

Opening remarks to the Joint Committee on Children, Equality, Disability, Integration and Youth.

Deputy Seán Canney TD

October 3rd 2023

I thank you for the invitation to present here today to the Joint Committee on Children, Equality, Disability, Integration and Youth on the Autism Spectrum Disorder Bill 2017.

This Autism Spectrum Disorder Bill 2017 was first introduced by Senator James Reilly, the former Minister for Health. It passed all stages in the Seanad but fell due to the dissolution of the Dáil in January 2020.

The Bill was re-introduced into the Dáil by the Regional Group of TDs and debated at second stage on 20th October 2021.

An amendment by the Government was accepted, which deemed that the Bill be read a second time on 20th October 2022 to allow for the development and implementation of a National Autism Innovation Strategy in line with commitments under the programme for the Government. The Bill passed second stage on 20th October 2022.

This committee refused to waive pre-Committee Stage scrutiny of the Autism Spectrum Disorder Bill 2017. This was unprecedented, as the Bill passed all stages in the Seanad and passed 2nd stage in the Dáil.

Following on from this, I received a copy of a letter sent to the Business Committee confirming this refusal and indicating that the Committee would scrutinise the Bill in February or March 2023.

I must express my disappointment that it has taken a year from 20th October to commence the scrutiny of the Bill.

Some concerns were expressed in relation to specific terminology within the Bill. As advised by my colleague Denis Naughton TD in a letter to the Chair dated 1st December 2022, significant amendments have been drafted and are ready for publication. These amendments have been drafted with detailed consultations with stakeholders and representative bodies advocating for autistic people.

The Bill seeks to provide for the development and implementation of a cross Department Multi-Agency Strategy to provide and implement services for autistic people.

The Regional Group of TDs continue to highlight that autism is not a health issue but a human rights issue.

No strategy has been put in place since the European Commission approved the Charter of Rights for People with Autism in 1996. The Charter states that autistic people should have the same rights enjoyed by all EU citizens, and these rights should be enforced by legislation. This has yet to happen in Ireland.

On average, the annual cost per child for families amounted to more than €28,000 related to private services, lost income, and informal care. Service provision for autistic people should not be discretionary. It should be a right protected in our legislation.

For this state, doing nothing will cost more in the long run.

Financial pressure is acutely felt by families who assume full-time caring roles for their autistic children, reporting that existing social welfare payments are insufficient to cover therapy costs and additional support.

The Regional members intend to work with all Oireachtas parties and stakeholders to ensure this legislation is fit for purpose and successfully progresses through the next stages in the Dáil. It will be a game changer for autistic people as it will enshrine their rights in law.

Thank you.