

HEALTH, SOCIAL CARE AND SPORT COMMITTEE

AUTISM SERVICES

EVIDENCE FROM THE MINISTER FOR HEALTH AND SOCIAL SERVICES

Purpose

The purpose of this paper is to provide the Health, Social Care and Sport Committee with an update on autism services.

Introduction

On 25 October 2018, I attended the Health, Social Care and Sport Committee to give evidence in relation to the Autism (Wales) Bill. At this session I agreed to return in a year to provide an update to Committee on autism services. This evidence paper provides an update on developments for autism services in the last year and in particular the areas which arose from the recommendations of the Committee's report *Autism (Wales) Bill Committee Stage 1 Report (December 2018)*.

Background

Following the publication of the updated Autistic Spectrum Disorder Strategic Action Plan (2016), the National Integrated Autism Service (IAS) has been rolled out through Regional Partnership Boards. £13m has been provided through the Integrated Care Fund to support this and implementation is supported by the National Autism Team, hosted by the Welsh Local Government Association and Public Health Wales. In July 2019 we published the second annual report on the delivery of our autism strategy¹. The three priority areas in the strategy are assessment and diagnosis; meeting support needs; and awareness raising, information and training.

Update

Neurodevelopment service

Since 2015, the Welsh Government has made available £2million annually to establish and deliver dedicated neurodevelopmental services across Wales. An autism diagnosis for children and young people would usually be undertaken by these teams. The service was set up under the Together for Children and Young People programme.

The service was set up to improve assessment services for young people under the age of 18 years who may have a neurodevelopment condition. Specialist services started to be set up in 2016 and are now available across all health boards in Wales. We have introduced a 26 week waiting time target for health boards and are working closely with health boards and the Welsh Informatics Service to make sure that the

¹ Welsh Government(2019) Autism Spectrum Disorder: Annual Report 2018-19
<https://gov.wales/autism-spectrum-disorder-annual-report-2018-2019>

data is accurate. Once I am assured about the validity of the data, it will be published on Stats Wales.

Demand for the service has significantly exceeded what health boards predicted. Therefore to better understand the demand and capacity of the service we intend to commission a scoping exercise, which will help inform future service development. The planned approach to that review is set out later in this paper.

I have recently agreed 'in principle' to extend our Together for Children and Young People programme. I expect this NHS led programme to continue to engage with people who use services, in order to drive improvements, improve quality and outcomes for people, including those who use neurodevelopment services across Wales

National Integrated Autism Service

The IAS has now been fully rolled out across Wales. IAS teams are operating in Cardiff and Vale, Cwm Taf, Gwent, Powys, North Wales, Western Bay and West Wales. The IAS has been working collaboratively at a local and national level, developing and maintaining close links with other agencies delivering support, particularly learning disability, mental health and social care services and with third sector organisations that are an essential element of the broad service offer.

Some recent examples of work being undertaken in collaboration with voluntary sector organisations include in recent months the delivery of a specially adapted patient education programme which particularly focuses on working with young people in Gwent. In Cardiff, a post diagnostic support and information programme for adults has been produced by 21 High Street, an autism charity based in Cardiff and the IAS. Both of these are now being rolled out across Wales.

Also all IASs and the National Autism Team are focusing on how best to support and work with autistic parents and carers. This work is being developed as a result of the enquiries from autistic parents as they have found that traditional parenting courses and support is not meeting their family's needs. New resources will be developed in partnership with parents and will also be shared with the wider childcare and family support sectors.

From April this year we have been piloting an outcome focussed data collection model to measure the impact of the services on the lives of autistic people being supported. In addition to this all the IAS are using the outcome star approach with each participant to agree goals and measure the distance travelled.

National Autism Team

The National Autism Team continues to have a central role in supporting the delivery of the Welsh Government's priorities for autism services. An annual work plan for 2019/20 has been agreed and published on their website². This includes supporting

² National Autism Team Work Plan 2019-20 https://www.asdinfo.wales.co.uk/resource/National-Autism-Team-Work-Plan-2019-20_eng.pdf

the Integrated Autism Service, as well as producing a wide range of resources for autistic people, their families and carers in collaboration with stakeholders which are available on the website www.asdinfo.wales.co.uk. The Team also published its second annual report in June this year³.

Some examples of what the Team has achieved in the last year include:

- A 62% increase in users of its website compared to the previous year, with an average 10,575 users per month - an increase of over 3,500 users on the previous year.
- The first National Autism Wales Conference “Promoting Autistic Wellbeing”, was held on 3rd April at the Liberty Stadium Swansea, its aim was to increase the wellbeing of autistic adults who are not necessarily in regular contact with public or third sector services, but for whom an event about wellbeing and increasing their capacity to cope with day-to-day life would be beneficial and positive. The event was a great success and its organisation was a good example of co-production in practice.
- The Team has completed a Work Based Learning (WBL) scheme co-produced with autistic learners, the National Training Federation Wales, the ASD Leads and Associated Community Training Limited (ACT). The aim of the WBL programme is to provide organisations with information and guidance on becoming autism aware, and to understand how to effectively support their learners with autism. This programme was launched by the Minister for Education on 24 September 2019.

Independent Evaluation

In April, I committed to the publication of the independent evaluation on the Integrated Autism Service⁴, the report stated that the IAS was a welcome new service, and made recommendations about areas that need more focus. In 2018 I also commissioned an extension to the evaluation to provide a clearer picture of current services, and to make sure we have the information we need to make the right decisions about future services. The evaluation report entitled a *Scoping Study for Alignment and Development of Autism and Neurodevelopmental Services*,⁵ was published and it provides further insight about the capacity of our services to respond to increasing demand for support.

We have accepted the recommendations made in the both of these independent reviews on autism services and are taking action.

³ National Autism Team Annual Report 2018/19
https://www.asdinfo.wales.co.uk/resource/National-Autism-Team_Annual-Report_2018-19_eng.pdf

⁴ Welsh Government (April 2019) Evaluation of the Integrated Autism Service and the Autistic Spectrum Disorder Strategic Action Plan: Final report
<https://gov.wales/evaluation-integrated-autism-service-and-autistic-spectrum-disorder-strategic-action-plan-final>

⁵ Welsh Government (2019) Scoping Study for Alignment and Development of Autism and Neurodevelopmental Services <https://gov.wales/autism-and-neurodevelopmental-services>

Code of Practice for Autism Services

The Welsh Government has committed to publish a Code of Practice on the delivery of autism Services under the Social Services and Well-being Wales Act 2014 and the NHS Act 2006. A consultation on our proposals for the Code opened on 30 November 2018 and closed on 1 March 2019. Four main stakeholder events were held in February, in Llandrindod Wells, Swansea, Llandudno and Cardiff. A consultation report on the responses was published in July⁶. Overall the responses were generally in support of the proposals. Most responses were based around suggestions of further issues which should be taken into account or requests for more clarity in some areas. Examples of the key issues for further investigation identified in the responses included detail on pathways and the role of the autism champion in Regional Partnership Boards.

Building on this first consultation, we continue to listen to autistic people through direct engagement at events and meetings across Wales. We held our first round of technical groups to advise on the code in July this year, they will meet again in November. We are organising further stakeholder events in both West Wales and North Wales during November. We are also attending events such as ADFest for people with learning disabilities, meetings with the Department of Work and Pensions (DWP), Social Care Wales, Health Education and Improvement Wales and representatives from several of the Royal Colleges. We are also meeting local authority workforce leads.

We are also working with our partners in local authorities and health boards to listen to the views of local stakeholder groups. For example, my officials recently met with a group of autistic adults in Powys to discuss their views and experiences to help to inform the development of the Code. We will continue this engagement with autistic adults across regions.

We are listening to the feedback and taking action. For example in response to requests for a clear and comprehensive approach that is also accessible, we will publish a succinct draft code of practice, with a separate guidance document to explain what is expected, and we are expanding the scope of the regulatory impact assessment to ensure the code is deliverable without having a negative impact on other services.

In my Written Statement on autism services on 23 September⁷ I have committed to sending a pre-consultation copy of the draft code to the Committee by the end of this calendar year for feedback. There is a great deal of work still to be done to ensure the Code of Practice when it is published places clear responsibilities on statutory organisations, but that it is also developed in a way that enables it to be implemented in practice. Our current plan is that a public consultation on the code, the

⁶ Report on the Consultation on Proposals for the Code of Practice on the Delivery of Autism Services
<https://gov.wales/code-practice-delivery-autism-services>

⁷ Written Statement – Improvements in Autism Services
<https://gov.wales/written-statement-improvements-autism-services>

accompanying guidance and the Regulatory Impact Assessment will be published before Easter 2020.

Demand and Capacity review

As part of the development of the Code of Practice on the delivery of autism services we are undertaking a comprehensive Regulatory Impact Assessment, to ensure the requirements of the code are realistic and can be delivered. To provide the necessary information to inform this assessment, we are undertaking a demand and capacity review of children's neurodevelopmental (ND) services, the Integrated Autism Service (IAS) and wider autism support. The first benchmarking phase will provide an accurate picture of how the ND and the IAS services are operating and managing rising demand within services.

Phase two of this review, will take into account wider autism services and consider the views of autistic people and their parents and carers. It will also focus on workforce barriers and seek to address gaps in provision. The review will also consider the relevant recommendations made in the first independent evaluation report published in April 2019 and the Scoping Review published in September.

Many of the issues highlighted in these reports are common across health and social care, within mental health and children services. Discussion with our partners including autistic people and services tells there is no easy solution to address increasing demand. It is not as simple as increasing funding to recruit more staff, because there is a shortage of suitably trained specialists. It will not be enough to impose legal duties and tighter targets, as this will place even more pressure on hard pressed services to concentrate on achieving targets at the expense of much needed support. We know that a focus on reducing waiting times is achieving results, but there is a cost as in many areas clinicians do not have capacity to provide post diagnostic support for children and their families. These are parents who are seeking re-assurance and support following their child's diagnosis and staff report their own frustration about the limitations in the range of support they can offer.

We are establishing a task and finish group to scope the second phase of the review which will include autistic people and their representatives. We will also invite representatives from education, the third sector, and from Social Care Wales and Health Improvement Education Wales. We want this work to be a thorough analysis and to provide options for improving services which are sustainable for the future. This review will need to work alongside the development of the Code of Practice and RIA and we anticipate it will be completed within 12 months so that the final Code of Practice will be published by spring 2021.

Alongside this the needs of autistic people go beyond the priorities which can be captured in a code. We are working to support services which assist autistic people to find and sustain employment. We have been working closely with the Department of Work and Pensions, Job Centre staff; to train and support their disability employment advisors. There are many examples of good practice, for example in North Wales and in most regions the IAS provide weekly drop-in sessions at local job centres, in SE Wales there are autism job clubs supported by the IAS and in SW Wales the local disability employment adviser lead attends the local authority autism

stakeholder groups. Links are also being made to local FE colleges to support autistic leavers' progress beyond college.

We are also working across Welsh Government to ensure that employment services across Wales will take account of the needs of autistic people. Our new employability service 'Working Wales' will deliver a national entry point to employability support. The service is delivered by Careers Wales as a national service of advice and guidance and provides employment focused support that is flexible and appropriate to individual circumstances.

We want to ensure that voluntary sector organisations have the opportunity to be part of our programme of autism reform. Alongside the collaborative work already being undertaken between local services, voluntary sector organisations have had the opportunity to submit an application to the Sustainable Social Services Third Sector Grant Scheme 2020-23. We have received several applications seeking to support autism services, and all applications are being assessed. I anticipate the outcomes of the assessment will be known by the end of November.

In my written statement, dated 23 September 2019, I also outlined that our priority for neurodevelopmental and autism services over the next year is to ensure that services are sustainable for the long-term. The investment we are making to children's neurodevelopmental services will continue and we are monitoring the outcomes closely. In that same statement, I announced that the £3m a year currently funding the Integrated Autism Services until March 2021 will now become recurrent without prejudice to any changes we may seek to make to the operating model of these services following the conclusion of our evaluation studies. I believe these actions reaffirms our commitment to improving lives for autistic people and their families and carers.