

TRANSFORMING LIVES

*PROGRAMME TO IMPLEMENT THE RECOMMENDATIONS OF THE 'VALUE FOR MONEY AND
POLICY REVIEW OF DISABILITY SERVICES IN IRELAND'*

REPORT ON FUTURE NEEDS FOR DISABILITY SERVICES



Working Group 1
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OUTLINE OF PAPER

This paper estimates the demand for HSE-funded disability services up to 2026, by examining both current levels of unmet need, and the impact of demographic change.

This work was carried out under the auspices of Working Group 1 of the Transforming Lives implementation process. The research and analysis, and the drafting of the report, were carried out jointly by the Chairperson of the Working Group (Eithne Fitzgerald) and members of the National Disability Authority research staff. Individual members of the Working Group prepared background papers which informed the report – these are available as appendices. The Health Research Board extracted special tabulations from its disability databases for the project. The Working Group provided overall guidance to the report, along with further inputs from the National Steering Group.

The costings are done at constant 2017 prices, and the impact of pay developments, and cost pressures because of regulation, are not factored in. Because of the range of assumptions underlying the estimates developed by the researchers, numbers on potential recipients and costs should be taken as ball-park not as precise estimates.

The paper is based on the current model of service¹ – in a separate piece of work, the Working Group is examining the costs and benefits of moving to the person-centred models of service in the **Transforming Lives** agenda. The paper examines the current service gaps and the factors driving future needs across the main elements of current service provision.

Section 1 provides the introduction to the paper.

Section 2 examines what proportion of the population is likely to require specialist disability services.

Section 3 examines trends in the number of people with a disability.

Sections 4 to 11 estimate demand for particular elements of service.

Section 4 – residential care

Section 5 – respite and other residential support services

Section 6 – services for under 18s

¹ By 'current service model' is meant the forms of service delivery in place in 2017. Changing the service model, e.g. to end congregated residential services, implement **New Directions** in full, and move fully to person-centred models of service, may involve a different cost base, something that is the subject of another project being conducted by the National Disability Authority and overseen by Working Group 1.

Section 7 – day services

Section 8 – adult therapy services

Section 9 – personal assistant, home support and other supports for those with physical/sensory disabilities

Section 10 looks at competencies and skill mix

Section 11 sets out conclusions

KEY FINDINGS

- Gross spending on disability services fell by 7% between 2009 and 2016, at a time when the population requiring services grew. For example, the numbers registered on the National Intellectual Disability Database grew by 8.4% over the same period (Section 1)
- The result has been significant areas of unmet need, spanning residential, respite, therapy and other services.
- We estimate that 1.3% to 1.6% of the adult population require specialist disability services and supports (Section 2).
- Changes in the size and age structure will drive an increase in demand for disability services, in addition to what will be required to address current gaps in service provision (Section 3).
- Data on intellectual disability services are more comprehensive than for physical and sensory disabilities. However it is likely that trends in demand for ID services are mirrored to some degree for physical and sensory disability services.
- Expenditure on elements like assistive technology, respite care, personal assistant, and community support services from specialist and peer-led disability organisations, while forming a relatively small section of total spending, may be critical in sustaining people to live at home and avoid more expensive forms of support.
- Residential care services constitute the largest element of disability expenditure, over €1bn from a total budget of almost €1.7bn (Table 1). About 90% of this is for people with an intellectual disability.
- We did a detailed analysis of anticipated future demand for residential places for people with an intellectual disability, looking separately at the impact of demographic change and of accumulated unmet need. In the absence of

adequate data in relation to the need for residential care places for people with physical or sensory disability, we assume for costing purposes that this would be pro rata (Section 4).

- While the total number of adults getting intellectual disability services has remained fairly stable in the last dozen years, an increasing number are aged over 50, at a period when they are more likely to require residential care rather than day support. The number of over-50s has gone up from 3,900 in 2003 to 5,200 in 2012 and 5,700 in 2015 (Table 4).
- **Demographic change** alone could increase the number of residential intellectual disability places required, relative to 2015, by about 400-500 by 2020 and by 700-800 by 2025 (Table 9).
- In addition, there is a backlog of **unmet need for residential care**, including an emergency waiting list of over 800 at end 2017 (Section 4).
- Around 15% of over-60s with intellectual disabilities live with family members, usually with siblings or parents. Given the ages of those involved, most of these arrangements will not be sustainable. We suggest residential use rates need to rise to 95% in this age group. That would add an additional 200 or so places by 2020, and about 370 extra places by 2025, over the extra places needed for demographic change (Table 9).
- The proportion of under-45s with ID getting residential care has fallen by about 10 percentage points from that of the pre-recession era (2007). This deferred demand has fed into rising numbers presenting for residential care as emergency placements. A return to the 2007 residential care rates would require an extra 1,200 or so residential places in both 2020 and 2025, over and above those due to demographic pressures (Table 9).
- Current (revenue) cost of a residential place was estimated at €132,000 a year based on a weighted profile of residential service users, over half of whom require high or intensive support (Table 13). Average capital cost per additional place is estimated as €0.5m for every four such places, or is €125,000 per place, based on the costs currently being experienced in the decongregation project.
- These costings are sensitive to the number of people requiring an intensive support package, which may be three times the cost of a high-support place.
- The ballpark costs of the additional residential places required are estimated as follows (see Table 10)

	2020	2025	2020	2025	2020	2025
	demographics		+ over 60s		+ pre-recession use	
Increase, ballpark (nos)	400-500	700-800	700-800	1,100-1,200	1,900- 2,000	2,300-2,400
Additional revenue cost	€55-60m	€95-105m	€95-105m	€145-160m	€250-€265m	€300-320m
Additional capital cost	€50-60m	€90-100m	€90-€100m	€140-150m	€240-250m	€290-300m

- Increased need for residential places in respect of people with physical or sensory disability could add a further 10% to these amounts.
- There are 1,200 people under 65 living in nursing homes and similar facilities, primarily designed to provide end of life care. These residents include people with long-term disabilities (e.g. acquired brain injury) who are inappropriately placed in these settings. The proportion of those inappropriately so placed is not known. The persistence of such arrangements is likely due to a combination of cost factors and lack of availability of purpose-designed residential options. Given the absence of data, no separate costing is provided in the paper to address this issue (Section 4).
- **Respite care** estimates from the Health Research Board show about 1,600 additional people with ID in 2017-21 will require a service. We assumed a further 10% for additional respite provision required for people with physical/sensory disabilities. We costed the additional respite at the median stay of 17 nights. We estimated current costs of the required extra respite provision at €11m, and capital costs of about €10m. (Section 5)
- **Children’s therapy services** currently are short about 300 to 400 posts. Cost of the extra staffing would be in the region of €16-21m a year (exclusive of pension or other overhead costs). In addition, a cross-sectoral group due to report early 2018 is assessing the need for additional nursing-type support for children with very complex medical needs (Section 6).
- In terms of the demographics, the 2008-10 baby boom is generating increased demand for school-age services, while the underlying demand for early intervention services should fall in line with reduced births since 2010. The overall impact of demographic change on the number of children’s therapy posts would be an increase of 50 by 2021, after which demand should stay steady or drop marginally to 2026. But later demand will be impacted by the future course of the birth rate, which is hard to predict.
- However, data from the Census and from the education system show an increasing proportion of children are being labelled as having a disability or special needs. This is particularly associated with an increased diagnosis of autism,

where the proportion of 9-year olds so identified has risen sharply over the four years 2011-2015. Some of this additional diagnosis may translate into additional demand for services for psychologists, speech and language therapists and occupational therapists (Section 6).

- Based on unmet need recorded on the disability databases, provision of **adult therapy services** would need to double from its 2016 level. As the number of staff currently providing such services is not known, and service providers suggest that the expansion to date of children's therapy services has been achieved partly through cutting services for adults, it is not possible to put any firm figures on the cost of meeting this shortfall. However, extrapolating ratios from children's services on staff numbers per service user would give 480 additional staff required now, and a further 100 by 2026 (Section 8).
- Demand for **adult day services** is rising every year due to an inflow of school leavers. This has been at a steady proportion of number of 18-year olds in the region of 2.3% to 2.4%. Those entering day services or Rehabilitative Training are not counterbalanced by any significant numbers exiting the adult day programme as they get older. So a step-wise increase in provision is needed each year to provide for new inflow (Section 7).
- As the 2008-2010 baby boom reaches school leaving age, gross school-leaver demand for adult day services is set to rise by 4% to 2021 and by 17% to 2026, above its 2016 level (Table 21). Net demand would rise slightly slower, with the regular turnover of Rehabilitative Training places freeing up some capacity.
- If outflow from day services were to increase, the number of new places required annually would slow down (Table 22, scenario 2).
- New day places were costed at an average of €20,000, and assumed every additional 30 places incurs a premises cost of €50,000 a year. On this basis, the baseline Scenario 1 shows a step increase of around €20m a year for running costs and around €1.5m for premises costs would be needed to address the continual net inflow. These figures would rise gradually to €24m a year for running costs and €2m a year for premises costs by 2026 (Table 22).
- It is possible that the increase in autism being seen in schools could partially translate into an increased rate of future demand for day service places for school leavers. If that were to raise gross inflow by an extra ten percentage points, the annual increment of spending required could be €3m more than in the baseline scenario (Table 22).

- The working group did not examine current unmet need for day services, as this is under review by Working Group 2. It is noted that a proportion of the 2,500 or so people in congregated settings have no meaningful day service provision. Moreover, to ration limited funds, some people only get a partial day service.
- There is an acknowledgement of significant unmet need for **personal assistant services**, but it is hard to get solid data on how many are outside the service, and how far the hours provided to those who get it falls short of what is required. Our best estimate is that an additional €17m may be required by 2021 for personal assistant or home support, and much of that would be immediate (Section 8 and Table 29). Getting better data here to inform planning and provision is a priority.
- Ireland's disability services evolved from a medical model, and the **skill mix** is still characterised by a high proportion of staff with nursing qualifications. In cost terms, however, nursing staff and social care workers earn equivalent amounts. In considering the skill mix the services of the future require, it would be important to develop an overall competency framework for disability services, informed by the suite of nine outcomes now officially adopted (Section 9).
- The following two tables bring together our estimates of the scale of current and capital expenditure required to meet the anticipated increased requirement for disability services due to demographic change, and to address identified gaps between current needs and current levels of provision.

Table A. Estimated additional current costs, 2020 and 2025

Service	2020	2025
	€m	€m
Residential ID		
- Scenario 1, population change only	€55-60m	€95-100m
- Scenario 2, increased provision over 60s	€95-105m	€145-160m
- Scenario 3, pre-recession rates	€250-265m	€300-320m
+ additional P&S residential services	€5-6m	€9-10m
Respite (ID plus P&S)	€11m	€11m
Children's therapy services	€16-21m	€16-21m
Adult day services	€62-65m	€150-190m
Adult therapy services	€27m	€27m
PA/home support and community services	€20m	€26m
Rounded total range (scenario 1, scenario 2)	€200m-€240m	€325m -€390m
Range, Scenario 3	€390m-€415m	€540m-€600m

Table B: Estimated additional capital costs, 2020 and 2025

Service	2020	2025
	€m	€m
Housing	2020	2025
- Scenario 1 (priced at €500k a house)	€50-60m	€90-100m
- Scenario 2 (priced at €500k a house)	€90-100m	€140-150m
- Scenario 3 (priced at €500k a house)	€240-250m	€290-300m
Adult day premises cost	€1.6m	€2m
Respite capital (priced at €500k a house)	€10m	€10m
Rounded total range (scenario 1-scenario 2)	€60m - €70m	€100m - €160m
Rounded range, scenario 3	€250-€260m	€300m-€310m

RECOMMENDATIONS

Based on the research and analysis conducted, the Working Group advises

SERVICES MUST PROVIDE FOR DEMOGRAPHIC CHANGE, OTHERWISE DEFICITS IN SERVICES WILL RESULT

- Provision is needed to meet demographic change, otherwise existing services will be spread more thinly on the population who require them

DATA

- There is an urgent need to improve data collection on physical and sensory disability to inform service planning, and to involve the service providers and the support organisations to achieve that
- To get a good baseline picture of the levels of service provision, to inform service forecasting, delivery and costing, it would be valuable to produce data which would aggregate the information in the Service Level Agreements and from HSE's own service delivery to achieve that, and to ensure that information would be available in computerised form to facilitate analysis
- Data on exits/vacancies from adult day services would improve forecasting of future additional places needed

- Collecting data on the type of school placement school-leaver applicants have attended (mainstream, special class or special school) would allow better use to be made of NCSE data to forecast future demand from school-leavers

COMPETENCY FRAMEWORK

- Consideration should be given to developing a national competency framework for disability services

1. INTRODUCTION

1.1 SCOPE OF WORK

As part of the Transforming Lives programme, Working Group 1, under the HSE's implementation structure, was asked to forecast future need for disability services, and estimate the financial implications. The Working Group comprised members of the NDA, the HSE, the HRB, representatives of service providers and disability organisations.

There are a number of factors which will drive the future cost of disability services in Ireland. They include

1. Demographic change
2. Trends in the prevalence of disability
3. Change in the profile of service users
4. Pent-up demand from the recession years
5. Regulatory and legislative requirements
6. Developments in pay and conditions for the public service and elsewhere in the disability sector

This paper sets out to quantify the effect of the first four factors on the likely future requirements for services, and their likely cost.

The paper maps the main forms of current service provision which are

- Residential services
- Respite
- Day services
- Therapies
- Personal Assistant and home support
- Assistive technology
- Community support, information and advice, generally from organisations serving people with a particular condition or functional difficulty

The focus of this paper is on the demand pressures that will arise based on the costs of delivering current service models² in these areas. Its primary focus is on the implications

² By 'current service models' is meant the forms of service delivery in place in 2017. Changing the service model, e.g. to end congregated residential services, implement **New Directions** in full, and move fully to person-centred models of service, may involve a different cost base, something that is the subject of another project being conducted by the National Disability Authority and overseen by Working Group 1.

of demographic change, and of unmet need in the form of waiting lists, for future service requirements. Estimates were based on best available data, subject to data limitations as detailed in s.1.5 of this paper.

The second phase of the Working Group's task is looking at the costs and benefits of newer person-centred models of service compared with traditional approaches. The research project is being delivered by the National Disability Authority, with fieldwork almost half completed by end 2017.

On completion of that work, the Working Group will examine the combined effect of quantitative changes and qualitative changes on funding requirements. It is taking these changes in combination that gives the best picture of future funding requirements.

For example if demographic changes adds 10% to the cost of current services, and the new service models which are now policy add 1%, the additional cost in combination would be (110%) x (101%), or an 11.1% increase in spending.

1.2 CURRENT SERVICE GAPS

Gross expenditure on disability services was reduced following the economic collapse and public financial crisis which emerged in 2008. This was a time of rapid demographic change which would have added to the need for these services. For example, the numbers registered on the National Intellectual Disability Database rose by 8.4% between 2009 and 2016, while gross disability spending fell by 7% over this period.³

While some of the spending reductions would have reflected the downward adjustment in pay rates applied across the public sector, and accelerated efforts to achieve savings and efficiencies, it is widely accepted that spending and staffing restrictions at a time of growing numbers has had a negative impact on the level of service provision relative to demand.

The result has been the emergence of significant waiting lists for particular services, notably over 800 people on an emergency list for residential care at the end of 2017, and significant waiting times for early intervention and other children's therapy services. Alongside emerging future demand for demographic reasons, this paper has attempted to quantify the costs of addressing these current service shortfalls.

³ Gross expenditure on disability services in 2009 was €1,789m, from Table 4.2 of the VFM and Policy Review of Disability Services (2012). Gross spending allocation for disability services in 2016 was €1,664.9m according to the HSE's 2016 Disability Service Plan. Gross spending for 2017 is targeted at €1,781.6m. More detail on how funding has changed over time is given in Appendix 2

1.3 FUTURE REQUIREMENTS FOR DISABILITY SERVICES NOT DETAILED IN OTHER HEALTH STUDIES

While a number of recent reports have examined future demand for health service spending arising from demographic change and gaps in provision, generally speaking these reports have not quantified the impact on future needs under the HSE's disability services programme. The ESRI's 2017 report *Projections of Demand for Healthcare in Ireland 2015-2030* does not cover the cost of the disability service programme. Nor does the Irish Government Economic & Evaluation Service's report '*Budgetary Impact of Changing Demographics 2016-2026*' (2016). The HSE's *Planning for Health 2017* discusses some of the forecasts from the NIDD, but does not provide any estimates of the cost of future additional demand for residential disability services, which is by far the most expensive element of the whole disability programme. The Sláintecare report (2017) acknowledged that it had not done any detailed analysis of needs in the disability area, but recommended earmarking of €290m. over ten years for expansion of these services.⁴

This paper complements those other pieces of work. It provides estimates of funding required by the Disability Services programme to address imminent demographic pressures as well as built-up unmet need.

1.4 APPROACH TO THE TASK

The Working Group oversaw and guided the project. Some members contributed specific background papers to inform the work. The project drew on a number of different data sources including the Census and the HRB's disability databases, and the HSE carried out special tabulations of its disability databases to assist the work. The research, analysis and drafting of the report was carried out jointly by the Chair of the Working Group (Eithne Fitzgerald) and members of the NDA's research team. This paper presents that analysis, and the Working Group's conclusions and recommendations.

The Working Group mapped out the main groups of service users and the main forms of service. The focus was on demand for services funded by the Social Care Division of the HSE for people with physical, sensory, intellectual or neurological disabilities, or autism. The work did not encompass mainstream or acute medical care, nor services for people with a mental health condition only.

⁴ P. 66, Sláintecare report (2017). Elsewhere it states "Other areas of social care require additional work to cost and examine staffing implications of reforms and the best way to provide services. These include, for example, the redesign of services for people with disabilities." (p. 61)

The Health Research Board provided more detailed breakdowns of data in its Disability Databases at the request of the Working Group. The group undertook a number of specific analyses which are presented in this paper, which included

- Forecast of future numbers on the NIDD in different age groups, and of future requirements for residential services that implies
- Forecasts of future demand for day services/supports (all disabilities)
- Future need for both children's and adults' therapy services (all disabilities)

In addition a number of separate working papers were prepared by members of the Group to examine different aspects driving future service requirements and costs. These have been synthesised in the current paper and form Appendix 3 to 5 of the paper (*submitted separately*).

These papers were

- An analysis of the prevalence of low, medium and high support groups in the overall population, drawing in particular on work by the Australian Productivity Commission
- A paper on end-of-life care needs for people ageing with an intellectual disability
- A paper on prevalence trends in Ireland and internationally for a number of key disabling conditions spanning both physical/sensory and intellectual disability, including material on community support, advice and advocacy services for people living with a disability at home, especially those with physical/sensory conditions

1.5 DATA LIMITATIONS

The research team drew extensively on data from the Health Research Board's disability databases, as well as from data from the Census. The National Intellectual Disability Database (NIDD) has excellent coverage of the population receiving or on a waiting list for disability services, and this data is reviewed annually. The National Physical and Sensory Disability Database (NPSDD) is much less comprehensive, and individual files are reviewed much less frequently.⁵ While there is detailed and comparable data over

⁵ Registration on the NPSDD is voluntary; geographical coverage may be incomplete; and over the 2012-2016 period, the proportion of registrants newly registered or reviewed each year ranged from 22% to 30%, being affected by other pressures on local HSE administrative staff. These factors make year to year comparisons difficult. It is also not known to what extent those reviewed in any year are

time for residential services on the NIDD, the same is not true for those in residential P&S services, who constitute about 10% of residents. So the best estimate was to take a pro-rata approach for these.

Forecasts for day services, and specifically the demand from school-leavers and other new entrants, cover people with physical and intellectual disabilities, as well as those with ID or autism. Likewise forecasts for future therapy needs include those with physical or sensory disability.

Analysis of demand for respite services is based on the NIDD, and we assume there would be broadly pro-rata changes in demand for those with P&S disability.

Personal Assistant and home support services are primarily provided for people with a physical or sensory disability, as are assistive technologies.

Community support organisations, such as condition-specific organisations providing information, advice and training to people to live with and manage their impairment and maximise their independence, play an important role, particularly for those with physical or sensory disability who predominantly live in the community.

1.6 BALL-PARK FIGURES ONLY

The figures in this paper are intended to give a ball-park picture of the scale of likely future demand for services, and the potential cost, on the assumptions given. They should not be interpreted as offering precise estimates. Some tables are presented, which are the output of the calculations, given the assumptions made – but these are intended to illustrate underlying broad patterns, and should not be taken as being precise.

1.7 MAJOR ELEMENTS OF SERVICE FROM A COST PERSPECTIVE

This paper concentrates on the major elements of service from a cost perspective, and the drivers affecting them. The HSE's Service Plan for 2017 provides for gross expenditure on disability services of €1,782m and net spending of €1,688m. The breakdown of that is as follows:

Table 1: Components of expenditure HSE disability budget 2017

representative of all registered, particularly when it comes to small sub groups such as those getting a personal assistant service.

	€m.	% of budget	No. of users	Unit cost
Disability service budget 2017				
Residential places	1,064.1	63%	8,371	127,100
Day services	364.4	22%	18,000	20,200
Respite	41.6	2%	6,320	6,600
Personal assistant and home support	79.0	5%	9,784	8,100
Multi-disciplinary therapy services	86.4	5%		
Other community services and supports	52.7	3%		
Net total spending	1,688.2	100%		

Source: HSE

Residential services are the single most significant element of cost, accounting for of the order of €1bn a year or almost two thirds of the total disability services budget. The cost of a 24/7 service covering 168 hours a week is a multiple of the cost of day services that offer around 30 hours a week of support. The unit cost figures used by the HSE in developing its 2017 Service Plan show a residential place costing around six times a day service place. Day services are the next largest item of spending, accounting for over a fifth of the total.

Other services which are a relatively small proportion of the total spend may be critical in enabling people live as independently as possible and in stemming the demand for expensive residential care. These include therapies and early intervention services, assistive technologies, community support services for people with disabilities, personal assistant services, and respite services which support families to cope. Together these constitute around 15% of total spend.

1.8 COSTING SERVICE REQUIREMENTS

Indicative cost figures for people with different levels of support need in residential care were supplied by the HSE to inform the costing of future service demand. A rough estimate of revenue costs of residential care services was derived, by using these figures to produce a weighted average cost reflecting the current support needs mix. This procedure can give a ball-park estimate, but is subject to a margin of error.⁶

⁶ This ball park figure is based on Section 38 and Section 39 service providers. Emergency placements in for-profit services may cost more. The HSE have told us that private providers are more likely to have prior HIQA-approved residential places available when emergency placements arise. Such places are typically more expensive than equivalent places with voluntary service providers.

The cost of delivering services in the short term reflects the current staffing complement and skill mix. For example, some services have a high complement of nursing staff, while others have a higher proportion of social care workers and assistants.

For the purposes of costing future services, the cost base was assumed to be static in order to illustrate the effect of demand factors on future service costs. However, there are a number of built-in factors which will operate to raise the underlying cost base of a given quantum of service. These include:

Pay rates

Staff in many services are on the HSE Consolidated Pay Scales. Annual salary increments and the pay restoration measures under the public service agreements can raise the cost from one year to the next of delivering a similar level of service. Increments may add about 2-3% to payroll costs, in addition qualifying staff will get pay restoration under the public service pay agreement.⁷ These elements have not been factored into the costings presented here.⁸

National standards

There is a significant cost to bring residential disability services into compliance with national standards and regulations, and to meet requirements set out by HIQA for individual centres. For example, many HIQA inspection reports have recommended that additional staff be employed in order to meet adequate levels of care or standards of safety. The HSE estimated that compliance with HIQA requirements raised the cost of disability services by €57m in 2015.⁹

Working Time Directive ruling on sleepover hours

A ruling under the Working Time Directive that sleeping over in a residential service is to be treated as regular working time will mean that provision of a sleepover on-call

⁷ Typical annual increments under the consolidated pay scales are about €1,100 a year for therapy grades and about €1,300 a year for social care workers. Pay restoration measures in 2017, worth an increase of €1,000 in the salary rates of under €65,000, are limited to HSE services and the S38 providers where staff enjoy equivalent conditions of service.

⁸ The HSE's 2017 Service Plan shows pay increases accounted for €19.6m of the €96.4m increase in disability services spend in 2017 over 2016

⁹ NDA (2015) Review of the implementation of regulations and inspections in residential services for adults and children with disabilities

arrangement may become as expensive as waking night cover. The HSE has suggested this has the potential to add up to €100m to the annual cost of disability services.¹⁰

Funding of overruns

Actual expenditure in a given year may not give a true picture of actual costs incurred in relation to that year, where services have run at a deficit.

After successive financial retrenchment since 2008, while demand has continued to rise due to population trends and ageing, at this stage the budgets for some services are below the actual cost of delivering the services contracted for with the HSE. Cost overruns in successive years are a regular feature in some providers. Where a service has run at a deficit in the previous year, some of the current year's budget must be diverted to meet the shortfall. For example, it is estimated that €31m of the additional funding provided in 2017 is required to meet the cost of emergency placements from preceding years for which no budget had been allocated.

Full-year costs of service developments of preceding year

The full-year costs of service developments, such as additional provision for school-leavers, which take place from mid-year, must be met in the subsequent year's budget. In the HSE's 2017 Service Plan, €11.8m was provided to meet the carryover costs of 2016 developments.

Constant prices

The estimates in this paper are based on constant 2017 price levels.

2. PROPORTION REQUIRING SPECIALIST DISABILITY SUPPORTS

2.1 THREE METHODS USED

In a background paper undertaken for the Working Group NDA researchers used three different approaches to estimate the proportion of the adult population aged under 65 who would require specialist disability services in 2026. These were

- Applying Australian prevalence estimates of demand for disability services from a detailed study by the Australian Productivity Commission to the Irish population

¹⁰ The HSE Service Plan 2017 provided €9.8m to meet the cost of the 'sleepover' recommendation, across all its services

- Examination of the numbers in Census 2011 and Census 2016 with combinations of functional difficulties
- Examination of the HRB's disability databases

The findings showed that the different approaches produced estimates in the range of 1.3% to 1.6% of the population aged 18-65. The CSO's M1F1 population forecast, made in 2013, suggested the 2021 population of adults under 65 would be about 4% higher than that in 2016, and by 2026, about 10% higher.¹¹

2.2 AUSTRALIAN ESTIMATES OF RATIO OF POPULATION REQUIRING SPECIAL DISABILITY SERVICES

The first method applied estimates to the Irish population that were drawn from a report by the Australian Productivity Commission¹² on disability service needs. The Commission had divided the population into three broad groupings, as set out below, representing different tiers of need, and we applied the estimate of the proportion of the population who would come within Tier 3, who would require specialist disability support services.

Australian Productivity Commission's proposed tiers of service

The three tiers set out were as follows:

- **Tier 1** is the whole population. The focus is on fostering social participation, and minimising the impact of disability
- **Tier 2:** People with, or affected by, a disability – this group needed information about the most effective care and support options, linkages and referrals to relevant services, such as mainstream services and community support groups and services. The Commission argued that the tier 2 population would be very high, but the overall costs would be small. A goal of tier 2 provision would be to strengthen voluntary links between the community and people with disabilities. The goal would be to increase, rather than crowd out existing formal and informal arrangements. For example, local area coordinators could help link

¹¹ Based on the M1F1 projection, the closest to the actual 2016 population. These forecasts were based on the outcome of the 2011 Census and will be revised in due course in the light of the 2016 Census findings. The findings cited here are for the age group 20-64.

¹² Australian Productivity Commission (2011) **Disability Care and Support**. Productivity Commission Report no. 54: Canberra. This is one of the most comprehensive exercises undertaken to estimate the proportion of the population who would require disability services, so in this section of the paper, we applied its methodology to Irish data.

people with disabilities to local community groups. Consistent with these aims, all government bodies would continue to support a range of community and carer support services for people with lower level or shorter-term disabilities.

- **Tier 3** would be targeted at the much smaller group of people with significant care and support needs, and would include early intervention, specialist supports for people with significant levels of intellectual, physical, sensory or mental health disability, along with some supports for carers.

This Commission's focus on those most in need of funded supports recognised that it is important that mainstream services, along with communities and families, would continue to ensure the needs of people with more limited support needs are addressed.

Applying the Australian estimates to the Irish population, and excluding those with a mental health condition who would not come under the HSE's Social Care directorate, suggests that in Ireland in 2026 about 1.6% of the population aged 15-64 would come under Tier 3 (and would therefore closely correspond to the HSE's Disability Services programme).

The Commission came to its estimates using two methods:

- The number of people who had a core limitation who needed help several times a day
- The number of people using disability services

The next sections outline the findings if these approaches are applied directly to Irish data.

2.3 PROPORTION OF ADULTS WITH SIGNIFICANT LIMITATIONS

This approach examined data from the Census on

- People with an intellectual disability **and** either 'difficulty in dressing, bathing or getting around inside the home' **or** 'a difficulty with going outside the home alone to shop or visit a doctor's surgery' (Q 17 of Census)

and

- People with physical or sensory disabilities and **both** a ‘difficulty in dressing, bathing or getting around inside the home’, **and** a ‘difficulty with going outside the home alone to shop or visit a doctor’s surgery.’¹³

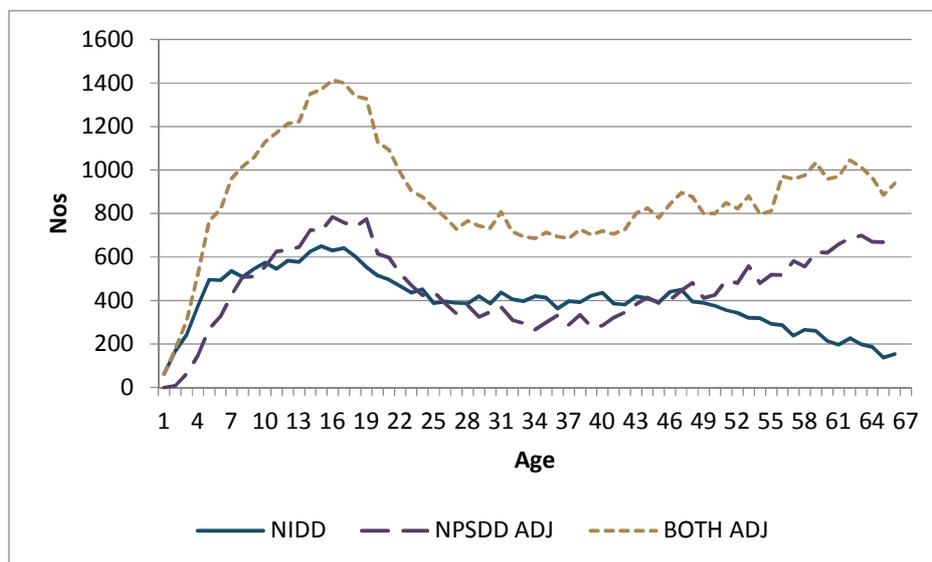
These groups together totalled 1.3% of the population aged 25-64 in the 2011 Census year and 1.4% in the 2016 Census.

2.4 PEOPLE REGISTERED ON THE HRB’S DISABILITY DATABASES

The third approach was to examine the proportion of the population receiving or on a waiting list for specialist disability services, using information from the Health Research Board’s Disability Databases. As regards projections of the numbers of adults requiring services up to 2026, it is worth noting that these are all already born. The numbers with a significant life-long disability are already in the system, however the numbers with an acquired disability might change.

Because of incomplete coverage of the National Physical and Sensory Disability Database, an estimate by the HRB of what the underlying numbers would be, were added to the data from the National Intellectual Disability Database, to create a combined estimate, and calculate prevalence for adults.

Chart 1: People with significant disabilities by age – NIDD + adjusted NSPDD data, 2014



¹³ ‘People with difficulty dressing, bathing, or moving around the home’ is the nearest approximation from the Census questions to people with difficulty with activities of daily living (ADLs). ‘People with difficulty leaving their home alone e.g. to shop or go to a doctor’s surgery’ is the nearest approximation from the Census questions to people with difficulty with instrumental activities of daily living (IADLs).

It is estimated that adults (aged 18-65) on the databases constitute about 1.3% of the relevant national population.

There is a pattern of increasing registrations during early childhood, and then exit of young people from age 18 onwards from the databases. Generally those with mild levels of disability do not receive specialist disability services after leaving school, and exit the database.

For people aged from their mid-forties and upwards, the prevalence of physical and sensory disability rises, reflecting onset of acquired disabilities as people get older. The prevalence of intellectual disability falls, reflecting that, although their life expectancy has increased steadily over time, this group experience much lower life expectancy than the average. The implications of past increased life expectancy for the demand for residential care is explored in section 3 of this paper. For the purpose of estimating the proportion of the population who require disability services, projecting increased life expectancy forward could raise the proportion of the population aged 18-65 eligible to be on the disability databases to 1.4%.

2.5 FROM 1.3% TO 1.6% OF ADULTS UNDER 65 MAY NEED SPECIALIST DISABILITY SUPPORT SERVICES

The analysis advised the Working Group that the three approaches came to broadly similar estimates of those who need specialist disability services:

- the Australian method implies approximately 1.6%,
- Census 2011 implies 1.3% and Census 2016 of 1.4%
- the HRB databases imply 1.3% (1.4% if increased longevity is factored in)

This gives upper and lower estimates for the proportion of the adult population requiring Tier 3 services.

As the age composition of the population changes, the proportion in different support categories may change.

Subset

These estimates are a subset of all persons with a disability, intended to focus on those who require specialist disability services and supports. While 13.5% of the population in Census 2016 recorded some form of impairment, in most cases their needs do not require specialist disability supports, or are met within older persons' services. Likewise, while estimates published by the NCSE suggest 1.6% of the population may have autism,

that covers the spectrum of impairment from mild to severe, and only a proportion would require specialist disability supports.

2.6 CO-MORBIDITY

The focus of this paper is on services funded by the Disability Services Programme, which is for people whose primary disability is intellectual, autism, physical or sensory, and excludes people with a mental health disability only (who come under the mental health services programme), and people with disability onset in old age (who come under the services for the older person programme). Co-morbidity between physical/sensory disability and intellectual disability comes within the disability services programme. In 2016, about 46% of those registered on the NIDD had both a physical or sensory disability as well as an intellectual disability.

There is data available from Census 2011 and Census 2016 on people with overlapping forms of impairment. The first table below gives the proportion for 2016 with another form of impairment, and the second table, the changes over that period. These data shows that over a third of people with intellectual disability had a concurrent physical disability, and a third had a concurrent psychological or emotional disability. 15% of people with a physical disability had a concurrent psychological or emotional disability.

Table 2: Proportion of people with another form of impairment, by other impairment
(Read down the columns)

	blind etc	deaf etc	physical	ID	learning etc	psych/em	other
1 impairment only	35%	47%	28%	18%	26%	40%	40%
Multiple impairment:							
Blindness or a serious vision impairment		13%	10%	9%	9%	6%	7%
Deafness or a serious hearing impairment	25%		15%	9%	12%	7%	11%
A condition that substantially limits one or more basic physical activities	46%	37%		36%	41%	31%	49%
An intellectual disability	10%	6%	9%		30%	19%	6%
Difficulty in learning, remembering or concentrating	25%	18%	25%	71%		38%	18%
Psychological or emotional condition	14%	8%	15%	36%	30%		14%
Other disability, including chronic illness	38%	31%	55%	25%	34%	33%	
Column totals	100%	100%	100%	100%	100%	100%	100%

Source: Census 2016

The picture is one of remarkable consistency over time, however there is some increase in the proportion with a concurrent psychological or emotional disability, particularly among those with an intellectual or a learning/remembering/concentrating disability. That underlines the importance of funding mental health services for people with an intellectual disability. The Sláintecare report has advised on provision of 120 additional staff in the next five years in this area, at a cumulative annual cost by year 5 of €8.5m.

Table 3: Change in proportion with other impairments, 2011-2016

	blind etc	deaf etc	physical	ID	learning etc	psych/em	other
1 impairment only	-2%	0%	-3%	-1%	-3%	0%	-3%
Blindness or a serious vision impairment		0%	0%	-1%	0%	-1%	0%
Deafness or a serious hearing impairment	1%		1%	0%	0%	-1%	0%
A condition that substantially limits one or more basic physical activities	1%	0%		-2%	1%	-2%	2%
An intellectual disability	0%	0%	0%		1%	-1%	0%
Difficulty in learning, remembering or concentrating	1%	0%	2%	1%		0%	1%
Psychological or emotional condition	1%	0%	2%	3%	3%		2%
Other disability, including chronic illness	1%	0%	2%	-1%	0%	0%	

3. TRENDS IN NOS. OF PEOPLE WITH A DISABILITY

3.1 LIFE EXPECTANCY DATA INCONCLUSIVE

The NDA examined the available literature to ascertain whether increased life expectancy generally is resulting in more years without disability, or whether people are living longer with a disability, and therefore require more years of support. This work was supplemented by input from working group members with expertise in specific conditions. There are contradictory findings in the literature, and so at this point the findings are inconclusive.¹⁴ The evidence available to date in respect of these conditions

¹⁴ A similar conclusion was reached by Wren et al (2017) in 'Projections of demand for healthcare in Ireland', 2015-2030, Dublin: ESRI Research Series no 67 has a detailed review of the literature in this area (s 2.6). The three hypotheses in the literature are (1) rising life expectancy leads to more years lived with disability; (2) Rising life expectancy leads to fewer years lived with disability; (3) Gains in longevity

suggests there are small increases in life expectancy, but no major increases in the number of years of life lived with a disability.

3.2 MOST COMPREHENSIVE INFORMATION IS ON INTELLECTUAL DISABILITY

Pending the publication of data from the HRB's new integrated disability database, which will cover physical and sensory disability and intellectual disability together, along with data on autism, the National Intellectual Disability Database (NIDD) is the most comprehensive statistical resource on the trends in demand for disability services.

As about 90% of those receiving residential care – the single most expensive item in the disability services programme – are people with intellectual disabilities, trends in the numbers and age composition of the NIDD is an important guide to future overall spending requirements.

Table 4 below shows that while the overall numbers registered on the NIDD have remained stable over time, these data show a long-term trend of significantly increased numbers of over-45s. Partly this is a cohort effect of a baby boom in the 1960s and 1970s, which has been visible for some time.¹⁵ It also reflects a long-term trend towards increased life expectancy of people with intellectual disabilities. It is also possible that, over time, the proportion of older adults with ID who are in contact with disability services has risen, and this could also contribute to rising numbers registered at older ages.

Thus the composition of the population receiving or awaiting intellectual disability services has shifted towards those in older age groups. As the age-specific residential care rates show, these are much more likely to be in full-time residential care rather than living with parents or siblings.

mean unchanged additional years with disability (although there may be more years of low-impact chronic illness). Both this study and the work of the subgroup concluded the evidence was mixed, with findings in some countries and some age groups supporting hypothesis (2) and in others pointing to hypothesis (3)

¹⁵ The 2005 report of the National Intellectual Disability Database referred to a peak in 10-14 year olds in the 1974 data, which could be seen in successive NIDD reports as a population bulge at different ages, and drew attention to the need to plan ahead for their needs as they aged. This group would be aged in their mid-60s in 2017.

Table 4: Number aged 20 years+ by age group, NIDD 2003–2015, selected years

Age group	2003	2005	2007	2010	2012	2015	2015 as % of 2003
20-24	2,521	2,365	2,281	2,234	2,239	2,391	95%
25-29	2,297	2,122	2,140	1,975	1,926	1,943	85%
30-34	2,358	2,162	2,077	2,071	2,021	1,923	82%
35-39	2,389	2,123	2,055	2,011	1,955	1,923	80%
40-44	1,954	2,035	2,149	1,985	1,995	1,958	100%
45-49	1,618	1,643	1,748	2,049	2,041	1,963	121%
50-54	1,310	1,319	1,435	1,629	1,686	1,850	141%
55-59	983	1,052	1,107	1,266	1,305	1,404	143%
60-64	668	670	776	947	974	1,022	153%
65-74	717	682	725	933	948	1,137	159%
75 +	191	207	236	306	311	311	187%
Total	17,006	16,380	16,729	17,406	17,401	17,872	105%
Total on NIDD	25,557	24,917	25,613	26,484	27,324	28,108	110%
Over-50s	3,869	3,930	4,279	5,081	5,224	5,724	

Source: NIDD, special tabulation

3.3 IMPLICATIONS FOR NOS. ON NIDD DATABASE IN 2020 AND 2025

The increase over time in the numbers of people in the older age groups on the database will in itself have implications for the numbers seeking services in future years, even without allowing for any possible further increase in life expectancy. We used an age cohort analysis to predict how many people in a given age group in 2015 would be still on the database in five or ten years' time. A simple assumption was made that for any age group, the proportion who would be on the database in five years' time would be constant, using the average of the 'survival rates' on the database for each age cohort observed from 2005 to 2010, and from 2010 to 2015. This gave predictions for 2020. In fact the 'survival rate' stayed generally steady or dipped slightly, with no real evidence especially among older groups of any continued increase in life expectancy after 2010. To make predictions for 2025, the ten-year 'survival rate' was used for each age group observed between 2005 and 2015. Appendix 1 gives details.

Table 5: Estimate nos. on NIDD 2020 and 2025 by age group, constant 'survival' rates

Age	NIDD 2015	Forecast nos 2020	Forecast nos 2025	2020 as % of 2015	2025 as % of 2015
20-24 years	2,391	2,571	3,034	108%	127%
25-29 years	1,943	2,038	2,083	105%	107%
30-34 years	1,923	1,894	1,944	98%	101%
35-39 years	1,923	1,787	1,761	93%	92%
40-44 years	1,958	1,835	1,742	94%	89%
45-49 years	1,963	1,954	1,778	100%	91%
50-54 years	1,850	1,859	1,780	100%	96%
55-59 years	1,404	1,685	1,677	120%	119%
60-64 years	1,022	1,199	1,433	117%	140%
65-74 years	1,137	1,388	1,611	122%	142%
75 years +	311	291	398	94%	128%
Total	17,872	18,501	19,241	104%	108%

Table 5 presents the output from the forecasting method used, but should not be taken as reflecting this degree of precision – rather the results give a rough guide as to the possible magnitude of changes. Table 6 below summarises and rounds the results in a way which brings the patterns into sharper focus.

Table 6: Forecast numbers of people on NIDD in different age groups, 2020 and 2025

Age	2015	2020	2025	2020/2015	2025/2015
20 to 29	4,300	4,600	5,100	106%	118%
30 to 49	7,800	7,500	7,200	96%	93%
50 +	5,700	6,400	6,900	112%	121%

This brings out that if 'survival rates' on the database by age group stay constant, the number of young adults (under 30) is set to rise, the numbers aged 30-49 is set to fall, and the number aged over 50 is set to rise. If life expectancy were to rise rather than remain steady, we could expect an even bigger rise in the number of over 50s, with implications for greater additional demand for residential places.

A key significance of this pattern is how it may affect the future demand for residential care, which is explored in the next section of the paper.

3.4 TRENDS IN NOS. OF PEOPLE WITH PHYSICAL OR SENSORY DISABILITY

Because of coverage and updating issues, trends in numbers on the NPSDD cannot be used to forecast numbers with physical or sensory disabilities who meet registration criteria. However, data from the 2016 and 2011 censuses, which asked identical questions, show the age-specific rate of physical or sensory impairment among under

65s, as well as the numbers with difficulties with Activities of Daily Living¹⁶ remained almost unchanged between the two Census years.

Table 7: Change in age-specific prevalence of P&S impairment 2011-2016

	blind etc	deaf etc	physical	Difficulty with ADLs
15 - 19 years	0.1%	0.0%	0.2%	0.3%
20 - 24 years	0.0%	0.0%	0.1%	0.1%
25 - 29 years	0.0%	0.0%	0.1%	0.1%
30 - 34 years	0.0%	0.0%	0.1%	0.1%
35 - 39 years	0.0%	0.0%	-0.1%	0.0%
40 - 44 years	-0.1%	0.0%	-0.1%	0.1%
45 - 49 years	0.0%	-0.1%	-0.1%	0.0%
50 - 54 years	0.0%	-0.1%	-0.2%	0.2%
55 - 59 years	-0.1%	-0.1%	-0.1%	0.1%
60 - 64 years	-0.1%	0.1%	-0.3%	0.0%

That means that it is mainly changes in the size and age-structure of the population, rather than any changes in underlying age-specific prevalence, which will drive any changes in the number of people with physical or sensory disability requiring disability services.

We applied the age-specific rates for 2016 for people with a physical disability, and for people with difficulty in activities of everyday living, to the CSO's M1F2 population projections for 2021 and 2026 to get estimates of the likely change in the size of the population of under 65s with a P&S disability. This suggested an increase of 5-6% over the 2016 level by 2021, and a further 7% increase from 2021 to 2026.

4. RESIDENTIAL CARE

4.1 DISABILITY RESIDENTIAL SERVICES

Residential care is the single most expensive element of the disability support programme. There are about 8,300 people receiving full-time residential support, with people with intellectual disabilities constituting about 7,500 or 90%, and about 800

¹⁶ Physical disability arising among over-65s is predominantly dealt with in the HSE's Older Services programme rather than Disability Services, so is not the focus of this paper. Difficulty with ADLs is a shorthand for the

being people with physical or sensory disabilities. There are about 1,200 people with intellectual disabilities in independent or semi-independent living.

The coverage of the National Intellectual Disability Database is much more comprehensive than the National Physical and Sensory Disability Database, so it is easier to make estimates of potential future demand for residential services in this area. The gaps in coverage of the National Physical and Sensory Disability Database, and the low proportion of cases updated annually, makes it less reliable as a basis for forecasting future demand. However, based on the research and analysis of this data, the Working Group felt it would be reasonable to assume that unmet need and future demand for residential services for people with physical and sensory disability would mirror forecast trends for those with an intellectual disability, and change broadly pro rata.

The factors driving numbers receiving residential care and its cost are

- numbers of people with a disability and trends in life expectancy
- age profile
- intensity of support need

Future service need includes both providing for demographic change, and addressing the current backlog of service need.

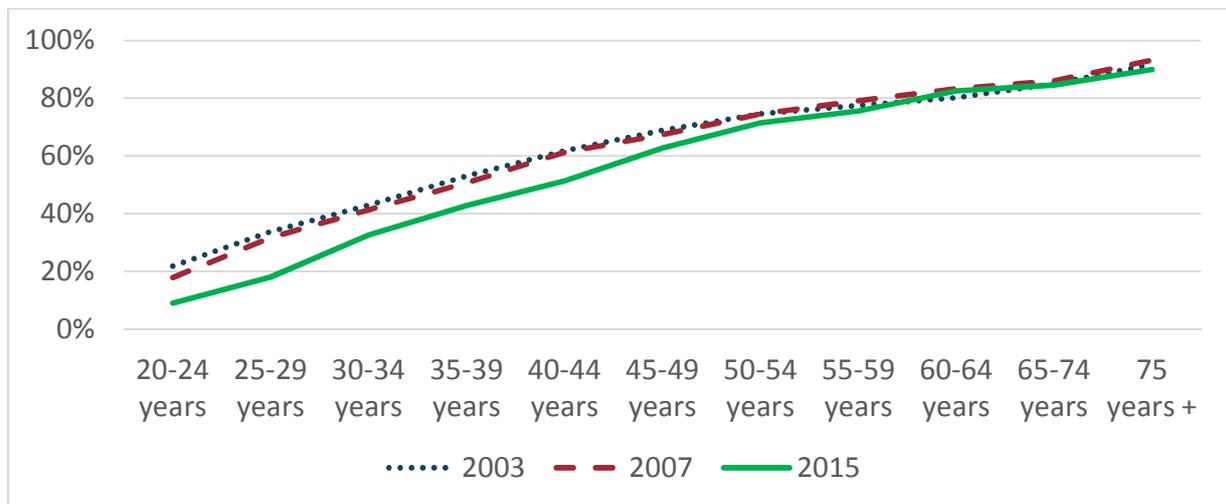
4.2 RESIDENTIAL CARE RISES STEADILY WITH AGE

The next stage of the analysis was to look at age-specific rates of being in a residential placement. As Chart 2 below illustrates, by age 45, 60% of people on the NIDD are in residential care. To do this exercise, we aggregated any form of residential care.¹⁷

Over the period reviewed, lower-intensity forms of residential care – independent living and 5 day care – were fairly stable in totalling around 8-9%, with independent living up from 4.4% in 2003 to 6.7% in 2015.

¹⁷ These include community group homes, residential centres, nursing homes, psychiatric units, and the category 'any other full-time care'. Excluded were people living with family or in independent/semi-independent living.

Chart 2: Proportion on NIDD in residential care at different ages, 2003, 2007, 2015



For those aged over 50, the proportion in any form of residential care was very stable over time. However, in 2015 the proportion of younger people with ID living in the parental home was significantly greater than in the pre-recession years of 2003 and 2007, and a lower share were in residential care.

While some of the shift of younger people from residential care may be for positive reasons, it could also be a legacy of the recession years, with it likely the 2015 ratio of people in residential services is unduly low in terms of longer-term patterns.¹⁸ The NIDD Report 2016 estimated about 2,200 additional residential places would be required between 2016 and 2021, with this representing the current backlog as well as additional anticipated future needs. A repressed demand for residential care has in recent years translated into emergency admissions when current support arrangements break down.

At end 2017, there were over 800 people with disabilities considered emergencies for residential services, however the HSE’s Service Plan 2017 provides for a residential care place for just 185 of these.

¹⁸ While we don’t have good data on repressed demand for residential care for people with physical or sensory disabilities, Working Group members reported that it is virtually impossible to secure a residential place for a younger person with such a disability due to lack of funding.

Table 8: age-specific residential care rates, 2007 and 2015

Age group	2007	2015
20 to 24	18%	9%
25 to 29	32%	18%
30 to 34	41%	33%
35 to 39	51%	43%
40 to 44	61%	51%
45 to 49	67%	63%
50 to 54	75%	71%
55 to 59	79%	76%
60 to 64	83%	82%
65 to 74	86%	85%
75+	93%	90%

There is also likely to be some latent demand for residential support among the very oldest age groups – it may not be sustainable in the longer term that a significant number of over 60s with intellectual disability are not in a supported residential place. As the effect of smaller family sizes works its way through the generations, in future there may be fewer siblings in a position to sustain older individuals with ID to remain living in the community without a formal support service.¹⁹ About 15% of people with intellectual disability aged 60 or over (about 400 individuals) are not in supported residential care (Chart 2 above).

4.3 HOW THE CHANGING AGE COMPOSITION MAY AFFECT DEMAND FOR RESIDENTIAL CARE

Section 3 provided estimates for the size and age composition of the NIDD in 2020 and 2025. Table 9 teases out the effects of this demographic change on demand for residential care places. The effects of demographic change alone, and in combination with addressing under-provision today, was examined using three different scenarios:

- the same age-specific residential care usage ratios as 2015
- the same age-specific 2015 ratios for under 60s, and raise for over 60s to 95%

¹⁹ About two thirds of over 55s living with family live with siblings (NIDD 2016, table 3.7a). Qualitative research has been published by the NDA on issues around sibling care, including for older adults with a disability. See Leane M, Kingston A, Edwards C (2016) <http://nda.ie/nda-files/Adult-Siblings-of-Individuals-with-Intellectual-Disability-Autistic-Spectrum-Disorder;-Relationships-Roles-Support-Needs.pdf>; <http://nda.ie/nda-files/Family-Carers%E2%80%99-Experiences-of-Caring-for-a-Person-with-Intellectual-Disability.pdf>.

- use the 2007 ratios (pre-recession), and raise rate for over 60s to 95%

These calculations were made to show a broad indication of the scale of potential demand, and should not be treated as giving precise numbers.

Table 9: Possible demand for residential places 2020 & 2025, on different assumptions

Age	2015	2020	2025	2020	2025	2020	2025
		Scenario 1		Scenario 2		Scenario 3	
		2015 ratios		Increase over 60s to 95%		2007 ratios and increase over 60s to 95%	
20 to 24	217	234	276	234	276	463	546
25 to 29	352	369	377	369	377	652	667
30 to 34	627	617	633	617	633	777	797
35 to 39	824	766	755	766	755	911	898
40 to 44	1,006	942	895	942	895	1,119	1,063
45 to 49	1,231	1,226	1,115	1,226	1,115	1,309	1,191
50 to 54	1,322	1,328	1,272	1,328	1,272	1,394	1,335
55 to 59	1,061	1,273	1,267	1,273	1,267	1,331	1,325
60 to 64	843	989	1,182	1,139	1,361	1,139	1,361
65 to 74	961	1,173	1,362	1,319	1,530	1,319	1,530
75+	280	262	358	276	378	276	378
Total	8,723	9,179	9,491	9,489	9,860	10,691	11,091
% of 2015		105%	109%	109%	113%	123%	127%
What each element adds		+456	+768	+210	+369	+1,202	+1,231
Total increase		456	768	766	1,137	1,968	2,368

Scenario 1 – demographic change only

The first scenario suggests an increase of 400-500 residential places would be required in 2020, and about 700-800 in 2025, because of the growth in, and ageing of, the ID population. The total percentage increase forecast from 2015 to 2025 taking demographics alone is 9% from 2015 to 2025.

Scenario 2 – raise housing rates to 95% for over-60s

In the view of the Working Group, having 15% of over 60s with intellectual disability living with family (parents or siblings) is not sustainable, and we suggest raising rates of residential usage to 95% for people in this age range is more realistic. This would add an extra 200 or so places to the 2020 requirement, and about 370 to the 2025 requirement.

It should lead to a reduced demand for emergency placements from the over 60s age group. Planned provision may come at lower unit cost than emergency provision.

Scenario 3 - A return to pre-recession rates of residential care (+ over 60s at 95%)

We also estimated the effect of a return to pre-recession rates of use of residential care in each age group, using the age-specific residential care use rates from 2007, and again the raised rate for the over 60s. This scenario captures the pent-up demand from the recession years, which has manifested itself in historically high numbers of emergency placements. This would add about 1,200 to demand in 2020.

Combining demographic demand with addressing unmet need

Table 10 summarises the position, in round terms.

Table 10: Summary of increased demand for ID residential care places

	2020	2025
Scenario 1 – demographic change only	400-500	700-800
Scenario 2 – demographic change + over 60s	700-800	1,100-1,200
Scenario 3 – demographic change + over 60s + pre-recession rates of provision	1,900-2,000	2,300-2,400

While this exercise used 2005-2010-2015 data to provide estimates of requirements in 2020 and 2025, it is likely that estimates of the scale of what will be required to 2021 and 2026 would be in the same general range.

Comparison with NIDD estimates

The NIDD 2016 estimates that an additional 2,164 individuals would require a residential service by 2021. This is slightly higher than our estimate for Scenario 3, which combines both demographic change and current unmet need.

The basis for the two sets of figures is slightly different. This paper looked at total residential places required in 2020 and in 2025, and how that might differ from current provision. The NIDD forecasts are based on aggregating unmet and anticipated needs of individuals registered on the database. Differences in the figures shown under the two approaches could arise because of deaths of people in residential care and of those on the waiting list, which would make a difference as between gross and net requirements.²⁰

²⁰ Between 150-170 people living in disability-specific residential care died in 2014, 2015 and 2016, which would have created potential vacancies for those on waiting lists. Over the same three years, deaths among adults living with family or independently were in the 40-60 range, some of whom would have been assessed as requiring a future residential place.

4.4 COSTING

Table 11 below estimates a weighted average revenue cost of a residential place as €132,000 a year.²¹ In addition there are generally capital costs associated with additional residential places, whether that is met from the Department of Housing budget or funded by the HSE, although some additional housing may be also sourced on the rental market.

Current costs

Based on figures supplied by the HSE, an indicative cost of services at different levels of care was used to calculate a weighted average running cost for additional residential care places. This figure is a ball-park estimate only.²² Weights are based on data in Table 13 below.

Table 11: Unit cost of ID residential places based on intensity of support need

	Unit cost of place €	Nos. of residents 2015	Estimated total cost €m
Minimum	40,000	485	19
Low	80,000	1,532	123
Moderate	112,500	1,583	178
High	150,000	4,100	615
Intensive	450,000	235	106
Total		7,935	1,041
Weighted average annual cost per person			€132,000

Sources: Unit costs – HSE. Weights – Table 13

Capital costs of extra housing

CSO average house price data for September 2017 shows mean house prices of €287,000, and median house prices of €235,000.²³ However, in practice housing costs for individuals with disabilities are often significantly higher. A house for four residents will be larger than average, adaptations will be generally required to provide for any

²¹ The HSE's Service Plan 2017 has been prepared assuming a cost per residential place of €127,000

²² Table 1 calculated the actual average cost per user for a residential place in 2017 at €127,100. The difference may reflect average costs which may be lower than the marginal cost of a new residential place.

²³ CSO StatBank/House Prices/HPM03. New houses were typically more expensive at a mean cost of €337,000 and a median cost of €300,000.

residents with mobility difficulties and to meet HIQA standards, and to provide any additional accommodation for staff. By end 2017, about 70 homes had been bought by the HSE under the programme to implement ‘Time to move on from congregated settings’, and the adaptations have averaged about 50% of the purchase cost. Overall, the combined purchase and adaptation cost has averaged about €127,000 per head, equivalent to a cost of about €500,000 for every four residents.

Table 12: Ball-park costs of additional ID residential places 2020 & 2025, each scenario

	2020	2025	2020	2025	2020	2025
	Scenario 1		Scenario 2		Scenario 3	
Est. total demand (nos) from table 9	9,179	9,491	9,489	9,860	10,691	11,091
Increase, ballpark (nos)	400-500	700-800	700-800	1,100-1,200	1,900- 2,000	2,300-2,400
Additional revenue cost @€132k	€55-60m	€95-105m	€95-105m	€145-160m	€250-€265m	€300-320m
Additional capital cost @€500k	€50-60m	€90-100m	€90-€100m	€140-150m	€240-250m	€290-300m

4.5 INTENSITY OF SUPPORT NEED

Something over half of those in ID residential care are assessed as having a high or intensive level of support need, and the combined share has been stable over time, however those labelled as ‘intensive’ have grown since this designation began.

Table 13: Intensity of support needs, people on NIDD in residential services

Year	Minimum	Low	Moderate	High	Intensive	Total	High + Intensive	H&I as % of total
2003	336	1,714	1,340	4,450	n.a.	7,840	4,450	57%
2005	349	1,671	1,435	4,514	n.a.	7,969	4,514	57%
2007	366	1,737	1,449	4,686	n.a.	8,238	4,686	57%
2010	448	1,608	1,565	4,619	65	8,305	4,684	56%
2011	475	1,613	1,607	4,555	95	8,345	4,650	56%
2012	500	1,627	1,594	4,441	120	8,282	4,561	55%
2015	485	1,532	1,583	4,100	235	7,935	4,335	55%

Source: HRB special tabulation

Additional costs for end of life care

As people get older and near end of life, supports needs can intensify, particularly for people with dementia. The report of Wave 2 of IDS-TILDA documented some of the growing medical needs as people with ID aged. It is notable that the number of people receiving intensive support in residential care has grown almost fourfold between 2010, when this data was first collected, and 2015.

One particular feature is the prevalence of early-onset dementia among people with ID. A 1999 report on people with ID and dementia concluded that quality of life for this

group was higher in community housing and in specialist dementia settings, however these were typically more expensive than delivering care in other settings.²⁴ A number of disability service providers have invested in provision of specialist dementia end of life units, and demand for such specialist facilities may grow. It may be wise to make such provision population-based rather than service-provider based.

4.6 CHILDREN IN RESIDENTIAL SERVICES

The number of children in residential intellectual disability services has more than halved between 2005 and 2016, and is a declining share of the numbers in the age group registered on the NIDD.

Table 14: Children with intellectual disabilities in residential services

	2005	2010	2015	2016
In residential care	298	262	163	136
Total	8,005	9,084	10,236	10,142
% in residential care	3.7%	2.9%	1.6%	1.3%

Source: NIDD, various years

While we expect the trend towards fewer children living in residential services to continue, sustaining this will require provision of appropriate respite support to parents. Many of the children affected have not only intellectual disabilities but also complex physical disabilities, who would require nursing support in any respite care setting. We have not provided for any continuing trend of reducing numbers in residential care. We have left the estimation of needs for additional nursing supports to the interdepartmental group looking at children with complex medical needs, and not covered it in our section on respite.

4.7 RESIDENTIAL PLACES FOR PEOPLE WITH PHYSICAL AND SENSORY DISABILITY

The data from the NPSDD does not allow an equivalent cohort analysis of future requirements for residential care for people with physical or sensory disability. However, as about 10% of those in disability residential care are those with a primary physical or sensory disability, a practical approach was to assume that demographic demand and unmet need would be roughly pro-rata with calculations of requirements for people

²⁴ McCarron and McCallion (2009) Cost effectiveness and quality of life in service delivery for persons with the dual diagnosis of Down Syndrome and Alzheimer’s dementia. Dublin: TCD school of nursing – report to the Health Research Board

with an intellectual disability. That would add an additional 10% to the costs set out in Table 11.²⁵

4.8 INAPPROPRIATE PLACEMENTS IN NURSING HOME CARE

There are also a number of younger people, for example people with acquired brain injuries or other neurological conditions, who are living in nursing homes which are primarily designed for end-of-life care for elderly people. Data from the Fair Deal scheme shows 1,200 under 65s in nursing home care.

The data series on long-stay units has now been discontinued, so it is hard to get more in-depth information on these residents.²⁶ A nursing home may be an appropriate setting for some of their younger residents, for example people with early onset dementia, or receiving end-of-life care, but there are others for whom it is clearly inappropriate as a setting in which to spend their adult life. However, some of these in inappropriate placements are there because there is no alternative suitable provision, whether that be a designated residential place for someone with a physical or neurological impairment, or personal assistant support to live independently.

More detailed data on age or presence of dementia might give more insight into the proportion of under 65s inappropriately placed in nursing homes and similar settings – in the absence of this, it is not possible to state what proportion of the 1,200 would be inappropriately so placed. A study of 48 residents underway by the Disability Federation of Ireland will give some insights.

²⁵ In s 3.4 numbers of people under 65 with physical or sensory disability are estimated to increase by 5-6% over the 2016 level by 2021, and a further 7% increase from 2021 to 2026. If we take the 2015 baseline as 100, the following table compares the overall growth in P&S numbers to the growth in ID residential care numbers in the three scenarios:

	2020	2025
P&S est growth	105	112
ID res scenario 1	105	109
ID res scenario 2	109	113
ID res scenario 3	123	127

²⁶ However, even when that Long Stay Activity data was available, the age breakdowns were under 40s (0.5% of all nursing home occupants in 2013) and 40-64 (about 4.5% of nursing home occupants in 2013). It would be expected that a very high proportion of those aged 60-64 would represent people with early onset of dementia or requiring end of life care, rather than those inappropriately placed in nursing homes, but at present the data to estimate that proportion are not available.

It may be that provision of a nursing home place is a slightly cheaper option than an alternative disability residential placement. It is also likely to be cheaper than the preferable option of supported independent living through provision of personal assistant supports.²⁷ To provide more suitable supports would cause off-setting savings on the Older Persons' Services side of the HSE's Social Care budget.

The NSPDD 2016 shows 3% of individuals, from recently-reviewed cases on the database, were in residential care (of which nursing homes accounted for almost half), and around 1% of individuals were deemed to require a residential service. Given the caveats about this data, and that this was a small sub-group, this is indicative only.

5. RESIDENTIAL SUPPORT SERVICES INCLUDING RESPITE

5.1 USAGE OF RESPITE SERVICES

Respite, defined as a service to allow families/carers have a break, is the main form of residential support service offered. It includes both planned and emergency respite services. In 2016, the median number of bed-nights of ID respite was 17, and the average was 26. The difference between the average and the median may be due to people placed in respite beds on an emergency basis, who have fairly lengthy stays in the absence of sufficient longer-term residential places. That would bring the average well up above the median.

Virtually all respite for people with intellectual disabilities is provided to people who are either living with their families or independently/semi-independently. Of those in these living arrangements, 13% of under 18s received residential support services, predominantly respite, in 2016, and about 30% of over 18s.

Usage of respite services is much lower among those with physical/sensory disabilities, according to data on the NSPDD in relation to recently-reviewed cases, although subject to the caveats about this data. This reported that 0.5% of under 18s and about 3% of adults on the database received planned respite in 2016, with an additional 0.6% of adults in emergency respite placements. Demand for additional respite was negligible

²⁷ The National Rehabilitation Hospital, in its submission to Oireachtas Committee on future of health service, stated "The increasingly difficult task of securing home care packages particularly for those with complex needs who have newly acquired injuries has in effect blocked the system for many patients. Local HSE disability managers regularly inform the Hospital that local budgets cannot support the very costly and complex care packages required for NRH patients." (Sláintecare report, p. 152)

for children, and came to about 1.6% of registered adults, two thirds of whom were deemed to require respite at present.

Table 15: Use of and requirement for respite services by people living in home/independent setting, NIDD 2016²⁸

	Number in receipt of crisis or planned respite in 2016	Number who did not receive respite but require it (2017-2021)
No.	4,194	1,371
% of those living with family or independent/semi-independently	20.6%	6.6%
% of those aged under 18	13%	
% of those 18+	30%	

Service providers report that HIQA requirements for respite houses have affected the supply of respite places. In particular, a restriction on the number of wheelchair users who can receive respite in the same house at the same time means that opportunities for respite are now more restricted for those with more complex disabilities than in the past. If families are not adequately supported to care for those with complex disabilities through getting appropriate respite breaks, family care is vulnerable to breaking down altogether, leading to earlier admission to full-time residential care, at a multiple of the cost of providing sufficiently frequent respite support.

Models of respite support are changing, with a greater role for options besides centre-based care.²⁹ In addition to the centre-based respite demand estimated in the table above, the HRB have also estimated there will be additional demand for other forms of respite – holiday residential placements, occasional respite with a host family, and overnight respite in the home. Together, these bring overall respite demand to 2021 to 1,600 places.³⁰

The other category of residential support listed in the NIDD is ‘support to people who are living independently or semi-independently’. In line with policy to maximise

²⁸ NIDD 2016, Tables 4.4 and 4.5. There is some regional variation within CHOs around these averages, with Area 3 (Mid-West) having significantly lower levels of respite use, and Area 9 (Dublin North) having significantly above average usage. An additional 190 or so individuals living in residential services also received respite in 2016.

²⁹ The HSE’s 2018 Service Plan provides for an additional 250 people to be served through new alternative respite options, and an extra 394 people through 12 new respite houses.

³⁰ Table 4.4 NIDD 2016

independence and choice, and reflect Article 19 of the UN Convention on the Rights of Persons with Disabilities, this form of support is likely to grow in years to come.

Adding respite and other forms of residential support together, the HRB estimate that 2,244 additional people with intellectual disabilities will require some form of residential support service over the 2017 to 2021 period.³¹The HSE's 2018 Service Plan provides for new respite care capacity to serve an additional 644 individuals.

5.2 COST OF ADDITIONAL RESPITE PLACES - ID

Centre-based respite costs are likely to be very similar to the cost of residential care, although if this disproportionately involves weekend support, the unit costs could be higher due to weekend premium payments. In providing additional places, however, there may be greater emphasis on developing the home stay model of respite as well as in-home respite compared to the current service mix.

As costs are included elsewhere in this paper for addressing shortfalls in the number of residential places, it would be double-counting to include the costs of individuals placed in respite beds in the absence of residential places. Therefore we have used the lower median stay of 17 nights rather than the average of 26 nights to cost additional respite places required.

Using the €132,000 annual cost of a residential place, the cost of 17 nights of centre-based respite works out at about €6,150 per person per year. On this basis, 1,600 additional respite places, if centre-based, would cost around an extra €10m a year or so. On the basis that respite for physical and sensory would cost an additional 10 percent this would mean the extra cost for covering respite services in 2021 would be €11m. It is assumed that this additional spend would also continue to apply in 2026, and have not made any further adjustment for possible demographic changes.

The actual costs will depend on what the mix is between centre-based respite and respite with host families, which is less expensive, as well as the extent to which unit costs for respite places are higher because of weekend payments. Additional centre-based places would also require capital investment – to provide 17 respite bed-nights for an extra 1,600 people a year would involve an additional 20 or so 4-bedded respite houses, however more might be required to accommodate the geographical distribution, and acknowledging peak demand at weekends. Taking an average cost per house of

³¹ NIDD 2016, Table 4.4

€300,000 would require a capital budget of the order of an extra €6m for additional forecast respite places required, or €10m if a higher average housing cost of €500,000 is used.³²

6. SERVICES FOR 0-18S

6.1 SERVICES REQUIRED BY CHILDREN AND YOUNG PEOPLE

Young people with disabilities predominantly live at home with their parents. The main HSE-funded service requirements for this age group are for therapy services including early intervention and school-age services, and for respite care. Child and adolescent mental health services are also an important requirement for children and young people with a dual diagnosis. For example, many children with autism also experience mental health difficulties.

6.2 CURRENT SHORTFALL IN THERAPY PROVISION (AS OF 2016)

Unlike in the education system, where provision of staffing has kept pace with the growth in the child population, staffing levels in the children's disability therapy services were adversely affected by recruitment embargos during the post-2008 financial crisis, and measures such as non-filling of maternity leave posts in this period had a further adverse effect in what are predominantly female professions.

A 2015 NDA paper calculated that children's therapy services based on the 2012 staffing complement were about 550-650 staff short, or a shortfall of between 50% and 58%. In addition, non-filling of maternity leave posts (since reversed) had added a further 10% shortfall in therapy capacity.³³

³² If some of the decongregated institutions can be re-purposed for respite this cost might be lower.

³³ NDA (2015) Children's Disability Services in Ireland, Table 4

Table 16: Staffing in children’s therapy services 2012 and 2016

	2012	2016
Specialty	WTEs	WTEs
Speech and language therapists	253.3	327.6
Occupational therapists	234.3	300.7
Physiotherapists	173.6	214.7
Psychologists	160.8	207.0
Social workers	98.8	131.4
Total	920.8	1,181.4
<i>Increase</i>		<i>+260.6</i>

The staffing complement in children’s disability services increased by 28% between 2012 and 2016. It is estimated that the number of children aged 0-18 has increased 2.4% in the intervening period.³⁴ Updating the original NDA estimate for 2012, to take account of both the growth in child population and the increased level of therapy provision to 2016, provides a revised estimate of a shortfall of 300-400 therapy posts.

6.3 NURSING SUPPORT FOR CHILDREN WITH HIGHLY COMPLEX NEEDS

There is a small group of children with highly complex medical needs who require nursing support to attend school. A cross-sectoral group of education and health authorities has been established to progress this, which should report during 2018. As such, the Working Group agreed not make any separate provision in the estimates for this factor.

6.4 FUTURE POPULATION TRENDS

Growth is expected in the older child population until at least 2021 on the basis of a baby boom that peaked in 2008-10, and whose effects will continue to be felt until these children reach adulthood. Annual births fell from 75,000 in 2010 to reach 66,000 in 2015, and if this trend continues, it should ease the pressure on pre-school and early intervention services. However, while fairly solid predictions can be made for children already born, the course of future births is much more uncertain. Future trends in births are difficult to predict, as they depend not only on trends in the fertility rate (which have followed a fairly steady course) but also on patterns of inward and outward migration of women in the childbearing age groups, which have been much more

³⁴ Survivorship rates from the Irish Life Tables 2010-12 (CSO, 2015) were used to derive estimates for 2012 of the number of 1-18 year olds, and births in 2012 were added to give an estimate of 0-18s in that year. This total was compared with the figures for 0-18s in 2016 taken from the Census.

volatile. For these reasons, it is difficult to predict future demand for early intervention services for young children, as that will depend on trends in births.

6.5 PREVIOUS HSE FORECAST FOR CHILDREN’S SERVICES

A 2015 paper from the HSE’s Population Directorate³⁵ applied NDA estimates of prevalence of children with multiple disabilities to the CSO’s population projections for 2016 and 2021. This paper projected a decreased demand for pre-school services of the order on 10% between 2015 and 2021, and an increased demand for school age services of the order of 11%.

Those CSO population forecasts were prepared in 2013, following the 2011 Census, and examined the implications of a higher fertility (F1) and lower fertility (F2) assumption, and three separate migration estimates from higher net inward migration (M1) to new outward migration (M3). All of these scenarios envisaged a continuing growth in the child population to 2021, while in some scenarios the number of under 18s begins to fall in the subsequent five year period.

Table 17: CSO forecast changes in population aged 0-18 from estimated 2016 level

	Forecast change 2016 to 2021	Forecast change 2021 to 2026
M1F1	4.5%	1.9%
M1F2	2.9%	-0.9%
M2F1	3.7%	0.0%
M2F2	2.0%	-2.7%
M3F1	2.6%	-2.0%
M3F2	1.0%	-4.5%

Based on CSO Population and Migration Estimates 2016-2046, published 2013

If we assume the high migration, low fertility scenario (M1F2) is the most plausible,³⁶ that would imply that by 2021, the additional therapists required for children’s services would be of the order of 350 to 450 over the 2016 level, with a small drop (about 15) in the number of therapists required in 2026.

Taking the mid-point of a basic therapy scale (such as OT) as €47,000, based on the January 2016 HSE Consolidated Pay Scales, the additional cost of extra staffing required for children’s therapy services would be of the order of €16m to €21m.

³⁵ Planning for Health – Trends and priorities to inform health service planning 2016

³⁶ This was the scenario that was closest to the actual 2016 population numbers.

6.6 INCREASED DIAGNOSIS OF DISABILITY

The Census results for 2016 suggest, that when allowance is made for differences in the age-structure of the child population, there has been some small rise in the reported rate of childhood disability, with emotional/psychological, learning and intellectual disabilities the categories showing the biggest increases. We applied the age-specific rates of disability for 2016 in the age groups 0-4, 5-9, 10-14 and 15-19 to the corresponding distribution of population in 2011 to make the like for like comparison.

Table 18: Prevalence rates children with disabilities, and change 2011-2016

	all disab	vision	hearing	physical	ID	learn etc	em/psych	other
2016 (at 2011 age structure)	6.7%	0.4%	0.4%	0.9%	1.9%	3.5%	1.5%	1.9%
2011	5.9%	0.4%	0.3%	0.7%	1.5%	2.9%	0.8%	1.9%
Difference	0.8%	0.1%	0.1%	0.2%	0.4%	0.5%	0.7%	0.0%

Source: Census 2011, Census 2016

This is consistent with evidence from the education system of an increasing proportion of children being diagnosed with special needs, largely driven by increases in the proportion labelled as having autism or being on the autistic spectrum. Between 2011/2 and 2015/6 school years, the total number of students rose by 10%, however the proportion receiving SNA support as having a special need grew by 34%.³⁷ Overall, the proportion of students with a 'special needs' label rose from 2.7% of the school student body to 3.3% in this four year period.

Table 19: Students with Special Needs Assistant support 2011-2015, by setting

	2011/2	2015/6	Change
Mainstream	12,150	16,874	39%
Special class	3,286	5,472	67%
Special school	6,848	7,607	11%
<i>Total with SNA</i>	22,284	29,953	34%
Total student population	825,333	907,667	10%
% of student population with SNA	2.7%	3.3%	

Source: Dept of Education Focused Policy Assessment of Data on SNAs

³⁷ <https://www.education.ie/en/Publications/Value-For-Money-Reviews/Focused-Policy-Assessment-of-Data-on-Special-Needs-Assistants.pdf>

Table 20: Proportion of age group that has access to an SNA

Age Group	2011%	2015%	Difference	% change in rate
6 years	1.52	2.27	+0.72	49%
7 years	1.87	2.45	+0.58	31%
8 years	1.88	2.44	+0.56	30%
9 years	1.93	2.62	+0.71	36%

Source: Dept of Education Focused Policy Assessment of Data on SNAs

While some of the increase at age 6 might be attributable to a pattern of earlier diagnosis, this is unlikely to be a factor driving the increased rate of SNA use at age 9.

The main underlying factor behind the increased use of SNAs was the increased numbers with a diagnosis of autism or ASD, which ran significantly ahead of the increase in the underlying child population over this period. While some of this is attributable to some degree of substitution from mild or moderate ID to a classification of ‘autism/ASD’ over the period, nevertheless when these three categories are grouped together, there was still a substantial underlying increase which ran ahead of population growth.³⁸ It should be noted that the proportion of schoolchildren with access to an SNA is higher than the proportion of adults estimated to require specialist disability services, which in section 2.4 of this paper was estimated as 1.3%-1.6%. It is also lower than the proportion of the relevant age group who apply for a day service (see below).

New model for resource teaching may affect diagnosis trends

Up to 2017, the systems for allocating resource teachers to schools, and for allocating SNAs to special classes, were based on specific diagnoses, with a diagnosis of ASD/autism attracting more resources than diagnoses, for example, of mild or moderate general learning disability.³⁹ From September 2017, the system for allocating resource

³⁸ In mainstream classes the number of students with ASD rose by 84% in these four years, and the number with ASD + mild ID + moderate ID rose by 56%, compared to a growth in overall student numbers, across all settings, of 11%. We don’t have data on the number of *students* in special classes by diagnosis, but the data on growth in *special classes* shows that autism classes (excluding early intervention classes) rose by 119% in the four years. Students with ASD + mild ID + moderate ID rose by 10% in special schools, in line with the growth in the overall student numbers over the period (table 16 <https://www.education.ie/en/Publications/Value-For-Money-Reviews/Focused-Policy-Assessment-of-Data-on-Special-Needs-Assistants.pdf>).

³⁹ For example, the relevant Circular, prior to the 2017 changes, provided an allocation of 3.5 hours a week resource teaching to a pupil with moderate general learning disability, and 5 hours to a pupil with ASD. Special class sizes for mild ID are 11:1; moderate ID, 8:1, and ASD, 6:1. The SNA ratio is 1 per 4 classes for mild ID; 1 per 2 classes for moderate ID, and 2 per class for ASD.

teachers is being reformed, to allocate these on the basis of the school’s profile rather than any particular diagnosis. The National Council for Special Education are also currently conducting a review of the SNA scheme, due to report in Spring 2018. It remains to be seen whether any changes arising from these developments will have affect the pattern of diagnosed special needs presenting in schools.

Special classes

Another indicator of growing demand for special need support has been the very rapid growth in the number of students in special classes, beyond the growth in the underlying school-going population. ASD classes constitute about three quarter of all special classes. While the number of students in special schools has grown exactly in line with the growth in the overall student population, the pace of growth in special classes has been well ahead of that. Provision of special classes at primary level in earlier years has been driving an increase in special classes in post-primary schools as these pupils transfer. That process is not yet complete, so that the numbers in special classes at post-primary level are set to increase as the system matures.

Maximum class size can vary with the diagnosis concerned – for students with ASD who constitute the majority in special classes, maximum class size is 6.

Table 21: No. of special classes in mainstream schools, 2010-2017

Year	Primary classes	Post-primary classes
2010/ 11	410	73
2011/ 12	407	107
2012/ 13	445	134
2013 /14	493	172
2014/ 15	557	202
2015/ 16	635	258
2016/ 17	713	309
2017/18	842	330

Source: NCSE, special tabulation (note: excludes early intervention classes)

Some of the growth in age-specific disability/SEN diagnoses is likely to result in higher demand for HSE therapy supports at school age. To the extent to which additional students labelled with ASD are at the higher-functioning end of the spectrum, the growth in demand for additional HSE supports could be lower than the growth in the number of children with an ASD diagnosis (when any substitution of ASD for an alternative diagnosis has been factored out). If we take a conservative assumption that only a third of the additional children requiring SNA support in 2011-2015 would require children’s disability therapy supports, that would mean that the 36% rise in the

proportion of 9 year olds requiring SNA support in the relevant four year period might translate into a 12% increase in the numbers in that age cohort requiring children's therapy support. That would still be a significant additional factor driving increased demand for such services, over and above any demographic pressures discussed above.

6.7 SPECIAL CLASSES GROWTH MAY FEED FUTURE SCHOOL-LEAVER DEMAND FOR DAY PLACES

The growth in special classes is significant not only for demand for HSE supports for school-aged children, but also it is likely that special classes along with special schools are the main feeder routes into demand for adult day services from school leavers. The Working Group advises that the school leaver assessment process should in future record whether those seeking a school leaver place have been attending a mainstream school, a special class in a mainstream school, or a special school, to assist in using NCSE data on current students receiving support at different ages to predict the course of future demand for school-leaver places.

7. ADULT DAY SERVICES

7.1 DAY SERVICE PROVISION LEVELS

According to the 2017 HSE Service Plan, there are approximately 20,000 people expected to receive a day service, partake in rehabilitation training, or engage in a work-type day placement, an increase of just over 900 on the out-turn for 2016. This increase reflects the population increase in the relevant age groups, with a negligible number of places freed up among older age groups.⁴⁰

7.2 UNMET NEED FOR DAY SERVICES

The process of transferring people from congregated settings to the community has highlighted that in a number of residential services, there was no staffing in place, other than staff providing basic care and supervision, to deliver a meaningful adult day programme for residents. This cohort could add potentially up to 2,500 to the number requiring a day service.

⁴⁰ If personal budgets are introduced, funding may move from adult day services to individual support and Personal Assistant type arrangements, but would not affect the overall financial sums here.

Additionally in the recession years, some people only got a partial day service. While the number of people whom this applies to is unknown, an exercise is currently underway by the HSE to establish the number of people affected by this.

In addition, people who acquire a disability after the age of 18, or who had a day service and left it, do not have an automatic entitlement to a day service if they otherwise meet the criteria. While some of the people who acquire a disability enter services through an RT place (the school leavers process is open to both school leavers and RT exits), there are people who are unnecessarily excluded from a day service. The extent of this unmet need is currently being explored by the HSE.

Finally, no additional funding has been allocated to support the implementation of New Directions. The principle of New Directions is individualised supports and these are likely to cost more money than was awarded historically – not least in the capital requirements to have more centralised, hubs. This element has not been costed in below.

As these are matters that another Working Group under the Transforming Lives process is pursuing (WG2) WG1 agreed not seek to quantify the scale of potential additional demand involved from this set of unmet needs.

7.3 DEMAND FOR PLACES FOR SCHOOL LEAVERS

School leavers requiring significant support may enter a day service or a Rehabilitative Training (RT) place (for up to three years), after which most will continue to remain in a HSE-supported place such as a day service place, vocational training or supported work. In addition, people who acquire a disability in adult life may enter the system via Rehabilitative Training and subsequently move into another form of day placement.⁴¹

Additional demand for adult day places arises every year from a new cohort of school leavers along with those leaving Rehabilitative Training, and their requirement for adult day services/supports is generally lifelong. However, overall the inflow exceeds the outflow, requiring additional places each year, as few resources are freed up at the other end of life.

⁴¹ Over the period 2014-2016, the number of people in RT/VT who exited the NIDD database was only 4-5% of the total numbers in these services. While 300 a year exit from the day service, it is unlikely that all of these currently have a meaningful day service, which would affect the extent to which day places are freed up for new entrants. Working Group 2 is estimating how many people in residential services do not have a meaningful, or any, day service.

7.4 MINIMAL VACANCIES AS SERVICE NEEDS OF OLDER DAY SERVICE USERS INTENSIFY

An analysis we carried out, based on NIDD 2016 data, showed there were approximately 16,000 over-18s in different forms of day services (excluding school-based services and those receiving multi-disciplinary support only). About 300 places, just 2%, in principle became available up through deaths (1.2%) or transfers off the database (0.8%).⁴² However, in practice, as the current population in day services ages, and their support needs intensify, more resources are required for existing day service users, freeing up much fewer places than that for new entrants. In 2017, only 9 day places became available to provide for those exiting RT.

7.5 DEMAND FOR DAY PLACES/ RT AS POPULATION CHANGES

Table 22 looks at the demand for school-leaver etc. places from 2014-2017 and relates it to the population of 18 year olds in the relevant year.⁴³ While the numbers of people seeking a place has risen by 9% over the period, this reflects exactly the changes in the population of 18 year olds, as the proportion applying for a place has been very stable at 2.3% to 2.4% of the relevant population. This suggests that any upward shift in the number of students recorded with ASD in the school system has not to date impacted on the scale of the demand, (however it is reported that ASD is adding to the complexity of cases).

Table 22: Award of school-leaver/RT exit day service places

	Total aged 18	Inflow day service and RT	% of population
2017	61,318	1,439	2.3
2016	61,294	1,443	2.4
2015	57,572	1,340	2.3
2014	56,337	1,365	2.4

The future demand from school leavers for a HSE-funded day service place is likely to reflect trends in three variables:

- The overall number of 18 and 19 year olds arising from demographic change.
- Any increased trend towards disability labelling or diagnosis among those reaching that age. In particular, trends in the number of students in special

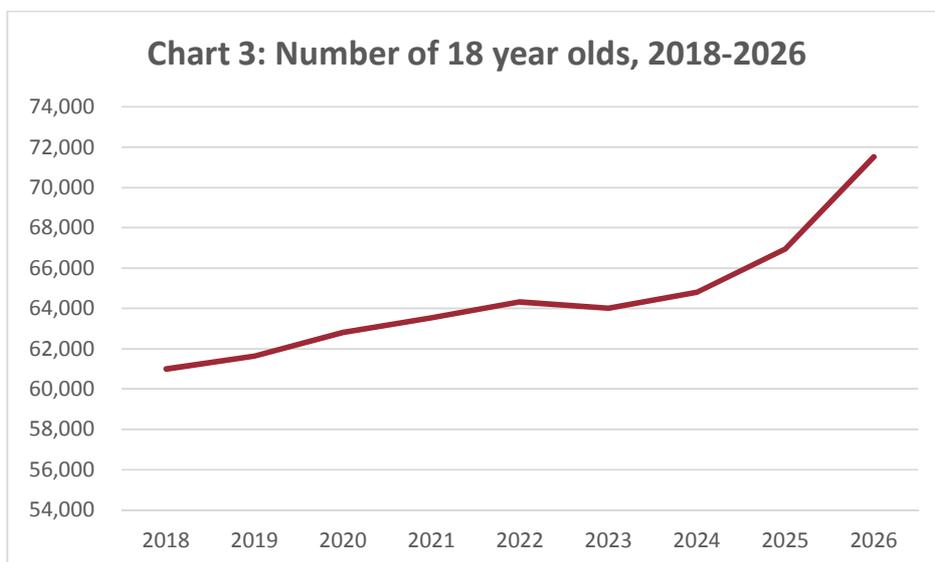
⁴² These are presumed to be individuals exiting disability services.

⁴³ The numbers aged 17, 18, 19, 20 in Census 2016 are taken to approximate the number of 18 year olds in the relevant years. This is a rough and ready way, as school leavers can be 18, 19 and occasionally aged 20, and RT exits are usually aged 21 or 22.

classes or special schools, the main feeder routes into adult day services, may affect the future numbers applying for school-leaver places.

- Increased complexity of cases. Anecdotally, service providers report that new entrants to day services have more complex needs than previously – often related to mental health issues. The data collected by the NCSE, and the disability figures by impairment in the Census 2016 highlight an increase in reporting of mental health problems among this cohort.⁴⁴ However without a standardised profiling tool, it is difficult to quantify the size, or even verify, this effect.

To estimate the demand for school-leaver places due to demographic change, we took the data on the young population by single year of age from the 2016 Census results (Chart 3). This shows a year-on-year increase in the demand for day services with a big increase between 2024 and 2026.



Source: Census 2016

We used the CSO's Irish Life Tables to convert the data on the population aged 8-18 by single year of age from the 2016 Census to the numbers who will survive to age 18 in the relevant year.⁴⁵ While this procedure does not take into account migration, it is

⁴⁴ Reported prevalence of psychological or emotional disability among 15-24 year olds in the Census doubled between 2011 and 2016 from 1.4% to 2.7% of the population. The proportion of people with ID who also reported a psychological or emotional condition increased from 33.5% in Census 2011 to 36% in Census 2016.

⁴⁵ The Life Tables are based on the 2011 census and provide estimates of 1-year survival rates, which we used to estimate how many 8 year olds in 2016 would survive to be 18 year olds in 2026, etc.

unlikely there would be significant migration among young people with disability, so a ratio of a static population is reasonable.

The number of school-leavers seeking day services was based on taking a ratio of 2.35% of surviving 18 year olds. (Note that this is a higher proportion of the relevant population than the 1.3% to 1.6% of all adults estimated to require disability services, as set out in Section 2 of this paper.) Table 23 sets out the outcome of these calculations.

Table 23:
Demand for day places due to demographic change, or demand shift post 2020

Year	Relevant age cohort 2016	Estimated 18 year olds	Est. school-leaver demand	As % of 2016 demand	Alternative total, if shift in demand from 2020 on	Alternative total as % of 2016 demand
2016	61,294	61,294	1,433	100%	1,433	100%
2017	61,318	61,298	1,439	100%	1,439	100%
2018	60,989	60,954	1,432	100%	1,433	100%
2019	61,643	61,597	1,448	101%	1,448	101%
2020	62,813	62,757	1,475	103%	1,622	113%
2021	63,531	63,469	1,492	104%	1,641	114%
2022	64,325	64,257	1,510	105%	1,661	116%
2023	64,014	63,942	1,503	105%	1,653	115%
2024	64,793	64,716	1,521	106%	1,673	117%
2025	66,950	66,866	1,571	110%	1,728	121%
2026	71,524	71,429	1,679	117%	1,846	129%

To test the implications of a possible upward shift in demand for day places, to reflect the increased proportion of school students classified as having special needs and in special classes, we also looked at the implications of raising the proportion of the age cohort of 18 year olds applying for school leaver day places by 10%, from 2020 on.⁴⁶ This is shown in the shaded area of the final two columns of Table 23.

Supply of day + RT places

People who move from RT to day services (or out of services) free up RT places for school leavers and other new RT entrants. Day service places may be in principle freed up as people die or leave disability services, but in practice few have materialised in

⁴⁶ This would imply an increased ratio of 2.59% of the relevant age group would be getting a disability day place from 2020.

recent years as older service users have become more resource-intensive.⁴⁷ So we modelled two scenarios to convert gross additional demand into net additional demand.

In 2017 of the 1,439 places allocated, approximately 500 went to an RT place (which are roughly fixed in number) or filled a pre-existing vacancy, meaning about 940 new places had to be created. **Scenario 1** continues this pattern.

Scenario 2 assumes that from 2022 onwards an additional 300 day places become available each year due to deaths/other net exits.⁴⁸

To convert the estimates of gross demand for day service places in Table 21 into estimates of the cost of new day service places, the following assumptions were made

- the ratio of day places provided to applicants remains constant
- the number of existing RT places that become available is a stable 500 a year
- the cost per place stays constant (i.e. the support-intensity mix remains constant), at about €20,000⁴⁹
- Each 30 additional places leads to extra premises cost of about €50,000 a year

As well as running costs, providing new day places brings additional premises costs. Using the New Directions model of day service ‘hubs’, it is estimated that a new hub is required for every 30 additional places. These hubs could be built, bought or leased, and located either in purpose-built premises, or in adapted premises. Whichever approach is taken for a given centre, a premises budget will be required for building work or for purchase or leasing costs, along with funding for any required adaptations such as installation of accessible bathrooms. While there is not a solid basis for estimating premises costs, for illustrative purposes in Table 24 we show the implications of a premises cost of €50,000 for every 30 additional day places.

⁴⁷ It is also not clear what proportion of those exiting have had a meaningful day service. The main areas where exits occur are labelled ‘day activation’, ‘service for the elderly’, and ‘sheltered work’ on the disability database.

⁴⁸ Based on HRB data on exits from day services due to deaths/deregistrations over the 2014-2016 period. We have not modelled how these might change over time

⁴⁹ The allocation of €20m. for 940 extra day places in 2017 included about €2m. in capital funding, which meant average current costs of a day place averaged roughly €20,000

Table 24: Increment of additional annual cost of new day places required⁵⁰

Year	Extra nos demographic change only	Extra running costs	New premises	Demand shift from 2020	Extra running cost	New premises
	Nos.	€m	€m	Nos.	€m	€m
Scenario 1						
2018	932	18.6	1.6	932	18.6	1.6
2019	948	19.0	1.6	948	19.0	1.6
2020	975	19.5	1.6	1,122	22.4	1.9
2021	992	19.8	1.7	1,141	22.8	1.9
2022	1,010	20.2	1.7	1,161	23.2	1.9
2023	1,003	20.1	1.7	1,153	23.1	1.9
2024	1,021	20.4	1.7	1,173	23.5	2.0
2025	1,071	21.4	1.8	1,228	24.6	2.0
2026	1,179	23.6	2.0	1,346	26.9	2.2
Scenario 2						
2018	932	18.6	1.6	932	18.6	1.6
2019	948	19.0	1.6	948	19.0	1.6
2020	975	19.5	1.6	1,122	22.4	1.9
2021	992	19.8	1.7	1,141	22.8	1.9
2022	710	14.2	1.2	861	17.2	1.4
2023	703	14.1	1.2	853	17.1	1.4
2024	721	14.4	1.2	873	17.5	1.5
2025	771	15.4	1.3	928	18.6	1.5
2026	879	17.6	1.5	1,046	20.9	1.7

As the inflow into day services year-on-year continues to exceed the outflow, under whichever scenario, a stepwise increase in total budgets would be required. The additional spend implied in these scenarios is set out in Table 25.⁵¹ For ease of reference we will call the demand shift scenarios 1b and 2b.

⁵⁰ To show how net inflow and elements of costs might evolve over time, Table 22 is based on the worked-out calculations, but given the range of assumptions involved should not be interpreted to this degree of precision, but just the orders of magnitude that follow from the underlying assumptions.

⁵¹ We have ignored the timing of the increases mid-way through the year as it would be lost in the rounding process

Table 25: Annual additional spend on adult day services

Scenario	1a	1b	2a	2b
	€m	€m	€m	€m
2018	20	20	20	20
2019	41	41	41	41
2020	62	65	62	65
2021	83	90	83	90
2022	105	115	99	108
2023	127	140	114	127
2024	149	165	130	146
2025	172	192	146	166
2026	198	221	166	189

The different scenarios show that spending on day services to meet demographic pressures will need to rise by the order of €80-€90m by 2021 over its 2017 level. This is predominantly the effect of a population bulge working its way through. By 2026, our estimates of additional cost have a wider range of the order of €170m to €220m, depending on whether an upward demand shift materialises reflecting what has been seen in the education system, and whether annual outflows from day services begin to be reflected in a greater supply of annual vacancies becoming available.

Introducing a deferral option would lower demand in the short run...

However, any decision to allow people to defer their school-leaver place while they pursue further studies or employment opportunities could cause a downward shift in demand in the short run to the extent that young people had confidence to try alternatives. Some of the deferred demand could appear in later years as people took up the deferred place, however it is likely that a proportion of those choosing to try something else on leaving school may ultimately not choose to use adult day services if their alternative choice proves successful.

...but it makes sense to invest to sustain alternative options to day places for those concerned

Any increased investment in supporting 'borderline' students to sustain a higher or further education place or an initial job could help moderate a demand from such students for what is likely to be much more expensive HSE-funded day service support. As well as enhancing social inclusion and lifetime chances for such students, and very much in the spirit of the Comprehensive Employment Strategy for People with Disabilities by offering support at a key transition point, additional spending on such an approach would be a good financial investment for the state.

7.6 WILL ANNUAL NO. OF VACANCIES RISE IN FUTURE?

The experience of the recent past is that an almost negligible number of new entrants to day services have been accommodated in vacancies, so that the total number in day services has grown virtually in line with the number of entrants each year. This is consistent with the findings in Table 4 that the numbers on the NIDD in the older age groups has risen steadily, and our forecast in Table 5 that the growth in older people is set to continue.

Figures received from the NIDD suggest that exits from adult day services through deaths or service/database exits were about 300 a year in each of 2014, 2015 and 2016, amounting to about 2% of total adult day places. If inflows are approximately 1,000 a year (table 22), and outflows in the region of 300 a year, the stock of day places will have to continually rise for the foreseeable future. In addition to a continual inflow of numbers, it is also likely that the complexity of cases will increase due to the increase in school leavers presenting with ASD which may bring significant communication needs or behaviour support requirements.

At some point in the future, however, inflows and outflows are likely to come into greater balance, enabling a higher proportion of entrants to be accommodated in vacant day service places becoming available. Often a vacancy is suppressed to take account increased need among existing clients as they age. Therefore far fewer than 300 places are created through exits each year. Adoption of a standardised profiling tool to estimate needs of service users at different points over their lifecycle may aid rebalancing.

8. ADULT THERAPY SERVICES

8.1 ADULT THERAPY SERVICES FOR PEOPLE WITH AN INTELLECTUAL DISABILITY

The Health Research Board has provided the Working Group with data on the number of adults on the National Intellectual Disability Database requiring new or enhanced therapy services over the period 2016-21.

Table 26: Adults (18+)with ID getting therapy etc supports, and future service needs 2016-2021

Service type	Has service in 2015	Needs enhanced service 2016-21	Needs new service 2016-21
ID-related medical services	7,473	2,144	862
ID-related nursing	6,192	1,944	652
Dietetics	2,849	1,279	3,454
Occupational therapy	3,820	1,869	4,078
Physiotherapy	3,769	1,838	2,162
Psychiatry	6,517	2,704	899
Psychology	5,298	2,570	4,492
Social work	7,527	3,119	2,695
Speech and language therapy	4,576	2,399	3,692
Other multidisciplinary service	4,935	1,253	1,964

Source: Health Research Board, special tabulation of NIDD 2015

The percentage increase in anticipated demand for each type of support was estimated, with 'new service' given the same weight as a current service, and using a range of weights for 'enhanced service' as representing an additional third, half or two thirds of current service provision.

has	needs enh	New needs
7,473	2,144	862
6,192	1,944	652
2,849	1,279	3,454
3,820	1,869	4,078
3,769	1,838	2,162
6,517	2,704	899
5,298	2,570	4,492
7,527		

	3,119	2,695
4,576	2,399	3,692
4,935	1,253	1,964

Table 27: Percentage increase in requirements for therapy etc. support for adults with ID, 2016-21

Service type	Weighting for 'enhanced service'		
	.5	.33	.66
ID-related medical services	26%	21%	30%
ID-related nursing	26%	21%	31%
Dietetics	144%	136%	151%
Occupational therapy	131%	123%	139%
Physiotherapy	82%	73%	90%
Psychiatry	35%	27%	41%
Psychology	109%	101%	117%
Social work	57%	49%	63%
Speech and language therapy	107%	98%	115%
Other multidisciplinary service	52%	48%	57%

Source: WG1 calculations based on Table 24

It is striking that demand for psychology, speech and language therapy is expected to double; for physiotherapy to rise by marginally less, and for occupational therapy to rise by around 130%. While the limited coverage of the NPSDD does not allow a similar calculation, a similar pattern of future demand for therapy supports could be expected.

The starting salary for a professional therapy grade such as Occupational Therapy was approximately €40,000 at the beginning of 2016, and the mid-point of the scale was approximately €47,000.⁵²

Unfortunately the calculation of the cost of adult therapy services is hampered by a lack of information on the number of therapists working in adult disability services. The *Value for Money and Policy Review of Disability Services (2011)* cited a figure of 5,276 health and social care staff,⁵³ which would include therapists, and also mentioned the problems disentangling numbers providing therapy services in primary care from those

⁵² HSE Consolidated pay scales

⁵³ Table 4.7 VfM Review

in disability services. The HSE 2017 Service Plan quoted 3,903 staff in the 'health and social care' category in Social Care (which includes older people's services).

The Working Group were informed by service providers represented on the Group that the expansion of therapy services for 0-18s under the Progressing Disability Services programme has to some degree come at the expense of therapy supports for adults, where therapists were switched into children's services. They also told the group that a shortage of occupational therapists was having an impact in delaying assessments for assistive technologies that could enhance people's wellbeing and independence. It was not possible for the group to quantify the impact of such factors. A study of demand for therapy services is being undertaken by the National Federation of Voluntary Bodies, however findings were not available at the time of completion of this report (February 2018) but may be available later in 2018.

Some insight might be gained by looking at children's services – Table 16 above highlights that there are 1,181.4 allied health professions in 2016. However this was between 300 and 400 posts short to meet the needs of children in 2016. Therefore, there should be approximately 1,550 posts for the 39,000 relevant children.⁵⁴ This is, approximately, one allied health professional (AHP) to every 25 relevant children.

8.2 ADDING IN DEMAND RE PEOPLE WITH PHYSICAL/SENSORY DISABILITY

The NIDD covers about 18,000 people aged 19 and over and the NPSDD lists about 8,000 people aged 18-65 (note slightly different age ranges). In addition the NPSDD is understood to only cover about two thirds of the relevant population.⁵⁵ Therefore weighting the NPSDD registered numbers to account for the under-coverage, and adding the demand estimated from NIDD data, means there are approximately 30,300 people who need services. Applying the ratio of Allied Health Professionals (AHPs) to children suggests there should be 1,200 AHPs specific to adult disability services. An increase by 8 percent to 2025 would imply a further 100 AHPs.

The difficulty arises in knowing how many extra AHPs are needed to meet this target without knowing the number in the system in the first place. Table 26 implies that there

⁵⁴ HSE (2017) in Planning for Health outline that there is 12,960 children in the 0-5 year age group and 25,990 in the 6-18 year age group who require a multiple-disciplinary team input (MDT) – that is 38,950 0-18s.

⁵⁵ The target coverage for the NPSDD in 2004 was approximately 41,000 (NPSDD Report 2004), with an achieved coverage that year of 60%. Overall coverage has varied over the years but the 2016 figure of about 22,000 registrations remains well below that target coverage of 41,000.

is up to 40% under provision at the moment. So it would need 480 appointments at the moment, and a further 100 to 2025. At a mid-point salary of €47,000 this implies an additional €27m. annually. However this figure must be treated with extreme caution, as it applies a staff to service user ratio taken from another age group, and imputes from that the current number of AHPs in adult services, for which we have no solid information.

Access to appropriate therapies can support people to be more independent. It can assist in modifying or reducing challenging behaviour, a major factor in high staffing ratios. Increased provision of timely therapy support for those with neurological conditions such as MS, acquired brain injury, spinal cord injury, and stroke has been found internationally to be cost effective, as argued in the National Neurorehabilitation Strategy (2011).⁵⁶

9. OTHER SUPPORTS FOR PEOPLE WITH PHYSICAL OR SENSORY DISABILITIES

9.1 IMPORTANT SERVICES TO SUPPORT INDEPENDENCE

Personal Assistant, Home Support, Assistive Technology /Aids and Appliances, and community support services from disability organisations specialising in specific conditions support people to manage their condition and live as independently as possible. Appendix 5 provides a picture of current services being provided, and presents the views of a number of providers as to what services are currently lacking or under pressure.

While no information is readily available on spending on Assistive Technology / Aids and Appliances, data for 2017 show that PA, home support, and community services together come to about 8% of the total disability services spend.

⁵⁶ Some of the therapy services for these conditions may be located in the primary care or hospital care programmes rather than in specialist disability services. The implementation plan for the Neurorehabilitation Strategy hasn't yet been prepared so there is no information yet available on overall costing. Based on draft proposals for CHO 6 and 7 for pilot neurorehabilitation services, this is likely to encompass acute rehabilitation services in acute hospitals; post-acute rehabilitation services which are consultant led, multidisciplinary services; community neurorehabilitation teams consisting of OT, physio, Speech and Language, Psychology, Rehabilitation Assistants; other community neurorehabilitation services (such as delivered by disability organisations working in this area like ABI, Headway, Enable Ireland); and complex home care packages for those discharged home. Respite and appropriate supported residential places are also likely to be required. See also Appendix 5.

9.2 UNMET NEED, HOME SUPPORT AND PERSONAL ASSISTANT SERVICES

The principal forms of personal support services funded by the HSE are home help/home care, and personal assistant services.

Just under 10,000 people currently receive Home Support or Personal Assistant hours – roughly twice as many hours are given in the form of Home Support.⁵⁷ That suggests the current budget of €79m consists of €52m for home support and €27m for PAs.

The NSPDD 2016, based on recently-reviewed files for about 6,100 people registered on this database, shows 18% of such adults receiving home care/home help, and 11% getting personal assistant services. Corresponding rates for children were 4% and 1%, based on very small numbers.⁵⁸

Unfortunately, there is no data collected on current unmet need for these or other personal support services from HSE. Therefore ‘nil’ unmet need is recorded in the NSPDD. Working Group members working in this field felt this did not express the true picture.⁵⁹ Current unmet need would comprise both those who need a service and don’t get one, and those who get a service, but with too few hours to meet their needs.

People who need it who get no service

To get a sense of the underlying number of adults in the eligible age group (under 65) for home support and personal assistant, our research focused on two sources – the National Disability Survey 2006, and a special tabulation of Census 2016.

We examined data from the National Disability Survey 2006 which asked about the degree of difficulty with everyday activities. We focused in on those with a mobility/dexterity difficulty who were aged 35-64 – in the disability services age range,

⁵⁷ There may be some interchangeability between these two categories – in certain cases, Home Support is seen as a more flexible option than Personal Assistant. The small number of hours recorded for most PA users suggests they are getting basic personal care only, not a personal assistant service.

⁵⁸ There were just under 500 individuals in 2016 receiving PA services whose records were updated on the database that year, an estimated 21% of total recipients of PA services. Incomplete coverage of the database, and how representative those whose records were reviewed of the total concerned can affect the validity of these data. The numbers of children receiving these services was too small to use as any basis for estimation.

⁵⁹ For example, it was reported to the Group that Cork CIL had a waiting list of 45 people for PA services at November 2017. The low hours of PA typically received, the numbers inappropriately placed in nursing homes in the absence of PA support for independent living, and the feedback from service providers reported in Appendix 5, all point to a level of unmet need for PA services, but in the absence of hard data the Working Group were unable to quantify that.

and at an age where parental support with personal care or participation in the community would be less available.⁶⁰ Of these, 15,000 people had a lot of difficulty with everyday activities, and 3,000 were unable to do them. Adjusting for changes since 2006 in the disabled population of that age,⁶¹ we estimate that would correspond to 25,000 and 5,000 people today in these two categories.

A special tabulation of Census 2016, covering people with significant physical/mobility difficulties aged 25-64, showed 36,000 people had difficulties with dressing, bathing or moving around inside the home, and 21,000 people experienced difficulties both with dressing etc., as well as with going outside the home alone. Looking at over 35s only, those numbers become 31,000 and 18,000.⁶² 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. While family and friends may be able to offer some or all of the support required, some in these categories will need HSE-funded services, Table 28 sets out the potential population who could have home care or PA support needs, alongside the level of current provision as per the 2018 HSE Service Plan.

**Table 28:
Potential nos requiring PA/home support services (35-64) and actual provision**

	PA group	Home support group
Census 2016 (potential)	18,000	31,000
National Disability Survey (potential)	5,000	25,000
Actual nos. getting PA, home support, 2018	2,357	7,447

These data are not able to pinpoint to what extent the number of people getting a PA or home support service falls short of the number who require it. But they do lend support to the experience of members of our group that there is significant unmet need for PA services. Further evidence of that is the numbers of people with disabilities living in nursing homes, who could live independently if appropriate PA support were available.

The Task Force on Personal Budgets which reports in early 2018 is examining how people could be given the option to purchase their own services, and it is likely that

⁶⁰ The Working Group recognise that younger people may also need PA or home support services – the over 35 cut-off was only used for estimating purposes.

⁶¹ We used the percentage change in the numbers with difficulties with dressing etc in 2006 and 2016 for the age group.

⁶² In the absence of a specific cross-tabulation in respect of over-35s, we took a pro-rata approach.

more people will opt for self-managed PA supports in the future. This option is likely to result in some of the latent demand for this service becoming more apparent.

People who need additional hours

The evidence is that existing PA resources are spread very thinly. Current understanding is that the allocation of PA hours is often guided by the need to spread a limited total pool of PA hours rather than by the level of such support required. Successive HSE Service Plans have generally kept the target total hours provided at the previous year’s level. As Table 28 shows, two thirds of those with PA support receive fewer than ten hours support a week, and only 7% receive more than 40 hours.

Table 29: Distribution of PA hours, 2017

Hours per week Personal Assistant	No.	%
1 to 5	957	42%
6 to 10	538	23%
11 to 20	397	17%
21 to 40	256	11%
41 to 60	73	3%
60+	83	4%
Total	2,304	100%

Source: Department of Health 2017 working paper to Task Force on Personal Budgets

Assistance of less than ten hours a week, under two hours a day, is unlikely to facilitate more than basic care – help with getting up and going to bed, washing, and feeding. That may be more properly described as ‘home care’ rather than ‘personal assistant’. If those who get this limited degree of help would need additional support to enable them undertake activities outside the home, they could need additional PA hours to do so. Even a minimal change, to award people in this group an additional three hours a week to facilitate some degree of social participation, would add almost a quarter of a million hours to the current annual PA total, or raise it by 15%.

There are also people who could be in employment but who might need PA support throughout the normal working day to assist with personal tasks like feeding or toileting. This is something that is coming into sharper focus under Action 5.1 of the Comprehensive Employment Strategy for People with Disabilities. To give an illustrative example, an additional 6 hours PA a day for 100 people would amount to an extra 150,000 hours a year or so, representing a 10% increase on the PA hours to be provided in 2018.

An exercise conducted by the Irish Wheelchair Association (which supplies 70% of all PA services), which we were unable to independently verify, gave their assessment that the

shortfall in PA hours, for their service users alone, could require total hours provided in 2018 to rise by 26%.⁶³

9.3 COST OF ILLUSTRATIVE EXAMPLES OF UNMET PA/HOME SUPPORT NEED

While there is no hard evidence on the scale of unmet need for PA or home support services, some examples were costed for illustrative purposes.

Table 30: Additional annual cost of illustrative examples

Example	€m
Add 100 PA recipients, current average hours	1
Add 500 PA recipients, current average hours	6
Add 100 PA recipients, 30 hours a week	3
Add extra 3 hrs PA a week to those getting 10 or less	4

Collecting and verifying data on current requirements for PA and home support services should be a priority in the development of the new combined database of support needs.

9.4 FUTURE SERVICE NEEDS, PA AND HOME SUPPORTS

In Section 3, we concluded that rates of difficulties with ADLs remained stable for under 65s between 2011 and 2016, therefore future population change alone would drive changes in demand. Using CSO population projections, demand would rise by 5 to 6%, relative to the 2016 level, by 2021. There would be a further rise of 7% to 2026.

⁶³ Figures were provided to the Working Group on behalf of the Irish Wheelchair Association, based on IWA's assessment of a sample of their PA users and what they might need. The Working Group did not have any details of the size or nature of the sample, and were not in a position to independently verify or endorse this information. IWA estimated that raising the minimum number of PA hours supplied to 21 a week for their service users alone would add some 383,000 hours a year.

Disability	Hours needed per day	Hours per Week
Cerebral Palsy	3 to 16	21 – 112
Multiple Sclerosis	5 to 8	35 – 56
Muscular Dystrophy	6 to 15	42 – 105
Paralytic Syndromes - Quadriplegia	9 to 15	63 – 105
Spinal injury – Tetraplegia	9 to 15	63 – 105
Spina bifida	2 to 6	14 – 42
Spina bifida and hydrocephalus	2 to 6	14 – 42

The NSPDD 2016 (its table 16), also looks at potential future demand to 2021 for PA and home-care services. These data suggest the demand for PA and for home help/home care from adults would each grow by about 22% to 2021.⁶⁴ While the data are labelled as ‘future’ rather than ‘immediate’, they may capture a sense of current unmet need. However, they are based on relatively small numbers, and may not be representative.⁶⁵ In particular, the NSPDD gives very small numbers as requiring an enhanced PA service, which does not seem plausible given how thinly current hours provided are spread.

Table 30: Future need for home support and PA services

	€m
Increase, NSPDD forecast to 2021	+17
<i>(Population change to 2021)</i>	<i>+4</i>
Additional population change to 2026	+6
<i>Extended hours, current PA recipients</i>	<i>+4</i>
<i>Additional recipients, per 100</i>	<i>+1</i>

The signs point to an immediate increased requirement for funding for PA and home support services, but it is hard to put reliable figures on it. The best estimate, in spite of the caveats in the data, is from the NSPDD forecast (which should have some built-in allowance for demographic change), and would require an additional €17m spend in this area by 2021. Much of this is likely to represent an immediate need. An additional €6m a year would be required by 2026 for further population change. Other possible elements of demand are shown in italics in the table.

Table 31: Estimated requirement for PA, Home support and community services

	2017	Est. 2021	Est. 2026
	€m	€m	€m
Personal assistant and home support	79	96	102
Other community services and supports	53	56	60
Total	132	152	162
Increase		+20	+10

⁶⁴ We looked at data for adults only. The NPSDD’s forecast future need figures for children were based on tiny numbers

⁶⁵ Using assessments of current cases may miss future inflows to the database of people with acquired disabilities, and outflows of those who will pass away. It is not clear how well the effect of population change would have been captured, and whether this should be considered additional

9.5 ASSISTIVE TECHNOLOGY/ AIDS AND APPLIANCES

There is little hard data available on current spend on assistive technology or on service requirements in this area. The list of products currently in use by those with up to date records on the NPSDD shows a very wide variety, much of it low-tech and inexpensive items such as grab rails or walking aids, and extending to expensive items like specialised or powered wheelchairs, which can help maintain and enhance independence and mobility.

A study for the NDA that examined the data on assistive technology availability and use from the 2006 National Disability Survey found that unmet need was over 50% for 11 of the 32 types of assistive technology covered in the survey. The greater likelihood of unmet demand, controlling for other factors, arose

- for those with lower levels of impairment
- when the AT was for an impairment was not the person's main disability
- for people living in communal establishments
- for disability onset after childhood⁶⁶

While the development of apps will have changed the landscape for certain types of supports in the intervening period, it has also coincided with significant restrictions on disability funding over the recession years, so that many of these findings may hold today.

9.6 COMMUNITY SERVICES AND SUPPORTS

Appendix 5 sets out data on the prevalence of nine selected disabling conditions, and documents the current scale of community activity by some of the service providers working in these areas (Table A5.5). Table A5.6 sets out a number of case studies prepared by these disability service providers what is available through specialist disability channels, and which services they see as lacking or in short supply to meet the needs of those they serve.

This paper acknowledges that timely and appropriate community supports may enable someone to live more independently and remain in their own home, as well as enhancing their quality of life. Relatively modest expenditures in this area may forestall the risk of much more expensive interventions being required. To use the Australian

⁶⁶ WRC (2015) Assistive Technology Usage and Unmet Need amongst People with Disabilities in Ireland - Analysis of Data from the National Disability Survey of 2006. www.nda.ie

terminology set out in s 2.1, providing adequate funding for these supports may help keep people in Tier 2 rather than Tier 3.

10. COMPETENCIES AND SKILL MIX

10.1 COST OF SERVICES REFLECTS HISTORIC GRADING STRUCTURE/SKILL MIX

The current cost of delivering disability services reflects the current grading structure and skill mix in services, which may reflect historical patterns rather than the new models of service set out in Transforming Lives.

10.2 NDA COMPARATIVE REVIEW OF COMPETENCIES AND SKILL MIX IN DISABILITY SERVICES

The National Disability Authority (NDA) undertook research on competencies and skill mix in disability services. The NDA work reviewed 13 competency frameworks related to the disability sector across four countries, including Ireland. It found that there were many overlaps in competency areas and that these competencies were required to achieve positive outcomes for people with disabilities. The most frequently included competencies were communication (77%), education, training and self-development (69%), and evaluation, observation and assessment (54%). Compared to some international frameworks, the Irish competency frameworks seemed to put less emphasis on the competencies of evaluation, observation and assessment, person-centred practice, and community living skills and supports. However, the NDA noted that there is no single competency framework for the disability services in Ireland, and its advice would be that the HSE/Department of Health should develop such a unified competency framework, based on the agreed suite of 9 Outcomes for disability services.

In reviewing the literature and practice in other jurisdictions, the NDA saw a shift in focus from achieving a specific mix of different types of personnel to adapting workers' attributes and roles to changing environmental conditions and demands. Workload studies have shown that most professional health staff spend a high proportion of their time performing tasks that do not require their expertise.⁶⁷ The focus is shifting away

⁶⁷ Wanless D (2002) Securing our future health: taking a long-term view. London: HM Treasury Public Enquiry Unit; Richardson, G., Maynard, A., Cullum, N. & Kindig, D (1998) 'Skill mix changes: substitution or service development?' Health Policy, 45(2), 119 – 132.

from the issue of numbers and occupational mix towards the range of roles, functions, responsibilities and activities each staff member is qualified and able to perform.⁶⁸

10.3 THE RIGHTS SUPPORT TO ACHIEVE PEOPLE'S OUTCOMES

This approach is relevant to the disability sector in Ireland where the emphasis is shifting from meeting care needs alone, to supporting people with disabilities, in addition, to achieve the goals set out in their person-centred plans.

In a consultation with people with disabilities undertaken on behalf of the NDA as part of the Outcomes project, the participants suggested listing the supports required to achieve the outcomes. These included:

- Having the right staff to give good supports
- Being involved in choosing the staff that support you
- Having staff with the right skills and attitudes
- Having staff that know you well and understand you
- Having assistance with communication where that is needed
- Having advocacy support

The research found no evidence or examples of the optimal numbers of staff, rostering arrangements and skill mix required to support people with varying levels of disability to live lives with meaning in the community. Developing such examples in an Irish context may be helpful.

Indeed some researchers have found cases where the staff ratio may be a weak predictor of staff performance and it is possible to have high staff ratios and yet poor performance.⁶⁹

11. CONCLUSION

This paper has brought together data on disability service use and some current service deficits to try and predict requirements for additional spending in the medium term (2021 and 2026) on disability services. There are a number of background papers

⁶⁸ Dubois CA Singh S (2009) 'From staff-mix to skill-mix and beyond: towards a systemic approach to health workforce management.' Human Resources for Health. 7:87.

⁶⁹ Mansell & Beadle-Brown, 2008 Mansell J and Beadle-Brown J (2008) Dispersed or clustered housing for disabled adults: a systematic review. Canterbury: Tizard Centre.

prepared for the Working Group which have been drawn on for this synthesis paper, which are available as appendices.

Given the limitations of the data, the forecasts in this paper tell just part of the story. These forecasts have not quantified future demand for areas like personal assistant or assistive technology – however, these demands could expect to rise pro-rata as the population to be served by disability services grows. The paper has identified important demand pressures in the area of residential services, children’s and adult therapy services, and the ongoing need to add additional day service places each year to meet school-leaver demand. In particular, current demographic pressures, even in the absence of any further improvements in life expectancy, would raise revenue spending on residential care by about €60m a year in 2020 from current levels, and by about €100m extra in 2025.

Table 32: Estimated additional current costs, 2020 and 2025

Service	2020	2025
	€m	€m
Residential ID		
- Scenario 1, population change only	€55-60m	€95-100m
- Scenario 2, increased provision over 60s	€95-105m	€145-160m
- Scenario 3, pre-recession rates	€250-265m	€300-320m
+ additional P&S residential services	€5-6m	€9-10m
Respite (ID plus P&S)	€11m	€11m
Children’s therapy services	€16-21m	€16-21m
Adult day services	€62-65m	€150-190m
Adult therapy services	€27m	€27m
PA/home support and community services	€20m	€26m
Rounded total range (scenario 1, scenario 2)	€200m-€240m-	€325m -€390m
Range, Scenario 3	€390m-€415m	€540m-€600m

Table 34: Estimated additional capital costs, 2020 and 2025

Service	2020	2025
	€m	€m
Housing	2020	2025
- Scenario 1 (priced at €500k a house)	€50-60m	€90-100m
- Scenario 2 (priced at €500k a house)	€90-100m	€140-150m
- Scenario 3 (priced at €500k a house)	€240-250m	€290-300m
Adult day premises cost	€1.6m	€2m
Respite capital (priced at €500k a house)	€10m	€10m
Rounded total range (scenario 1-scenario 2)	€60m - €70m	€100m - €160m
Rounded range, scenario 3	€250-€260m	€300m-€310m

These numbers seem large but in the context of the demographic changes and the current budget of almost €1.7bn are not disproportionate. If the HSE disability budget was just increased proportionally in line with per-capita spending and projected population growth (and disregarding the impact of regulatory and policy changes and the ageing of the disabled population) the increase in the budget would be €56m to €135m in 2021, and €111m to €193m in 2026 (Appendix 2).

Demographic change is real, and it entails necessary changes in the scale and deployment of expenditure. It has long been accepted that social welfare pensions and child benefits, and teacher and ancillary school personnel numbers, should adjust automatically in response to demographic pressures. If demographic pressures in disability services are not similarly catered for, the inevitable result is a dilution in the volume or quality of service made available as funding and services get spread too thinly to meet demand.

RECOMMENDATIONS

BASED ON THE RESEARCH AND ANALYSIS CONDUCTED, THE WORKING GROUP CONCLUDES THAT SERVICES MUST PROVIDE FOR DEMOGRAPHIC CHANGE, OTHERWISE DEFICITS IN SERVICES WILL RESULT

- Provision is needed to meet demographic change, otherwise existing services will be spread more thinly on the population who require them

DATA

- There is an urgent need to improve data collection on physical and sensory disability to inform service planning, and to involve the service providers and the support organisations to achieve that
- To get a good baseline picture of the levels of service provision, to inform service forecasting, delivery and costing, it would be valuable to produce data which would aggregate the information in the Service Level Agreements and from HSE's own service delivery to achieve that, and to ensure that information would be available in computerised form to facilitate analysis
- Data on exits/vacancies from adult day services would improve forecasting of future additional places needed
- Collecting data on the type of school placement school-leaver applicants have attended (mainstream, special class or special school) would allow better use to be made of NCSE data to forecast future demand from school-leavers

COMPETENCY FRAMEWORK

- Consideration should be given to developing a national competency framework for disability services

APPENDIX 1 – AGE COHORT ANALYSIS OF NIDD DATABASE

The data in Table 1 in the main paper showed that a substantial increase has already taken place since the early 2000s in the number of people aged over 50 on the National Intellectual Disability Database. If the number of people aged 50 has risen now, in five years' time, the number aged 55 will also rise, as will the number of 60 year olds in ten years' time. That has implications for the number of people requiring full-time residential care, the most expensive element of disability service provision which absorbs about two thirds of the total disability budget.

We used an age cohort analysis, based on data for 2005, 2010 and 2015, to try and quantify the effect of demographic change. We compared the number of people aged 20-24 on the database in 2005, with the number aged 25-29 five years later in 2010, and the numbers aged 30-34 in 2015. We did similar calculations for other age cohorts. Generally speaking, the ratio five years on is less than 100%, as a result of deaths or of people moving out of disability services (there is a major exodus from registration at the point of leaving school, as Chart 1 in the main paper illustrated). Occasionally the ratio can be greater than 100%, for example if people who previously had not been in touch with disability services come forward to apply, and are put on the database.

It is hard to come up with appropriate terminology, but it was agreed to use the term 'survival rate' as a label for the ratio between the numbers from a given age cohort on the database at a point in time, relative to the numbers at a previous time.

It was easy to compare data set out in five-year age-groupings from one period to the next, but we had to infer five-year sub-groupings for the 65-74 and 75+ groups, using the relevant Census ratios. As it happened, altering how these age groupings were broken down as between younger and older sub-groupings made only marginal differences to the outcome of the calculations, so it was agreed to keep with the Census ratios (shaded data in Table A1).⁷⁰

We also wanted to make projections for five years and ten years hence. For the ten year projection, to 2025, the 10-year age-specific 'survival rates' (column D, Table A1) were used. For projecting five years hence, to 2020, the analysis looked at the five-year survival rates 2005-2010, and 2010-2015, and took the average between the two

⁷⁰ Census 2016 showed 65-69 year olds constituted 57% of the combined 65-74 age group, and 75-79 year olds were 44% of the over 75 grouping. We also tried tested alternative weights of 70% and 60% respectively, but this made negligible difference to the overall results.

(Column C, Table A1). The survival rates in the later of these two periods were similar to, but in some cases, lower, than they had been five years earlier. That suggests that among the over-45s, the trend to increasing life expectancy had stalled in 2010-2015, if it had not gone slightly into reverse (but there is always a random factor when underlying numbers are small). So the working assumption was made that age-specific 'survival' rates would remain constant over the next five and ten year periods.

Table A1: Cohort analysis – survival on database 5, 10 years later

Age	5-year survival rate 2005-2010, to this age (A)	5-year survival rate 2010-2015, to this age (B)	Average of A and B (C)	10-year survival rate, to this age 2005-2015 (D)
20-24	75%	86%	81%	100%
25-29	84%	87%	85%	66%
30-34	98%	97%	97%	81%
35-39	93%	93%	93%	91%
40-44	93%	97%	95%	91%
45-49	101%	99%	100%	92%
50-54	99%	90%	95%	91%
55-59	96%	86%	91%	85%
60-64	90%	81%	85%	77%
65-74	97%	84%	91%	76%
75+	59%	52%	55%	51%

The highlighted 75% 'survival rate' to age 20-24 means that the numbers on the database in 2010 who were aged 20-24 represented 75% of those who had been on the database in 2005 aged 15-19.

The average calculated 5-year survival rate of 81% to age 20-24 in column C was used to convert the numbers aged 15-19 in 2015 to an estimate of the numbers aged 20-24 in 2020. The output from these calculations is set out in Table 2 in the main part of this paper.

APPENDIX 2: DISABILITY BUDGETS 2008-2026

Table A2.1: Net funding for HSE Disability Services

	Net disability budget (€m)	At 2016 prices	Estimated population (m)	Disability budget per head of population
2008	1,485	1,503	4.49	331.10
2009	1,508	1,458	4.53	332.64
2010	1,582	1,516	4.55	347.33
2011	1,554	1,528	4.57	339.68
2012	1,554	1,552	4.59	338.29
2013	1,535	1,541	4.61	332.63
2014			4.65	-
2015	1,499	1,503	4.69	319.66
2016	1,558	1,563	4.74	328.76
2017			4.79	-
2021	1,614f		4.88	331.10
2026	1,669f		5.04	331.10

Note: population for 2021 and 2016 are m2f2 source:

http://www.cso.ie/en/media/csoie/releasespublications/documents/population/2013/poplabfor2016_2046.pdf. Annual disability budgets come from HSE National Service Plan – note 2014 not listed separately <http://www.hse.ie/eng/services/publications/serviceplans/>. Inflation figure is from CSO Consumer Price Index (Base Dec 2016=100) for all items

The table above shows the disability funding allocations up to 2017, and the expenditure which would be required in 2021 and 2026 to restore funding to the real per-capita rate which prevailed in 2008.

Table A2.2: Projected budget in 2021 and 2026 based on updating for population only

Year	Updated to 2008 per capita spend (€m)	Updated to 2010 per capita spend(€m)
2021	55.9	135
2026	111.2	193

There are a number of caveats to use of these figures to estimate future budget requirements, as they do not take account of the following:

- ageing of the disability population
- backlog of service need that has been built up

- any services transferred to or from disability services from another budget line
- spending changes caused by regulatory change, e.g. HIQA requirements for more staff on at night
- changes in pay scales, or the effect of incremental salaries on costs