



Llywodraeth Cymru
Welsh Government

The Report of the ASD Adult Diagnostic Task and Finish Group April 2016

The Assessment and Diagnosis of Adults with
Autistic Spectrum Disorder in Wales

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Recommendations of the Welsh Government Autistic Spectrum Disorder Diagnostic Task and Finish Group

Introduction

1. The Autistic Spectrum Disorder Diagnostic Task and Finish Group was established by the Welsh Government in 2015 to provide advice to the Minister for Health and Social Services on ASD diagnostic services for children and adults. The recommendations made by the group would be used to inform the refresh of the Autistic Spectrum Disorder Strategic Action Plan (ASD SAP) which was being developed at this time. As a matter of priority the group considered concerns raised by the National Assembly for Wales Petitions Committee in relation to waiting times for ASD diagnosis for children and was requested to provide expert advice on diagnosis and, pre and post diagnostic support for both children and adults.
2. In May 2015 the Minister for Health and Social Service announced new funding to support the Together for Children and Young People Programme (T4CYP); £2m recurring funding has been specifically allocated for neurodevelopmental conditions including ADHD and ASD. To avoid duplication members of the task and finish group representing children's services transferred their membership to the T4CYP neurodevelopmental implementation group. The Terms of Reference are at appendix one
3. The terms of reference for the task and finish group were amended from 19 November 2015 to focus on advice and recommendations for adult diagnosis and post diagnostic support only. Both groups retained some shared membership including representatives from Public Health Wales and Welsh Government. The adult group also co-opted the membership of the Adult ASD Expert Advisory Group; the latter had been maintained as part of the Welsh Government's interim ASD delivery plan. The membership of the group is at appendix two.
4. The remit of the reformed adult diagnostic task and finish group is to provide advice and recommendations in relation to:
 - Minimising diagnostic waiting times for adults.
 - Establishing a consistent framework for diagnosis which complies with NICE¹ guidelines on the referral, assessment and diagnosis of adults with ASD.
 - Consolidating the achievements made by the Adult Diagnostic Pre/Post Counselling Network.

¹ National Institute for Health and Social Care Excellence

- Identifying and sharing good practice in assessment and pre and post diagnostic support services.
- Ensuring links between the T4CYP neurodevelopmental work stream are established and maintained to ensure synergy of approaches to diagnostic practice, post diagnostic support and transition processes.

Strategic Context

5. The Welsh Government published the ASD Strategic Action Plan in 2008 (ASD SAP), the priorities for action included, considering the needs of adults with autism who required access to diagnostic services and support. An adult task and finish group was subsequently established to agree and facilitate a standardised approach to assessment, to develop and deliver training for clinicians and to enable sharing of best practice. Acting on the recommendations of the Adult group, in 2011 the All Wales Autistic Spectrum Disorder Diagnostic Pre/Post Counselling Network for Adults was established. The Network was hosted by Betsi Cadwaladr University Health Board, between 2011- 2014 and by Aneurin Bevan University Health Board in 2014-2015. During this five year period the Welsh Government provided the health boards with £1.041 million to take forward the identified priorities for action co-ordinated by the Adult Diagnostic Network.
6. Since 2011 the Adult Diagnostic Network members have met each month to develop and deliver a consistent approach to adult ASD diagnostic and post diagnostic support. Progress has been achieved, a standard assessment pathway has been developed and promoted across health boards and training has been rolled out to clinicians. However members found that improvements were only being driven by clinicians engaged with the network, as there has been an absence of strategic direction for autism services across health boards.
7. In May 2015 the Welsh Government published the Interim Delivery Plan for the ASD SAP, which was being refreshed. The actions included undertaking a scoping exercise to understand the benefits of integrated autism services which were available in other parts of the UK, this would include assessing how the needs of adults could be met as part of this approach.
8. The ASD SAP has been refreshed with the support of an ASD stakeholder advisory group, which has taken into account available evidence, including consultation and engagement with stakeholders and the key findings of the independent outcomes evaluation of the first ASD SAP. The group also considered the outcomes achieved by the ASD Interim Delivery Plan published in 2015. The refreshed action plan takes an all age approach, the consultation document published in March 2016, focuses on four priority areas, awareness raising and training, assessment diagnosis and support, addressing unmet support

needs and education and employment. All of these areas include consideration of services for adults with autism.

9. The ASD Diagnostic Task and Finish Group has considered the legacy of the Adult Diagnostic Network and has taken into account the future policy direction of the ASD SAP. Members have also considered wider Welsh Government legislation and policy direction which is focussed on improving well being, with an emphasis on early intervention and prevention, receiving appropriate support (no more, no less) and reducing inappropriate variation via the use of evidence based practices. The key areas considered include the Well-being of Future Generations (Wales) Act, the Social Services and Well-being Wales Act (2014), the Prudent Health Care Agenda and the Welsh Government Together for Mental Health Strategy.
10. The task and finish group have also considered the improvements being developed as part of the Together for Children and Young People programme (T4CYP) neurodevelopmental work stream. Close links have been established with members of the T&F group being involved in the Neurodevelopmental Implementation Group which was established in September 2015. This group is working to develop a standardised children's diagnostic pathway to be implemented across Wales which is NICE compliant.

Current Position

Review of current service provision for adults

11. The ASD Adult Network was successful in developing a standardised diagnostic assessment approach which was NICE compliant. This paved the way for consistency of diagnostic assessment across health boards whilst enabling some local flexibility in the way in which these services were delivered.
12. To support the work of the ASD Diagnostic Task and Finish Group a review into current service provision was undertaken by the ASD National Development Lead. The report - *Assessment and Diagnosis of Autistic Spectrum in Wales* although highlighting the progress made, clearly demonstrated that a more robust strategic approach was required to place ASD diagnosis and support on a sustainable footing.
13. It was found that whilst the majority of diagnostic assessments met the set agreed criteria in most health board areas, there remained some variation across health boards and sometimes within health boards, which has resulted in there continuing to be an inconsistent picture across health boards.
14. The review also found significant variance in access to diagnostic services across Wales, although data collection was not reliable,

overall it was found the minimum waiting time being two months and the maximum waiting time being 18 months.

15. The key findings of the review acknowledged the commitment and dedication of the clinicians in the Adult Diagnostic Network, their work being the catalyst for developments at the health board level. The network however did encounter many barriers to achieving the improvements they were seeking to embed within health boards. These are reflected in the key findings of the review which were:

- Data in relation to the time individuals wait for a diagnostic assessment is not routinely collected, and in some cases is incomplete or unavailable.
- There is inequality of access to ASD assessment. In some areas people may not be able to access diagnostic assessment if they do not have a coexisting mental health issue or learning disability.
- There is inequality of provision, related to the skill mix available which varies across health boards - with diagnostic services being provided by different professional groups.
- Waiting lists vary across health boards, and appear to be increasing.
- There is a lack of guidance (and therefore consistency) in relation to who should undertake the diagnostic assessment, and whether it should be in primary or secondary care, in a single specialist service or in local, non-specialist teams. Such a variety of service models may lead to inappropriate variations in practice and service costs.
- Training undertaken has met some of the needs of professionals but further training is required for a range of staff at both an undergraduate and post graduate level.
- Despite there being a number of good examples the provision of good quality written information is not widely available across Wales.
- Significant gaps in on-going support for adults with ASD following diagnosis remain.
- Governance and reporting structures for ASD work within Health Boards are often unclear.
- In some areas, there is a lack of strategic commitment at a health board level. Where service development has taken place it may not be sustainable as it has often been reliant on Welsh Government short term funding and has been led by interested and committed clinicians.

There appears to be a number of significant challenges to achieving good multi-agency working, particularly when seeking to support effective transitions from child and young people's services to adult services.

Stakeholder Feedback

During 2015 the ASD National Development Lead undertook a series of on-line surveys and direct engagement with people with autism and their parents and carers. One of the on-line surveys was aimed at adults with ASD, asking individuals about the support they received and their wider support needs.

There were 130 respondents to this survey although not all completed all questions. Data collected by the community monitoring and support projects during 2014 also provided information on individual's support needs, which has contributed to the intelligence about the delivery of autism services in Wales.

The consultation identified gaps in provision and issues that are experienced as being broadly similar for children and adults, and there is a similar pattern of unmet needs reflected across all activities undertaken.

Concerns were highlighted regarding the assessment and diagnosis process (children) in several areas, with many families experiencing difficulties in accessing diagnostic assessment. The major issues impacting on families appear to be:

- Long waiting times
- Lack of information prior to, during and following completion of the diagnostic assessment
- Little or no provision of advice and support at point of, and immediately after diagnosis

Feedback gathered from other informal sources, also reflect that this situation is likely to be similar for adults seeking support services, though this issue was not drawn out in this consultation.

With regard to ongoing support and provision the most frequently reported areas of unmet need across children and adults are:

- Support for emotional / behavioural issues
- Support for ASD specific issues and life skills
- Access to social and leisure opportunities within own community

In addition the lack of support for employment was a frequently reported as an unmet need for adults.

Assessment and Analysis of the current situation

For many individuals the benefits of being able to access a timely and high quality diagnostic assessment can be significant. A meaningful assessment can;

- Enable the individual to understand about their condition, strengths and why they may find some things difficult.
- Support the individual to access appropriate support moving forward.
- Help the people around the individual such as family, friends or work colleagues understand more about the individual and how they best be able to support them.

The task and finish group have considered all of the evidence presented on current service provision, professional experience and stakeholder feedback. Five clear themes have emerged which require further exploration and action to be taken to secure sustainable improvement. The five themes identified are:

- Equality in access and service provision
- Post diagnostic support.
- Training and development needs
- Acknowledging a wider neurodevelopmental and mental health perspective
- Strategy and governance for autism services

Equality of Access and Service Provision

The evidence demonstrates an inequality of access to ASD diagnostic assessments and significant variances in provision of services across health boards which should be addressed. This included significant differences in diagnostic waiting times between health board areas. Although the Adult Diagnostic Network has influenced planning for sustainable services in some areas, this isn't a consistent pattern and in some areas services may have diminished.

In view of the investment in neurodevelopmental diagnostic services being developed as part of the T4CYP programme, there is a corresponding need to develop sustainable adult diagnostic services as autism is a life long condition. Any new service development should ensure there is an appropriate service model and skill mix in each area. There is also a need to assess whether each health board is compliant with NICE guidelines and to provide more opportunities for peer multi-disciplinary consultation. There could also be more provision for targeted diagnostic work for some individuals with other neurodevelopmental conditions known to have projected high rates of autism.

Support Post Assessment

The ASD Adult Diagnostic Network diagnostic pathway set standards which included immediate personalised post diagnostic support including aspects of education, counselling and signposting. There has been wide variability in the delivery of this aspect of the pathway, with some authorities having dedicated counsellors, and in other areas post diagnostic support is minimal.

Individuals with an autism diagnosis often require different types of support according to their needs, which may vary from support for needs arising directly from having ASD, or assistance to address multiple areas of unmet need, such as support with employment, daily living, relationships and sometimes arising out of contact with the criminal justice system. The needs of this group may also extend to support for co-existing mental health and behaviour problems. The ASD SAP has supported the development of written guidance – *Autism: A Guide for Individuals Following Diagnosis*, which is used by some areas to provide some information and advice.

The refreshed ASD SAP recognises the unmet needs of some adults with autism and it is clear that more needs to be done to provide low level preventative interventions for some people with ASD, to de-escalate problems and to avoid the need for more intensive interventions.

Training and Development

Implementation of the ASD Strategic Action Plan to date has involved initiatives to improve awareness and recognition of ASD. The impact of this training has been variable across Wales, although significantly more targeted training and awareness raising is being developed as part of the ASD Interim Delivery Plan. A training package for secondary mental health and learning disability practitioners has been developed and delivered in a number of areas and a further training package is being developed for primary health care professionals.

The ASD Adult Diagnostic Network had some success in delivering training for clinicians in evidence based diagnostic methods in all health board areas. Unfortunately the opportunity for clinicians to put these new skills into practice has been limited and a structured approach is needed to focus on the training needs of clinicians where there are identified gaps in knowledge and skills.

As part of an improved strategic approach to autism, health boards and their partners should consider the training and development needs of the existing workforce, which would include both assessment services and post diagnostic support.

Acknowledging a Wider Neurodevelopmental and Mental Health Perspective

Individuals with autism often have more than one developmental disorder. Evidence demonstrates that at least 50 % of people with ASD will also have a learning disability of varying severity and between 30 and 50 % of people with ASD show features of ADHD. There is a case to be made to consider wider neurodevelopmental disorders when developing adult autism services.

Further complexity arises as some people with neurodevelopmental disorders will have a high vulnerability to additional mental health problems. The T4CYP programme has acknowledged these complexities for children and young people and the ongoing risks of missed or inaccurate diagnoses, increasing risks and disability, inappropriate and unsuccessful interventions with impaired efficacy. There is therefore a corresponding need to address additional complex needs in the adult population.

Strategy and Governance

Both the review of current adult diagnostic provision and the experience of the Adult Network members demonstrate that in many areas there is a lack of clarity about health board or multi agency responsibilities for autism services.

The review found that it was difficult to identify evidence of consistent and executive board leadership for autism or wider neurodevelopmental issues within health boards. It also found that there was little wider engagement between agencies concerning services for people with ASD. An analysis of the membership of local ASD steering groups established as part of the ASD SAP revealed that less than half had membership from adult mental health or learning disability services. There was little evidence of joint working or joint responsibility agreed between agencies and in some cases this resulted in duplication of services.

A clear strategic direction and improvements in governance is required to address issues around responsibility for autism services both within health boards and between agencies, particularly health and social care. These concerns were also reflected in the feedback received from the stakeholder consultation, where individuals reporting difficulty in accessing services, which was especially true for transition support.

Recommendations

The development of the refreshed ASD Strategic Action Plan has included a commitment to develop an integrated autism service for Wales. This new investment is welcomed and members of the task and finish group believe that such an investment could provide an opportunity to reduce the length of time individuals and their families wait for a diagnostic assessment and improve outcomes for individuals via access to appropriate support.

The task and finish group would endorse a service model which covers the entire life span and includes adult diagnostic services, the provision of post diagnostic support and the delivery of appropriate interventions and support at the right time delivered by a skilled and competent workforce. It will be essential to ensure that there is effective multi-agency planning at a local/regional level to ensure the new services are developed and implemented in line with evidence based practice. It will also be important for appropriate evaluation and that a robust monitoring system is put in place.

As new services are developed for adults with autism it will be crucial to consider the evidence presented by the ASD Diagnosis Task and Finish Group to ensure that new services are developed which build on existing provision, addressing current gaps in services and support workforce development.

The following recommendations should be taken into account when developing and delivering an integrated autism service for Wales.

Strategic Planning, Leadership and Governance and equality of Access

- The Task and Finish Group note that the recently formed Regional Partnership Boards will be required to take a key role in overseeing the strategic development of the integrated service. It is believed that this will provide an opportunity to develop a co-ordinated multi-agency

approach to autism services and secure senior commitment from key agencies.

- In addition to the role of the Regional Partnership Board it is recommended that Welsh Government give further consideration as to how to raise the profile of service provision for people with ASD at a board level within Health Boards. One possibility could be to request health boards to appoint an Executive or Independent Member ASD champion.
- As autism is a life long condition it is important that multi-agency regional planning acknowledges the need to plan and develop support for individuals across the life span.
- A NICE compliant pathway for adults as developed by the Adult Network, should be promoted and a supporting toolkit developed, reflecting the principles of Prudent Healthcare.
- The single assessment pathway should be agreed across health boards providing diagnostic services for all referrals, including individuals with or without co-morbid learning disability or mental health diagnosis.
- To reflect NICE best practice, a multi-agency steering group covering the entire life span should be established to oversee and support the implementation of the integrated service for each health board foot print area.
- It is important for local regions to ensure that they develop mechanisms to enable people with autism and their families and carers to actively contribute to the development of new service models and initiatives as meaningful partners.
- The new integrated autism service must align the work of the T4CYP programme for children and young people, to ensure there is a life span approach to service delivery.

Training and Development

- There should be an ongoing, sustainable training approach for staff in mental health and learning disability services, ASD specialist support and local authorities, taking into account accessibility and staff turnover.
- Training should include recognition of core symptoms of ASD, diagnostic assessment and adaptation of interventions for people with ASD across the age range.
- Diagnostic training should be broad based and not restricted to a single diagnostic model.
- Undergraduate training programmes in health services for should include autism in core training and support provided to develop appropriate training approaches.

Pre and Post Diagnostic Support

- Guidance and support should be provided to enable adults to understand the process and implications of an ASD assessment, which is compliant with NICE guidelines.
- Individuals must have access to good quality pre and post diagnostic support which meets NICE guidelines
- Additional pre and post diagnostic assistance for adults entering the assessment pathway, could be delivered by a range of existing practitioners, from differing professional groups, they should receive training and resources and support to undertake this work.
- Increased collaboration and integrated working across both statutory and third sector agencies is required to ensure the holistic needs of an individual and their carer(s) are addressed.

Quality Improvement and Performance Monitoring

- Various approaches are currently used to gather information on the length of time individuals are waiting for a diagnostic assessment. It is recommended that Welsh Government issues clear guidance for Health Boards in relation to how they should record and monitor such waiting times. Such data should be routinely provided to the Welsh Government via appropriate performance monitoring/ informatic mechanisms.
- In addition to considering how long a person waits for a diagnostic assessment it is essential to consider what outcomes are achieved for the individual and their experience of contact with services. It is recommended that further consideration is given to the development of a person centred outcome measurement framework that focuses on “what matters” to the individual.

Sharing Good Practice

- It is important to ensure there are continued opportunities for sharing of good practice across Wales and the group recommends that a Community of Practice is developed and supported by Welsh Government.
- There are many examples of excellent initiatives and resources that have been developed in a number of services across Wales. In order to support the dissemination of such work it is recommended that a compendium of good practice and resources is developed and widely shared.

Conclusion

The needs of adults with autism were recognised in the first ASD Strategic Action Plan. Action has included support for the ASD Adult Diagnostic Network and the introduction of the Community Monitoring Support posts to

provide low level support for adults. Recent evidence from the independent evaluation of the ASD Strategic Action Plan 2008 has shown that although some progress has been achieved, more work needs to be done and a sustainable approach is now required to secure the lasting improvements.

A key factor for success is to ensure that the provision of ASD services across the age range is placed high on the strategic agenda within health boards and responsibility is shared across agencies. This can only be achieved by investment in the infrastructure of autism services within health boards and their partners, which will include support to build capacity and skills within the workforce.

References

Manikiza J, Sundari (undated) Autism: A Guide for Adults Following Diagnosis. ASD info Wales.

Welsh Government. Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan Final Report

ASD Info Wales (2015) Consultation Summary: Mental Health and Learning Disability Practitioners.

Appendix one

The Autistic Spectrum Disorder Strategic Action Plan ASD Diagnosis Task and Finish Group

TERMS OF REFERENCE

1. The ASD Diagnosis Task and Finish Group (ASD DT&FG) has been established by the Welsh Government to provide advice to the Minister for Health and Social Services on children and adults autism diagnosis. As a matter of priority the group will consider concerns raised by the National Assembly for Wales Petitions Committee in relation to waiting times for ASD diagnosis for children and to provide expert advice on diagnosis and pre and post diagnostic support for both children and adults, to inform the refresh of the ASD Strategic Action Plan.
2. In May 2015 the Minister for Health and Social Service announced new funding to support the Together for Children and Young People Programme (T4CYP). £2m has been allocated for neurodevelopmental conditions including ADHD and ASD. To avoid duplication from November 2015, members of the task and finish group representing children's services have agreed to transfer their membership to the T4CYP neurodevelopmental implementation group.
3. All members of the ASD Adult Diagnostic Pre/Post Counselling Network/Adult Expert Group have been invited to become full members of the task and finish group from November 2015.
4. Links between the two diagnostic groups will be maintained to exchange information and to ensure that cross cutting themes such as transition are discussed. Welsh Government officials will attend both groups and relevant members will also attend both groups.
5. The revised ASD Diagnosis Task and Finish group will provide advice and recommendations in relation to:
 - Minimising diagnostic waiting times for adults.
 - Establishing a consistent framework for adult ASD diagnosis which complies with NICE guidelines on the referral, assessment and diagnosis of adults with ASD.
 - Consolidating the achievements made by the Adult Diagnostic Pre/Post Counselling Network.
 - Identifying and sharing good practice in assessment and pre and post diagnostic support services.
 - Ensuring links with the T4CYP programme neurodevelopmental work stream and are established and maintained.

6. In providing any advice to the Welsh Government on matters in relation to paragraph 5 above, the DT&FG will, where necessary, include in their advice their assessment of any additional costs for organisations in complying with their advice.

7. The DT&FG may, where they consider that it will facilitate their work, invite non-members to attend for either part or the whole of any meeting and, with the chairs' agreement, to contribute to the discussions at the meeting.

8. Except where otherwise determined by the Welsh Government or the DT&FG, members may, where they believe that this will facilitate their work, consult with non-members about matters referred to the DT&FG pursuant to paragraph 1 above.

9. Except where otherwise determined by the Welsh Government or the DT&FG, the group may, where they believe that this will facilitate their work, consult with individuals with autism and their parents and carers about matters referred to the DT&FG in pursuant to paragraph 1 above.

10. The Welsh Government will determine the Terms of Reference for the ASD DT&FG. These will be discussed and agreed at the first meeting and as necessary in future meetings.

ADMINISTRATION

11 The Welsh Government will appoint the chair and members of the ASD DT&FG.

12. The DT&FG will hold meetings as and when the chair considers necessary, but shall meet a minimum of three times and shall complete its work by March 2016.

13. General secretariat services for the DT&FG will normally be provided by officials from the Delivering Policy for Children and Adults, Social Services and Integration Division of the Welsh Government.

14. The Welsh Government will determine the date when the ASD DT&FG will be dissolved.

Appendix two

Membership of the Autistic Spectrum Disorder Diagnosis Task and Finish Group

Name	Organisation	
Chris O'Connor (Chair)	Aneurin Bevan University Health Board	2014/15
Carolyn Samuel	Abertawe Bro Morgannwg University Health Board	2014/15
Alka Ahuja	Aneurin Bevan University Health Board	2014/15
Anne Marie McKigney	Aneurin Bevan University Health Board	2014/15
Julie Mullis	Cardiff and Vale University Health Board	2014/15
Jenny Hunt	Cardiff and Vale University Health Board	2014/15
Tansy Mayfield	Cardiff and Vale University Health Board	2014/16
Darrell Clarke	Cwm Taf University Health Board	2014/15
Zed Sibanda	Cwm Taf University Health Board	2014/15
Juan Delport	Cwm Taf University Health Board	2014/16
Catrin Simpson	Cwm Taf University Health Board	2014/15
Rebecca James	Powys Teaching Health Board	2014/16
Johanna Manikiza	Welsh Local Government Association	2014/15
Louise Albert	National Autistic Society Cymru	2014/16
Catherine Jones	Wales Autism Research Centre	2014/16
Sue Leekam	Wales Autism Research Centre	2014/16
Tracy Jelfs	Association of Directors of Social Services Cymru	2014/16
Christine Griffiths	Welsh Therapies Advisory Committee	2014/16
Heather Payne	DHSSC, Welsh Government	2014/15
David Williams	DHSSC, Welsh Government	2014/16
Penny Hall	DHSSC, Welsh Government	2014/16
Julie Annetts	DHSSC, Welsh Government	2014/16
Wendy Thomas	Carmarthenshire County Borough Council	2014/16

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Jacquelyn Elias	Association of Directors of Education Cymru	2014/16
Sarah Dudley	Hywel Dda University Health Board	2015/16
Alan Downe	Betsi Cadwaladr University Health Board	2015/16
Christine Fretwell	Aneurin Bevan University Health Board	2015/16
Phil Dore	Welsh Local Government Association	2015/16
Helen Matthews	Hywel Dda University Health Board	2015/16
Nicola Jones	Powys Teaching Health Board	2015/16
Sundari Umapathay	Aneurin Bevan Health Board	2015/16

Secretariat: Alyson Collins and Susan Ellis, DHSSC Welsh Government