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## DÁIL ÉIREANN

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### *Motion re: National Autism Empowerment Strategy*

That Dáil Éireann –

Recognises that:

- the special interests and strengths of autistic people are a vital part of our society and that we lose out when their unique insight, experience and contribution is lost, and that they require and deserve inclusion, equality and accountability;
- for autistic people and their families, the delays, cancellations and curtailments in healthcare, education and other public services caused by Covid-19 have made what was already a poor situation considerably worse, and that as a result they are in a uniquely isolated and vulnerable position;
- this isolation has been reinforced by the discovery that the State through the Department of Health has surreptitiously compiled dossiers of sensitive personal information, from medical and other healthcare and educational sources, on children with autism, and which is a practice that this Dáil should condemn, and noting that the publication of an internal review into this matter will do nothing to restore confidence as it lacks the independence and transparency so urgently required;

notes that:

- the long-standing adversarial approach taken by the State when services which children are entitled to, or urgently need access to, are absent or failing has put major strain on families and carers, and destroyed the trust of many in the State;
- early diagnosis and intervention for autistic children is critically important, but waiting times for both assessments and services have always been bad, and are now intolerable;
- in a recent reply to a parliamentary question, the HSE confirmed an average 19-month waiting time for children's assessment of needs, with 5,078 assessment of need applications overdue for completion, which is in contravention of the legal requirements under the Disability Act 2005, where it is set out that assessments for children with additional needs, such as autism, should be commenced within 3 months and completed within 6 months; that less than 10% of assessments of need are being carried out within the statutory time-frame, and is also in contravention of the Government's own National Autism Plan which promotes timely access to diagnostic assessment, and which is indicative of the Government's abject failure to support families with autistic children;
- due to Ireland's two-tier health service, families from more disadvantaged backgrounds or without the financial resources cannot access timely intervention, which is leading to increased levels of stress and difficulties for families with autistic children;
- many provisions within the Education for Persons with Special Needs Act 2004 (EPSEN) remain to be commenced;

- €63,000 a day, or €11.6 million a year is spent transporting autistic children and those with special needs in south Dublin to schools in other parts of the city due to a failure to provide appropriate places locally;
- A study by DCU academics in August 2020 showed that as a result of COVID-19 restrictions, a decline was reported for 61% of autistic children, with parents noting:
  - a decline in their child’s ability to self-regulate emotions in the case of 34% of children;
  - a decline in motivation to engage in activities, including school work in the case of 18% of children;
  - a decline in academic skills such as maths, reading and writing, in the case of 14% of children;

Calls for:

- A fully independent review, commissioned by a body other than the Department of Health, into the Department of Health’s practice of surreptitiously compiling dossiers of sensitive personal information, from medical and other healthcare and educational sources, on children with autism;
- a new National Autism Empowerment Strategy, which takes a right-based approach to the inclusion and acceptance of autistic people in Irish life, that recognises the significant strengths of autistic people and that places their voices, and those of their families at the heart of planning and decision making process, is underpinned by a budget and by draft legislation, and for the Strategy to be published and submitted for the approval of both Houses of the Oireachtas by the end of July, and that the Strategy should include –
  - direct involvement in its development from autistic people and their families through the establishing of a working group and direct consultation with the community;
  - learning from best practice abroad such as the Maltese Persons with the Autism Spectrum (Empowerment) Act 2016, and to lay out the establishment of an Irish Autism Advisory Council, similar to the Maltese Autism Advisory Council, to advise and guide Government on autism strategy and which holds Government to account;
  - the immediate abandonment of the new ‘Standard Operating Procedures’, which have reduced assessments of children to a meaningless box-ticking exercise, and put in its place a system for professional, multidisciplinary, in-depth assessments of need that will both provide a detailed description of a child’s needs and set out proposals for tailored, specific and evidence-based intervention;
  - urgent action to address waiting lists for assessments of needs, occupational therapy, speech and language, audiology and other areas of concern, with the immediate recruitment of additional therapists to ensure early intervention;
  - a best practice model of service delivery, assessment, diagnosis and intervention for service users with autism, drawing on international expertise, with guidance for health service providers on how to meet the needs of both autistic children and autistic adults, and their families and carers;

- a clear and detailed intervention plan, funded and time bound, on support services for families and carers and a fully established roadmap on how family support services are to be developed;
- appropriate amendments to the definition of disability in equality legislation so as to include specific reference to autism and other developmental issues that affect a person's capacity to take part in social interactions or to form social relationships, and to incorporate a rights-based, child-centred and inclusive approach;
- a sustained autism inclusiveness campaign and the provision of autism inclusion procedures and real engagement, including training for all professionals who frequently deal with adults with autism;
- appropriate regulation of autism services and therapies and recommendations on appropriate action to be taken in relation to therapies which are not medically or evidence based, make false claims or are dangerous to the welfare of autistic people;
- the inclusion of a question on autism in the next national census to determine the number of autistic people in the State;
- the implementation of the recommendations of the report by the Ombudsman for Children's report 'Unmet Needs', including and not limited to additional resources, including a refund element for private assessment to get to grips with the significant waiting lists, changes to the 2005 Disability Act to ensure a holistic and multidisciplinary approach to the assessment and identification of a child's development needs; recognition of the special educational needs of children in legislation, via changes to the Education of Persons with Special Educational Needs Act (EPSEN) Act to ensure these needs are met in a timely and appropriate manner.
- the commencement and resourcing of all relevant disability legislation without delay;
- in relation to adults with autism, access to diagnostic services, to key worker support and appropriate mental health care where required, and a pathway of care which clearly maps services and ensures their consistent availability across the State and outlines of how the health care, educational, employment and social needs of adults with autism are to be addressed throughout their lives and across the public service in terms of access to services, justice, housing, employment and social inclusion, with parity of access as the underpinning goal; and
- a clear system of accountability and scrutiny relating to autism service provision.

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