

## **Autism in Northern Ireland: The contribution of research and evaluation**

### **A briefing paper to the NI Assembly Health Committee from Professors Laurence Taggart and Roy McConkey, Ulster University**

Our thanks to the Committee for the opportunity to highlight our support for the Autism (Amended) Bill (NIA Bill 31/17-22). We congratulate the Assembly on passing the original Bill which at the time was the most comprehensive piece of legislation relating to Autism in these islands. In the intervening 10 years, a great deal of further learning has been accumulated locally and internationally regarding how the needs of children and adults with Autism can be effectively and efficiently met. In particular, we want to highlight the contribution that research and evaluation has made to this.

#### **Evidence-based practice**

We especially support the proposal to have an independent Autism Reviewer as we see this as a key vehicle by which evidence-based practice can be consolidated within health, social care, and educational supports in Northern Ireland. This is essential to furthering the Executive's Transformation of Health and Social Care Services, ensuring more cost-effective use of existing resources and helping to guarantee that new resources are applied to more timely, local and efficient new forms of service delivery.

#### **Northern Ireland Research into Autism.**

Since the late 1990s, a series of research and evaluation studies were conducted by Ulster University in conjunction with HSC trusts and voluntary providers. These resulted in improved assessment and diagnostic practices, family-based early interventions strategies, training courses for families and practitioners and innovative 'wrap-around' community supports for transitions to adulthood. However, the uptake of these insights was variable across HSC trusts and non-statutory providers. A listing of projects and publications is given in an Appendix.

An Autism Hub was established within the Centre for Intellectual and Developmental Disabilities at Ulster University (leader Prof Taggart) to bring together practitioners from multiple disciplines who identified future research priorities and instigated a number of projects. The Department of Health established a Northern Ireland Autism Strategy Research Advisory Committee (NIARAC); chaired by Dr Arlene Cassidy of which Prof McConkey was a member. However, their work was temporarily paused by the DoH in March 2018 and has not been resumed. This is very regrettable.

#### **Recent research in prevalence of autism in Northern Ireland.**

A recent analysis of the school census data collected in the four UK nations has enabled comparison to be made of the numbers of pupils identified as being on the Autism Spectrum. The steady increase in numbers from 2011 to 2019 occurs in all the nations but Northern Ireland consistently has the highest prevalence rates: reaching 3.20% by 2018/19 compared to 1.92% in Wales (McConkey, 2020). A further analysis of the census returns in Northern Ireland showed that Belfast, Northern and South-East areas had markedly higher rises and prevalence rates than Southern or Western areas. In all areas, pupils living in locations with greater social deprivation had higher rates of ASD. This information was shared with the DoH in October 2017 through NIARC.

The variation in a small region such as Northern Ireland, is suggestive of inefficiencies within the systems but this does not appear to be currently being addressed. An Autism Reviewer would help to

ensure that research is undertaken into these unacceptable and potentially inequitable variations. In particular, an urgent examination of the costs of involved in the provision of assessment and diagnostic services across the five Trusts is needed and their operating procedures.

### **Post-diagnostic support**

Parents across the UK are not satisfied with the support they receive after their child is diagnosed as being on the Autism Spectrum. Northern Ireland is no different (Broken Promises Report, 2017) but attempts have been made to address this. Three innovative projects funded by the Big Lottery and undertaken by AutismNI, Cedar Foundation and Positive Futures provided home-based, family-centred post-diagnostic support to children and families from 2017 onwards. Detailed evaluations of the outcomes for children and families were made and these have been reported in international, peer-reviewed research journals. HSC Trusts referred around 800 children with the assumption that if the services proved effective, the Trust would assume the running costs. This has not happened, and the projects have been or soon will be suspended. Even when evidence is presented to justify the costs and outcomes of the service it is not acted upon whereas existing provision continues even when it is not evaluated, or the costs determined. A Research Reviewer could call commissioners and providers to account.

### **Transitions to adulthood**

The growing number of children identified on the Autism Spectrum will invariably mean an increase in the number of adults with the condition who will need support, notably in further education, vocational training, employment and leisure pursuits. A report commissioned by the HSC Board in 2010 highlighted the need for action but many of the recommendations have yet to be implemented. Of particular concern is the increased mental health issues experienced by teenagers and young adults and the long-waiting times to receive professional help. A project undertaken in the WHSC Trust by Cedar Foundation with support from the adult ASD team, has demonstrated the impact that a person-centred, low-cost intervention can make and the potential for preventing more costly interventions being needed (McConkey et al, 2021). A research reviewer would help to ensure that good practice is shared across Northern Ireland with 'preventative' projects having a priority rather than investing still more money in secondary and tertiary provision as currently happens.

### **Developing an ethos of evidence-based practice.**

The Research Reviewer as the NI Champion for Autism will be strengthened by being underpinned by legislation. However, the role would be enhanced by the Department reviving the Research Advisory Committee with nominees from universities, PHA, Trusts and the community and voluntary sector.

The R&D Office (NI) could assist in funding research and development projects or signposting applicants to NIHR and UKRC funding streams. Transnational research projects can be especially insightful.

The NI Assembly Research and Information Service (RaISe) could hold copies of pertinent research and evaluations reports for Members to access and also could be commissioned by Assembly Members to collate information relating to issues raised the Research Reviewer.

**In sum, the amended Bill has the potential to re-boost more effective and efficient services to people on the Autism Spectrum. We know what needs to be done, we know what could be done but the basic problem is that it not being done.**

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