



INCLUSION IRELAND

National Association for People with an Intellectual Disability

Submission to the Department of Health on
Working Together For Health: A National Strategic
Framework for Health

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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.

Introduction

Children and adults with disabilities use the health system, the same as everyone else in society. There are a number of specific areas of health care that are of particular importance to people with intellectual disabilities. To realise their fullest potential in life, children with a disability often require timely access to therapeutic inputs. Speech and language therapy is one such therapeutic input. In addition, people with intellectual disabilities and autism are much more likely to require access to mental health services.

Access to mental health and speech and language therapy services are characterised by long waiting lists to get assessed and for treatment. Children are missing out on realising their fullest potential.

Additional demand factors

There are arguments that the prevalence of autism is on the rise. In the not too distant past, autism was diagnosed in 1 in every 150 children. The National Council for Special Education in 2016 noted that 1.55% or 1 in every 65 children at school has autism.¹ The Irish health service is not planning for this level of autism in therapy provision for children.

In commencing the Assessment of Need under the Disability Act, the intention was to provide assessments for children under 5 only. However, a court ruling means this was extended to children born after June 1st, 2002. While the HSE was only resourced to provide assessments for children under 5, children who are 15 can now avail of an assessment. As a result, the demand for assessments has increased year on year with no additional resources.² Assessment applications have increased from 2,535 in 2008 to 5,992 in 2016; a 136% increase.

Child and Adolescent Mental Health Services initially provided support to children up to 16 years of age. In recent years, this has been extended to children up to 18 years of age. However, the staffing recommendations of 'A Vision for Change' in 2006 have never been fulfilled.

Assessments of need

Under the Disability Act 2005 a person may have their health needs as occasioned by their disability assessed. This has only ever been commenced for children born after June 2002.

The Disability Act places a statutory obligation on the Health Service Executive to begin an assessment within 3 months and complete the assessment within another 3 months.³ These timeframes are not being met. For the first 3 months of 2017, there was a 28.1% chance of a child

¹ Supporting Students with Autism Spectrum Disorder in Schools, National Council for Special Education, 2015.

² Health Service Performance Report October-December 2016, Health Service Executive.

³ Disability Act 2005, Ireland, The Stationary Office.

being assessed within the statutory timeframes.⁴ This is a slight improvement on 2016 figures.

This is not a full picture, as if a child lives in Galway, Roscommon or Mayo (CHO 2) there is almost a 100% chance of being assessed on time. In Dublin north, only 1.4% of assessments meet the timeframes.⁵ Essentially, a postcode lottery exists.

Families have had to resort to entering the courts to have their child assessed.

Access to therapy services

In September 2014, Inclusion Ireland published 'The case of speech and language therapy'. This report painted a picture of poor staffing levels, varied service levels depending on where you live and thousands of children waiting years for treatment.⁶ No area of Ireland had enough speech therapists to meet international case load recommendations. It was estimated the number of speech therapists in disability services would need to double (from 283 to 565) to meet demand.

The National Disability Authority (NDA) examined the overall picture of therapy provision to children with a disability in Ireland. This included speech and language therapy, occupational therapy, physiotherapy, psychology and social work. The NDA indicated that children's disability services had 550-650 to few therapists to meet demand, "there needs to be substantial recruitment and training of appropriate therapists for early intervention and school aged teams".⁷ It also noted that as many as 10% of staff are on leave at any time and not replaced.

These reduced staffing numbers have a direct effect on waiting lists. For 2016 more than 20,000 people (adults and children) were waiting more than 12 months for speech and language therapy treatment in primary

⁴ Performance Profile, January-March 2017, Health Service Executive.

⁵ *ibid*

⁶ Conroy, P., The Case of Speech and Language Therapy, Inclusion Ireland, 2014.

⁷ Children's Disability Services in Ireland, National Disability Authority, 2015.

care. More than 65,000 people were waiting in excess of 12 months for occupational therapy assessment in primary care.⁸ Inclusion Ireland noted almost 3,000 children with a disability waiting on speech therapy for more than 12 months in 2014.

Mental Health Services

In 2006 a Vision for Change was published. This seminal document contained a blueprint for the development of mental health services in Ireland and the staffing requirements to achieve a world class mental health service for Ireland over the following 10 years.⁹

It is widely documented that people with intellectual disabilities experience a higher instance of mental health difficulties than the rest of the population. This is highlighted in the Mental Health Commission's annual report 2014: "The incidence of mental illness is higher in people with an intellectual disability than in the general population and sometimes people with an intellectual disability and a mental illness require admission to an approved centre".

A Vision for Change recommended the establishment of specialist mental health – intellectual disability teams for adults and also for children. Children and adolescents with mild intellectual disability should be seen in mainstream Child and Adolescent Mental Health Services (CAMHS), but they are often being excluded. A Vision for Change recommends children and adults with moderate to severe intellectual disability should be seen by 15 CAMHS intellectual disability teams across the country.

A Vision for Change, A Coalition of Adult Services, Mental Health Commission, June, 2015 reported: "There is a lack of specialist services for children and young people with intellectual disabilities. There are 12.95 adult Mental Health Intellectual Disability (MHID) posts under the auspices of or funded by the HSE. Approximately 300 posts for adult

⁸ February 2017 Management Data Report, Health Service Executive.

⁹ A Vision for Change, Government of Ireland, The Stationary Office, 2006.

MHID were recommended in A Vision for Change. An additional 150 MHID posts were recommended for child and adolescent mental health services”.

In 2015, only 4% of the staffing recommended in A Vision for Change required for adult mental health and CAHMS intellectual disability teams had been provided.

Recently, half of the beds in a CAMHS inpatient unit in Dublin closed due to staffing shortages.

Mainstream CAMHS services have extensive waiting lists. In December 2016, 1,252 children were waiting more than 3 months to access CAMHS and 218 were waiting more than 12 months for an appointment.¹⁰

Parents have informed Inclusion Ireland of their child not being able to access CAMHS services due to the level of the child’s intellectual disability. They cannot even get onto the extensive waiting lists noted above. The only option is to pay substantial money in the private system.

Additional interfaces

It has been acknowledged that a failure to commence the Education of Persons with Special Education Needs (EPSEN) Act 2004 has led to addition pressure being brought to bear on the Disability Act. Children are being assessed to get vital educational supports that should be identified by assessments under the EPSEN Act. At a 13 year delay, it is high time that the EPSEN Act was commenced.

Data gaps

There is no accurate data on the amount of speech therapists (and others) working in disability services in a local area. Waiting lists are not published for speech and language therapy (in disability services) for a given area. When a politician asks for this information in the Oireachtas, it

¹⁰ Health Service Performance Report October-December 2016, Health Service Executive.

is not provided by the Minister in question. The request is sent to the Health Service Executive who writes to the politician in a private manner.

No waiting lists are published for the Assessment of Need under the Disability Act 2005. Compliance rates, which are dreadful, are published. However, there is no data on the length of time an assessment takes in local Health Service Executive areas. The Act places a statutory obligation to complete an Assessment within 6 months. Anecdotally, families tell Inclusion Ireland they can wait for years for an assessment to be completed.

Such data is essential to determine where resources need to be deployed for the benefit of children with disabilities. This data will also highlight how Ireland compares with international recommendations on caseload levels for therapists in disability services. In 2014, Inclusion Ireland noted the best staffed area of Ireland for speech and language therapy was Wicklow with 93 children with a 'complex need' per speech therapist. International caseload recommendations are for between 30 and 60 children per therapist. Wexford had 388 children per speech therapist.

The last annual report publically available for CAMHS was published for the years 2012-2013. These reports were a valuable source of data on the implementation of A Vision for Change. The CAMHS reports indicated less than half of staffing was in place and that some areas were better staffed than others. Waterford/Wexford had only 30% of recommended in place while Mayo had 55%. As in disability services, a postcode lottery in access to services exists.

Recommendations

- Recruit sufficient speech and language therapists (and other therapists) as recommended by Inclusion Ireland and the NDA to ensure no child is waiting for years for vital treatment.

- Recruit sufficient therapy staff to meet statutory obligations set out in the Disability Act 2005 of assessing the needs of a child within 6 months.
- Fully commence the Disability Act to include all people with a disability and not just those born after June 2002. This requires a provision for additional staff.
- Recruit sufficient therapy staff at primary care level to reduce the unacceptable waiting lists that currently exist.
- A Vision for Change is 11 years old. There must be a government commitment to fund the staffing levels recommended in this report.
- The 15 Child and Adolescent Mental Health and Intellectual Disability teams recommended in A vision for Change need to be put in place and staffed efficiently by professionals with knowledge of mental health and intellectual disability.
- The adult mental health teams recommended in A Vision for Change need to be put in place, staffed by the relevant experienced professionals.
- Publish clear data on waiting times for disability therapeutic inputs for local HSE Areas.
- Publish data on waiting times for assessments of need waiting times for local HSE areas.
- Resume publishing the CAMHS annual reports with accurate data on the implementation of A Vision for Change.