



Llywodraeth Cymru
Welsh Government

CLOSED CONSULTATION

Report on the consultation on the draft statutory code of practice on the delivery of autism services and accompanying guidance document

Summary of the draft responses to the public consultation on the Code of Practice on the Delivery of Autism Services and supporting guidance.

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Summary

The public consultation on the draft Statutory Code of Practice on the Delivery of Autism Services and accompanying guidance document ran between 21 September 2020 and 14 December 2020. 103 written responses were received to the consultation. A further 149 responses were received as part of a consultation exercise undertaken by the National Autistic Society.

Due to the coronavirus pandemic and social distancing guidelines engagement events took place online with two held in November attended by nearly 100 autistic people, families and health and social care professionals.

Overall the responses were in favour of the draft Statutory Code of Practice and supporting guidance. The key issues for requiring further detail and stronger emphasis were identified as follows:

- timescales, pathways and support available
- clarity on single point of access
- provision of reasonable adjustments
- ability to diagnose co-occurring conditions
- importance of assessments being in the persons first language
- preventative services
- maintaining records of diagnosis across health and social care services
- recognising different ways of supporting individuals
- self advocacy
- mental health support/collaborative working
- guidance on how workplaces can be more autism aware
- guidance on what needs to be included in general awareness raising and

- staff training
- how monitoring will be undertaken to ensure that training is being implemented
- more detail on individual roles and team roles identified in the Code
- collection of data
- more information on formal complaints
- the impact on other neurodevelopmental (ND) conditions.

Introduction

Although much has been achieved by the autism strategy, first published in 2008, the Welsh Government acknowledges that there is still a pressing need to increase the scale and pace of autism service improvement. We have listened when autistic people and their families and carers have told us that, despite reforms, it can still be a struggle to access much needed support and services. These experiences were highlighted during the debate around the Autism (Wales) Bill during 2018 which enabled the Senedd to recognise the needs of autistic people, and to illustrate how in some areas they are still unmet.

In response to these concerns, and significant support for the aims of the bill we made a commitment to issue a statutory Code of Practice on the Delivery of Autism Services. The Code will underpin existing duties in the **Social Services and Well-being (Wales) Act 2014** and the **NHS (Wales) Act 2006**. Between November 2018 and March 2019 we consulted on our proposals for the Code and a copy of the consultation report can be found at [Code of Practice Consultation on proposals](#).

During 2019/20 we built on the results of the consultation and established technical groups which met in July 2019 and November 2019 advising on each area of the Code. Members of the technical groups included autistic people and their parents and carers, local authority autism leads, Integrated Autism Services (IAS) and neurodevelopmental (ND) service representatives and third sector organisations. At each meeting, attendees went through the relevant chapter and had an opportunity to comment in detail on a draft which was shared with them prior to the meeting. Feedback at each of the meetings was positive and constructive.

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We also undertook a programme of wider engagement with autistic people, their parents and carers and with professionals across Wales. The National Implementation Advisory Group also met twice during the year and these meetings focussed on the development of the Code.

By March 2020 having worked closely with stakeholders the draft Code of Practice and accompanying guidance was ready for publication, but this was delayed due to the impact of the Covid-19 pandemic. Arrangements resumed during the summer of 2020 and publication of the consultation went live on 21 September 2020, and closed on 14 December, with two online public consultation events taking place in November 2020.

This report reflects the analysis of all the feedback received, identifying a number of recurring themes. The next steps section of the report explains the actions we will take in response to the consultation and other feedback we have received. We will continue to listen and work closely with our stakeholders in order to co-produce the final Code and guidance document to complete both documents by March this year.

Brief overview of the Code and guidance document

This report summarises the responses received to the consultation on our proposals for a draft Statutory Code of Practice on the Delivery of Autism Services and supporting guidance document. The consultation documents can be accessed here: [Code of Practice consultation](#).

The Code will place duties on both local authorities and health boards to adapt their service provision to meet the needs of autistic people and their parents and carers. It will have the power to place these duties upon both Health Boards and Local Authorities because it is issued under the **Social Services and Well-being (Wales) Act 2014** and the **NHS (Wales) Act 2006**. It will place specific duties under each of the sections as set out below.

1. Arrangements for autism assessment and diagnosis.
2. Arrangements for accessing health and social care services.

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3. Arrangements for awareness raising and training on autism.
4. Arrangements for planning and monitoring services and stakeholder engagement.

This Code is for:

- autistic people, including those with co-existing conditions
- providers of social care and health support for autistic people and their families and/or carers
- practitioners in social care and health who work with autistic people and their families and/or carers
- commissioners and people with a strategic role in assessing and planning local services for autistic people and their families and/or carers
- practitioners in other related services providing support for autistic people and their families and/or carers, for example employment, education and criminal justice
- service providers and practitioners providing services for autistic people with co-existing conditions.

As an outcome from our consultation with engagement groups and technical groups the Code will refer to the following as a definition of autism:

“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”. ”

The Code will use the term ‘autistic people’ rather than ‘people with autism’, this is to reflect the language preferences expressed by autistic people who have contributed to the development of this Code.

This Code will also use the term ‘practitioners’ rather than referring to individual professions. This is to reflect the language preferences expressed by all individuals who contributed to the development of this Code.

This Code does not extend to other neurodevelopmental conditions but

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recognises that some individuals will have autism with other co-occurring conditions which may impact on their care and support needs.

Overview of responses

The consultation document asked 16 questions on the Code and supporting guidance, about the definition of autism used in the Code and whether the Code should be expanded to cover other neurodevelopmental conditions. It then asked 5 questions on the effects of the Code on protected characteristics and the Welsh Language, before asking respondents to raise any other related issues. We received 103 complete responses through online forms and emailed letters. We are grateful to the National Autistic Society (NAS) which also undertook a consultation exercise to encourage responses and a total of 149 responses were received from their participants, which will inform the finalising of the draft Code and supporting guidance document. **Figure 1** below provides a breakdown of the consultation respondents by type. For further detail on the respondents see [Annex 1](#).

Responses (Figure 1)

Responder	Organisations including third sector, local authorities, statutory bodies, local health boards and integrated autism service.	36
Responder	Autistic people, parents, families, carers and individuals working in organisations.	67
Responder	NAS responses from autistic people, families and carers	149
Responder	Total	252
Type of response	Online consultation form	47

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Type of response	Response direct to consultation mailbox	56
Type of response	NAS responses	149
Type of response	Total	252

Overall, for most areas of the Code, few responses stated that they ‘disagreed’ with the duties placed on service providers. Most responses ‘agreed’, marking either the ‘agree’ or ‘tend to agree’ boxes. However, there were many comments on how the Code could be further improved and clarified. These suggestions and concerns are explained below. They are organised by each section of the Code and its’ associated questions. The figures of percentages are taken from the online responses received and have been rounded up or down to the nearest percentage.

Additional learning needs

Many responses received asked for more clarity about alignment between the Code and the new Additional Learning Needs (ALN) system. The Additional Learning Needs and Education Tribunal (Wales) Act 2018 will create a unified legislative framework to support learners from 0 to 25 years who have ALN. Its focus is on ensuring all children and young people that require additional support to meet their learning needs, have that support properly planned for and protected.

Implementation of the new ALN system will commence on a phased basis from September 2021, with the statutory roles created under the Act commencing in January 2021.

The intention is for the Code of Practice on the Delivery of Autism Services to align with the ALN reforms to ensure that support needs, such as social care services, which are in addition to learning needs delivered through ALN are also

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available for children, young people and their families and carers when needed.

Definition of autism

- Do you agree with the definition of autism used within this Code and guidance?
- Is the proposed definition accurate for service providers and acceptable to autistic people?

Agree	Tend to agree	Tend to disagree	Disagree	No response
47%	26%	9%	15%	0

75% of respondents either agreed or tended to agree with the definitions adopted by the code which was agreed through consultation with engagement groups and technical groups when drafting the Code. The following definition of autism was used in the consultation document replacing the previously used “autistic spectrum disorders (ASD)”: *“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”*.

The consultation version of the Code also used the term ‘autistic people’ rather than ‘people with autism’; this is to reflect the language preferences expressed by autistic people who have contributed to the development of this Code.

One organisation said “We are grateful to see that you have now adopted ASC instead of ASD. Our members have called for some time for this change to take place. We were pleased to see the definition of ‘autistic people’ also included as this definition is a preference for some of our members. In the spirit of celebrating the gifts as well as challenges experienced by people on this Spectrum”

The planned response is for ASC and “autistic people” definitions to remain the

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terminology used in the final versions of the Statutory Code and supporting guidance document.

Should the Code be wider than autism?

Do you agree that the Code should focus on autism services or could be expanded to cover other neurodevelopmental conditions?

Autism only	All neurodevelopmental conditions	No opinion
48%	41%	11%

In the consultation, responders were asked to comment on whether the Code should focus only on autism services or could be expanded to cover other neurodevelopmental conditions. The feedback from the online and direct responses was slightly in favour of autism only, with responses in favour mainly received from autistic people, parents and carers. The following is an example of feedback from one organisation in favour of the Code covering autism only: *“Neurodevelopmental disorders are a large group, with different pathways and needs. To cover all within one chapter would be complex and not particularly useful given the very broad range of needs, which would then have to be covered. We feel to include all neurodevelopmental conditions would make the document too long.”*

41% of responses asked for the Code to cover all neurodevelopmental conditions and to take a holistic approach to neurodiversity within the population. Throughout the debate on the Autism (Wales) Bill and the subsequent development of the Code, parents and carers particularly wanted to see a focus on autism, therefore the Code will remain for autism alone. However, work in the wider neurodevelopmental services continues and the Code and its implementation will inform future policy development, which will take note of emerging evidence and good practice.

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Responses to arrangements for autism assessment and diagnosis

Are the proposed requirements in this section of the Code right for both service providers and autistic people?

Agree	Tend to agree	Tend to disagree	Disagree	No response
28%	38%	17%	17%	0

Does the guidance provide enough clarity and information for this section?

Agree	Tend to agree	Tend to disagree	Disagree	No response
33%	37%	20%	10%	0

Overall majority of responses either agreed and tended to agree with the consultation document (66%), it is acknowledged that approximately a third (32%) were not supportive. There were five key themes which emerged from the consultation feedback in response to the questions on autism assessment and diagnosis which we have considered in the final code.

Timescales, pathways and support

Responders to the consultation commented that further information was needed in the Code on the following three areas: timescales; pathways and support. For timescales responders asked for more details on waiting times for assessment. They also asked, in relation to pathways that they should include those with existing or co-occurring health conditions. Finally for support, they asked for further information on the support available particularly in an educational setting when going through the assessment process.

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Single point of access

Responders asked for clarity on the Single Point of access and whether it covers both children and adult referrals. In response officials will clarify within the Code. Officials will also offer examples of good practice in the guidance document.

Reasonable adjustments

Responders asked for more information to be included on reasonable adjustments including some examples for accessing services such as health services - longer *appointment times and quiet environments*.

Co-occurring conditions

Responders asked for the ability for crossover with assessments for other conditions such as ADHD and dyspraxia to be included within assessment pathways, including for people with other existing conditions.

Importance of assessments being in the person's first language

Responders asked that the Code emphasises the importance of assessments being in the person's first language. People may have an English assessment but the assessor needs to take into consideration that Welsh may be the person's first language.

Responses to arrangements for accessing health and social care services

Are the proposed requirements in this section of the Code right for both service providers and autistic people?

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Agree	Tend to agree	Tend to disagree	Disagree	No response
28%	44%	16%	12%	0

Does the guidance provide enough clarity and information for this section?

Agree	Tend to agree	Tend to disagree	Disagree	No response
29%	47%	14%	10%	0

Again the majority of responses were either agree or tend to agree with the draft code (72%) though 28% disagreed with the code. There were five key themes which emerged from the consultation feedback in response to the questions on accessing health and social care services, we have considered this feedback in the re-drafting of the final Code.

The five themes are:

Preventative Services

Responders felt that there was more detail and emphasis needed on preventative services. For example one individual said “*the purpose of preventative services should be to enable autistic people to live a good life however they may define that*” and “*Preventative support at the point of contact as opposed to reactive crisis intervention.*”

Primary Care Services

Responders felt in relation to primary and secondary care services that GPs and hospitals must include an autism diagnosis on patient files.

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Provision of Support

Responders felt that the Code needed to emphasise the importance of moving away from mainstream support and recognising different ways of supporting individuals, for example the need to *“provide better/ specific support for autistic people during crisis moments and there should additionally be an emphasis on support given to adults, not just “autistic people’s families” as this tends to mean ‘children and their families’.*

Self Advocacy

Responders felt that more information needed to be included on self advocacy including promoting the voice of the child, with one individual stating *“In our experience, self-advocacy is the ultimate preventative service and is essential to voice, choice and control for people with a learning disability and/or autism”.*

Improving Mental Health Support

In relation to mental health support, responders commented on the need for stronger emphasis on improving mental health support /collaborative working for example more community therapy and consideration of mental health issues in relation to confinement and limited liberty.

Responses to arrangements for awareness raising and training on autism

Are the proposed requirements in this section of the Code right for both service providers and autistic people?

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Agree	Tend to agree	Tend to disagree	Disagree	No response
25%	46%	17%	13%	0

Does the guidance provide enough clarity and information for this section?

Agree	Tend to agree	Tend to disagree	Disagree	No response
29%	51%	13%	7%	0

Raising awareness in the workplace

71% agreed or tended to agree with the draft code, with around 29% disagreeing with the Code, although 80% agreed or tended to agree with the guidance. Responders felt that there should be more guidance on how workplaces can be more autism aware. This would include organisations such as education, health services, GP practices, retail places and public-facing services.

Guidance on training

Responders asked for more information on who could provide the training.

Monitoring the implementation of training

Responders asked for clarity on how Welsh Government will monitor that training is being implemented.

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Funding for training

Responders asked who will fund the extra training for organisations on autism awareness.

Responses to arrangements for planning and monitoring services and stakeholder Engagement

This chapter in the Code had three consultation questions, in order to effectively address its three parts: planning, monitoring and stakeholder engagement. The majority agreed or tended to agree with the Code, though the pattern of around 30% disagreement remains evident, particularly in relation to monitoring where this figure rises to 38%. This is also compared with high rates of agreement for planning (74%) and stakeholder engagement (80%) for the code and guidance.

Planning

Are the proposed requirements in this section of the Code right for both service providers and autistic people?

Agree	Tend to agree	Tend to disagree	Disagree	No response
33%	41%	14%	12%	0

Does the guidance provide enough clarity and information for this section?

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Agree	Tend to agree	Tend to disagree	Disagree	No response
28%	51%	15%	6%	0

Monitoring

Are the proposed requirements in this section of the Code right for both service providers and autistic people?

Agree	Tend to agree	Tend to disagree	Disagree	No response
30%	32%	24%	14%	0

Does the guidance provide enough clarity and information for this section?

Agree	Tend to agree	Tend to disagree	Disagree	No response
25%	48%	16%	11%	0

Stakeholder engagement

Are the proposed requirements in this section of the Code right for both service providers and autistic people?

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Agree	Tend to agree	Tend to disagree	Disagree	No response
36%	44%	9%	11%	0

Does the guidance provide enough clarity and information for this section?

Agree	Tend to agree	Tend to disagree	Disagree	No response
31%	50%	12%	7%	0

Clarity on roles

Responders commented on the need for more clarity on the roles such as the autism champion appointed within the Regional Partnership Board.

Data collection

Responders felt that more detail was needed on what data would be collected, from which organisations, who would collate the data and how often. Respondents felt that all organisations should include autism data collection.

Complaints

Responders felt that more information should be included on how to make a formal complaint and how complaints are handled; this includes when local health boards and local authorities are not complying with the duties in the Code of Practice.

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National Autistic Society's consultation exercise

The National Autistic Society (NAS) undertook a consultation exercise to encourage responses and a total of 149 responses were received from autistic people, families and carers. NAS developed a simple response template to help as many people as possible to have their say. The template included a brief summary of the proposals most relevant to what autistic people and their families had told them are the biggest challenges they face. The template gave them space to have their say under the following headings which link to the four chapters of the Code: getting an autism assessment; finding care and support; mental health; your rights; going out and other.

Positive and negative impacts on protected characteristics

Some respondents felt that the Code will have a positive impact on disability for autistic people, as it will improve the services that they receive and ensure their voices are heard. In equal numbers, respondents raised concerns that the Code could lead to pressure on services to 'filter out' and prioritise autistic spectrum conditions from the neurodevelopmental pathway, risking creating an 'unmet middle' of children with ADHD, sensory processing disorders, learning disabilities and those who have experienced chronic trauma.

Impacts and opportunities for the Welsh language

Comments on this theme focussed mainly on, services that are signposted through this Code should be available in Welsh and English. Additional comments included, all autistic people should be able to communicate for example in assessments through their first and most comfortable form of communication, be that Welsh or sign language if preferred.

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Conclusion and next steps

The consultation found that most respondents supported the proposals with suggestions for improvement and expansion. It was evidence for many questions there was a pattern of around 70% in agreement and 30% disagreement. In many areas further clarity or detailed information was sought.

The main recommendations and next steps which have emerged from the consultation are summarised below and included actions for both the Code and supporting guidance document:

- Use of the terminology of Autistic Spectrum Condition (ASC) and autistic people in the Code and supporting guidance document where appropriate
- That the Code will currently focus on autism but future policy developments may see developments in the wider neurodevelopmental services
- Clearer reference in the Code on the importance of the Welsh language in assessments.
- Strengthen reference and terminology in both the Code and the supporting guidance document especially regarding choice, participation and the voice of the child.
- Update the supporting guidance document to include signposting details on how to access local information on timescales including differences between adults' and children's waiting times. To include examples of pathways and who will develop and review these.
- Information on support will be made more detailed in line with Social Services and Wellbeing Act Wales guidance.
- Clarity in the Code on the Single Point of access and whether it covers both children and adult referrals. Examples of good practice to be included in the supporting guidance document
- More detail on reasonable adjustments and offer examples of good practice within the supporting guidance document.
- Update the supporting guidance to include pathways, referral systems and best practice for co-occurring conditions.
- More detailed information on preventative services to be included and signposted.
- Stronger emphasis in the Code regarding the provision of alternative

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support. The supporting guidance will be updated to offer examples of good practice.

- Clearer reference in the Code regarding offering advocacy support including self advocacy. The supporting guidance will be updated to include more detailed information on self advocacy.
- The supporting guidance will be updated to include more detailed information on accessing mental health support/collaborative working.
- The supporting guidance will be updated to include more detailed information on how workplaces can be more autism aware.
- The supporting guidance will be updated to include more detailed information on training needs analysis and examples of training content.
- The supporting guidance will include more detailed information on the role of Welsh Government in overseeing training in health and social care sectors as part of its regional partnership board reporting and monitoring activities.
- The supporting guidance document will be updated to include more detailed information on the individual roles within the Code.
- The supporting guidance will be updated to include more detailed information on the collation of data and the reporting structure.
- The Code will make reference to formal complaints. The accompanying guidance will be updated to reference more detailed information on how individual organisations manage complaints they receive.

Finalising the draft Code

The Code and supporting guidance will be finalised by March 2021. Welsh Government will work with our autism advisory group to consult with them as amendments are made.

The Code will be laid before the Senedd in March 2021 and will come into force in September 2021. Implementation will begin in September 2021 and will be supported by an implementation plan. This plan will be developed in partnership with stakeholders.

The Welsh Government established the ASD implementation advisory group to support the delivery of the autism strategy published in 2016, this group met between January 2018 and February 2020. A successor group is now being

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established to support the delivery of the Welsh Government's future autism priorities. This will include the implementation of the statutory Code of Practice on the Delivery of Autism Services.

Glossary

Additional Learning Needs: Learners are defined as having **additional learning needs** when he or she has a learning difficulty or disability, which means they need additional learning provision.

Additional Learning Needs Reform: a new program of reforms to help children and young people who need extra support to learn.

Information, Advice and Assistance services: The Social Service and Wellbeing (Wales) Act 2014 states that all Local Authorities must “*secure the provision of a service for providing people with information and advice relating to care and support, and assistance in accessing care and support*”. You can access this service by contacting your Local Authority.

NHS (Wales) Act 2006: The **NHS (Wales) Act 2006** consolidates a range of regulatory requirements relating to the promotion and provision of the health service in Wales. It sets out Welsh Ministers' duty to promote health service and General power to provide services. It also describes provision of particular services, provision of services otherwise than in Wales, NHS Contracts; and provision of services otherwise than by Welsh Ministers.

Pathways: A pathway is a tool used across Health and Social Care in order to map out health, care and support journeys, where the different steps an individual can expect to pass through are defined and sequenced.

Population Assessments: The **Social Services and Wellbeing (Wales) Act 2014** requires that local authorities and local health boards must jointly carry out an **assessment** of the **needs** for care and support, and the support **needs** of carers in the local authority areas. They are overseen by the **Regional Partnership Boards** whose purpose is to drive the strategic regional delivery of social services in close collaboration with health.

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Regional Partnership Boards: In April 2016 as part of the **Social Services and Well Being (Wales) Act 2014**, seven statutory regional partnerships came into being across Wales. Their purpose is to drive the strategic regional delivery and partnership of social services and health. They are attended by both Local Authorities and Health Boards, alongside key community members and service users.

Social Services and Well-being (Wales) Act 2014: The Social Services and Well-being (Wales) Act came into force on 6 April 2016. The Act provides the legal framework for improving the well-being of people who need care and support, and carers who need support, and for transforming social services in Wales. Its key principles are: Voice and control, Prevention and early intervention, Well-being and Co-production.

Learning disability: Taken from **NICE Guidelines:** Lower intellectual ability (usually defined as an IQ of less than 70) that leads to problems in learning, developing new skills, communication and carrying out daily activities. **Learning disability** severities are defined by the following IQ scores: mild=50–69, moderate=35–49 and severe=20–34. A person with a mild to moderate **learning disability** may only need support in certain areas. However, a person with a moderate to severe **learning disability** may have no speech or limited communication, a significantly reduced ability to learn new skills and require support with daily activities such as dressing and eating. Learning disabilities are different from 'learning difficulties', like dyslexia, which do not affect intellect. **Learning disability** is sometimes also called 'intellectual disability'.

Annex 1: List of respondents

A total of 103 complete responses were received through online forms and emailed letters. A total of 67 responses were received from autistic people, parents, families and carers and individuals working in organisations. The remaining 36 respondents are listed below:

1. All Wales People First
2. Pembrokeshire People First
3. Royal College of Paediatrics and Childrens Health

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4. National Mental Health Network
5. Bridgend County Borough Council
6. Cymdeithas yr Iaith
7. Torfaen County Borough Council
8. Children's Commissioner for Wales
9. Cwm Taf Morgannwg University Health Board
10. Estyn
11. Ceredigion County Borough Council
12. Gwent Integrated Autism Service
13. Gwent Regional Partnership Board
14. Hywel Dda University Health Board
15. Neath Port Talbot Steering Group
16. Royal College of Occupational Therapists
17. Autistic UK
18. Royal College of Speech and Language Therapists
19. North Wales Integrated Autism Service
20. Association of Educational Psychologists
21. Together for Children and Young People Programme
22. Wales Autism Research Centre
23. Public Service Ombudsmen for Wales
24. Learning Disability Wales
25. National Autistic Society Cymru
26. Colegau Cymru
27. Denbigh Local Authority Education and Psychology Support
28. West Glamorgan Mental Health Support
29. Cardiff and Vale Integrated Autism Service
30. Welsh Local Government Association
31. Parents Voices in Wales
32. Western Bay Integrated Autism Service
33. Mudiad Meithrin
34. Cwm Taf Integrated Autism Service
35. Cardiff University, representing the Cardiff University Centre for Human Development Science, School of Psychology (1), the Institute of Psychological Medicine and Neurology, School of Medicine (2), the MRC Centre for Psychiatric Genetics and Genomics, School of Medicine (3), and the Wolfson Centre for Young People's Mental Health (4).

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36. The Welsh Language Commissioner

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