

Consultation Document:

Proposed Private Members' Bill on Autism

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1. Introduction

Ms Pam Cameron MLA and Chairperson of the All Party Group on Autism (APGA) proposes a Private Members' Bill (PMB) on Autism, with the support of the APGA.

The PMB Proposal seeks to amend the Autism Act (NI) 2011 to enhance the effectiveness of its provisions.

2. Background and terminology

The key duties conferred upon the Department of Health (DoH) and other Northern Ireland (NI) departments by the Autism Act (NI) 2011 include:

1. to prepare an autism strategy;
2. to request every Health & Social Care Trust (HSCT) to provide data on the prevalence of autism in its area;
3. to require the strategy to set out how the needs of families, carers and autistic individuals are to be addressed;
4. to keep the autism strategy under review, and publish a revised strategy at intervals of not more than seven years
5. to monitor the implementation of the autism strategy by the Northern Ireland Departments;
6. to require other departments to co-operate with the Department in relation to the preparation, review and implementation of the autism strategy;

7. to require that the Department and the other departments must implement that part of the autism strategy which falls within their responsibilities;
8. At regular intervals (i.e. every 3 years), the Department must prepare a report on implementation of the autism strategy which should be laid before the Assembly.

In summary, the PMB Proposal seeks to “amend the [2011 Act] to address emerging gaps and to strengthen its impact” by introducing new duties to:

1. Review and update the current Programme of Care (PoC) designations;
2. Establish a cross-departmental independent scrutiny mechanism (such as an autism advocate); and
3. Develop and fund a cross-departmental NI autism training strategy.

3. Current Arrangements

In June 2018, the Research and Information Service (RaISe) of the NI Assembly submitted a set of questions to the Department of Health (DOH) concerning progress on the implementation of the 2011 Autism Act, including whether any consideration had been given to the establishment of an independent autism advocacy service to support those with autism and to provide guidance in the sector.

In August 2018, The DOH provided the following response via email:

‘The appointment of an independent autism advocate would be a matter for an incoming Minister to consider. However, a range of services are currently commissioned by the statutory sector to support people with autism and the people who support them. These services are provided in many different ways and can involve information sharing, the development of support networks and training facilitation. Statutory bodies also work in collaboration with a wide range of community and voluntary disability organisations to ensure that people are signposted to services appropriate for their needs. Furthermore, in line with the vision set out in Health and Well-being 2026 Delivering Together, DoH is committed to working with all stakeholders in the design, delivery and evaluation of services. That is why, as noted in A1 above, on receipt of the draft regional framework, it is intended that a process of engagement will be undertaken with all stakeholders, with a view to developing future agreed key cross-departmental actions for consideration by an incoming Minister and Executive.’¹

The response from the DOH went on to provide further information concerning structures that had been put in place to oversee the implementation of the Autism Strategy and Action

¹ Email Communication from DALO, Department of Health, received on 18th June 2018, REF Number: STOF-0105-2018

Plan for Northern Ireland, which are set out below. The DOH stated that these structures were terminated circa 2017/18.

- **The Autism Strategy Interdepartmental Senior Officials Group (ASISOG)** which met on a bi-annual basis throughout the life of the 2013-2017 Action Plan. The group was made up mainly of departmental representatives.
- **The Autism Strategy Regional Multi-Agency Implementation Team (ASMAIT)** chaired by a Regional Autism Co-ordinator which met in a bi-annual basis. The Regional Autism Co-ordinator was recruited by the Health and Social Care Board and was filled from October 2014 until the end of March 2018.
- **Northern Ireland Autism Strategy Research Advisory Committee (NIASRAC)** which was made up of departmental representatives as well as representatives from advocacy and academic institutions.

4. Proposals for Reform

a) Programme of Care and Capitation Formula

An issue that sets Northern Ireland apart from other UK jurisdictions and the Republic of Ireland (ROI), is the composition and number of layers within our Health and Social Care system (government department (DoH), regional Health & Social Care Board (HSCB), 5 HSCTs as well as numerous PoCs). Common across all UK jurisdictions is a system of capitation with funding allocations to services weighted by need (for example: population size, age profile, special needs). The RaISe did not identify any comparable PoC system in Great Britain.

The sponsor believes that the current historic Programme of Care framework in Northern Ireland makes the system more complex, with fixed and outdated categories (referred to commonly as 'silos') and less accessible in terms of public transparency, and therefore accountability.

Northern Ireland's PoC model of organization confines autism to a learning disability classification with an overlap into mental health and physical/sensory classifications. The sponsor contends that this system does not accommodate autism, which in 1992 was considered a rare condition (4:10,000 of the population) akin to learning disability (and thus accommodated within the Learning Disability PoC) but which now is recognised as impacting the lives of 1:24 of school age children, most of whom do not have a learning disability. The sponsor observes that the Autism Act (NI) 2011 amendment to the Disability Discrimination Act was insufficient to change the practice by some HSCTs of using IQ inappropriately as a service allocation determinant for autistic individuals.

The potential consequence of this error (in understanding and designation of autism) can be delay, inappropriate referral and lack of access to the specialised early and rapid

intervention which research supports as vital in realising the full potential of autistic individuals. The Proposal seeks to remove this barrier.

The Proposal seeks to create a **social and communication disability** division that recognises the possibility but not inevitability of co-occurring issues such as Learning Disability and Mental Health, recognising the accelerating prevalence data and that autism requires a social, rather than a medical service model from diagnosis (psychological/multidisciplinary not medical) through to intervention (multidisciplinary). It is the sponsor's view that this would more accurately reflect operational and strategic pressures, including the appropriate allocation and placement of an autism budget within a social and communication division. This would have a cross departmental dimension, to stimulate and initiate cross departmental service planning and funding as was envisaged by the 2011 Act, thus sharing the responsibility and resources required. Development and publication of a transparent and accountable capitation formula that is reviewed and updated annually will align more effectively with the ongoing data collection on autism and associated analysis. It will address the legacy of autism service underfunding and the budget allocated devoid of a connection to prevailing DoH published autism data (required under the Autism Act (NI) 2011).

The sponsor has been unable to identify any economic analysis in NI that would test if financial investment in autism services is commensurate with need.

A DoH or NI Executive Office capitation system will create a fairer and more flexible process for provision of autism services in Northern Ireland.

b) Cross Departmental Independent Scrutiny Mechanism (Autism Advocate)

Northern Ireland is the only jurisdiction across the UK or Ireland or Europe with autism legislation that is targeted to the full lifespan of autistic individuals and which is cross departmental in scope. It is also the only jurisdiction devoid of a formal engagement mechanism with stakeholders since 2012. The sponsor therefore proposes an innovative level of oversight and accountability requiring an independent structure.

Research was therefore unable to identify any independent Autism Advocate/Champion type role fitting the criteria set out in the proposals for the Private Members Bill in any of the regions examined within the UK.

Nevertheless, research has identified that Wales, Scotland, England and the Republic of Ireland, as well as Malta, do have various bodies and structures in place sanctioned by government to monitor implementation and suggest improvements to services, research and training aimed at improving the lives of people with Autism (see table 1).

Of the other jurisdictions that were examined, two had roles analogous to the “Autism Advocate” outlined in the PMB Proposal:

- France has an Inter-ministerial Delegate.
- The USA has a National Autism Co-ordinator.

Table 1: Research regarding independent scrutiny mechanisms found in a range of jurisdictions:

| Jurisdiction | Organisation | Makeup | Remit |
|---------------------|---|---|---|
| Wales | The ASD National Development Team (NAT) funded by the Welsh Government | A National Strategic Lead for Autism A National Professional Lead for Autism | To implement the WG Code of Practice on the delivery of autism services and support in Wales. To implement the Welsh Autism Strategy including development of the new integrated Autism Services (IAS) supporting research and training. |
| Scotland | Scottish Executive Autism Strategy Review Group | 1. Autism Third Sector. 2. Autism Network Scotland 3. Scottish Government 4. Local Authorities (COSLA) | To engage with the Scottish Autism Strategy (budget of £10m over 4 years) which is aimed at ensuring progress in delivering quality services for people with autism and their families. |
| England | NHS Taskforce for young people’s hospital mental health, learning disability and autism care. | | To improve current specialist children and young people’s inpatient mental health, autism and learning disability services in England. The taskforce was launched in response to sustained campaigning from various groups concerning the |

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| | | | treatment of young people's in-patient mental health care as well as a report carried out by the Children's Commissioner 'Far less than they deserve: Children with learning disabilities or autism living in mental health hospitals'. |
| ROI | Recently appointed Autism Spectrum Disorder Programme Board following prevalence and services review; initial resource in 2020 budget of €2 million | Senior operational and clinical decision makers from within the HSE as well as independent professional academic support and persons with lived experience of ASD, including representation from Autism charities | <i>"to lead on the implementation of these (review) recommendations at local and national level. This is particularly important in a context where we received feedback which suggested that previous reviews had not resulted in actual changes in service delivery"</i> (Minister for Health Simon Harris) |
| Malta | Autism Advisory Council established by legislation: The Persons within the Autism Spectrum (Empowerment) Act 2016. | 1. Government Ministers 2. Academics 3. Equality Commission 4. Third Sector | To draft a national strategy on autism. To assist the government planning on autism service needs and design. |
| USA | 1. National Autism Coordinator (NAC) ² | | 1. The NAC is responsible for ensuring the implementation of national autism research, |

² NIMH's Dr. Ann Wagner Designated as the National Autism Coordinator, National Institute of Mental Health, 28th February, 2018 <https://www.nimh.nih.gov/news/science-news/2018/nimhs-dr-ann-wagner-designated-as-the-national-autism-coordinator.shtml>

³ <https://iacc.hhs.gov/about-iacc/overview/>

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| | 2. Interagency Autism Coordinating Committee (IACC) | 2. The IACC is a Federal Advisory Committee and has public and Federal members. Meetings are held in public. ³ | services and support across Federal agencies. 2. The IACC is a Federal Advisory Committee that coordinates Federal efforts and provides advice to the Secretary of Health & Human Services on autism issues. |
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| France | 1. Interministerial Delegate (ID) | 1. The ID office has 5 staff (management/communications/projects/special adviser/secretary) | 1. The ID monitors and supports the implementation of France's 344m Euro funded National Autism Strategy (2018/22). The ID reports to the Secretary of State to the Prime Minister and liaises with the TND General Secretary. |
| | 2. National Council for Autism Spectrum Disorders (ASD) and Neurodevelopmental Disorders (TND) | 2. The TND membership includes the Third Sector, State and Local Authorities, medical and research bodies | 2. The TND meets every 6 months and supports the ID with the implementation of the Strategy. |

Case for reform: to provide an **independent** scrutiny mechanism such as an **Autism Advocate**.

The Autism Act (NI) 2011 and its mandated NI Autism Strategy 2013/20 was signed off by all government Ministers without a designated budget to facilitate and encourage implementation or a jointly funded mechanism to facilitate cross departmental cooperation and service development.

The Autism Act (NI) 2011 placement of oversight as well as implementation responsibilities with the Department of Health has produced subjective rather than objective scrutiny and evaluation of progress as is evidenced within the mandated Progress Reports presented to the Northern Ireland Assembly. The PMB Proposal **removes** this conflict of interest scenario.

The establishment of an independent scrutiny mechanism which has effective links with the NI Executive Office, the NI Assembly and the NI Autism Strategy Implementation structures is proposed. The absence (since 2012) of a formal engagement mechanism (with autistic individuals, families, carers and the autism advocacy bodies that represent and support them) is noted and the PMB Proposal places this duty within the remit of the autism scrutiny mechanism.

This would reflect the accountability, implementation and scrutiny requirements identified by other jurisdictions:

1. Operational Requirements: Internal government implementation which is required to deliver services set out in the NI Autism cross departmental Autism Strategies that have measurable targets and outcomes with active inclusion of the autism Third Sector as advisers and partners and advocates.
2. Policy, Strategic and Funding Requirements: Accountability and oversight by the government (NI Executive Office and the NI Assembly). Autism Advocate role imbedded, providing objective evaluation and research data to inform planning and investment. Relevant examples include the NAT (Wales);
3. Scrutiny Requirements (Autism Advocacy dynamic):
 - Guaranteeing the momentum of service development (early intervention that is multidisciplinary anchored and consistent across all HSCTs, accredited workforce training and appropriate adult services) through objective research and evaluation and engagement with a dedicated budget to commission such research.
 - Providing a vehicle for stakeholder advocacy and a repository for evidence of need through sustained and effective engagement with autistic individuals, families, carers and the advocacy bodies that represent and support them.
 - Liaising with autism policy leads across UK and ROI jurisdictions to investigate and assess the development of adult services especially the impact of the English Autism Act which was limited to adult service issues.

The inter-connectivity between all of the above structures is a matter for detailed regulations and duties and resourcing including agreed penalties for inaction and effective communication to stakeholders:

- The PMB Proposal requires that government adopt a proactive culture of evidence based practice and practice based evidence, viewing research as a cross cutting dynamic to ensure credible evaluation (for strategic development) and viable service development (for effective services). An example of local comprehensive

independent research being operationally and strategically unrecognised (but shared with Wales and Scotland) is the multidisciplinary and multiagency KEYHOLE Programme of Early Intervention which was a collaboration between government and the Third Sector over two decades supported by European Union and NI Executive funds and with Ulster University as the external research body.

- The PMB Proposal requires that a formal mechanism is established for engagement with autistic individuals, families, carers and the advocacy bodies that represent and support them.

The placement of the structures that are created (such as an Autism Advocate with support staff) to carry out the above requirements is a matter for detailed negotiation.....

- **within** and **across** Departments: should the NI Executive Office assume the role of lead Department for implementation **or** become an active arbiter within government for autism policy development?
- **outside** Departments: should the duties of one of the Statutory Compliance Scrutiny Bodies such as the Equality Commission for NI (ECNI) be strengthened to accommodate the Autism Advocate Office **or** is a stand alone Autism Advocate Office the only way to guarantee equality and momentum?

c) Cross Departmental NI autism training strategy

The Autism Act (NI) 2011 provided for progressive NI Autism Strategies to be implemented and the first was launched to cover the period 2013-2020. The Act required the provision of an autism awareness programme for frontline staff and the promotion of opportunities for raising awareness generally.

The absence of coordinated and objective evaluation, monitoring or research on autism training delivered means that there is no measurement of effectiveness nor is there any strategic document detailing policy in this area. Neither is there any available criteria for any agency (regarding expertise required, accreditation or training content) choosing to deliver such training. The NI Autism Strategy Progress Reports provided by the DoH as well as evidence from correspondence from Departments to the APGA, indicate a preference for an opt-in policy for workforce training rather than a statement that such training is a requirement for staff working with autistic individuals. Much training is rarely accredited with any academic body and therefore fails to record an enhancement of professional or career development.

Two decades ago, the DoH commissioned the Ulster University to review the issue and the report recommendations included the development of a regional autism training strategy. The report recommendations were not accepted or implemented.

The Broken Promises report published in 2016 by Autism NI and the National Autistic Society (NI) recommended a more robust approach to training.

On 3rd February 2020 the NI Assembly resolved the following:

“That this Assembly recognises the specific needs of pupils with autism in our schools; values and supports the role of all educators in ensuring pupils with autism have the best educational outcomes; and calls upon the Minister of Education to introduce mandatory autism training for all trainee teachers, teachers and classroom assistants”.

Autism training for frontline staff has been the focus of more advanced strategic planning in other neighbouring jurisdictions (UK and Ireland) than is the case in Northern Ireland:

- In England, mandatory training across education, health and social care sectors is being trialled. Statutory guidance has been drawn up. Repeated mention of the issue is noted in strategies in 2010, 2014, 2018 and 2019 and an Executive Group created a Task and Finish Group to progress the debate to its current stage.
- In Wales, there is detailed priority given to workforce training in the Wales Autism Strategies of 2009 and 2016. The National Autism Team (NAT) is tasked with delivery.
- In Scotland, autism training is highlighted in 2 out of the 10 strategic indicators of the Scottish Autism Strategy with a training subgroup being set up within the main reference group. In 2014, a Progress Report considered a national autism training framework and in 2018/21 priority was given to investment in this training framework.
- In the ROI Health Service Executive Review (2012) autism training was referenced but no plan emerged. However, by 2018 autism training had emerged to become 1 out of 9 strategic themes.

The Autism Act (NI) 2011 requirement on the DoH to gather statistics on autism has provided the data to underpin the need for a more strategic cost effective and longterm approach to autism training for staff within the education, health and social care sectors to replace a predominantly random opt-in system to ensure that autistic individuals are understood, reach the appropriate services they might need and are met with appropriately skilled and confident professional staff.

The incremental approach to autism training across jurisdictions is noted. The PMB Proposal reflects that developmental approach in the recognition of the need to move forward more strategically with the issue of autism training.

The PMB Proposal seeks to establish an autism training strategy that is tiered in composition to reflect the graded needs of a range of staff from those requiring accredited courses to those requiring more practical options or a combination of both. A register of accredited autism training bodies subject to predetermined criteria is also recommended as best practice.

5. Further Reading

Thompson, J. 2020. Autism: (i) Programmes of Care and (ii) Use of Language. (accessed via; <http://www.niassembly.gov.uk/assembly-business/research-and-information-service-raise/research-publications/>)

Potter, Michael. 2020. Autism: Training and Capacity Building. (accessed via; <http://www.niassembly.gov.uk/assembly-business/research-and-information-service-raise/research-publications/>)

McMurray, Sinead. 2020. Review of Independent Scrutiny Mechanisms to Monitor Implementation of Autism Strategies in Various Countries. (accessed via; <http://www.niassembly.gov.uk/assembly-business/research-and-information-service-raise/research-publications/>)

6. Equality considerations

An equality screening exercise on the policy proposals for the current “Autism Strategy 2013-20) and Action Plan (2013-16)”⁴ was undertaken by the Department of Health, Social Services and Public Safety (‘DHSSPS’). In the screening document, the DHSSPS asserts that the policy proposals for the strategy and action plan would have a positive impact on a number of Convention rights, including: Article 3 (Right to freedom from torture, inhuman or degrading treatment or punishment); Article 6 (right to a fair and public hearing within a reasonable time); and Article 8. Furthermore, the DHSSPS stated that those policy proposals had a neutral impact on other Convention rights and would have no negative impacts on any Convention rights.

⁴https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/autism-strategy-action-plan-2013_0.pdf
see Appendix 4