

**Vaughan Gething AC/AM**  
**Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol**  
**Minister for Health and Social Services**



Llywodraeth Cymru  
Welsh Government

Ein cyf/Our ref: MA-P/VG/3156/19

Dai Lloyd AM  
Health, Social Care and Sport Committee Chair  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA

12 November 2019

Dear Dai,

### **Autism Services in Wales**

Thank you for your letter of the 29 October, following my attendance at Committee on 23 October to update on developments in autism services. At the meeting, I agreed to provide further information on two areas as set out in your letter. Please find the information below:

I agreed to provide details on the engagement being undertaken as part of the consultation which will inform the Code of Practice for Autism Services.

In the session and the evidence paper, I gave some examples of the engagement which has taken place this included the stakeholder technical groups, attending events such as ADFest for people with learning disabilities, meetings with the Department of Work and Pensions, Social Care Wales, Health Education and Improvement Wales and representatives from several of the Royal Colleges. We have also been 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.

A “toolkit” for engagement with autistic people and their families/carers has also been developed and sent to all local authority Autistic Spectrum Disorders leads and Integrated Autism Service leads to enable conversation and feedback on the development of the Code.

I attach a copy of a document which provides information on the meetings held to date and also plans for future meetings. This is a working document and will develop further as future engagement opportunities emerge.

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Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

The National Autism Team have also published an engagement and participation strategy, which can be found at the following link:

<https://www.asdinfo.wales.co.uk/resource/Engagement-and-Participation-Strategy-march-19-final-2.pdf>

My officials are continuing to work with primary care services on the GP register. I agreed to provide an update on the position to publish the waiting times data for children's neurodevelopmental services.

Our intention was to commence formal publication of the Children and Young People's Neurodevelopment data in April 2019, as official statistics they are subject to the data meeting the NHS Wales Informatics necessary standards of quality. Official Statistics should be fit for purpose and robust. In this case, despite working with health boards during the pilot, we did not have the sufficient assurances that the data are fit for purpose for publishing.

The review of the data by NHS Wales Informatics Service (NWIS) identified areas of inconsistency that are yet to be fully resolved. Welsh Government and NWIS are working with health boards to resolve these issues. In the interim, health boards continue to collect and report this data as management information as part of the NHS framework and we will use that information to determine improvement in quality and consistency.

We are working with Local Health Boards to achieve a consistent and high quality data collection. Data from health boards that are in the strongest position on data quality will be published via their own reporting mechanisms once their data quality is agreed. The focus remains on bringing all health boards up to the data standard required to complete a national data set.

You will be aware I have already provided the management data from April 2018 - April 2019 to the Children, Young People and Education Committee during their follow up work related to their *Mind Over Matter* report:

<http://www.senedd.assembly.wales/documents/s92916/Letter%20from%20Minister%20for%20Health%20and%20Social%20Services%20following%20the%20evidence%20session%200on%2020%20June%202019.pdf>

Yours sincerely,



**Vaughan Gething AC/AM**

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Minister for Health and Social Services

## CODE OF PRACTICE FOR AUTISM SERVICES – ENGAGEMENT

The following is a breakdown of engagement activity and reach undertaken and planned during the development of the Code of Practice for Autism Services.

**Month:** June 2019

Engagement	Date	Activity at the event/meeting	Reach
Meeting with All Wales People First – Chief Executive	4 June 2019	Updated on developments – Code, technical groups and the third sector grants scheme.	Chief executive – key third sector partner
Neurodevelopmental (ND) National Stakeholder Group	5 June 2019	Update on Code of Practice	Range of neurodevelopmental stakeholders – professionals, third sector and Integrated Autism Service (IAS).
Links with Education and the Additional Learning Needs (ALN) code	10 August 2019	To discuss the Code of Practice and cross referencing with the ALN Code.	Cross departmental working with education in Welsh Government.

**Month:** July 2019

Engagement	Date	Activity at the event/meeting	Reach
Meeting with representatives of the Royal Colleges.	9 July 2019	To discuss the consultation on what to be included in the code and also the technical group meetings.	Representatives from the Royal Colleges and the Welsh NHS Confederation.

Code of Practice Technical Group: Assessment and Diagnosis	11 July 2019	Feedback on consultation on proposals for the code. Opportunity to share thoughts on what should be included in the assessment and diagnosis section of the code.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Autistic people and families;</li> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
Code of Practice Technical Group: Accessing Care and Support	16 July 2019	Feedback on consultation on proposals for the code. Opportunity to share thoughts on what should be included in the accessing care and support section of the code.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Autistic people and families;</li> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists.</li> </ul>

Code of Practice Technical Group: Awareness Raising and Training	17 July 2019	Feedback on consultation on proposals for the code. Opportunity to share thoughts on what should be included in the assessment and diagnosis section of the code.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Autistic people and families;</li> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
IAS Leads Meeting	18 July 2019	Update on Code of Practice	Meeting of all the IAS leads and the National Autism Team (NAT).
Code of Practice Technical Group: Planning, Monitoring and Stakeholder Engagement	22 July 2019	Feedback on consultation on proposals for the code. Opportunity to share thoughts on what should be included in the assessment and diagnosis section of the code.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Autistic people and families;</li> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>

Meeting with Powys Health Board representatives	24 July 2019	To discuss autism service delivery and update on the Code	Powys HB – implication for service provision for autistic people living in Powys region
NAT development day	31 July 2019	Planning future work	NAT team and Welsh Government Autism team. Future planning for autism services across Wales.

**Month: August 2019**

<b>Event</b>	<b>Date</b>	<b>Activity at the Event</b>	<b>Reach</b>
Meeting with Department of Work and Pensions (DWP) – Autism Awareness	5 August 2019	To discuss Autism Awareness and links to the Code of Practice	DWP and the National Autism Team.
Links with Education and the ALN code	6 August 2019	To discuss the Code of Practice and cross referencing with the ALN Code.	Cross departmental working in Welsh Government.
NAT meeting	7 August 2019	Update on agreed plan	NAT and Welsh Government.
Meeting – ND/Autism Workforce Development	15 August 2019	To discuss the workforce implications for the Code of Practice and the draft Health and Social Care Workforce Strategy.	Social Care Wales and Health Education and Improvement Wales (HEIW)

Primary Care and the Code of Practice	28 August 2019	To discuss the Code and first steps in engagement with health board directors for primary care.	Welsh Government Primary and Community Care.
Meeting with Welsh Government Legal department	28 August 2019	Update on Code – legal implications.	Welsh Government – Autism team and Legal department.
Meeting with HEIW	29 August 2019	Meeting to discuss development of the Code of Practice for Autism Services and input and links with HEIW.	HEIW

**Month:** September 2019

Event	Date	Activity at the Event	Reach
Education Meeting	10 September 2019	Discuss Autism referrals from schools	Welsh Government - Education
Community of Practice	11 September 2019	Share progress with development of Code of Practice.	Clinicians across the Autism Service.
Children and Adolescent Mental Health Services (CAMHS) and Vulnerable Groups Meeting	13 September 2019	Discuss demand and capacity for autism diagnosis and support.	Welsh Government – Health, implications for the Code
ND National Stakeholder Group	18 September 2019	Update on Code of Practice	Range of ND Stakeholders – professionals, third sector and IAS.

Employment and Skills Meeting.	19 September 2019	Discuss employment and training.	Welsh Government - Employment and Skills.
Participation and Engagement (Powys - North)	19 September 2019	Testing of the toolkit developed for engaging with people with autism.	Autistic people
Launch of Work Based Learning Programme	24 September 2019	Launch of: <i>Autism: A Guide for Work-Based Training Providers</i> and <i>Autism: A Guide for Work-Based Learners and Providers.</i>	Range of stakeholders – education, employment and autistic people.
IAS Leads Meeting	25 September 2019	Update on Code of Practice	Meeting of all the IAS leads and the NAT.
Meeting with National Autistic Society (NAS) Cymru	23 September 2019	Catch up meeting to discuss progress with the code of practice.	NAS is a key stakeholder representative and partner
Autism Code of Practice and local authority workforce	26 September 2019	To discuss the workforce implications for the Code of Practice and the draft Health and Social Care Workforce Strategy.	Social Care Wales
Autistic Spectrum Disorder Implementation Advisory Group Meeting	30 September 2019	Update since the previous meeting in February 2019. Opportunity to update on the development of the Code of	Range of stakeholders including the NAT, Third Sector including NAS, autistic

		Practice – following consultation on proposals and the first round of technical groups in July. The meeting also provides an opportunity to share next steps and plans for groups in November.	people and parents and carers.
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**Month:** October 2019

<b>Event</b>	<b>Date</b>	<b>Activity at the Event</b>	<b>Reach</b>
NAT meeting	2 October 2019	Update on NAT work plan	Welsh Government and National Autism Team
Together for Children and Young People (T4CYP) meeting.	3 October 2019	Networking / Informal discussions regarding the Code	ND practitioners, police, autistic young people and carers and NHS Delivery Unit.
All Health Board Directors of Primary and Community Care Meeting	4 October 2019	Paper on the Code – and raising awareness with health board directors of primary and community care.	Health Board Directors of Primary and Community Care and National Director and Strategic Programme for Primary Care.
All Wales People First – Adfest Village Hotel Cardiff	18 October 2019	Opportunity to speak briefly at the conference and also a table in the main milling area.	Autistic people and their families / carers. Third sector advocacy organisations.

Cardiff University	28 October 2019	Discuss outcomes of evaluations of teaching and awareness raising research.	Researchers in Cardiff University.
Code of Practice Technical Group meeting with representatives of the Royal Colleges.	29 October 2019	Technical Group type meeting to share consultation on proposals feedback and to share draft structure of the code and guidance document to get feedback.	Members/representatives of the Royal Colleges of : <ul style="list-style-type: none"> <li>• Psychiatrists;</li> <li>• Paediatrics and Child Health;</li> <li>• Occupational therapists;</li> <li>• Speech and Language Therapists;</li> <li>• Welsh NHS Confederation.</li> </ul>
Welsh Government Employability Policy	30 October 2019	Working across Government policy areas.	Welsh Government - Employment and Skills.

**Month:** November 2019

Event	Date	Activity at the Event	Reach
Swansea University – SAIL	4 November 2019	Exploring data analysis available in primary care.	Stakeholders – for future service provision
Code of Practice Technical Group: Assessment and Diagnosis	5 November 2019	Sharing draft of assessment and diagnosis section of the code and accompanying guidance with stakeholders.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> </ul>

			<ul style="list-style-type: none"> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
Code of Practice Technical Group: Accessing Care and Support	7 November 2019	Sharing draft of accessing care and support section of the code and accompanying guidance with stakeholders.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
Parents Voices in Wales	11 November 2019	Opportunity to meet with parents and carers to discuss experiences and views on what should be included in the Code of Practice.	Parents and Carers
Code of Practice Technical Group: Awareness Raising and Training	12 November 2019	Sharing draft of awareness raising and training section of the code and accompanying guidance with stakeholders.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> </ul>

			<ul style="list-style-type: none"> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
Code of Practice Technical Group: Planning, Monitoring and Stakeholder Engagement	14 November 2019	Sharing draft of planning, monitoring and stakeholder engagement section of the code and accompanying guidance with stakeholders.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
Heads of Primary care and associate medical directors	15 November 2019	Engagement to raise profile of autism in health boards	Health board /Primary health care teams
Code of Practice Technical Group – North Wales Event (St George Hotel, Llandudno)	20 November 2019	Day event to cover all four chapters of the code and to feedback on the consultation and the work so far. Opportunity for attendees to comment on any areas that the code needs to address.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Autistic people and families;</li> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> </ul>

			<ul style="list-style-type: none"> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
1000 lives – Improvement Cymru conference	25 November 2019	Networking – raising awareness of autism.	Health Workforce Wales
Code of Practice Technical Group – West Wales Event (Halliwell Centre, Carmarthen)	26 November 2019	Day event to cover all four chapters of the code and to feedback on the consultation and the work so far. Opportunity for attendees to comment on any areas that the code needs to address.	Key stakeholders including: <ul style="list-style-type: none"> <li>• Autistic people and families;</li> <li>• Third Sector;</li> <li>• Integrated Autism Service;</li> <li>• Education;</li> <li>• Local Authority;</li> <li>• Public Health Wales</li> <li>• Speech and Language Therapists;</li> <li>• Occupational Therapists</li> </ul>
ND National Stakeholder Group	29 November 2019	Update on Code of Practice	Range of neurodevelopmental stakeholders – professionals, third sector and IAS.

**Month:** December 2019

<b>Event</b>	<b>Date</b>	<b>Activity at the Event</b>	<b>Reach</b>
Participation and Engagement (Powys - North)	4 December 2019	Follow up from previous meeting 19 September 2019 to share draft sections of the Code of Practice for feedback.	Autistic people
IAS and ASD Leads meeting	5 December 2019	Update on Code	IAS and ASD leads
NAT Carer / parent guide review	12 December 2019	Engagement event to review / update current guidance	Carers /parents of autistic adults/children

**Month:** January 2020

<b>Event</b>	<b>Date</b>	<b>Activity at the Event</b>	<b>Reach</b>
Parents and Carers Group	13 January 2020	Opportunity to meet with parents and carers to discuss experiences and views on what should be included in the Code of Practice.	Parents and Carers
Local Authority Workforce Leads	Date tbc	Engagement in relation to the code and demand and capacity review	Workforce planning

Community of Practice	23 January 2020	Share progress with development of Code of Practice.	Clinicians across the Autism Service.
Demand and Capacity review task and finish group	Meeting planned	Meeting of the task and finish group.	All key stakeholders

**Month:** February 2020

Event	Date	Activity at the Event	Reach
Meeting with DWP – Autism Awareness	4 February 2020	To discuss Autism Awareness and links to the Code of Practice	DWP and the National Autism Team.
Autism / CAMHS symposium	25 February 2019	To discuss service provision to young adults and its provision in the Code	Autism / CAMHS practitioners, Welsh Government, NAT, IAS.

**Month:** March 2020

Event	Date	Activity at the Event	Reach
Community of Practice	12 March 2020	Share progress with development of Code of Practice.	Clinicians across the Autism Service.
ASD Implementation advisory group	23 March 2019	Update and discussion on the Code	Professionals and representatives of organisations and autistic people and carers

**Month: April 2020**

Event	Date	Activity at the Event	Reach
Code of Practice – consultation events	To be confirmed		

**Month: May 2020**

Event	Date	Activity at the Event	Reach
Code of Practice – consultation events	To be confirmed		

**Month: June 2020**

Event	Date	Activity at the Event	Reach
Code of Practice – consultation events	To be confirmed		