



**MEETING TO DISCUSS THE FINDINGS OF THE NATIONAL AUTISM PROJECT AND THEIR RELEVANCE TO THE LIVES OF AUTISTIC PEOPLE IN NORTHERN IRELAND**

Tuesday 28<sup>th</sup> November 2017

D2 Conference Room, Castle Buildings, Stormont Estate, Belfast

**Attendees**

**NAP Delegation**

Kerry Boyd (Autism NI)

Claire Burke (autistic advocate)

Kelly Maxwell (Autism NI)

Ian Ragan (National Autism Project)

Shirelle Stewart (National Autistic Society NI)

**NI Departments/agencies**

Carol Carser (Department of Justice)

Frances Curran (Department of Education)

Robert Heyburn (Department for Communities)

Chris Matthews (Department of Health)

Alison McCaffrey (Department of Health)

David Nugent (Department of Health)

Joy Peters (Health and Social Care Board)

Heidi Rogers (Department of Health)

Sean Scullion (Department of Health)

**Background**

*The National Autism Project's report 'The Autism Dividend: Reaping the Rewards of Better Investment' had been launched in London, Cardiff and Edinburgh in January and February 2017, but the planned launch in Belfast had been postponed because of the political uncertainty of the time. Nevertheless, Ian Ragan and Arlene Cassidy (then CEO of Autism NI) had continued to consider holding a meeting with civil servants in the NI government at a later date, to look at the report and its subsequent impact. The Department of Health was open to this, and Chris Mathews and Sean Scullion deserve many thanks for arousing the interest of colleagues in their own and other government departments to attend and for generously offering to host the meeting. Thanks also to Arlene Cassidy for her persistence and for preparing the accompanying briefing document, which was based on similar documents that had been used in meetings with government departments in London. Finally, thanks to Kerry Boyd and Claire Burke for presenting their perspectives on autism in NI.*

*This report has been prepared by Ian Ragan with input from several of those attending the meeting.*

Alison McCaffrey welcomed attendees to the event, and explained that it had been organised to allow Government Departments in NI the opportunity to be briefed on the findings of the NAP Report, 'the Autism Dividend'. She outlined the current policy context for ASD in NI, and welcomed

CHAIR OF STRATEGY BOARD  
Lady Elizabeth Vallance JP PhD

DIRECTOR  
Dr C Ian Ragan



the representation from other Departments at the event which reflected the cross Government approach taken in NI to delivering on the aims of the Autism Act 2011.

**Ian Ragan introduced the National Autism Project (NAP) explaining that it was a 3 year project funded by The Shirley Foundation to tackle the continuing failure to address the needs of autistic people in the UK.**

Ian explained that, since the economic impact of autism on the UK economy is £32 billion per annum, much of which is opportunity cost, the project aimed to identify and promote evidence-based and cost-effective practice that would address the needs of autistic people and reduce costs by spending more wisely. It was hoped that this “Autism Dividend” would appeal to cost-conscious policy makers.

During his presentation, Ian made the following key points:

- The report identified several areas for cost-effective improvements to practice but found that the evidence-base was not nearly as thorough as it should be and that evidence on cost-effectiveness was particularly thin. Even so, much could be done with current evidence, and the report calls on policy-makers and service providers to always consider the feasibility, affordability and cost-effectiveness of practice. It may seem obvious, but the economic case is not always made.
- Attempts to change practice have, of course, been limited by the political instability of the UK over the past two years and NAP largely abandoned efforts to reach up to ministerial level. However, work has continued to promote the findings among members of both Houses of Parliament in London, and with civil servants. There is a tendency for policy makers to quote policy when responding to complaints about lapses in practice. But these are often not deficiencies in policy but in implementation. Therefore much time has been invested in unearthing specific examples of such lapses which have been differentiated according to the responsible government department. Examples include Transforming Care, excessive school exclusions, overuse of restraint, poor access to mental health services and underemployment. It has also been necessary to differentiate according to nation (as has been done for NI) where responsibility for both policy and implementation has been devolved from central government in London. In doing this, five recurring areas were identified that can impact on support: the lack of autism-specific data in health records, the lack of a specific autism identity in the minds of service providers, the lack of evidence-supported practice, poor training of professionals dealing with autistic people and the lack of adequate research to support good practice.
- On the latter area, the project made a number of recommendations for research topics and called on research funders to increase their current unjustifiably tiny investment in autism research. Ian Ragan pointed out that past research priorities had focused on basic biological understanding of autism and on early interventions, and that social research on the needs of autistic adults had been particularly neglected or was of poor quality. There was a real need for top-down incentives to encourage movement of researchers into this latter area, where research findings could be readily translated into immediate benefits for autistic people. Such research need not be particularly costly and could just involve systematic data collection on the impact of ongoing interventions.



- Finally, Ian Ragan described the evolution of NAP in 2018 into the NAP Legacy Forum and the National Autistic Taskforce. The latter is an independently funded project (again by The Shirley Foundation) designed and led by autistic people. This unique body will address the needs of those autistic people who lack an effective voice – for example, those autistic adults in residential care who have little autonomy and higher support needs. The group will also aim to develop and establish a community of practice that can genuinely contribute to transforming care.

**Kerry Boyd spoke to the briefing document which assessed the issues in NI according to the five areas mentioned above. Kerry's key points are summarised below.**

- The lack of robust data collection has an adverse impact on support for families, and NI needs an anonymous National Care Primary register for autism, robust local data collection of autism populations and the introduction of autism specific indicators in Health & Social Care accountability frameworks. The recent recommendation by NICE for GPs to develop a national autism register as part of the quality outcomes framework was welcomed and it is hoped that GPs in NI will follow suit.
- Lack of guidance on evidence-supported and cost-effective educational practice leads to disputes, lack of reasonable adjustments, and exclusions. Health and Education should provide comprehensive information on educational practice but at present, there is no systematic data collection, information is not fed through and there is no evaluation of the effectiveness of practice. There needs to be a review of children's and adults' social care eligibility, as evidence from local authority self-assessments in England is that only a minority of eligible people receive support. All autistic children moving to adult services should receive transition assessments at age 14, including personal plans and circles of support.
- Kerry agreed that the creation of an autism identity would be useful. Autism does not fit into other categories such as mental health or learning disability, and establishing an autism identity would be helped by increasing the number of psychologists with specialist autism knowledge. In schools, better appreciation of autism is needed to successfully implement the reasonable adjustments which are required under the Autism Act (NI) and for improved IEPs.
- Better training is fundamental for improving service delivery, whether in education, employment, health, benefits assessment or the criminal justice system. In education in NI, there seems little government investment in autism training for teachers as many undertake this at their own expense. In the employment sector, a programme focused on the positive impact of autistic people in the workplace would help to counter-balance existing perceptions. Current training in "autism awareness" tends to be cursory and focused on the theoretical (what autism is) rather than the practical (how to understand autistic people). Autistic people should be involved in the design, content and training to ensure that autistic needs are met. Recognised independent formal accreditation through an approved independent agency would raise standards.



- Finally, on research, the Ulster University Autism Research Hub was established in partnership with Autism NI on the recommendation of the NI Autism Strategy. However, it is not supported by any direct government funding and is independent, free of influence and agenda promotion. It is overseen by a group of multi-disciplinary academics and researchers. The Hub's aim is to identify and enhance trans-disciplinary expertise in autism research and the translation of research into practice.

**Claire Burke presented a personal account of living as an autistic adult in NI and what she perceived as the most pressing needs. Her views coincided exactly with those presented by Ian and Kelly.**

- Claire received a late diagnosis of autism and was unaware of the existence of adult services. She queried whether there are good quality data on adult provision including basic facts such as diagnosis and prevalence.
- She stressed the importance of early intervention to maximise life chances and supported more research on their effectiveness i.e. their benefit to autistic children. Interventions must be personalised and take account of the co-occurring conditions so prevalent among autistic people.
- Better autism awareness is needed across the board, with the emphasis on the practical not the theory. Autistic involvement is essential for design and delivery of training and Claire mentioned her involvement with training in the CJS. There is also a great need for more autism-trained specialists in the health sector.
- Employers need to make reasonable adjustments and Claire stressed the advantages that autistic people can bring to the workplace, even those who are not high functioning.
- Although autism is not in itself a mental health disability, Claire made clear that the challenges and problems it presents can be debilitating and incapacitating, in particular the anxiety and difficulties of dealing with the outside world. She was aware that many do not like to refer to autism as a mental health condition, but sometimes there is no other 'label' that can be used. The incapacity caused by dealing with outside world cannot really be seen as anything other than mentally debilitating.

**Discussion points**

In the ensuing discussion, the following points were made:

- Health and education need to work together more effectively, one of the recommendations of the Autism Dividend. After diagnosis it can be years before an education path has been established. Advice and guidance needs to be improved and a review of children's services should be undertaken.
- Frances Curran spoke about the excellent training programmes of the Middletown Centre for Autism. However, it cannot meet all needs such as training in the school environment to deal with individual problems. Shirelle Stewart agreed that there was some excellent



training available; however this training was not mandatory so teachers were not obligated to undertake it. This needs to change.

- Kerry Boyd also acknowledged the work undertaken by Middletown; however, she also highlighted the huge number of ongoing requests received via Autism NI's Helpline in relation to lack of support for pupils with autism, particularly in mainstream education. She went on to explain that teachers have reported that they have not been sufficiently trained in autism strategies to work with pupils on the autism spectrum. Kerry also stated that this was confirmed within a recent statement from the general secretary of the Ulster Teachers' Union, Avril Hall-Callaghan, who said "pupils were still not getting the support to which they were statutorily entitled" and that "with a higher proportion of ASD children being excluded and suspended, there was a need for mandatory funded training".
- Frances Curran advised that the Education Authority also provides autism training. Each school should identify the CPD needs of staff within its school development planning process and produce a training and development plan appropriate to the needs of their school and pupils. Teachers also have access to 'A Resource File for schools to support children with SEN', which includes a chapter on autism, written by specialist practitioners, outlining effective strategies and resources available.
- There is a lack of provision and support for autistic children and adults with complex needs which can result in behaviours that others find challenging (NB NAP prefers the term 'stress behaviours'). The lack of provision means that some children and adults with complex needs are sent to other parts of the UK or the South of Ireland to access the support they need.
- The NAP view is that restraint is greatly overused for autistic children and adults and the need can be much decreased by better training in understanding autism and what leads autistic people to display stress behaviours.
- The potential impacts of the welfare reform assessment process on individuals with ASD, particularly in relation to PIP, were also discussed. Concern was expressed that the benefit assessment process has a disproportionate focus on the negative aspects of an individual's condition, which can be a disempowering and demoralising experience for individuals, with consequent negative impacts on their mental health. It was also noted that it is important for the assessment process to take due account of the support provided to individuals by their informal carers, as this can potentially influence an individual's assessment of their own capabilities, which in turn may lead to a very different benefit entitlement assessment than the individual's actual circumstances and assistance levels merit.

Alison McCaffrey concluded the meeting by thanking Ian, Kerry and Clare for their presentations, and Departmental colleagues for their attendance and contributions to the discussion. It was agreed that it would be beneficial for NI to be kept informed of the work of the NAP through its new Legacy Forum and the National Autistic Taskforce.