Report on the Consultation on Proposals for the Code of Practice on the Delivery of Autism Services

November 2018 - March 2019
Contents
1. Summary ......................................................................................................................... 4
2. Introduction ....................................................................................................................... 4
3. Brief Overview of the Code ............................................................................................. 6
4. Overview of responses ...................................................................................................... 6
5. Responses to Arrangements for Assessment and Diagnosis ............................................ 7
   Waiting times .................................................................................................................. 7
   Expertise in Autism across pathways .............................................................................. 7
   Assessing and diagnosing autism with co-existing conditions ...................................... 8
   Clarity ............................................................................................................................... 8
6. Responses to Arrangements for Accessing Care and Support .......................................... 8
   IQ .................................................................................................................................. 8
   Carer’s Assessments ....................................................................................................... 8
   Post-diagnostic support ................................................................................................. 8
   Awareness of care and support pathways ....................................................................... 9
7. Arrangements for awareness raising and training ........................................................... 9
   Training is vital ............................................................................................................... 10
   Balancing between general awareness and specialist expertise .................................... 10
   Suggestions of who should be trained in Autism ......................................................... 10
8. Planning, Monitoring and Stakeholder Engagement ....................................................... 10
   Planning ......................................................................................................................... 11
   Monitoring ..................................................................................................................... 11
   Stakeholder engagement ............................................................................................... 12
9. Positive and Negative Impacts on Protected Characteristics ......................................... 12
10. Impacts and Opportunities for the Welsh Language ...................................................... 12
11. Cross-cutting issues ....................................................................................................... 13
    Collaborative working ................................................................................................. 13
    Resource ....................................................................................................................... 13
    Powers ........................................................................................................................... 14
    Clarity ............................................................................................................................. 14
12. Conclusion and Next Steps ............................................................................................. 14
13. Finalising the Draft Code ............................................................................................... 15
Glossary ............................................................................................................................... 16
Annex 1: List of respondents .............................................................................................. 18
1. Summary

1.1 The public consultation on the Welsh Government’s proposals for a Code of Practice on the Delivery of Autism Services ran between November 2018 and March 2019. 65 written responses were received to the consultation document. Four main engagement events with autistic people and professionals were also undertaken, these were in Llandrindod Wells, Swansea, Llandudno and Cardiff.

1.2 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. The key issues for further investigation identified in the responses are as follows:

- A clear explanation is needed on how an autism code aligns with a needs based approach to services, as advocated in legislation such as the Social Services and Well-being (Wales) Act 2014.
- The code should be carefully balanced between assessment, diagnosis and the provision of direct support services.
- There should be more detail on pathways for assessment and support, including those for people with co-existing conditions, including mental health and learning disabilities.
- There should be better access to information on how to access support. This information should be available for various services, including within primary and secondary care, and with regards to support during transition.
- A clear explanation should be provided on how the powers in the code would be exercised to ensure compliance by public bodies.
- More information should be included on the role of the autism champion in Regional Partnership Boards (RPBs).
- The code needs to have a clear writing style and full glossary.
- More information should be included on how the duties around how training will be delivered in order to improve knowledge and skills in different parts of the workforce.
- There were significant concerns that a code would place substantial additional pressures on already stretched services, and questions as to how this would be acknowledged and addressed.
- The approach to collaborative working was welcomed, with agreement that autistic people need to be at the centre of service design and delivery.
- More clarity is needed on how the code links to education and Additional Learning Needs reform.
- There needs to be more recognition and links to the importance of third sector involvement in the delivery of services.
- There should be more detail on the data collected to monitor service delivery.

2. Introduction

2.1 The Welsh Government has invested in a substantial programme of autism service reform and, although good progress is being achieved, there are
always further improvements to be made. We are firm in our commitment to continue our reforms at pace, in a way that enables autistic people to live happy and fulfilling lives.

2.2 Since the ASD Strategic Action Plan was published in November 2016, there have been significant positive changes to Welsh autism services. These have included the continuation of the National Autism Team to support the implementation of the Integrated Autism Service; improvements to Children’s and Young People’s Neurodevelopmental Services, and the Additional Learning Needs and Educational Tribunal (Wales) Act 2018. More information on all of these changes can be found on the Welsh Government website: https://gov.wales.

2.3 The Welsh Government acknowledges that there is 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 National Assembly for Wales to recognise the needs of autistic people, and to illustrate how in some areas they are still unmet.

2.4 In response to these concerns, we have made a commitment to issue a Code of Practice on the Delivery of Autism Services. This 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. The Code aims to raise awareness of the needs of autistic people and places duties upon local authorities and health boards to ensure that their needs are being addressed.

2.5 The consultation sought views on whether the duties proposed were appropriate and what else should be included in the code of practice. Autistic people, their parents and carers and the professionals who deliver autism services responded to the consultation. They provided written responses or attended the consultation events we held in February 2019 in Llandrindod Wells, Swansea, Llandudno and Cardiff. A list of the respondents can be found in Annex 1.

2.6 This report reflects the analysis of all the feedback received, identifying a number of recurring themes. Many were similar to those found in the feedback and recommendations made in the evaluation of the Integrated Autism Service, published in March and in the National Assembly of Wales Committee Reports on Stage One Scrutiny of the Autism (Wales) Bill published in December 2018. These can be found in Annex 2.

2.7 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 code and aim to complete the draft code and publish it for consultation by the end of the year.
3. Brief Overview of the Code


3.2 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 places 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 sections as set out below.

1. Arrangements for assessment and diagnosis.
2. Arrangements for accessing care and support.
3. Arrangements for awareness raising and training.
4. Arrangements for planning, monitoring and stakeholder involvement.

4. Overview of responses

4.1 The consultation document asked 12 questions on the codes four areas. 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 gathered responses from consultation events, and received 65 complete responses through online forms and emailed letters. Figure 1 below provides a breakdown of the consultation respondents by type. For further detail on the respondents see Annex 1.

<table>
<thead>
<tr>
<th>Responder</th>
<th>Individuals and parents including anonymous</th>
<th>27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professional Bodies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Public Bodies and Statutory Bodies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third Sector</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Universities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Integrated Autism Service</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>38</td>
</tr>
<tr>
<td>Type of Response</td>
<td>Consultation form</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>Letter</td>
<td>5</td>
</tr>
</tbody>
</table>

4.2 Overall, in 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 uncertainty on the codes ability to deliver on the expectations the new duties would create. These suggestions and concerns are explained below. They are organised by
each section of the code and its’ associated questions. Terms in the text in bold are described in the glossary at the back.

5. Responses to Arrangements for Assessment and Diagnosis

| Are the proposed requirements in this section right for service providers? |
|-------------------------------|----------------|----------------|---------|---------|---------|
| Agree                        | Tend to Agree | Tend to Disagree | Disagree | No Response |
| 18                           | 19            | 13             | 1       | 12       |

Waiting times

5.1 Individuals largely welcomed the proposed implementation of 26 week waiting time targets, citing anecdotal stories of how distressing it can be when the diagnosis process takes longer. Interest groups and individuals wanted to know how they could ensure that professionals were meeting the proposed targets. Some individuals queried why there wasn’t a target for adults, whilst others thought that 26 weeks was still too long to wait. To ease distress around long waiting times, professionals suggested increasing pre-diagnostic support, and for the code to be clearer on what ‘waiting time’ the code was actually measuring.

5.2 Conversely, professionals who undertake assessment and diagnosis spoke of how waiting time targets may lead to a lower quality of assessment and put great pressure on small staff teams who are working at full capacity but are already struggling to meet demand. Examples were given of the long waiting lists they are trying to manage across Wales. They were unsure how they would meet targets, stating that even with additional financial resource, there is a lack of available, relevant expertise in the workforce. They showed certainty that meeting targets would reduce their ability to provide other services for this group. If there are to be further targets, professionals wrote that they would need time to prepare for them.

Expertise in Autism across pathways

5.3 In order to increase capacity for early diagnosis, it was repeatedly highlighted by professionals that competency to perform assessment and diagnosis needs to be developed in primary and secondary services within both Health and Social Care, not just in specialist teams such as the IAS. Currently, professional bodies had concerns that the expertise and capacity to do so is lacking. Further, they highlighted that differences in ND practice between health board services resulted in perceived patchy and unequal access for assessment and diagnosis for individuals. To remedy this, some respondents suggested that health and social care professionals, particularly GPs, need better awareness of the pathways that connect them, and better communication along these connections. Individuals supported these claims with anecdotes of being ‘bounced’ back and forth between services, and there were also queries as to why there was a wide neurodevelopmental pathway for children, but a much narrower one for adults.
Assessing and diagnosing autism with co-existing conditions

5.4 Unequal access to assessment and diagnosis was a particular concern with regard to autistic adults with co-existing conditions, such as learning disabilities or mental health. There was a worry that there is a lack of expertise to assess and diagnose these individuals in the relevant primary or secondary setting and it is not within the IAS’s remit to provide assessment services for them, meaning individuals struggle to access support anywhere. Respondents also stated that there needs to be increased expertise in autism with professionals working within the relevant primary or secondary setting, with regards to co-existing conditions beyond learning disabilities and mental health, which also need to be referenced in the code.

Clarity

5.5 A number of the answers also appeared unclear on what the remit of the IAS is, indicating that it would be helpful to outline this in the code. Further, it was repeatedly raised that the code is unclear on what “assessment” means, and the need to distinguish between diagnosis and assessment.

6. Responses to Arrangements for Accessing Care and Support

<table>
<thead>
<tr>
<th>Are the proposed requirements in this section right for service providers?</th>
<th>Agree</th>
<th>Tend to Agree</th>
<th>Tend to Disagree</th>
<th>Disagree</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>23</td>
<td>5</td>
<td>6</td>
<td>15</td>
<td></td>
</tr>
</tbody>
</table>

IQ

6.1 The most common response to this question concerned IQ. Many professionals and individuals welcomed the codes recognition that IQ should not be being taken into consideration to determine access to support. However one professional from the IAS suggested that the code should clarify that whilst IQ will not determine whether or not support is received, it may be taken into consideration to determine what type of support is received, in order to ensure that the support is appropriate to the individual.

Carer’s Assessments

6.2 The inclusion of carers assessments in the code was welcomed, but a number of individuals, both online and at our consultation events, stated that although they had been given a carers assessment, their assessed needs were rarely met, or their care packages delivered. There was a consensus that this should be monitored more closely to ensure commitments are delivered, and that parents and carers should be made aware of their rights to access an assessment.

Post-diagnostic support
6.3 There was a view amongst respondents that there is currently a lack of follow up support after diagnosis for both children and adults. This was reported anecdotally by individuals. Professional bodies explained that they felt squeezed towards providing diagnosis over support, with a concern that waiting time targets for diagnosis re-enforced in the code could perpetuate this unintended consequence.

6.4 A number of the IASs’ reported that the code’s duties would result in increased referrals for support to them, which they would be unable to provide given current resource. Alongside changes to funding, it was suggested that the code could prevent this by being clear about the support that is available in primary mental healthcare and support services and widening pathways out to include multidisciplinary practices and community care. Respondents suggested that this could help avoid duplication of support and could also help meet both the demand for support that the IAS is currently struggling to provide for, and any additional demand generated by the code.

Awareness of care and support pathways

6.5 A lack of clarity on the appropriate support services available, both within and outside of the IAS, was cited as a significant concern for many individuals, especially for those in rural areas. Alongside autistic people and their parents and carers being unaware of available support services, the consultation responses also showed a concern that professionals in health and social care did not know where to refer individuals for support, and were giving conflicting advice due to a lack of communication between services.

6.6 To address a lack of awareness of care and support pathways, there were three common suggestions. These were 1) a clear, easy to follow, illustrated pathway of support to be included in the code 2) more links to DEWIS 3) improved training of professionals on pathways, and of the Information, Advice and Assistance services within Local Authorities, to ensure the provision of adequate signposting.

6.7 In one area, respondents were concerned that there a lack of clarity about pathways for individuals with some co-existing conditions. Explicitly mentioned were autistic young people without a learning disability but with a mental health condition, who would be unable to access the IAS but also unable to access CAMHS. One respondent suggested this could be tackled by taking a more flexible approach to eligibility for support in some specific cases.

7. Arrangements for awareness raising and training

| Are the proposed requirements in this section right for service providers? |
|---|---|---|---|---|
| Agree | Tend to Agree | Tend to Disagree | Disagree | No Response |
| 16 | 25 | 6 | 4 | 14 |
Training is vital

7.1 There was a broad consensus that more training in autism is vital, with some welcoming improvements in awareness raising in recent years. However, many individuals stated that training programmes need to work harder to recognise autism as a spectrum, presenting in all individuals differently. It was important to many that training should be used as a tool to challenge stereotypes around autism rather than to enforce them, particularly around autistic women and Black and Minority Ethnic individuals (BAME). For some, updating training in line with new research and language was vital to this aim, and others stated that monitoring the quality of that training was similarly important. It was suggested that training needs to take into account different learning styles, and also to be available in Welsh.

Balancing between general awareness and specialist expertise

7.2 It was repeatedly stated that it is hard to source health and social care professionals with expertise in autism, especially with regards to co-existing conditions, and that it is a careful balancing act between building specialist teams e.g. the IAS, without draining expertise from more general ones in primary and secondary services. Training in more general teams was identified as tackling this issue, though its expense was highlighted, and the Royal College of GPs did warn that general health professional’s time is already very stretched.

Suggestions of who should be trained in Autism

7.3 The National Autistic Training Framework was welcomed by some as a tool, with two regarding it as ‘aspirational’. Whilst many agreed that training would need to be continual throughout careers, there was disagreement as to who should be trained in autism and to what degree. The strongest consensus was that teachers need training in autism and that education needs further recognition here, others believed that all social and health care staff need training whilst others extended this to including any businesses with a public facing role, suggesting trained businesses could be given accreditation. Some commented that they would like to see a record of who has been trained.

8. Planning, Monitoring and Stakeholder Engagement

8.1 This is one section in the code. It had three consultation questions, in order to effectively address its three parts: planning, monitoring and stakeholder engagement. One overarching theme that came up across all three of these was that there needs to be more clarity on the autism champion role. Respondents wanted a clearer description of the champion’s role responsibilities and powers. They wanted clarification on whether champions would replace ASD leads and to know if the role was suitable for one
individual rather than multiple, given the level of responsibility and geographical area that the role seemed to cover.

Planning

| Are the proposed requirements in this section right for service providers? |
|-------------------------------|----------------|----------------|----------|----------|
| Agree                         | Tend to Agree | Tend to Disagree | Disagree | No Response |
| 22                            | 21            | 5               | 3        | 14        |

8.2 A large number of respondents confirmed that it was positive that the code was making autism a stand alone theme in population assessments. However, there were warnings that it could lead to duplication as autistic individuals were recorded by multiple services. There were also uncertainties around how broad neurological differences would be captured in data, and respondents linked this back to wider criticisms of the code as placing too much emphasis on a diagnosis at the expense of those without one and of treating individuals according to their needs. Some asked why education wasn’t listed as a data source, given the wealth of data held there, and others asked why secondary and tertiary services and the third sector were not explicitly identified as data sources, or as needing to make adaptations to their provision of services for autistic people.

Monitoring

| Are the proposed requirements in this section right for service providers? |
|-------------------------------|----------------|----------------|----------|----------|
| Agree                         | Tend to Agree | Tend to Disagree | Disagree | No Response |
| 22                            | 19            | 3               | 5        | 16        |

8.3 This section gained support for its encouragement of integrated working and in the aspiration that it would offer consistency across Wales. There was the acknowledgment though, that this section would be hard to deliver due to a current lack of connections between services and the third sector, different IT systems and different ways of working within services. However some of those who responded thought that the code needed to encourage further monitoring, with the collection of data in relation to assessment, diagnosis and intervention for instance. Others were unclear on what data would actually be collected or monitored, and would appreciate further clarity.

8.4 Whilst some asked for clarification on what ‘Welsh Government waiting time standards’ were, the collection of waiting time data was seen as positive by some. However, others believed that waiting time data alone would not necessarily capture the whole experience of families moving along pathways, for instance some could be receiving support during waiting times, which would not be recorded. As such, the mention of the collection of qualitative evidence was welcomed.
Stakeholder engagement

| Are the proposed requirements in this section right for service providers? |
|---|---|---|---|---|
| Agree | Tend to Agree | Tend to Disagree | Disagree | No Response |
| 21 | 14 | 6 | 4 | 20 |

8.5 It was clear that many respondents supported increased representation and involvement of autistic people. This was discussed in relation to a number of areas within service provision, whether that be in the co-production of training materials, the delivery of training, having an autistic presence in stakeholder groups as part of service design, planning and monitoring. If autistic people were to be further involved, some respondents remarked that they firstly need to be representative of the autistic population, not just the most vocal stakeholders or interest groups; that representatives should not just be tokenistic and the Children’s Commissioner added that children and young people should also be included. Some commented that autistic people should be remunerated for their involvement in services in the same way that any professional would be.

8.6 It was remarked that this section would benefit from further clarity on whose role it is to engage with autistic people, and for it to recognise the importance of the involvement of the third sector. In order for stakeholders to feel included in the Welsh autistic community and the services offered within it, individuals asked that information on opportunities to be involved in the delivery of them be shared online all across Wales.

9. Positive and Negative Impacts on Protected Characteristics

9.1 Some participants agreed that this would have positive effects on the characteristic of ‘disability’ because of the support it would give to autistic individuals, and many welcomed the support it would give to autistic adults in particular, whom they felt had previously been without much support. For other respondents, there was a concern that a code could have a negative impact on ‘disability’ because the focus on autism diagnosis could negatively impact an individuals’ ability to access services without one. It was appreciated that there was specific mention of women and girls and BAME individuals in the code, but it was stated that these groups are still being misunderstood and their needs need to be kept in mind across all four areas of the code. Some commentators were doubtful that it would have any impacts, positive or negative, without additional resource.

10. Impacts and Opportunities for the Welsh Language

10.1 Many comments in relation to this theme surrounded respondents wanting services to be delivered bilingually if needed, and for autistic people to be able
to communicate with their service providers in Welsh if they wanted to. However, there was also a recognition that it was difficult to find staff with the necessary expertise who could also speak the Welsh language. It was important for some that training be delivered in Welsh and materials also be provided in Welsh, though some individuals welcomed that autistic individuals were not required to learn the Welsh language at school because of the pressure they already felt from learning English.

11. Cross-cutting issues

Collaborative working

11.1 Overall respondents welcomed the encouragement of collaborative working. This was both in regard to multi-agency professional connection and to co-production with autistic people and their parents and carers. There was great support for the need to increase awareness of and training in autism across all sectors. However, a large number of respondents thought that linkages could go further, particularly with education and the Additional Learning Needs and Educational Tribunals Act (2018).

Resource

11.2 Whilst most respondents broadly agreed with the proposals, a common concern for individuals and professional bodies alike was that, without additional resource, it would be unable to deliver on these commitments. They spoke of how the code would raise expectations amongst stakeholders of an already overstretched system. In particular, there were concern from services about the Integrated Autism Service (IAS) being expected to fulfil a level of support which may be unrealistic given current resourcing, and one that extends much further that its original remit, which many were also unclear on. They worried that this pressure could potentially lead to a fall in the quality of service currently provided by the IAS.

11.3 Whilst individuals were largely supportive of the proposals placing importance on an autism diagnosis; professional respondents felt that the code focused too heavily upon it throughout all four of the areas. They gave a number of reasons for this concern. Firstly, because diagnosis-specific legislation moves away from the Social Services and Wellbeing (Wales) Act 2014 needs based approach to services. Secondly, because linking eligibility criteria for services to an autism diagnosis could result in reduced services and support for individuals with a high level of need but no autism diagnosis or a different neurological diagnosis. Thirdly, because cementing the importance of autism diagnosis and introducing waiting time targets would divert resource away from pre and post diagnostic support.
Powers

11.4 In all areas of the code, respondents, and particularly interest groups, wanted to know how the duties would be enforced, and clarity on the difference between ‘must’, ‘should’ and ‘could’ duties. They wanted to know the process for both Ministers and individuals to challenge local authorities and health boards who were not complying. They suggested that more clarity on Ministers’ powers would be helpful, that the code should provide diagrams of clear, easy to follow pathways and expected timelines to which individuals could hold local authorities and health boards account, and that there be some provision or linkages to advocacy services to support this.

Clarity

11.5 A final cross-cutting issue surrounds the issues many raised with language and structure throughout. Many respondents highlighted a lack of consistency in the language used, that it was confusing in places, and that some terms needed better defining, especially the term ‘assessment’. Solutions suggested for these issues were to use uncomplicated language, to provide a glossary, to provide links to online resources and to give examples where appropriate. Another issue of language was the interpretation of the consultation form’s use of the term requirements being right for ‘service providers’. This may have been interpreted as are these the right duties to place on providers, rather than placing an emphasis on the rights of autistic people themselves. There was a worry from a number of respondents that could this could create dependency on services, rather than empowering autistic people to achieve their own wellbeing outcomes as part of a social model.

12. Conclusion and Next Steps

12.1 The consultation found that most respondents supported the proposals with suggestions for improvement and expansion. In many areas further clarity was sought and more detail requested on specific duties and on how the improvements would be delivered and monitored.

12.2 The main recommendations which have emerged from the consultation are summarised below, many have also been echoed by other feedback received through the recent evaluation and the scrutiny committee reports.

- A clear explanation is needed on how an autism code aligns with a needs based approach to services, as advocated in legislation such as the Social Services and Wellbeing (Wales) Act 2014.
- The code should be carefully balanced between assessment, diagnosis and the provision of direct support services.
- There should be more detail on pathways for assessment and support, including those for people with co-existing conditions, including and beyond mental health and learning disabilities.
• There should be better access to information on how to access support. This should be available across services, including primary and secondary care, and on support during transition.
• A clear explanation should be provided on how the powers in the code would be exercised to ensure compliance by public bodies.
• More information should be included on the role of the autism champion in Regional Partnership Boards.
• The code needs to have a clear written style and full glossary.
• More information should be included on how the duties around workforce training will be delivered in order to improve knowledge and skills in different parts of the workforce.
• There were significant concerns that a code would place substantial additional pressures on already stretched services, and questions as to how this would be acknowledged and addressed.
• The approach to collaborative working was welcomed, with agreement that autistic people need to be at the centre of service design and delivery.
• More clarity is needed on how the code links to education and Additional Learning Needs reform.
• There needs to be more recognition and links to the importance of third sector involvement in the delivery of services.
• More detail on the data collected to monitor service delivery.

13. Finalising the Draft Code

13.1 Technical groups are being established to provide advice and guidance on the development of the draft code. Members will include autistic people, parents and carers, professionals from a range of services including, mental health, local authorities and education. We will also ensure that we organise meetings across Wales and will seek the views of autistic people and their families separately.

13.2 The technical groups will consider the feedback provided through this consultation and other reports such as the recently published autism evaluation and reports of the National Assembly scrutiny committees in relation to proposals for autism legislation. The recommendations from these report are at Annex 2. We aim to publish the draft code for a further public consultation by the end of the year, when we will organise further public consultation events.

13.3 We want the final code to remain up to date for as long as possible. As many of the responses to this consultation are requesting more detailed information on how the code will be delivered and monitored, there may be a need to provide additional guidance for the main code which can be update regularly as service arrangements progress. We will work ensure that this guidance is co-produced with autistic people.
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.

**Carer’s Assessment**: A carer is defined in the Social Services and Wellbeing (Wales) Act 2014 as a person who provides or intends to provide care for an adult or a disabled child. A carer’s needs assessment is a legal entitlement and is for all carers who, regardless of their age, care for someone who is disabled, ill or elderly. The assessment is carried out by the carer’s Local Authority. The Local Authority will assess the carer’s needs to see what support or services may be needed to help carry out their caring role.

**DEWIS**: DEWIS Cymru is an online service which provides information about well-being in Wales. It has information about well-being and support, along with information about local organisations and services that can help!

**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.

**Integrated Autism Service**: The Strategic Action Plan acknowledged gaps in services for some autistic people, particularly as many may not be assessed as having eligible social care support needs under the Social Service and Wellbeing (Wales) Act 2014. We recognise that many autistic people may none the less have significant support needs, which if not addressed could escalate and result in the need for more intensive service interventions. The Integrated Autism Service offers a service which provides targeted support and assistance for autistic people and their families and carers.

**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.

**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. The National Autistic Training Framework: This has been developed by the National Autism team and describes what level of Autism training is recommended for different roles based on their involvement with Autistic individuals. It also recommends useful resources.  

**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. The easy read version can be found here:  

**Transition:** Moving between different stages of life, such as school, college and work. This can be challenging for many Autistic people.

**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 65 complete responses were received through online forms and emailed letters. A total of 27 responses were received from individuals and parents. The remaining 38 respondents are listed below:

Third Sector
Alcohol Change UK
National Autistic Society Cymru
Pembrokeshire People First
The AWE Project
All Wales People First

Professional Bodies
All Wales Orthoptic Advisory Committee
Charted Society of Physiotherapy in Wales
Royal College of Nursing Wales
Royal College of Psychiatrists in Wales
Royal College of General Practitioners Wales
Royal College of Paediatrics and Child Health Wales
Royal College of Occupational Therapists Wales
Royal College of Speech and Language Therapists Wales
Welsh NHS Confederation

Public Bodies and Statutory Bodies
Information Commissioner’s Office – Wales
Board of Community Health Councils
Welsh Language Commissioner
Children’s Commissioner for Wales
Welsh Local Government Association
Flintshire Local Voluntary Council
Hywel Dda University Health Board
North Wales Community Health Council
Powys Regional Partnership Board’s Live Well Disability Partnership Group
Wrexham County Borough Council – Education Inclusion Service
Directors of Therapies, Health Care Scientists and Psychology in Abertawe Bro Morgannwg University Health Board
Social Care Wales
Carmarthenshire County Council
Flintshire County Council
Ceredigion County Council - Autism Spectrum Monitoring Groups for adults and for children
Betsi Cadwaladr University Health Board
Conwy County Borough Council Social care and Education Department
West Wales Care Partnership
Cwm Taf University Health Board
Wrexham Educational Psychology Service

Universities
Centre for Academic Success, Swansea University

Integrated Autism Service (IAS)
North Wales Integrated Autism Service
Gwent Integrated Autism Service
West Wales IAS Regional Strategy Group
## Annex 2: Recommendations from reports related to Welsh Autism Services

<table>
<thead>
<tr>
<th>REPORT</th>
<th>RECOMMENDATION</th>
</tr>
</thead>
</table>
| Report on consultation on proposals for autism code of practice        | - A clear explanation is needed on how an autism code aligns with a needs based approach to services, as advocated in legislation such as the **Social Services and Wellbeing (Wales) Act 2014**.  
- The code should be carefully balanced between assessment, diagnosis and the provision of direct support services.  
- There should be more detail on pathways for assessment and support, including those for people with co-existing conditions, including and beyond mental health and learning disabilities.  
- There should be better access to information on how to access support. This should be available across services, including primary and secondary care, and on support during **transition**.  
- A clear explanation should be provided on how the powers in the code would be exercised to ensure compliance by public bodies.  
- More information should be included on the role of the autism champion in **Regional Partnership Boards**.  
- The code needs to have a clear written style and full glossary.  
- More information should be included on how the duties around workforce training will be delivered in order to improve knowledge and skills in different parts of the workforce.  
- There were significant concerns that a code would place substantial additional pressures on already stretched services, and questions as to how this would be acknowledged and addressed.  
- The approach to collaborative working was welcomed, with agreement that autistic people need to be at the centre of service design and delivery.  
- More clarity is needed on how the code links to education and **Additional Learning Needs reform**.  
- There needs to be more recognition and links to the importance of third sector involvement in the delivery of services.  
- More detail on the data collected to monitor service delivery.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
<p>| ASD Strategic Action Plan Main evaluation April                         | <strong>Recommendation 1.</strong> The Welsh Government and the National Autism Team should review the communication strategy, to provide clarity about the IAS role and remit.                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |</p>
<table>
<thead>
<tr>
<th>Recommendation</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. <strong>Recommendation 2</strong></td>
<td>The Welsh Government and the National Autism Team should identify how more information about the progress in establishing the IAS, the challenges encountered, and its performance, can be appropriately shared with (i) stakeholders involved in the development and establishment of the IAS (e.g. through the National Advisory Implementation group and the community of practice) and (ii) autistic adults, children and young people and their families, and the general public, through, for example, ASDInfoWales and local ASD steering groups.</td>
</tr>
<tr>
<td>3. <strong>Recommendation 3</strong></td>
<td>The Welsh Government, National Autism Team and RPB Autism Champions should continue to monitor the continuing development and performance of the first five IASs (Cardiff and Vale, Cwm Taf, Gwent, Powys and North Wales) and the establishment of the two remaining services (Western Bay and West Wales).</td>
</tr>
<tr>
<td>4. <strong>Recommendation 4</strong></td>
<td>The Welsh Government, National Autism Team and RPBs should review the adequacy of overall funding for the IAS, given the demand for assessment and diagnosis, support and collaborative work with other services.</td>
</tr>
<tr>
<td>5. <strong>Recommendation 5</strong></td>
<td>The National Autism Team should ensure that monitoring consistency through compliance with the IAS’s national standards is complemented by a benchmarking of outcomes across IASs. This should be done intelligently and the reasons for differences in outcomes explored; for example, differences in resources and context are likely to impact upon outcomes. Improvements in the measurement and reporting of outcomes using Outcome Stars will be crucial to enable this.</td>
</tr>
<tr>
<td>6. <strong>Recommendation 6</strong></td>
<td>The Welsh Government and National Autism Team should review the apportionment of funding to each IAS in the light of the evidence of the demand for each service.</td>
</tr>
<tr>
<td>7. <strong>Recommendation 7</strong></td>
<td>Each IAS should periodically review its work with other services to ensure that a strategic approach is taken, and that engagement with different services is prioritised (e.g. which services are engaged with as a priority) and planned. Opportunities to involve autistic adults and also family members in this review should be taken.</td>
</tr>
<tr>
<td>8. <strong>Recommendation 8</strong></td>
<td>The Welsh Government, National Autism Team and RPB Autism Champions should</td>
</tr>
</tbody>
</table>
examine how the interface between the IAS and other services develops, including, in particular, its impact upon access to mental health services and social care and upon outcomes for autistic adults and parents and carers.

**Recommendation 9.** As outlined in the draft Autism Code of Practice, “Local Health Boards must ensure healthcare professionals have the knowledge and training in autism they need to undertake their roles”. As part of this, LHBs should review assessment and diagnosis practice in adult mental health and learning disability services and, where needed, invest in workforce development to address confidence and skill gaps.

**Recommendation 10.** IASs should continue to monitor the profile of autistic adults accessing the service in order to assess how well suited the IASs’ support offer is to the needs of different groups, such as autistic adults, those with mental health difficulties and those with sensory needs. This should be informed by analysis of data on outcomes.

**Recommendation 11.** IASs should assess the capacity of the service to respond to changes in people’s circumstances and needs; for example, this could include monitoring the numbers of autistic adults who receive a short term, outcome focused intervention, and who subsequently re-engage with the IAS at a later point, when their circumstances or needs change.

**Recommendation 12.** The National Autism Team and IASs should continue to monitor and evaluate the extent to which the interventions and support they offer for adults and parents and carers meets their needs. Where gaps in support are identified, consideration should be given to whether IASs should develop their offer and/or work with others services to meet the need.

**Recommendation 13.** The National Autism Team should work with IASs, RPBs, voluntary sector and service users, to consider the scope and ambition of the IAS; for example, should the IAS (i) focus its work upon a small number of services such as mental health, learning disability and social care services, or (ii) should it seek to take on a more ambitious agenda, to also work systematically with other services such as leisure, employment and housing services? This should consider both which organisation/s are best placed to deliver this, and their capacity to do so.

**Recommendation 14.** The Welsh Government and National Autism Team should work with other stakeholders
to explore where responsibility for regional and local ASD policy development should lie.

**Recommendation 15.** As the IAS becomes firmly established, the Welsh Government, National Autism Team, RPBs, PSBs and Local ASD Leads should work with autistic adults and their families, and the voluntary sector, to identify the next priorities for action; for example, support in education, for **transitions** and employment appear to be key unmet needs, but is too early to judge if actions in the refreshed autism strategy are sufficient to address this.

**Recommendation 16.** The Welsh Government should ensure that the impact of the new Autism Code of Practice is evaluated and that, for example, the impact upon access to social care is considered.

**Recommendation 17.** As far as possible, future evaluations of other key elements of the autism strategy, such as the Employability Programme and ALN Transformation Programme, should be required to identify and report on their impact upon autistic people.

**Recommendation 18.** Local Health Boards and Local Authorities hosting IASs should monitor staffing and the impact of decisions about terms, conditions and pay upon services’ budgets and their ability to recruit and retain staff.

**Recommendation 19.** IAS should work with the National Autism Team and RPBs to ensure the evidence needed to inform decisions about the long term funding is available.

**Recommendation 20.** The Welsh Government should make its expectations about long term funding of the IAS clear; for example, whether the expectation is that if the model is proved cost effective, it will continue to be funded through the ICF, or if, for example, LHBs and LAs will be expected to fund the service after March 2021.

**Recommendation 1.** We recommend that the Welsh Government directs the Integrated Autism Services to improve the consistency of the services across the regions, to ensure a national approach, and reports back to the Committee within six months. We also recommend that they produce clear public information to clarify what people can expect from the Integrated Autism Service.

**Recommendation 2.** We recommend that the Welsh Government increases the provision of direct ASD
| Recommendation 1. | Support services across Wales (beyond the services currently offered by the Integrated Autism Service), and ensures vital third sector services receive sustainable funding to continue and expand their specialist support services, which are providing direct frontline support and plugging the gaps which the Integrated Autism Services cannot deliver. |
| Recommendation 3. | We recommend the Welsh Government takes urgent action to address the clear need for employment support for adults with ASD. There must be a clear pathway for adults to be able to access support to assist them into employment. Careers Wales should play a greater role but there is also a case for providing additional funding to third sector agencies to deliver specialised employment support services. |
| Recommendation 4. | We recommend that the Welsh Government amends the Codes of Practice for Parts 3 (assessing the needs of individuals) and 4 (meeting the needs) of the Social Services and Well-being (Wales) Act 2014 to include specific provisions on ASD. |
| Recommendation 5. | We recommend that the Welsh Government instructs Health Boards and local authorities to ensure there are multiple, appropriate, clear referral pathways available to all, including a specific primary care pathway, and that existing barriers between the health, care and education sectors are removed, for example to enable GPs to refer children for education support. |
| Recommendation 6. | We recommend that it should be mandatory for all school staff (particularly teachers and teaching assistants) to receive training in awareness and understanding of ASD, during their initial teacher training and as part of their continuing professional development. |
| Recommendation 7. | We recommend that the implementation of the Additional Learning Needs and Education Tribunal (Wales) Act 2018 is closely monitored to assess whether it meets the needs of children and young people with ASD considered “high functioning” and who do not have a co-occurring learning disability. |
| Recommendation 8. | We recommend that, if the Bill proceeds to Stage 2, an amendment should be brought forward to ensure that Judicial Review is not the only route available for individuals to assert their rights. |
| Recommendation 9. | We recommend that the Welsh Government’s Code of Practice makes provision to ensure that individuals can access appropriate information and support in their language of choice. |
| National Assembly for Wales, Finance Committee. Autism (Wales) Bill Stage One Report. | **Recommendation 1.** In future, should the Assembly vote in favour of the motion tabled in accordance with Standing Order 26:91 the Committee recommends that the Welsh Government commits to providing information to ensure that costs in an explanatory memorandum are as comprehensive and detailed as possible utilising cost information which the Welsh Government has available. |