

National Disability Authority Policy Advice

Health Service Capacity Review in Ireland 2017

I. Context

The National Disability Authority welcomes the opportunity to contribute to the Department of Health’s public consultation on its **Health Service Capacity Review in Ireland 2017**, which is committed to in the **Programme for Partnership Government**. While this Review will contribute to the mid-term review of the current Capital Investment programme 2016-2021, the National Disability Authority welcomes the intention that it will also inform more broadly policy considerations across the timeframe from 2017-2030.

As the independent statutory advisory body to Government on disability policy, our main concern in addressing various capacity issues is that people with disabilities are viewed as an important cohort as part of this Review. This includes people with disabilities availing of mainstream health and social care services and those availing of specific disability services. While, the National Disability Authority welcomes the terms of reference, which cover both health and social care services’ capacity and recognises their interdependence, we note there is no explicit mention of disability in the consultation paper. The National Disability Authority sees this review as having significant implications for health and social care services capacity now and into the future for people with disabilities.

It is the National Disability Authority’s view that the needs of people with disabilities are considered, along with the capacity issues arising from a number of national policies that can have an impact on their lives, including:

- **Transforming Lives – Value for Money and Policy Review of Disability Services in Ireland (2012)**
- **Time to Move on from Congregated Settings: A Strategy for Community Inclusion (2011)**
- **New Directions (2012) – adult day services for people with disabilities**
- **Progressing Disability Services for Children and Young People 0-18 years**
- **A Vision for Change: Report of the Expert Group on Mental Health Policy (2006)**

Consideration should also be given to any implications arising from the Houses of the Oireachtas Committee on the **Future of Healthcare Sláintecare Report (2017)**. Such considerations will help inform future investment decisions in health and social care.

2. Capacity in health and social care

The National Disability Authority’s advice regarding capacity is primarily focussed on disability. In this review, the National Disability Authority views ‘capacity’ from the following perspectives:

1. Infrastructure in specific locations.
2. Resources and competent staff to deliver key disability/health policies and services.
3. Integrated working ensuring disability understanding and competence in mainstream health services for their effective design and delivery to persons with disabilities across the spectrum, and more effective use of resources.
4. Ensuring multi and interdisciplinary teams, for example mental health teams working with intellectual disability and/or autism expertise where required.

It is the National Disability Authority’s view that these factors combined can lead to an enhanced service for people with disabilities. It is critical however, that there is sufficient capacity both in mainstream and disability specific services to meet the needs of this cohort whose number and needs are changing over time.

It is important also, in any decision-making around capacity, that it would be helpful to have it informed by agreed principles. In this regards, the National Disability Authority suggests the following principles, which are based on recent national policies, including:

- Person centredness
- Equity of access
- Enabling independence and choice
- Maximising participation in the community
- Delivering services/care in the community and as close as possible to where the person lives
- Establishing multi and interdisciplinary teams that reflect both social and medical models of disability

- Universal Design¹

The **Disability Act 2005** defines Universal Design, as:

The design and composition of an environment so that it may be accessed, understood and used in the most independent and natural manner possible without the need for adaptation, assistive devices or specialised solutions, by persons of any age or size or having any particular physical, sensory, mental health or intellectual ability or disability. In relation to electronic systems, this refers to any electronics-based process of creating products, services or systems so that they may be used by any person.

The National Disability Authority also advises that the recommendations on capacity arising from this Review should be disability-proofed in line with good practice.²

3. What changes in models of care and in the way we deliver care are (a) most urgent, and (b) what implications will this have on capacity requirements?

The Government has committed to a number of key disability policies, which have implications for capacity planning. These policies, outlined in Section 1 above, represent a critical transformation in the manner of provision of disability services and involves new models of person centred service provision within social care.

Significant system capacity is required in parallel with capital investment to deliver the government’s disability policies. For example, in **Transforming Lives – Value for Money and Policy Review of Disability Services in Ireland** there is a need to develop an essential systems architecture to fully implement this policy, including,

- A National Needs Assessment Framework
- A System for Resource Allocation
- A System for Individualised Funding
- Systems for data collection and analysis

¹ **Universal Design Principles** (<http://universaldesign.ie/What-is-Universal-Design/The-7-Principles/>)

² A useful document for this purpose is, “**How to Conduct a Disability Impact Assessment**”, **Department of Justice and Equality 2012.**

Progress in some areas has been slow and mixed to date with significant additional capacity required to fully deliver on these policies.

This is particularly relevant to the implementation of policies such as **Time to Move on from Congregated Settings**. While the target numbers for moving people out of congregated settings are small (173 for 2017 plus 50 remaining from 2016 target out of a national total of 2,218 people) a key challenge is the acquiring of suitable accommodation in the community. Residential service providers are now competing for scarce available housing in the open market and in some cases there are examples of service providers outbidding one another to acquire suitable accommodation. There are significant capacity and cost issues going forward, some of which involve not only the acquiring of the property but the costs involved in making adaptations to existing houses.

Similarly, the implementation of **New Directions** programme will require changes in the location of services. **New Directions** states that

“Service Locations should be decided with a view to enabling people with disabilities to be an integral part of the community rather than segregated or removed from the community. As far as possible buildings where services are provided should be located in integrated community settings. Any new physical development should take the form of a “hub”(service location) from which people with disabilities can be supported to access local services”.

The location from which people receive their supports impacts on such things as:

- Building community opportunities and support so that people can have ordinary lives in ordinary places
- Maximising opportunities for individuals to avail of community services
- Facilitating active citizenship is how individuals gain access to opportunities based upon what resources are available in a person’s community
- Enhancing the potential for building support around people
- Enabling people to do things that are meaningful for them to do and connecting with local people

HSE Guidance on Service Locations for **New Directions** states:

In the above context, it is critical that new Service Locations comply with well defined criteria. New Directions’ core values are - Community Inclusion, Active Citizenship, Quality and Person Centredness and these values are the road map for clarifying the

characteristics of a “Service Location” that is in line with New Directions policy.

Currently, HSE funds day services for nearly 24,000 adults with disabilities who are supported from over 1,100 service locations. There are challenges in identifying suitable accessible locations as close to where a person lives and close to the local community from where an individual can be supported from. Again, service providers are competing in the open commercial market for suitable buildings that can be rented, part let, shared with other community groups etc. This is a capacity issue of moving away from the “traditional” centre based segregated day service to providing supports to individuals at the heart of their community. In this regard, the National Disability Authority notes that to date no additional funding has been allocated to support the implementation of **New Directions**. The only funding to date under the **New Directions** Programme has been annualised funding for school leavers.

Another area for consideration by the Capacity Review Group is the policy of mainstreaming disability. This is a complex policy area with significant implications for capacity planning. For example, increasingly children with disabilities are educated in mainstream schools and the issue of how their health needs can be delivered in the school setting needs to be considered. This idea of providing healthcare in non-traditional settings is illustrated in the Department of Education and Skills **Action Plan for Education 2016-2019**:

“We will introduce a new in-school speech and language service creating stronger linkages between parents, teachers and Speech and Language Therapists”

It may also be worth exploring how health and social care capacity planning can be aligned with developments in other non-health/social care sectors, such as transport, early childcare, housing etc.

New models of care arising from disability policies such as **New Directions** and **Time to Move On**, and broader health policies around integrated care, are transforming the roles of health and social care workers. For example, **Time to Move On from Congregated Settings** will likely result in an increased demand for new community connector roles; the role of the Registered Nurse for Intellectual Disability may be developed as a clinical nurse specialist or advanced nurse practitioner; and additional nurse-led services may be required as greater numbers receive care at home and in primary care settings. The National Disability Authority is currently developing a **Competencies and Skills Mix for a Community Based Model of Disability Care**, which will inform workforce planning (staff capacity and competencies) to fully support the implementation of disability policy goals. Research from the HSE’s National Doctors Training and Planning Unit and findings from consultations on the health

and social care roles such as the new **Policy for Graduate, Specialist and Advanced Nursing and Midwifery Practice** will help to guide changes to existing roles and the creation of new roles. This workforce planning needs to be funded, as it will further inform where the capital investment needs to be made.

With regards to mainstream health services the National Disability Authority would stress the importance of an integrated approach. Different health service settings or specialties should not operate as individual silos unless there is good reason. Liaison between professionals is important to identify the services needed for individuals and to enable professionals to deliver integrated care that is centred on the individual and their needs. This should happen in whatever setting those needs are met from time to time. For example, where appropriate:

- Teams working in primary, specialist, rehabilitation and hospital care can share their knowledge and experience so that person-centred care becomes the norm
- Those treating general illnesses can liaise with those providing specialist care or support for the underlying disability and
- Hospitals can put in place discharge planning and follow-up with the person's GP and specialist disability support, to ensure continuity of care and support on discharge. This is essential, especially for those with a severe and prolonged disability

In 2016, the National Disability Authority with the HSE developed and published **National Guidelines on Accessible Health and Social Care Services**.

These guidelines cover how to make buildings, facilities, information etc accessible but also how specific services such as GP surgeries, health care centres, primary care centres, hospital services, emergency departments, maternity services etc can be made accessible. This is a useful resource for the planning of services in the future and a significant amount of the guidance is cost neutral. While these guidelines refer to specific disabilities, where services are made accessible it positively influences the experience of all people who use these services.

4. How can current capacity be more effectively used?

The National Disability Authority supports the **systems-approach** to policy implementation outlined in the consultation document. It is widely recognised that implementing policies in some areas of health and social care can reduce capacity requirements elsewhere.

Implementation of the recommendations contained in the **Sláintecare** report to create an integrated health and social care service would reduce the burden on acute care as more people receive early intervention and chronic disease management in community and primary care settings. As stated in that report, entitlement and capacity are interlinked. This review should consider capacity requirements arising from universal entitlement to basic packages of health and social care services including GP, primary care and home care services. The National Disability Authority supports the broad principles contained in **Sláintecare**, however, there are concerns about the suggested funding allocations for disability services, which will not be sufficient to meet future demand.

Strong **auxiliary policies** in the areas of Home Care Services (currently under public consultation), Personal Assistance, respite services (in-home and out of home), household adaptations/reasonable accommodations, Assistive Technology, Telehealth and Telecare, disease prevention, health promotion and end-of-life care can all contribute to supporting people with disabilities and older people to stay healthy and remain in their homes for longer.

Efficient and equitable capital spending requires robust data on **population need**. The process of decision-making should begin with an assessment of population-level (at national and CHO level) for health and social care. **Sláintecare** states the Government is currently working on population level needs assessment to inform workforce planning and ensure the availability of staff with the appropriate skills. Capital investment planning should consider both population needs and the workforce capacity required to meet those needs. The implementation of integrated models of care is a shift away from care pathways focused on the healthcare setting (hospital or primary care setting) towards care pathways that provide services wherever the person requires them. The idea of the “hospital without walls” is a useful way to reorient services around the individual’s need rather than the needs of the healthcare provider or institution.

The National Disability Authority also welcomes the establishment of a Review Group to examine the role of voluntary organisations in the operation of health and personal social services in Ireland. This should include, and promote public discussion on, the question of **ownership** of existing and new state-funded health and social care infrastructure, particularly where public-private partnerships are involved.

The National Disability Authority also sees that Commissioning can play an important role in a more effective use of resources. In this regards, the Authority sees commissioning as a strategic process linking resource allocation with assessed current and future needs, in order to achieve best outcomes for citizens in line with policy objectives, as well as achieving better value for money and high quality service.

The National Disability Authority through its work over the last few years on Commissioning³ is of the view that a good approach to strategic commissioning can provide:

- Increased choice and control for the individual
- Improvements in human, social and community services and better outcomes for citizens
- A framework within which interested parties can work together collaboratively to achieve a shared vision and goals
- A transparent process which provides an evidence based rationale for decision making, informed by the assessed needs of people and the capacity of service providers
- Auditable objectives, including cost benefit analysis, which ensure that value for money services deliver the required outcomes for individuals

The National Disability Authority has undertaken and is continuing a programme of research and analysis to inform key elements of a commissioning framework for disability services including

- Research and advice on resource allocation models to underpin matching of resources to individual needs, including choice of needs assessment system. This advice has been provided to the Department of Health and HSE and a decision is expected soon on the preferred resource allocation tool
- Work on standards and quality systems for disability services
- Research and guidance on person-centred planning

³ **National Disability Authority advice paper on commissioning to Department of Public Expenditure and Reform, 2016**

5. What do you consider to be the priorities for capital investment over the next 15 years?

The National Disability Authority recognises that the health and social care services are experiencing significant capacity demands and that there is a high level of unmet need. In determining what services are prioritised, decision-makers should be informed by research on cost-effectiveness and also societal needs and priorities as well as a transparent resource allocation framework for guiding decisions such decisions. All decisions should aim to protect the most vulnerable and reduce health inequalities in the population. This point is underlined in the HSE report Planning for Health 2017:

“Excluded and disadvantaged groups within the population carry a significant burden of disability. Inaccessible and inadequate support for disability may generate and sustain long-term homelessness and multimorbidity.”

In considering the priorities for capital investment over the coming years, we need to consider the estimated future need and costs of disability services. Under the HSE’s **Transforming Lives** Programme, the NDA was tasked, as part of a HSE-led working group, with estimating future need and the cost of disability services up to 2025. This work focuses on demand for services funded by the Social Care Division of the HSE for people with physical, sensory, intellectual or neurological disabilities, or autism. It does not encompass mainstream or acute medical care, or services for people with a mental health condition only. While this research is still underway, an interim report identifies key areas likely to have a bearing on future capacity requirements and capital costs:

- Demographic change in cohorts of people with disabilities
- Trends in the prevalence of disability
- Change in the profile of service users
- Unmet demand for services (and impact of funding cuts during the recession)
- Regulatory and legislative requirements (that is, capital costs involved in bringing residential disability services into compliance with HIQA national standards and regulations)
- The National Disability Authority advises regarding the future capital costs in new builds or retrofitting of existing buildings for these services - both for Primary Care services as well as homes for people to live in, that Universal

Design Guidelines are followed. In this regards, the National Disability Authority recommends that for community dwellings its publications on **Universal Design Guidelines for Homes in Ireland** and for community health care centres that **Building for Everyone: A Universal Design Approach** guidelines are adhered to.

The National Disability Authority through its work in informing the Transforming Lives Working Group on identifying future need and demand for services has identified a number of clear trends from the evidence gathered so far which highlight a number of priority areas for capacity planning (Sources: CSO, **Planning for Health**, HSE 2017, National Intellectual Disability Database):

- The CSO **2016 Census** reports a total of 643,131 people with a disability (13.5% of the general population), up from 595,335 (13%) in 2011. The number of people with an intellectual disability rose from 57,709 people in 2011 to 66,611 in 2016
- The life expectancy of people with intellectual disabilities (ID) has increased in the last decade or so. It is becoming more common for people with ID to outlive their parents. There were 5,580 people over 50 years of age with intellectual disability recorded on the National Intellectual Disability Database in 2014. At this age, they are more likely to require residential care rather than day support, therefore, it is likely demand for residential intellectual disability places will increase year on year
- **TILDA** identified higher levels of multi-morbidity in those with intellectual disability compared to the general population. This group requires greater levels of service input, especially in the areas of mental health and neurological services
- 20.8% of the total population recorded on the National Intellectual Disability Database have an identified need for respite care
- Residential care for people with Intellectual Disability, especially those offering 24/7 services, is the most significant element of total spend on disability services
- The proportion of under-45s in residential care fell during the economic recession and this has contributed to rising demand for emergency placements in residential care
- The population aged 85 years and over is estimated to grow by 22% between 2017 and 2022, which has implications for service provision given the high levels of disability in this age cohort
- There is a growing proportion of school children presenting for disability supports and this will feed into increased future demand for adult day service supports

- In 2014, there were 22,908 people recorded on the National Physical and Sensory Disability Database (NPSDD). The estimated coverage of the NPSDD is 67%, which would equate to an estimated 34,200 people nationally living with physical and sensory disability. While only 4% of those on the NPSDD are recorded as being in residential care, of these, 34% are living in nursing homes. Residents aged less than 65 years occupy approximately 5.5% of nursing home beds equating to 1,670 residents. In both children and adults (people over 18 years) the recorded use of respite care is about 10% (9% in children and 11% in adults). There is considerable demand for therapeutic services across all ages and the need for personal support services, while low for those less than 18 years, increases in the adult population
- In children with a disability, there is significant demand for speech therapy in the age group 0-17 years. This is as a result of a cumulative demand from children with an intellectual/learning disability and children with an isolated speech disability
- It is estimated that 3% of children aged 0-18 years with a disability require a multi-disciplinary team service. In 2017, this equates to 12,960 children in the 0-5 year age group and a further 25,990 children in the 6-18 year age group. The greatest demand for multi-disciplinary service to children is in CHO Areas 4, 6, 7 and 9. The number of children and adolescents living with disability in the 6-18 year age group is projected to increase by 1.9% in 2017 and continue increasing up to 2022, giving rise to an increased demand for school support teams and placements for school leavers
- The development of multi-disciplinary teams for children with disabilities (although it is progressing very slowly) may be constraining resources available to adult multi-disciplinary supports. When people reach the age of 18, whatever supports they have been able to avail of are abruptly withdrawn, leading to people falling out of services and living less healthy, less integrated and less productive lives. Greater mainstreaming at all ages could improve this
- Appropriate residential placement for those over 18 years of age continues to be a challenge with people inappropriately placed in nursing homes for the elderly and psychiatric inpatient facilities

6. Health Issues

There are a number of visible trends in terms of health status and service usage among groups with disabilities, which will help to inform priority areas for investment. As people with disabilities are increasingly living to old age, **TILDA** has begun to explore the prevalence and effect of chronic disease in this ageing population. There is evidence that some people with intellectual disability, experience age-related conditions earlier than the general population (for example, dementia and musculoskeletal disorders) and that there may be higher prevalence of diseases and multi-morbidity in this group. Similar to the general population, there are high levels of obesity in populations with intellectual disability and those with physical impairments that affect mobility, for example, cerebral palsy and spina bifida. Levels of physical activity are lower than in the general population.

The **TILDA 2014 Intellectual Disability Supplement** reports that utilisation of health and specialist health and social care services and medications are higher for people with intellectual disability as they age than for the general population. Use of services by people with intellectual disability is high in all areas but particularly for psychiatry, chiropody, dental, optician, residential and day centre services. The research also points to a link between higher levels of service utilisation and movement to a more restrictive residential setting.

TILDA reports a high prevalence of mental health problems among its disability cohort (60% of participants have received a diagnosis of an emotional or psychiatric disorder). **Sláintecare** highlights the problems of underfunding of resources for mental health and overreliance on medication in the absence to a range of allied health professionals including counsellors, speech and language therapists and occupational therapists. This review should examine how the expansion of primary/community mental health services can reduce delayed diagnosis and treatment, which currently can lead to emergency admission to acute services.

The consultation document provided for this review states,

“The high level of risk factors in the population has been aggressively targeted through strategies on tobacco, alcohol, physical activity and obesity. These strategies have set ambitious targets for risk factor reduction but will take a number of years before they impact on the levels of chronic disease.”

There are multiple strategies designed to tackle risk factors for chronic disease, however, but have not been fully implemented. The National Disability Authority advises that it is critical that with the implementation of health policies there are specific targets for people with disabilities. In addition, many of the generic strategies to prevent many chronic diseases (some that cause disability), for example, efforts that are taken to address commercial and social determinants of those diseases, for example, restricting advertising of unhealthy foods, taxing sugar-sweetened beverages and subsidising healthy foods, information campaigns etc. should be communicated in accessible formats to people with disabilities. The **Healthy Ireland Implementation Plan and Outcomes Framework** should be published without delay to measure progress in tackling the causes of chronic diseases, which threaten to overwhelm our health services.

The consultation document refers to new models of care that include, “A shift in care to the lowest level of complexity consistent with patient safety”. The National Disability Authority advises that the idea of “lowest level of complexity” should be carefully considered, in the context of people with disabilities and multi-morbidities. While the person/patient may not have an acute level of a single disease, they may have multiple health conditions, which may require complex care and an understanding of how those conditions interact. With the proposed delivery of the majority of care in the community, the National Disability Authority advises that it is critical that the health community care practitioners, GPs, etc. are upskilled and disability competent.

The National Disability Authority would be happy to discuss further any of the points and advice in this submission.