

An Autism Empowerment Strategy for Ireland

What is Autism?

Autism is a lifelong neurodevelopmental difference which relates to how a person interacts with others and how they experience the world around them. Challenges reaching and building on developmental milestones in one's life are linked to it, typically in terms of:

- Communication and social skills;
- Forming and keeping relationships with other people;
- Physical coordination and;
- Sensory processing.

Autism is often thought of as an 'invisible' condition. No two people living with it will look or sound the same. Equally, no two people will experience their autism in exactly the same way. This is because autism is a spectrum; some autistic people may manage their challenges more independently, whereas others are in need of long-term support throughout their lives.

Autism in Ireland

Several laws have been enacted to help support and meet autistic people's needs, namely through:

- the Equal Status Acts 2000 - 2015;
- the Education of Persons with Special Needs (EPSEN) Act 2004 and;
- the Disability Act 2005.

The State is legally obligated to provide an assessment for a person who thinks they might be autistic through the HSE and, in the event that they are, inform them of what services are available to meet their needs, as well as promote accessibility and participation in civic life alongside their non-autistic peers.

There are nonetheless major gaps in the current continuum of provision. As diagnostic rates have increased, waiting lists for assessments and follow-up services continue to rise with them. An unequal focus exists on what supports are available at a particular age; those diagnosed during adulthood suddenly find themselves without parity of access to basic services. The human cost of these gaps are acutely felt when one considers that:

- Up to 80% of autistic people are under or unemployed¹;
- The average cost to family budgets amounts to €28,464.89 spent on private services per autistic child², and;

¹ Singh, Maanvi. 'Young Adults With Autism More Likely To Be Unemployed, Isolated.' 21st April 2015. *National Public Radio*. Online. Available at: <https://www.npr.org/sections/health-shots/2015/04/21/401243060/young-adults-with-autism-more-likely-to-be-unemployed-isolated>

² Roddy, Áine, O'Neill, Ciaran. 'The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?', (October 2018). Online. Available at: <https://journals.sagepub.com/doi/full/10.1177/1362361318801586>

- Early death rates (including suicide) are 2.5 times higher in autistic people than the rest of the population³.

What is an Autism Strategy & how does it work?

An Autism Strategy, in its purest terms, is a plan to achieve meaningful inclusion and empowerment of autistic people within wider society. Governments usually play a key role in their development and delivery. They provide a clear focus to addressing a major issue of inclusion and implementing full equality across all aspects of daily life.

These strategies typically begin by identifying key areas where autistic individuals are facing particular challenges and exclusion. Solutions are drafted over a period of close consultation and collaboration with medical professionals, educators, advocates, families and, of course, autistic individuals themselves. A roadmap is planned, detailing what actions and actors are needed to tackle a particular challenge within a key policy area.

As each stage progresses, reports are delivered to parliament and relevant committees. Stakeholders are engaged throughout the process, directly involving autistic people and their families. In doing so, such strategies recognise and are regularly kept informed about the unique challenges faced by the autistic community.

Where are Autism Strategies already in place at the moment?

Autism strategies are well-established across several European states. Governments in countries such as Denmark, Hungary, the UK and, most recently, Malta have enshrined autism inclusion into their respective legislative agendas.

Greater public awareness about autism and of the challenges faced by those living with it in recent years has signalled a marked shift in conversations around disability rights and inclusion. Countries with these strategies in place are internationally recognised as leaders in implementing best practices for citizens with disabilities' inclusion and empowerment.

Why does Ireland need an Autism Strategy?

In March 2018, Ireland officially ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD). Signatory states are obligated to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that they enjoy full equality under the law. Despite ratifying the UNCRPD, autistic people continue to experience discrimination.

Several pieces of legislation have attempted to kick-start a definitive response from the Government on specifically supporting autistic people, with Deputy Michael McCarthy's Autism Bill and Senator Dr James Reilly's Autism Spectrum Disorder Bill being the latest initiatives. None of these, however, have yet been translated into meaningful action. To this day there is no explicit reference to autism on any of the Statute Books.

³ Hirvikoski, et al. 'Premature mortality in autism spectrum disorder,' *The British Journal of Psychiatry*. Vol. 208, Issue (3rd March 2016), pgs. 232-238. Online. Available at: <https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/premature-mortality-in-autism-spectrum-disorder/4C9260DB64DFC29AF945D32D1C15E8F2>

Devising effective policies to fill these gaps means policy-makers need an informed picture of the situation with reliable data, from studies and censuses alike. There is a very real challenge in measuring this within an Irish context. Unlike other disability, there is no public registry or census option for autism. Parity of access to services is a mainstay of the National Disability Strategy, yet autistic people are often overlooked in several of its important clauses.

A clear manifesto commitment to legislate for an Autism Inclusion Strategy from a political party or independent candidate would signal a major game changer in Ireland's journey to become truly autism-friendly. Parity of access to public services must be the underpinning goal of any such Strategy, with measurable targets and the tools to oversee their delivery and impact.