

Autism: Houses of the Oireachtas Report

The Houses of the Oireachtas Report on Autism was published on June 14, 2023. The Report runs to 180 pages and makes 109 recommendations. The chairman Michael Carrigy stated that key issues were identified including delays in the assessment of need (AON), poor access to services, lack of inclusion in education, and insufficient employment supports.

The Report was produced by the Houses Joint Committee with cross party support. The committee was established in Feb '22 and had significant engagement between June '22 and May '23. There were 23 public committees, 32 private meetings, and direct dialogue with autism self-advocates and families.

The issues around assessment of need (AON) were the subject of much discussion. AON is a process which seeks to identify the needs of an individual who is suspected of having a disability. There appears to be some confusion. There is a perception that an AON should function as the key to unlocking services for autistic children. The HSE, however, maintain that an AON is not required to access services. Services should not be withheld or delayed on the basis that the child does not have a completed AON report. One of the current anomalies is that while there is a statutory right to assessment, there is no statutory right to services. The staff who are qualified to perform the AON are the same staff who provide the interventions. As of Dec '22 there were 4,000 AONs overdue.

A Standard Operating Procedure (SOP) was introduced by the HSE in January 2020, which stated that the full diagnostic assessment of children would be replaced by a much shorter process. This new process comprises of a desktop assessment, followed by a preliminary team assessment which is time-limited to 90 minutes.

While the AON is important, the HSE needs to begin to redirect some resources to service provision.

Progressing disability services (PDS) has received positive comments. It is based on a child and family-centred approach. It focuses on the child rather than the diagnosis. The HSE estimate that 3.5% of children require specialist input from a multidisciplinary team and another 0.5% require services from a single discipline therapist. However, there is a lack of workforce planning. Understaffing is the primary reason for the lack of services under PDS. There are 850 vacant therapist posts. There are 91 children's disability network teams (CDNTs) across the 9 community healthcare organisations (CHOs). The average national vacancy rate in the CDNTs is 34%.

There are challenges in both recruitment and retention. There are plans to increase the number of 3rd level courses and to develop additional postgraduate programmes to address these shortcomings.

Animal assisted interventions should be better funded and more widely available. The inclusion of animals in intervention for autistic people is increasingly common practice internationally. Horses are the most researched animals followed by dogs. The primary benefit is increased social interaction. Autism Assistance Dogs Ireland placed 19 dogs with families last year but 199 other applicants were unsuccessful.

Respite care provides relief to the patient's caregivers. There are both day breaks and overnight stays. There are summer programmes. The service is in high demand and the number of places is limited. The capacity needs to be increased.

There is no public pathway for adults to access an autism diagnosis. Neuro Pride Ireland state that a diagnosis of autism can be of great importance to people as a matter of identity. It is about being accepted and valued for who they are. If not diagnosed they can feel misunderstood. In addition they are at a higher risk of health-related problems. One Stop Shops would allow autistic people and those who wish to access a diagnosis an easy access point for information on where to access services. It is estimated that 50% of autistic people have a co-occurring intellectual disability while another 50% do not. For this reason, a needs-led approach is required to ensure that all autistic persons can access the supports that they need at the right time and that specialist supports are reserved for those with high support needs.

There are 3 types of schools for autistic pupils – mainstream classes, special classes in mainstream schools, and special schools. There are no second-level special schools but some schools provide special classes. For the forthcoming year there will be 2184 autism special classes providing places for 13,000 autistic students in our schools. This is an increase of 56% over the past decade. For the forthcoming September there will be an additional 306 new autism classes. One of the challenges facing planners is determining the prevalence of autism. Presently a figure of 1.55% is being used but the true figure appears to be higher. In other services including Northern Ireland a figure of 3% is being quoted.

The Report contains extensive sections on transitioning to secondary and 3rd level education.

Augmentative and alternative communication (AAC) systems should be available for non-verbal autistic children. This should include sign language, Braille, and alternative communication assisted technology.

The Summer Programme is very important for the child and the family. It is recognised that autistic children can regress over the summer months with increased sensory overload, increased behavioural problems, and absconding in some cases. Parents have reported difficulties in securing places for their children. In 2023 an additional 40 million Euro was provided. A national summer programme co-ordinator has been appointed. Each school is

advised to appoint a manager for the summer programme. The main challenge is recruiting staff to participate in the programme.

When considering social protection, the committee believes that it is important to eliminate the risk of poverty faced by the autistic community. If a person with autism secures a job, their supports such as free travel and the medical card should not be removed.

The financial impact of caring for a child is difficult to estimate. This is in part related to the degree to which the child is affected. Figures of up to 28,000 Euro per year are quoted with the State providing 14000 Euro.

Employment is challenging for autistic people with 85% either unemployed or underemployed. There are many perceptions that will need to be overcome. Many companies believe that employing autistic people would be too costly. The pathway to work 2021-5 has addressed many of the problems. There is a wage subsidy scheme for disabled people.

Autistic people have poorer health outcomes with most medical conditions being more common. They have a life expectancy which is 16-30 years lower than the general population. As many as 20-40% of autistic people have epilepsy compared with the 1% background rate. Autism is associated with a 7-fold increased risk of suicide. One of the problems for autistic people is communicating with and accessing healthcare services. There are discussions about the referrals to CAMS. The Minister of State told the Committee that children with a primary diagnosis of autism are typically referred to a CDNT as they require multidisciplinary support. She elaborated that those with a primary diagnosis of a mental condition, such as depression, and a secondary diagnosis of autism generally receive support from CAMHS.

Autism increases the likelihood of homelessness. The underlying factors are unemployment, social isolation, poor skills, discrimination, and difficulty in dealing with bureaucracy. It is essential that housing and homelessness supports are made more easily accessible to autistic people. There is a need for a review of the social housing application process as well as the application forms associated with it. Information regarding supports must be accessible to autistic people and disabled people and any barriers which inhibit their access to applying for social housing must be removed.

This Report is a comprehensive, up-to-date, balanced review of all the medical, family, social, and societal challenges facing a child or an adult with autism. It outlines an ambitious programme of measures to improve the quality of life and outcomes of those with the condition. Finally, one of the recommendations is to enact legislation which requires the State to publish an autism strategy every three years, establish a committee featuring autistic people to participate in drafting and monitoring the strategy. Also the Minister for Disabilities

of the day should address both houses of the Oireachtas annually to provide an update regarding its progress

JFA Murphy

Editor

References

1. Joint committee on Autism. Final report on the joint committee on Autism. Houses of the Oireachtas. June 14, 2023.