



An Comhchoiste um Leanaí, Comhionannas, Míchumas, Lánpháirtíocht agus Óige

Tuarascáil maidir leis an nGrinnscrúdú Mionsonraithe
roimh Chéim an Choiste ar an mBille um Neamhord
Speictream an Uathachais, 2017 [GCP]

Aibreán 2024

Joint Committee on Children, Equality, Disability, Integration and Youth

Report on Pre-committee stage Detailed Scrutiny of
the Autism Spectrum Disorder Bill 2017 [PMB]

April 2024

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Related information

Publications

All publications for this committee are available on the [Oireachtas website](#).

Committee videos

Footage of Committee proceedings can be found on the [Committee videos page](#).

Contact details

The contact details for the Committee can be found on the [Committee page](#).

Terms of reference

Read the [terms of reference](#) for the Committee.

Committee Membership

Cathaoirleach

[Kathleen Funchion TD](#), Sinn Féin

Leas-Cathaoirleach

[Patrick Costello TD](#), Green Party

Members

[John Brady TD](#), Sinn Féin

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[Senator Tom Clonan](#), Independent

[Senator Erin McGreehan](#), Fianna Fáil

[Senator Ned O'Sullivan](#), Fianna Fáil

[Senator Lynn Ruane](#), Independent

[Senator Mary Seery Kearney](#), Fine Gael

Forward

The Autism Spectrum Disorder Bill 2017, a Private Members' Bill, was originally sponsored by former Senator James Reilly and restored to the Dáil Order Paper by a motion moved by Seán Canney T.D., on 28th of April 2021. The Bill seeks to:

“Provide for the development and implementation of a cross-departmental multi-agency autism spectrum disorder strategy and to provide for related matters.”

The Joint Committee scrutinised the Bill and reported thereon in this report on Pre-committee stage Detailed Scrutiny of the Autism Spectrum Disorder Bill 2017 [PMB]. However, the Select Committee, at its meeting of 16 April 2024, made the decision to recommend that the Autism Spectrum Disorder Bill 2017 [PMB] should not proceed to Committee stage, in line with standing order 178(4). Minister O’Gorman, in his capacity as an ex-officio member of the Committee, was given an opportunity to make a contribution to the drafting of the report and to attend the private Select Committee meeting at which the report was finalised and adopted. This is provided for in standing order 106.

In conducting pre-committee stage detailed scrutiny of this Bill, the Committee sought a number of written submissions seeking the views of selected stakeholders and held a public meeting with the sponsor of the Bill and a number of stakeholders, which provided an opportunity for Members and witnesses to discuss the provisions of the Bill.

In addition, Members also requested a legal opinion from the Houses of the Oireachtas Parliamentary Legal Advisers (OPLA) to ascertain the legal and constitutional implications of the proposed legislation, and a briefing paper from the Parliamentary Library and Research Service. Our thanks to the OPLA and the Library and Research Service for their assistance on this matter.

The Committee welcomes many of the objectives of this Bill and is in agreement that the autistic community and the wider disabled community have been underserved for far too long. However, the Committee also has significant concerns with elements of the Bill, which are explored in this report.

The Committee is also very mindful that, to date, adequate supports have not been provided to autistic people and that promises of a National Autism Innovation Strategy have

still not been actioned. That said, progress in that direction has been made, with a public consultation on the draft strategy having launched, with a closing date of 1 March 2024.

The Committee recognises that one of its key functions is to scrutinise draft legislation and it takes this role extremely seriously. It also recognises the unique needs of the autistic community. However, the Committee is mindful that great care must be taken when deciding whether legislative proposals should progress, hence its decision to refuse a request for a waiver of pre-committee stage detailed scrutiny of this Bill.

I would like to commend Deputy Seán Canney and Deputy Denis Naughten for their dedication to the progression of this legislation and for their efforts to address the serious issues facing the autistic community. I would also like to express my gratitude on behalf of the Committee to all those who assisted the Committee in scrutinising the Bill, particularly those with lived experience of the issues and parents and carers whose dedication the Committee commends.

Based on these combined inputs the Committee decided to recommend that the Bill does not proceed to committee stage. This report provides some explanation as to why the Committee arrived at its decision.

Kathleen Funchion TD

Cathaoirleach to the Committee

24 April 2024

Introduction, witnesses and transcripts

In 2018, a Memorandum of Understanding (MoU) between the Government and Dáil Éireann on Private Member's Bills was agreed which requires that Private Members Bills be examined according to specific criteria.¹ The MoU remains in place.

As previously stated, the Autism Spectrum Disorder Bill 2017, Private Members' Bill was originally sponsored by former Senator James Reilly and restored to the Dáil Order Paper by a motion moved by Seán Canney T.D., on 28th of April 2021.

On 20 October 2021, Deputy Seán Canney moved "that the Bill be now read a Second Time."² When Deputy Canney moved that the Bill be read a second time in the Dáil, Minister of State Anne Rabbitte moved the following amendment:

To delete all words after "That" and substitute the following:

"Dáil Éireann resolves that the Autism Spectrum Disorder Bill 2017 [Seanad] be deemed to be read a second time this day twelve months to allow time for development and implementation of a national Autism Innovation Strategy, in line with commitments under the Programme for Government."

Minister Rabbitte stated:

"Plans to develop and implement the autism innovation strategy are already under way and it is for this reason, to give these plans time to work and to ensure that we continue to legislate for persons with disabilities in an equal and holistic manner, that the Government will not oppose the Private Member's Bill today but will instead propose a timed amendment to reconsider the Second Stage of the Bill in October 2022, when the initial working of the innovation strategy can be considered. The Deputies can then judge me on my actions."

Minister O'Gorman stated:

"In conjunction with the Minister of State, Deputy Rabbitte, I support the Government's decision not to oppose this Private Members' Bill, the Autism

¹ [2019-04-29_report-memorandum-of-understanding-between-the-government-and-dail-eireann-on-private-members-bills_en.pdf \(oireachtas.ie\)](#)

² [Autism Spectrum Disorder Bill 2017 \[Seanad\]: Second Stage \[Private Members\] – Dáil Éireann \(33rd Dáil\) – Wednesday, 20 Oct 2021 – Houses of the Oireachtas](#)

Spectrum Disorder Bill 2017, but to propose a timed amendment whereby the Bill will receive Second Stage consideration in October 2022. As the Minister of State outlined, this will allow time for the development of the national autism innovation strategy, which the Minister of State is leading and is a commitment in the programme for Government. It also gives us the time to be held to account in our delivery of that autism innovation strategy.”

One year on, in October 2022, Deputy Canney wrote to the Business Committee stating that the Bill had passed second stage in the Dáil and sought to waive the requirement for detailed scrutiny of the Bill and move the Order for Committee Stage at the first practicable opportunity.

At its meeting on 22 November 2022, the Joint Committee agreed to decline the request to grant a waiver of pre-committee detailed scrutiny of the Bill. The Business Committee also declined to grant a waiver.

At the time of writing this report, over two years on from the agreement to defer progression of the Bill at second stage for 12 months to allow the Government’s Autism Strategy to bed in, no such strategy has been published, although a report on stakeholder consultation in relation to it was published in April 2023. As mentioned in the foreword, a public consultation on the draft strategy has now launched with a closing date of 1 March 2024.

This report details some of the issues that arose during the Committee’s consideration of whether or not to recommend that the Bill should progress. It does so across four sections as follows:

1. The public meeting held on the Bill is discussed,
2. The submissions made in relation to it are discussed,
3. The legal opinion from the OPLA is summarised; and
4. The Committee provides some rationale for its decision on whether or not to recommend that the Bill should progress.

1. Detailed Scrutiny

Meeting on 3 October 2023

On 3 October 2023 the Committee held a public meeting to conduct Pre-committee stage detailed scrutiny of the Bill. The transcript is available [here](#).

The following witnesses attended:

Session one: 15:00 – 16:30

- Seán Canney T.D. (Sponsor of the Bill) and Denis Naughten T.D.
- Officials from DCEIDY:
Mr Niall Brunell, Principal Officer; Ms Clare Gray, Assistant Principal; Mr Jason Doran, Assistant Principal and Mr Donie O’Shea, Policy Advisor.
- Officials from the HSE:
Mr Bernard O’Regan, head of operations in the HSE’s disability services, and Dr Rosie Gowran, clinical lead of the national clinical programme for people with disability.

Session two – 4:30 – 6 pm

- Seán Canney T.D. (Sponsor of the Bill)
- AsIam:
Mr Adam Harris, Chief Executive Officer, and Mr Carl Morris, Policy Officer
- Middletown Centre for Autism:
Mr Stephen Douthart, Chief Executive Officer, Dr Fiona McCaffrey, Head of Research and Development, and Mrs Jill McCanney, Head of Learning, Sport and Assessment
- Neuro Pride Ireland:
Mx Nem Kearns, co-founder

Some of the main issues raised by stakeholders in their opening statements and in response to questions from Members were as follows:

Deputy Seán Canney (sponsor) and Deputy Denis Naughten

Deputy Seán Canney, in his opening remarks, stated:

“The Bill seeks to provide for development and implementation of a cross-departmental multi-agency strategy to provide and implement services for autistic people. The regional group of Deputies continues 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 supports. The members of the regional group 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 and will enshrine their rights in law.”

While Deputy Naughten acknowledged multiple issues with the Bill as drafted, he made the case that legislation has been essential to all significant gains made in respect of disability, and that, because a two-year period has passed since the Department promised an autism strategy, this Bill should be progressed. He stated:

“We contend that enshrining this in law, with the amendments the Department has suggested and the amendments we have proposed and with engagement with the parents, would be far better than not having a law in place. Sadly, history has proved us right. Down through the years, it is only after legislation has been put in place that we have seen movement in terms of the delivery of services.”

Both Deputies expressed a commitment to amend the Bill as necessary to bring it into line with current best practice and to work with relevant stakeholders to incorporate amendments that respond to their concerns at future stages of the legislative process should the Bill proceed.

Officials from the Department of Children, Equality, Disability, Integration and Youth and Health Service Executive

- The Department intends to deliver a draft autism strategy by the end of 2023 depending on the exact timing of consultations. The Department will work with its

implementation and oversight group on that and hopes to move with autistic people in developing it.

- The strategy will focus on bolstering provision within the mainstream offering in terms of services and initiatives for autistic people, without creating overly rigid or separate structures at a time when our understanding of autism continues to evolve, and without establishing sets of rights not enjoyed by other persons with disabilities. It will have provisions relating to data collection.
- Autism and the increasing rates of it are still being understood and researched in an evolving way so overly rigid structures are not the way forward. Complex and evolving issues are better addressed through more responsive frameworks, such as national strategies with robust monitoring and accountability mechanisms that can pivot in real time to changing needs and issues.
- Equality among disabled persons and in the provision of supports is important. The Bill may jar with elements of the UNCRPD convention and be open to legal challenges on an equality basis. Generally, impairment specific or medicalised categories and hierarchies within disability are to be avoided. While it is acceptable to respond to bespoke needs, we should not grant one cohort of disabled persons rights and entitlements that are not enjoyed by all disabled persons.
- The Government is committed to many of the actions called for in the Bill. The disability services action plan, the progressing disability services (PDS) roadmap, and the autism innovation strategy will further these actions. Alignment across these policies is important. It is hoped that the action plan will be published in the autumn, the PDS roadmap soon after and a draft autism strategy by the end of 2023.
- A potentially significant amount of technical and drafting issues arise in the Bill which may have unintended consequences. An example is that definitions in the Bill are based in the language of medical diagnoses, which we know will evolve in line with our understanding and with clinical practice. Moreover, medical categorisation itself risks accidentally excluding some people and does not align with the language and ethos of the UNCRPD, which the Committee is aware emphasises a social model understanding of disability.

- The creation of separate or parallel channels for services and assessments for autistic people gives rise to significant operational concern and duplication of efforts in these areas and could undermine efforts now under way to drive the very improvements the Bill seeks to bring about. It is not clear from the language of the Bill why creating a separate stream for assessment that is autism-specific really drives any improvement.

Bernard O'Regan of the HSE, who appeared with the Department, told the Committee that the current assessment of need process is an agreed upon legal framework, which allows for an equitable approach to how assessments are done (chronologically) and the timeframes that they are to be done within and that is inclusive of the autistic community. He acknowledged the issues with that system which have been well documented by the Committee. He informed the Committee that:

“Substantial additional work has been done on developing a tiered approach to assessments of need and diagnosis in the context of autism. That is being piloted at the moment in four CHO areas. It is at an early stage. We have no data on it yet; it is in the process of being rolled out. The intention behind it is to have a clinically informed, evidence-based approach to how diagnosis is undertaken for the autistic community - children and adults - in order that it can be approached in a way that is predicated on individual circumstances as opposed to having only one way of doing it. That will be an important part of how assessment and diagnosis are undertaken.

AsIAM

- AsIAM passionately believes in the need to legislate for a national autism strategy due to a crisis of support across both children and adult services and due to the pervasive and distinct challenges faced by autistic people.
- Putting in place a national autism strategy would be complementary to the existing framework of disability policy and law, but would recognise the unique needs of our community, including the experiences of autistic adults and those in our community with high support needs.

- The autistic community has awaited meaningful action and implementation since the task force report on autism in 2001. That is why the critical recommendation of the recent report by the Joint Committee on Autism is to legislate for such a strategy.
- Should the Bill proceed, it is important that it be reviewed to ensure the most up-to-date language around autism is used throughout, that a rights-based approach is taken, and that the approaches to support autistic people described within the Bill are neuro-affirmative and rooted in the principles of the United Nations Convention on the Rights of Persons with Disabilities, UNCRPD.
- The Act that needs to come out of this process, is fundamentally quite a simple piece of legislation that requires an autism strategy, that sets out the terms of that strategy, and that critically places the voice of autistic people at the heart of that strategy. The Autism Empowerment Act in Malta is a good example and a very simple piece of legislation.

Middletown

- Middletown operates under the Good Friday Agreement's education policy initiatives. It collaborates with statutory and voluntary providers to enhance autism services in the education sectors of Ireland and Northern Ireland and its Board of Directors is nominated by both departments of education in Ireland and Northern Ireland and funded equally, with the chair rotating between the respective Ministers for Education every three years.
- Middletown does not have the remit to comment on the specifics of the Bill under discussion, but, if it is passed, it will engage with the Departments of Education on it and will embrace any new roles assigned to it as a result.
- Middletown welcomes any new provision that would improve access to assessments and any consequential support services or any provision, whether legislative or administrative, that would improve the lives of autistic children or young autistic people.

- Middletown Centre is an established leader in fostering the development of neuro-affirming practices in schools. The centre's training model is rooted in evidence-based practices and is consistently evaluated as excellent. It is uniquely positioned to share best practice.
- Middletown already fulfils many of the points set out in the in the Autism Spectrum Disorder Bill, for example by:
 - Providing transdisciplinary assessment and support for autistic children and young people, including access to educational specialists, occupational therapy and speech and language therapy.
 - Delivering a person-centred model, ensuring the wishes of the young person are communicated as part of the assessment process and that these remain integral to the support plan developed for the young person.
 - Supporting the young person and their family in accessing community services, including respite care and local facilities.
 - Establishing links with services relevant to the young person, striving towards an ongoing network of support from the education, health and voluntary sectors.

Neuro Pride Ireland

- A specific acknowledgement that autistic people are not just users of services, but full and equal citizens, must be included in section 3(1) to stipulate that a national strategy for autistic people must advance autistic people's access to the full range of the UNCRPD rights. This will provide a useful reframing of the legislation and reassure the public and the community that it is in no way intended to create a segregated approach to autistic people's rights and issues.
- One of the provisions of the Bill that was progressed before the ratification of the UNCRPD refers to the consultative duty conferred on the Minister, which includes no mention of the prioritisation of direct consultation with autistic people through their representative organisations, as required under Article 4(3) of the convention. Nor has the Bill itself undergone such a robust consultative process. This should be

explicitly addressed, and the scope of section 2(1) should be expanded to include a non-waivable duty for direct consultation with a broad range of autistic people by the Minister and throughout the development of the strategy.

- There are concerns that the Bill will be over medicalised and will concentrate on the idea of autistic people as recipients of services and medical care, not persons and rights holders.
- Clarification is needed around the assessment of needs process in the Bill, including:
 - Whether it is intended to be a full assessment of need process or more of an organic assessment to evaluate the best placed supports and services for a person at each stage in their lives and at transition points.
 - How it is envisioned that the assessments under the provision will interact with the children’s disability network teams, CDNTs, and the progressing disabilities framework, which was introduced after this Bill was drafted.
 - Whether it will include mental health assessment and support, which is currently gravely lacking for autistic people for all ages despite the autistic community having a much higher risk of depression and suicide than their peers, and many autistic children in Ireland being denied access to CAMHS due to their diagnosis of autism.
 - Whether there is a need to stipulate a multidisciplinary assessment.
- The Bill refers to a restricted list of professionals that includes behavioural therapists. There is a growing and very robust body of evidence that that is not the support being sought out by the autistic community. In its report on aligning disability services with the UNCRPD, the Joint Oireachtas Committee on Disability Matters found that there is great reason to believe that behavioural therapist interventionist practices do not align with the UNCRPD.
- Concerns are raised about how capacity is dealt with in the Bill. It is important to ensure that assisted decision-making is not inadvertently undermined through the Bill. Neuro Pride Ireland stated:

“We are moving away from a view that capacity is either something an individual has or does not have, to a more rights-based understanding that

capacity is something that the State, through its agents and those working directly for the State with individuals, has a duty to provide all possible supports and to empower individual decision-making on a case-by-case basis. We also have concerns about the wording around capacity, which stipulates that if decision-making capacity is deemed not to be present for an individual, the decision is to be made by their parent or primary caregiver, which does not align with the provisions of the Assisted Decision-Making (Capacity) Act.”

- The provision for data collection is also of great concern, including around section 3(j) of the Bill, which refers to the collection of data from service providers. The Bill predates the UNCRPD and GDPR. There is great discomfort around the use of autistic people’s data and the non-consensual gathering of data, and there are well-founded reasons for that within the autistic community, as highlighted by the recent autism dossier scandal and the HSE data breach. So much more scrutiny of the provisions around data collection is needed.
- Consultation with a broader range of stakeholders, especially DPOs, is needed and while it is welcome that other groups have been given a chance to contribute the inclusion of DPOs is particularly important as underlined in the UNCRPD.

Conclusion

The meeting offered a good opportunity to explore the strengths and weaknesses of the Bill, the changes that need to be made to improve it and the benefits and risks of allowing it to proceed. The contributions from the Department and HSE echoed almost exactly the serious concerns raised by the OPLA and L&RS. Stakeholders expressed support for appropriate legislation for addressing the unmet needs of the autistic community. Deputies Canney and Naughten were praised for their efforts in advocating for the autistic community. Their core argument in favour of the Bill progressing was that imperfect legislation is better than none at all and that, given the failure of the Department to deliver an autism strategy to date, letting the Bill progress is sensible. Some Members expressed uncertainty as to whether letting this Bill, which is in need of many changes and which came

about before the rigorous PMB development process now in place is the right course of action.

2. Summary of Written Submissions

Some of the issues flagged by stakeholders that were invited to make submissions are described below.

The Irish Society for Autism

- The Irish Society for Autism submission argues in favor of legislation.
- It acknowledges that there are language and terminology issues but that these have been communicated and will be amended.
- It states that there is a basis for both Disabled Persons Organisations (DPOs) input and non-DPO input contained in the UNCRPD (Article 33), stating:

“While there is clearly a defined role to be played by DPOs in the formation of any plans and strategies that impact on their lives, there is a clear provision in Article 33 for input from non-DPO organisations. Those who cannot represent themselves must have their rights and needs represented and respected. Their needs can only be represented by listening to family members and organisations that have lived experience of those with significant needs.”

- It highlights aspects of recent work at United Nations, World Health Assembly and European Union level that supports the creation of specific measures for autistic people.
- The submission also points to Northern Ireland as an example of a jurisdiction with legislation that:

“Provides practical guidance on methodology for the autism strategy, specifics in relation to funding, the appointment of an independent reviewer and the provision of data collection.”

- It argues that:

“It is only through comprehensive and inclusive legislation specifically in relation to Autism that Ireland can achieve this” as many reports, strategies and policies have failed to have a substantial impact on the lives of autistic people to date “due to the lack of a legal framework to drive significant change.”

- It suggests that Section 7 of the Bill, which deals with data gathering, should place more emphasis on the needs of autistic people throughout their life, pointing to the work of the 2001 Taskforce on Autism’s then recommendation for the urgent establishment of an autism database and prevalence records to facilitate proper planning.³ The submission states:

“At a minimum all professionals and providers, public and private, involved in the area of Autism should be legally bound to provide the data required in order to achieve comprehensive statistics. If there is no legal requirement the exercise will be futile. The strategy will have no valid foundation.”

- Given the aging nature of our population, the submission highlights the need to further understanding of the aging autistic adult and their needs.

The Irish Society for Autism submission makes the case for codes of practice, plans or strategies to be included in the legislation so that they hold weight and do not rely on political will.

Any legislation must, it says:

- Comprehensively represent, in all aspects of the bill and in all consultations, those who require very substantial support and residential services throughout their lives.
- Encompass the full spectrum of autism.
- Include multi-perspective training, from and to autistic people, parents and family members, caregivers and professionals.
- Recognise service provision as a right, not something discretionary.

³ [Report of the Task Force on Autism \(PDF Format 1 MB\) \(sess.ie\)](#)

- Not rely on the medical model of disability.

The Special Needs Schools and Classes Parents Group

- The submission makes a distinction between the children that this group advocate for, who it says generally have “autism plus complex, comorbid disabilities”, substantial care needs 24/7, and the rest of the autistic community.
- It is not possible to only see the needs of such children (majority of whom are the most critical, lifelong disabled people on this planet) as a social model, it says. The submission recommends that the needs of such families are seen with a holistic approach instead, stating:

“It is essential, that while always having an assumption of competence, we are mindful of disability policies based on fantastical conceptualisation of ability. An unwavering desire for social good can lapse into a trivialising of this serious and often devastating disability.”

- In relation to language, the submission says that while many prefer identity first language, they as parents of children with very complex needs need language that reflects that reality.

It makes the following recommendations in relation to the draft legislation:

- A recognised definition of the parent/carer of a person with autism, who does not have the capacity to self advocate, while also requiring a very high level of life support. This recognition must carry equal advocacy rights to that of the verbal self advocate.
- The Autism Spectrum Disorder Bill should be recognised as the Autism Bill 2021.
- The ‘Assessment of Need’ period to remain at the current time frame of 1 year.
- A recognition of the term ‘profound autism’.
- It concludes by saying:

“In summary, autism is an encompassing term which will always need meaningful subcategory recognition. Only then can we have robust, appropriate legislation.”

Middletown Centre for Autism

While Middletown Centre for Autism appeared before the Committee, they also provided a written submission. However, the submission does not make specific recommendations in relation to the Bill, as the centre's remit does not include such contributions. The submission does offer an insight into the work of the centre, and could serve as a good tool or reference for those drafting autism policy, be that legislation or a strategy or otherwise. The Committee would urge policymakers working in this area, be that within the Department or outside it, to consult with Middletown as a best practice centre.

3. Legal opinion

A private meeting of the Committee took place on 26 September 2023 for the purpose of obtaining a legal briefing from the Office of Parliamentary Legal Advisors (OPLA) on its analysis of the Bill.

Some of the main issues raised in the legal opinion were as follows:

- It appears that an un-intended legal consequence could be the creation of a new assessment system specifically for persons who may be autistic, which would run parallel with the existing assessment system for persons who may be disabled. This could create complexity and confusion in administering the parallel regimes.
- There is a question whether section 3(1)(b) of the PMB is compatible with the right to equality under Art 40.1 of the Constitution, as the PMB requires the creation of a new system of assessment for persons who may be autistic, separate to the existing system of assessment for persons who may be disabled in other ways. However, it is permissible for the State to discriminate, or to legitimately differentiate, between classes of people, so long as the legitimate differentiation is not arbitrary, capricious or irrational.
- There is also a question whether s.3(1)(b) of the PMB is compatible with Art 14 of the European Convention on Human Rights, which is the prohibition on discrimination, as the PMB requires the creation of a new system of assessment for

persons who may be autistic, separate to the existing system of assessment for persons who may be disabled in other ways. If legislation discriminates, to be compliant with Art 14, the discrimination must be in order to achieve a legitimate aim and to do so in a way that is proportionate to the aim to be achieved.

- There are multiple instances of ambiguity in the drafting which could lead to the legislation not achieving its objectives and which could cause litigation. The multiple instances of ambiguity in the drafting constitute serious drafting deficiencies and technical drafting errors.
- The use of language in the PMB does not reflect what disabled persons' organisations recommend in relation to autism:
 - "Autism Spectrum Disorder" is a medical term. The recommended social term is "autism";
 - "An autistic person" is preferred, which reflects autism as an identity rather than a medical condition, instead of "a person with autism."

4. Observations of the Joint Committee on Children, Equality, Disability, Integration and Youth

Stakeholders, including the sponsor of the Bill, recognise that there are significant issues with the provisions of the Bill. The sponsor has provided a list of proposed amendments for consideration at committee stage. Although the proposed amendments are welcome, they do not address all the issues with the Bill and there is no guarantee these amendments will be agreed at committee stage should the Bill proceed.

Members are also aware that this Bill was drafted and was passed by the Seanad in advance of the establishment of the Office of Parliamentary Legal Advisors' drafting service for PMBs and prior to the formalised PMB policy research now offered by the Parliamentary Research Service. It would therefore appear that it was not subject to specialised policy and drafting assistance in its initial drafting.

While there are significant issues regarding the provisions of the Bill, Members recognise that there has also been a significant delay by the Department introducing a National Autism Innovation Strategy on a non-legislative basis. To date, the Government have highlighted their concerns with some of the provisions/objectives of the Bill but have not definitively opposed it. The Bill seeks to introduce a statutory requirement to create a national strategy for autism. It is the Government's view that this can best be achieved through continued development of a new national strategy on autism, rather than through primary legislation.

Establishing an autism strategy via legislation risks creating inflexibility in the State's response, with a risk of rigidity, or locking people out of supports as unintended consequences of the legislative approach. There is also a risk of being perceived to create a statutory hierarchy in the State's response to disability issues. The Disability Act 2005 takes a holistic and inclusive approach to disability issues. Despite these risks, the needs of the autistic community are not being adequately met and the first recommendation made by the Special Joint Committee on Autism is to enact legislation which requires the State to publish an autism strategy every three years.

Stakeholder input into the consideration of the Bill highlighted some issues that any future legislation or non-statutory autism strategy should address, including the crucial need to:

1. Incorporate the views of autistic people themselves and to work with DPOs, as underlined by the UNCRPD,
2. Approach data collection with caution and with regard to GDPR, the UNCRPD and protecting autistic people's rights, and
3. Create appropriate services and protections for the broad range of autistic individuals that are in line with current best practice, i.e. rights-based, and rooted insofar as possible in a social, not medical, model of disability, and based on an assumption that everyone has some level of capacity.

On point three above, the need for workable language and appropriate supports for parents and carers of those with very complex needs must be addressed. However, the Committee

has consistently supported the presumption of capacity and highlighted the importance of will and preference and reiterates its commitment to those principles.

Recommendation to the Dáil

The Select Committee has determined that the Bill has serious technical issues in several sections. That it also may have unintended policy consequences, that elements of it are outdated and contradict protections for vulnerable people now set out in other legislation (for instance on capacity). That several sections of the Bill have serious issues that could potentially render it vulnerable to challenge before the courts. That the equality implications of having an autism strategy set out in legislation when policies relevant to other disabilities are not needs careful consideration, and that, if a Bill pertaining to autism is to progress, it should be a new Bill, subject to the rigorous processes and having availed of the supports that are now in place for drafting PMBs.

Therefore, the Select Committee recommends that the Autism Spectrum Disorder Bill 2017 should not proceed to Committee stage.

The Committee thanks Deputy Canney, the Bill's sponsor and Deputy Naughten who assisted him, for creating an important spotlight and impetus around an autism strategy. Their efforts have not been in vain as the Committee will continue to push for appropriate action in this area. The Committee also wishes to commend the Special Joint Committee on Autism for its important work in this area.

The Committee wishes to emphasise that the failure to provide timely and appropriate policies and supports to the autistic community and to disabled people in general that has occurred to date in this country is completely unacceptable. Disability must be a key priority area for Government in 2024 and into the future.

Appendix 1: Submissions

List of written submissions

Stakeholder
Irish Society for Autism
Middletown Centre for Autism
Special Needs Schools and Classes Parents Group