
DÁIL ÉIREANN

Motion re: Access to Autism and Disability assessments and supports

That Dáil Éireann –

recognises that:

- the needs of children should be met by the State through the provision of well-resourced public health and education services particularly for those with additional needs, that early intervention is vital, but in far too many cases children are being failed by an under resourced, and over capacity system for assessment of needs and provision of essential supports and therapies once a diagnosis of autism or disability is secured;
- the Ombudsman for Children in his 2020 report ‘Unmet Needs’ and in his 2022 annual report ‘Falling Behind’, highlighted significant delays in the provision of assessments of needs (AONs), while the Joint Oireachtas Committee report on Assessments of Need for Children published in February made 39 recommendations that need to be implemented;
- the HSE has a ‘Progressing Disability Services for Children and Young People’ project but that enormous capacity constraints remain, and it is not working for far too many families;

notes that:

- assessment delays, multi-year waiting lists for therapies and lack of access to education supports and appropriate school places is profoundly impacting on thousands of children;
- as of March, 10,696 children have been waiting for over 12 months for initial contact with a Children’s Disability Network Team (CDNT), an increase of 836 since December, and 17,157 were waiting in total;
- 4,613 children were waiting on an AON under the Disability Act at the end of 2022, 3,155 of those were waiting more than 3 months, and that these figures are a significant underestimate of the actual number waiting;
- 102,581 children were waiting for a primary care disability intervention in March, and these figures don’t include those on CDNT lists, with:
 - 14,891 children waiting for psychology appointment;
 - 15,305 children waiting for an occupational therapy first time assessment;
 - 8,054 children waiting for a physiotherapy assessment;
 - 31,073 children in total waiting for speech and language therapy; with 14,927 awaiting initial assessment, 7,606 awaiting initial therapy, and 8,540 waiting on further therapy;
 - 6,517 children waiting for a dietetics appointment;
 - 15,985 children waiting for an ophthalmology appointment, and;
 - 10,756 children waiting for an audiology appointment;

- the most recent HSE staff census in October 2022 showed 34% or 707 posts were vacant across CDNTS, and there is an urgent need for strategic work force planning;
- Individual Family Service Plans (IFSPs) often limit access to waitlisting for direct clinical therapeutic supports despite clear indication of need;
- without early intervention, diagnosis and swift access to supports a child is at risk of permanent developmental delays, leaving parents who can afford it with no choice but to resort to private healthcare;

further notes that:

- an important precedent was set by the HSE when it picked up the cost of a local private psychological assessment in 2023 for Neil Darmody who had waiting many years for re-assessment therefore delaying access to appropriate school supports;
- parents and caregivers are deeply frustrated with the lack of accountability and a fit for purpose external or independent complaints system in the HSE;
- 39% of CAMHS referrals were not accepted in 2022, and in some cases, this is due to behaviours being interpreted as consistent with autism and related diagnoses, with children falling through the gap in services between mental health and disabilities;
- there is in practise no public diagnostic service for autistic adults in Ireland outside of in-patient mental health services, and there is a lack of financial support for Autistic-led and parent-led community groups across the country;
- A 2021 study on the economic costs and unmet needs of autistic children found the annual cost per child for families amounted to over €28,000 as a result of paying for private autism services, lost income and informal care;
- the restrictive means test and low rate of Carer's Allowance payment and complex application for Domiciliary Care Allowance is not sufficient to meet the financial needs of those caring for dependents;
- ongoing problems with the provision of special classes and schools, delays in the annual allocation of SNAs, and the adequacy of Summer Provision is a further burden on parents and caregivers;
- the work of the Special Oireachtas Committee on Autism in considering matters relating to services and supports for autistic people is vital and due to report in June, but this will not address in the short term the current crisis in accessing assessment, therapies and supports;

recalls that:

- there have been multiple motions and bills proposed in the Oireachtas to address these issues including Labour's National Autism Empowerment Strategy motion in April 2021 and Autism Bill in June 2022;
- workers in Section 39 organisations still do not have pay parity or comparable terms and conditions with their colleagues in the HSE;

calls for:

- the immediate provision of financial relief for parents and caregivers forced to pay for local private assessments and therapies by allowing the cost to be either reimbursed, or paid for through the National Treatment Purchase Fund or Joint

Waiting List Initiative if waiting more than six months, until such time as backlogs are cleared;

- increased accountability from the HSE in relation to Child Disability Services, and the introduction of a fit for use, external and independent complaints process, along with funding for autistic-led, and parent-led community support groups;
- a full review of Carers' Allowance and other social protection income supports to ensure it meets the needs of parents, guardians and next of kin caring for relatives, with the introduction of a cost of disability payment in the next Budget;
- a workforce planning strategy to address staff shortages in Disability services, alongside pay parity for those in Section 39 organisations;
- increased resources for the school Summer Programme which should be offered in every special school, alongside improvements to the terms and conditions of SNAs;
- A National Autism Strategy underpinned by legislation, and a review of the Disability Act.

- *Duncan Smith, Ivana Bacik, Alan Kelly, Brendan Howlin, Ged Nash, Aodhán Ó Ríordáin, Seán Sherlock.*