INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Department of Health

On the health service Capacity Review 2017

September 2017

This document is written in font 12 Verdana in line with Inclusion Ireland plain English guidelines.

1. About Inclusion Ireland

Established in 1961, Inclusion Ireland is a national, rights based advocacy organisation that works to promote the rights of people with an intellectual disability.

Inclusion Ireland uses a human rights-based approach to its work. This recognises persons with an intellectual disability as rights holders with entitlements, and corresponding duty bearers and their obligations. Inclusion Ireland seeks to strengthen the capacities of persons with an intellectual disability to make their claims and of duty bearers to meet their obligations.

The vision of Inclusion Ireland is that of people with an intellectual disability living and participating in the community with equal rights as citizens, to live the life of their choice to their fullest potential. Inclusion Ireland's work is underpinned by the values of dignity, inclusion, social justice, democracy and autonomy.

2. Introduction

Inclusion Ireland welcomes the opportunity to contribute to the Department of Health's Capacity Review of the health service. Analysis of current and future demands for health and social care services and future capacity requirements is essential to meeting the needs of the population into the future.

In carrying out its review, the Department should note the range of policy commitments that require ongoing implementation over the coming years, including:

- A Time to Move on from Congregated Settings
- Progressing Disability Services for Children and Young People
- New Directions
- Sláintecare report
- The Disability Act 2005
- The National Disability Inclusion Strategy 2017-2010
- The Public Sector Duty under the Irish Human Rights and Equality Act 2014
- Pending ratification of the UN Convention on the Rights of Persons with Disabilities
- The Assisted Decision Making (Capacity) Act 2015

Health and social care services will need to have the capacity to deliver on the requirements of the above legislation and policy and a detailed analysis of these should form part of the Capacity Review.

The Assisted Decision-Making (Capacity) Act provide a good example of the need to consider the implications of a changing policy environment. The Act provides significant challenges to the way that health services are currently run. While the HSE is reviewing training needs, it is clear that public bodies will need designated staff with responsibility for implementing this changed system. There will be investment required in IT systems relating to decision-making supports records and staff will all require training on implementing the new system.

3. Disability and health

The Capacity Review should also take into account the poorer health outcomes currently experienced by people with disabilities as well as current and future demand for health and social care services and supports.

It is well documented that people with disabilities experience poorer health than the general population. A recent study on quality of life among different social groups revealed that 55% of adults with a disability and 53% of children who have a parent with a disability, experienced multiple quality of life challenges - more than three times that of the general population[1]. Poor health and mental distress were among the main reasons that quality of life is lower for people with disabilities.

People with disabilities experience many barriers to good health. For example, women with disabilities have lower uptake of health promotion and health screening services than non-disabled women. Rates of screening for both cervical and breast cancer are lower among women with disabilities than the general population and especially low for women with severe and profound intellectual disability[2]. Inaccessible promotional or information materials or concerns relating to capacity to consent act as barriers in many instances.

[1] Watson, D et al, *Social Risk and Social Class Patterns in Poverty and Quality of Life in Ireland*, 2016.
[2] McCarron, M. et al. *Advancing years, Different challenges: Wave 2 IDS-TILDA: findings on the ageing of people with an intellectual disability: an intellectual disability supplement to the Irish Longitudinal Study on Ageing*. Dublin: Trinity College Dublin, 2014.

2.1 Current demand and future need

Disability policy actively promotes community inclusion and person-centred services and supports for people with disabilities. People with disabilities should be able to access a range of health and social care services in the community such as personal assistance, home care, therapy services and mental health services.

The recently published Sláintecare report acknowledged the reality that "people with disabilities often wait a long time to access rationed services without choice of service provider. They also end up paying out of pocket for such services. There are significant geographic differences in access to such care"[3].

Current demand for health and social care services among people with disabilities is outstripping availability in many areas:

- Only 4% of the staffing required for adult mental health and intellectual disability teams has been provided[4]
- Access to speech and language therapy varies widely across the country with an estimated 1 Speech and Language Therapist for every 83 children with complex needs in Wicklow and 1 for every 388 children in Wexford[5]
- The compliance rate for assessment of need within the timescale set by the Disability Act is at 25% nationally and as low as 6% in some CHO areas

The Department of Health have correctly identified the need to plan for changing population needs into the future. According to the Central Statistics Office (CSO), the population of over 65's is set to double in less than 30 years. The CSO estimates that there will be about 20,000 more people over the age of 65 every year until 2040[6].

There is a strong link between ageing and acquired disability. Among people in their twenties, less than 10% have a disability. The likelihood of having a disability increases with age and is over 20% by age 60. From age 70 on, rates increase more sharply with 75% of all women aged 85 and over having a disability[7].

[3] Committee on the Future of Healthcare, *Sláintecare Report*, 2017.
[4] A Vision for Change, A Coalition of Adult Services, Mental Health Commission, 2015
[5] Conroy, P. *The case of speech and language therapy*. Dublin: Inclusion Ireland, 2014
[6] Department of Housing, Planning, Community and Local Government, *Ireland 2040: Our Plan. Issues and Choices Consultation Paper*, 2017.
[7] CSO. Census 2011.

In keeping with general population trends, people with intellectual disabilities are also living longer. While this is good news, it has an impact on policy and service provision. As they age, people with disabilities are more likely to experience:

- Vision and mobility challenges
- A higher prevalence rate for falls
- An increased risk of dementia among people with Down Syndrome
- A higher incidence of mental health and emotional health issues, particularly for those living in residential centres[8]

Future planning needs to take into account this growing population of people with disabilities and their support needs.

4. Changes in models of care and implications on capacity requirements

Inclusion Ireland has identified the following key changes that are required in the model of care or the way care is delivered and the implications of these changes for health and social care capacity:

4.1 Housing in the community

'A Time to move on from congregated settings – a strategy for community inclusion' is Ireland's policy for the closing of institutions. At the time of publication in 2011, the policy set a target of closing all large residential centres within 7 years (by 2018). At the time, there was slightly over 4,000 people living in these settings[9]. As of February 2017, there were 2580 people with disabilities living in large institutions in Ireland[10].

The report recommended that where people with a disability choose to live together, there should be a maximum of 4 people per house. Of the 150 people who moved in 2015, 53% moved into a new home of at least 5 people. Less than 10% of people moved into their own single occupancy home.

[8] P. McCarron, M; Swinburne, J; Burke, E; McGlinchey, E; Mulryan, M., Andrews, V., Foran, S., McCallion, *Growing Older With an Intellectual Disability in Ireland 2011: First Results from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing.* Dublin: School of Midwifery and Nursing, TCD., 2011.
[9] A time to move on from congregated settings – a strategy for community inclusion, HSE working group, 2011.
[10] Answer to PQ 5585/17, HSE, 2017.

The UN Committee on the Rights of Persons with Disabilities, in a recent draft statement noted, "neither large scale institutions with more than a hundred residents nor smaller group homes with five to eight individuals can be called independent living or community living arrangements.[11]"

In 2016, significant funds were made available to purchase houses and to assist the transition from institutions but little of this has been used (see section 6.2 of this submission).

As well as those moving out of institutions, there is also a need to cater for the housing needs of the many people with disabilities currently living in other types of housing that may wish to live in their own home in the community. In an inclusive, equal society, young people with disabilities would be supported to make the transition from the family home to an independent setting like all young people.

Thought should be given to future proofing in the provision of housing for people with disabilities. Houses should be adaptable to changing needs as people age. Individuals who move from an institution to the community should not then move back to other institutions such as nursing homes.

Capacity requirements

- There is an urgent need to increase the stock of available housing and to make funding available for housing adaptations where required.
- Capital funds must be made available in a timely manner to complete the purchase of a house
- In some cases, providing residential supports to people in smaller numbers means additional staffing is needed. Staff need to have the right skill mix to support people to live independent lives in the community. This may mean more Personal Assistants, home help workers and therapists.

4.2 Implement a model of personal budgets

The Value for Money and Policy Review of Disability Services recommended the restructuring of disability services in Ireland through personalised supports and more effective systems of resource allocation. Despite this, three quarters of the total disability spend is still dedicated to funding services in outdated, group settings.

[11] Committee on the Rights of Persons with Disabilities, *Draft General Comment No. 5*, 2017.

Internationally, personal budgets are acknowledged to result in better outcomes for persons with disabilities. The Programme for a Partnership Government commits to 'devolve budgets to the person'. This step is taken "in recognition that personalised budgets provide an individual with more control in accessing services, giving them greater independence and choice".

The Task Force on Personalised Budgets, established last year, will report by the end of 2017. The National Disability Inclusion Strategy commits to "examination of the recommendations of the report of the Personalised Budgets Task Force, with a view to introducing the option of availing of a personal budget as one approach to individualised funding".

Inclusion Ireland has compiled a document outlining the essential principles of personal budgets. These include that personal budgets should be available to all persons with disabilities regardless of age or complexity of needs, should be cross-departmental, should be outcomes focused and should be flexible and responsive, changing as circumstances change through the lifespan.

Capacity requirements

- The provision of personal budgets must be approached from a cross - departmental perspective with a solid commitment to co-ordination between the appropriate departments within the government.
- Each department should develop a unit to co-ordinate that department's personal budget responsibilities.
- A focal point for the co-ordination of personal budgets must be established and to act as a mechanism for all stakeholders to cut down on the burdensome administrative requirements
- Merely providing a personal budget will not automatically result in a person enjoying better outcomes. There will be a need to improve the range and quality of services and supports available to choose from.

4.2 Move to a rights-based model of services and supports

The lack of rights based legislation for people with disabilities has been a concern for many years. When it was enacted in 2005, the Disability Act fell significantly short of the comprehensive rights-based legislation that people with disabilities had campaigned for.

The Disability Act 2005 provides for an assessment of need and related services and places obligations on public bodies in the areas of accessibility and employment. However, there is no right to seek judicial remedies where things provided for in the Act are not carried out.

The failure of successive governments to provide a rights based, legislative framework means that services to people with disabilities remain a privilege, rather than a right.

The commitment in the Sláintecare report to provide an entitlement to health and social care services is very welcome. As acknowledged in the report, guaranteeing entitlement does not ensure access unless there is sufficient capacity on the supply side.

Capacity requirements

- A significant expansion in the provision of community based supports and services, including therapists, personal assistance, assistive technology, home care, and other health and social care services.

4.3 Move to a commissioning model of service delivery

Services for people with disabilities are currently funded through block grants to large service providers. People with disabilities have little or no say in how this money is allocated or spent. As a result, people with disabilities are forced to accept services and settings that are unsuitable and do not take into account their wishes.

Disability services were funded €1.7bn in 2017. A Value for Money and Policy Review of Disability Services was unable to determine whether there is value for money from this spend[12]. Much of it is spent on models of service provision that do not support community inclusion, choice, control or independence for people with disabilities.

Inclusion Ireland is campaigning for a change in the way services are funded beyond the traditional block grant system. Commissioning is a cyclical process by which public bodies assess the needs of people in an area, determine priorities, design and source appropriate services and monitor and evaluate their performance.

[12] Department of Health, *Value for Money and Policy Review of Disability Services*, 2012.

Good commissioning should work within a societal value framework[13][14]. This means that public money should be spent on services that maximise values, such as equity, accountability or quality. Effective commissioning could result in better outcomes for people using the service; give people more choice and control and increase the quality of services.

Capacity requirements

- A key element of the commissioning cycle is the gathering and analysis of data to inform planning. There is a need for systems to collect and analyse disaggregated data
- Commissioners and other staff need skills in analysing data, monitoring and evaluation
- Systems are needed to consult with and involve individuals with disabilities and communities in the commissioning cycle
- There will be a need for an independent commissioning agency to oversee the move from group-based services towards personalised supports and coordinate commissioning activities

4.4 Change culture and values

Through our advocacy work, Inclusion Ireland has met many people with disabilities who have told us about the culture and deep power imbalance that exists between people with disabilities and public bodies such as the HSE, and government departments. They have reported feeling powerless when negotiating services and supports or when trying to claim their rights and entitlements.

There is a need for a fundamental shift in the culture of public services; from a top down, hierarchical approach to one where the person, the family and the community is at the centre.

The National Disability Inclusion Strategy (NDIS) 2017-2020 makes a number of commitments aimed at changing culture. There is a commitment to the development and roll out of a reform and culture change programme under the objective of ensuring that people with disabilities are treated with dignity and respect and free from abuse.

[13] *Programme for Partnership Government*, 2016.
[14] N O'Connor, *Commissioning for Communities*, 2016.

There is also a commitment to changing the model from one of "care" to one of "support" to achieve independence. This is welcome and is more reflective of the social model of disability.

Reforming culture requires the engagement of multiple stakeholders, including people with disabilities, service provider staff and management, commissioners of services, government departments, trade unions and regulatory and professional bodies. It should be driven by values and underpinned by principles of equality and human rights.

The Public Sector Duty has the potential to drive cultural change in the public sector as it emphasises rights and equality and requires that these are part of the ongoing work of the organisation.

Capacity requirements

- The commitment in the NDIS to implement a culture change programme led by the HSE and disability service providers will need to be broadened to include non-disability service providers and other stakeholders.
- All public sector bodies should develop and publish own values statement in consultation with stakeholders. Annual reports should evidence how these values are upheld through the work of the organisation
- Each public sector body should have a designated officer for co-ordinating the planning, monitoring and reporting requirements of public sector duty work

5. Using current capacity more effectively

Inclusion Ireland has identified the following ways in which current capacity can be more effectively used:

5.1 Ring-fence funding for person-centred supports

The Department of Health has highlighted the limitations of exchequer funding for implementing health and social care reforms. Ring-fencing some of the existing disability spend for innovative, person-centred and community-based models of provision would be a cost neutral way of improving services.

Public expenditure on social care services to persons with disabilities is around €1.7 billion per year. Much of this spend is tied up in the provision

of models of service where persons with disabilities have no control or say in how services and supports are delivered.

The restructuring of disability services in Ireland through personalised supports and more effective systems of resource allocation has been recommended many times[15].

Current capacity would be more effectively used if between 8%-15% of the current HSE disability budget, which is governed by service level agreements (SLAs), is ring-fenced for individualised and community-based models of supports.

5.2 Build the capacity of current staff

A capacity building programme to ensure that the people working in health and social care services have the right approach and the right skills would help to deliver better services for people with disabilities within the current staffing capacity.

An understanding of human rights law, equality law, social role valorisation (SRV) and the Public Sector Duty should be a requirement for all staff. Other general skills and capacities include customer service skills, how to produce easy-to-read documents, evaluation skills, writing in plain English and intercultural awareness.

In a recent consultation with our stakeholders, basic skills like listening, communication skills, patience and empathy emerged as being of key importance to people with disabilities[16].

Changing legislative and policy contexts mean that there is an ongoing need for health and social care staff to have an understanding of new developments.

The implementation of the Assisted Decision Making (Capacity) Act 2015 has implications for those working in health and social care areas. Changes to the law on safeguarding of vulnerable people, the implementation of a patient safety, complaints and advocacy policy and the establishment of a patient advocacy service will require changes to

[15] Value for Money and Policy Review of Disability Services in Ireland ; New Directions (2012); A Time to Move on from Congregated Settings (2011); Government for National Recovery (2011); Programme for Partnership Government (2016).
[16] Inclusion Ireland (2017). Submission on the development of the public sector.

practice and all those working in the health service will need to have a clear understanding of their obligations.

6. Priorities for capital investment over the next 15 years

The Capital Investment Plan 2016-2021 includes an allocation of just over €3bn for health infrastructure. The Department of Health has indicated that investment in social, community and primary care are among its priorities for this period[17].

In assessing priorities for capital investment, consideration should be given to the positive impact they will make on equality and social inclusion. The Department should give regard to the requirements of the Public Sector Duty in determining priorities.

6.1 Accessible community and primary care infrastructure

The move towards person-centred, community health and social care services for people with disabilities requires investment in developing the infrastructure. This includes the development of primary care facilities across the country.

Where the HSE undertakes or funds a large development project with public access, such as a new primary care centre or hospital, these should incorporate Universal Design principles and be accessible to all. This includes the provision of a 'Changing Place' fully accessible bathroom.

Where the HSE provides capital funds to a disability service provider for day services, a fully accessible toilet and changing facility should be provided as part of the sanitary accommodation for that centre. From our advocacy work, Inclusion Ireland is aware of people being refused a place in a disability service due to the lack of a Changing Place in the service.

6.2 Housing

The provision of housing in the community is also a key priority. The Department of Housing, Planning, Community and Local Government made €10 million available to purchase houses to move people out of

[17] Department of Public Expenditure and Reform (2015). *Building on Recovery: Infrastructure and Capital Investment 2016-2021.*

institutions in 2016. Only €2.3 million of this fund was drawn down in 2016.[18]

A Service Reform Fund was established to assist with transitioning people out of institutions and into ordinary homes. The fund has €27m available to services over a 3-year period. Despite being announced in June 2015[19], no money has been allocated from this fund as of May 2017.

The Capital Investment Plan 2016-2021 includes an investment of €300 million in replacing, upgrading and refurbishing long-term care facilities for older people and people with disabilities. A more effective use of this spend would be on supporting people to live in their own homes in the community. Where investment is made in housing, attention should be paid to making properties accessible and adaptable to changing needs in the future.

[18] Irish Examiner, 'Only €2.3 million of disability fund spent', July 2017.

[19] Lynch welcomes collaboration with The Atlantic Philanthropies on service reform fund, press release, June 16th 2015, available at www.merrionstreet.ie