gaps in services.

The *Disability Capacity Review* sets out a range of revenue costings for delivery of services to 2022, 2027 and 2032 based on:

## Introduction to Disability Services (continued)

- (i) demographic change only
- (ii) unmet need (minimum, intermediate and pre-recession), in addition to demographic change.

In addition, this Review sets out a range of costings for capital spend to 2022, 2027 and 2032 based on:

- (i) demographic change only
- (ii) unmet need (minimum, intermediate and pre-recession), in addition to demographic change.
- (iii) completion of closure of congregated settings.

The costings and service levels set out in the Review were prepared on a pre-Covid 19 basis. The increases in spending required are calculated from a baseline of 2018 expenditure (Table A6.1).

### 1.5 Key Emergent Issues for Future Service Planning

This *Disability Capacity Review* has identified significant levels of unmet need for disability services, and that changes in the size and age profile of the disability service population will add to unmet need over the coming decade. Addressing demographic change alone would not be sufficient, as the current level of unmet need is not sustainable. While the costs of addressing both are projected to be significant, if no measures are taken, unmet need and demographic change will continue to grow and become more acute as the disability population ages. In addition, there will be a significant human cost for the individuals concerned and their families. Different strategic scenarios and their likely consequences are set out. Actions to moderate the rise in demand for high-cost services will be required in any scenario.

#### Key findings – Demographics (section 3)

- The size and age structure of the population requiring specialist disability services are expected to change.
- The number of adults requiring these services is expected to be around 5% higher in 2022, 10% higher in 2027, and 17% higher in 2032 compared to their 2018 level. Similar rates of growth are predicted for those with intellectual and those with physical or sensory disabilities.



## Introduction to Disability Services (continued)

- The central projection shows adults with intellectual disabilities needing specialist services will grow by a sixth between 2018 and 2032.
- Fastest growth will be for young adults (up a third by 2032) and over 55s (up a quarter by 2032).
- If current disability prevalence remains constant, the overall number of children with disabilities is expected to fall to 2032, with the fastest drop among pre-schoolers
  - Pre-schoolers will fall by 15% to 2032.
  - The number of school-age children will rise to the mid-2020s, then by 2032 will drop to around 9% below their 2018 level.
- The pace of demographic change for young adults and over 55s will have implications especially for numbers entering day services, and for numbers needing full-time residential support as their parents get older.

### Key findings – Residential care (section 4)

- A significant increase in the number of people in disability residential care/ supported housing would be required to deal with the impact of demographic change, and to address a substantial backlog of need.
- About 90% of those in disability residential care have an intellectual disability. Most people with intellectual disabilities will require supported housing/ residential care when their parents can no longer care for them at home.
- An average of about 90 new residential places will be needed every year from 2020 to 2032 to cater for changes in the size and age structure of the disability population.
- Access to residential care has fallen since the 2008 recession. Supply did not keep up with population growth, but actually fell, as some places did not meet regulatory standards.
- The resulting shortfall is estimated to range from a minimum of 800 places, up to 2,300 places.
- The minimum is based on HSE's Emergency/Urgent waiting list, which is incomplete. The top estimate is based on restoring the 2007 level of provision, alongside better access for over-60s.

## Introduction to Disability Services (continued)

- To deal with both the backlog and with demographic change, overall an extra 1,900 residential places would be needed by 2032 under the Minimum scenario, and an extra 3,900 under the Pre-recession scenario.
- The extra annual cost of meeting demographic need only would be around €60m a year by 2022, €120m a year by 2027, and €160m a year by 2032.
- The annual extra cost of addressing both demographic change and unmet need would range from an extra €320m a year by 2032 under the Minimum scenario, and an extra €550m a year under the Pre-recession scenario, at current unit costs.
- Pay changes, additional staffing for regulatory compliance, and increasing prevalence of intensive support needs could all drive unit costs up further.
- Capital cost for the additional places could range from €250m to €520m over the period to 2032, depending on the scenario.
- In addition, the replacement cost of the 2,100 places currently in congregated settings which are scheduled to close would add another €280m. That would bring the total capital needed to between €500m - €800m.

### Key findings – Day services (Section 5)

- There is a range of adult day programmes which support people with disabilities during the ordinary weekday. These include adult day services (the largest programme); training programmes, principally Rehabilitative Training; and work programmes like sheltered work (being phased out).
- In general, people enter adult day services on leaving school, or after an initial period in Rehabilitative Training. Some also do after acquiring a disability.
- Following the baby boom of the 2000s, a growing number of school-leavers are expected to apply for day services up to the end of the 2020s.
- Participation in day services is virtually lifelong, while participation in training programmes is time-limited. Many participants with intellectual disabilities transfer to day services on completing Rehabilitative Training.
- The limited data on outflows suggests that inflow of school-leavers into day services are likely to outweigh anticipated outflows over the period to 2032.

## Introduction to Disability Services (continued)

- That will mean a step-wise increase will be required every year in number of day service places to meet demographic demand. From 2015 to 2019, about 1,000 additional places a year were provided to meet the excess of school-leaver inflows over exits from day services.
- The HSE estimates there may be 600 people with no day service who need one. There is also unmet need for those getting partial day services, which is estimated would be equivalent to an extra 600 full-time day places.
- To meet unmet need of those who get partial or no day services would cost €30m a year, at a unit cost for a new place of €25,000 a year.
- To meet continuing demographic need is likely to require an annual stepwise increase in spending. Under the 'high exit' scenario, the annual step in expenditure needed to provide additional day places would be about €5m. By 2032, additional demographic need under this scenario could have reached €60m above the 2020 level. On a 'low exit' scenario, the annual incremental step in spending could average around €20m a year. By 2032, the extra cost of meeting this demographic demand would be around €250m above the 2020 level. On an intermediate exit scenario, the annual step would be around €12m, and the additional cost in 2032 over the 2020 level would be around €140m.
- Because demographic demand is very sensitive to the annual exit rate from day programmes, it is difficult to provide a narrow band of estimates of potential overall cost of meeting both demographic and unmet need. On different assumptions about the exit rate, the combined additional costs of demographic demand and unmet need could fall within a range of an extra €90m to €280m a year required by 2032.

### Key findings – Multidisciplinary therapy services (Section 6)

- Multidisciplinary therapies play a vital role in maximising the potential of those born with a disability and in rebuilding capacity of those who have acquired a disability.
- There are significant shortfalls in access to specialist disability therapy services for both adults and children, and their access to mainstream therapies via primary care is sporadic.

## Introduction to Disability Services (continued)

- The National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland has identified a major shortfall in access to timely neuro-rehabilitation.
- Current use of different therapies varies by age and type of impairment, with speech and language therapy for example most commonly availed of by children.
- Demographic demand for children's therapy services, at current use rates, will be broadly stable up to 2027, as fewer young children will be largely counterbalanced by larger numbers of teenagers. By 2032, however, the total number of children will fall, lowering demand for children's therapy services by about 10%.
- The number of adults with a disability will rise steadily. Taking adults and children together, total numbers of people with disabilities will rise.
- Overall, demographic change will lead to an increase in demand which by 2032 is expected to be about 7-8% higher than in 2018.
- The combined impact of addressing unmet need and of demographic change will raise overall demand for therapy services by about two thirds by 2032.
- For people with an intellectual disability, provision of dietician services would need to more than double, provision of psychology and occupational therapy would need to double, while provision of speech and language therapy, physiotherapy, and social work would need to grow by around three quarters.
- Spending on specialist disability therapies would need to increase by around €54m a year, most of it to tackle unmet need. That cost could rise to around €80m if the demonstration phase for specialist community-based clinical rehabilitation networks were to establish these would not overlap with the requirement for additional disability therapy provision identified in this *Disability Capacity Review*.

### Key findings – Home support, home care and Personal Assistant services (Section 7)

- Data on unmet need has not been systematically recorded, given the fixed number of service hours available to deploy, but there are signs it is substantial.
- The additional costs of demographic change are estimated at €4m a year by 2022, €10m a year by 2027, and €15m a year by 2032.

## *Introduction to Disability Services (continued)*

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- In addition, an indicative package to provide greater access to those with no service, and additional levels of support for those who currently have minimal hours of support, has been costed at €30m a year.

### **Key findings – Respite/short breaks (Section 8)**

- Respite has a key role in supporting family carers and the person with a disability.
- How future requirements for respite will alter given demographic change will depend on the scale of residential care provided, and how that impacts on the number of people with disabilities living with family carers.
- Data for 2017 shows only one in four family carers of over 5s with ID had received any respite, and only one in three family carers of adults.
- Latent unmet need could be considerably higher than what is recorded.
- If no progress were made on the backlog of unmet need for residential services, the numbers living with family would be 20% higher in 2032 than in 2017, at an annual extra cost of €10m.
- The cost of meeting the level of unmet need for respite recorded in 2017 could be €16m to €20m a year. Additional latent need could bring that higher.
- Key findings – Other community services and supports (Section 9).

### **Key findings – Other community services and supports (Section 9)**

- There is a wide range of community support and advice services, including those offering peer support to people with a specific condition
- To maintain current levels of provision in the face of demographic change could cost an extra €3m a year in 2022, €6m in 2027, and €9m in 2032.

### **Key findings – Overall financial implications (Section 10)**

- This Capacity Review has examined and quantified the implications of demographic change and of currently-unmet need for the funding needed for disability services.
- Changes in the size and age-structure of the disability population will increase demand particularly for residential care and adult day services.

## Introduction to Disability Services (continued)

- Relative to a baseline of 2018, spending in 2032 would need to be between €250m-€450m higher to meet demographic need.
- There is also considerable unmet need, particularly for residential places, therapy services, personal assistance, and respite.
- To address unmet need, alongside demographic change, would require current disability spending in 2032 to rise by €550m to €1,000m, above its 2018 level.
- In broad terms, current spending on disability services would need to rise by between a quarter and a half to deliver the capacity required.
- Additional capital spending for housing to meet residential care needs and complete the closure of residential institutions could cost in the region of €500m to €800m over the period to 2032.
- These figures have not provided for any increase in unit costs that may occur due to pay developments, regulatory compliance, or increased complexity and support-intensity of service need.

### Tables summarising overall financial implications

The modelling for the current paper has been underpinned by annual forecasts of population, however for ease of presentation the results are generally presented at five-year intervals from the 2017 baseline, and show expected expenditure requirements in 2022, 2027 and 2032. These show the general direction of travel, not precise timings. Detailed tables in this Review illustrate the calculation process underpinning the projections, however the figures are not to be read as precise estimates, but as a guide to the likely order of magnitude.

Tables 1a and 1b and Table 2 provide an overview of the broad general scale of additional annual funding required to meet demographic and unmet need, and additional housing capital required for disability services to 2032. Table 1a sets out the lower end of the range of estimates, and Table 1b the higher range. In broad terms, at the lower end, current spending would need to rise by roughly a quarter, and at the higher end, by roughly a half, to address the combination of providing for demographic change, and tackling current levels of unmet need. The difference between the two sets of estimates depends on

## Introduction to Disability Services (continued)

what proportion of residential care needs would be met (section 4); the scale of drop-out/vacancy rates in day services (not currently available) which affects the net change in places required (section 5); and different estimates of unmet need for therapy services.

**Table 1a: Estimate, additional annual funding required to meet demographic and unmet need – low**

Type of disability service	Demography only			Demography + unmet need		
	2022	2027	2032	2022	2027	2032
	€m	€m	€m	€m	€m	€m
Residential – Minimum scenario	60	120	160	220	280	320
Day services	8	30	60	40	60	90
PA & home help	4	10	15	34	40	45
Therapies	3	5	6	48	48	54
Respite	2	3	4	18	21	25
Community services	3	6	9	3	6	9
<b>Total (rounded)</b>	<b>80</b>	<b>170</b>	<b>250</b>	<b>350</b>	<b>450</b>	<b>550</b>

Estimates are indicative only. Totals may not add up due to rounding

**Table 1b: Estimate, additional annual funding required to meet demographic and unmet need – high**

Type of disability service	Demography only			Demography + unmet need		
	2022	2027	2032	2022	2027	2032
	€m	€m	€m	€m	€m	€m
Residential – Pre-recession scenario	60	120	160	400	500	550
Day services	40	140	250	70	170	280
PA & home help	4	10	15	34	40	45
Therapies	3	5	6	74	74	80
Respite	2	3	4	18	21	25
Community services	3	6	9	3	6	9
<b>Total (rounded)</b>	<b>110</b>	<b>280</b>	<b>450</b>	<b>600</b>	<b>800</b>	<b>1,000</b>

Estimates are indicative only. Totals may not add up due to rounding

*Introduction to Disability Services (continued)*

**Table 2: Additional housing capital required for disability services to 2032**

	Demography only	Demography + unmet need			Congregated settings
Year	Demography		Intermediate	Pre-recession	
	€m	€m	€m	€m	€m
Now	0	100	200	310	280
2022	60	160	270	380	
2027	110	210	330	450	
2032	150	250	380	520	



# Chapter 2

# Methodology

# Methodology

## 2.1 Specialist disability services – updated projections of future needs

This paper sets out estimates of future disability service needs based both on the changing size and age structure of the population requiring specialist disability services, and on the level of currently-unmet need. This paper has been produced under Action 1.3 of the Sláintecare Action Plan for 2019, and aligns with the other work on budgeting for Sláintecare.

Specialist disability services cater for people with significant physical, sensory or neurological disabilities who are aged under 65, or who acquired a long-term disability before then, and for people with intellectual disabilities of all ages. Older people with the former disabilities are provided for under the Services for Older People programme.

This paper examines service and expenditure requirements under the following headings, with their share of total disability service spend in 2018:

**Table 3: Distribution of net current provision for disability services 2020, and service user numbers**

Type of service	Net expenditure	% of total	Estimated no. of service users	Average per head
Residential care – supported housing	€1,245m	61%	8,400	€149,000
Adult day programmes	€484m	23%	19,000*	€25,500
Multidisciplinary therapies	€99m	5%	Children - 42,000 Adults - n.a.	n.a.
Personal assistance and home support	€96m	5%	9,800	€9,750
Respite	€62m	3%	6,100	€10,100
Other community services and supports	€67m	3%	n.a.	n.a.
<b>All specialist disability services</b>	<b>€2,056m</b>	<b>100%</b>	<b>ID- 29,000 P&amp;S – n.a.</b>	<b>n.a.</b>

Pre-Covid Estimates provision. ID = intellectual disability. P&S = physical or sensory disability. n.a. = not available

\*Formal day programmes; in addition some people in residential care receive on-site day support. Unit cost calculated by dividing total by those in formal programmes

## *Methodology (continued)*

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While residential services and adult day services together constitute 84% of overall spending, other supports like respite, therapies, personal assistance and community supports can be critical in maximising people's capacity, independence and quality of life.

### **Building on and updating earlier forecasts**

The *Report on Future Needs for Disability Services (2018)*, prepared by Working Group 1 of the Transforming Lives disability reform programme, made estimates of future service needs out to 2025/6 based on anticipated population change and an assessment of current gaps in services. For convenience, that 2018 report is referred to as WG1. The WG1 report had documented a considerable level of unmet need across disability services. The scale of unmet need had reflected pauses or reductions in levels of service provision following onset of the recession in 2008, and during that time the population of people with a disability continued to grow.

This *Disability Capacity Review* builds on and updates the WG1 Report in the light of later data, and extends the projections out to 2032. Like the earlier report, it examines the implications of anticipated changes in the size and structure of the disability population, and estimates the scale of unmet need to be addressed. It also considers the combined impact of a change in the baseline level of service to tackle unmet need, and likely demographic change. The estimates presented here have drawn on the latest available data from the disability databases, which is for 2017, and on special tabulations of that data provided by the Health Research Board. The WG1 residential service projections had been based on 2015 data, the latest available at that time of its preparation.

Notable developments affecting the cost of future service delivery since completion of work on the earlier WG1 report, have been an increase in number of people on the highest level of support-intensity in residential care, and the effect of pay developments including pay restoration on the cost of these labour-intensive services. Housing costs have also risen against the background of a general shortage of housing relative to demand. The Housing Strategy for People with Disabilities is also scheduled for review.

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## *Methodology (continued)*

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### **2.2 Guide to order of magnitude, not precise estimates**

As in any forecasting exercise, it is not possible to predict the future with certainty. The estimates produced are a guide as to the likely scale and trajectory of change needed, and are not to be taken as precisely exact in terms of quantity or timing.

The projections reflect particular assumptions which are plausible, but which may or may not hold for the future. For example, forecasts of the size and age-distribution of the future intellectual disability population are based on assumptions about certain ratios which prevailed over an average of years in the recent past remaining constant for the future. The proportion of this population who will require residential services in future has been based on past age-specific ratios. For these reasons, the estimates represent a best attempt to ascertain the likely scale of future need and of currently-unmet need, not precise forecasts. The modelling for the current paper has been underpinned by annual forecasts of population, however for ease of presentation the results are generally presented at five-year intervals from the 2017 baseline, and show expected expenditure requirements in 2022, 2027 and 2032. These show the general direction of travel, not precise timings. Detailed tables included in this paper are there to illustrate the calculation process underpinning the projections, however the figures are not to be read as precise estimates, but as a guide to the likely order of magnitude.

### **Data caveats**

There are also caveats about the data on which the forecasts are based. The National Intellectual Disability Database, on which much of the estimates are based, is not fully comprehensive in its coverage, as it omits some of the HSE-funded for-profit services, which form about 4% of the overall total. The National Physical and Sensory Disability database has never achieved comprehensive coverage of its target population. It offers a guide as to patterns of service use, but the overall scale of services and of unmet needs in this area is unknown (see 2.3 below).

As a result, this paper has in many cases had to extrapolate from more solidly-based estimates in respect of people with intellectual disabilities to calculate the scale of provision required across people with disabilities as a whole. So, for example, future requirements for residential care for people with physical or sensory disabilities in this paper were based on adding a standard percentage to detailed forecasts carried out for the intellectual disability population.

## *Methodology (continued)*

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A major gap in information is the exit rate from adult day services, a combination of deaths and drop-outs. The estimates of demand for day services are highly sensitive to the drop-out rate – a range of possible exit rates drawn from the National Intellectual Disability Database and another inflow-outflow simulation exercise produced widely varying estimates of future needs (Section 5).

A further uncertainty is how unit costs will evolve, due to regulatory compliance, increasing complexity of need, and changes in pay rates.

The commencement of the Assisted Decision-Making (Capacity) Act will have implications for practice in supporting service users, and will require, at a minimum, investment in training of disability service staff in relation to operating in the changed legal environment. This *Disability Capacity Review* has not factored in any additional costs that might arise in that regard.

### **2.3 National disability databases and other data sources**

The paper draws significantly on the data in the Health Research Board's disability databases, along with the Census and the CSO's population forecasts, and administrative data from the HSE.<sup>2</sup>

The National Intellectual Disability Database (NIDD) provides largely comprehensive coverage of the population with intellectual disabilities who are receiving or who require specialist disability services, up to 2017. However, it does not cover the small number of people using for-profit services funded by the HSE.<sup>3</sup> Around 90% of those living in residential services, which form around two thirds of the disability services budget, have an intellectual disability.

The coverage of the National Physical and Sensory Disability Database (NPSDD) has been much less comprehensive than that of the NIDD. Those eligible to be

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<sup>2</sup> Special thanks are due to the Disability Databases team in the Health Research Board, who prepared a number of special data runs for this project, to HSE Disability Operations team for information on service demand, usage and expenditure, to Gráinne Collins in the National Disability Authority for her input and advice, particularly her work on adult day services; and to Aoife Brick in the ESRI for her very helpful advice and data-checking.

<sup>3</sup> A data matching exercise by the ESRI found agreement of over 98% between the NIDD numbers in residential services in 2017, and the corresponding HSE data.

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## *Methodology (continued)*

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included on the NPSDD were individuals aged under 65 receiving a specialist disability service. Participation was voluntary. In addition, neither the HSE nor the relevant disability service providers had adequate systems or staffing in place to ensure comprehensive levels of coverage of those opting to register. As staffing embargos were implemented during the recession, and other work including statutory Assessment of Need took priority, data collection for the NPSDD was affected. So the number of registrations achieved in any particular year largely reflects the resources given to the task at that time, and cannot be used to predict trends in numbers needing services. It is also difficult to get a reliable grossing-up factor to apply to any estimates based on incomplete NPSDD figures. The best estimates are that in the region of 30,000 to 42,000 people could have been included if the databases were complete.<sup>4</sup>

The NPSDD data are useful for examining patterns of use in high-volume areas, but are not a very reliable guide to overall scale of use or provision, nor in respect of low-volume services.

Since 2019, the National Ability Supports System (NASS), which supersedes both the NIDD and the NPSDD, has more comprehensive coverage of people with physical or sensory disability, people with autism, and those in state-funded for-profit disability services.<sup>5</sup> For the future, this will provide a stronger basis for modelling service needs.

### **2.4 Summary**

Residential care and adult day services constitute over 85% of public spending on disability services, but other services and supports play a critical role in maximising people's capacity and independence. This paper presents a set of estimates to 2032 of the levels of service required and the additional cost involved, arising from anticipated demographic change and from current levels of unmet need. These estimates are based on a set of assumptions that are considered reasonable, and

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<sup>4</sup> While the expectation when the NPSDD was introduced was that up to 42,000 people would be eligible to register, only 20,000 were registered in 2013, down from the 2007 peak of 27,000. Many of these files had not been reviewed in years. Data are available for about 9,000 files reviewed in the period 2013-17, and for around 6,000 files reviewed in 2017, but it is not known how representative that is of the overall group requiring specialist P&S disability services.

<sup>5</sup> Data collection started in mid-2019, and the first output is due in 2020.

## *Methodology (continued)*

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on the best available, but imperfect data. The results presented are a guide to the general scale of what is involved and to the likely pathway over time, but do not constitute precise estimates as to amounts or timing.

## *Methodology (continued)*

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# Chapter 3

## Forecasting the future disability services population

# Forecasting the future disability services population

The future size of the adult population requiring specialist disability services to 2032 is likely to be more predictable, as they are already born. The population of younger children requiring services will depend on the course of future births, which is intrinsically less certain.

## Key findings

- The size and age structure of the population requiring specialist disability services are expected to change.
- The number of adults is expected to be around 5% higher in 2022, 10% higher in 2027, and 17% higher in 2032 compared to their 2018 level. Similar rates of growth are predicted for those with intellectual and those with physical or sensory disabilities.
- The central projection shows adults with intellectual disabilities needing specialist services will grow by a sixth between 2018 and 2032.
- Fastest growth will be for young adults (up a third by 2032) and over 55s (up a quarter by 2032).
- If current disability prevalence remains constant, the overall number of children with disabilities is expected to fall to 2032, with the fastest drop among pre-schoolers
  - Pre-schoolers will fall by 15% to 2032.
  - The number of school-age children will rise to the mid-2020s, then by 2032 will drop to around 9% below their 2018 level.
- The pace of demographic change for young adults and over 55s will have implications especially for numbers entering day services, and for numbers needing full-time residential support as their parents get older.

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## Forecasting the future disability services population (continued)

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### 3.1 Adults with intellectual disability

The age profile and life expectancy of people with disabilities are different than for the population at large. Life expectancy on average is nineteen years lower.<sup>6</sup> For that reason, a special forecast was made of the future adult population with an intellectual disability, based on the National Intellectual Disability Database (NIDD), in a procedure described in Appendix 1. Two separate forecasts were made. The central forecast was based on continuing stability of the average age patterns of remaining in specialist disability services that had pertained over the period 2008-2017. An alternative 'youth inflow' projection assumed a rise in the proportion of people in their early twenties who would use specialist disability services, gradually working its way up the age bands. This projection reflects a potential increased rate of entry of school-leavers into adult day services, which would reflect the rising prevalence of childhood disability reported in the 2016 Census.

### Results

The central projection shows a steady increase is forecast in the numbers of adults with ID requiring specialist disability services, rising by about 3,000 or about 17% from 2017 to 2032 (Table 4). If a fast increase materialises in young adults in disability services, the scale and rate of increase could be roughly twice that shown in the central forecast.

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<sup>6</sup> Research by Prof Mary McCarron and colleagues found that life expectancy for people with intellectual disabilities on the NIDD was on average 19 years lower than the population at large. See McCarron et al (2015) *Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012*. Journal of Applied Research into Intellectual Disabilities, 28(5). September 2015. A 2019 research paper by the CSO found that life expectancy for males fulfilling the broader Census definition of disability was 16 years lower at birth than non-disabled males, and almost 14 years lower at age 35, and broadly equivalent gaps for females. <https://www.cso.ie/en/releasesandpublications/in/mdi/mortalitydifferentialsinireland2016-2017/>.

*Forecasting the future disability services population (continued)***Table 4: Projections of adults with ID needing specialist disability services, 2018-32**

Year	Central projection (rounded)	Cumulative increase from 2017	'Youth inflow' projection (rounded)	Cumulative increase from 2017
2018	18,400	0%	18,400	0%
2019	18,600	1%	18,700	2%
2020	18,700	2%	18,900	3%
2021	19,000	3%	19,300	5%
2022	19,200	5%	19,600	7%
2023	19,200	5%	19,800	8%
2024	19,500	6%	20,200	10%
2025	19,600	7%	20,500	12%
2026	19,900	8%	20,800	14%
2027	20,200	10%	21,200	16%
2028	20,300	11%	21,500	17%
2029	20,600	12%	22,000	20%
2030	20,900	14%	22,400	22%
2031	21,200	15%	22,700	24%
2032	21,400	17%	23,000	25%

Note: Figures should be taken as indicating the likely scale, not as precise estimates as to numbers or timing

**How population change will impact different age groups**

Table 5, based on the central projection, shows how the forecast rate of increase is much larger for younger adults (affecting inflows to adult day services) and for older adults (affecting the scale of requirements for residential placements and other supported housing, and for end-of-life care). The 'youth inflow' projection also predicts that the greatest rates of increase will be for younger and older adults.

### Forecasting the future disability services population (continued)

**Table 5: Central projection of adults with ID needing specialist disability services 2022, 2027 and 2032**

	Actual 2017	2022	2027	2032	Change 2017-2032
20-24 years	2,600	2,800	3,200	3,600	37%
25-29 years	2,000	2,300	2,500	2,800	37%
30-34 years	1,800	1,900	2,200	2,400	29%
35-39 years	1,900	1,800	1,900	2,100	8%
40-44 years	1,900	1,900	1,700	1,800	-6%
45-49 years	1,900	1,800	1,800	1,600	-16%
50-54 years	1,900	1,800	1,700	1,700	-12%
55-59 years	1,500	1,700	1,600	1,500	1%
60-64 years	1,100	1,300	1,400	1,300	22%
65-69 years	800	900	1,000	1,100	46%
70 +	900	1,100	1,300	1,500	74%
<b>Total adults 20+</b>	<b>18,400</b>	<b>19,200</b>	<b>20,200</b>	<b>21,400</b>	<b>17%</b>
<b>Change from 2017</b>		<b>+800</b>	<b>+1,800</b>	<b>+3,000</b>	
<b>% increase from 2017</b>		<b>4.5%</b>	<b>10%</b>	<b>16.5%</b>	

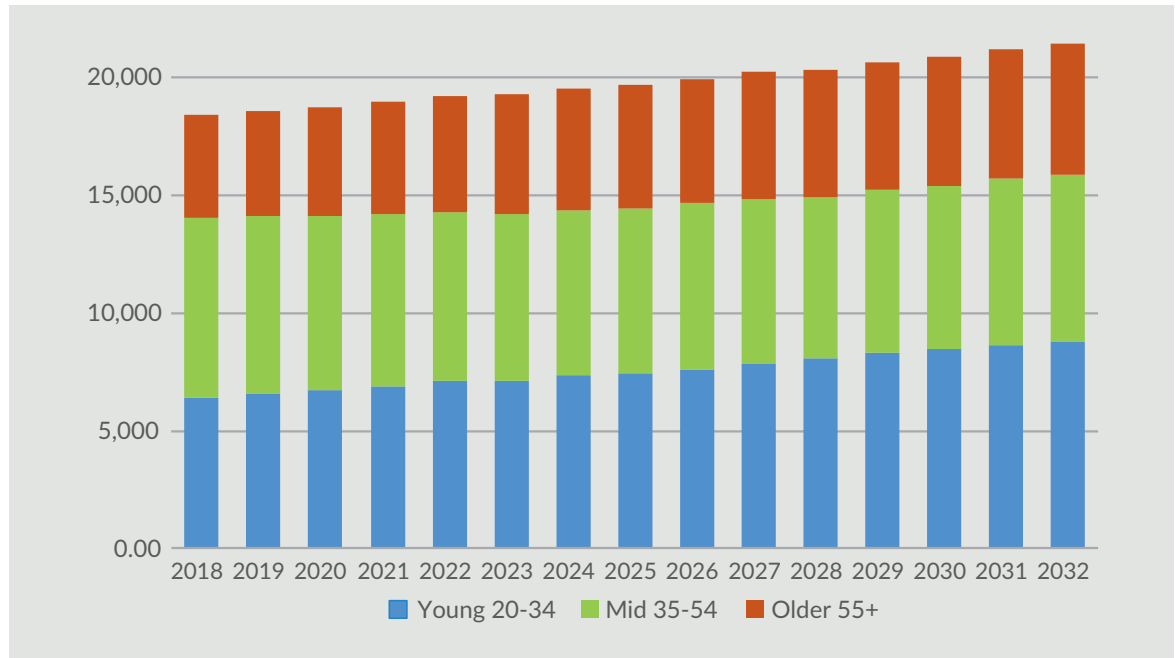
Note: Figures should be taken as indicating the likely scale, not as precise estimates. Totals may not add due to rounding

Chart 1 displays the same information in visual format, where three age groups are shown – younger (aged 20-34), mid (35-54) and older (55+). The numbers in younger age groups are predicted to rise by about a third, those in the mid-group to fall marginally, and those in the older age group, to rise by about a quarter.

*Forecasting the future disability services population (continued)*

**Chart 1: Projected adults needing ID services 2018-2032**

By broad age group



**Lifetime participation**

Table 6 presents the ‘survival rates’ that underpin the central forecast of the population needing specialist ID services. These show a strong level of continuity in disability services throughout adulthood. A small proportion of those in their early twenties exit specialist disability services (they may be completing specific education or training programmes and do not progress afterwards into other day programmes). Otherwise, exit rates from the database are very low until people reach their mid-fifties, when the effect of early mortality is seen. For most, participation in specialist adult intellectual disability services is lifelong.

*Forecasting the future disability services population (continued)***Table 6: Survival rates on the NIDD database by age group**

(Proportion of those in preceding 5-year age group on the database five years later)

	Average ratios used in central forecast
	(Average of annual ratios from 2008-13 to 2012-17)
25-29 years	89%
30-34 years	95%
35-39 years	96%
40-44 years	95%
45-49 years	96%
50-54 years	94%
55-59 years	89%
60-64 years	85%
65-69 years	80%
70-74 years	73%
75-79 years	69%
80+	86%

**3.2 Adults with physical/sensory/neurological disability**

Because of poor year to year coverage of the National Physical and Sensory Disability Database (NPSDD), it was not possible to do a similar exercise based on 'survival rates' on the database to forecast the population with physical, sensory or neurological disability requiring specialist disability services.<sup>7</sup>

The proportion of the adult population on the National Physical and Sensory Disability Database rises with age, suggesting that many of these impairments emerge or are acquired over the course of adult life. Over half of those registered have neurological disabilities, which includes acquired conditions like acquired brain injury or multiple sclerosis. The size of the general adult population, which is significantly affected by migration flows, can have an impact on the numbers who acquire a disability in adult life. Age-specific prevalence rates were applied to a

<sup>7</sup> There are some data from hospitals and the trauma audit on new occurrences of major trauma and stroke. With more people surviving major trauma and stroke, the numbers are set to increase. In 2017, around 1,100 people experienced a severe head injury, and around 650, a serious spinal injury. Around 7,600 people had a stroke in 2017, of whom about 10-15% (800-1,100) are expected to have lasting disability.

### Forecasting the future disability services population (continued)

central CSO population forecast (M2F2).<sup>8</sup> Two sources of relevant prevalence data were tested, with similar results in terms of trends over time. One was based on the age pattern of those registered on the NPSDD, the other on those reported in the Census to have difficulties with basic activities of daily living like washing and dressing themselves. The two ways of measuring prevalence produced very similar results in predicting future change in the population requiring P&S disability services.

As Table 7 shows, similar rates of growth are predicted for adults with intellectual disabilities or with physical/ sensory/neurological disabilities.

**Table 7: Predicted increase relative to 2018 in no of adults for specialist disability services**

Year	2022	2027	2032
Service users aged 20+ with a physical, sensory or neurological disability	+5%	+11%	+17%
Service users aged 20+ with an intellectual disability (central projection)	+5%	+10%	+17%

### 3.3 Forecasts of under-20s with disabilities

As the future course of births is unknown, predictions of the size of the child population with a disability 15 years ahead, is an inherently uncertain exercise. Added to uncertainties about the size of the underlying population, information from the Census suggests some increase in the prevalence of disability, although to what extent that reflects increased disclosure or labelling of disability is not clear. Improvements in health care may at the same time reduce the incidence of some disabling conditions, and also lead to increased lifespans for those born with complex medical conditions. Even small changes in numbers with such conditions may have considerable resource implications for those children requiring around the clock care.

<sup>8</sup> M2F2 is a CSO population projection based on assumptions of reducing fertility and moderate net inward migration. Because Brexit and the after-effects of the Covid-19 shut-down may dampen future economic growth and affect migration, this was chosen as the basis for estimation in preference to its forecasts which assumed higher inward migration. The impact using higher or lower CSO population forecasts was also explored.



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### *Forecasting the future disability services population (continued)*

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It was not considered appropriate to base projections of children with disabilities on the 'survival rate' on the disability databases of numbers in their age cohort. Very large gross movements onto and off the disability databases in the course of childhood, (inflows at younger ages when children register for disability services, and a big outflow at school-leaving age), mean that minor changes in timing or in gross flows could have a significant impact on the figures.

Projections of children were based on the CSO's lower fertility, moderate net inward migration, population projection labelled M2F2. The most frequently-used specialist disability services by children are multi-disciplinary therapies. To predict future change in demand for individual therapies, the age-pattern of children's use of each therapy type was applied to the projection of the future child population in different age groups (See Section 6).<sup>9</sup>

#### **Overall decline in under 20s by 2032**

**Early Intervention age-group (0-5s).** The CSO's M2F2 projection implies a steady decline to 2032 in the number of under-6s, and projects a 15% drop by 2032, relative to the numbers in 2018. This is the age-group served by Early Intervention multidisciplinary therapy teams.

**School-age services group (ages 6-17).** The CSO projects a small rise of around 3% over the 2018 population to the mid-2020s, declining to around 91% of the 2018 level by 2032. In this age group, the main disability service availed of is multi-disciplinary therapy from school-age teams. A small proportion receive some respite/short breaks.

**School-leaver age-group (ages 18-19).** The CSO projects that numbers will rise steadily to about 20% above their 2018 level by the end of the 2020s, and then begin to decline to around 15% above the 2018 figure by 2032. This reflects the continuing impact of the baby boom which occurred during the first decade of the millennium. The number of school leavers is a key element in forecasting the

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<sup>9</sup> Around 90% of children registered on the NIDD use multi-disciplinary therapies, and these are also the most frequent services used by children registered on the NPSDD. Around 15% of children on the NIDD get occasional respite, around 9% get home help, fewer than 1% are in residential care. Only 75 out of almost 9,000 children registered on the NIDD in 2017 were in a residential care place. In addition, there were 179 children with intellectual disabilities in foster care or boarding out arrangements, which for this age group are generally funded by TÚSLA.

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## *Forecasting the future disability services population (continued)*

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demand for entry into adult day programmes. Given that the school leavers up to 2032 are already born, this is the most predictable element of the under-20s forecasts.

Taking these three groups together, the total number of under-20s is expected to rise slightly to the middle of the 2020s, falling back by 2032 to possibly 6% below its 2018 level.

### **Increased prevalence of childhood disability?**

The Census in 2016 recorded a measurable increase in the prevalence of certain forms of childhood disability, compared to five years earlier, in particular for intellectual disability and for emotional/ psychological disability, along with a minor change for physical disability (Table 8). It is not clear to what extent there may be a real underlying change in prevalence of disability, or whether this reflects an increased likelihood that a disability label was recorded.<sup>10</sup>

Data from the National Council for Special Education records an increase in prevalence of emotional/behavioural difficulties, and of autism in children, although it may be a factor that a diagnosis of autism has given better access to education supports than other diagnoses or none.<sup>11</sup> More generally, there is debate internationally as to whether there is a real increase in autism prevalence, or increased public and professional awareness, and changes in diagnostic practices.<sup>12</sup>

Some children with very complex physical disabilities and medical conditions, which were considered life-limiting, are now living into adulthood. While the

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<sup>10</sup> Under the Progressing Disability Services for Children & Young Adults programme and associated National Access Policy, young people will access services based on the complexity of their need rather than a specific Diagnosis.

<sup>11</sup> See for example the Focused Policy Assessment on data on Special Needs Assistants (Department of Education, 2016). Access to educational resources such as an SNA, to a pupil teacher ratio of 6:1 in a special class, and up to 2017/18, to resource teaching, has been more generous for those with a diagnosis of autism than for those with other conditions.

<sup>12</sup> See Department of Health (2018) Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population: A review of data sources and epidemiological studies. A meta-analysis by Rødgaard and colleagues (2019) concluded that increased prevalence may reflect changes in the definition of autism from a narrowly defined population, to a wider and more inclusive spectrum. See Rødgaard et al (2019) Temporal changes in effect sizes of studies comparing individuals with and without autism – a meta-analysis. JAMA Psychiatry doi:10.1001/jamapsychiatry.2019.1956.

### Forecasting the future disability services population (continued)

numbers are small, and it is difficult to predict the numbers into the future, the very intensive support they require is extremely expensive, and even small increases in absolute numbers can give rise to significant additional expenditure.

While no clear picture can be seen at this stage on whether overall prevalence of disability among children is changing, there is some evidence of a higher share of children and young people presenting with more complex needs, which is driving up average unit costs of disability services. The HSE is seeing this factor in the school-leavers entering day programmes, and also in a small but growing number of children and young people with highly complex medical or behavioural needs presenting for residential services.<sup>13</sup>

**Table 8: Age-specific prevalence of certain disabilities in children, Census 2011 and 2016**

	Emotional/ Psychological disability		Intellectual disability		Physical difficulties	
	2011	2016	2011	2016	2011	2016
0- 4 years	0.3%	0.5%	0.7%	0.8%	0.6%	0.7%
5 - 9 years	0.9%	1.5%	1.6%	2.0%	0.8%	1.0%
10 - 14 years	1.0%	1.7%	1.9%	2.4%	0.8%	0.9%
15 - 19 years	1.2%	2.5%	1.9%	2.4%	0.8%	1.0%

### 3.4 Summary

Overall, the disability population is expected to grow up to 2032, with a change in the overall age structure which will affect demand for disability services. For adults, similar rates of increase are forecast for those with an intellectual or other form of disability. The central projection forecasts that the number of adults with a disability would grow by around 17% over the period 2018-2032. If the pace of entry of young adults to intellectual disability services were to rise ('youth inflow' projection), the increase in the adult disability population would be above that.

Critically, the number of older adults is set to rise, driving up demand for full-time residential services when parents are no longer in a position to continue to care

<sup>13</sup> Information on severity of impairment was to be collected in the 2021 Census. This has been delayed due to COVID-19.

### *Forecasting the future disability services population (continued)*

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at home. The baby boom of the 2000s will lead to a continuing rise in the number of school leavers presenting for adult day services to the end of the 2020s. The number of young children is scheduled to fall, counterbalanced to some extent by changes in the number of teenagers. Demographic pressure on early intervention therapy services will fall, although as Section 6 of this paper documents, this is an area where there remains considerable unmet needs. The 2011-2016 Census period documented an increase in the prevalence of childhood disability. It is unclear to what extent that reflects changes in underlying prevalence, or changes in having a label of disability, nor to what extent there would be a continuing increase in recorded prevalence.

# Chapter 4

## Forecasting future need for residential services/supported housing

# Forecasting future need for residential services/supported housing

## Key findings

- A significant increase in the number of people in disability residential care/supported housing would be required to deal with the impact of demographic change, and to address a substantial backlog of need.
- About 90% of those in disability residential care have an intellectual disability. Most people with intellectual disabilities will require supported housing/residential care when their parents can no longer care for them at home.
- An average of about 90 new residential places will be needed every year from 2020 to 2032 to cater for changes in the size and age structure of the disability population.
- Access to residential care has fallen since the 2008 recession. Supply did not keep up with population growth, but actually fell, as some places did not meet regulatory standards.
- The resulting shortfall is estimated to range from a minimum of 800 places, up to 2,300 places.
- The minimum is based on HSE's Emergency/Urgent waiting list, which is incomplete. The top estimate is based on restoring the 2007 level of provision, alongside better access for over-60s.
- To deal with both the backlog and with demographic change, overall an extra 1,900 residential places would be needed by 2032 under the Minimum scenario, and an extra 3,900 under the Pre-recession scenario.
- The extra annual cost of meeting demographic need only would be around €60m a year by 2022, €120m a year by 2027, and €160m a year by 2032.
- The annual extra cost of addressing both demographic change and unmet need would range from an extra €320m a year by 2032 under the Minimum scenario, and an extra €550m a year under the Pre-recession scenario, at current unit costs.

## Forecasting future need for residential service/supported housing (continued)

### Key findings (continued)

- Pay changes, additional staffing for regulatory compliance, and increasing prevalence of intensive support needs could all drive unit costs up further.
- Capital cost for the additional places could range from €250m to €520m over the period to 2032, depending on the scenario.
- In addition, the replacement cost of the 2,100 places currently in congregated settings which are scheduled to close would add another €480m. That would bring the total capital needed to between €700m - €1bn.

Residential care services constitute about two thirds of the disability budget. Most commonly these take the form of supported housing in the community shared by a group of four to six people with disabilities, known as group homes, but there are other forms of residential support.<sup>14</sup> Other residential support arrangements include semi-independent living. All but a small percentage receiving this service are adults. The projections made in 4.1 to 4.7 below generally relate to adults (over-20s), while 4.8 deals with children.<sup>15</sup>

About 90% of those in disability residential care have an intellectual disability. As there was good-quality data for this group, it was possible to estimate how changes in the size and structure of the population with an ID would affect their need for residential places, using current usage rates for each age group.

People with a physical or neurological disability, reflecting that for many there is later onset, are more likely to have their own home and live with a partner and family.<sup>16</sup> Around 800 people with a physical, sensory or neurological disability live in supported disability accommodation. There are however in addition about 1,300

<sup>14</sup> Residential centres and individual group homes are 'designated centres' which must be registered with HIQA. Other arrangements can include support to live independently (semi-independent living), home sharing and host family models.

<sup>15</sup> The age group of over-20s rather than the more usual over-18s was used for the estimation exercise for adults, because it made population projections and supported housing projections more straightforward, by using five-year age bands. As fewer than 100 18- or 19-year olds with ID are in a residential service, this procedure is unlikely to have made any material difference to the scale of overall predicted future requirements. Under-20s on the HSE's 'active waiting' list group were included in the Minimum scenario on unmet need (s 4.4).

<sup>16</sup> See for example Wittenberg et al (2018) Projections of demand and expenditure on adult social care 2015-2040 PSSRU Discussion Paper 2944 which incorporates projections of marital status into its forecasts of care needs for England.

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## *Forecasting future need for residential service/supported housing (continued)*

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adults aged under 65 living in nursing homes.<sup>17</sup> This is likely to include a significant proportion of people with physical or neurological disabilities for whom this would not be the most appropriate long-term care setting. There may also be people with intellectual disabilities who are inappropriately placed.

In the absence of good data to underpin a separate forecasting exercise for people with physical or sensory disability who need residential care, an additional 10% was added to the estimates of ID residential care, reflecting their share of total residential disability services.

### **4.1 Projecting demand for residential care/supported housing for people with ID**

The projections of the number of adults with intellectual disability in different age groups were used to estimate how many people would require intellectual disability residential services at future points in time, based on age-specific usage patterns.

The data from the NIDD that underpinned the projections did not capture all of those receiving state-funded private residential services, a small but growing part of the total. HSE data on overall residential service numbers offered a guide as to the scale of this omission.<sup>18</sup>

### **4.2 Residential care rates**

#### **What is counted as supported residential care for the purpose of estimation**

The NIDD details different forms of residential care, including residential centres, group homes, nursing homes, and psychiatric hospitals. The proportion of people with ID who were living in any of these settings (as well as, on the advice of the HSE, those living semi-independently) was used to calculate the likelihood of adults in any given age group requiring a residential place.<sup>19</sup> This exercise has not

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<sup>17</sup> Long Stay Activity Statistics 2017, Table 3b, Department of Health.

<sup>18</sup> There are some other differences between the data on number of residential places cited in the HSE's Service Plans, and the National Intellectual Disability Database. See Appendix 3.

<sup>19</sup> Some of these residential places (e.g. some of the places in nursing homes or psychiatric hospitals) may not be funded under the HSE's disability programme, but may be funded under Fair Deal or Mental Health. (Historically, some intellectual disability services were delivered in psychiatric hospitals — de-designated units, and progressively this practice is being ended.) However, it was felt that aggregating all residential settings would give a better read on the likelihood someone of a given age would be in residential care. See Appendix 3 for a breakdown comparing the numbers included in this paper's definition of residential care use, and those in the HSE disability performance indicators. Note that those in independent living who had been included in the WG1 calculations of residential usage rates, are not so included in the current exercise.



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## Forecasting future need for residential service/supported housing (continued)

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covered people who are in shared care arrangements (such as week-on, week-off, or 2-3 days residential care per week); about 120 adults with ID in 2017 received this form of regular support. Nor has it covered those in foster-care arrangements. About 350 people with intellectual disability, half of them children, were in such arrangements in 2017.<sup>20</sup>

### Fall in quantum of residential care, and proportion of by age

Following the economic crash in 2008, the programme of multi-annual investment in additional residential capacity undertaken under the National Disability Strategy came to an end. The number of existing disability residential places also reduced over time, a process linked to the introduction of regulation, and to the adoption of the policy to allow no new admissions to congregated residential centres.<sup>21</sup> In the light of a growing population of people with disabilities, the result was a reduction across different age groups in the proportion of people with an intellectual disability in a residential service. Since 2016, there have been some additional places provided under the label of funding for emergencies, however with a continuing loss of some of the existing stock of places, by end 2018 the net addition to overall capacity has been marginal.<sup>22</sup>

## 4.3 The impact of demographic change on future need

### Based on 2017 usage rates

To calculate the pure impact of demographic change, this paper has used the latest available rates of residential care usage by age group for people on the NIDD, which are for 2017. These are lower than the corresponding 2015 rates used to

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<sup>20</sup> Foster care arrangements for under-18s would normally be funded by Túsla, not by the disability programme.

<sup>21</sup> HIQA as regulator has demanded that overcrowding be addressed, shared bedrooms eliminated, and unsuitable premises be phased out. In congregated settings, while replacement accommodation is provided for those transitioning to the community, in general (except for a small number of admissions/readmissions), vacancies created when a resident dies are not filled. Based on the *Time to Move on Progress Reports*, this last factor would have resulted in a net overall reduction of 370 residential places over the period 2012-2017, and of 61 places in 2018.

<sup>22</sup> Outturn data from HSE Service Plans suggest that there was a net increase of about 90 places from 2016 to the end of 2018, with a net fall during 2017 offset by the scale of additional places provided in 2018. Details from the HSE on residential care places by agency and centre suggest that much of the fall in places occurred in congregated settings, reflecting policy not to fill vacancies there, as they are due to close.

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### *Forecasting future need for residential service/supported housing (continued)*

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calculate estimates of future demographic need in the WG1 Report.<sup>23</sup> Between 2015 and 2017 (the last year of NIDD data), both the number and proportion of adults with intellectual disabilities in supported housing fell, with a drop from 45% of adults to 43%. Compared to the WG1 report, that means a lower share of projected need is attributed here to demographics, and a higher share to unmet need. The overall total level of need projected is not affected by this procedure.

#### **Around 90 new places a year needed 2020-2032 for population change**

On these projections, the number of ID residential places required in 2032 to deal with changes in the size and age-structure of the population would be of the order of around 1,000 higher than were provided in 2017 (Table 9). Adding in demographic demand for P&S residential places would raise that total to around 1,100. As demographic growth has not been factored in over the interim period, averaging the additional supply required over the period 2020-2032 would translate into around 90 new places required each year just to keep pace with demographic change.<sup>24</sup>

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<sup>23</sup> A further difference between the two sets of estimates is that the current exercise, on the advice of the HSE, covers those in semi-independent living, whereas the WG1 Report had also included those living independently in its supported housing calculations. Usage rates in the current paper are lower by around 10% due to that factor. However, with those with most minimal housing support excluded, unit costs should be correspondingly higher.

<sup>24</sup> This is lower than the demographic forecast of around 100 places a year set out in Table 5 of the WG1 Report. This difference is due to the use of the lower residential care usage rates for 2017 as against 2015. If the 2015 rates had been used in the demographic element of the forecast of future needs, a similar figure of about 100 places a year would have resulted.

*Forecasting future need for residential service/supported housing (continued)***Table 9: Projected need for ID residential places, demographic demand, 2018-32**

Central projection and constant 2017 age-specific residential care ratios

Year	Projected	Cumulative increase from 2017
2017 actual	(7,822)	
2018	7,898	76
2019	7,975	153
2020	8,046	224
2021	8,145	323
2022	8,228	406
2023	8,246	424
2024	8,325	503
2025	8,388	566
2026	8,480	658
2027	8,554	732
2028	8,561	739
2029	8,641	819
2030	8,693	871
2031	8,774	952
2032	8,842	1,000
<b>Increase by 10% for P&amp;S</b>		<b>1,100</b>
<b>Average annual increase 2017-32</b>		<b>Around 75 a year</b>
<b>Averaged over 2020-32</b>		<b>Around 90 a year</b>

Note: Output from calculations – this indicates the broad scale expected, not precise estimates of numbers or timing

In addition, demographic change is also likely to affect the number of residential places required for people with physical, sensory or neurological disabilities, which currently form roughly a tenth of all residential disability places. Given that the number of adults under 65 with physical or sensory disabilities is predicted to rise at a roughly similar rate to those with intellectual disabilities (see Table 7), around 10% could be added to that total. In round terms, that would bring total demographic demand to an extra 1,100 places by 2032, or an extra 80 or so places a year.

**Youth influx**

The 'youth influx' scenario would initially have little impact on demand for residential places, as the vast majority of adults with ID in their twenties live with

## Forecasting future need for residential service/supported housing (continued)

their families. However, as that influx gets older, it would have a more perceptible impact on demand for residential places. Simulations, using different assumptions, show that a youth influx to disability services could possibly by the early 2030s raise the demand for residential places by 200-400 places, relative to the central projection. The associated revenue cost would be an extra €30m-€50m a year, above the central projection.

### Sensitivity analysis

Different tests were conducted of the sensitivity of the projections for residential places to the methodology used in forecasting the ID population. Lower- and upper-bound estimates of the ID population were used to create lower and upper bounds for the likely requirements for residential places (Table 10). The procedure and results are described in Appendix 1.<sup>25</sup> This exercise showed that even on a minimalist projection of likely population growth for people with intellectual disabilities, there is going to be an additional requirement for residential care/supported disability housing due to population change.

**Table 10: Increase over 2017 in ID residential places to address demographic change – sensitivity testing**

	2022	2027	2032
Central forecast	410	730	1,020
Lower bound	240	380	430
Upper bound	710	1,370	2,030

Figures are indicative of general order of magnitude only

### 4.4 Unmet demand for residential care

Demand for residential care significantly exceeds supply. Since the onset of the recession, the provision of residential places for people with disabilities has

<sup>25</sup> These population projections were created by using the minimum (lower bound) or the maximum (upper bound) 'survival rates' observed for each age group over an eight year range to 2017, along with different ratios of 20-24 year olds in disability services relative to their birth cohort. In practice it is unlikely that all survival rate values would be uniformly low, or uniformly high, and in any five-year interval there would more probably be a mix of higher and lower values observed across different age groups. So a smaller margin around the central forecast would be more realistic. Inner upper and lower bounds were also tested using maximum and minimum survival rate values over the five years prior to 2017. These gave a narrower margin around the central forecast.

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### *Forecasting future need for residential service/supported housing (continued)*

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not kept pace with the growth in the population. Not only that, the supply of residential places has actually fallen. First, while the introduction of Regulations, standards and HIQA inspections of residential disability services from 2013, has demonstrably improved quality, it has reduced the supply of beds which did not meet regulatory requirements. For example, sharing a bedroom is no longer acceptable. Second, there are no new admissions to institutions or residential campuses, for example on the death of a current resident, as part of the policy to close such congregated settings.

The outcome has been the emergence of significant waiting lists for residential care. These include people living with very elderly parents, and younger people with complex medical needs or behavioural issues which require intensive supports. The proportion of people with ID in residential care has fallen significantly from its pre-recession rate. In the absence of a planned programme to meet identified needs, there is only a limited pool of extra places provided for those classified as emergency. With such limited places, it is only those in the most extreme situations who are getting a residential place.<sup>26</sup> In addition, in the absence of planned transitions to supported housing as people with disabilities get older, unplanned emergency transitions can occur when a parent dies or another family emergency arises.

#### **Different unmet need scenarios**

This paper has looked at different scenarios to measure existing levels of unmet need

- **Minimum** – based on HSE list, limited to ‘active applications’ since 2018
- **Pre-recession** – based on 2007 usage rates, plus raised provision for over-60s
- **Intermediate** – midway between current and pre-recession rates

Estimates of additional places needed have been measured for the baseline year, and out to 2032, to capture the impact of population change on any increased

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<sup>26</sup> 132 emergency residential places were provided in 2018 and 61 in 2019, a majority in the for-profit sector, however these would have been offset by continuing reduction in capacity in congregated settings in the public and voluntary sectors. An overall reduction of 74 residential places occurred between 2017 and 2019.

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### *Forecasting future need for residential service/supported housing (continued)*

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rates of provision. These scenarios are then compared with the estimates from the NIDD of current and future need for the period 2017-22.

While there are some differences between the measure of residential places used in this paper, and that used in HSE Service Plans, it is expected that changes in the number of disability places required on the two measures will be very similar.

#### **(a) Minimum scenario – based on HSE profiling of ‘active applications’ since 2018**

This provides a minimum estimate at mid-2019 of about 800 people with unmet needs for a supported residential place.

The HSE began in 2018 to profile<sup>27</sup> individuals who had applied for or who they were actively aware of who needed a disability service, be that a residential service, enhanced support in an existing residential place, or other non-residential services such as respite or home support. The HSE recognises this list does not fully capture the level of unmet need in the system, both because there may be people meeting the criteria (including for emergencies) who so far have not actively presented for the required disability services, or because legacy applicants, those prior to 2018, might not be included.

Those on the system are listed as emergency, contingency or future need. Those listed as ‘emergency’ are very high-risk situations such as vulnerable individuals at high risk of abuse, those at high risk of abusing others, or where due to sudden death or serious illness of the primary carer, home care is no longer possible. The ‘contingency’ group consists of people who face similar high-risk situations, but where the family is just about managing to cope. However, breakdown of the family support system may be imminent. The remainder of those profiles are listed under the label ‘future need’. In other words, there is an acknowledged current need, but the situation is not yet as risky as in the other two categories, and there is a lower urgency status.

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<sup>27</sup> The profiling tool developed by the HSE, the Disability Supports Management Application tool or DSMAT, records factors like age, type of disability, type/level of challenging behaviour and behaviour support need, and complex medical/daily care needs (such as tracheostomy, PEG feeding, colostomy), to derive a composite care need score.

### Forecasting future need for residential service/supported housing (continued)

Data in mid-2019 from this profiling exercise showed a total of 776 (Table 11) on this 'active' waiting list who required residential care, with the great majority being people with an intellectual disability, autism, or both, with just 6% with a primary physical or sensory disability. What is really striking is that almost 40% of those listed, almost 300 people, were aged under 30. Such young people constituted almost half of those in the highest need category of 'emergency'. Typically, these are mostly male, have a combined diagnosis of intellectual disability, and autism and/or mental health difficulties, and a very high score on behaviour support needs. This is against a background of a halving of the rate of residential provision for young adults since the recession (from 17% of those aged 20-24 on the NIDD in 2007 to 7% in 2017). This has left behind a significant number of young people with very high support needs, whose current living arrangements with their families are no longer sustainable.<sup>28</sup>

**Table 11: Age profile of people on HSE 'active' list for disability residential care, mid-2019**

Age	0-17	18-29	30-39	40-49	50-59	60-69	70-79	80+	Total
Emergency	24	92	37	54	29	11	1	0	248
Contingency	4	72	47	43	17	11	2	0	196
Future Needs	23	79	82	58	46	17	14	6	325
<b>Total</b>	<b>51</b>	<b>243</b>	<b>166</b>	<b>155</b>	<b>92</b>	<b>39</b>	<b>17</b>	<b>6</b>	<b>769</b>

Source: HSE. No age data was available for 7 people – total on list is 776

Relatively few of those who might be usually considered to constitute a backlog of unmet need – people with disabilities in middle age or older, whose access to a residential care service has not been met in an era of falling supply and rising demand – are on this active waiting list. This is consistent with the fact that legacy demand in the system was not covered by this exercise. So the figure of a little under 800 people listed for residential care in mid-2019 is very much a minimum estimate of unmet need.

<sup>28</sup> A rough estimate of the scale of demand for residential services from young adults relative to levels of current provision can be got by calculating the proportion those aged 18-29 in Table 8 represent of those aged 20-29 on the NIDD who are already in residential care. Providing a residential place to those in the emergency and contingency categories would increase numbers in their age group in supported housing by around a third. If those in all three categories on the HSE list got a place, it would raise the numbers in their age group in residential care by around a half.

*Forecasting future need for residential service/supported housing (continued)*

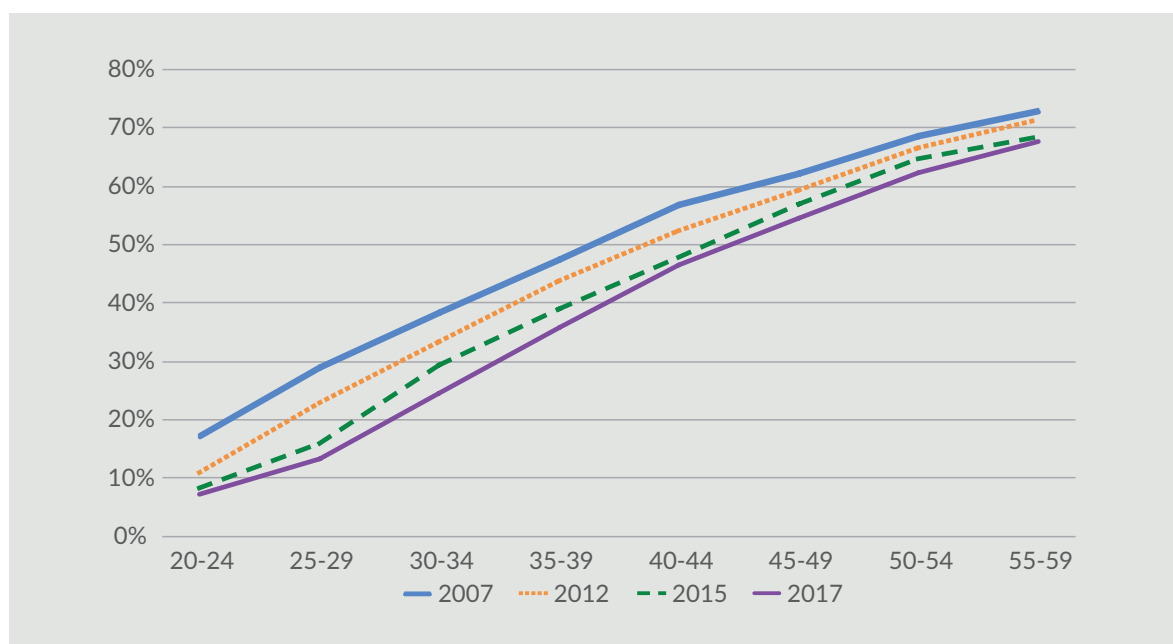
**(b) Pre-recession rates, along with higher provision for over-60s with ID**

The 2018 WG1 Report on Future Need for Disability Services took two proxies for current unmet need – restoring the rate of disability residential care under-60s to its pre-recession level, and raising the proportion of over-60s getting residential care support to a more sustainable 95%. The current paper has similarly considered the combined effect of restoring 2007 rates of use by age, and providing residential care to 95% of over-60s with ID. The overall level of unmet need as of 2017 measured by this scenario is around 2,300 residential places.

**Pre-recession rates**

In 2004, the National Disability Strategy provided for a programme of multiannual investment in additional residential places for people with disabilities. That came to a halt with the onset of the recession in 2008. Since then the combination of a rising ID population, and a reduction in supply particularly following the introduction of regulation, has led to a fall in the proportion of people with ID in a residential place. While the decline has been sharpest among younger age groups – the share of under 25s in residential care has halved since 2007 – the fall has been there for all age groups. This is shown by the gap between the top line in Chart 2, showing the proportion in 2007 in a disability residential place, and the lowest line, which shows those data for 2017.

**Chart 2: ID Residential use by age 2007-2017**





*Forecasting future need for residential service/supported housing (continued)***Raise provision for over-60s to a more sustainable level**

The proportion of people with intellectual disabilities aged over 60 living at home with family members (23% in 2017) seems unsustainably high. As people with intellectual disabilities get older, their ageing parents or other family members have much less capacity to care for them at home, both because of increasing support needs of a person ageing with a disability, and because the primary carer may also be experiencing significant health issues. A majority of over-60s who are at home are living either with ageing siblings, or with a parent likely to be aged in their eighties or older (Table 12).<sup>29</sup> There is a high risk that these caring arrangements will break down when a parent is hospitalised or passes away, or an ageing sibling can no longer manage. Societal change is also likely in years to come to see a reduction in the availability of siblings to act as primary carer.

**Table 12: Family arrangements of older people with ID living in home setting, by age group, 2017**

Age	At home with both parents	At home with one parent	At home with sibling	Other
40-49	47%	38%	12%	3%
50-59	21%	36%	39%	4%
60+	4%	17%	68%	12%
All ages	68%	24%	5%	3%

Some of any additional provision for this older group may be in mainstream nursing homes (funded under the Fair Deal scheme), some in specialist disability services for older people, and some in standard community housing. The National Disability Authority is conducting research into the most appropriate setting for older people with disabilities. The estimates in this paper are based on all additional residential places required being in disability services.

<sup>29</sup> The National Federation of Voluntary Bodies sought information from their members on the numbers of service users living with very elderly parents. In the 18 service providers that reported on this by June 2019, there were 473 service users living at home with a carer aged 70-79, and 183 living with a carer aged over 80. While it is noted that the HSE's 'active applications' list may exclude many older service users, the profiles of the 2,000 or so service users on this list (combining those looking for residential and those seeking non-residential supports) show that over 360 had a primary carer aged over 70, of which 139 had a primary carer aged over 80. For the future, the NASS will have data on the age of primary carers.

## Forecasting future need for residential service/supported housing (continued)

### (c) Intermediate scenario

This takes an intermediate interpretation of the scale of unmet need, based on

- Restoration of half the gap between pre-recession (2007) and 2015 levels of provision
- At least 90% of over-60s with ID have a residential support place

This scenario results in an estimate of a backlog of unmet need in 2017 of around 1,700 places, when an allowance is made for unmet need for supported housing for people with physical/sensory disability.

### Age pattern of unmet need under the different 'unmet need' scenarios

Table 13 sets out the current (2017) age-related rates of ID residential care, and under the different scenarios, each one providing for a progressively higher proportion of each age group. By design, the intermediate and pre-recession scenarios identify significant under-provision for over-60s. The pre-recession scenario recognises the halving of supported housing provision for people in their twenties since the recession. In consequence, its projections point to a requirement for large-scale provision of supported accommodation for younger adults, as well as for the very elderly.

**Table 13: Proportion of adults with ID in supported housing, different unmet need scenarios**

Age	2017 rates	Minimum	Intermediate	Pre-recession
20-29	10%	15%	17%	22%
30-39	31%	35%	39%	43%
40-49	51%	55%	56%	60%
50-59	65%	67%	68%	71%
60+	77%	80%	90%	95%

### Unmet need - people with physical/sensory/neurological disabilities

People with physical, sensory or neurological disabilities form about 10% of those in disability residential care.<sup>30</sup> In the absence of any comprehensive up to date

<sup>30</sup> In 2017, people with physical, sensory or neurological disabilities constituted 10.6% of all those in disability-specific residential care.

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### *Forecasting future need for residential service/supported housing (continued)*

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figures on which to base a separate forecast for this group, it is assumed that they would have a proportionate scale of unmet need.<sup>31</sup> As the Minimum scenario was based on all disabilities, an additional 10% was added to the other two scenarios.

#### **(d) Estimates of unmet/future need from National Intellectual Disability Database**

This database has estimates of currently-unmet need for residential care alongside anticipated future requirements, compiled by service providers (including HSE-provided services) in relation to their own service users. This is separate from the HSE's profiling of individuals presenting with an emergency or urgent need for residential care shown in Table 11 above, which is less comprehensive in its coverage. In 2017, almost 2,200 individuals registered on the National Intellectual Disability Database were identified who required an immediate residential service or would require one in the next five years. While the data does not show what share of this represents immediate need, it could be expected that around 400-500 would emerge in the 2017-22 period (in line with expected demographic need 2017-2022 shown in Table 14 below). That would imply about 1,700 people with ID who in 2017 had a currently-unmet need for a residential service. That is exclusive of any unmet need for supported housing for people with a physical, sensory or neurological disability.

The NIDD's methodology aggregates expected needs of individuals, without allowing for the effect of mortality which could free up vacancies, or of deaths among those waiting for a residential service. These two factors are built in to the methodology in the current paper, which is based on differences in aggregate need between different time periods. The NIDD's estimate of unmet need lies between the Intermediate and the pre-recession scenarios presented here.

#### **4.5 Residential care for children with disabilities**

Generally speaking, public policy is to support children with disabilities to live with their families. The number of children living in residential services has fallen steadily over time. In 2017, the NIDD listed 170 under-20s, of whom 75 were

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<sup>31</sup> Some data is available in relation to people experiencing major trauma. In 2017, about 13% of those discharged after trauma went to a residential service, or roughly 650 people. In 2018, 34 people were discharged to residential care from the National Rehabilitation Hospital's brain injury and spinal injury programmes, while 39 were discharged back to acute hospital as there was no funding for onward care.

### *Forecasting future need for residential service/supported housing (continued)*

under 18, in a residential service. Those constituted 0.9% of under-18s registered on the NIDD. There were an additional 179 (2%) under-18s living with foster families. Some of those foster children may require a disability residential place when they move into adulthood.<sup>32</sup>

With numbers of children in residential care so small, demographic change will have no noticeable impact on numbers.

#### **Young people with intensive support needs on waiting list**

In addition to those already in residential disability care, the HSE also recognises there are a number of children and young people who urgently require a residential placement (See Table 8 above). In mid-2019, the HSE had listed just over 50 children who required one; 24 of these were listed as emergencies. Most of these are teenage boys.

The profiling exercise showed that many of these young people have a dual diagnosis of mental health issues and or autism alongside an intellectual disability, manifest extreme challenging behaviour, and their family situations have broken down completely or are on the point of breaking down. Their support needs in a residential placement are very high.<sup>33</sup>

#### **Major long-term cost implications, even for small numbers**

While overall numbers may be small, the cost implications now and into the future are substantial. The average full-year cost of an 'emergency' residential placement in 2018 was €291,000. Some of the young people with complex behaviour issues who have received placements in 2018-19 under the funding are costing in the region of €450,000-€500,000 a year. At that range of costs, the annual cost of placements just for the 24 young people under 18 listed in the emergency category, for example, could total some €7-€12m a year. The total costs over those young people's lifetimes would be exceptionally large should that level of cost persist over that period. An in-depth review of such placements being conducted in 2019-20 will be valuable in managing those costs.

<sup>32</sup> A joint protocol has been agreed which inter alia transfers responsibility for foster care of people with disabilities in adulthood from TÚSLA to the HSE.

<sup>33</sup> For more on the support needs of people with autism, see HSE (2018) Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders. <https://assets.gov.ie/10708/33f312f0421443bc967f4a5f7554b0dd.pdf>.

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## *Forecasting future need for residential service/supported housing (continued)*

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### **Project examining appropriateness of arrangements under Emergency funding**

The HSE National Placement and Oversight Review Team (NPORT) is conducting a project in 2019/20 to individually review the high-cost residential placements made under the Emergency funding package, with a view to ensuring the person is getting a good-quality person-centred service at the most economical cost. The project is reviewing those individuals' current care and financial arrangements, with a view to providing the most appropriate health and social care support in the most appropriate setting. The project is examining whether people currently living in high-cost intensive placements can transition to less-intensive medium to longer-term residential services in their communities of main origin, following a reasonable period of intensive work to ameliorate the complex difficulties they originally presented. It is reviewing whether alternative support arrangements, for example periodic therapeutic stays, would be more appropriate to meeting individuals' needs than long-term intensive residential placements.

### **4.6 People with disabilities inappropriately placed in nursing homes**

There are about 1,300 people under 65 living in nursing homes, which includes people with disabilities (mainly with neurological disabilities) living there long-term, as well as younger people receiving end of life care. A study on this published in 2018 had a small non-random sample of 48 residents aged between 18 and 65.<sup>34</sup> The size and nature of the sample make it difficult to estimate with any confidence what proportion of these younger residents would be inappropriately placed. Nevertheless, the indications from this study, along with data on very long stays, suggest those numbers are likely to be substantial. The cost of alternative disability-specific residential care, or of sufficient Personal Assistance hours to enable these residents live independently, is likely to be well in excess of the current costs to the HSE of supporting them in nursing homes. The cost to the state of a standard nursing home package under the Nursing Home Support Scheme is around €50,000 a year, although in some cases where there are exceptional care needs a top-up may be paid from the disability services budget to a nursing home caring for a person with a disability.

To make a very crude estimate of the possible additional current cost of offering disability residential places to those inappropriately placed, assume around a third

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<sup>34</sup> Pierce et al (2018) The situation of younger people with disabilities living in nursing homes in Ireland. [https://www.disability-federation.ie/download/pdf/dfi\\_rr\\_2018\\_web.pdf](https://www.disability-federation.ie/download/pdf/dfi_rr_2018_web.pdf).

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### *Forecasting future need for residential service/supported housing (continued)*

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or 400 of younger nursing home residents are inappropriately placed, and that the additional cost to the Exchequer of a disability-specific residential support package would be €80,000 (roughly the difference between the average cost of a nursing home place under the Nursing Home Support Scheme (NHSS), and of a disability support place).<sup>35</sup> That would give an additional Exchequer cost in the region of €32m a year to transfer these residents to a more appropriate support package, alongside a transfer of any monies being paid under the NHSS to the Disability Services programme. The higher the number affected, or the higher the cost of alternative placements, the higher the total could be.

In the absence of better data on overall supported accommodation needs for people with a P&S disability, it is not possible to assess at this stage to what extent the ‘inappropriately placed’ might be accommodated within the 10% funding envelope provided in this exercise for residential support places for people with a physical, sensory or neurological disability.

#### **4.7 Completing the deinstitutionalisation project**

Following the recommendations of the report *Time to Move on from Congregated Settings* (2011), it is Government policy to close residential institutions and campus settings for people with disabilities, and transition their residents to ordinary homes in the community. This is in line with Article 19 of the UN Convention on the Rights of Persons with Disabilities, which Ireland has ratified, and the clear evidence from international studies that ordinary housing in the community provides a better quality of life. Furthermore, many of the remaining centres are required by HIQA to close due to non-compliance with standards.

By end 2018, the number of people resident in these centres had reduced from 3,401 in 2012 to 2,136. Over 800 people had transitioned to the community over this period, while almost 700 had died. A further 102 people were scheduled to transition to the community in 2019.<sup>36</sup> If the deinstitutionalisation project is to

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<sup>35</sup> This could be very much a minimum estimate. Many of those concerned have complex needs requiring a high degree of support, and so the cost of a disability residential place, or of support to live independently, is likely to be well above the cost of an average disability residential place.

<sup>36</sup> 2019 outturn figures show around 1,950 remaining in congregated settings. As replacement housing in the community is required for a reduction in congregated residential places where people died, the cost of additional community housing required remains similar.

### *Forecasting future need for residential service/supported housing (continued)*

be completed during the decade to 2030, additional current and capital funding will be required when the current funding under the Service Reform Fund and the €100m housing capital 2016-21 come to an end.

To illustrate the scale of what may be required, completion of decongregation by 2030 would require around 150 people a year to transition to the community from 2020 onward, assuming the current mortality rate of 4% among those remaining in the institutional settings.

#### **Current costs are already in the system, but may require some adjustment**

The costs of staff to support the 2,100 or so people still living in congregated settings in 2018 are already in place. However, additional funding may be needed as the remaining people transition to the community – first to support the transition process and second to cover any dual costs involved while both old and new services are still running in parallel. The decongregation process may also result in additional costs as a result of the more decentralised delivery of services and the loss of any ‘economies of scale’ that might be associated with large group care. Supporting people in community housing can require higher staffing costs, e.g. due to the requirement for night staffing ratios to ensure safe evacuation in case of fire, and additional dedicated time for a greater number of Person-in-Charge roles. These may be offset to some extent by other savings, such as the elimination of housekeeping and grounds maintenance roles associated with large campuses. Work on comparing the cost of institutional models of service delivery with alternative community-based models for equivalent residents is underway in the National Disability Authority, and not yet finalised.

2015 was the last year in which transitions took place without some revenue funding to support them, and those earlier transitions had involved organisations and individuals who were more ready to move. Since then, the Service Reform Fund has provided around €18.5m over a four-year period to support transitions of people from 10 priority congregated sites into the community. On completion of this programme, some additional seed funding may be required to effect the remaining transitions.

#### **Capital costs of replacing institutional accommodation could total almost €300m**

If the overall supply of available residential places is not to reduce, the replacement



### Forecasting future need for residential service/supported housing (continued)

of some 2,100 current residential places in campus settings by alternative community housing will require additional capital funding.<sup>37</sup> The cost of this is estimated to total some €280m.

Given location, physical condition and ownership of many of these campus and congregated settings, there may be limited scope to achieve any offsetting savings for the disability programme by either selling or repurposing these premises.

#### 4.8 Summary of aggregate estimates of demographic and unmet need

Table 14 sets out estimates of the number of additional residential places required to address both demographic change and the backlog of currently-unmet need, using the different 'unmet need' scenarios set out in section 3.4 above.

**Table 14 Estimates of additional disability residential places required (over 2017 level) to address demographic and current unmet needs 2017-2032**

Year	Demography only	Demography + unmet need			
		Minimum	Intermediate	NIDD	Pre-recession
2017	-	800	1,500	1,700*	2,300
2022	450	1,200	2,000	2,200*	2,900
2027	800	1,600	2,500	n.a.	3,400
2032	1,100	1,900	2,900	n.a.	3,900

Note: These estimates show broad orders of magnitude, in line with the assumptions underpinning the different scenarios

\*Intellectual disability only

#### 4.9 General figures on future cost of residential places – taking into account data uncertainties

The cost of meeting anticipated needs due to demographic change and of tackling the backlog of unmet need cannot be measured with precision. The figures presented in this paper provide a general measure of the likely scale of what is required.

<sup>37</sup> If overall supply is not to reduce as campuses and residential institutions close, then replacement places will be required not only for those who transition, but also for places vacated due to deaths of residents.



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### *Forecasting future need for residential service/supported housing (continued)*

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Uncertainties include:

- Agreement on an appropriate way to measure unmet need
- The pace at which unmet need would be addressed
- The pace of future growth in young adult population getting services, and its impact on residential demand
- The numbers of people with or who acquire P&S disability who require a residential place
- How many people with disabilities are inappropriately placed in nursing homes, and any additional cost of more suitable provision for them
- The future policy mix between residential places, and additional support to remain in the family (generally parental) home
- The quality of data on unit costs
- The evolution of future costs given an increasing share of complex need

#### **4.10 Cost pressures in residential provision**

The estimates of future cost of additional residential places needed have been prepared on the basis of constant annual unit cost. Recent experience however has been that unit costs have moved upwards over time, increasing for example from an estimated €133,000 a year in 2017 to €144,000 in 2018. The factors involved in the upward movements in cost have included:

- Rising pay rates including public sector pay restoration
- Increased staffing levels arising from regulatory requirements
- Increased intensity of support need of those currently in a service, both due to an ageing population, and to complex behavioural or medical issues
- The HSE has been a price taker for emergency residential placements, most of which have been provided in the for-profit sector
- Additional residential placements provided since 2016 under designated 'emergency' funding have usually been for people with high or intensive support needs, and at a much higher than average unit cost. The average intensity of

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## *Forecasting future need for residential service/supported housing (continued)*

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support need and the average unit cost of the overall case-mix in residential care has risen as a result

Similar pressures driving up unit costs are likely to persist over the medium term. As a labour-intensive sector, any changes in wage levels has an almost proportionate impact on overall costs. Further increases in staffing may be required in particular services to achieve regulatory compliance. High-cost placements are likely to be a continuing feature given the high support needs of those on the emergency waiting list. The carryover cost into the subsequent year of any such placements made mid-year results in an increase in overall unit cost.

### **Compliance with regulation**

The introduction of regulation, standards and inspection has undoubtedly raised standards in disability services, but there is still some way to go. A 2019 report by HIQA on the first five years of inspection of disability services reported that overall compliance rates in these services over the period had increased from 59% in year one of the process to 76% in year five.<sup>38</sup>

HIQA has required some disability centres to have increased numbers of staff on duty. In many of these cases the regulator has recommended additional staff overnight to address their concerns around safe evacuation in the event of fire. Managing challenging behaviour is resource intensive and with changing practice on the use of psychotropic medication and physical restraint this has led to increased staffing requirements. The second round of registration inspections, and the thematic inspections around restraint underway during 2019, may lead to further recommendations in some services that staffing be increased to ensure safe and appropriate services. In particular, those services which marginally achieved registration first time around may be required to provide additional staffing when they are reviewed.

### **Change in support-needs mix**

This is already a cost pressure within the system. For example, in 2018, the HSE spent €6m more than was budgeted for on disability services to provide enhanced levels of residential support to its existing service users.

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<sup>38</sup> See: <https://www.hiqa.ie/reports-and-publications/key-reports-and-investigations/five-years-regulation-designated-centres>.

### Forecasting future need for residential service/supported housing (continued)

Demographic change will alter the overall age-profile of those receiving residential care, as would any increase in the share of over-60s who get access to a residential support place. If residential care provision rises to meet demographic change alone, the proportion of over-60s would be scheduled to rise steadily from 27% of ID residents in 2017, to 35% by 2032. Under any of the ‘unmet need’ scenarios, the increase in the proportion of over-60s would be virtually the same. As people ageing with an intellectual disability may have increasingly complex support needs, this increase in age-profile is likely to lead to a continuing increase in unit costs.<sup>39</sup>

Data from the National Intellectual Disability Database for 2015 and 2017 show an increase in support-intensity of residential services between the two periods, in particular a sharp rise in the numbers in the high-cost ‘intensive’ category. Table 15 shows the financial impact of this change at constant prices, using 2017 estimates of unit costs for different levels of support.<sup>40</sup> The effect, in particular the switch of some places from the high-support to the intensive support category, would be to raise the overall cost by around €18m., in spite of lower overall numbers in a residential service in 2017.

**Table 15: Cost of change in intensity of residential support 2015-17 at constant prices**

	No of ID residents		2017 as % of 2015	Unit cost of place	at 2015	at 2017	Increase
	2015	2017					
	No.	No		€	€m	€m	€m
Minimum	485	513	106%	40,000	19	21	2
Low	1,532	1,484	97%	80,000	123	119	-4
Moderate	1,583	1,531	97%	112,500	178	172	-6
High	4,100	3,955	97%	150,000	615	593	-22
Intensive	235	343	146%	450,000	106	154	48
<b>Total</b>	<b>7,935</b>	<b>7,826</b>	<b>99%</b>		<b>1,041</b>	<b>1,059</b>	<b>18</b>

### Implications of ‘emergency’ placements in future years

In 2018 and 2019, funding for additional placements in residential care has been limited to those on an emergency list. This list has largely comprised people with

<sup>39</sup> See McCallion et al (2011) “Meeting the End of Life Needs of Older Adults with Intellectual Disabilities”, in Chang & Johnson (eds) Contemporary and Innovative Practice in Palliative Care. <https://www.intechopen.com/books/contemporary-and-innovative-practice-in-palliative-care/meeting-the-end-of-life-needs-of-older-adults-with-intellectual-disabilities>.

<sup>40</sup> These unit costs were supplied by the HSE and used in the WG1 Report.

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### *Forecasting future need for residential service/supported housing (continued)*

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very complex needs arising from either extreme medical needs, very challenging behaviour, or co-morbidities e.g. both disability and significant mental health issues. Reflecting this complexity of need, the unit costs of those placed under that programme are much higher than average. The HSE has estimated that average full-year unit cost of those placed in 2018 was around €330,000 per place for those placed in private or out-of-state facilities, and over €210,000 in voluntary providers. Detailed profiling shows that a significant proportion are children or young adults with significant behaviour difficulties, so these high-cost placements are likely to form a growing proportion of the total numbers in residential care in years to come.

#### **4.11 Additional residential places costed at €144,000 average annual unit cost in 2018**

In general, the 2018 average revenue cost of a residential disability place has been used as the basis for costing.<sup>41</sup> The exception is in the 'Minimum' scenario where the backlog of unmet need would be limited to those on the HSE's emergency list – average cost of those off that list taken as €200,000 a year each.

#### **Demographic need alone – €160m more a year by 2032**

To keep pace with demographic change alone, an average of around 80 new places a year is required each year. The revenue cost of that is of the order of an additional €12m a year, every year.

Providing for demographic need, above a 2017 baseline, would raise spending by €60m a year by 2022; by €120m a year by 2027, and by €160m a year by 2032.

#### **Demographic need + Minimum scenario, unmet need – €320m more a year by 2032**

As the HSE's 'active' waiting list of about 800 people is heavily weighted towards younger people with complex needs requiring intensive support, providing a residential service to this group is likely to come at a higher unit cost. At an illustrative unit cost of €200,000 a head, the annual cost would be around €160m a

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<sup>41</sup> The WG1 Report had used a weighted average unit cost of €132,000, very close to the HSE outturn unit cost for 2017 of €133,000. While that report had included those in independent living in its calculations of numbers requiring support, these were not in fact included in its pricing which was based on a separate analysis from the HRB of intensity of support need in residential care.

### Forecasting future need for residential service/supported housing (continued)

year. Added to the cost of meeting demographic need, additional current spending would need to rise by €320m or so by 2032.

#### Demographic need + Intermediate scenario, unmet need - €400m a year more by 2032

The annual costs of meeting unmet need alone under this scenario would be of the order of €300m a year. Adding in demographic need would require additional annual spending, over the baseline, of around €300m in 2022, €350m in 2027, and €400m in 2032.

#### Demographic need + Pre-recession scenario, unmet need – €550m a year more by 2032

Adding this element of unmet need alone would cost of the order of €350m a year. When demographic pressures are added (alongside the interaction of demographic change with higher levels of residential provision to the growing proportion of over 60s and of young adults), additional annual costs would run at over €400m a year in 2022, €500m in 2027, and over €550m in 2032.

#### 4.12 Current cost of extra residential places needed - €300m to €550m a year by 2030s

The scale of demographic and unmet need, and the financial implications, pose significant challenges. Table 14 summarises the revenue cost involved. By 2032, annual spending on disability residential care would need to be at a minimum over €300m higher than at present, and possibly up to €550m higher.

**Table 16: Broad estimates of possible annual costs of additional residential care required**

Year	Demography only	Demography + unmet need		
		Minimum	Intermediate	Pre-recession
Central projection	€m	€m	€m	€m
2017	0	160	220	340
2022	60	220	300	400
2027	120	280	350	500
2032	160	320	400	550
2032 'youth inflow' scenario	+40	+40	+70	+100

Figures are not to be taken as precise and only show likely order of magnitude

*Forecasting future need for residential service/supported housing (continued)*

**4.13 Capital costs between €700m and €1,000m**

The capital cost of additional housing places for people with disabilities would be the responsibility of the Department of Housing, Planning and Local Government. The WG1 paper had used an average figure of €500,000 for a four-person group home to include upgrading to meet fire regulations etc., based on end-2017 prices HSE was paying for purchase and adaptation of housing under the decongregation programme. National house prices have risen in the intervening period, and based on the CSO’s house price index for April 2019, a revised house price of €530,000 is used in the calculations.

Table 17 sets out the capital costs of the additional residential places required, to address demographic change, tackle unmet need, and replace the current stock of congregated institutional and campus residential provision.

On the minimum scenario, plus replacement of remaining places in congregated settings, the total capital cost to 2032 would be over €700m. Taking the pre-recession scenario, the total capital cost would total about €1bn.

**Table 17: Capital cost of additional residential provision required**

Year	Demography only	Demography + unmet need			Congregated settings
	Demography	Minimum	Intermediate	Pre-recession	
	€m	€m	€m	€m	€m
Now	0	100	200	310	280
2022	60	160	270	380	
2027	110	210	330	450	
2032	150	250	380	520	

Figures are not precise and only show likely order of magnitude

**4.14 A strategic approach to planning for future residential provision**

There is a foreseeable need for additional residential care places, and the vast majority of the individuals concerned are already within the disability care system and their locations, needs and preferences are readily identifiable.

## *Forecasting future need for residential service/supported housing (continued)*

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### **1,000-1,500 new houses at a minimum**

In total, some 1,900 to 3,900 additional places will be required to meet demographic demand and unmet need, depending on how that is measured or addressed. In addition, replacement housing will be required for the outstanding 2,100 places currently provided in congregated settings. So the total number of residential places required will be of the order of 4,000 to 6,000 over the period to 2032. If all of these were to be four-person group homes, that would translate into an extra 1,000 to 1,500 such houses/apartments required. If there is a range of smaller and more personalised accommodation, then the number of additional housing units required would be greater.

As well as a big financial requirement, this presents a major procurement, planning and logistical challenge. The experience to date with the decongregation programme shows the considerable time it takes to procure and adapt, fit out, and secure HIQA approval for a premises.<sup>42</sup> If any accommodation is to be purpose-built, there is a significant lead time involved in design, securing planning permission, procuring a contractor, and final delivery of a premises that meets the required standards and specifications. Under the Housing Strategy for People with Disabilities, and in line with the principle of mainstreaming embodied in s26 of the Disability Act 2005, responsibility for provision of housing for people with disabilities falls to housing authorities, where provision of support services to live in the community are a Health responsibility. Co-ordinating the joint procurement and simultaneous delivery of both housing and disability support services as an integrated package, and on the scale required, will be a major logistical task.

### **Planned approach to future needs more cost-effective**

All of these reasons show the importance of a multi-annual current and capital funding programme to secure effective and timely delivery, at the most reasonable cost. This would enable the detailed forward planning to be made to ensure that services become available where and when they are needed.

There is a long time-lag on delivery of housing, whether acquired and adapted or purpose-built, because of the need to complete legal and planning formalities, procure contractors, and sign off that the finished product meets required

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<sup>42</sup> See <https://www.hse.ie/eng/services/publications/disability/review-of-time-to-move-on-policy-implementation-2012-2017.pdf>.

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### *Forecasting future need for residential service/supported housing (continued)*

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standards. HIQA approval must be secured before the premises can be operated as a residential disability centre.

With the limited number of additional places becoming available under the Emergency funding stream (60 such places provided for in 2019), the majority of such places have been provided in the for-profit sector, in situations where the HSE is a price-taker. This is the only sector that has HIQA-pre-approved spare capacity. So a multi-annual plan is a better way to ensure that services provided are cost-effective.

A planned approach would enable a greater range of providers to become involved. This could also enhance continuity of services for individuals who may have the option to transition from day services with a particular provider to residential support from the same provider.

The scale of additional supported residential places required warrants greater consideration of alternative models of support where they meet individuals' needs, such as supported independent living, home sharing and host family models. Given the scale of additional housing provision identified as needing to be provided, it would appear sensible to modify the current regulatory requirements in order to permit temporary registration for a period of additional homes provided by approved quality providers, before the individual building is required to be inspected and approved.

#### **4.15 Summary – future need for residential places**

Changing demographics will mean a greater number of people with an intellectual disability, and more of them in the older age groups where they are most likely to need full-time residential care. The detailed population forecasts prepared for this group were used to project future demographic need, with on average around 90 additional places a year required to stand still at 2017 rates of provision by age. The scale of unmet need, however measured, is substantial, and it would not be sustainable to simply provide for demographic change at current use rates. Three different scenarios around unmet need were presented and costed. This included factoring in how improved rates of provision by age would be impacted by demographic change.



In the absence of good data on which to prepare separate projections for the numbers of people with a physical, sensory or neurological disability requiring a supported residential place, an additional 10%, representing their current share in the total, was added on top of the projections in respect of people with an intellectual disability.

The results showed an additional 1,900 residential places would be required by 2032 under the Minimum scenario, and an additional 3,900 places under a Pre-Recession scenario. The annual revenue cost would be in the region of over €300m a year by 2032 under the Minimum scenario, and around €550m a year under the Pre-Recession scenario, at a constant 2018 unit cost. It was recognised that there are significant pressures that are likely to drive up unit cost – pay changes, achieving full regulatory compliance, and growing complexity of need.

Currently there are 2,100 people living in congregated settings, and suitable replacement housing will need to be secured if these centres are to close, including replacement of places vacated when a resident dies, so that overall residential provision does not fall. The total capital cost of providing additional housing required to address demographic change, unmet need, and the closure of remaining institutions and campuses, comes to over €700m on the Minimum scenario, and €1bn on the Pre-recession scenario. Providing this accommodation will be a major logistical as well as financial challenge. A multi-annual funding programme would enable proactive planning and more cost-effective delivery of the scale of expansion in services required.

*Forecasting future need for residential service/supported housing (continued)*

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# Chapter 5

## Adult day programmes

# Adult day programmes

## Key points – Day Services

- There is a range of adult day programmes which support people with disabilities during the ordinary weekday. These include adult day services (the largest programme); training programmes, principally Rehabilitative Training; and work programmes like sheltered work (being phased out).
- In general, people enter adult day services on leaving school, or after an initial period in Rehabilitative Training. Some also do after acquiring a disability.
- Following the baby boom of the 2000s, a growing number of school-leavers are expected to apply for day services up to the end of the 2020s.
- Participation in day services is virtually lifelong, while participation in training programmes is time-limited. Many participants with intellectual disabilities transfer to day services on completing Rehabilitative Training.
- The limited data on outflows suggests that inflow of school-leavers into day services are likely to outweigh anticipated outflows over the period to 2032.
- That will mean a step-wise increase will be required every year in the number of day service places to meet demographic demand. From 2015 to 2019, about 1,000 additional places a year were provided to meet the excess of school-leaver inflows over exits from day services.
- The HSE estimates there may be 600 people with no day service who need one. There is also unmet need for those receiving partial day services, which is estimated would be equivalent to an extra 600 full-time day places.
- To meet unmet need of those who get partial or no day services would cost €30m a year, at a unit cost for a new place of €25,000 a year.
- Meeting continuing demographic need is likely to require an annual stepwise increase in spending. Under the 'high exit' scenario, the annual step in expenditure needed to provide additional day places would be about €5m. By 2032, additional demographic need under this scenario could have reached €60m above the 2020 level. On a 'low exit' scenario, the annual incremental

## Adult day programmes (continued)

### Key points – Day Services (continued)

step in spending could average around €20m a year. By 2032, the extra cost of meeting this demographic demand would be around €250m above the 2020 level. On an intermediate exit scenario, the annual step would be around €12m, and the additional cost in 2032 over the 2020 level would be around €140m.

- Because demographic demand is very sensitive to the annual exit rate from day programmes, it is difficult to provide a narrow band of estimates of the potential overall cost of meeting both demographic and unmet need. On different assumptions about the exit rate, the combined additional costs of demographic demand and unmet need could fall within a range of an extra €90m to €280m a year required by 2032.

### 5.1 Principal adult day programmes

Adult day programmes form the second-largest area of expenditure, accounting for about 21% of the disability services budget.

HSE-funded day programmes for people with intellectual disabilities, autism, or complex physical disabilities include a range of centre-based and community-based activities, including day services of different kinds, and sheltered work. Most of these are long-term programmes with typically lifelong participation, although the mix of activities and supports can change over the person's lifecycle. While a standard programme is usually five days a week, there are also people who attend for fewer days, often because available funding was spread to give people at least some level of service.<sup>43</sup> Some people in residential services are supported in situ rather than participating in a formalised day programme off-site, but most would attend a day service. The NIDD in 2017 recorded around 7,500 people with intellectual disabilities living in residential care who participated in a formal day programme.

<sup>43</sup> Individuals may also attend more than one day programme. For example, while about 600 people on the NIDD in 2017 had supported employment given as their principal day programme, in total 1,600 people on the NIDD were engaged in supported employment. So for about 1,000 of these, most of their week would be spent in a day service, with perhaps a day a week in supported employment. See NIDD 2017, Table 3.7.

### *Adult day programmes (continued)*

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A transition is under way from traditional centre-based day services to the New Directions model of person-centred supports, based on the individual's needs and wishes. The focus is on supporting people to participate in the mainstream activities and in the life of their community. Sheltered work, for example, is being phased out, with more emphasis on supported mainstream employment.

Rehabilitative Training (RT) is a lifeskills and pre-vocational training programme, built around a person's Individual Training Plan. While most participants are people with an intellectual or physical disability or autism, about one in every six participants are people with a primary mental health condition. The standard duration is around two years, although a minority spend up to four years or longer on the programme. Some participate on a part-time basis. There are around 2,200 places each year. On completion of RT, many participants will transfer to a general disability day services programme.

The entry pathway for disability day services is via the local regional branch of the HSE, the Community Healthcare Organisation (CHO), with entry limited to qualifying school leavers and those leaving Rehabilitation Training. Potential entrants in these categories are profiled every year to ascertain the level of support they need. People with intellectual disabilities or autism form a large share of new entrants to day services. Of those entrants profiled in 2018, 73% had an intellectual disability, and 35% had ASD, and overlapping impairments were common.

Table 18, relating to participants with intellectual disabilities, gives more detailed information on the relative scale of individual day programmes.

*Adult day programmes (continued)***Table 18: Adults on NIDD in 2017 by principal day programme**

<b>Day Services (other than training or employment)</b>	
Activation centre	8,242
Generic day services	557
Special high-support day service	746
Special intensive day service	482
Programme for the older person	566
Outreach programme	418
Other day service	615
<b>Subtotal</b>	<b>11,626</b>
<b>Training/education</b>	
Rehabilitative training	1,406
Vocational training	225
Third level education	66
<b>Subtotal</b>	<b>1,697</b>
<b>Work/Employment</b>	
Sheltered work centre	2,250
Supported employment	632
Sheltered employment centre	35
Open employment	144
Enclave within open employment	5
<b>Subtotal</b>	<b>3,066</b>
<b>Overall total</b>	<b>16,389</b>

Note: some of the education, training and employment programmes are under the aegis of other Departments, not the HSE

## 5.2 Limitations of data on participation in adult day programmes

Formalised disability day programmes for adults are delivered by over 90 service provider organisations at over 1,000 locations. The HSE has established a database to document people receiving formalised day services (which covers all such day programmes, including sheltered workshops – a separate database covers those in RT). This database showed around 16,400 people were in a formalised disability day programme at end February 2020 (which includes day services and sheltered workshops) and in addition around 2,250 people with disabilities participated in Rehabilitative Training. These data do not include people in residential care who receive day support but not as part of a formalised programme. Preliminary indications are that around 3,000 people receive a partial day service only, in

### *Adult day programmes (continued)*

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other words, limited days or hours of service. In some cases a full-time service is required, so some of these 3,000 people have unmet needs for day support.

As of early 2020, systematic tracking of entries and exits had not yet occurred, so there was no information on exit rates. This is the next stage of development of the database, was a priority action in 2020. These data depend on accurate returns being made by service providers – a systematic validation process is not yet in place. The development of the National Ability Supports System as the core of the HSE’s new management information and case management system will provide a means to systematically track inward and outward flows, and keep track of net changes.

#### **Modelling possible exit rates**

The gross inflows to day services can be calculated readily from national population forecasts, given the proportion of 19 year olds entering day programmes has been quite stable over the period 2015-18. However, without reliable data on exit rates, the net change in day service numbers is more difficult to estimate. A range of scenarios were modelled, based on a range of possible exit ratios derived from the National Intellectual Disability Database. When solid data on exit rates become available, these projections can be revisited.

#### **5.3 Interplay between Rehabilitative Training and Day Services**

There is cross-movement between individual day programmes. In particular, Rehabilitative Training (RT) acts as a stepping stone into adult day services for a proportion of school-leavers. For others, it offers a time-limited support – the great majority of adult entrants to RT exit specialist disability services once they complete the programme. Table 19 gives the data for 2018 on flows into day services and RT, and between these programmes.



*Adult day programmes (continued)***Table 19: Adult day service entry and RT activity 2018**

Day services – school leavers and RT exits transferring in	
Profiled for day service entry	1,657
- 1,170 school-leavers	
- 487 RT leavers	
Offered a day place (day service or RT - excludes 53 deferrals)	1,358
Did not take up place offered, approximately	100
Net number seeking places (a)	1,258
Additional day service places needed (b)	1,059
Vacancies available to meet demand (a) – (b), approximately	200
Rehabilitative Training	
No. of places	2,193
Trainees at end 2018 (includes part-time participation)	2,260
Entries	1,050
Exits	1,132
To Day Services	443
To RT	52
Complete exits (leave HSE day programmes)	637

Source: HSE, Annual reports on Rehabilitative Training and on school leaver process

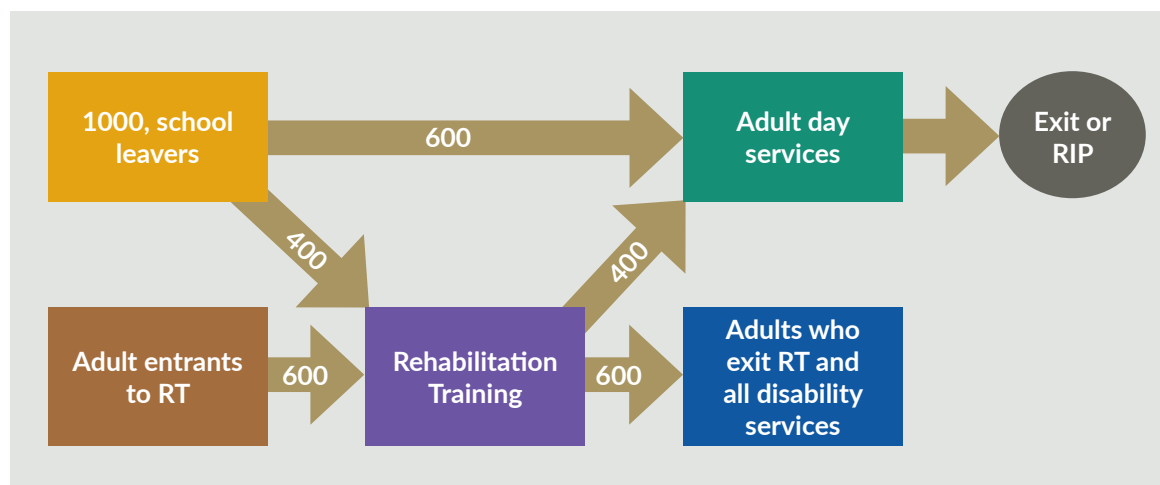
Every year, the HSE profiles school-leavers with a disability who have applied for entrance to HSE adult day service programmes. Following assessment, a proportion do not meet the criteria to enter these programmes. Of those school-leavers who qualify for a day programme, around 70% go straight into a Day Service, while around 30% are deemed to require an initial period in Rehabilitative Training to acquire the life-skills needed to benefit from the Adult Day Services programme. These school leavers are prioritised in the allocation of the finite number of Rehabilitative Training places. Following completion of two or more years in RT, the great majority then transfer into the Adult Day Service programme, where their participation is generally lifelong.

There are also adult entrants into Rehabilitative Training, for example people who acquire a brain injury in the course of adult life. After two years of the programme, the great majority of these have acquired the skills required to manage their condition, and they exit specialist disability services altogether.

## Adult day programmes (continued)

Chart 3 is a stylised representation of the flows into, and out of, Rehabilitative Training and Day Services.

**Chart 3: Inflows and outflows - day services and RT**



### 5.4 Factors impacting on future spending on day programmes

The future level of spending on disability day programmes will reflect

- Demographic change affecting inflows of school leavers
- Any increase in disability prevalence which would impact on the proportion qualifying for day services – trends in the proportion of students in special classes or special schools could herald future change in the proportion of school-leavers entering specialist disability day programmes.<sup>44</sup>
- The number and age-profile of day service users, which will affect exit rates
- Increased complexity of cases, with those ageing with a disability, or with dual diagnoses typically having higher support needs. Data from the HSE show that new entrants to day services have more complex needs than previously – often related to mental health issues, autism or both. The disability figures by impairment in the Census 2016 highlight an increase in reporting of mental health problems among young people.<sup>45</sup>

<sup>44</sup> Young people who get disability support in mainstream classes may also apply to enter disability day services, but those in special settings in their school years are considered more likely to do so.

<sup>45</sup> The number of those profiled for entry to adult day services with autism rose from 582 in 2018 to 704 in 2019. The proportion of people with an intellectual disability reporting a concurrent mental health condition was 3 percentage points higher in Census 2016 than in Census 2011.

*Adult day programmes (continued)***5.5 Modelling future need for disability day programmes****Annual demand has exceeded exits from day programmes**

Table 20 sets out the scale of inflow to Day Services and Rehabilitative Training respectively over 2015-19, and the number of additional places required to be found each year. Around 1,000 additional day service places have been required every year between 2016 and 2019.

**Table 20: Demand for day and RT places 2015-18, and additional places needed**

	2015	2016	2017	2018
Required/Commenced an RT Place	362	349	348	433
Required/Commenced a Day Place (includes RT exits)	960	988	1,004	991
<b>Total (a)</b>	<b>1,322</b>	<b>1,337</b>	<b>1,352</b>	<b>1,424</b>
Net additional places needed (b)	832	988	c1,000	1,059
Implied vacancies – including vacated RT places (a-b)	490	349	c350	363

Source: HSE

**Steady inflows of young people exceed small outflows at older ages**

Given the relatively small number of estimated annual vacancies arising through exits from day programmes (Table 20 above), additional levels of service provision have been required every year over this period as the number of young people reaching adulthood who require these services has been far greater than the numbers of vacancies arising from deaths or other exits. To cater for this annual influx of new users, since 2015 additional funding has been provided to cater for additional places required for school-leavers and for those leaving Rehabilitative Training (RT) who subsequently require a day service. The pattern over the period from 2015 has been that roughly 1,000 additional day places have been required each year to provide for the excess of inflow over outflows.

**Change in places needed = inflows minus outflows**

The model used assumes that when someone leaves a day service, an additional place becomes available for someone else. This simple entrance-exit model may not apply in practice. Some of those who exit may only be accessing part-time day support, so will not release a full day place. Some of those who exit a formal day programme as they get older, may still require equivalent support resources to care for them during the day. If the service user population is ageing, the resources freed up by a vacated place when someone dies may be fully or partly absorbed in

## Adult day programmes (continued)

providing additional supports required by other ageing service users who may have increasing care needs for example due to dementia.

The separate influences on inflows and outflows were modelled – while inflows are a fairly straightforward function of the school-leaving aged population, there are a range of possible estimates of the rate of outflow.

### Model ignores cross-flows with other day programmes

Because day programme provision is dominated by Day Services and Rehabilitative Training (RT), the model ignores all other external inflows, outflows or cross-flows affecting individual day programmes. It assumes that all non-school-leaver RT entrants leave disability services on completing their course, and that RT exits entering day services comprise those who entered RT as school-leavers two years earlier. It is recognised this is a simplification of what are complex inter-programme flows. Data from the National Ability Supports System, when available, will facilitate a better understanding of those inter-programme flows.

### Formal representation of the model

Let

$S(t_0)$  represent the current year's school leavers entering day programmes (whether RT or day services)

$S(t_{-2})$  represent similar school-leavers from 2 years previously

$N_{19}(t_0)$  the average number of 19-year olds in the current year

X represent day service exits

$f()$  describes a functional relationship between variables

If 70% of school-leavers go straight to day services, and 30% to RT, then the model can be expressed as:

$$\text{Increase in day service places} = .7 S(t_0) + .3 S(t_{-2}) - X$$

$$S(t_0) = f(N_{19}(t_0))$$

There is very little practical difference between the results of calculating 30% of 19 year olds two years previously, and 30% of today's 19 year olds, particularly given that the 30% fraction is a rough estimate in itself.

## Adult day programmes (continued)

Therefore the model approximates to

$$\text{Increase in day service places} = S(t_0) - X$$

### 5.6 Stable relationship between nos. of day service entrants, and their birth cohort

There has been a steady relationship between the number of 19-year olds in any given year, however measured, and the number entering day services. So it is reasonable to assume a similar proportion of 19-year olds in future would convert into demand for day service places. While day service entrants are a mixture of school leavers and RT exits, many of the RT exits are the school leavers of a couple of years previously.<sup>46</sup>

For the years 2015-18 for which data are available, the number of entrants to day services (school leavers + RT exits) had a stable ratio to the school leaver peer age group, whether this is measured by reference to those born 19 years earlier (adjusted for mortality), where the ratio averaged 1.9%, or by reference to the CSO's estimate of the total population aged 19, where the ratio averaged 1.7%.<sup>47</sup>

Separate forecasts of 19 year olds out to 2032 were available, one based on births 19 years previously (adjusted for mortality), and others drawing on the CSO's population projections, and these were used to predict future gross inflow to day services, on the assumption the relevant ratios above would remain stable. The two methods produced fairly similar results with a slightly higher inflow predicted

<sup>46</sup> The number of those entering RT from school over 2015-18 had a fairly stable relationship to the numbers in their birth cohort, averaging just under 0.7%. The number of such RT entrants is expected to be approximately the same as the number of RT exits moving to day services two years later.

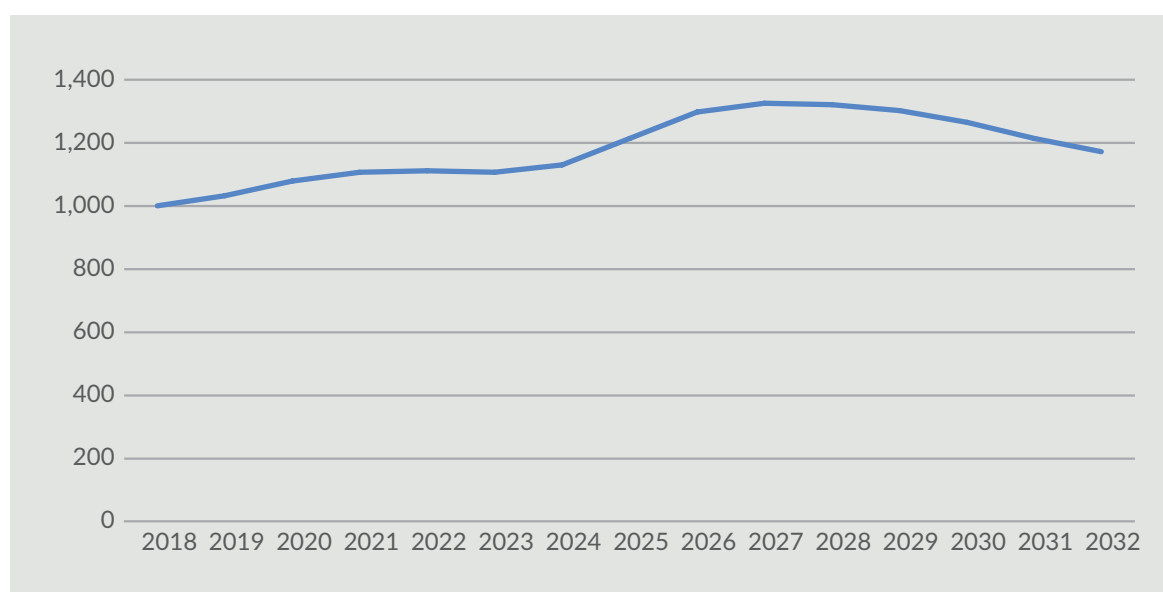
<sup>47</sup> The birth cohort, adjusted for mortality, takes no account of migration, and may be a more appropriate basis for estimating the ratio of future service users with ID, who may be less likely to migrate than their peers. The ratio of entrants to day services to 19 year olds is slightly more stable on the birth cohort basis than on total population of that age. However, the expected inflow to day services computed using the birth cohort method is only marginally different than if either the CSO's M2F2 population forecast (moderate inward migration, falling fertility) or the M1F2 (high inward migration, falling fertility) are used.

### Adult day programmes (continued)

using the birth cohort method, as this leaves out possible migration flows. The birth cohort method suggested annual inflow to day services would rise gradually from around 1,000 a year in 2018, peak at around 1,300 in 2027, and drop back to around 1,200 by 2032 (Chart 4). If the proportion of school leavers entering a day service remains stable, these inflow figures should be reliable, based as they are on young people already born who will reach school-leaving age over this period.

#### Chart 4: Projected annual inflow to day services

Mirrors changes in population aged 19



#### 5.7 Is proportion of young people entering day services set to rise?

Another issue that could affect demand for day services would be an increased prevalence of significant disability, leading to a step increase in the proportion of the age cohort who enter HSE day programmes, above what may already have occurred. The increased prevalence of childhood disability recorded between Census 2011 and Census 2016 is mirrored by a growth in the prevalence of special education needs, primarily autism, in schools. The Census also reported a growth in the proportion of young people who have both an intellectual disability and a mental health difficulty. Already these factors are appearing in increased intensity of need among the school-leaver cohort, with a growing number with autism, and increased numbers in the ‘intensive’ bracket (although when numbers are small this may be just random variation – the overall bell curve distribution of assessment scores has remained very stable since profiling began).

*Adult day programmes (continued)*

About 1,700 people (school-leavers plus those leaving Rehabilitative Training) were profiled in 2019 in connection with applications for adult day services. Table 21 gives the breakdown by impairment type.

**Table 21: Applicants for day service places 2019 by impairment type**

	Intellectual	Autism	Physical	M Health	Sensory	Multiple
Only this impairment type	42%	14%	5%	0%	1%	37%
Any impairment of this type	73%	35%	17%	8%	7%	

Source: HSE

If around 1.9% of the relevant birth cohort aged 19 enters a disability day service programme (the average for the period 2015-2018), and if 73% of those have an intellectual disability, as per Table 21, then people with ID entering day services would constitute around 1.37% of the relevant birth cohort. This compares with data for 2017 from the NIDD showing that those aged 15-19 in specialist disability programmes constituted 1.17% of their reference birth cohort, and those aged 20-24 represented 1.05%. That suggests there may be some increase in the proportion of young adults entering specialist disability services. This factor has been taken on board in preparing a 'youth inflow' projection of the future population requiring specialist ID disability services, as an alternative to the central population projection which assumed that young adults in disability services would be a stable proportion of their age peers.

Other data sources, from the Census to participation rates in special needs education, suggest there has been an increase over time in the proportion of young people recorded with a disability or special needs. It is not clear whether this is a real increase in prevalence, better identification and recording, or whether children with a more minor level of functional difficulty are more likely to be labelled as having a disability than in the past.

The proportion of 15-19 year olds recorded with an intellectual disability rose from 1.9% in Census 2011 to 2.4% in Census 2016. Between the school years 2011/12 and 2017/18 the proportion of school-age children in special schools or classes rose from 1.1% of their age group to over 1.6% and the proportion of children in

### *Adult day programmes (continued)*

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mainstream school with Special Needs Assistant (SNA) support to their age group rose from 1.4% to 2.1%. The growth in children presenting with autism is a key factor – 70% of special classes in 2017/8 were for autism, and this has also been a lead factor behind the growth in SNAs relative to the school-age population. It remains to be seen whether a rising prevalence of intellectual disability and of autism observed in the school-age population will translate into a higher proportion of school-leavers requiring adult day services, or whether current rates of entry to adult day services already reflect those factors.

#### **5.8 Exits from day services**

Without good data on exits from day services for all groups of service users, the best available guide is the National Intellectual Disability Database. Data were available from the NIDD on exits from disability day programmes over the period 2014-17, as well as overall exits from the database, by age.<sup>48</sup> Table 22 shows a 1.5% exit rate from adult day programmes (excluding Rehabilitative Training) in 2017. A set of simulations modelled this exit rate, along with variants which ranged from 1.4% to 1.7% (the average exit rate in that period, the highest exit rate in any of the four years, and the average exit rate excluding non-HSE programmes). The results showed no significant difference in predicted day places required across this set of exit rates (Appendix 4).

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<sup>48</sup> These cover exits due to deaths or leaving specialist disability services, but not inter-transfers between different programmes or services. Exit data cover those aged 20 and over, while the data on day service participants refers to those aged 18+.



*Adult day programmes (continued)***Table 22: Exits and exit rates from day services and other programmes in 2017**

	ID adult service users	RIP	Other exits	Total exits
Activation centre	8,242	75	13	88
Sheltered work centre	2,250	10	6	16
Special high support day service	746	10	0	10
Supported employment	632	2	5	7
Other day service	615	8	9	17
Programme for the older person	566	23	6	29
Generic day services	557	1	1	2
Special intensive day service	482	4	0	4
Outreach programme	418	4	1	5
Vocational training	225	0	21	21
Open employment	144	0	12	12
Third level education	66	0	11	11
Sheltered employment centre	35	0	0	0
Enclave within open employment	5	0	0	0
<b>Total</b>	<b>14,983</b>	<b>137</b>	<b>85</b>	<b>222</b>
<b>Percentage exit</b>		<b>0.9%</b>	<b>0.6%</b>	<b>1.5%</b>

Source: NIDD, special tabulation

A further set of simulations looked at the exit rate of all adults from the NIDD over that same four year period. Again, the 2017 rate, the average rate, and the highest exit rate were modelled (2.5%, 2.7%, 3.3%).

In addition, an exercise was conducted to establish what annual exit rate would have yielded the February 2020 total of 16,400 participants, had the proportion of 18/19 year olds entering day services been at its 2015-18 steady rate back to the mid-1960s. This exercise produced a possible exit rate of 5.4% a year.<sup>49</sup> This is likely to be an upper bound to possible exit rates, as participation in day programmes would have been significantly lower in earlier periods when disability services were less well developed, and a lower inflow rate implies a lower exit rate to arrive at the 2020 participation level.

Simulations were carried out using each of these potential exit rates weighted across all age groups. Because exit rates in the NIDD vary considerably over the age span – young adults are more likely to quit specialist disability services,

<sup>49</sup> This approach was suggested by Dr Gráinne Collins of the National Disability Authority.

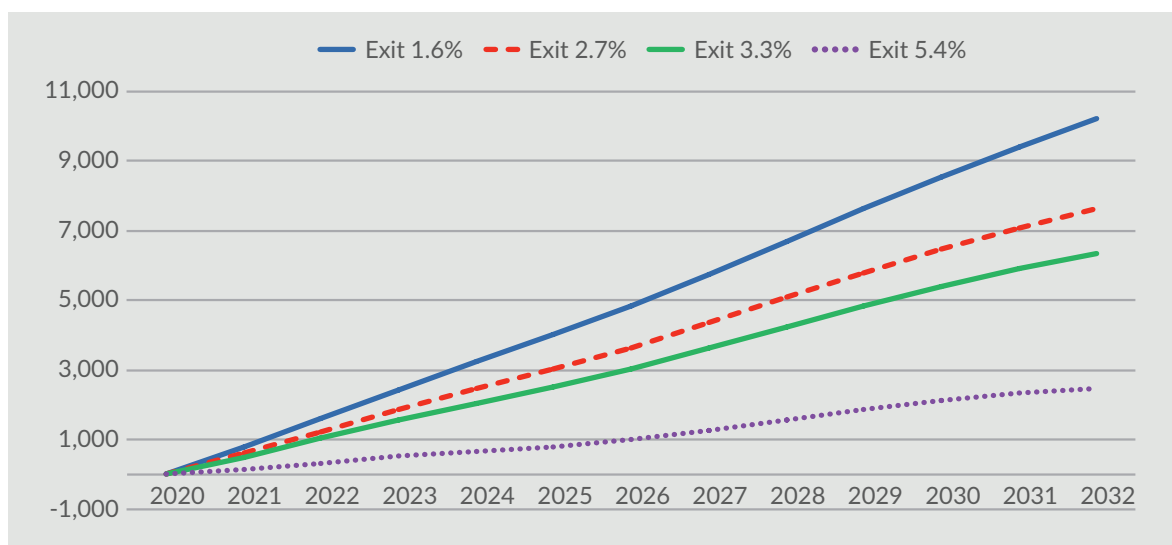
### Adult day programmes (continued)

and older adults to pass away – these baseline exit rates used in the modelling were therefore reweighted in line with the age pattern of the central population projection. Because of the changing age-structure of the population, the weighted exit rates associated with any given starting value rose somewhat over the period – for example the overall weighted 1.5% exit rate in 2017 had become a weighted 1.75% by 2032.

Starting with an estimated 16,400 formal day service places in 2020, the inflow based on school leaver population was added, the exits as a proportion of that year’s day places were deducted, and the net balance added to form the starting point for the following year. Further details of the procedure and the output from the calculations are shown in Appendix 4.

The additional day places required to meet anticipated population change depended critically on the exit rate used in any version of the model. With an exit rate of 1.6% (based on exit rates of ID service users from day services in the 2014-17 period), about 10,000 more day places than in 2020 would be required by 2032. With an exit rate of 2.7% (based on average exits of adults from the NIDD), an extra 7,500 places required in 2032.<sup>50</sup> If the exit rate is 3.3% (the 2014 exit rate), an extra 6,000 or so places would be needed in 2032. An exit rate of 5.4% (based on modelling steady inflow/outflow back to the 1960s) would mean an extra 2,500 places needed by 2032 (Chart 5).

**Chart 5: Range of forecast increase in adult day service nos**



<sup>50</sup> The projections using the M2F2 population forecasts rather than the birth cohorts produced demand forecasts that were around 500 lower for each exit rate modelled.

*Adult day programmes (continued)*

If each additional place is costed at around €25,000<sup>51</sup> (to include both current costs and premises costs associated with day service hubs), the projected increase in spending is as follows:

**Table 23: Projections of increased annual spending on day services to 2032 due to demographic change, on different exit rate assumption**

	Low 1.6%	Medium 2.7%	High 5.4%
	€m	€m	€m
2021	20	15	4
2022	40	31	8
2023	61	47	13
2024	81	62	17
2025	100	76	20
2026	121	91	25
2027	144	109	32
2028	168	127	40
2029	191	145	47
2030	213	161	53
2031	235	177	58
2032	255	191	62

Note: output from model calculations suggest broad order of magnitude for given assumptions, not precise amounts or timing

What is certain is that the number of young people entering day services is scheduled to grow if the ratio to their peers remains the same. The number of vacancies created through deaths is small, however the major unknown is the size of any drop-out rate. Because of the lack of solid information on exit rates, it is difficult to pin down the likely scale of service required over the coming decade. However, the range here suggests that at a minimum, additional stepwise capacity for day services will continue to be required over the period to 2032. Until there

<sup>51</sup> The New Directions day service model envisages people with disabilities being supported to engage in mainstream community activities where possible, rather than people staying in a day centre for most of the day. The focal point from where activities are organised is called a hub. HSE Disability Services said the average cost of a new Day Service place had risen to €25,000 by 2019. The increased cost per place reflects the more complex needs presented by those entering day services, in particular the increasing prevalence of autism with behaviour challenges requiring additional support.

## Adult day programmes (continued)

are better data on exit rates, it will be difficult to narrow this very wide range of potential variation in the possible costs of meeting demographic need for adult day services. It is anticipated that by end 2020, the HSE will have better information on the scale of exit rates from day programmes.

Appendix 4 sets out the detailed calculations and assumptions that underpin the projections of future demand for day services set out above.

### 5.9 Unmet need

#### Those with no day service at present

There are only small numbers of people who are documented in the NIDD as having no day services but who require one – 185 individuals in 2017.

#### Lack support for a meaningful day

However, there are people living in supported disability housing who may have a level of day support that falls short of what would be required to ensure they can have meaningful day activities and engagement in their community in line with the principles of New Directions. This has come into sharper focus when people transfer out of congregated settings into an ordinary house in the community.

The *Time to Move on from Congregated Settings* report in 2011 had documented that of the 3,900 people then in these centres, around 1,100 people (around 30%) had either no day service or a very limited one. It also indicates that 1,600 people (around 40%) were receiving a day service that was campus based. As no funding has come available in the interim period to provide for day services in these centres, it is likely that at a minimum 30% of those who remain living in congregated settings would still lack a day service, which would translate to over 600 people. The cost of providing day services for these would total around €15m a year, offset by any substitution for existing staff support during the regular weekday. The cost of day programmes required for those who have already moved out is not readily available. In addition, campus-based day services which haven't done so would require to be reconfigured in line with New Directions principles. Netting out these different factors, an indicative cost of €15m a year is provided for current and former 'congregated settings' day services.

## *Adult day programmes (continued)*

### **Current day service users with additional service needs**

The HSE estimates that about 3,000 day service users are only receiving a partial day service – while it is not known what would be the balance between those who have unmet needs, and those who are satisfied with their current level of provision, their best estimate is that about half of those concerned would require an additional two days service a week, equivalent to an extra 600 full-time places. The additional cost would come to about €15m a year.

There are also people who require a service change as they get older. If that is just an inter-transfer between services that have similar levels of cost, there are no financial implications. However, some people may need more intensive day support as they get older. Some of those who are currently part-time attendees, perhaps reflecting a rationing of available services, may need additional days of support.

### **5.10 Summary – day services**

#### **Scale of demographic need critically depends on rate of exits**

Over the period 2015 to 2018, about 1,000 new day places had to be created each year to ensure that school leavers and those leaving Rehabilitative Training who required a place in a day service would have one available to them. This pattern of an annual step increase in the number of day service places required is likely to continue over the period from 2019 to 2032, given the large numbers reaching school-leaving age over that period. However the scale of the step increase required is uncertain. While a small number of places become available as older service users pass away, the scale of drop-outs from day service programmes is not known, and a range of plausible exit rates modelled produce estimates of future capacity requirements that vary very widely in scale. On a low exit rate, the size of the annual step increase in provision required could average around an additional €20m. On a high exit rate, the annual step might be as low as €5m a year.

#### **Unmet need may cost €30m a year**

Information from HSE suggest two main areas of unmet need are

- People in or exiting congregated settings who have no formal day programme
- People receiving a partial day service who may require additional hours or days of support

The numbers involved are estimated by the HSE to be considerably greater than the small numbers recorded on the NIDD as requiring a service or an additional service – perhaps 600 people in congregated settings with no service, and 3,000 people who get a partial day service only. The combined additional cost of addressing such shortfalls is estimated to be €30m a year.

### Overall estimates of additional funding required for adult day services

Table 24 summarises the range of estimates of additional service needs arising from the combination of demographic change and unmet need together.

**Table 24: Additional cost of adult day services – demographic and unmet need combined**

	Demographic change			Unmet need	Total	Total Rounded
	Low	Medium	High			
	€m	€m	€m	€m	€m	€m
2022	8	31	40	30	38-70	40-70
2027	32	109	144	30	62-174	60-170
2032	62	191	255	30	92-285	90-280

# Chapter 6

## Multidisciplinary therapy services

# Multidisciplinary therapy services

## Key points

- Multidisciplinary therapies play a vital role in maximising the potential of those born with a disability and in rebuilding capacity of those who have acquired a disability.
- There are significant shortfalls in access to specialist disability therapy services for both adults and children, and their access to mainstream therapies via primary care is sporadic.
- The National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland has identified a major shortfall in access to timely neuro-rehabilitation.
- Current use of different therapies varies by age and type of impairment, with speech and language therapy for example most commonly availed of by children.
- Demographic demand for children's therapy services, at current use rates, will be broadly stable up to 2027, as fewer young children will be largely counterbalanced by larger numbers of teenagers. By 2032, however, the total number of children will fall, lowering demand for children's therapy services by about 10%.
- The number of adults with a disability will rise steadily. Taking adults and children together, total numbers of people with disabilities will rise.
- Overall, demographic change will lead to an increase in demand which by 2032 is expected to be about 7-8% higher than in 2018.
- The combined impact of addressing unmet need and of demographic change will raise overall demand for therapy services by about two thirds by 2032.
- For people with an intellectual disability, provision of dietician services would need to more than double, provision of psychology and occupational therapy would need to double, while provision of speech and language therapy, physiotherapy, and social work would need to grow by around three quarters.



## Multidisciplinary therapy services (continued)

### Key points (continued)

- Spending on specialist disability therapies would need to increase by around €54m a year by 2032, most of it to tackle unmet need. That cost could rise to around €80m if the demonstration phase for specialist community-based clinical rehabilitation networks were to establish that these would not overlap with the requirement for additional disability therapy provision identified in this Disability Capacity Review.

### 6.1 Background

Multidisciplinary therapies such as physiotherapy, speech and language therapy, occupational therapy and psychology play a vital role, particularly in maximising the potential of young people born with a disability, and in the re-ablement of people who have acquired a disability. While people with disabilities may access some therapies via primary care, acute hospitals, or privately,<sup>52</sup> there are also specialist therapists and multi-disciplinary therapy teams for people with disabilities funded under the HSE's Disability Services programme. Disability therapists working with adults are usually attached to a particular service provider, while children's services are being reorganised into area-based teams. In 2018, specialist disability therapy services accounted for €84m or 4% of overall disability expenditure. An additional 100 posts for children's disability therapy services allocated in Budget 2019 were being filled during 2019, with a full-year cost of €6m., bringing total cost of delivering the new level of service to around €90m.

### Services to people with ID

Around 9,000 children and 16,000 adults with intellectual disabilities received therapy services in 2017, constituting 88% of children and 81% of adults registered on the NIDD, while almost 20,000 of those registered required new or enhanced therapy services.<sup>53</sup>

<sup>52</sup> ESRI research has found considerable geographic variation in the distribution of therapy professionals in Ireland, along with substantial private provision of physiotherapy, the one profession for which they had that information. See Smith S et al (2019) Geographic Profile of Healthcare Needs and Non-Acute Healthcare Supply in Ireland. ESRI Research Series no 90.

<sup>53</sup> People were recorded as receiving a therapy service if they got at least four inputs of that service.

*Multidisciplinary therapy services (continued)*

The principal therapies used vary by age (Table 25). For children with intellectual disabilities, speech and language therapy, followed by occupational therapy, are the most frequently used. As people age, ID medical services and ID nursing are the most frequently-used therapeutic inputs.

**Table 25: Use of different therapies by age, people with intellectual disability**

% of those on NIDD at different ages who got at least 4 units of specific therapies, 2017

Therapy type	under 20s	20-29 years	30-49 years	50-65 years	66 and over
Speech/ language therapy	65%	27%	23%	26%	29%
Occupational therapy	49%	19%	19%	23%	32%
ID-related medical services	39%	27%	38%	49%	57%
Physiotherapy	38%	17%	18%	22%	30%
Psychology	36%	28%	29%	29%	21%
Social work	35%	35%	38%	37%	33%
Other	23%	20%	28%	30%	25%
ID-related nursing	22%	18%	33%	42%	54%
Dietician	10%	8%	14%	21%	27%
Psychiatry	7%	16%	34%	47%	56%

Source: NIDD 2017, special tabulation

**Physical, sensory or neurological disability**

About 88% of people with physical, sensory or neurological disabilities registered on the NPSDD receive some therapy or community support worker input, while around 30% require either new or enhanced therapy services.<sup>54</sup> Here again, use rates of different types of therapy vary by age. Speech and language therapy, followed by occupational therapy, and physiotherapy, in that order, were the three most common services for children. Community support workers, physiotherapy, and occupational therapy were the most commonly used services by adults (Table 26).

Note that with the exception of public health nursing and community support workers, access to support in these areas is significantly lower for adults than

<sup>54</sup> Based on about 5,700 files on the NPSDD that were registered or reviewed in 2017.

*Multidisciplinary therapy services (continued)*

for children. This reflects the reality that therapy services in the community are predominantly focused on the under 5s and over 65s, with many in the 18-64 age group routinely unable to access therapy services.<sup>55</sup>

**Table 26: Principal therapies etc availed of by children and adults with P&S disability**

% of those on NPSDD who got at least 4 units of specific therapies, 2017

	Children	Adults
Speech and Language Therapy	50%	7%
Occupational Therapy	50%	28%
Physiotherapy	47%	37%
Psychologist	25%	5%
Orthotist/Prosthetist	24%	13%
Social Worker	18%	8%
Clinical Nutritionist	13%	8%
Public Health Nurse	12%	20%
Audiology	11%	9%
Community Resource Worker	10%	54%
Assistive Technology/Client Technical Service	9%	8%

Source: NPSDD Table 13. Cases registered or reviewed in 2017, N=5,654

**Community neuro-rehabilitation**

The National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland has identified a major shortfall in access to timely neuro-rehabilitation. Under the Implementation Framework, a tiered model of care with appropriate clinical pathways is proposed – complex specialist rehabilitation services; specialist in-patient rehabilitation services; and community specialist rehabilitation services. A proposal has been developed under that Framework for a demonstration project of a Specialist Managed Clinical Rehabilitation Network in CHO 6 & 7, which cover about a fifth of the population. The staffing would be additional to the current disability therapy teams. This demonstrator project is costed at about €5.2m. Subject to the findings during a pilot phase, a full roll-out of that model to all geographic areas would cost around €26m a year.

<sup>55</sup> While fewer adults require speech and language therapy, this is an important element of rehabilitation following onset of a neurological disorder, or for assistance with swallowing.

### *Multidisciplinary therapy services (continued)*

The success of improved trauma and stroke services is leading to an increase in survival rates to the order of 30% to 40%. Over 40% of those survivors will have an acquired brain injury or spinal cord injury. No additional provision has been made in this forecasting exercise for a continued growth in the number of survivors requiring specialist neuro-rehabilitation or other specialist disability therapies, above what is provided for under the Neuro-rehabilitation Strategy implementation framework.

It would remain to be established over the course of the rehabilitation demonstrator project, and in the light of data to emerge from the National Ability Supports System, to what extent there would be an overlap between service needs identified in the neuro-rehabilitation strategy, and service needs identified in the current *Disability Capacity Review*. For the purposes of the current exercise, the €26m cost of a specialist managed community clinical rehabilitation network is treated as additional to any specialist disability capacity needs identified here, however that can be revisited in the light of findings emerging from any demonstration project.

#### **Access to mainstream therapy via primary care is uneven**

In principle, people with disabilities may access mainstream therapy services delivered via primary care.<sup>56</sup> Some of the services listed in Tables 25 and 26 above, like public health nursing, are only delivered through primary care. Specialist disability therapy teams deliver services like speech and language therapy, occupational therapy, psychology and physiotherapy that are in principle also available through primary care, but it is often difficult for someone with a disability to access the generic community service.

That people with disabilities are less well-served than others by primary care can be illustrated by their oral health status. Data from the IDS-Tilda longitudinal study of people with intellectual disabilities has shown that almost one in five had neither any natural teeth nor any dentures. They were twice as likely to have no natural

<sup>56</sup> Under s26 of the Disability Act 2005, public bodies are obliged to include people with disabilities in their mainstream services where practical and appropriate.

## Multidisciplinary therapy services (continued)

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teeth as their peers. Where no natural teeth were present, their peers were twelve times more likely to have had dentures fitted.<sup>57</sup>

### Adults

A 2019 study by the National Federation of Voluntary Bodies has documented access to primary care therapy services for service users with intellectual disabilities, across a sample of its member organisations.<sup>58</sup> This showed that for adults in these services, access to therapy services via primary care is far from the norm. The study showed different experiences across CHOs, and across residential settings. In general, those living with family had the best level of access to mainstream services, and those in congregated settings, the least access, and with group homes and congregated community settings in intermediate positions. These service providers reported that in CHO6, irrespective of where they were living, people with intellectual disabilities had no access to primary care therapies.

### Children

Children with disabilities have also experienced difficulties in accessing primary care therapies, particularly if they are on a waiting list for a statutory Assessment of Need under the Disability Act. In some areas, it has been the practice that a child can be either on a disability list or a primary care list, but not both, even if the disability list has long waiting times for assessment and follow-up intervention. Under the Progressing Disability Services for Children programme, children's disability therapy teams are in the process of being reorganised into area-based multi-disciplinary teams, with a view to serving all children in their catchment areas who have complex needs, irrespective of their affiliation with any particular

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<sup>57</sup> McCarron et al (2017) *Health, Wellbeing and Social Inclusion: Ageing with an intellectual disability in Ireland*. Dublin: TCD. The sample was 692 people with an intellectual disability, aged 40 or over at the time of the original sample. People with intellectual disabilities and no teeth were three times more likely than others to have difficulty eating, twice as likely to be on a liquid diet, and twice as likely to experience chronic constipation.

<sup>58</sup> 33 disability services participated in the survey, representing providers delivering services to about 10,000 people with intellectual disability, or roughly half the adult ID population. See National Federation of Voluntary Service Providers (2019) *Listen to our Voices: Report on therapy services for adults with an intellectual disability in Ireland*.

## Multidisciplinary therapy services (continued)

service provider.<sup>59</sup> HSE estimate that roughly 3.5% of the child population require specialist disability input from multidisciplinary children's Disability Network Teams while a further 0.5% with non-complex needs (or complex needs requiring single discipline rather than interdisciplinary team input due to their disability) are likely to require Primary Care episodic interventions.

### 6.2 Forecasting methodology

There is no comprehensive data on the number on people with a physical or sensory disability who get therapy services; on the number of staff delivering a specialist therapy service to adults; nor on access to primary care teams. So the principal approach has been to estimate what proportion of existing service levels would be required to tackle current unmet need and address the likely changes in the size and age composition of the disability population, and to apply that percentage change to the current therapy services budget.

### Population change

Data on the age pattern of current therapy use (from both the NIDD and the NPSDD) were used along with relevant population forecasts to calculate the weighted impact of likely population change on the use of different therapy inputs. The projections of the adult population with intellectual disabilities as set out in Section 2 of this paper were used for that group. For children with intellectual disabilities, and for people with a physical/sensory disability, the CSO's M2F2 population projections were used to predict the likely rate of change in the size and age structure of these populations. This projection suggests that while the number of young children is expected to fall as a result of falling birth rates, this is significantly counterbalanced by continuing growth predicted in the number of teenagers. Section 6.3 sets out the implications of demographic change alone, assuming that the usage rate for each age group remains constant at its 2017 level. Section 6.4 estimates the change in services required to address current levels of unmet need, and Section 6.5 estimates the impact of demographic change if the baseline rate of provision were changed to eliminate unmet need.

<sup>69</sup> Some children may also attend therapists privately. Rose et al (2015) documented parents paying for private assessments and therapies, given long queues for public provision. Project Iris – Inclusive research in Irish schools, NCSE Research Report 19 <https://ncse.ie/wp-content/uploads/2016/07/02383-NCSE-Research-Report-19-Project-IRIS.pdf>.

## Multidisciplinary therapy services (continued)

### 6.3 Results - Implications of demographic change alone

The impact of falling birth rates on lowering the demand for children's therapies is outweighed by requirement for additional services to meet current shortfalls in levels of provision, so overall, a significant net increase in therapy services is required over the period to 2032.

#### Children with ID

Table 27 sets out the change in the level of therapy service required by children with ID at current use rates. There is a small increase in demand forecast in the early 2020s, followed by a slight fall to 2027, and a greater fall to 2032. By 2032, at current use rates, the changing demographics would lower the demand for children's ID therapy services by about 9% below its 2017 level.

**Table 27: Future demographic demand for children's ID therapy as ratio of 2017 provision**

	No. of users in 2017	% as a ratio of 2017		
		2022	2027	2032
Speech/ language therapy	5,925	102%	99%	91%
Occupational therapy	4,563	102%	98%	91%
Physiotherapy	3,556	102%	98%	91%
ID-related medical services	3,522	102%	98%	91%
Social work	3,121	102%	99%	91%
Other	2,133	102%	98%	91%
ID-related nursing	2,015	102%	98%	91%
Psychology	3,228	103%	99%	91%
Dietician	898	102%	99%	91%
Psychiatry	527	104%	101%	92%
<b>All therapies</b>	<b>100%</b>	<b>101%</b>	<b>96%</b>	<b>90%</b>

#### Add in adults with ID

At current age-related use rates, the impact of demographic change for adults with ID was estimated using both the central population forecast, and the 'youth inflow' forecast. The results were then aggregated with those for children (from Table 27 above), and are shown below in Table 28. Demand from a larger expected population of adults with ID counteracts the effect of the expected fall in the number of children. The highest overall rate of increase is predicted for psychiatry,

### Multidisciplinary therapy services (continued)

reflecting the growth in the older population and prevalence of dementia among older adults with ID. Growth in speech and language therapy is very modest, reflecting the expected fall in the number of younger children. Overall, demographics on their own are predicted to create a modest growth in demand, based on the central population projection for people with ID. The figures are slightly higher when the 'youth inflow' projection is used.

**Table 28: Estimated change from 2018 in demand for ID therapy services due to demographics, all ages**

Central and 'youth inflow' projections

	2017	2022	2027	2032	2022	2027	2032
	No of users	Central projection			Youth inflow projection		
ID-related medical services	11,193	4%	6%	8%	6%	10%	14%
Speech/ language therapy	11,129	3%	4%	4%	5%	9%	10%
Social work	10,275	3%	6%	8%	6%	11%	16%
Occupational therapy	8,791	3%	4%	4%	5%	8%	9%
Psychology	8,700	3%	5%	6%	6%	10%	13%
ID-related nursing	8,382	4%	6%	9%	5%	10%	14%
Physiotherapy	7,489	3%	4%	5%	5%	8%	10%
Other	7,203	3%	5%	7%	5%	9%	13%
Psychiatry	7,002	4%	8%	12%	6%	11%	18%
Dietician	3,779	4%	7%	9%	6%	10%	14%
<b>All therapies</b>	<b>83,943</b>	<b>3%</b>	<b>6%</b>	<b>7%</b>	<b>5%</b>	<b>10%</b>	<b>13%</b>

### Physical and sensory disability

There was data available from the NPSDD for about 9,000 people whose details were registered or reviewed between 2013 and 2017. While this data does not cover all of those registered on the NPSDD, it is expected that the age-related pattern of therapy service use from a dataset of this scale could be fairly representative in respect of the higher-volume therapies.<sup>60</sup> Holding this rate of usage constant, the implications of the changing size and structure of the population for the scale of therapy use were calculated, as shown in Table 29 below. The calculations covered both children and adults, and were based on the

<sup>60</sup> There were about 9,000 NPSDD files reviewed 2013-17 and about 5,600 in 2017 – it was expected the pattern of use would be more representative for the bigger set. In fact, except for psychology, the results are very similar whichever data set is used.



### Multidisciplinary therapy services (continued)

M2F2 population projection. That projection expects a continuing fall in the birth rate, leading to fewer young children, and a significant increase in the over-50s.

Some of the services listed, like public health nursing, are an intrinsic part of Primary Care. However the data do not distinguish to what extent other services like occupational therapy are delivered as part of a specialist disability service rather than through Primary Care.

Given the expected lower birth rates, and a significant increase in the over-50s, the results show a slightly lower demand for speech and language therapists where under-6s are heavy users, and an increased demand for services like community resource workers, public health nurses and physiotherapy, used more frequently by older age groups.

Demand for particular therapies in some cases is predicted to grow faster for people with ID (Social work, psychology, speech and language) and in others for people with P&S (Physiotherapy and occupational therapy). However, taken overall, the impact of demographic change will result in a very similar change in demand for people with ID and P&S, over the forecast period.

**Table 29: Change from 2017 in need for selected therapies due to demographics, people with P&S**

	No of users, from files reviewed 2013-17	No of users, from files reviewed 2017	2022	2027	2032
Physiotherapy	4,116	2,284	+5%	+8%	+9%
Occupational Therapy	3,588	1,998	+4%	+7%	+7%
Community Resource Worker	3,393	2,217	+5%	+10%	+15%
Speech and Language Therapy	2,086	1,212	+3%	+2%	-2%
Public Health Nurse	1,926	978	+5%	+9%	+13%
Orthotist/Prosthetist	1,750	940	+5%	+7%	+7%
Social Worker	1,339	624	+4%	+5%	+3%
Psychologist	1,273	646	+4%	+5%	+2%
<b>Weighted average, these therapies</b>			<b>+5%</b>	<b>+7%</b>	<b>+8%</b>

Given the closeness of the estimates for those with ID and those with P&S, and the absence of any clear data on the relative weight of the two groups in the totality of disability services, the expected proportionate increase for people with ID (central projection) was chosen as the indicative figure for the costings. This suggests that

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### *Multidisciplinary therapy services (continued)*

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demographics, while maintaining current use rates constant, could add €3m to expenditure required on therapy services in 2022, €5m in 2027, and €6m in 2032.

#### **6.4 Unmet need for therapy services**

Data were available from the NIDD on people who currently have a therapy service, but require additional therapy inputs, as well as people with no current service who require one. There was limited usable data from the NPSDD in this area, where most of those listed were awaiting an assessment. Under the Progressing Disability Services policy, disability therapy services for children are in the process of moving towards delivery to all children with significant disabilities in the catchment, with a single pathway into services, rather than separately by impairment type. It is also likely that waiting lists for adult therapies for people with a P&S disability are subject to the same pressures as for ID service users. So while it was only possible to directly estimate the scale of unmet need for people with ID, it was assumed that a similar percentage deficit would apply in relation to people with P&S.

The data on unmet need from the NIDD covers people who are getting no service, and people who are getting some service, but require additional therapy sessions. Given significant waiting lists for assessment in both children's services, and P&S services, there was little basis to assume that those who did not get a therapy service would have lower needs than those who did. So to quantify the service gap, it was assumed that those with no service for a particular therapy would on average require the same level of input as those currently getting a service. Where someone required an enhanced service, the alternatives modelled were that they required a third, a half or two thirds more than they were already getting.

The additional services for each therapy type to address unmet need were aggregated across all age groups, and the results are set out in Table 30. Current services most closely match requirements in the cases of ID-related medical services and ID-related nursing where nevertheless the estimated shortfall is roughly a quarter of current provision. The highest relative deficits were for dieticians, psychology and occupational therapy, where the level of service needs to roughly double. Speech and language therapy, physiotherapy and social work needs to increase by roughly two thirds. Aggregating all therapies, expenditure in this area would need to rise by between a half and two thirds to address unmet need.

*Multidisciplinary therapy services (continued)***Table 30: Estimated unmet need as % of current provision, by therapy – people with ID (all ages)**

Weighting for 'enhanced service needed'	.33	.5	.66
Dietician	110%	117%	123%
Psychology	85%	93%	100%
Occupational therapy	80%	88%	94%
Speech and language therapy	57%	65%	72%
Physiotherapy	54%	61%	68%
Social work	50%	57%	64%
Other	42%	45%	49%
Psychiatry	30%	37%	43%
ID-related nursing	21%	27%	32%
ID-related medical services	19%	23%	27%
<b>All therapies</b>	<b>51%</b>	<b>58%</b>	<b>64%</b>

**6.5 Combining unmet need and demographic change**

If the level of access to therapy services were raised in each age group to meet unmet need, that would affect the measured impact of demographic change. This exercise was done in relation to the forecast population with an intellectual disability, using the central projection. Table 31 sets out the central percentage rate of change required for different therapies for people with ID if both unmet need and demographic change are to be addressed, relative to the 2017 level of provision. The results suggest that the number of dieticians needs to more than double,<sup>61</sup> the number of psychologists and occupational therapists needs to double, and the number of speech and language therapists, physiotherapists and social workers needs to grow by in the region of two thirds to three quarters. Aggregating across all therapies, provision for people with intellectual disabilities needs to rise by around 70% by 2032.

<sup>61</sup> Data from the IDS – TILDA, the intellectual disability supplement to the longitudinal study on ageing, shows a deterioration in health outcomes by Wave 3 compared to Wave 1, particularly in areas where the input of a dietician would be valuable. The Wave 3 findings include that 80% of those surveyed were overweight or obese. Almost half experienced regular constipation. See <https://idstilda.tcd.ie/about/physicalhealth.php>.

*Multidisciplinary therapy services (continued)***Table 31: Percentage increase required in ID therapies, over 2017 level, to meet combined unmet need and demographic change**

	2022	2027	2032
Dietician	126%	127%	140%
Psychology	100%	100%	107%
Occupational therapy	95%	95%	99%
Speech and language therapy	71%	72%	75%
Physiotherapy	68%	68%	72%
Social work	63%	63%	71%
Other	50%	50%	57%
Psychiatry	43%	43%	54%
ID-related nursing	32%	32%	39%
ID-related medical services	28%	29%	34%
<b>Weighted Total</b>	<b>64%</b>	<b>64%</b>	<b>71%</b>

The estimates are based on those who require an enhanced service needing on average 50% more service

If a similar volume increase were required for people with a physical/sensory disability, the overall volume of therapy services would also need to rise by over two thirds.

### 6.6 Cost of meeting additional therapy needs

Staffing in children's disability therapy services in 2018 was the same as in 2017. On the assumption that staffing of adult therapy services was also the same in both those years, then we can apply the 71% increase required by 2032 over 2017 service levels to the 2018 baseline expenditure of €84m. That would give a gross increase in required spending on disability therapy services of €60m. Offset against that would be the €6m full-year cost of the 100 children's therapy posts which came on stream during 2019, to give a net increase of around €54m over 2018 spending required by 2032.<sup>62</sup>

### 6.7 Future staffing needs in children's disability therapy services

For children's therapy services only, there is information on the numbers of staff in

<sup>62</sup> Based on those who require an enhanced therapy service needing on average 50% more service. If their service shortfall were just a third, the estimate would be €6m lower, and if their service shortfall were two thirds, €6m higher.

### Multidisciplinary therapy services (continued)

2018 across five principal specialties. From this, it is possible to look at change in staffing levels required in these areas for children's teams.

While there are minor differences as between children with ID and children with P&S in relative use by age of particular therapies, the impact of demographics on their own on therapy requirements is very similar for the two impairment groups. Unmet need by speciality is also likely to be very similar for the two impairment groups, given the development of integrated therapy teams. So when these two elements of future need are combined, it is expected that the change in the volume of therapy services required will be similar for children with ID, and those with P&S disability. So the calculated rate of change required in the supply of services for children with ID was assumed to apply to all children with disabilities. Table 32 shows staffing levels in children's therapy teams in 2018, and the estimated staffing required if both unmet need and demographic change were to be provided for. These figures should be taken as a guide to the general size and composition of children's therapy teams rather than as precise numbers. For each specialty, to fully address unmet need from a current date would require a significant increase in staffing, and then a gradual reduction, from the middle of the 2020s, in that higher staff complement required. By 2032, staffing levels in children's therapy services across these specialties would need to be about 350-400 higher than they will be when the 100 new posts provided for in the 2019 Budget are fully deployed.

**Table 32: Staffing of children's therapy teams 2018 (WTEs), and estimates of future staffing needed**

	Current (Jan 2018)	2019	2022	2027	2032
Occupational therapist	299	491	494	476	440
Speech & Language therapist	326	474	477	460	425
Psychologist	205	377	380	367	338
Physiotherapist	213	305	306	295	273
Social Worker	130	196	197	190	176
<b>Total</b>	<b>1,172</b>	<b>1,843</b>	<b>1,853</b>	<b>1,788</b>	<b>1,651</b>
Unallocated by specialty	9				
<b>+ 100 new posts from 2019</b>	<b>1,281</b>				

The estimates are based on those who require an enhanced service needing on average 50% more service

## Multidisciplinary therapy services (continued)

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### 6.8 Policy considerations

Article 26 of the UN Convention on the Rights of Persons with Disabilities covers habilitation and rehabilitation, and states that such supports should begin at the earliest possible stage, and be based on the multidisciplinary assessment of individual needs and strengths.

#### Early intervention

Early intervention is key to maximising individuals' capacity. Conversely, when assessment and access to treatment is delayed, the result may be that a person is more dependent or has higher support needs than would otherwise be the case. The data shows increasing numbers of young people with dual diagnoses that may combine autism, intellectual disability or mental health difficulties, alongside significant levels of challenging behaviour, who require high or intensive levels of support, often at very considerable cost. This section of the paper has identified a substantial shortage of therapy support, especially in psychology and occupational therapy, which if deployed early can play a big role in minimising and managing distress and behaviour difficulties.

#### Access to mainstream therapies and mental health support

Section 26 of the Disability Act 2005 places a duty on public bodies to include people with disabilities in mainstream services, where practical and appropriate. Equal access to health treatments is also a key theme in Article 27 (Health) of the UN Convention on the Rights of Persons with Disabilities. In practice, there is often restricted access for children and others with disabilities to mainstream therapy services delivered through primary care. It is essential to ensure that people with disabilities are not disadvantaged in this regard. As additional resources are put into primary care therapy services under Sláintecare, and integrated health service delivery becomes the responsibility of the six new regional health bodies being established, it will be essential to ensure that people with disabilities can access such mainstream services.

In spite of widespread dual diagnoses of disability and mental health difficulties, mental health supports are often not available through CAMHS or other mental health services once a person has a diagnosis of disability. This is another area where timely intervention and support could help reduce the incidence of extreme personal distress and associated behaviours that challenge. This *Disability Capacity*

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### *Multidisciplinary therapy services (continued)*

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Review has already drawn attention to how intensive levels of support needed for young people with disabilities and significant challenging behaviour has been a major factor driving up unit costs in both residential care and in day services.

#### **Workforce planning for therapy services**

Expanding the provision of therapy services needs to be accompanied by a strategy to ensure the availability of people with the relevant skills and qualifications to deliver them, where and when they are needed. Disability service providers report that children's therapy teams under Progressing Disability Services have been staffed at the expense of adult services. Even where additional therapy posts are approved, recruitment may be slow because of shortages in a given specialty. Psychologists are in particularly short supply, while this paper has estimated that their number in disability services needs to roughly double. Another practical issue in that regard is that pay rates are higher for this grade than for other therapies, which may prove a barrier to getting the optimal skill mix, relative to need, from a finite budget.

By the end of the 2020s, the total number of children will have fallen, while the number of adults with disabilities will have increased. Although the overall demand for disability therapies will rise, it may be necessary to deploy staff from children's to adult therapy teams.

#### **6.9 Summary – therapy services**

Current patterns of therapy use vary by age, with children for example more likely to require speech and language therapy. Expected population change will bring overall an increase in the numbers with a disability, a change in the age profile, and fewer young children as the number of births continues to fall. If population change were the only consideration, we would see a fall in demand for children's therapy services emerge at the end of the 2020s, while overall demand will continue to rise a little. However significant shortfalls in current therapy provision are documented, with statutory maximum waiting times for children's assessments being regularly breached, and reports that therapists have been withdrawn from adult services to bridge some of the gap. The scale of unmet need more than counterbalances the demographic decline. Combining unmet and demographic needs, it is estimated that ID therapy services would need to increase by around 64% by 2022, and by 71% by 2032. The rate of change for P&S services is probably roughly pro rata.

### *Multidisciplinary therapy services (continued)*

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Spending on therapy services needs to increase by around €50m a year, rising to around €54m a year by 2032 if those needs are to be addressed.

For people with ID, access to dieticians needs to more than double, the number of psychologists and occupational therapists needs to roughly double, while speech and language therapy, physiotherapy, and social work are estimated to need to increase by around three quarters. For people with physical or sensory disabilities, access to community support workers, public health nurses and physiotherapy are the main areas where the changing age structure of the population will drive demand.



# Chapter 7

## Personal assistance and home help

# Personal assistance and home help

## Key points

- Data on unmet need has not been systematically recorded, given the fixed number of service hours available to deploy, but there are signs it is substantial.
- The additional costs of demographic change are estimated at €4m a year by 2022, €10m a year by 2027, and €15m a year by 2032.
- An indicative package to provide greater access, and additional levels of support for those who currently receive minimal hours, has been costed at €30m a year.

Personal Assistant (PA), Home Support, Assistive Technology (provided and funded under Primary Care), and community support services from disability organisations specialising in specific conditions all play an important role in supporting people, particularly those with physical, sensory or neurological disabilities, to manage their condition and live as independently as possible. The principal forms of personal support services funded by the HSE are home support including home help/home care, and personal assistant services.

Just under 11,000 people currently receive Home Support or Personal Assistant hours – roughly twice as many hours are given in the form of Home Support. The 2018 budget breaks down roughly as €55m for Home Support and €32m for PA services.

About 2,500 people get a PA service averaging around 12 hours a week, and around 8,000 people get home support hours averaging around 7 hours a week. Data from the NIDD for 2017 showed around 1,900 people (half of them children) receiving home support. That suggests that people with intellectual disabilities account for around one in four home support recipients, while those with physical/sensory/neurological disabilities would constitute the balance. Personal assistance services support people with physical/sensory/neurological disabilities. Data from the NPSDD suggests that 90% of those with P&S disability who use home care, home help, or PA are adults.

## Personal assistance and home help (continued)

### 7.1 Impact of demographic change

Given that the most typical home care and PA recipients are adults with a physical or sensory disability, the impact of demographic change on likely future demand can be approximated by applying the expected rate of growth in the number of adults (under 65) with P&S disability, as shown in Table 33. About two thirds would be for home care/home support, one third for PA services.

**Table 33: Additional funding required home support/PA services to meet demographic change**

	2022	2027	2032
Expected change in adults with P&S disability v 2018	5%	11%	17%
Increase in funding needed for demographic change	€4m	€10m	€15m

### 7.2 Unmet need for home support and PA services

While the organisations working in the area of physical and sensory disability report considerable shortfalls in the level of provision relative to need, there are little or no usable data on the scale involved. This is because it has not been the practice by service providers or the HSE to document unmet need for these services. The budget for PA services has remained unchanged since 2008, so the HSE has been managing a fixed number of support hours each year.<sup>63</sup> As a result, as reported to the Dáil, the HSE may from time to time reduce an individual's support hours in order to address priority needs of other people with disabilities within that community.<sup>64</sup> A high volume of representations and Parliamentary Questions on the topic is another indicator of the pressures on the system that are not being met. As unmet need had not been systematically recorded, the NPSDD and the NIDD have only captured negligible levels of unmet need, be that those without any service, or those whose hours of support are below what they currently need.

<sup>63</sup> There has been some substitution of PA or home care for respite, but no overall increase in support hours available. Pent-up demand for residential placements and respite from people on the emergency list has resulted in the increased usage of in-home support hours as a holding strategy to somewhat ameliorate the high risks in the home. This consequently limits the availability of hours to other people with disabilities requiring home care or Personal Assistance.

<sup>64</sup> Reply to Oral PQ 41186/19.

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### *Personal assistance and home help (continued)*

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The National Ability Support System will begin to collect more comprehensive information on unmet need.

#### **People with difficulty with ADLs who get no service**

Current provision of PA and home support services caters for just a fraction of the people with disabilities who experience difficulties with activities of everyday living such as washing or dressing themselves, or would need to be accompanied to leave their homes. As the National Disability Survey 2006 showed, the main sources of support people draw on are their family or friends. It is not known how many people face significant difficulties because they do not have access to the level of support they need from either informal or formal sources.

Data from the NPSDD 2017 showed around 38% of people surveyed on the database had difficulties with basic self-care like getting dressed or taking a bath/shower.<sup>65</sup>

Some degree of the reach of HSE-funded provision relative to the potential numbers with difficulties in this area can be gauged from a special tabulation of Census 2016, and from the National Disability Survey. As a minimum estimate of potential need, the focus was limited to those in the age range 35 to 65. Census 2016 showed 31,000 people with physical/mobility in this age range who had difficulty with personal care (dressing/bathing) or moving around their home. 18,000 people had difficulties both in this area, as well as in going outside the home alone. The first group may need home care assistance or assistance with household tasks, the second group may also need assistance to get out and about. Data from the National Disability Survey 2006 showed 15,000 people with a physical/mobility disability in this age range who had a lot of difficulty in everyday activities, and 3,000 who were unable to do such activities. Adjusting those figures for changes in the size and age structure of the population in the intervening period would give 25,000 in the 'lot of difficulty', and 5,000 in the 'unable to do' categories. Table 34 compares the scale of the potential numbers who could require support with the current level of HSE-funded support provision.

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<sup>65</sup> NPSDD 2017, Fig 7. This is based on almost 7,000 people on the database who answered a suite of questions (WHODAS 2.0) on difficulty experienced in different aspects of daily living.

*Personal assistance and home help (continued)***Table 34: Potential nos aged 35-64 requiring PA/home support services, and actual provision**

People with a physical/mobility disability and significant difficulty in everyday activities or personal care

	Home support group	PA group
Census 2016 (potential)	31,000	18,000
National Disability Survey (potential)	25,000	5,000
Actual nos. getting PA, home support, 2018	8,000	2,500

**Those getting some support who need additional hours**

There may also be latent demand from those who already get a PA service but require additional hours. Two thirds of those with PA support receive fewer than ten hours support a week, and only 7% receive more than 40 hours (Table 35). A PA service of two hours or less a day is unlikely to be able to go much beyond the provision of basic personal care, or unlikely to enable someone achieve independent living.

**Table 35: Distribution of PA hours, 2018**

Hours per week Personal Assistance	No.	%
1 to 5	1,066	44%
6 to 10	584	24%
11 to 20	424	17%
21 to 40	240	10%
41 to 60	64	3%
60+	58	2%
<b>Total</b>	<b>2,436</b>	<b>100%</b>

Source: HSE

**7.3 Illustrative provision for unmet need****Those with no service at present**

For illustrative purposes only, a costing was done on a 20% increase from current levels of provision in terms of numbers of recipients. This is likely to be well within the boundaries of potential unmet need given that those with support needs around personal care are a multiple of those who currently get it.

## Personal assistance and home help (continued)

### Those who need more hours of support

Again for illustrative purposes, the following changes were costed:

- Increase Home Support hours of current recipients by 10%
- Double the PA hours of those currently getting 1 to 5 hours a week
- Provide 5 hours a week more to those on 6-10 hours PA a week

**Table 36: Cost of illustrative improvements in provision of Home Care/Home Support/PA**

Measure	€m
Increase no. of recipients of each scheme by 20%	17
Increase Home Support hours by 10%	6
Double the PA hours of those on 1-5 hours a week	5
Provide 5 hours a week more PA to those on 6-10 hours	3
<b>Total (rounded)</b>	<b>30</b>

When better data becomes available, once the National Ability Supports System is fully populated and bedded down, any subsequent forecasting exercise should revisit the scale of the need for these services which is not currently being met.

### 7.4 Summary - home support/home care/PA

The growth and ageing of the disability population is likely to drive increased demand for these services, which are largely directed to people with physical or sensory disabilities. The additional cost of demographic change could rise to an additional €15m a year by 2032.

Many signs point to a considerable shortfall in provision of these services relative to need, however this has not been officially quantified, in circumstances where the total amount of service available is capped, and sometimes pressing needs can only be met by reducing someone else's hours of support. Data from the Census and other sources suggests that the potential pool of those who might require these services is a multiple of those who currently get them. For illustrative purposes, an increase in the number of service users, and in the support hours received especially by those with minimal PA hours which might go a small way towards meeting gaps in service was costed, and came to €30m.

# Chapter 8

## Respite

# Respite

## Key points

- Respite has a key role in supporting family carers and the person with a disability.
- How future requirements for respite will alter given demographic change will depend on the scale of residential care provided, and how that impacts on the number of people with disabilities living with family carers.
- Data for 2017 shows only one in four family carers of over 5s with ID had received any respite, and only one in three family carers of adults.
- Latent unmet need could be considerably higher than what is recorded.
- If no progress were made on the backlog of unmet need for residential services, the numbers living with family would be 20% higher in 2032 than in 2017, at an annual extra cost of €10m.
- The cost of meeting the level of unmet need for respite recorded in 2017 could be €16m to €20m a year. Additional latent need could bring that higher.

Respite care, or short breaks, play a crucial role in supporting families caring for a person with a disability. HSE spending on respite rose from about €43m in 2017 to €52m in 2018, with the introduction of additional respite capacity under a special programme to open twelve new respite houses, and expand provision of non-traditional respite options.

About 6,000 people with disabilities received a respite service in 2018. The target for 2019 was for just under 6,600 individuals to get such breaks, as the 12 new respite houses came on stream. Overnight respite is the most common form provided – in 2018, the HSE estimated there were about 165,000 respite bed-nights, compared with 41,000 day-only sessions. However, the additional respite funding provided in 2018 had a dedicated funding scheme to provide alternative forms of respite including summer programmes for children, and in-home respite.



*Respite (continued)***8.1 Number of family carers**

Respite services are primarily intended to support family carers, and to provide a good experience for the person with a disability. The level of future demand for respite is therefore inversely related to the scale of residential provision likely to be made, and should be proportionate to the number of people with disabilities living with family carers.

To illustrate that point, Table 37 sets out the expected percentage change in the number of adults with ID living with family under some of the different residential care scenarios set out in Section 3 of this paper. If provision of residential care were only to keep pace with demographic demand, the proportion of adults living at home would rise steadily, and an equivalent increase would be required in access to respite services. Under the Intermediate or Pre-recession scenarios, demand for respite care could soften, with fewer adults living with family carers.

**Table 37: Number of adults with ID living with family, as % of 2017 level, under different scenarios**

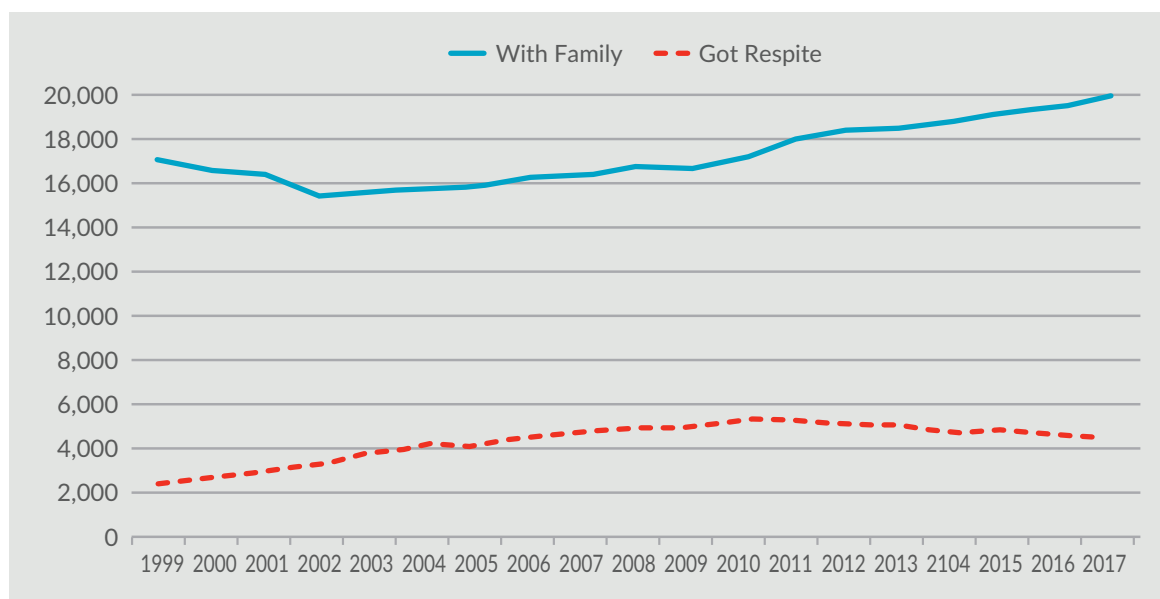
Year	Demographics only	Intermediate	Pre-recession
2022	105%	92%	84%
2027	111%	97%	89%
2032	120%	105%	96%

For example, if there were no provision made to address the backlog of unmet need for residential care, in that scenario, the requirement for adult respite would rise by around 20% to 2032, at a cost of about €10m. a year to provide it. If the demand for respite care were simply to grow in line with the expected increase in the population with a significant disability, then the increase required over the period to 2032 could rise gradually from €2m to €4m extra a year.

In the 2020 Budget, additional funding is being provided for intensive respite support for families where the person with a disability is on the urgent emergency waiting list. While intensive respite support can cost a lot, the expectation is that in offering this support, it may delay or reduce the need there would otherwise be for a very expensive long-term residential place.

## Respite (continued)

### 8.2 Significant levels of unmet need reported



The introduction of regulation led to a loss of some traditional respite capacity – it is no longer acceptable to offer a temporarily vacated bed in the home of a disability service user to someone for a respite stay. In addition, during the recession years when budgets were particularly tight, core day and residential services were prioritised, and short breaks were further down the queue. A further factor affecting supply is the impact of pent-up demand for residential care. This has led to long-term use residential respite places by people for whom there is no permanent residential place, taking those places out of service for respite purposes.<sup>66</sup>

#### Level of unmet need reported in 2017

In 2017, the Health Research Board estimated that about an additional 1,600 people with ID (adults and children) who did not get respite required overnight respite breaks then or within the next five years. In addition, around 1,000 people (out of 4,100 getting overnight breaks) would need additional breaks to be provided. Just under 600 people with ID got day respite that year; estimated additional requirements would raise that by a quarter.<sup>67</sup> Although the NPSDD has

<sup>66</sup> In 2017 there were 75 people with intellectual disabilities recorded as 'occupying a support place', i.e. a respite bed, with Galway, Cork and Dublin the areas most affected. If it is assumed a respite bed can be used 6 nights a week, 48 weeks a year, the potential additional bed capacity that could be unblocked could give over 21,000 bednights.

<sup>67</sup> NIDD 2017 Tables 3.3., 4.4, and 4.10.

*Respite (continued)*

less complete data, they point to an equivalent proportion of unmet need among people with a physical, sensory or neurological disability.

The cost of providing for this level of unmet need could be in the region of an extra €16-20m a year, depending on the relative level of increase required by those whose needs are being partially met. However, there also is potentially a very large latent unmet need for respite, as less than one in four parents caring for children or adults with a disability receive any.

### Just one in four with ID got HSE-funded respite

Fewer than one in four people with intellectual disability living at home with their family received any form of HSE-funded respite service in 2017, and only a third of adults. Access to respite for people with a physical or sensory disability living at home was considerably lower.

**Table 38: Estimated % of those with ID living at home who got different forms of respite, 2017<sup>68</sup>**

	ID	P&S
<b>Overnight respite</b>	%	%
Planned respite in a respite centre	21%	4%
Crisis respite in a respite centre	1%	0%
Occasional respite with host family/ breakaway	2%	1%
Overnight respite in the home	0%	0%
Holiday residential placement	1%	3%
<b>Day respite</b>		
Day respite in the home	0%	-
Centre-based day respite service	3%	-
Summer camp (day)	-	1%

Sources: Adapted from NIDD 2017, Tables 3.3, 3.7; NSPDD Table 20

<sup>68</sup> For NIDD, respite service users in each subcategory are shown as a % of those living in a home setting, however 7% of respite users are in other living arrangements. The NSPDD figures are based on about 5,600 service users whose data was updated in 2017 (of about 20,700 on the database). Some individuals may have got more than one form of respite.

## *Respite (continued)*

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### **8.3 Summary – Respite**

The estimated cost of meeting declared unmet need for respite could be in the region of €16-€20m a year, but latent unmet need could be significantly higher, given that three quarters of families get no respite at all. If no inroads are made on the unmet need for supported housing, then the impact of demographic change could raise the cost of respite provision by around €10m. On the other hand, under the Intermediate or Pre-recession scenarios, the number of adults with disabilities living with family would fall, and, other things being equal, that could lead to a small fall in the overall demand for respite.

# Chapter 9

## Other community services and supports

## Other community services and supports

### Key points

- There is a wide range of community support and advice services, including those offering peer support to people with a specific condition.
- To maintain current levels of provision in the face of demographic change could cost an extra €3m a year in 2022, €6m in 2027, and €9m in 2032.

This heading covers a range of services that support people to live as independently as possible and to participate in the community. It includes for example the services offered by a large number of organisations and peer support groups for people with particular conditions, which offer practical advice, mutual support and social opportunities.

Roles like community connectors, local area co-ordinators, case co-ordinators, can play a vital role in linking people in to mainstream activities and supports in their communities. Where these roles are available, people with disabilities can be enabled to access mainstream activities and services, slowing down or reducing the uptake of more traditional disability services.

This heading accounted for around €53m or 3% of the disability budget in 2018. It is expected that this would need to change broadly pro-rata to the expected growth in the expected size of the population with physical or sensory disabilities. That would suggest that expenditure under this heading would need to be about €3m higher in 2022, €6m higher in 2027, and €9m higher in 2032, compared to its level in 2018.

# Chapter 10

## Summary of changes in funding needs for disability services

# Summary of changes in funding needs for disability service

## Key points

- This Capacity Review has examined and quantified the implications of demographic change and of currently-unmet need for the funding needed for disability services.
- Changes in the size and age-structure of the disability population will increase demand particularly for residential care and adult day services.
- Relative to a baseline of 2018, spending in 2032 would need to be between €250m-€450m higher to meet demographic need.
- There is also considerable unmet need, particularly for residential places, therapy services, personal assistance, and respite.
- To address unmet need, alongside demographic change, would require current disability spending in 2032 to rise by €550m to €1,000m above its 2018 level.
- In broad terms, current spending on disability services would need to rise by between a quarter and a half to deliver the capacity required.
- Additional capital spending for housing to meet residential care needs and complete the closure of residential institutions could cost in the region of €500m to €800m over the period to 2032.
- These figures have not provided for any increase in unit costs that may occur due to pay developments, regulatory compliance, or increased complexity and support-intensity of service need.

## 10.1 Global totals

Table 39 summarises the overall broad level of additional current funding that would be required in 2022, 2027 and 2032, relative to the 2018 level of expenditure, in order to address demographic change and tackle the current gaps in service provision. Two main factors account for the range of estimated funding required

- The scale of residential care to be provided, whether minimum, intermediate, or pre-2007 levels



*Summary of changes in funding needs for disability service (continued)*

- The annual vacancies arising in adult day services, in particular an unknown scale of drop-outs

The figures are not precise as to amounts or timing, but indicate the likely broad order of magnitude, the relative contributions of demographics, and of different elements of service, to the overall totals.

Table 40 shows the estimated additional housing capital that would be required. The total involved would be in the region of €500m to €800m, depending on which ‘unmet need’ scenario is used.

These costings have not made any allowance for any changes in unit costs, although it is recognised there are a number of factors likely to drive unit costs up over the period, including

- Pay developments
- Increasing complexity of need with an ageing population
- Increasing prevalence of complex medical need or extreme challenging behaviour requiring very intensive support
- Achieving full regulatory compliance

**Table 39: Broad estimate, additional annual funding required to meet demographic and unmet need**

Type of disability service	Demography only			Demography + unmet need		
	2022	2027	2032	2022	2027	2032
	€m	€m	€m	€m	€m	€m
Residential – Minimum scenario	60	120	160	220	280	320
<i>Residential – Pre-recession scenario</i>				400	500	550
Day services	8-40	30-140	60-250	40-70	60-170	90-280
PA & home help	4	10	15	34	40	45
Therapies	3	5	6	48-74	48-74	53-79
Respite	2	3	4	18	21	25
Community services	3	6	9	3	6	9
<b>Total (rounded)</b>	<b>80-110</b>	<b>170-280</b>	<b>250-450</b>	<b>350-600</b>	<b>450-800</b>	<b>550-1,000</b>

Estimates are indicative, to show broad order of magnitude. Totals may not add up due to rounding

*Summary of changes in funding needs for disability service (continued)*

**Table 40: Additional housing capital required for disability services to 2032**

	Demography only	Demography + unmet need			Congregated settings
Year	Demography			Pre-recession	
	€m	€m	€m	€m	€m
Now	0	100	200	310	280
2022	60	160	270	380	
2027	110	210	330	450	
2032	150	250	380	520	

Estimates are indicative only to show broad order of magnitude. Totals may not add up due to rounding

**10.2 Relative increase required in current spending**

In 2020, the HSE Service Plan provided for current spending on disability services of just over €2 billion (€2,049m). The figures in Table 39 suggest that current spending would need to rise by something between a quarter and a half to meet the identified capacity needs.

# Chapter 11

## Reflections on policy choices

## Reflections on policy choices

The analysis in this paper has identified significant levels of unmet need for disability services, and that changes in the size and age profile of the disability service population will add to that over the coming decade. The costs of tackling this are very significant. However, if no measures are taken to address this, unmet need will continue to grow and become more acute as the population ages. There will be a significant human cost for the individuals concerned and their families. The chart below sets out the main strategic approaches and their likely consequences.

No change	Meet anticipated need at current service mix	Action to moderate rise in demand for high-cost services
Unmet need grows and becomes more acute as people age. Human cost.	Multi-annual programme and advance planning for service growth	In any scenario, additional residential and day places needed
Expensive crisis interventions – emergency beds cost double the average	Planned services more cost-effective than spot-buying in emergencies	Scope to delay/divert at the margins if investment in right supports
Shortfalls in early intervention – more troubled teens as emergencies	Addressing shortfalls in earlier intervention can pay off later in life	Earlier interventions can maximise achievement of capacity
‘Coping’ families’ lack of supports undermines ability to care	Services can be better planned around the individual’s needs	Effective therapy and mental health supports can moderate challenging behaviours
Increasing court and media pressure leading to reactive overspend	Reassurance to families that services will be there when needed	Support young people to choose mainstream education/ job options
Financial sustainability of services is at risk	Facilitates workforce planning	Supports to families can enhance resilience and capacity to care
Service quality deteriorates as reform programme stalls	Significant cost implications	PA/home support maximise independence, support to remain at home

### 11.1 Consequences of no change

If no future actions are taken to address the imbalances between the current level of supply of disability services and current and anticipated future needs, there will be consequences for individuals and families, and the pressures on the system may lead to unplanned spending and budget over-runs.

### *Reflections on policy choices (continued)*

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If the long waiting lists for assessment and early intervention therapies for children continue, there is likely to be a further increase in the number of teenagers and young adults with disabilities with significant behaviour and mental health issues where family placement is no longer sustainable. This is currently a major component of the emergency waiting list for residential care. Residential placements in these cases can be extremely expensive with the likelihood these could become lifelong costs.

If limited resources in areas like respite or home support continue to be focused on crisis situations, at the expense of supporting other families, the resilience of these other families will be undermined. Ultimately, more of them will move into the 'crisis' bracket, particularly as family carers age.

Overall, a failure to address identified current and future need is likely to increase demand for crisis unplanned interventions, at significantly higher unit cost than planned services. For example, the unit cost of crisis residential places is currently approximately double the average. While some of this reflects the acute levels of need concerned, there is also the factor that the HSE is a price-taker when a place must be sourced in an emergency rather than in a planned way.

This is likely to see an increase in reactive rather than planned spending, driven by pressure from the courts, the political system and the media. Ultimately, that leads to a less cost-effective use of resources than where services are planned. That is also likely to lead to a continuing pattern of overspends, and further build-up of voluntary sector deficits as they respond to local pressures.

It is essential therefore to give consideration to putting in place processes to move to a multi-year budgeting framework in order to meet service need and move towards financial sustainability across the disability services.

The continuing need to reform service models, the service delivery system, enhance cross-departmental working, is critical to enhancing the response to service need.

A significant reform programme has been underway in disability services, guided by the principles set out in the Value for Money and Policy Review of Disability

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### *Reflections on policy choices (continued)*

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Services (2012). Echoing the values of the UN Convention on the Rights of Persons with Disabilities, this programme aims to move away from more segregated and institutionalised models to more person-centred services, to support individuals with disabilities achieve a good quality of life, and to live ordinary lives in ordinary places. It becomes much more difficult to follow through and complete delivery of this reform programme in situations where service providers are operating under severe financial and demand pressures, and where managing crises absorbs the energies needed to deliver the reforms.

#### **11.2 Outcomes if anticipated needs are met with the current service mix**

If a funding programme is made available to address the current shortfall in services and anticipated future needs, it could greatly ease the current critical pressures in the system.

A multi-annual funding framework would facilitate advance planning for service needs, enabling services to be better tailored around individuals' needs, and providing a more cost-effective solution than the current system of spot-buying in emergencies. A planned programme could also facilitate workforce planning to meet the changing size and profile of the disability population.

The uncertainty that families face around whether services will be there for them when they need them adds to the stresses such families are under, and can undermine their resilience. Demonstrating to families that services will be there when they need them could provide significant relief.

Currently, there are significant waiting lists for therapy services for children and adults. Better early intervention services, and better timely access to appropriate therapies including behaviour and mental health support may help mitigate the significant pressures on families and on services of dealing with young people with severely challenging behaviour and intensive support needs. The HSE currently has an emergency waiting list for residential care that includes over 100 young people under 30 with severe behaviour difficulties – the annual costs of a residential place for people with these intensive support needs can be from €300,000 to €500,000.

#### **11.3 Meet anticipated service needs, but refocus service mix**

Meeting anticipated needs with the current service mix has significant cost

### *Reflections on policy choices (continued)*

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implications. Residential care services currently account for around two thirds of the specialist disability budget, serving around 8,300 people at an annual unit cost of around €144,000.

Residential and day services currently absorb around 85% of the disability services budget, however the anticipated growth in demand for these high-cost services could be moderated to some degree by strategic investments in other community-based disability support services. Although additional residential and day places will be needed to address the needs of an ageing disability population, there may be some scope at the margins to divert from or delay entry to high-cost options if there is timely investment in the right supports.

Earlier intervention and improved access to supports for children born with a disability or for those experiencing onset of a disability can help maximise achievement of and retention of capacity. As noted above, effective therapy and mental health supports may help moderate challenging behaviours that may otherwise require long-term intensive support levels.

Structured assessment and guidance, particularly for school leavers, along with supports to engage in mainstream education and employment, can enable more young people with disabilities pursue these options rather than lifetime participation in day services.

Better supports to families, including respite, can enhance resilience and capacity to care, and facilitate delayed entry into long-term residential care. Better access to home support and personal assistance service could maximise people's independence and their ability to live at home for longer.

#### **11.4 Getting the right balance across services**

Given the scale of the challenge, it would be timely to conduct a strategic review of the optimum mix of services across therapies and early intervention; community supports to individuals (and their family carers) who continue to live in the family setting; other community support arrangements; and current models of residential care. While a significant increase in provision of residential places will be required to address unmet need and as a result of demographic change, at the margin there may be scope to moderate or delay entry to residential places through investing

## *Reflections on policy choices (continued)*

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in other community supports. The HSE, for example, has increased its expenditure on intensive respite supports given the numbers of families in crisis, and the small number of emergency residential places available to offer.

### **11.5 Supporting mainstream services and choices**

#### **Transitioning from school**

This paper has identified an apparent growth in the proportion of young adults with a disability entering day services on leaving school. This also follows on from the very large increase in the number of children being educated in special classes. While for some, this is the appropriate pathway, for others, the better path would be to choose a mainstream option for training education or employment, with appropriate supports. Systematic assessment and guidance at this critical turning point could encourage more young people to try out mainstream options, and integrate into mainstream life in the community. There have been positive experiences among those young people who have secured deferment of a day service place, and many have chosen to continue in the mainstream. The Comprehensive Employment Strategy for People with Disabilities has identified the importance of assisting at such transition points.

#### **Better access to mainstream primary care and mental health services**

Increased access to therapies through primary and mainstream services could play a significant role in tackling the current backlog with people accessing the most appropriate services at the lowest level of complexity. Better access to mental health services could help address the anxieties and mental distress that frequently underpin challenging behaviour.

#### **Building capacity in the mainstream**

Building inclusive communities, strengthening capacity of mainstream health and community services to support individuals with disabilities, and deployment of individuals in 'community connector' roles to link people with disabilities in with what is happening in their communities, all have a role to play in enhancing the ability to support people with disabilities in the mainstream. In turn, such initiatives may moderate the extent to which people with disabilities require specialist disability supports.



## *Reflections on policy choices (continued)*

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### **11.6 Are lower rates of residential care of young adults sustainable?**

The current proportion of individuals in a given age group who get residential support has not been the result of an explicit policy, rather it has been the outcome of reductions in supply alongside an underlying growth in the relevant population. The halving since 2007 of the rate of residential provision for people with intellectual disabilities who are in their twenties may be sustainable for some families with appropriate community support, however it is instructive that the largest scale of extremely urgent needs documented by the HSE in its 'active' waiting list is concentrated among the under-30s.

### **11.7 Support to remain in the family home on death of a parent**

When a parent dies or enters long-term care themselves, it has been standard practice that the adult child with a disability would move to a HSE-funded care facility, rather than supporting them to remain living in their familiar home environment and neighbourhood, although some examples of the latter approach are emerging. Issues around ownership of property and inheritance can come into play in these circumstances.

There is scope to consider a wider variety of supported housing options. While group homes shared by a number of individuals with a disability, and supported by staff, is the main form of disability residential care, other arrangements include people living on their own with support, home sharing and host family models, where these meet people's needs. Another model can be a shared housing arrangement where the person with a disability may share with or sublet to non-disabled people, providing natural informal support.

### **11.8 Investing in early intervention and therapeutic support**

There is huge distress for individuals and their families coping with severe behaviour difficulties often associated with a dual diagnosis of mental health issues and disability, as well as enormous costs to the state of supported housing for these individuals. Provision of sufficient early intervention services, and adequate access to therapeutic supports like mental health services, psychology, behaviour support, occupational therapy, and social work supports for families, alongside specific targeting of those at most risk, could play a role in preventing and mitigating the serious emerging problem particularly among young people.

## *Reflections on policy choices (continued)*

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### **11.9 Specialist end of life care**

The increased numbers of people ageing with an intellectual disability, the associated health complications, and the high rate of early-onset dementia, suggest there will be a growing need for specialist and intensive support as people approach end of life. Some service providers (for example St Michael's House, Daughters of Charity) have developed some specialist facilities for end of life care. The National Disability Authority is planning a study on the optimum settings to deliver end of life care to people with disabilities. Should that be appropriate, it may be possible in some cases to repurpose campus-style accommodation, otherwise scheduled to close, to deliver such specialist end of life services.

### **11.10 Personal budgets**

The personal budgets model is scheduled for a two-year trial 2019-20. Depending on the outcome of that process, it is possible that in the future some of the additional demand identified will be addressed via a personal budget rather than the provision of direct services.

### **11.11 Workforce planning**

Any scaling up of current levels of service provision will require workforce planning to ensure the availability of appropriately-trained staff with the right skill mix to deliver the services where and when they are needed. As the age structure of the population changes, some staff would need to be redeployed from children's to adult services. In particular, the significant deficits in therapy provision identified in this paper have implications for the number of psychologists and occupational therapists being trained and available to deploy in disability services. This assessment of the staffing needed for disability services fits into the wider workforce planning programme under Sláintecare.

### **11.13 Regular updating of estimates as new data becomes available**

This paper has prepared a set of broad estimates of future service requirements drawing on a rich source of data in terms of service use and needs for people with intellectual disabilities, and on other data from the Census, from HSE administrative sources, and from the National Physical and Sensory Disability Database. The limitations of the latter data meant that in many cases inferences had to be drawn that the scale of provision required for people with ID could also apply in respect of people with P&S disability.

### *Reflections on policy choices (continued)*

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The integrated National Ability Supports System, when it fully comes on stream, should enable a better assessment be made of specialist disability service use and requirements for people with physical, sensory or neurological disabilities, or autism. Census 2022 will for the first time collect data on the degree of limitation being experienced by people answering the suite of disability questions. It would be valuable to revisit the work done in this *Disability Capacity Review* as relevant new information comes on stream, so that the estimates of future need can be better refined.

## *Reflections on policy choices (continued)*

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# Definitions

# Definitions

## **Supported housing/residential care – 64% of disability budget**

About 8,400 people with disabilities – 90% being people with an intellectual disability (ID) – live in residential care. The most common form this takes is a group home – an ordinary house in the community shared by 4 to 6 people, along with support staff. About 750 people with ID live ‘semi-independently’ with limited staff support. About 2,100 live in ‘congregated settings’ – residential institutions or residential campuses with ten or more people living together. It is Government policy to replace these with ordinary housing in the community, in line with Article 19 of the UN Convention on the Rights of Persons with Disabilities, which Ireland has ratified. The policy that new group homes should have no more than four residents is based on the recommendation of the Congregated Settings report, rooted in the evidence.

About 80% of residential places are provided by non-profit s38 and s39 providers. There is a small but growing for-profit sector, with about 300 residents. It is generally the only sector which has HIQA-approved spare capacity available for emergencies.

The overall supply of residential places has fallen over time, with substandard accommodation withdrawn from service to comply with regulations. At the same time the relevant population has increased. The result has been a consistent fall in the proportion of people under 60 who are in residential disability care, and a corresponding increase in the number of parents caring for adult children.

## **Emergency places**

Lack of access to residential places and limited availability of other supports, have contributed to situations for some where family care is no longer sustainable. Families may be under enormous pressure where there is extreme challenging behaviour, or highly complex medical needs. Carer incapacity, mental illness, or risk of abuse can be other triggers. The HSE estimates there are 250 people whose current care arrangements are in crisis, and a further 200 where that is imminent. This has led to unplanned admissions to emergency residential care, many at very high cost. Some of these were mandated by court orders due to clinical risks and

## *Definitions (continued)*

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safeguarding concerns. In 2018 there were 132 emergency residential places provided, and there is a budget for 60 more places in 2019. The HSE has begun a process of clinical, financial and service reviews into these recent residential placements and examining possible alternatives. This project is to complete in 2020.

### **Day services – 21% of budget**

These offer support during the weekday, with about 80% of service users having an intellectual disability. While some travel independently, many are collected from home in the morning, and are brought home in mid-afternoon. Alongside those who live with family, most people in residential care also attend a day service. Traditionally, day services were delivered in large day centres or sheltered workshops, but under the New Directions reform, the focus is on supporting people to engage in mainstream activities in their community, and a more person-centred approach based on the individuals' preferences.

For most, participation in day services is virtually lifelong. However, Rehabilitative Training is a time-limited programme of two to four years, which offers life-skills training. Some people, particularly school-leavers, do a spell in Rehabilitative Training before moving to day services, others leave day services on completion.

### **Multi-disciplinary therapy services**

Disability service providers have traditionally employed specialist therapy professionals like physiotherapists, occupational therapists, speech and language therapists, social workers or psychologists. Their services play an important role in child development and in ongoing rehabilitation. They constitute the main service input received by children. For example, speech and language therapy is a key support to children with intellectual disability or autism to learn to communicate. Occupational therapists support people to manage activities of daily living, and help people with autism manage sensory issues which may cause them great distress. Psychologists and behaviour specialists can help prevent and manage challenging behaviour.

Children's therapy services are being reorganised into multidisciplinary teams in a given catchment area, to serve local children with disabilities regardless of service provider or type of impairment. Those born after June 2002 (now under-

## Definitions (continued)

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17s) are entitled to apply for a statutory Assessment of Need. Conducting these assessments is a significant part of the workload for children's therapy services. 100 new therapy posts are being recruited in 2019 to help ensure assessments are carried out within the statutory timeframes.<sup>69</sup>

### Respite/short breaks

About 6,300 people with disabilities get respite to enable their primary carers have a break and sustain their ability to continue in that role. About one in four carers of people with ID, and fewer carers of people with physical/ sensory disabilities get respite. Where residential care is low, the need for respite to support families to continue in their caring role is greater.

The main form of respite has been overnight care in a 'respite house'. Supply of respite places has fallen as a result of regulatory compliance (e.g. if someone is staying with parents for the weekend, their room can no longer be used for respite for someone else). Some respite places are also blocked by people who need a long-term care place. Houses may not always operate to their nominal capacity, e.g. where someone with very significant behaviour issues is on a respite break, and it's not reasonable to ask others to share the house. €2m of the €10m increase in respite spending in Budget 2018 has gone on alternative options such as day respite, in-home respite and summer programmes.

### Home Support and Personal Assistants

Both schemes are intended to promote independent living. About 7,500 people get Home Support that can include support with washing, showering, meals or household tasks. About 2,300 people with physical or sensory disabilities have a Personal Assistant whose role is to support them to live independently, to participate more fully in the community, and choose how they live their life.

### Regulation

Residential and overnight respite services come under the Regulations and Standards for residential services for people with disabilities. Since 2013 when they

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<sup>69</sup> People who request one are entitled to a statutory Assessment of Need, which must begin within three months of application and conclude within a further three months. They must be issued with a Service Statement within a further month, which sets out the level of service the HSE commits to deliver.



## Definitions (continued)

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came into force, HIQA has registered almost 1,200 homes providing long-term or respite care, and conducted 3,800 inspections. Overall compliance has improved from 59% to 76% over this period, delivering significant improvement, but with some way to go.

### Disability prevalence

**Prevalence** of disability refers to the number of people living with a disability in a given time period e.g. a year. **Incidence** refers to the number of **new** cases of disability identified in a time period such as a year.

Disability is defined separately in different contexts, and the measured prevalence of disability depends on the definition used and how the data are collected. Neither the Disability Act 2005 nor the World Health Organisation's International Classification of Function, Disability and Health (ICF) label particular conditions as constituting a disability – rather the emphasis is on the degree of functional impairment and restriction in participation in everyday society experienced in a given environment and social context. Disability is a continuum where people may experience from mild to severe or profound difficulties in aspects of everyday functioning or social participation.<sup>70</sup> The measurement of prevalence depends on where on the continuum a line is drawn between having a disability and otherwise. This factor, along with different cultural interpretations, has bedevilled international comparisons of prevalence. Under the World Health Organisation, a common short set of disability questions for use in national censuses has been developed, which distinguishes between levels of difficulty – when difficulties in accomplishing tasks like self-care or walking a minimum distance are severe, there is less ambiguity about whether someone is experiencing disability.<sup>71</sup>

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<sup>70</sup> The Disability Act 2005 defines disability as means a substantial restriction in the capacity of the person to carry on a profession, business or occupation in the State or to participate in social or cultural life in the State by reason of an enduring physical, sensory, mental health or intellectual impairment. The World Health Organisation's International Classification of Function, Disability and Health (ICF) uses a biopsychosocial model which sees disability as the interaction between a person's impairments, activity limitations and participation restrictions and contextual environmental and personal factors.

<sup>71</sup> [https://www.cdc.gov/nchs/washington\\_group/wg\\_questions.htm](https://www.cdc.gov/nchs/washington_group/wg_questions.htm).

### *Definitions (continued)*

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In modern times, Census 2002 was the first to collect data on disability prevalence, where disability is self-reported. The disability questions have evolved over time, with only 2011 and 2016 using identical definitions. These questions cover broad types of long-lasting impairment – vision impairment, hearing impairment, physical/mobility difficulties, intellectual disability, difficulty in learning remembering or concentrating, emotional or psychological difficulties, and other conditions (including chronic illness). Only the vision and hearing categories had any test of degree of difficulty, excluding those for example who can see well when wearing glasses or contact lenses. A second Census question considers difficulties in aspects of functioning and social participation such as difficulty in self-care, or difficulty in participating in work. Under this fairly broad set of definitions, Census 2016 reported a disability prevalence rate of 13.5%. Census 2022 moves closer to the recommended international set of short disability questions, by including for the first time a measure of the degree of difficulty being experienced under any heading.

The prevalence of disability, as measured in the Census, rises steadily with age. This reflects the fact that apart from conditions such as intellectual disability, and other congenital conditions that are present from birth, most impairments emerge in the course of adult life and particularly as people age. As the age-structure of the population changes, so too will the overall prevalence of disability, even if underlying age-specific prevalence remains unchanged.

In Ireland, most people with disabling conditions are supported through mainstream community and medical services, and through older people's services. This *Disability Capacity Review* deals with the requirements for specialist disability social care and supports, including multi-disciplinary therapies, but not with acute or primary care medical services. The numbers using these specialist services, roughly 60,000 people, represent under 10% of the 630,000 people who reported some form of disability or long-term condition in the 2016 Census.

Disability does not necessarily imply ill-health. However, the risk of ill-health is higher among people with disabilities, and some disabling conditions arise from a health condition, or have commonly-associated comorbidities. In the National Disability Survey 2006, half the respondents with a disability described their

### *Definitions (continued)*

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health status as 'very good' (15%) or 'good' (35%),<sup>72</sup> and a quarter of people with disabilities were not on any medication connected with their disability.<sup>73</sup> In the Irish Health Survey 2015, which used a different definition of disability, almost 40% of people with disabilities described their health as 'very good (10%) or 'good' (28%), compared with a total of 89% of non-disabled people in these categories.<sup>74</sup> The evidence that one in five people with intellectual disabilities have no natural teeth nor dentures suggests that people with disabilities have difficulty getting access to services for support for health conditions that are not in any way related to their disability.

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<sup>72</sup> National Disability Survey 2006 Vol 2 Table 10.3 (CSO).

<sup>73</sup> National Disability Survey 2006 Vol 2 Table 10.1 (CSO).

<sup>74</sup> Irish Health Survey 2015, Statbank Table 4. If a respondent had identified 'a lot of difficulty' or 'cannot do at all' as a response to any sub-categories in question ten (difficulty with seeing, hearing—even with use of vision/hearing aids, walking 1/2km, walking up or down a flight of stairs), or if the respondent has identified 'Quite a bit' or 'Extremely' as a response to question twelve (to what extent had pain interfered with normal work, either inside the home or outside), they were identified as having a disability.

## *Definitions (continued)*

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# Appendix 1

## Methodology and projections of future ID service population

# Methodology and projections of future ID service population

The population projections used in this Review were

- A special projection of the adult (over 20) population with an intellectual disability requiring specialist disability services, based on the register of those receiving such services, the National Intellectual Disability Database (NIDD)
- For all other potential service users, projections based on the Central Statistics Offices population projection M2F2, which assumes declining fertility and moderate inward migration<sup>75</sup>

## Why a separate projection of adults with ID

People with an intellectual disability have a significantly different age profile than the rest of the population, and have an average life expectancy which is nineteen years lower than the general population.<sup>76</sup> In addition, while migration flows are an important factor in predicting the size of the population at large, inward and outward migration flows are likely to be far lower for people with a lifelong intellectual disability. For both these reasons, the Central Statistics Office's population forecasts are of limited value in forecasting the future size and age structure of those who need specialist intellectual disability services. Therefore, this Disability Capacity Review has prepared its own projections of the expected size and age-structure of the number of adults with an intellectual disability who receive or require specialist disability services. The projections were based on the national Intellectual Disability Database (NIDD) figures up to 2017, the latest year for which these data were produced, prior to replacement by the National Ability Supports System.

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<sup>75</sup> See [www.cso.ie](http://www.cso.ie). Statbank Table PEA22. The assumptions underlying this population projection are that total fertility rate (the average number of children a woman will have in her lifetime) will decline from 1.8 in 2016 to reach 1.6 in 2031, and stay steady thereafter; and that net inward migration will average 20,000 a year. This is an intermediate projection between alternative projections with assumptions of steady fertility at 1.8 and higher inward migration (M1F1), and declining fertility and low inward migration (M3F2).

<sup>76</sup> See McCarron et al (2015) *Mortality Rates in the General Irish Population Compared to those with an Intellectual Disability from 2003 to 2012*. Journal of Applied Research into Intellectual Disabilities, 28(5). September 2015.

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## *Methodology and projections of future ID service population (continued)*

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### **Cohort analysis**

The great majority of adults who will require specialist disability services over the period to 2032 are already known to services, and are registered on the NIDD. The attrition rate from this database for any age cohort was assumed to be stable, and was used to make the forward projections. Five-year age groups were used, with 'survival rates' calculated as the percentage of those in a given age cohort who were still on the database five years later. An example of a 'survival rate' would be the ratio of the numbers aged 35-39 on the NIDD in 2015 to those aged 30-34 on the NIDD in 2010. An age cohort approach also underpins the CSO's population projections. This methodology was very similar to that used in the WG1 Report on Future Needs for Disability Services.

The 'survival rate' is a composite of

- movements on to the database, as people register for services
- movements off the database
  - deaths
  - people leaving disability services (especially school leavers who do not progress to adult disability services)

So, some variability in a net measure like this might be expected. This has been addressed by averaging the estimates over a number of year pairs. As might be expected, at older ages, there was more volatility in the calculated survival rates. Overall numbers are small, and slight variations in numbers of deaths can affect the survival rates in any year. For example, the survival rates of those reaching 75-79 years of age over the period 2006-2010 to 2013-17 ranged between 66% and 73%. Here the averaging procedure smooths year to year volatility.

For each 5-year age band, survival rates were calculated in respect of the following pairs of years: 2008-13, 2009-14, 2010-15, 2011-16, and 2012-17, and then averaged. While there were only small differences in the average survival rates calculated over longer periods, there was less volatility in annual values over the chosen period.<sup>77</sup> In addition, by averaging over this set of five year-ranges, no one

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<sup>77</sup> Other ranges examined were the set of five year periods from 2003-2008, and from 2005-10, which produced fairly similar average survival rates, but greater distances between highest and lowest values for a given age group.

### Methodology and projections of future ID service population (continued)

year was counted twice. These average survival rates are set out in Table A1.1, and are very similar to the ratios calculated for the WG1 report Future Need for Disability Services,<sup>78</sup> shown in the right-hand column. So the resulting population projections are very similar.

**Table A1.1: Survival rates on the NIDD database by age group**

(Proportion of those in preceding age group on the database five years later)

Survival on database to age band	Average ratios used in central forecast (Average of annual ratios from 2008-13 to 2012-17)	Ratios using average of 2005-10 and 2010-15
25-29 years	89%	87%
30-34 years	95%	95%
35-39 years	96%	95%
40-44 years	95%	96%
45-49 years	96%	97%
50-54 years	94%	95%
55-59 years	89%	90%
60-64 years	85%	86%
65-69 years	80%	81%
70-74 years	73%	75%
75-79 years	69%	66%
80+	86%	84%

These average survival rates were then used to predict annual future ID service population at different ages. For example, the numbers aged 25-29 in ID disability services in 2020 were estimated by taking 89% of those on the database in 2015 who were aged 20-24. Projections forward from 2020 to 2025 were made by applying the relevant survival rates to the projected 2020 ID population.<sup>79</sup> This procedure assumes survival rates for each age group remain constant, however some variations were also tested as part of the exercise.

<sup>78</sup> While the original WG1 Report had used incorrect data received for 2010 (2011 data supplied in error), the comparison column in Table A1.1 is based on corrected figures for this period. The WG1 calculations had used the average of 2005-10 and 2010-15, where the year 2010 featured twice.

<sup>79</sup> While the survival rates were averaged, the base-years were not. So for example a slight change in pattern in a particular year (for example fewer deaths in an exceptionally mild winter) will affect the calculated projections at five year intervals. So the annual projections are a guide, but are not precise as regards timing, nor as to individual year to year changes.



## Methodology and projections of future ID service population (continued)

### Young adults 20-24 – survival rates from childhood may not be a good guide

The survival ratios for those reaching 20-24 years showed a trend increase over time, rising from 74% in the 2005-2010 interval to 85% in the 2012-2017 interval. However, because of the magnitude of flows into the database in childhood and off the database at school-leaving stage, survival rates on the database may not offer the best basis for future projections in respect of 20-24 year olds. Small changes in the timing or magnitude of these flows can affect the numbers of children in a particular age group used as the base for forward projections, and the calculated survival ratios. It could be problematic to use the numbers aged 5 to 9 on the database in 2017 as a basis for projecting 20-24 year olds on the database in 2032, as these could be affected by delays in getting a diagnosis or the timing of seeking specialist disability supports.

**Table A1.2: NIDD 5-year survival rates in childhood**

5-year survival rates, to age	2005-2010	2007-2012	2010-2015	2012-2017
5-9 years	216%	257%	245%	216%
10-14 years	137%	125%	125%	113%
15-19 years	118%	121%	113%	106%

### Ratio of NIDD to peer age group

As those who will be adults in 2032 are already born, the alternative approach adopted was to base projections of future numbers of 20-24 year olds with intellectual disability on the ratio of those on the database to their peer age group. This approach removes any source of volatility arising from registration patterns in earlier childhood.

Given that the CSO's population estimates incorporate significant migration for this age group, which is unlikely to be a factor for people with ID, the peer age group was calculated by looking at those born 20-24 years earlier, adjusted for mortality.<sup>80</sup>

<sup>80</sup> This approach to estimating this age group differs from that adopted in the WG1 Report which had used survival rates to estimate 20-24 year olds. The birth cohort figures were adjusted for mortality using the Irish Life Tables 2011, CSO Statbank VSA32. However, alternative calculations using the CSO population estimates made little difference to the outcome.

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### *Methodology and projections of future ID service population (continued)*

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For simplicity, the central projection used the NIDD to population ratio for 2017. Variations in the forecast number of 20-24 year olds have little impact on the demand for residential care, by far the largest element of expenditure, as only 7% in this age group in 2017 got a residential service.

#### **Youth inflow projection**

However, the NIDD ratio to their birth cohort for this age group has shown a small but steady upward trend over time. In 2007, the ratio was 0.73% and by 2017 it had reached 1.05%, with the annual increase averaging around 0.03 percentage points. Data for school leaver entrants to adult day services also show a rising proportion of their peer age group entering adult disability services.

For these reasons, a set of 'high youth inflow' population models were also developed, allowing for a continued increase in the proportion of their age group in disability services. Depending on assumption on the pace of change, the 'high youth inflow' models showed about 23,000-24,000 adults over 20 in specialist ID services in 2032, compared to around 21,500 in the central projection. The youth inflow projection presented here in Table A1.3 is based on the ratio of 20-24 year olds to their birth cohort rising by 0.03% a year from 2017 (average annual increase since 2008) and stabilising once it reaches 1.25% (estimated ratio of day service entrants with ID to their birth cohort).<sup>81</sup> That would represent an increase from the 1.05% ratio of in the 20-24 age group recorded on the NIDD in 2017. Such an increase in the proportion of their peers in disability services may be a consequence of increased rates of ID in teenagers recorded in the 2016 Census.

As better data becomes available from the National Ability Supports Database, and on day service inflows and outflows, it will be possible to see to what extent increased youth inflows as a proportion of their peers are occurring or are translating into long-term increases in the disability service population.

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<sup>81</sup> The youth inflow projection presented here is based on the ratio of 20-24 year olds to their birth cohort rising by 0.03% a year from 2017 (average annual increase since 2008) and stabilising once it reaches 1.25% (estimated ratio of day service entrants with ID to their birth cohort). School leaver entrants to adult day services averaged 1.8% of their age cohort in the four years 2015-2018 – adjusting for the proportion with intellectual disabilities and for the recorded exit rate from intellectual disability services in this age group, the net annual inflow of young adults into ID services could reach 1.25% of their peer age group.

*Methodology and projections of future ID service population (continued)***Table A1.3 Central and youth inflow projections of ID population by age group**

Age	2017	Central projection			Youth inflow projection		
		2022	2027	2032	2022	2027	2032
20-24	2,596	2,829	3,157	3,563	3,234	3,813	4,277
25-29	2,043	2,308	2,515	2,807	2,308	2,875	3,390
30-34	1,838	1,932	2,183	2,379	1,932	2,183	2,720
35-39	1,945	1,763	1,853	2,094	1,763	1,853	2,094
40-44	1,886	1,857	1,683	1,769	1,857	1,683	1,769
45-49	1,910	1,803	1,774	1,608	1,803	1,774	1,608
50-54	1,892	1,788	1,688	1,661	1,788	1,688	1,661
55-59	1,486	1,679	1,587	1,498	1,679	1,587	1,498
60-64	1,104	1,258	1,422	1,344	1,258	1,422	1,344
65-69	780	887	1,011	1,142	887	1,011	1,142
70-74	475	572	650	741	572	650	741
75-79	236	326	392	446	326	392	446
80+	165	202	279	336	202	279	336
<b>Total 20+</b>	<b>18,356</b>	<b>19,204</b>	<b>20,196</b>	<b>21,389</b>	<b>19,609</b>	<b>21,211</b>	<b>23,027</b>
	100%	105%	110%	117%	107%	116%	125%

The figures here represent the output of the calculations. They are not precise, but illustrate broad scale

### Sensitivity testing

A core assumption underpinning the central population projection was that age-specific 'survival ratios' used to project the over 25s would remain constant. To smooth random year-to-year variability, average values for each age group over the reference period were used in the main projections.

Two sets of sensitivity tests were conducted. Set A was based on the range of variation in key NIDD variables over the 2013-17 period, while Set B set used the longer 2010-2017 reference period. For each set of tests, low (MIN) and high (MAX) projections of the ID service population were made, using the following:

- for over-25s, consistently low or consistently high values for each age-specific survival ratio, based on observed highest and lowest values in the reference period
- low or high values for the ratio of 20-24 year olds to their birth cohort

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### *Methodology and projections of future ID service population (continued)*

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For example, while the average of survival rates to age 75-79 that underpinned the central forecast was 69%, for Set A sensitivity testing, the lowest value in the same reference period of 66% was used for each year's forecast in the MIN scenario, and the highest value of 72% was used to derive the MAX estimates. It would be highly unlikely that the lowest values (or conversely the highest values) would apply uniformly across age groups and over time, so the results of this exercise set upper and lower bounds to the likely range of results.

High and low estimates for the 20-24 age group, based on ratios to their birth cohort, were also included in the projections. For both the A and B sets, the MAX projection used the same assumptions as the 'youth inflow' projection described above, of a rising proportion of their peer age group getting specialist disability services until stabilising when that proportion reached 1.25%. MIN projection A took the average value of the ratio of the NIDD to their birth cohort over the 2013-2017 period, which was 0.97%. MIN projection B took that average over the 2010-2017 period, which was 0.91%. These were both a good bit lower than the actual 2017 value of 1.05% that was used in the central projection. If these low historic averages were to materialise, that would imply a reversal of the trend of the last decade for the proportion of all young adults in specialist disability services to rise slightly year on year. On a no policy change basis, that seems unlikely, but it sets a lower bound.

Initial high or low values for 20-24 year olds over the period 2018-2022 are transmitted over time into subsequent age groups – the estimated 25-29 year olds for 2023-27, and estimated 30-34 year olds for 2028-2032. Variations in the parameters underpinning estimates of 20-24 year olds accounted for the biggest element of the gap between upper and lower projections of the ID services population, where Table A1.3 shows that in 2032, the largest gaps between the lower and upper bound projections were in respect of people aged under 35, as those initial values worked through to succeeding age groups. However, because the use of residential care by under 35s is fairly low, this factor had only a modest impact on the spread of numbers requiring residential care (Table A1.5).

*Methodology and projections of future ID service population (continued)***Table A1.4: Minimum and maximum projections of ID service population to 2032 (A)**

Reference period 2013-2017

	MIN 'survival ratio'	MAX 'survival ratio'	2022 MIN	2022 MAX	2027 MIN	2027 MAX	2032 MIN	2032 MAX
20-24 years	(0.97% of birth cohort)	(rising share of birth cohort to reach 1.25%)	2,611	3,234	2,914	3,813	3,288	4,277
25-29 years	87%	91%	2,262	2,369	2,275	2,951	2,539	3,479
30-34 years	94%	95%	1,915	1,950	2,120	2,261	2,133	2,816
35-39 years	94%	96%	1,755	1,772	1,829	1,880	2,025	2,180
40-44 years	95%	96%	1,842	1,876	1,662	1,710	1,732	1,814
45-49 years	95%	95%	1,789	1,807	1,747	1,798	1,577	1,638
50-54 years	93%	97%	1,771	1,806	1,658	1,709	1,620	1,700
55-59 years	88%	92%	1,668	1,693	1,561	1,616	1,462	1,529
60-64 years	85%	88%	1,237	1,283	1,388	1,461	1,299	1,395
65-69 years	80%	82%	870	907	975	1,054	1,094	1,201
70-74 years	73%	77%	553	600	617	699	691	812
75-79 years	66%	73%	314	343	366	433	408	504
80+ years	81%	85%	190	214	253	311	294	393
<b>Total</b>			<b>18,777</b>	<b>19,855</b>	<b>19,365</b>	<b>21,696</b>	<b>20,161</b>	<b>23,738</b>

*Methodology and projections of future ID service population (continued)***Table A1.5: Lower, central and upper bound projections of ID residential care places 2022-2032 (A)**

Reference period 2013-2017; demand based on demographics only

	2022 MIN	2022 Central	2022 MAX	2027 MIN	2027 Central	2027 MAX	2032 MIN	2032 Central	2032 MAX
20-24 years	183	198	226	204	221	267	230	249	299
25-29 years	294	300	308	296	327	384	330	365	452
30-34 years	479	483	487	530	546	565	533	595	704
35-39 years	632	635	638	658	667	677	729	754	785
40-44 years	866	873	882	781	791	804	814	832	852
45-49 years	966	973	976	943	958	971	851	869	885
50-54 years	1,098	1,109	1,120	1,028	1,046	1,059	1,004	1,030	1,054
55-59 years	1,134	1,142	1,151	1,061	1,079	1,099	994	1,018	1,040
60-64 years	903	919	936	1,013	1,038	1,067	948	981	1,018
65-74	1,110	1,138	1,176	1,241	1,296	1,367	1,392	1,469	1,570
75+	438	459	484	538	584	647	611	680	780
<b>Total</b>	<b>8,102</b>	<b>8,228</b>	<b>8,385</b>	<b>8,295</b>	<b>8,554</b>	<b>8,907</b>	<b>8,437</b>	<b>8,842</b>	<b>9,440</b>
<b>Increase over 2017</b>	<b>280</b>	<b>406</b>	<b>563</b>	<b>473</b>	<b>732</b>	<b>1,085</b>	<b>615</b>	<b>1,020</b>	<b>1,618</b>
<b>Range Min-Max</b>	283			612			1,003		

Table A1.6 shows the upper and lower projections of residential care need from both the A and the B sets of sensitivity testing. A key point to note is that even on the lowest of the lower bound assumptions, which is set B (MIN), demographic change will require additional residential places to be provided for people with intellectual disabilities. While the central projection provides the most plausible scenario and suggests that an additional 1,000 or so residential care places will be required in 2032 just to meet demographic demand, the very minimum end of the range required is over 400 additional places by 2032.

**Table A1.6: Upper and lower bounds to demographic residential care demand, under A and B**

	2022 MIN	2022 Central	2022 MAX	2027 MIN	2027 Central	2027 MAX	2032 MIN	2032 Central	2032 MAX
Total A	8,102	8,228	8,385	8,295	8,554	8,907	8,437	8,842	9,440
Total B	8,065	8,228	8,530	8,198	8,554	9,193	8,250	8,842	9,849
Change over 2017 A)	280	406	563	473	732	1,085	615	1,020	1,618
Change over 2017 (B)	243	406	708	376	732	1,371	428	1,020	2,027

### Demographic need at 2015 rates (as in WG1) v at 2017 rates

The WG1 projections used the 2015 age-specific use rates of residential care to forecast future demand arising from demographic change. This Disability Capacity Review has used the 2017 use rates by age, the latest available, which are lower. The lower rates are because of a fall in public and voluntary sector beds, while the NIDD may not have fully captured any extra private sector beds which came on stream in that period.<sup>82</sup> If the current projections had been based on the 2015 residential use rate, more of the service gap would have been attributed to demographic change and less to unmet need, however the overall estimated total need would have been similar. As shown in Table A1.7, roughly 400 residential places now attributed to demographic demand in the forecasts in each of 2022, 2027 and 2032 would have been counted in the ‘unmet need’ category if the 2015 usage rates had been applied

**Table A1.7: Projected ID residential needs due to demographics, at 2015 and 2017 NIDD usage rates**

	2022	2027	2032
At 2015 usage rates	8,656	9,036	9,351
At 2017 usage rates	8,278	8,642	8,939
Difference	378	394	412

Figures are the output from the calculations, and represent broad orders of magnitude only

<sup>82</sup> An examination by location and service of bed reductions in 2019 suggests that most reductions are arising in congregated settings which are scheduled to close. While replacement places are provided for those who move out, vacancies arising on deaths of residents in these centres are generally not filled or replaced elsewhere in the system.

## Appendix 2

# Change in numbers of adults with P&S requiring specialist disability services



## Change in numbers of adults with P&S requiring specialist disability services

The number of adults with physical, sensory or neurological disability requiring specialist disability services is not known, given the limited coverage of the NPSDD. However, it is possible to estimate the likely rate of **change** by combining the CSO's population forecasts by age with known age patterns of disability. The age-range 18-65, corresponding to coverage of adult disability services, was used. Two separate ways of deriving the age pattern were tested, which were

- From Census 2016, using the prevalence rate by age of difficulty in activities of daily living (ADLs) such as dressing, bathing or getting around inside the home – this group was thought to best correspond to those with significant levels of disability requiring specialist disability services.
- From the NPSDD, applying the age pattern of the roughly 7,000 people aged 18-65 whose files had been reviewed or added in the period 2013 to 2017. Age-groupings available were 18-24, 25-39, 40-59, and 60-65. The weights so derived are set out in Table A2.1.

**Table A2.1: Age pattern of those registered on the NPSDD**

(where files reviewed 2013-2017)

Age	Nos on NPSDD	As % of 2016 population in age group
under 18s	2,986	0.24%
18 to 24	879	0.22%
25 to 39	1,395	0.13%
40 to 59	3,292	0.26%
60 to 65	1,404	0.50%
<b>Total</b>	<b>9,956</b>	
All over 18s	6,970	

Sources: NPSDD 2017; Census 2016

The central forecast was based on the CSO's M2F2 projection – moderate net inward migration and low fertility – considered the most plausible in case of the post-Covid economic scenario as well as a possible post-Brexit slowdown

*Change in numbers of adults with P&S requiring specialist disability services (continued)*

in the economy.<sup>83</sup> High and low forecasts were also calculated based on the CSO's highest and lowest population projections were also calculated.<sup>84</sup> As Table A2.2 shows, the different methods of deriving the age structure of the disability population produced almost identical results for each forecast of overall population change.

**Table A2.2: Estimates of increase in adult population with P&S disability, relative to 2017**

CSO forecast used	2022	2027	2032
<b>Central (M2F2)</b>			
NPSDD basis	7%	13%	17%
ADL difficulties basis	7%	13%	19%
<b>High (M1F1)</b>			
NPSDD basis	9%	16%	22%
ADL difficulties basis	8%	15%	22%
<b>Low (M3F2)</b>			
NPSDD basis	6%	11%	14%
ADL difficulties basis	6%	11%	16%

<sup>83</sup> CSO Statbank PEA22. Over the 2016-19 period, net immigration has remained high, while births were a little below the CSO low fertility forecast.

<sup>84</sup> The highest CSO projection was M1F1 (high inward migration, high fertility), and the lowest M3F2 (low inward migration, low fertility).

## Appendix 3

# How residential services were defined for calculations, and reconciliation with HSE data

## How residential services were defined for calculations, and reconciliation with HSE data

Future need arising from demographic change for residential services for people with intellectual disabilities was projected by applying constant (2017) age-specific ratios of residential service usage to the ID population forecasts described in Appendix 1. The data underpinning the calculation of these ratios came from a special tabulation by the HRB of residential usage by age, mostly in five year age groupings. People whose age or residential status was unknown were omitted in calculating the ratios. These omitted cases totalled 35 in 2017; 28 in 2017; and 75 in 2007. Rates of residential service use by people with ID were based on the following types of residential service (see NIDD Table 3.3):

- Living semi-independently
- Community group homes (5 day and 7 day)
- Residential centres (5 day and 7 day)
- Nursing homes
- Mental health community residence
- Psychiatric hospitals
- Intensive placement (challenging behaviour)
- Intensive placement (profound or multiple disability)
- Occupying a full-time support place
- Other full-time residential service

To simplify the calculations, and given the numbers involved were a very small fraction of the total, no downward adjustment was made for five-day as against full-time services, and neither was any upward adjustment made by adding in regular part-time or shared care arrangements to the definition of residential care. In 2017, there were 354 people with ID in 5-day places (4% of the total), and 153 people (2%) in regular part-time or shared care arrangements, so a net 2% of places were involved.

The definition of what constitutes a disability residential place used in this Disability Capacity Review's calculations, as set out above, includes settings like nursing homes or mental health settings which may fall outside the scope of the

### *How residential services were defined for calculations, and reconciliation with HSE data (continued)*

HSE's Disability Service programme. However, it was considered best to use the likelihood that someone of a given age with ID would be in **any** long-term residential care setting as the basis for forecasting age-specific use rates of such care. It was also considered likely that the scale and pace of change over time would be very similar, whichever definition of disability residential care was used as a baseline.

As about one in ten of those in residential disability services are in the P&S category, an extra 10% was added to the projections of ID residential care need, to include the P&S group.

Table A3.1 shows for the 2017 data how concept of disability residential care underpinning this *Disability Capacity Review's* forecasts can be reconciled with the HSE's outturn figures in its Service Plan.

**Table A3.1 Reconciliation of statistics on ID residential care used for forecasting, and HSE totals**

Definition of residential service	Nos. in 2017
Baseline used calculation of residential care ratios – persons aged 20+ on NIDD in a residential service or in semi-independent living	7,822
Less semi-independent living	-462
Equals those on NIDD in a residential facility	7,360
Add under 20s on NIDD in residential service	+ 170
Total NIDD in a residential facility	7,530
Less NIDD in nursing home or mental health facilities	-365
Net nos. of persons on NIDD in disability-specific residential facilities (a)	7,165
HSE outturn figures on nos. in a disability residential service, from Service Plan (b)	8,371
Difference (b) – (a)	1,206
Less HSE figures for people with physical or sensory disability in residential care	- 889
Residual – mainly for-profit ID care (c)	317
NIDD in disability-specific care as % of HSE total residential nos. (a)/(b)	86%
Residual as % of HSE residential outturn (c)/(b)	4%

# Appendix 4

## Calculating future day service usage

## Calculating future day service usage

The estimated change in numbers using adult day services in any year is the annual inflow less annual outflow. Gross inflow comprises school-leavers entering day services directly, plus RT exits, who in turn are those who entered RT from school two years previously. The outflow comprises those who quit day services, and those who pass away. The HSE's count of adult day service numbers includes all those in formal day activities or programmes, other than those in Rehabilitative Training who are on a separate database. People not in a formal day programme are not included in this count, although some of these (e.g. those in this position living in congregated settings) may have on-site staff support during the daytime.

### Gross inflows

Estimation of gross inflows to day services were based on taking the proportion of their age peers (age 19) entering day services. This included school leaver entrants plus people entering day services on exiting Rehabilitative Training (RT), who would largely consist of the school-leaver generation of two years previously.

The data available on entrants to day programmes for 2015 to 2018 show they formed a fairly stable proportion of their peers aged 19. The average ratio of such entrants to their peers aged 19 over that period was then applied to forward projections of the number of 19 year olds, to estimate future entrants to day services. Two different ways of deriving the age cohort were calculated – one based on the number of births 19 years previously, adjusted for mortality (but not for any migration). The other approach tested was to use the CSO's population forecasts (which incorporate net migration). However, migration is expected to be low for people with intellectual disabilities, the main users of adult day services). For the birth cohort 19 year olds, the average ratio over the four years 2015-2018 was 1.88%, and to CSO population estimates of 19 year olds, 1.67%. The average ratio for the birth cohort method over the four years 2015-2019, was the more stable, and the results cited in the body of this report were based on that approach. These ratios were applied to the forecast number of 19 year olds out to 2032, based on births 19 years previously (adjusted for mortality) and the CSO's population projection M2F2, respectively.

### Calculating future day service usage (continued)

The calculations were performed for three sets of estimates of 19 year olds

- Forecasts based on the birth cohort (births 19 years previously, adjusted for survivorship, using average of CSO survival from birth ratio for males and females, Irish Life tables, Table VSA 32 from CSO's Statbank). This procedure assumes the population from which Day Service entrants are drawn will not be affected by inward or outward migration flows
- CSO population forecast M1F2 (High net inward migration, declining fertility)
- CSO population forecast M2F2 (Moderate net inward migration, declining fertility)
- It made little difference which of the CSO's forecasts were used, with estimates of day service use based on the higher of the two CSO population forecasts only marginally above those using the other one.

It made little difference which of the CSO's forecasts were used, with estimates of day service use based on the higher of the two CSO population forecasts only marginally above those using the other one.

**Table A4.1: Ratios of school leavers entering day programmes to their peer age group**

	2015	2016	2017	2018	total	av. ratio
Required/Commenced a Day Place (incl RT exits)	960	988	1,004	991		
School leavers to RT	362	349	348	433		
19 yr olds CSO population estimates <sup>85</sup>	55,785	57,267	61,344	62,506		
% of 19s, CSO population estimates	1.72%	1.73%	1.64%	1.59%	6.67%	1.67%
19 year olds birth-cohort survivors	50,338	52,445	53,631	53,586		
% of birthcoh 19s	1.91%	1.88%	1.87%	1.85%	7.51%	1.88%

<sup>85</sup> From CSO Statbank series PEA11 of population estimates. Numbers of 19 year olds for 2017 and 2018 are slightly different to those in the M2F2 population forecast, but the average percentage of the population of 19 year olds represented by day service entrants is the same whichever series is used.



### Calculating future day service usage (continued)

**Table A4.2: Projected five-year and cumulative gross inflows to 2032, birth cohort and M2F2**

Population estimate	M2F2	Birth cohort	M2F2	Birth cohort	M2F2	Birth cohort
Period	2018-2022		2023-2027		2028-2032	
Increase at end of period	5,250	5,296	5,690	6,002	6,230	6,397
Cumulative increase	5,250	5,296	10,940	11,298	17,171	17,695
Cum. increase (birth cohort) minus cum. increase (M2F2)		46		258		524
Annualised difference between birth cohort and M2F2 estimates		9		26		35

Note: These figures show the outcome of the computation process, and are just a guide to general order of magnitude

The calculated cumulative gross inflow is of the order of 17-18,000 over the 15 year period 2019-32, with the birth cohort method producing marginally higher estimates (using the M1F2 population forecast produced figures that were between the two shown in Table A4.2).

### Exits

The HSE database of day services does not yet include data on exits. One indicative sources of data on day service exits come from implied vacancy rates derived from additional day service places needed 2015-18. Average vacancies of around 400 a year are mainly the places vacated by those leaving RT to move to day services (Table A4.3).

**Table A4.3: Inflow to day services and RT 2015-18 and additional places needed**

	2015	2016	2017	2018
Commenced an RT Place	362	349	348	433
Commenced a Day Place	960	988	1,004	991
Total	1,322	1,337	1,352	1,424
Net additional places needed	832	988	1,000	1,059
Implied vacancies (including RT exit)	490	349	352	365
Average vacancies	389			

Source: HSE

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## Calculating future day service usage (continued)

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### Exit rates NIDD – exits from day programmes

As a large majority of those using day services are people with an intellectual disability (73% of entrants in 2019, and only 5% with a physical disability only, see Table 21 in Section 5), their exit rates should be a reasonable guide as to what the total exits might be. The HSE's database of day services covers non-RT formal day programmes, however titled, and from this we have a figure of 16,400 participants in February 2020; RT has a separate database. So exit rates from day programmes, which were available for 2014-2017, were used for one set of calculations. Based on Table A4.4 below, exit rates of 1.5%, 1.6%, 1.7% were tested. 1.6% is the average exit rates from non-RT day programmes over the 2014-17 period. To test how sensitive the results would be to using this average, the 2017 exit rate (1.5%), and the highest exit rate in the 2014-17 period (1.7%) were also tested, but the results showed little difference. Equally, using the average 1.4% exit rate for strictly HSE-funded programmes (Table A4.5) made little difference.

February 2020; RT has a separate database. So exit rates from day programmes, which were available for 2014-2017, were used for one set of calculations. Based on Table A4.4 below, exit rates of 1.5%, 1.6%, 1.7% were tested.<sup>86</sup> 1.6% is the average exit rates from non-RT day programmes over the 2014-17 period. To test how sensitive the results would be to using this average, the 2017 exit rate (1.5%), and the highest exit rate in the 2014-17 period (1.7%) were also tested, but the results showed little difference. Equally, using the average 1.4% exit rate for strictly HSE-funded programmes (Table A4.5) made little difference.

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<sup>86</sup> The exit rates were calculated as the proportion of people aged 20+ exiting from the database (deaths or deletions) who had been receiving an adult day service, as a proportion of those aged 18+ whose principal day service was one of the listed adult day service types.

### Calculating future day service usage (continued)

**Table A4.4: NIDD Exit rates from all day programmes, 2014-7**

Day Programme	2014	2015	2016	2017	2014	2015	2016	2017
	Service users aged 18+				Exits aged 20+ (deletions + RIP)			
Activation centre	7,647	7,763	7,946	8,242	90	104	114	88
Sheltered work centre	2,669	2,564	2,487	2,250	25	45	39	16
Special high support day service	755	764	775	746	8	18	15	10
Supported employment	758	765	662	632	7	2	4	7
Other day service	521	548	567	615	11	8	12	17
Programme for the older person	625	592	577	566	42	31	28	29
Generic day services	435	454	503	557	5	5	2	2
Special intensive day service	426	464	477	482	3	7	5	4
Outreach programme	236	301	355	418	4	3	8	5
Vocational training	276	273	278	225	34	13	22	21
Open employment	156	152	158	144	2	4	2	12
Third level education	56	70	71	66	1	5	3	11
Sheltered employment centre	51	52	38	35	2	0	1	0
Enclave within open employment	9	14	11	5	0	0	0	0
<b>Total</b>	<b>14,620</b>	<b>14,776</b>	<b>14,905</b>	<b>14,983</b>	<b>234</b>	<b>245</b>	<b>255</b>	<b>222</b>
Exit rate					1.6%	1.7%	1.7%	1.5%
<b>Average</b>					<b>1.6%</b>			

### Calculating future day service usage (continued)

**Table A4.5: NIDD Exit rates from HSE-funded day programmes, 2014-7**

Day Programme	2014	2015	2016	2017	2014	2015	2016	2017
	Service users aged 18+				Exits aged 20+ (deletions + RIP)			
Activation centre	7,647	7,763	7,946	8,242	90	104	114	88
Sheltered work centre	2,669	2,564	2,487	2,250	25	45	39	16
Special high support day service	755	764	775	746	8	18	15	10
Supported employment*	758	765	662	632	7	2	4	7
Other day service	521	548	567	615	11	8	12	17
Programme for the older person	625	592	577	566	42	31	28	29
Generic day services	435	454	503	557	5	5	2	2
Special intensive day service	426	464	477	482	3	7	5	4
Outreach programme	236	301	355	418	4	3	8	5
Sheltered employment centre	51	52	38	35	2	0	1	0
Enclave within open employment	9	14	11	5	0	0	0	0
<b>Total</b>	<b>14,132</b>	<b>14,281</b>	<b>14,398</b>	<b>14,548</b>	<b>197</b>	<b>223</b>	<b>228</b>	<b>178</b>
Exit rate					1.4%	1.6%	1.6%	1.2%
<b>Average</b>					<b>1.4%</b>			

\*Some supported employment is under the DEASP scheme, some workers are supported by disability service staff

#### Exit rates, all adults

A second set of calculations looked at all over-20s who exited day services. Table A4.6 shows that deaths accounted for somewhat under half of all exits.

### Calculating future day service usage (continued)

**Table A4.6: Total exits aged 20+, 2017**

	Nos	Deaths	Rate	Deletions	Rate	All exits	Rate
20-24 years	2,596	9	0.3%	108	4.2%	117	4.5%
25-29 years	2,043	6	0.3%	39	1.9%	45	2.2%
30-34 years	1,838	8	0.4%	17	0.9%	25	1.4%
35-39 years	1,945	12	0.6%	16	0.8%	28	1.4%
40-44 years	1,886	9	0.5%	13	0.7%	22	1.2%
45-49 years	1,910	13	0.7%	11	0.6%	24	1.3%
50-54 years	1,892	26	1.4%	15	0.8%	41	2.2%
55-59 years	1,486	37	2.5%	7	0.5%	44	3.0%
60-64 years	1,104	23	2.1%	4	0.4%	27	2.4%
65-74 years	1,255	38	3.0%	15	1.2%	53	4.2%
75 years+	401	29	7.2%	3	0.7%	32	8.0%
<b>Total</b>	<b>18,356</b>	<b>210</b>	<b>1.1%</b>	<b>248</b>	<b>1.4%</b>	<b>458</b>	<b>2.5%</b>

Table A4.7 shows overall adult exit rates from the NIDD over the four years 2014-17, and the average of 2.7% over this period. As before, to get a range around this average, simulations were also run with the 2017 value (2.5%), and the highest value in any one year (3.3%).

**Table A4.7: Range of exit rates of adults from NIDD 2014-17**

	2014	2015	2016	2017
On NIDD aged 20+	17,727	17,872	18,133	18,356
Exits aged 20+	577	497	479	458
Exit rate	3.3%	2.80%	2.60%	2.5%
Average rate	2.7%			

#### What exit rate would give the 2020 figure for day service use at constant entry rates

The third approach to examining exit rates was to consider what exit rate would have been necessary to reach the February 2020 user numbers of 16,400, if entry to day services had been a stable proportion of 18/19 year olds going back to the 1960s.<sup>87</sup> Two different starting points for this exercise were tried, 1966

<sup>87</sup> This follows up a suggestion from Dr Gráinne Collins of the National Disability Authority. Annual data by single year of age were only available back to 1996, and for prior Census years; an average ratio of 38% of 15-19 year olds being aged 18 or 19 was used to interpolate in non-Census years.

### Calculating future day service usage (continued)

and 1970, with little difference between the results, which both gave an implied annual exit rate of 5.4%. For the purpose of this exercise, the entry rate was assumed to be similar to the average over the 2015-18 period for which data are readily available. It is acknowledged that in earlier years, before services were as well developed as in the 21st century, entry to day programmes is likely to have been a lower proportion of the relevant age group. For example, European Social Funding enabled a significant expansion of day programmes in the 1980s, and improvements in disability provision continued in the 1990s. So the 'steady inflow' hypothesis is likely to overestimate the exit rate, and underestimate as a consequence the number of places needed – it sets a lower bound to the extra places required. An alternative simulation along the same lines, with lower initial inflows to the mid 1990s, then gradually rising to reach today's rate by 2005, produced an estimated exit rate of around 5%. The upper exit rate of 5.4% produced an estimate that 15% more day places would be needed by 2032 to address rising numbers of school leavers. The 5% exit rate translated into an increase of 19% in places required by 2032.

### Reweighting global exit rates to reflect changing age structures over time

There is a distinct age pattern to exits from the NIDD. There is an exodus of people in their early 20s,<sup>88</sup> largely as people complete education or training programmes or exit specialist multi-disciplinary therapy services, and then exits of people aged over 50, largely due to deaths. As the changing age-composition forecast for ID service users would affect the age structure of the population in specialist disability services, the global exit rates used for the different day services simulations were reweighted, using the 2017 age-specific rates from Table A4.6 above, to produce adjusted exit rates to reflect the likely age-pattern of the service user population from the central ID population forecast. So for example, a weighted starting exit rate of 1.6% would be equivalent to 1.7% by 2032, and a starting value of 5.4% would become 5.9% by 2032.<sup>89</sup>

<sup>88</sup> In 2017, of those aged 20-29 who exited the NIDD (other than through deaths), 24 had been getting specialist therapy services, 27 had been in education, 19 had been in RT, and 17 in vocational training, and only 8 exits from other day services.

<sup>89</sup> Note however that the inflow-outflow exercise back to the 1960s had modelled a constant outflow rate, not one weighted by the age structure of the population.

## *Calculating future day service usage (continued)*

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### **Modelling inflows, outflows and net additions**

Starting with the figures for day service recipients in 2018 from the HSE's National Service Plan 2019, a series of simulations were conducted based on estimated average rates of inflow, and the range of different possible exit rates described above. Separate sets of simulations were run based where inflows were based on birth cohort, on the CSO's M2F2 population projection, and its M1F2 projection. How the underlying adult population was projected made little difference, so the results presented in Table A4.7 below are based on the birth cohort approach. There was little difference between the exit values based on NIDD exits from day services (1.4%, 1.5%, 1.6% and 1.7%), nor on whether the 2017 (2.5%) or the average value (2.7%) was used for total NIDD exits, however the high value for this variable recorded in 2014 (3.3%) did mean a noticeable change. The highest exit rate used in the simulations, 5.4% did produce significantly different results, showing how sensitive the projections are to higher rates of exit.

The results show that while a growth in the underlying population of school-leaving age will drive a gradual increase in inflows until the late 2020s, different assumptions as to the likely rates of outflow from day services produced widely varying estimates of additional places needed to cope with demographic change, ranging from around 2,500 extra places in 2032 (an increase of around 12%) up to around 10,000 extra places, or around 60% more. While all the indicators are that additional places will be needed, without accurate exit data, it is difficult to pin down how many extra into a narrower range.

**Table A4.8: Calculations of inflows, outflows and net additions to adult day service population**

	2020	2022	2027	2032	Increase 2020-2032	% increase
<b>Exit rate - 1.6%</b>						
Inflow	1,062	1,118	1,334	1,197		
Exits	269	300	379	464	10,198	62%
Total in day services	16,400	18,014	22,146	26,598		
<b>Exit rate 2.7%</b>						
Inflow	1,062	1,118	1,334	1,197		
Exits	453	495	599	708		
Total in day services	16,400	17,640	20,745	24,038	7,638	47%
<b>Exit rate 3.3%</b>						
Inflow	1,062	1,118	1,334	1,197		
Exits	554	598	707	819		
Total in day services	16,400	17,437	20,018	22,760	6,360	39%
<b>Exit rate 5.4%</b>						
Inflow	1,062	1,118	1,334	1,197		
Exits	907	940	1,021	1,111		
Total in day services	16,400	16,738	17,671	18,869	2,469	15%

Note: Figures are the output from calculations and indicate general order of magnitude only, on different assumptions



# Appendix 5

## Respite services

## Respite services

An additional table shows an analysis of the numbers of people with ID living in a home/family setting who had access to any respite service in the selected years. This shows that one in four of those aged over five had any respite in 2017, rising to one in three over 20s. The table also shows how access to respite declined over this period with a contraction in particular of overnight respite beds following introduction of regulation in 2013. An additional 12 respite houses, plus additional day respite capacity was put in place in 2018-19, following a special budget allocation for that purpose.

**Table A5.1: People with ID living in a family setting, by whether they got any respite**

Year	Nos. who got respite	Nos. living with family	% who got respite	% of over 5s	% of over 15s	% of over 20s
2007	4,615	16,366	28%	30%	34%	36%
2012	5,137	18,330	28%	30%	36%	39%
2017	4,531	19,599	23%	24%	29%	32%

Source: NIDD, special tabulation by HRB

# Appendix 6

## Baseline disability spending 2018

## Baseline disability spending 2018

The estimated requirements for future spending on disability services in this Disability Capacity Review have been calculated from a baseline of 2018. Table A6.1 gives details of the 2018 expenditure.

**Table A6.1: Distribution of net spending on disability services 2018**

Type of service	Net expenditure	% of total
Residential care – supported housing	€1,196m	64%
Adult day programmes	€390m	21%
Personal assistance and home support	€87m	5%
Multidisciplinary therapies	€84m	4%
Respite	€54m	3%
Other community services and supports	€53m	3%
<b>All specialist disability services</b>	<b>€1,865m</b>	<b>100%</b>

ID = intellectual disability. P&S = physical or sensory disability. n.a. = not available. Outturn 2018 as per HSE Service Plan 2019





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