

## REPORT TO THE CARE SCRUTINY COMMITTEE

<b>Date of meeting:</b>	<b>30 November 2021</b>
<b>Cabinet Member:</b>	<b>Councillor Dilwyn Morgan Councillor Dafydd Meurig</b>
<b>Contact Officer:</b>	<b>Aled Gibbard, Senior Manager</b>
<b>Contact E-mail:</b>	<b>aledwyngibbard@gwynedd.llyw.cymru</b>
<b>Title of Item:</b>	<b>Autism Plan 2021-23</b>

### **1 BACKGROUND**

- 1.1 Members will already be aware that autism is a priority for us as a Council, therefore, it is my pleasure to present this Plan to the Care Scrutiny Committee today.
- 1.2 We intend to make improvements within the field, jointly with our key partners, namely the Health Board and also Anglesey Council.
- 1.3 The work is partly influenced by the work which has been carried out as a result of a complaint made to the Council in relation to the service provided. The complaint was referred to the Public Services Ombudsman, and the Ombudsman provided recommendations to us as a Council. Therefore, this Plan seeks to respond to the lessons from that complaint, together with the Ombudsman's recommendation, and it is important to note our continued commitment to try to improve our service in response to the opinion of our users.
- 1.4 Another key part which has been carried out in order to ensure that we are able to create an Autism Plan with the right foundation, was commissioning an external Consultant (namely Hugh Morgan, a very prominent expert in the field of learning disabilities and autism here in Wales), to undertake a comprehensive multi-agency review of the field, giving us his opinion on what needed to change and develop.
- 1.5 He was asked to focus specifically on the criteria for receiving a service; the assessment process; access to children and young people with high-functioning autism; autism and no learning disability, and the handover period to services such as Adults. The intention was to create a plan which would ensure that these children and young people gain access to support tailored to their individual needs.
- 1.6 The consultant's review was, therefore, crucial for us in order to develop the Autism Plan which is presented to you today.
- 1.7 It is also important to draw members' attention to the fact that the Welsh Government has published a consultative Code of Practice of the Delivery of Autism Services. This Code of Practice came into force on 1 September this year. The consultant's work considered the Code of Practice when completing the review. The Code requires a Local Autism Plan as well as the need to review it

annually, therefore, as a Council and sub-region, we will be well-positioned in terms of the Code of Practice in having this Plan adopted and implemented.

- 1.8 Though the initial work started from the Derwen Service direction (namely the Anglesey and Gwynedd integrated service for disabled children and children who are ill), this service is only one part of the bigger picture. It cannot be considered as a separate entity to all public services involving the autism field of work. The Consultant's review confirms that the Derwen Service (Social Services, Nurses and Psychologists) has expertise and a good understanding of children and young people with autism. However, it must be noted that autism is not necessarily an obvious and visible disability and it is unavoidable, therefore, children on the spectrum come into contact with children services at a more general level. Consequently, the Derwen Service also acts as a resource which provides advice and guidance to children services at a more general level.
- 1.9 It is important to give you as members the context in terms of the significant increase we have seen in the number of children receiving a diagnosis of autism in the County. We anticipate that there will be a significant increase in the demand for children services as well as adults services over the coming years. It has become apparent that there is a gap in services for those children with autism, but no learning disability, particularly for young people aged 14-17. Working alongside the Education Department will, therefore, be crucial as we move forward.

## **2 THE PLAN**

- 2.1 As noted above, it is essential with this field that key partners work together if we are to see a sustainable and effective change in the future. Having received the external Consultant, we as a Council asked Anglesey Council and Betsi Cadwaladr Health Board for their agreement to establish a sub-regional Autism Project Board, in order to create the Autism Plan 2021-23 for the local area. We are very grateful to our partners for agreeing to this proposal.
- 2.2 Though members will be entirely aware of the work context in terms of Covid-19, it is important to note that the work which has happened across partners, and also in terms of the work of the external Consultant, happened while also trying to cope with one of the biggest challenges in our history as a Council and the wider public sector. It is, therefore, testament to our commitment to the field, that the work which started before the pandemic began, has continued despite the enormous pressure on managers, officers and staff. I would like to acknowledge and thank everyone for prioritising the work during such a challenging period.
- 2.3 The Project Board was established in 2020, and the Board includes representation from Gwynedd Council, Anglesey Council and Betsi Cadwaladr Health Board. Many services are provided jointly, therefore, it was essential for the Plan to be co-developed. As a result of the Consultant's review, there was a golden opportunity for the Council to offer guidance and a clear direction to

ensure that the multi-agency plan is developed to improve the experiences of children, young people and their families across the sub-region.

- 2.4 The Council presented the recommendations of the external consultant's Review to the Project Board, and they were accepted in full. The Project Board has been spending the past year addressing those recommendations, in order to develop this Autism Plan, together with developing action points.
- 2.5 As members will see from the action points, a few actions have already been implemented. A co-ordinator has already been identified and has started in order to implement some elements. Initially, they will assist with elements of developing the training programme and focusing on gathering data and information from relevant agencies regarding children and adults with autism. This will allow the Project Board to have a firm picture when reviewing the Plan and forward-plan once the Plan has been adopted.
- 2.6 For information, there is a National Autism Team (IAS) who have a central role in raising awareness of autism in the community. This work is developed with a specific aim of including autism people in the process of developing and disseminating resources. In addition, post-diagnostic support is provided by neuro-developmental health services and the IAS for adults, parents, children, carers and professionals. By now, a representative from the Children and Adults Department meets regularly with the National Autism Team in order to share information and promote developments in the field.
- 2.7 The plan as a whole is not cost-neutral, and additional resources are needed for it to be realised. To fund the jobs element, it is estimated that an additional investment of £150,000 will be needed at this point. As it is a joint plan, it is expected that the partners will contribute to the total cost. It is, therefore, anticipated that the Gwynedd Council contribution will be £50,000.

### **3 EQUALITY**

- 3.1 The Equality Act 2010 places clear duties on public sector organisations to prevent discrimination and promote equality for people with specific Protected Characteristics. These are - age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, pregnancy and maternity. Specific duties involve providing reasonable adaptations for disabled people, including autistic people, to help them to access the services they need.

### **4 NEXT STEPS AND TIMETABLE**

- 4.1 The report will be submitted to the Cabinet on 30 November asking them to approve the Autism Plan 2021-23, included in Appendix 1.

## APPENDIX 1

### Autism Plan 2021-23

<b>1.</b>	<b>The definition of Autism</b>
	<p>“The term autistic spectrum condition (ASC) is used to describe the group of complex neuro developmental symptoms, of variable severity, that are characterised by challenges in social interaction and communication and by restricted or repetitive patterns of behaviour, thought and sensory feelings”.</p> <p><i>(Code of Practice on the Delivery of Autism Services, Welsh Government 2021)</i></p> <p>An autistic spectrum condition (ASC) is a developmental disability that affects how people communicate, behave or interact with others. Some people may have very obvious features, and others may not. The common thread is differences in social, communication and behavioural skills compared with people who are not on the spectrum. In women, the presenting features can be very subtle, which makes it more difficult to identify the signs, as women and girls can be very good at hiding symptoms and hiding the condition from their friends, family and professionals in the health field in particular.</p>
<b>2.</b>	<b>The Purpose of the Plan</b>
<b>2.1</b>	The aim of the plan is to provide the context for developing a strategic direction in order to improve outcomes for people with autism and their carers.
<b>2.2</b>	A review of the current provision, undertaken by an independent consultant and reported to a project board which included Gwynedd Council's Children and Adults Services, Isle of Anglesey Children and Adults Service and the Betsi Cadwaladr University Health Board, identified gaps in the provision for people with autism, particularly for those who do not have a learning disability.
<b>2.3</b>	The autism code of practice came into force on 1 September 2021. It provides clarity to local health boards, local authorities and Regional Partnership Boards on the Social Services and Well-being (Wales) Act and / or NHS (Wales) Act 2006 and the responsibilities and the services that they are required to provide in order to support autistic people in their daily lives. Therefore, this plan will provide a focus to ensure compliance with the new Code of Practice.
<b>2.4</b>	Considering the financial constraints faced by the Council, some of the recommendations are achieved by re-designing services or re-prioritising budgets. However, the plan asks for greater focus on raising awareness, partnership methods and better coordination of Services - additional funding will be needed for these initiatives. In addition, partnership working provides opportunities to align community resources and attract third sector funding.

3.	<b>Key Issues</b>
3.1	<b>Access to health and social care services</b> - a key feature of people with autism is a difficulty in communicating and expressing themselves and their needs. Assessing an individual with autism who does not have a learning disability is challenging as their needs are often hidden and their impact can depend on the circumstances. The families of people with autism tell us that professionals often miss or are unable to understand the impact of communication difficulties when carrying out assessments. Someone who may appear to have capacity could have difficulties because of their inability to communicate or understand social situations that others take for granted.
3.2	<b>Diagnosis</b> - In line with the national strategy, we need to develop easy access to a diagnosis and post-diagnosis support, which is coordinated to assist people to access services and social care networks. There is a need to develop clearer roles and guidance to provide support to families as they await an assessment and a diagnosis.
3.3	<b>Post-diagnosis Advice and Support</b> - The range of people's needs and the support they will require after their diagnosis will vary greatly. Most people with autism, but who do not have a learning disability, will have low or moderate care needs and their requirements will mainly relate to communication, building a social network, promoting independence, employment, housing and maintaining stability. However, some may have critical or substantial needs and they will require 24 hour support and supervision. Access to post-diagnosis advice and support will vary. There is a need to develop clear guidance regarding the level and type of post-diagnosis intervention, advice, support and review. This would ensure that people know / can contact relevant support services.
3.4	<b>Young People during the transition period</b> - The largest proportion of children with ASD receiving a service from the Derwen Integrated Team are in the 14-17 year old category. Therefore, the transition from children services to adults services is a pinch point for the service. The transition pathway is complex, as the transition age into adults services is not the same in every service. There is a need to focus more on those children with autism who do not have a learning disability and who would therefore not be in receipt of a service from Derwen at present.
3.5	<b>Training</b> - Every member of staff who works directly with children, young people or adults should undertake awareness training. Evidence suggests that raising a basic awareness and providing training on autism can substantially improve people's ability to communicate with people with autism. We are developing focussed training materials on understanding autism, including an information booklet and e-learning module. We have started to map the education and training requirements of practitioners. In partnership with Anglesey Council and Betsi Cadwaladr University Health Board, we will

	<p>develop tiers of training for general and specialised services. This will be steered by work being done on a national level through the National Autism Service.</p> <p>In addition, statutory bodies will be expected to undertake an analysis of autism training needs for their staff, tailored to their professional needs.</p>	
<b>3.6</b>	<p><b>National Autism Service</b> - The Service offers a diagnostic assessment for adults, but they do not work directly with children and young people. There is a need to strengthen the link with the service from the direction of Children's Services and Adults Services. Developing a pattern of information sharing and collaboration on developing useful resources in the field is essential in order to influence the improvement of services locally.</p>	
<b>3.7</b>	<p><b>Third Sector</b> - There is a need to identify partners who can provide low level services for people with ASD. The voluntary sector can play its part in developing skilled, low level and low-cost practical support services for young people with autism or who do not have a formal diagnosis of a Learning Disability in Gwynedd that needs to be addressed. Introducing a similar model in Gwynedd would provide an effective service that improves the quality of life of young people with autism; helping prevent emergencies from happening, but it will also reduce the pressure on the statutory services. The need for such services will become increasingly important should the current increase in ASD diagnosis lead to a greater demand on statutory services.</p>	
<b>4.</b>	<p><b>Actions for 2021-22</b></p>	<b>Timetable</b>
<b>1</b>	<p><b>Establishment of a Local Autism Partnership Board</b> - In accordance with the Code of Practice, regional partnership boards, local health boards and local authorities must gather information about the degree in which outcomes are improved and the quality of the services provided to autistic people and their family or carers. Service improvements need to align with Welsh Government's autism strategic action plan. The local plan also needs to be reviewed on an annual basis. Currently, the project board includes key partners from the statutory agencies. Therefore, it is recommended that the current Project Board transforms into a Local Autism Partnership Board, to include representation for autistic people. This will ensure supervision of service development and improvement, gather key strategic data and an annual review of the plan.</p>	<b>Established</b>
<b>2</b>	<p><b>Appointment of a Coordinator / Project Officer to develop Autism Services</b> - Currently, there is a lack of data in relation to the numbers and profiles of children and young people who have a diagnosis of ASD. Establishing this role to collate this information across the local authority, the health board and education will assist when planning to improve services. The post would also offer a regular</p>	<b>November 2021</b>

	<p>contact with the National Autism Service, avoiding any duplication, identifying gaps and developing a network for professionals involved with the provision of services for autistic people. The post will also assist with the implementation of elements of the action plan.</p>	
<b>3</b>	<p><b>Establishing the Role of ASD Transition Practitioner (14-25 years)</b> - This post would be co-located across children and adults Learning Disabilities Services and would include access to those children and young people where there is no learning disability diagnosis.</p>	<p><b>April 2022, subject to financial investment</b></p>
<b>4</b>	<p><b>Establishing the Role of ASD Practitioner (Support during the assessment / diagnosis) (14-25 years)</b> - The increase in the demand for an ASD assessment means that there is a waiting list. Providing advice and support at this point would assist to manage the demand for post-diagnosis services and would promote support and early intervention with the aim of reducing the demand for post-diagnosis statutory services.</p>	<p><b>April 2022, subject to financial investment</b></p>
<b>5</b>	<p><b>ASD Training</b> - A multi-tier programme of training, including e-learning, is being developed. This is provided across general services to increase autism awareness as well as more specialised training for practitioners who work directly with autistic people.</p> <p>Undertake an audit of staff training needs, giving consideration to the level of contact of individual roles with autistic people. This will consider direct work with autistic people as well as jobs where it is possible, via face-to-face contact with the public, to come into contact and therefore there is a need for a level of awareness about their needs.</p>	<p><b>September 2021 - March 2022</b></p> <p><b>November 2021 - March 2022</b></p>
<b>6</b>	<p><b>Engagement with the National Autism Service</b> - Undertake a mutually-beneficial engagement strategy that will avoid any potential duplication, ensuring clarity of information and advice provided to adults and children and young people and their families. Effective communication and information sharing will assist to develop services and share information in relation to the outcomes for autistic people in Gwynedd.</p>	<p><b>Already happening</b></p>
<b>7</b>	<p><b>Investigate the potential for developing third sector Autism Services</b> - there is a need to further investigate the development of skilled, low level practical support services. There are examples of practical activities being undertaken by third sector organisations that receive Welsh Government and other grant funding. Introducing such a</p>	<p><b>April 2022</b></p>

	model in Gwynedd provides an effective service to improve the quality of life of people with autism and manage any additional demand on statutory services.	
--	---	--

This is a scheme under the supervision of the joint Project Board with Anglesey County Council and Betsi Cadwaladr University Health Board. This will be monitored and reviewed annually.

Welsh Government has declared with a monitoring framework will be developed jointly with the Regional Partnership Boards. Additionally, a review of neurodevelopmental services has commenced since February 2021. This review will be completed by March 2022 and will consequently inform the second clause of the Government's Action Plan for 2022-23. Any outcomes from this work will be reported to the Board and will be included in the plan as appropriate.