



Northern Ireland
Assembly

Research and Information Service Briefing Paper

Paper No. 38/20

28th May 2020

NIAR-159-2020

Sinéad McMurray

Review of Independent Scrutiny Mechanisms to Monitor Implementation of Autism Strategies in Various Countries

The purpose of this briefing note is to inform a proposed Private Member's Bill to amend the Autism NI Act 2011 to address gaps and strengthen its impact. The paper explores whether any countries are using an independent scrutiny mechanism, such as an Autism Advocate, to monitor the progress of legislation or strategies aimed at improving services for people with Autism.

Contents

- 1. Background and context3
- 2. Previous implementation structures set up under the NI Autism Strategy3
- 3. Implementation and oversight arrangements in other jurisdictions5
 - 3.1 Wales - The National Autism Team (NAT)5
 - 3.2 England – NHS Taskforce for young people’s hospital mental health, learning disability and autism care.....8
 - 3.3 Scotland – Autism Strategy Review Group.....9
 - 3.4 Republic of Ireland – National ASD Programme Board 10
 - 3.5 Malta - Autism Advisory Council..... 10
 - 3.6 France – Interministerial Delegation..... 12
 - 3.7 USA – National Autism Coordinator 13
- 4. Conclusion 14

1. Background and context

Proposals for a Private Member's Bill (A proposed Private Members Bill) submitted in March 2020 sets out to amend the Autism Act (NI) 2011 to address gaps and strengthen its impact through a number of measures including the establishment of a cross departmental independent scrutiny mechanism (such as an Autism Advocate) accountable to the NI executive to:

- Commission and oversee an objective research strategy;
- Drive the development of an evidence based early intervention model which is consistent and uniform through each HSC trust area; and
- Drive the provision for adult services to include supported living, employment and emotional well-being.

The purpose of this research is to identify whether the role of an independent Autism Advocate, or similar, exists in other jurisdictions. RaISe conducted a search of:

- The jurisdictions within the UK;
- Various EU countries with autism plans and/or strategies including the Republic of Ireland, France, Denmark, Hungary, Italy, Malta, Bulgaria and Lithuania; and
- Jurisdictions outside the EU namely, Australia, Canada and the USA.

The research was unable to identify any independent Autism Advocate/Commissioner type role fitting the criteria set out in the proposals for the Private Members Bill in any of the regions examined within the UK and Europe. Of the jurisdictions that were examined outside Europe, the USA is currently the only country that has a 'National Autism Co-ordinator', details of which are provided below.

However, the research has explored existing scrutiny mechanisms and structures that provide oversight and drive implementation of an autism strategies/legislation in various jurisdictions which the Member may find helpful.

2. Previous implementation structures set up under the NI Autism Strategy

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 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** 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 Regional Multi-Agency Implementation Team** 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** which was made up of departmental representative as well as representatives from the third sector and academic institutions.

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

3. Implementation and oversight arrangements in other jurisdictions

3.1 Wales - The National Autism Team (NAT)

The National Autism Team in Wales is highlighted because it performs several functions concerning oversight and implementation of the Welsh Autism Strategy including development of the new Integrated Autism Services (IAS)² across Wales and supporting research and training.

The NAT is funded by the Welsh Government and is hosted by the Welsh Local Government Association (WLGA), working in partnership with Public Health Wales (PHW). The overall purpose of the NAT is to assist the Welsh Government in rolling out its Autism Strategy across Wales. The team provides a vehicle through which the WLGA and PHW can work in partnership to achieve the commitments set out in the ASD refreshed Strategy Action Plan (2016) and the associated delivery plan.³ The NAT has been assigned core funding from the Welsh Government until 2022.

National Autism Team (NAT) Structure

Formerly known as the ASD National Development Team, the team was renamed and new structures were introduced following an informal review in 2017. The new structure which is set out in figure 1 included the appointment of two national leads who were initially appointed on a six month basis but whose roles have been extended⁴:

- (1) **A National Strategic Lead** who provides strategic oversight to the team and engagement with the seven Health and Social Care collaborative Regional Partnership Boards as well as key partners and stakeholders; and
- (2) **A National Professional Lead** who provides key professional oversight and input to the Team and partners in the rollout of the new Integrated Autism Services (IAS) and ASD resources.

Both leads report into the Director of Social Services & Housing of the WGLA. The team works closely with:

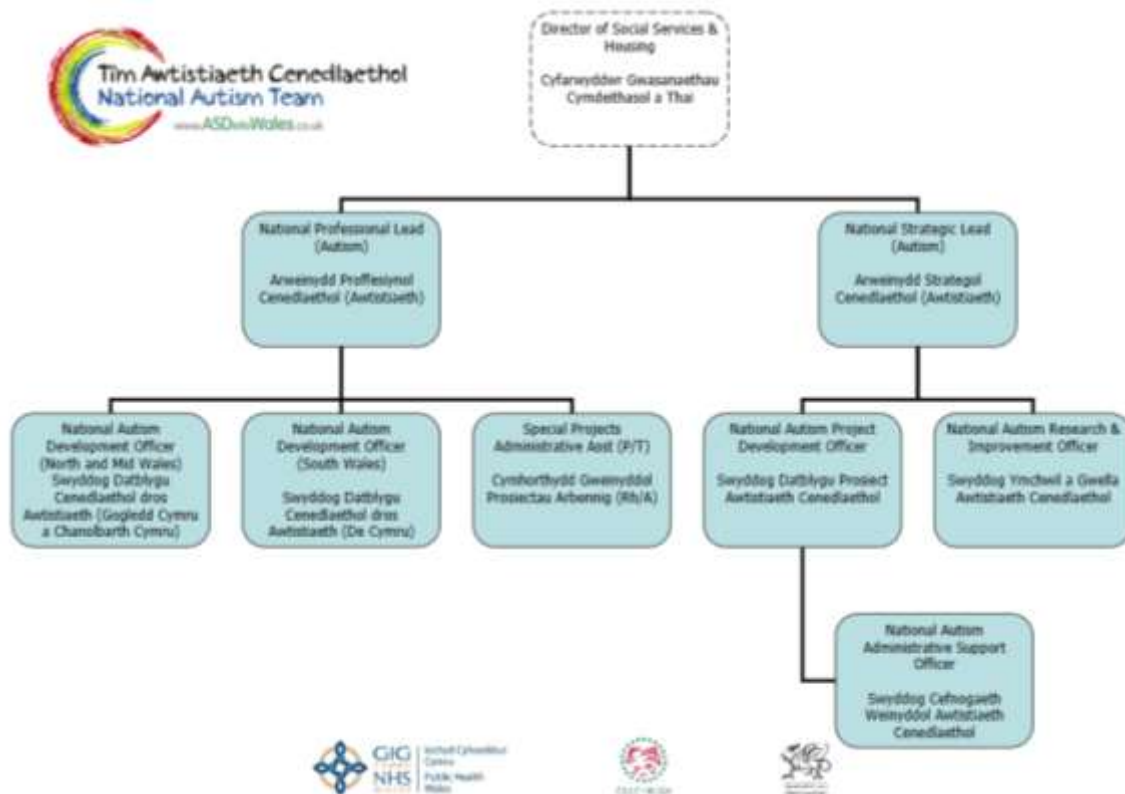
² The Integrated Autism service (IAS) is a set of new specialist teams across Wales, providing adult diagnosis, support in the community and advice and information for adults with autism and for their family and carers. It also supports the improvements in children's diagnosis, treatment and support services through the Together for Children and Young People programme. The ¹IAS service was developed to fill the gap identified in existing services and complement those services, rather than establish a complete new set of services

³Memorandum of Understanding between the Welsh Local Government Association and Public Health Wales, NHS Trust, Welsh Local Government Association, December 2018 https://www.asdinfo.wales.co.uk/resource/MOU-WLGA-and-PHW_Dec-2018-2019.pdf

⁴National ASD Development Team Annual Report 2017-18, 31st May 2018, National ASD Development Team, https://www.asdinfo.wales.co.uk/resource/ASD-Team-Annual-Report-2017-18-final_180615.pdf

- The Welsh Government;
- Local ASD leads and health leads within local authorities and health boards;
- The new Integrated Autism Services (IAS);
- Key stakeholders and providers in the third sector; and
- Relevant advisory boards.

Figure 1 – National Autism Team



What does the National Autism Team do?

The NAT has several functions, which are set out in their work plan for 2019-20⁵:

1. Supporting the development and roll out of the new IAS throughout Wales and :

- Supporting the implementation of the IAS data / performance monitoring system;
- Reviewing and updating IAS guidelines; and
- Increasing awareness of the IAS service across Wales.

⁵National Autism Team Workplan 2019-20, Final Version, 17th June 2019 https://www.asdinfo.wales.co.uk/resource/National-Autism-Team-Work-Plan-2019-20_eng.pdf

2. Facilitating networks and working with partners and stakeholders, including the Welsh Government by:

- Supporting the development and implementation of the WG Code of Practice on the delivery of autism services and support in Wales;
- Facilitating the National ASD Leads Forum the National IAS Network;
- Building close working relationships with the Third Sector with a view to increasing joint delivery of services with the sector;
- Maintaining strong links with Regional Partnership Boards for Health and Social Care and ongoing work at local and regional levels on autism; and
- Working closely with the Wales Autism Research Centre.

3. Training

- Supporting the roll out of the National Training Framework; Commissioning specialist training and developing new resources in relation to co-occurring mental health and autism in Children and Young People;
- Evaluating adult mental health training in autism to inform future work and;
- Revising and updating current training resources.

4. Resources

- Making necessary adjustments to resources and materials taking into account feedback from stakeholders;
- Furthering development of post diagnostic support for the parents / carers of autistic children/ young people;
- Undertaking pilot evaluations of various schemes including the learning with Autism scheme; and
- Maintaining, reprinting, storing and distributing free bi-lingual autism resources.

5. Increasing Awareness and Understanding of Autism by:

- Supporting the increased use of ASD training and support materials that have been developed by the National Autism Team;
- Supporting and further developing the ASDInfoWales website (<https://www.asdinfowales.co.uk>);
- Implementing the “Can You See Me” Campaign⁶;
- Publishing the Autism Housing and Homelessness Guidance; and
- Producing an Implementation Plan with WG for the consistent rollout of the Employment resource; and
- Implementing the Further Education and Work Based Learning resource in partnership with key stakeholders.

⁶ Can You See Me? Autism Awareness Campaign, ASDInfoWales website, <https://asdinfowales.co.uk/can-you-see-me>

RaISe contacted the Welsh National Autism Team Strategic Lead Sara Harvey to find out more about their role and responsibilities and received the following response via Email on the 27th May 2018:

'We are employed by the WLGA (Welsh LGA), we are jointly hosted by the WLGA and Public Health Wales (health) and we are fully grant funded (staff and core budget) by the Welsh Government (WG) to assist the WG in delivering its Autism Strategy. We report as a team to a Management Group which comprises the three core partners (WLGA, PHW, WG). We are managed on a day to day basis by the WLGA's Director of Health and Social Care. It is a "good" structure and governance arrangement because we then sit in the context of a political organisation that has access to social care; education; regeneration; housing and community services.

We link in with 22 ASD Leads across Wales, employed by the 22 Councils in Wales (a couple are full time but most cover other matters in education or social services). We oversee the Integrated Autism Services in Wales which bring together health and social care staff to deliver a single service for autistic adults in Wales and provide support for those adults pre and post assessment.'

3.2 England – NHS Taskforce for young people's hospital mental health, learning disability and autism care

Although this taskforce is concerned with a very specific and vulnerable population, children receiving inpatient mental health care, it has been included here to highlight the role of the Children's Commissioner in supervising and reporting on the work of the taskforce.

In October 2019, the NHS announced that a new taskforce was being set up 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 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*'.⁷ The report demonstrated that too many children are being admitted to secure hospitals unnecessarily and highlighted poor and restrictive practices including sedation and restraints as well as a lack of regular review of children's care plans.

The aim of the new taskforce is to concentrate on the way that autistic children and children with a learning disability or mental health problem end up in hospital, often for long periods. Specifically the taskforce is required to make a rapid set of improvements in the quality of

⁷ Far less than they deserve. Children with learning disabilities or autism living in mental health hospitals, Children's Commissioner, <https://www.childrenscommissioner.gov.uk/publication/far-less-than-they-deserve/>

care in existing mental health hospitals for children under 18 years old over an 18 month period as well as exploring how this care could take place in the community setting.⁸

An independent oversight group was established alongside the taskforce to provide independent, expert advice and scrutiny on the work of the Taskforce. The Taskforce is chaired by Anne Longfield OBE, the Children's Commissioner for England.⁹ The Children's commissioner commented¹⁰:

'Research published by my office earlier this year found that far too many children are stuck in hospital for months or even years when they do not need to be there. I am pleased that this taskforce has been announced to change this unacceptable situation, and I am delighted to Chair this Independent Oversight Group to amplify the voice of these children and their families, scrutinise progress and hold the system to account.'

3.3 Scotland – Autism Strategy Review Group

The Autism Strategy Review Group (previously the Autism Strategy Reference Group) was established to help monitor and co-ordinate implementation of the Scottish Strategy for Autism (2011).

The key aim of the Scottish strategy is to ensure that progress is made across Scotland in delivering quality services for people with autism and their families. The strategy was backed up with funding of £10m over four years.

In 2017 the Scottish Government ran a consultation to refresh the 2011 strategy, which resulted in a new publication the 'Scottish Strategy for Autism: outcomes and priorities 2018-2021', in March 2018.

Members of the review group include representatives of autistic people's organisations along with the main national autism charities, Autism Network Scotland (the national autism information hub), Scottish Government and COSLA.

⁸National Quality Improvement Taskforce for children and young people's mental health inpatient services, NHS England, Mental Health, <https://www.england.nhs.uk/2019/10/nhs-taskforce-to-drive-improvements-in-young-peoples-hospital-mental-health-learning-disability-and-autism-care/>

⁹National Quality Improvement Taskforce for children and young people's mental health inpatient services, NHS England, Mental Health, <https://www.england.nhs.uk/mental-health/cyp/children-and-adolescent-mental-health-service-inpatient-services/improvement-taskforce-children-young-people/>

¹⁰ World Mental Health Day: NHS announces taskforce on children's mental health hospitals, National Autistic Society, 10th October 2019 <https://www.autism.org.uk/get-involved/media-centre/news/2019-10-10-world-mental-health-day-nhs.aspx>

3.4 Republic of Ireland – National ASD Programme Board

The National ASD Programme Board was chosen for inclusion in the research as they are recently established, include representation from several sectors including those with lived experience of ASD and are responsible for driving improvements to Autism services in the Republic of Ireland (RoI). As the board is recently established there is limited information about any work they have undertaken but a request has been submitted by RaISe for further information on their role, responsibilities and level of autonomy.

In 2018, the Minister for Health (Simon Harris) commissioned two separate reports on both the prevalence of autism in the RoI and a review of the services for people with autism.¹¹ Following the publication of the reports, the Minister for Health committed €2 million funding in the 2020 budget to improve available services for people with ASD¹². The Minister also instructed the HSE to establish an implementation group based on a recommendation included in the review¹³:

'We recommend that an implementation group be established to lead on the implementation of these 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.'

In 2019, The HSE established the 'National ASD Programme Board' to implement the recommendations of the review report, specifically leading on an agreed set of priorities that will have greatest impact in terms of improving how services can be delivered to people with ASD and in respect of creating greater awareness of ASD.¹⁴

The Board consists of 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 charities¹⁵.

3.5 Malta - Autism Advisory Council

In May 2016, Malta became the first country to adopt an autism acceptance law, the "Persons within the Autism Spectrum (Empowerment) Act",¹⁶ A provision of the act was to establish an Autism Advisory council which was officially launched in 2018.

¹¹ Reports on the prevalence of autism in Ireland and a review of the services for people with autism, Department of Health Publication, Irish Government, 31st May 2019 <https://www.gov.ie/en/publication/0cc791-reports-on-the-prevalence-of-autism-in-ireland-and-a-review-of-the-s/>

¹² Minister Harris announces €2 million funding for Autism Plan, Government Website <https://www.gov.ie/en/press-release/4b6d68-minister-harris-announces-2-million-funding-for-autism-plan/>

¹³ <https://www.oireachtas.ie/en/debates/debate/dail/2019-11-14/32/>

¹⁵ AsiAm website (2020) Adam Harris Appointed To HSE Programme Board, Featured News, January 17th 2020, <https://asiam.ie/adam-harris-appointed-to-hse-programme-board/>

¹⁶ Newly set up Autism Advisory Council to work on National Autism Strategy, Malta Independent, 2nd April, 2018 <https://www.independent.com.mt/articles/2018-04-02/local-news/Newly-set-up-Autism-Advisory-Council-to-work-on-National-Autism-Strategy-6736187350>

Autism Advisory Council Activities

The Council's initial aim when it was established was to draft a national strategy on autism within the timeframe of a year as well as advising and assisting the government with a wide ranging number of objectives some of which include¹⁷:

- Developing and promoting a coordinated body of research;
- promoting vocational training and skills development programmes for persons within the autism spectrum;
- enhancing access to appropriate support services;
- formulating feasible, effective and sustainable intervention programmes;
- training for parents and other persons who work with persons within the autism spectrum;
- training for professionals ;
- empowering persons within the autism spectrum by providing for their health, education, well-being and participation in all aspects of society and the betterment of their living conditions; and
- encouraging early identification of children within the autism spectrum and providing early intervention services for children to achieve optimal participation in their home, school and locality.

Make-up of Autism Advisory Council members

The Council is composed of a Chairperson and eleven members who are divided into two categories:

(a) Eight 'Ex officio' members including the¹⁸:

- Director General (Health);
- Director General (Education);
- Director General (Social Welfare);
- Dean of the Faculty for Social Well-being;
- Dean of the Faculty of Medicine and Surgery;
- Dean of the Faculty of Education;
- Commissioner for the Rights of Persons with Disability; and
- Chief Executive Officer Agenzija SAPPOR (Social Services);

(b) Three 'other members' including representatives of non-governmental organisations supporting individuals within the ASD and their families, of which at least one should be an adult with autism.

¹⁷ Malta adopts its new Act for the empowerment of people on the autism spectrum, Autism Europe, 4th April 2018 <https://www.autismeurope.org/blog/2018/04/04/malta-adopts-its-new-act-for-the-empowerment-of-people-on-the-autism-spectrum/>

¹⁸ the Persons within the Autism Spectrum (Empowerment) Act, 2015, Maltese Government, 2016, <http://justiceservices.gov.mt/DownloadDocument.aspx?app=lp&itemid=27230&l=1>

The act also makes provision for individual working groups to be set up where necessary to progress certain parts of the act. The proposed autism strategy, which was due for publication in April 2019 is not available yet and there is limited publicly available information on how the work of the council has progressed to date.

3.6 France – Interministerial Delegation

The French government announced its National Autism Strategy in April 2018. A total of 344 million euros was set aside for implementation of the strategy between 2018 and 2022. The strategy revolves around five major commitments, as stated by the French government¹⁹:

- To put science back at the heart of public policy concerning autism by endowing France with research of excellence;
- To intervene as early as possible with regards to young children;
- Catch up with other countries in the area of education;
- Support the full citizenship of adults; and
- Support families and recognise their expertise.

In addition to developing a new strategy, the government also appointed an Interministerial Delegation to monitor and support the implementation of the strategy. The Interministerial Delegation is led by an Interministerial delegate, Claire Compagnon who reports to the Secretary of State to the Prime Minister responsible for People with Disabilities. The delegation also acts in close collaboration with the Secretary General of the Interministerial Committee on Disability. In addition to the Interministerial Delegate, the delegation team is made up of:

- A special adviser;
- A general secretary;
- A project manager;
- A communications officer; and
- A management assistant.

The role of the inter-ministerial delegate and her team is to monitor the implementation, at inter-ministerial level, of the national strategy and:

- Ensure its incorporation into associated ministerial policies;
- Consult regularly with service users, professionals and scientists;
- Coordinate the implementation of the strategy across all French regions;

¹⁹ French government announces its new autism strategy, Autism Europe, 19th April 2018

<https://www.autismeurope.org/blog/2018/04/19/french-government-announces-its-new-autism-strategy/>

- Respond to the needs of awareness raising, information and training;
- Propose necessary changes to ensure operational implementation of the National Strategy;
- Work in collaboration with individual ministerial departments to ensure each is progressing their relevant actions set out in the national strategy;
- Organise inter-ministerial management; and
- Guarantee progress towards achievements as well as adherence to milestones and deadlines set out in the strategy.

In addition to the establishment of the Interministerial Delegation, a '**National Council for Autism Spectrum Disorders (ASD) and Neurodevelopmental Disorders (TND)**' was set up to support the Interministerial Delegation with implementation of the strategy.

The council which meets every six months is composed of:

- Representatives from Autism charities that support service users and their families;
- Representatives of State and local authorities;
- Medical professionals; and
- Research bodies.

3.7 USA – National Autism Coordinator

The National Autism Coordinator is responsible for ensuring the implementation of national ASD research, services, and support activities across federal agencies. This role complements the activities of the Interagency Autism Coordinating Committee, which includes public and federal members, takes place in a public forum, and focuses on sharing information about ongoing activities and providing advice to the Secretary of Health and Human Services on issues related to ASD. ²⁰

Interagency Autism Coordinating Committee (IACC)

The IACC is a Federal advisory committee that coordinates Federal efforts and provides advice to the Secretary of Health and Human Services on issues related to autism spectrum disorder (ASD). Through its inclusion of both Federal and public members, the IACC helps to ensure that a wide range of ideas and perspectives are represented and discussed in a public forum. The IACC mission is to:

- Provide advice to the Secretary of Health and Human Services regarding Federal activities related to autism spectrum disorder;

²⁰ 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>

- Facilitate the exchange of information on and coordination of ASD activities among the member agencies and organizations; and
- Increase public understanding of the member agencies' activities, programs, policies, and research by providing a public forum for discussions related to ASD research and services.

IACC meetings are open to the public and include presentations and discussions on a variety of topics, including activities and projects of the IACC, recent advances in science and autism policy issues. A portion of each meeting is reserved for public comment.²¹

4. Conclusion

This research sought to identify whether any countries are using an independent scrutiny mechanism, such as an Autism Advocate, to monitor the progress of legislation or strategies aimed at improving services for people with Autism. In the course of the research several countries that has autism strategies and legislations in place were scrutinised including the jurisdictions within the UK, the Republic of Ireland, France, Denmark, Hungary, Italy, Malta, Bulgaria and Lithuania. Jurisdictions outside the EU namely, Australia, Canada and the USA were also explored.

The research was unable to identify any independent Autism Advocate/Commissioner type role fitting the criteria set out in the proposals for the Private Members Bill in any of the regions examined. However several countries 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.

²¹ <https://iacc.hhs.gov/about-iacc/overview/>