## PE1704/E

Scottish Government submission of 30 October 2018

The Committee can be assured that the Scottish Government is committed to improving the lives of autistic people in Scotland. Firstly, following an engagement exercise last year the Scottish Government published a comprehensive analysis of that engagement <sup>1</sup> and refreshed its priorities they were published in March 2018<sup>2</sup>. This publication was jointly agreed with Ministers and COSLA. It is recognised that a concerted effort across all sectors is required. Secondly, in the Programme for Government we reiterated our commitment to transforming the lives of autistic people and addressing the inequalities, they can face throughout their lives. The refreshed priorities focus on ensuring people with autism live healthier lives, have choice and control over the services they use, and are supported to be independent and active citizens. We are committed to delivering those priorities by 2021.

There have been a number of tools and resources developed through the strategy to support local practioners right across statutory and third sector bodies in Scotland and these are highlighted where relevant in this response.

In terms of the Petition target that every person in Scotland going through an autism diagnostic procedure will be assessed within a calendar year and receive a statutory services assessment from a qualified social worker as an integral part of this process, within twelve months from the date of their initial referral.

Diagnostic waiting times have always been a challenge for NHS Boards and since 2011; there have been strategy investments in NHS Boards to improve diagnostic waiting times. This continues to be a challenge in terms of capacity and resource. Initiatives have included the development and the sharing best practice in child diagnostic pathways and the development of an adult neurodiversity pathway. Strategy investment has gone into training in diagnostic assessment tools such as DISCO and ADOS. In partnership with NHS NES, we fund an Autism Training Team who developed the ASD Training Framework<sup>3</sup> - detailing the knowledge and skills required at different levels within the workforce to achieve key outcomes for people with ASD. The Training Plan <sup>4</sup> outlines the training that is needed to fulfil the requirements of the NHS Education for Scotland Autism Training Framework by (i) identifying currently available training; (ii) identifying gaps in training provision, and, where appropriate, (iii) guiding the commissioning or development of appropriate training.

The Scottish Government has committed to continue to work with NHS Boards and special boards to build the knowledge of autism amongst staff to improve access to services for autistic people and reduce waiting times by sharing improvement initiatives and sharing best practice through Improvement Programmes and the Autism Knowledge Hub. There has been no specific discussions on a waiting times target but a recognition that varying waiting times across Scotland are too long and should be improved. There is a recognition that this can't be achieved solely by one strategy and that work across government is required to

<sup>&</sup>lt;sup>1</sup> <u>http://www.autismnetworkscotland.org.uk/files/2018/04/The-Scottish-Strategy-for-Autism-Engagement-Analysis.pdf</u>

<sup>&</sup>lt;sup>2</sup> <u>https://beta.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/</u>

<sup>&</sup>lt;sup>3</sup> <u>http://tailoredfoundation.co.uk/wp-content/uploads/2014/12/NHS-Education-for-Scotland-Autism-Training-Framework-Optimising-Outcomes.pdf</u>

<sup>&</sup>lt;sup>4</sup> http://www.knowledge.scot.nhs.uk/media/9595218/asd%20web%20final%20%282%29.pdf

make the necessary improvements in services for example Mental Health services, including CAMHS.

The Scottish Government commissioned Dame Denise Coia to lead a Child and Young People's Mental Health Task Force<sup>5</sup> to consider a programme of work to improve MH services. It is expected the needs of autistic children and young people will be considered in this programme of work.

The Scottish Intercollegiate Guidelines Network has also produced a renewed autism guideline. The guideline provides recommendations for best practice in the screening, surveillance, diagnosis, assessment and clinical interventions for children and young people with ASD. NHS Boards should be following these guidelines in delivering autism services. It also incorporates evidence and recommendations on assessment, diagnosis and interventions for adults with ASD. The guideline will be of interest to healthcare professionals and other multiagency colleagues who work with children and adults with ASD, as well as people with ASD, their parents, carers, relatives, partners and others with whom they interact.<sup>6</sup>

The Patient Rights (Scotland) Act 2011 gives everyone receiving NHS services the right that the health care they receive will consider their needs, consider what would most benefit their health and wellbeing, encourage them to take part in decisions about their health and wellbeing, and provide them with the information and support to do so. The <u>Charter of</u> <u>Patient Rights and Responsibilities</u> says: You have the right to have your needs taken into account when receiving NHS services -

- Your Health Board must take account of your needs when providing health services.
- However, your Health Board must also consider the rights of other patients, clinical judgement and the most efficient way to use NHS resources.

The diagnosis of autism spectrum disorder is based on a clinical assessment. NHS Boards refer through different local pathways, some people with autism and a learning disability are assessed through Learning Disability Services, and in some Boards specialist autism diagnostic services are available and in some appropriate referrals are made to Mental Health (MH). MH services are clinically triaged according to severity and risk and go onto a waiting list to see an appropriate mental health professional. The referrals that go to a specific autism mental health service may have a standardised assessment that differs from the more generic mental health assessment done in a community mental health team or indeed a primary care team. There is no one size fits all – so applying an assessment standard of within a calendar year does not make clinical sense. All appropriate and accepted referrals to a community mental health team would be normally seen in a matter of weeks. Referrals for psychological therapies are subject to an access standard of 90% within 18 weeks and this is monitored centrally by ISD.

Whilst Scottish Government provides NHS Boards with the tools and resources to deliver autism diagnostic services in Scotland how those services are delivered in terms of, waiting times for diagnosis are the responsibility of the Health and Social Care Partnerships.

Autism spectrum disorder represents a spectrum of need and complexity – with some severe disabled people at one end and others who function well with minimum difficulty. Social work

<sup>&</sup>lt;sup>5</sup> <u>https://www.gov.scot/Publications/2018/09/9044</u>

<sup>&</sup>lt;sup>6</sup> https://www.sign.ac.uk/sign-145-assessment,-diagnosis-and-interventions-for-autism-spectrum-disorders.html

worker assessment is not appropriate, nor necessary for many so it would be inappropriate to make it a requirement of autism spectrum assessment and management.

Work is underway to look at adult social care reform and in that programme of work in terms of the gap between referral and assessment, we have been offering limited support of a Health Improvement Scotland member to work with the Community-led Support areas. As part of wider work aimed at improving their systems, the four sites in Scotland currently) have seen:

- Reduced waiting times e.g. between first contact and an initial (first) conversation and between that conversation and accessing support of some kind;
- Reduced waiting lists i.e. numbers of people waiting to be seen/accessing support;
- Devolving financial decision making to community teams and front-line practitioners within agreed parameters leading to timely decisions
- A link between more people using different access points (including community hubs and drop ins), reduced waiting times/lists and quicker access to support;
- Holistic solutions as community teams pool expertise and information to offer, for example, friendship groups and social activities alongside mobility aids and carers' support;
- The same or lower cost of providing different services (e.g. community vs acute, different support options) with better outcomes for people.

Given these outcomes, we hope to increase that capacity to another four local authorities next year.

Whilst Social Workers would not be involved in diagnosis they do have the responsibility to assess needs and to care plan and to arrange care where needed – including Self Directed Support. This responsibility is identified in the Community Care and Health (Scotland) Act 2002, Self-Directed Support (Scotland) Act 2013, the Children's (Scotland) Act 1995 and the Children & Young People Act 2014. The primary legislation for all of this is the Social Work (Scotland) Act 1968. It is the responsibility of Health and Social Care Partnerships to undertake assessments of need and make care plans, where necessary.

In terms of the Petition target that children with autism in mainstream schools will have their assessed needs for classroom support met by an ASL assistant with a recognised autism qualification as part of a mandatory registration process for ASL professionals.

Children with autism in mainstream schools will have their assessed needs for classroom support met by an ASL assistant with a recognised autism qualification as part of mandatory registration for ASL professionals. We are clear that for children to get the right support in school it is important that their individual needs are known and understood. To support this, needs assessment for pupils is a part of their day-to-day learning and teaching in schools. This starts in ELC and continues throughout a child or young person's time in school. This should not be a one-off activity, but a process of gathering information to get a picture of a child's progress. There is currently no recognised autism qualification for teachers to complete. All teachers provide support to pupils not just 'support for learning' teachers. Assessment is carried out by teaching and support for learning staff in school. Although for most pupils, assessment is part of day-to-day learning in school, some pupils may have more complex needs with parents or professionals identifying that a more in-depth type of assessment or examination is needed. In this case, a specific assessment or examination may be needed, involving teachers, parents and carers, as well as professionals.

Student teachers training in Scottish universities are training to achieve the Standard for Full Registration (SFR) and therefore to be registered with The General Teaching Council for Scotland as the independent, regulatory body for the teaching profession and has the legislative functions of regulating and being the custodians of the suite of Professional Standards for teachers. The SFR specifies what is expected of a teacher who has successfully completed their teacher education course and is defined in terms of benchmark statements. These statements also specify the design requirements for programmes of teacher education provided in universities. One of the expected features of the SFR at 3.1.4 "Professional Skills and Abilities" is that "Registered Teachers identify effectively barriers to learning and respond appropriately, seeking advice in relation to all learners' needs as required.

The current mechanisms for influencing the content of Initial Teacher Education (ITE) provision are through the <u>GTCS Evaluation Framework for the Accreditation of ITE</u> <u>Programmes</u> and the <u>GTCS Standards for Registration</u>. The evaluation framework confirms that it is for GTCS to set the policy on the content, nature and duration of programmes leading to teaching qualifications (TQs) for the primary and secondary sectors and to ensure these requirements are met through the accreditation of all programmes of Initial Teacher Education (ITE) in Scotland. Very specifically, this framework confirms that GTCS requires ITE providers to provide 'an outline of how student teachers are supported to develop an understanding of current national policy and to make a positive contribution in areas such as Inclusion (including Additional Support Needs); and that ITE providers are required to 'outline how programmes are designed to develop and promote equality, diversity and address any potential discrimination to embrace diversity, challenge discrimination and promote the equal opportunity requirements laid down by statute.'

The professional standards confirm the values and personal commitment that is core to being a teacher, which includes 'valuing as well as respecting social, cultural and ecological diversity and promoting the principles and practices of local and global citizenship for all learners'; that all teachers must have 'an understanding of current, relevant legislation and guidance such as the Standards in Scotland's Schools etc. Act (2000), Education (Additional Support for Learning) (Scotland) Act 2004, the Equality Act 2010 and GIRFEC'; and that teachers must 'know how to promote and support the cognitive, emotional, social and physical wellbeing of all learners, and demonstrate a commitment to raising all learners' expectations of themselves'.

In the refreshed autism strategy priorities the Scottish Government has committed to reviewing the current autism resource in schools - the Autism Toolkit<sup>7</sup> to better meet the needs of teachers and education staff working with autistic pupils. We have also committed to exploring with Strathclyde University a pilot in their Initial Teacher Education provision.

In terms of the Petition target that young adults with autism will have a statutory right to specialist support from their local authority up to the age of 25. There are various guidance materials available e.g., Getting It Right for Every Child (GIRFEC) guidance<sup>8</sup> and the Principles of Good Transitions 3 Autism Supplement <sup>9</sup> to support practioners deliver specialist support to autistic young adults.

<sup>7</sup> http://www.autismtoolbox.co.uk/

<sup>&</sup>lt;sup>8</sup> <u>https://www.gov.scot/Topics/People/Young-People/gettingitright</u>

<sup>&</sup>lt;sup>9</sup> http://www.autismnetworkscotland.org.uk/the-principles-of-good-transitions/

We have committed to ensure that that each young person be offered an appropriate place in post 16 learning to equip them with skills and knowledge to progress into adulthood. Local authorities have duties to plan for a young person with additional support needs leaving school, and must consider the needs of each young person with additional support needs when helping them plan for leaving school. They should do this by working in partnership with agencies to identify opportunities for each young person leaving school – including those with additional support needs. In addition to this, if a child or young person wishes to go on to further or higher education then the Local Authority may provide adequate and efficient education whether this be in schools or other places, such as colleges

In terms of the Petition target that an Autism Act will be in place within the next 5 years to enshrine specific rights and services for autistic people in our legal system. In 2010, Hugh O'Donnell MSP introduced a Private Member's Bill to the Scottish Parliament – the Autism (Scotland) Bill. Then – as now – there was no legislation that related specifically to autistic people. The Bill's objective was to place a statutory duty on the Scottish Government to 'prepare and publish a strategy to meet the needs of children and adults with autism; consult with appropriate organisations and people; and issue statutory guidance to local authorities and health boards on their services for children and adults with autism'.

Stage 1 of the Bill commenced on 10 November 2010, with the Education, Lifelong Learning and Culture Committee as lead Committee. The Committee considered a substantial body of evidence from autistic people, their families, carers and support organisations. Those who participated in the Committee's evidence sessions generally welcomed the idea of introducing a national autism strategy, and the Committee itself was convinced such a strategy could help ensure that services were delivered more effectively for autistic people.

Later in 2010, following the Bill's introduction, the Scottish Government published a draft autism strategy for consultation - *Towards an Autism Strategy for Scotland*. The Government argued that legislation was not required to underpin such a strategy, while existing inclusive legislative measures already made provision for people with additional support needs, including autism. While those in favour of the Bill said these existing measures had not been implemented effectively, the Committee felt there had not yet been sufficient passage of time to properly evaluate their impact. The Committee also said it was inappropriate to introduce new legislation as a countermeasure to the poor implementation of existing legislation.

After due consideration the Committee concluded that the Autism (Scotland) Bill, as it was introduced, would not create robust enough obligations for local authorities and health boards to deliver meaningful change to services for autistic people. Resources, the Committee said, would be better used if they focussed on implementation of existing legislation and duties. As such, the Committee recommended to Parliament that the general principles of the Bill not be agreed to, and the Bell fell at Stage 1.

In the autism strategy engagement last year the appetite for an Autism Act was not high on the issues autistic people and their families felt were better needed to improve their lives. The engagement analysis<sup>10</sup> bears this out. Given that there is there is currently little appetite, we still think it inappropriate to introduce new legislation to countermeasure the implementation of existing legislation. Even if there was an appetite for an Autism Act and Minsters signed up to it, given the parliamentary timetable they could give no firm guarantee that it would be passed within the 5 year period.

<sup>&</sup>lt;sup>10</sup> <u>http://www.autismnetworkscotland.org.uk/files/2018/04/The-Scottish-Strategy-for-Autism-Engagement-Analysis.pdf</u>

The Committee may wish to note that the Scottish Government invested in a piece of work to determine the economic cost of autism in Scotland. The Microsegmentation Report<sup>11</sup> was published earlier this year and it highlights per capita costs for autism with the aim of informing local autism strategy and planning. Scottish Autism published a service provider response<sup>12</sup> to that report and made a number of calls for action for consideration at national and local level.

Whilst the response above details the policies, frameworks, guidance and resources available in Scotland, we accept that much more needs to be done to improve the lives of autistic people in Scotland. We will continue to work with relevant statutory bodies and third sector partners to ensure that the inequalities autistic people face daily are addressed across all sectors including education, health and social care.

<sup>11</sup> <u>http://www.autismnetworkscotland.org.uk/files/2018/04/The-Scottish-Strategy-for-Autism-Engagement-Analysis.pdf</u>

<sup>12</sup> https://beta.gov.scot/publications/microsegmentation-autism-spectrum/

<sup>13</sup> <u>https://www.scottishautism.org/news/service-providers-response-microsegmentation-report</u>

<sup>&</sup>lt;sup>11</sup> <u>https://beta.gov.scot/publications/microsegmentation-autism-spectrum/</u>

<sup>&</sup>lt;sup>12</sup> <u>https://www.scottishautism.org/news/service-providers-response-microsegmentation-report</u>