



**INCLUSION IRELAND**

National Association for People with an Intellectual Disability

# **Submission to the Health Service Executive**

**On the review of autism services**

**September 2017**

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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 is the national association for persons with intellectual disabilities. We believe that there should not be a distinction between services for people with autism and people with a disability in general. Regardless of the nature or extent of their disability, people should have their needs individually assessed and treated as per assessment.

Support or treatment should be appropriate and right across the life-course, from children's therapy services, to community living supports to mental health supports.

This submission will examine some of the shortfalls in provision that apply to people with disabilities, including people with autism.

## **3. Key issues**

### **Children's therapeutic inputs**

Therapy services, especially speech and language therapy are under resourced for all children with a disability. The shortfall has been highlighted in reports by Inclusion Ireland<sup>1</sup> and the National Disability

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<sup>1</sup> The case of speech and language therapy, Conroy, P., 2014, Inclusion Ireland.

Authority (NDA). The NDA note that there are approximately 550-650 too few therapists in the system.<sup>2</sup> Both reports highlight an average of 10% of staff on maternity leave at any time and thousands of children waiting for more than a year to access services. This is despite the knowledge that early intervention is the most effective time to work with children with disability.

Families will often resort to borrowing money to pay for private therapy services as they have no option. In some cases, family support groups fundraise significant funds to subsidise therapy sessions for their children as HSE services are so poorly staffed. For example Laois Offaly Families for Autism (LOFFA) spent more than €27,000 subsidising therapies for children with autism in one year.<sup>3</sup>

The under-resourcing of therapy staff is no more evident than in the assessment of need process under the Disability Act. By law an assessment must be started within 3 months and completed within another 3. This timeline is met in 28.1% of cases nationally and in 1.4% of cases in north Dublin.<sup>4</sup> Anecdotally, people tell Inclusion Ireland they can wait up to two years for an autism assessment.

The situation on assessments of need has gotten so bad that families have resorted to entering the courts to have their child assessed.<sup>5</sup> In addition, other families have sought private assessments which have caused substantial financial strain and inequity in service provision.

### **Adult day services**

New Directions is a person centred policy that envisages a move away from congregation and segregation to people being involved in their community to the greatest degree possible.

The problem with adult day services is the huge variance in quality. New Directions is being rolled out at a very slow pace; albeit there are pockets of good person centred, community-based work going on.

The HSE has introduced standards for day services. However, these standards are self-inspection only and do not have the independence of an external regulator such as the Health, Information and Quality Authority (HIQA).

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<sup>2</sup>Children's Disability Services in Ireland, National Disability Authority, 2015.

<sup>3</sup> <http://www.loffa.ie/>

<sup>4</sup> Performance Profile, January-March 2017, Health Service Executive.

<sup>5</sup> <http://www.irishexaminer.com/breakingnews/ireland/families-sue-hse-for-delay-assessing-needs-of-disabled-children-788825.html>

## **Child and Adolescent Mental Health Services (CAMHS)**

A particular area of concern for children and adolescents with autism is the lack of access they have to CAMHS should they experience any mental health difficulties. Through our advocacy work we know that children and adolescents are often turned away from CAMHS as their difficulties are viewed as part of their autism rather than a mental health difficulty. This has resulted in many young people falling through the cracks and not receiving the support they so desperately need.

If the child has a co-existing intellectual disability that is moderate or more significant there is very little chance of them being seen by CAMHS. Again, families have to pay privately.

## **Institutions**

At present 2580 people live in an institutional setting,<sup>6</sup> many of whom live with autism. However, this is a significant underestimation as residential services for people with autism were never included in the original report, nor were private providers. National policy is to close all institutions by 2018.<sup>7</sup> However, government have issued a less ambitious target of reducing the numbers living in congregated settings by 1/3 by 2021.<sup>8</sup> This is an utter failure to deliver government policy and will ensure that people with disabilities are living in outdated institutions.

Some people are moving out of institutions into private small institutions in the community. A number of private providers operating on a for profit basis are providing residential services for an increasing number of people with disabilities (especially people with autism). It begs the question: why are the HSE contracting services that have a 'for profit' model? Profit will always come before quality.

Residential services are fertile grounds for human rights abuses. "Unfortunately, there are still a significant number of people living in residential centres for people with disabilities that are not fit-for-purpose, where practices are institutionalised, and where vulnerable people living there are not adequately safeguarded. While increased funding and resources are necessary elements of addressing these failings, there is

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<sup>6</sup> Answer to PQ 5585/17, HSE, 2017.

<sup>7</sup> A 7 year timeframe was set down in 'A time to move on from congregated settings – a strategy for community inclusion' in 2011 to move all people from congregated settings.

<sup>8</sup> A program for partnership government, 2016.

also a need to address outmoded staff practices, inappropriate placements and poor governance arrangements.”<sup>9</sup>

#### **4. Recommendations**

- Recruit therapist numbers as recommended by the NDA and Inclusion Ireland. Remove the burden from families and family support groups to fund raise for therapy services in the absence of a properly functioning public service
- Ensure therapists have the required training to work with all children with a disability including autism.
- Comply with legal obligations under the Disability Act 2005.
- Staff CAMHS services to the levels recommended in a ‘Vision for Change’ with appropriate numbers of staff experienced in autism and/or intellectual disability.
- Increase the rate of people moving out of congregated settings. People moving must be supported to have real choice in where and with whom they live within an inclusive community setting.
- Examine the role of ‘for profit’ providers in the provision of services to people with disabilities.

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<sup>9</sup> 2016 Overview of regulation, Health Information and Quality Authority, 2017