



Key Budget 2022 Priorities

1 Address urgent unmet needs of people with disabilities and plan for the future



The recent publication by the Government of the *Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032* is very significant and its findings concerning. The report quantifies very serious levels of unmet need and signals the required investment to adequately support people with disabilities over the coming years.

The Capacity Review provides a stark picture that reinforces the messages we have provided over successive budget campaigns, showing that many people lack the supports that they need and some get no supports at all. Significant investment will be needed in Budget 2022 to address this crisis.

Residential supports and respite

- The Capacity Review confirms that currently, there is no planned pathway in place to access residential support when an adult with intellectual disability (ID) no longer wishes to live with their family, or when family carers can no longer provide support. Provision of residential support has been driven over the past decade through crisis and emergency responses.
- Residential supports provided in response to crisis are often considerably more expensive and often result in less favourable outcomes for the person and their family than planned supports, provided at the right time.
- Our figures show that there are over 1200 family carers over the age of 70 providing primary care for their loved ones, approximately 400 of whom are over the age of 80. This is a result of successive years of underinvestment. Budget 2022 must put an end to this unsustainable and unfair lack of planning, and instead support people with ID to live independent lives in the community, while supporting their families to plan for the future with peace of mind.
- There are at least 2,100 people who remain living in congregated settings, a decade after the publication of the report that set out to close these institutional settings. The investment made in Budget 2022 must give these people the opportunity to live their lives included in community, in line with the rights set out in Article 19 of the United Nations Convention on the Rights of Persons with a disability (UNCRPD).
- A range of options is needed that encompasses supported independent living, personal assistance, home support, and full-time residential supports - depending on the needs and wishes of the individual and in line with Article 19 (UNCRPD).
- With the lack of available residential supports, and the additional pressures brought about for family carers during the Covid-19 pandemic, there is a particular need for funding of additional respite – using both traditional and alternative short break models.

Day Services

- The provision of Day Services requires investment, both to ensure sufficient funding for new entrants and also to provide for appropriate supports for those established within day services - as we are supporting an ageing population with significant associated additional challenges.
- The banding for new admissions to day services should be reviewed, particularly in light of the significant number of people with complex needs who are approaching school-leaving age.
- Funding for day services should take into account the will and preference of those using the service - including for instance, older people who have expressed their wish to retire and receive their supports at home.

Supports for children

- Whilst there have been significant positive developments in children's services, there remain waiting lists and delays for children to access required supports in a timely manner. Time is of the essence, and early intervention is key for children and their families.
- Budget 2022 should place a focus on addressing waiting lists for children with disabilities and ensure early access to the necessary therapy inputs.

With the Government's own evidence putting the minimum investment for the coming year at an additional €350million revenue and between €500 to €800million in capital spend over the period to 2032, the Capacity Review report signals that the crisis being experienced by people with disabilities is a serious national priority that must be actioned in Budget 2022. Multiannual funding is required to ensure best value for money for the State and security for people requiring a service, as set out in the Department of Health Capacity Review.

We are calling on Government, in Budget 2022, to invest in the required supports in line with the requirements set out in the Capacity Review. At a minimum, to meet the lower end estimates of the Review, this will require €350million additional revenue funding in 2022 and between €500-€800million in capital spend over the period to 2032.

2 Coordinate services to put the person at the centre



It has become apparent over recent years that where responsibility falls between two or more Government Departments for the delivery of services and supports to people with disabilities, the citizen is often left without the support that they need. The National Federation has set out a detailed account of particular areas in which a lack of coordination is causing the citizen to be left without support, in two key submissions:

- Our submission in response to the [Draft Initial State Report under the United Nations Convention on the Rights of Persons with Disabilities](#) report; and
- Our submission into the [development of the new Housing Strategy for Disabled People](#)

There is a need for clear responsibility for budget lines in the following areas to be set out in Budget 2022 to ensure that the citizen is not left without support:

- As set out in detail in our submissions above, there is a need for coordination of housing provision and the required supports in order for people with disabilities to be able to access living options in line with Article 19 of the UNCRPD. This will require significant coordination between the relevant Departments and a joined-up approach to the budgetary allocations in relation to both housing and relevant supports. Currently, opportunities for individuals to access housing are lost when the required supports cannot be allocated in a coordinated approach.
- The allocation of funding to provide transport to day services, upon which many people with ID rely to access their supports, is not currently provided to the HSE. However, this responsibility is not taken up by the Department of Transport. Investment to address the ageing transport fleet in disability services, and clarity of funding responsibility is urgently required to ensure safety and accessibility.
- Special schools are not currently allocated guidance counsellors, in spite of children attending mainstream school having access to this support. A funding allocation to provide access to guidance counselling in the context of transition planning is required to adequately, equitably and positively plan for the future of young people attending special schools.
- HSE has indicated that the Day Services programme does not provide funding for employment supports to those entering its services. However, the mainstream Intreo services have not been resourced to take up the specialised requirements for supported employment required by people with ID.

We are calling on Government to act in Budget 2022 to ensure clear budget lines of responsibility in relation to areas of supports that cross between Departments, and to ensure coordination takes place between Departments to put the citizen at the centre.

3

Address the long-term sustainability of services and supports



High quality services for people with intellectual disabilities are built on a foundation of relationship-based trust and support, maximising the ability, potential and independence of the person.

The stability of staff in place with a long-term commitment to the people they support was a key driver of the low infection and mortality rates from Covid -19 in disability services in Ireland compared with many other jurisdictions.

However, there are a range of challenges now threatening the sustainability of the supports provided to people with disabilities, and these require coordinated Government action to safeguard the future of these supports and services.

- There is a severe shortage of staff making it very challenging to recruit and retain people in many sectors, and this is being acutely experienced in Disability Services.
- For organisations to be able to recruit and retain high quality staff, they must show prospective candidates that they are valued equally; paid equally for the same work, whether they work for a Section 38, Section 39 organisation or the HSE. Citizens with disabilities should not experience differing stability or turnover of their support staff based on the funding model of the service provider.
- We recommend that a workforce planning task group should be established nationally to ensure that the conditions are put in place to attract and retain high calibre staff to support people with ID, valuing their work and contribution over the coming months and years.
- The issue of pay parity for Section 39 disability service providers should be addressed to enable services to be equipped to respond to the evolving and unmet need identified by the Department of Health's Capacity Review report.
- There is a requirement for funding to be allocated in Budget 2022 to address the acute underlying and current deficits that have been caused by many years of underfunding of disability services.
- Currently there is an absence of an agreed, uniform and consistent national costing methodology for disability services, which is urgently required to guide equitable investment in the required supports. This will facilitate sustainable planning and resource allocation.
- There has been a significant impact on the ability of service providers to provide frontline support by virtue of the increased burden of compliance with a wide variety of regulation from a range of Government Departments. Whilst the majority of regulations themselves are welcome and necessary, the State must assess the impact of new regulation to agree the resourcing required, before implementation.
- The Capacity Review report confirms that 70% of disability services are provided on behalf of the State by not-for-profit service providers. There are legal requirements on services to implement national pay awards, pension entitlements and implement regulation. When these agreements and regulations are made at national level it is essential that the full cost of implementation is equally allocated to not-for-profit service providers who are contracted by the HSE to provide services on behalf of the State, and those provided directly by the HSE.

To access equal support, the same funding should be provided for the same service, regardless of the type of organisation the person accesses their service from.

We are calling on Government to act in Budget 2022 to safeguard the sustainability of the high quality, relationship-based supports required to ensure stability and quality of service to people with disabilities.

Appendix I: What the Disability Capacity Review is telling us

The evidence provided in the Disability Capacity Review is of central importance in identifying the scale of current unmet need for supports for people with disabilities, and in guiding the planning for services and supports over the next decade. The key findings of the report set out as follows:

Residential supports

- A significant increase in the number of people in disability residential care/supported housing would be required to deal with the impact of demographic change, and to address a substantial backlog of need.
- About 90% of those in disability residential care have an intellectual disability. Most people with intellectual disabilities will require supported housing/residential care when their parents can no longer care for them at home.
- An average of about 90 new residential places will be needed every year from 2020 to 2032 to cater for changes in the size and age structure of the disability population.
- Access to residential care has fallen since the 2008 recession. Supply did not keep up with population growth, but actually fell, as some places did not meet regulatory standards.
- The resulting shortfall is estimated to range from a minimum of 800 places, up to 2,300 places.
- The minimum is based on HSE's Emergency/Urgent waiting list, which is incomplete. The top estimate is based on restoring the 2007 level of provision, alongside better access for over-60s.
- To deal with both the backlog and with demographic change, overall, an extra 1,900 residential places would be needed by 2032 under the Minimum scenario, and an extra 3,900 under the Pre-recession scenario.
- The extra annual cost of meeting demographic need only would be around €60m a year by 2022, €120m a year by 2027, and €160m a year by 2032.
- The annual extra cost of addressing both demographic change and unmet need would range from an extra €320m a year by 2032 under the Minimum scenario, and an extra €550m a year under the Pre-recession scenario, at current unit costs.
- Pay changes, additional staffing for regulatory compliance, and increasing prevalence of intensive support needs could all drive unit costs up further.
- Capital cost for the additional places could range from €250m to €520m over the period to 2032, depending on the scenario.
- In addition, the replacement cost of the 2,100 places currently in congregated settings which are scheduled to close would add another €280m. That would bring the total capital needed to between €500m - €800m.

Day Services

- Following the baby boom of the 2000s, a growing number of school-leavers are expected to apply for day services up to the end of the 2020s.
- Participation in day services is virtually lifelong, while participation in training programmes is time-limited. Many participants with intellectual disabilities transfer to day services on completing Rehabilitative Training.
- The limited data on outflows suggests that inflow of school-leavers into day services are likely to outweigh anticipated outflows over the period to 2032.
- That will mean a step-wise increase will be required every year in number of day service places to meet demographic demand. From 2015 to 2019, about 1,000 additional places a year were provided to meet the excess of school-leaver inflows over exits from day services.
- The HSE estimates there may be 600 people with no day service who need one. There is also unmet need for those getting partial day services, which is estimated would be equivalent to an extra 600 full-time day places.
- To meet unmet need of those who get partial or no day services would cost €30m a year, at a unit cost for a new place of €25,000 a year.

- To meet continuing demographic need is likely to require an annual stepwise increase in spending. Under the 'high exit' scenario, the annual step in expenditure needed to provide additional day places would be about €5m. By 2032, additional demographic need under this scenario could have reached €60m above the 2020 level. On a 'low exit' scenario, the annual incremental step in spending could average around €20m a year. By 2032, the extra cost of meeting this demographic demand would be around €250m above the 2020 level. On an intermediate exit scenario, the annual step would be around €12m, and the additional cost in 2032 over the 2020 level would be around €140m.
- Because demographic demand is very sensitive to the annual exit rate from day programmes, it is difficult to provide a narrow band of estimates of potential overall cost of meeting both demographic and unmet need. On different assumptions about the exit rate, the combined additional costs of demographic demand and unmet need could fall within a range of an extra €90m to €280m a year required by 2032.

Multidisciplinary therapy services

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

Respite/short breaks

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

Home support, home care and Personal Assistant services

- Data on unmet need has not been systematically recorded, given the fixed number of service hours available to deploy, but there are signs it is substantial.
- The additional costs of demographic change are estimated at €4m a year by 2022, €10m a year by 2027, and €15m a year by 2032. In addition, an indicative package to provide greater access to those with no service, and additional levels of support for those who currently have minimal hours of support, has been costed at €30m a year.

The National Federation warmly welcomes the recent publication by the Department of Health of the *Review of Disability Social Care Demand and Capacity Requirements up to 2032*. Budget 2022 provides an opportunity for the State; the providers in Voluntary Sector, and the HSE to collaboratively work in partnership to address the significant and serious unmet and evolving needs of people with disabilities set out in this report.

Key findings – Overall financial implications

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

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

Source: Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032. [View full report online at this link](#)

The National Federation of Voluntary Service Providers

Approximately 70% of disability support services in Ireland are provided on behalf of the State by Section 38 and Section 39-funded organisations. The National Federation of Voluntary Service Providers Supporting People with Intellectual Disability is the national umbrella organisation of not-for-profit agencies providing direct supports and services to people with intellectual disability in Ireland. Across almost 60 organisations, our members support approximately 26,000 children and adults with intellectual disabilities and their families, providing services and supports throughout the lifespan. National Federation member organisations have community presence and connection across large urban centres and small villages throughout Ireland.