30 May 2022

Mr. Niall Brunell,

Department of Children, Equality, Disability, Integration and Youth,

Block 1, Miesian Plaza, 50 – 58 Lower Baggot Street ,

D02 XWI4

# Subject: Autism Innovation Strategy

Dear Niall,

The National Disability Authority (NDA) is the independent statutory body with a duty to provide information and advice to the Government on policy and practice relevant to the lives of persons with disabilities, and to promote Universal Design.

The NDA welcomes this opportunity to input to the public consultation to inform the design and development of the Autism Innovation Strategy and the opportunity to identify the particular challenges and barriers faced by people with autism which may not be fully addressed in current Government policy or strategies.

The NDA advises that it is important that the work of the Autism Innovation Strategy be framed within the United Nations Convention on the Rights of Persons with Disabilities and Ireland’s emerging arrangement to progressively realise its commitments under same. We also advise that due regard is given to Ireland’s existing Government policy on disability which has been based on mainstreaming and addressing access to services for all people with disabilities rather than different strategies for groups of people with particular disabilities. We note that some stakeholders have called for the development of a neurodiverity strategy (as opposed to an autism-only strategy). We would advise that while that would go some way towards recognising that an autism-only strategy may underestimate the degree of overlap with other disabilities it would be best to find some key actions that will make a significant difference to the lives of people with autism / neurodiversity and to see how those actions can be embedded within Ireland’s UNCRPD framework and within Ireland’s existing Government policy on disability.

We advise that the design and implementation of the Autism Innovation Strategy is progressed within the framework of the UNCRPD and Ireland’s existing Government policy on disability for a number of reasons. Firstly, many people with autism also have other disabilities. It is estimated that between a third and a half of people who have autism also have an intellectual disability[[1]](#footnote-1). About 70% of children with autism are estimated to have a mental health co-morbidity[[2]](#footnote-2). Studies are also emerging of co-morbid disabilities for people with autism as they age[[3]](#footnote-3). Therefore, it is without doubt that across many sectors there is a need to build capacity around autism awareness but it will be important that those providing support or supporting accessing to a service have an understanding of autism but also a broader understanding of disability.

Secondly, care will need to be taken that the Autism Innovation Strategy does not move away from the social model of disability. In the social model of disability the focus is on removing the physical, social and attitudinal barriers which restrict people exercising their right to access services and living an ordinary life in the community regardless of their specific disability. It is therefore important in the context of the social model of disability that the Autism Innovation Strategy is seen to focus on building the knowledge base and capacity to further remove these barriers faced by people with autism rather than being perceived to be focusing on a particular disability.

Finally, many Departments and state agencies who will have responsibilities under any new Autism Innovation Strategy will have similar implementation and reporting responsibilities under other disability related strategies including the National Disability Inclusion Strategy and the Comprehensive Employment Strategy for People with Disabilities. Therefore, if the Autism Innovation Strategy is too far removed from the UNCRPD and Ireland’s existing Government policy on disability it risks resulting in duplication of effort and more reporting, perhaps diverting focus from implementation.

It should be noted that under the National Disability Inclusion Strategy there was a Programme of Actions on Autism developed (signed off by the Cabinet sub-committee on Social Policy in 2015). It should be noted that this Programme of Actions was developed based on research and policy / provision mapping and it was informed by consultation with autism stakeholders, including some consultation with adults with autism. The NDA was assigned a number of actions under the Programme of Actions on Autism. For example, we developed the following guidance targeted at sectors identified in the mapping and consultation:

* NDA (2018) Assisting People with Autism: Guidance for Justice Professionals
* NDA (2018) Assisting People with Autism: Guidance for Local Authority Housing Officers
* NDA (2018) Assisting People with Autism in Employment: Guidance for Line Managers and HR Professionals
* NDA (2017) Models of good practice in effectively supporting adults with autism

These guidance documents and other NDA publications on autism are available at <https://nda.ie/publications/disability-supports/autism/>

We believe that while the above documents did raise awareness of the issues around autism in some key sectors where there had been no previous guidance we have no evidence about whether or not they have had lasting impact on how people with autism experienced engagement with organisations and professionals in those areas. Moreover, it is unclear whether progress was ever made on some of the other actions in the Programme of Actions on Autism by other named public bodies. Therefore, while the Programme of Actions on Autism shows that knowledge and capacity building actions (based on gathering evidence and consultation with people with autism) were developed within the framework of the National Disability Inclusion Strategy it also shows that some of those actions appear to not to have been progressed.

Therefore, the NDA advises that a key consideration for the Autism Innovation Strategy will be to find an approach to developing and monitoring the implementation of actions focused on building knowledge and capacity around autism that both fits within the UNCRPD and Ireland’s existing Government policy structures but also ensures that those actions don’t get lost within the wider set of UNCRPD / NDIS actions.

Separate to the questions about structure, the NDA advises that it may be useful for the Oversight and Advisory Group to establish what actions from the Programme of Actions on Autism were progressed and which weren’t and to seek answers as to why those actions weren’t progressed. The background papers such as the mapping and consultation reports can also be made available.

Set out below are some areas where the NDA suggests, based on our research and engagement with people with disabilities, need to be progressed to address concerns raised frequently by autism stakeholders. In keeping with the points made above most of these areas relate to issues that are not unique to autistic people.

## Early Education and Care / AIM

* The 3 year Evaluation of AIM will be published in the coming months. It is likely to have some recommendations around children with autism in mainstream early education and care. The publication of the Evaluation will also prompt questions about the ongoing provision of (Department of Education funded) Early Intervention Classes and the remaining HSE funded special pre-schools (some of which children with autism attend). Therefore, there is likely to be a need for a plan to build autism knowledge and capacity among Early Education and Care professionals.

## Progressing Disability Services

* The Programme of Actions on Autism contained a commitment to evaluate the Progressing Disability Services model. The NDA understands that the evaluation was put off until the model was fully implemented. Now that there are Disability Network Teams in place across the country the NDA advises that it would be appropriate to evaluate the Progressing Disability Services model to see how it is meeting the needs of all children with disabilities (including autism) and their families[[4]](#footnote-4).
* Any evaluation of Progressing Disability Services is likely to show up that many of the Disability Network Teams do not have the capacity to meet demand. The need for more therapists has been demonstrated by previous work by the NDA[[5]](#footnote-5), HSE with assistance from the NDA[[6]](#footnote-6) and Department of Health[[7]](#footnote-7). The NDA understands that there is work being progressed by the Department of Health and the Department of Further and Higher Education to increase the supply of therapists. The NDA advises that an action around supply of therapists should be included in the Autism Innovation Strategy. In addition to the supply issue it will be important that initial and ongoing training for therapists reflects the changed context of working with children with disabilities, including children with autism, so that therapists are comfortable working in inter-disciplinary teams and working indirectly with children through building school and teacher capacity.

## School places and school inclusion

* Recent years has seen a very steep rise in the number of special classes, many of them to meet the demand for special class places for children with autism. Despite the rapid increase in the number of special classes being opened, the introduction of 37A of the Education Act 1998 (as inserted by Section 8 of the Education (Admission to Schools) Act 2018) and improvements in the Department of Education and the NCSE’s process to estimate and plan for new special classes meeting demand has proved to be challenging.
* The rapid increase in special class places has taken place despite the absence of evidence (to either support or refute the position) that children with disabilities, including children with autism, have better social and education outcomes in mainstream or special classes. The ratification of the UNCRPD, the publication of the NCSE Policy Advice on the Future Role of Special School and Special Classes and the review of the EPSEN Act mean that over the next few years there will be an opportunity to shape the vision of inclusive education policy in Ireland for coming decades. The NDA suggest that the Autism Innovation Strategy provides an opportunity to include some actions which could contribute to shaping that vision of inclusive education which would maximise the potential of children with autism to progress through the school system on to employment, further and higher education and training options that most suit them.

## Assessment of Need under the Disability Act / autism diagnostic assessments

* The challenges posed by Part 2 of the Disability Act have had a significant impact on the capacity of services to provide intervention to children with disabilities, including children with autism. Delays related to operating Assessment of Need under the Disability Act have meant that some families have faced lengthy delays in receiving a diagnosis of Autism which is still required to access certain supports (for example Special Schools and Special Classes) and many parents feel that a diagnosis is very important to them to help them understand their child’s needs. The implications of recent court decisions mean that the challenges of conducting assessments (in line with the Court’s interpretation of the Act) within the statutory timeframes will potentially be even more challenging. The NDA is concerned that the operation of Assessment of Need under the Act is contributing to delayed intervention for children despite the HSE’s efforts to streamline the process. The NDA is of the view that Part 2 of the Disability Act should be reviewed (ideally in parallel to the review of EPSEN). Therefore, the NDA advises that an action under the Autism Innovation Strategy could be for some research on systems of assessment and intervention for children with disabilities, including autism, in other jurisdictions to inform a future review of Part 2.
* To ensure that scarce clinical resources are best utilised a standardised approach to autism diagnostic assessments (whether or not children are assessed under Part 2 of the Disability Act) should be agreed between the HSE and relevant professional bodies. In line with the HSE 2018 review of autism services[[8]](#footnote-8) this should be a tiered approach to assessment whereby the intensity of a diagnostic process is determined by the complexity of presenting issues and clinicians’ judgement.

## Assessments and services for adults with autism

* As noted above the NDA undertook a piece of research on service provision for adults with autism (NDA (2017) Models of good practice in effectively supporting adults with autism) which looked at the support needs of adults with autism who did not have an intellectual disability. While the report found that there was a lack of evidence around the optimal configuration of services and the most effective and efficient supports that are required to ensure that adults with autism without an intellectual disability can live as independent and fulfilling a life as possible it did highlight the need for such services to be developed. The report also highlighted the lack of a clear pathway to diagnosis and assessment for adults with autism. The NDA advises that the Autism Innovation Strategy could look to pilot and evaluate some of the models of service provision identified in the 2017 report. Similarly it is important that a clear pathway to diagnosis and assessment for adults with autism are developed and communicated to key health and social care personnel such as GPs and mental health professionals.

## Review service models

* People with autism and their families can sometimes feel that they are slotted into services that were developed with a different population in mind. For example, children with autism can be offered respite in services which were originally developed to meet the needs of children with other disabilities. With increased demand for disability supports from families with autistic children there is a need to reflect on whether the model of respite, for example, is meeting the needs of the child with autism and their family or whether there is a way of configuring respite which better meets their needs. The NDA advises that the Autism Innovation Strategy identifies some key disability services areas which have become increasingly used by people with autism which should be reviewed against best practise in meeting the needs of children / adults with autism.

## Consultation

* Articles 4(3) and 33 of the UNCRPD require people with disabilities through their representative organisations to be involved with the development of policy and in the implementation and monitoring structures for the UNCRPD. While many Department and agencies may have built up a certain level of knowledge around making consultation processes accessible to disabled people this could be built upon. The NDA will shortly publish our revised Ask Me Guidelines which will support Departments and agencies to plan for accessible consultation processes. Building on this work the NDA advises that Autism Innovation Strategy could include capacity building in key Department and agencies on accessible consultation processes with a particular focus on including autistic people in such consultations.

## Data

* The Department of Health 2018 Report **Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish Population** highlighted theneed for more accurate data on autism prevalence. Challenges around the provision of special school and class places highlights the difficulties which not having accurate data can create (though the NDA acknowledges that there are many other factors at play in providing special school and class for children with autism). Recent changes in the Health Research Board’s disability database (replacing the National Physical and Sensory Disability Database and the National Intellectual Disability Database with the National Ability Support System [NASS]) means that it now has more potential to capture data on autism. The planned introduction of a common information system (Children’s Disability Network Team Information Management System) across all Disability Network Teams, which has the potential to link with the HRB’s NASS could contribute significantly to the availability of more comprehensive and timely data on support provision and unmet need for children with autism. The NDA advises that an action around expediting the rollout of the Children’s Disability Network Team Information Management System and linking it the HRB’s NASS would be important for the Autism Innovation Strategy.

## Participation on the Oversight and Advisory Group

As noted above the NDA has developed a number of pieces of guidance on autism aimed at personnel working in key areas where people with autism may require support or particular accommodations. The NDA has undertaken and funded research in areas such as models of support provision for adults with autism (without a concurrent intellectual disability) and the support requirements for people with autism experiencing homelessness. The NDA plays an important role in supporting and assessing progress in relation to a number of cross-Departmental structures such as the National Disability Inclusion Strategy and the Comprehensive Employment Strategy and would be willing to support the work of the Oversight and Advisory Group through the development of guidance, research, consultation and our facilitation role.

 Yours sincerely,

**Dr. Aideen Hartney, Director, National Disability Authority**

1. Department of Health (Estimating Prevalence of Autism Spectrum Disorders (ASD) in the Irish

Population: A review of data sources and epidemiological studies). [↑](#footnote-ref-1)
2. Crow, B. and Salt, A. (2015) “Autism: the management and support of children and young people on the autism spectrum (NICE Clinical Guideline 170)”, **Archives of Disease in Childhood - Education and Practice**. 100/1, pp20-23 [↑](#footnote-ref-2)
3. Miot, S. et al (2019) Comorbidity Burden in Adults With Autism Spectrum Disorders and Intellectual Disabilities-A Report From the EFAAR (Frailty Assessment in Ageing Adults With Autism Spectrum and Intellectual Disabilities) Study. **Front Psychiatry** September 2019; 10:617. [↑](#footnote-ref-3)
4. Assessment of Need under the Disability Act, 2005 will be discussed further below. [↑](#footnote-ref-4)
5. NDA (2015) **Children’s Disability Services in Ireland**. https://nda.ie/publications/health/health-publications/children%E2%80%99s-disability-services-in-ireland.html [↑](#footnote-ref-5)
6. HSE (2018) **Transforming Lives - Working Group 1 Report on Future Needs for Disability Services**. https://www.gov.ie/en/publication/4b75a-transforming-lives-working-group-1-report-on-future-needs-for-disability-services/ [↑](#footnote-ref-6)
7. Department of Health (2021) **Disability Capacity Review to 2032 - A Review of Social Care Demand and Capacity Requirements to 2032**. https://www.gov.ie/pdf/154163/?page=1 [↑](#footnote-ref-7)
8. HSE (2018) **Report of the Review of the Irish Health Services for Individuals with Autism Spectrum Disorders**. https://assets.gov.ie/10708/33f312f0421443bc967f4a5f7554b0dd.pdf [↑](#footnote-ref-8)