



Autism ACHIEVE Alliance



Autism Spectrum Disorders:
Waiting for assessment

Executive Summary

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Executive Summary

Phase 1: What is the problem?

The Autism ACHIEVE Alliance was asked to investigate waiting times in the diagnosis of Autism Spectrum Disorder (ASD), as per the Scottish Strategy for Autism Recommendation 21:

'It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings'.

The Scottish Government are keen to not only establish the extent of delays, but to find out what is causing them and what can be done to address this at a national level, so that there is a consistent, sustainable approach across Scotland. In addition, this research was designed to be able to contribute information to other Scottish Strategy for Autism recommendations, including Recommendations 22, 23, 24 and 25.

Where are services?

Recommendation 24 stated *"it is recommended that the Directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland is reviewed and updated"*. The AAA research initiative needed to identify where services (who diagnose ASD) were located and, therefore, could provide information to inform this recommendation.

A sampling frame (comprehensive list of services) was generated from a broad range of sources inclusive of: the National Autistic Society's UK-wide Autism Services Directory Website, the NHS Education for Scotland Directory, Information Services Division, Health Networks, Education Networks, Voluntary Sector, Scottish Government, essay (the statistics project of the Scottish Consortium for Learning Disability), and a comprehensive web search. This list can be sourced at [<http://www.autismnetworkscotland.org.uk/>].

A telephone survey was then conducted using this comprehensive list and 457 calls were made across Scotland to ascertain which services conduct diagnostic assessment of individuals with ASD. This telephone survey resulted in a list of 94^[1] services which conduct diagnostic assessment with 68% (64/94) of these being child services and 32% (30/94) adult services. Of these services, 68 routinely^[2] assess for ASD with 78% (53/68) of these being children services and 22% (15/68) adult services representing all 14 Health Boards. Of the 53 child services, 44% (23/53) are Child and Adolescent Mental Health Services (CAMHS), 28% (15/53) are Child Development Centres or equivalent, and 28% (15/53) are specialist ASD or communication teams. Of the 15 services identified as routinely providing diagnostic assessment of ASD for adults, 53% (8/15) were Learning Disability Services, 27% (4/15) were Mental Health Services and 20% (3/15) were specialist ASD services. In summary, overall there are more child services than adult services, most services are in urban areas, there are fewer services further north, there are few adult services in rural areas, excluding the national services, there is no ASD diagnostic assessment provision for adults without an intellectual disability in many areas and there are no island services for adults.

^[1] In Phase 2 of this study two further adult services (not included in phase one) were identified. The complete list of services is available in a separate document entitled *Services that provide diagnostic assessment of Autism Spectrum Disorder (2013)*

^[2] In this study, 'routinely' was defined as services which reported that they assess at least 10 individuals per year.

What did we do?

The research used proportionate stratified random sampling¹ to obtain a sample of those services which routinely assess for ASD. In order to select these services, the 68 eligible services in Scotland (53 child and 15 adult services) were categorised as being 'urban' or 'rural'. This was based on the Scottish Government's 6-fold classification, and was calculated by using each service's postcode. From these categories, a random sample was conducted and the sampled services (n=16) were then invited to participate.

How are services comprised?

The child sample comprised 50% CAMHS services, 37% Child Development Centres or equivalent, and 13% joint service with input from both CAMHS and Child Development. All child services were provided through multi-disciplinary teams.

🌀 The 8 child teams sampled averaged 5.2 MDT members per service (range 3-9 members). The following professionals were included in the teams:

- 87.5% had a Speech and Language Therapist
- 75% had an Adolescent Psychiatrist
- 75% had an Occupational Therapist
- 62.5% had a Clinical Psychologist
- 62.5% had a Paediatrician
- 50% had a Specialist Nurse
- 37.5% had an Educational Psychologist
- 12.5% had a Community Mental Health Worker
- 12.5% had a General Psychologist
- 12.5% had a Social Worker
- 0% had Physiotherapy involvement within their teams.

37.5% reported including 'other' professionals working within their teams. Other professionals involved included Psychotherapists (n=2), a Family Therapist(n=1) and a Nursery Nurse(n=1).

The adult sample comprised 37% (3/8) Learning Disability Services, 25% (2/8) Adult Mental Health services and 37% (3/8) services that only take referrals for ASD. 62.5% of the adult services had MDT Involvement.

🌀 The 8 adult teams sampled averaged 2.75 MDT members per service (range 1-7 members). The following professionals were included in the teams:

- 50% had an Adult Psychiatrist
- 37.5% had a Speech and Language therapist
- 37.5% had a Clinical Psychologist
- 37.5% had a Specialist Nurse
- 25% had an Occupational Therapist
- 12.5% had a Physiotherapist

¹ In a proportionate random sampling method, the researcher stratifies the population according to known characteristics, and subsequently randomly draws the sample in a similar proportion from each stratum of the population according to its proportion. In this case, stratification of services was based on the Scottish Government definition of urban/rural classification.

- 67.5% reported including other professionals within their teams. Other professionals involved included: a Charge Nurse (n=1); a CPN (n=1); a Community Nurse (n=1) and a Clinical Autism Co-ordinator (n=1).

We conducted a retrospective case note analysis of 150 individuals diagnosed with ASD by these services². This analysis allowed us to gain an understanding of the ASD diagnostic assessment process and to provide information for the “Scottish Strategy for Autism Recommendation 21”. Where possible (without significantly increasing the time to gather data) the case note analysis was also structured to provide information to inform Recommendations 22, 23, and 25.

What did the sample look like?

- 🌀 As expected, there were more males with ASD in the sample than females
 - The child sample comprised 79% males and 21% females
 - The adult sample comprised 64% males, 34% females and 1% transgender³
- 🌀 The average referral age for pre-schoolers was 3.6 years (SD=1.3 years), for school age children 10.3 years (SD=3.2 years), and for adults 31.2 years (SD=11 years).
- 🌀 In the child sample, males were diagnosed at a significantly younger age than females (8.4 years vs. 10.8 years); however, in the adult sample there was no significant difference.
- 🌀 Overall, 97.5% of the child cases and 67.1% of the adult cases were considered to have clinical features that conferred risk for ASD⁴.
 - For the children, the most common risk factors were; having additional support needs in school, speech delay and a family history of related conditions.
 - For the adults, the highest risk factors were; speech delay, having an intellectual disability, being involved in supported social care and having had additional support needs in school.

How long is the wait for diagnosis?

Recommendation 23 states *“it is recommended that the ASD Reference Group explore the ways diagnostic processes for adults and children are different and how this should inform practice”*. The below findings are, therefore, presented separately for adult and children services.

- 🌀 Waiting for diagnosis has three parts, namely:
 - wait for first appointment (from referral)
 - duration of assessment
 - wait to receive diagnosis.

Together these give the total wait for diagnosis (i.e. from referral to receiving diagnosis).

- 🌀 There is a wait for diagnostic assessment for both children and adults.
 - For the child cases, the average total wait for diagnosis from referral to receiving the diagnosis was **331 days**; however there was a wide range (30-1942 days).

² These were systematically identified as the last 10 cases that had been diagnosed within the last two years by each service.

³ These figures do not add up to 100% due to rounding.

⁴ The consensus framework used to identify risk cases was generated based on current practice guidelines, literature review and expert opinion. A composite risk total for each individual was calculated. The factors considered to place someone at risk for ASD were the following: whether they had a neurological disorder or an intellectual disability, had experienced a speech delay or regression, had been born preterm, had additional support needs, had supported social care needs (adults only), had a parental history of psychosis or affective disorders or had a family history of ASD or other related conditions.

- Of the child cases, **74% took longer than 119 days**, which is the recommended maximum time from referral to sharing the diagnosis (National Autism Plan for Children, NAP-C, 2003).
- The average total wait for diagnosis for the adult cases was **162 days** from referral to receiving diagnosis, again with a wide range (14-511 days).
 - Of the adult cases, **59% took longer than 119 days** from referral to sharing the diagnosis.
- 🌀 Children had a statistically significant longer wait between referral and first appointment, and a longer overall wait between referral and receiving the diagnosis, compared to adults.
- 🌀 There was, however, no statistically significant difference between assessment durations for children and for adults.

What affects the length of the wait?

- 🌀 Statistical analysis of the 150 cases illustrated:
 - In child cases, having more information about the child prior to diagnosis was associated with shorter assessment durations.
 - In adult cases, the presence of risk factors for ASD was associated with a shorter wait between referral and first appointment; however, it was also associated with a longer assessment duration and greater number of contacts.
 - Adherence to the evidence-based guidelines (SIGN/NICE) or to the Quality Diagnostic Standard (QDS 2006) does not have a detrimental effect on the total wait for diagnosis.
 - This suggests that a good quality service, as indicated by higher adherence, does not have to have a cost in terms of increased waiting times.
- 🌀 Child and adult service focus group discussions suggested frequent reasons for delays included:
 - less efficient working and communication
 - high non-attendance rates
 - inappropriate referrals
 - ineffective care pathways.

Are standardised diagnostic assessments used?

Recommendation 22 states “initiatives to address waiting lists for assessment should include consideration of further training on the use of the ADOS, ADI-R, 3di and DISCO to meet increased levels of demand”. Our findings below can inform this recommendation. The findings indicate that standardised assessments are being used in the diagnostic assessment process with DISCO and ADOS being the most frequently used. There were no instances of the ADI-R or 3di being used.

The data gathered had little variation (i.e., either standardised assessments were used or they were not used across the sample) and, therefore, there was not enough statistical power to understand the impact of using standardised assessments on waiting times (i.e., would using a standardised assessment help to reduce waiting times). There was no significant difference in the complexity of cases who had standardised assessments compared to those who did not.

🌀 children's services

- completed a clinical history in 100% of cases, however, did not use a standardised assessment to complete this
- completed a clinical diagnostic observation in 100% of cases and used a standardised assessment with 86% of cases (ADOS)
- 100% of children services reported they had a least one lead clinician who was in the local area trained in and regularly using a standardised diagnostic assessment.

🌀 adult services

- completed a clinical history in 100% of cases and used a standardised assessment with 29% of cases (DISCO)
- completed a clinical diagnostic observation in 67% of cases and used a standardised assessment (ADOS) with 3% of cases
- 50% of adult services reported they had a least one lead clinician who was in the local area trained in and regularly using a standardised diagnostic assessment.

To what extent do services adhere to the Quality Diagnostic Standard?

Recommendation 25 states *"it is recommended that a review is conducted with a view to updating and re-distributing the Scottish Quality Diagnostic Standard if it is found to continue to be of benefit"*. AAA research provided an opportunity to review current diagnostic assessment practices relative to the *Quality Diagnostic Standard for children and adults with autistic spectrum disorders* (annexe 3 of Scottish Executive report 2006). Our findings were as follows:

- 🌀 For those QDS items which could be measured, and taking account of cases where the item was not applicable or the response was unknown
 - 50% of the standards were adhered to in more than 80% of cases for adult services
 - 91% of the standards were adhered to in more than 80% of cases for child services.
- 🌀 The Quality Diagnostic Standard was issued in 2005 with the statement *"It is intended to complement the SIGN guideline currently being developed"* (p13 Scottish Executive 2006).
- 🌀 SIGN/NICE guidance is now available and covers all the content of the QDS⁵, however, additionally asks for consideration of assessments for sensory issues, risk and challenging behaviour and the development of a risk management plan if applicable.
- 🌀 The QDS could be reviewed in the context of the SIGN and NICE guidance which a) are now freely available and provides a statement of a quality of provision based on research evidence, b) adhering to SIGN and NICE also do not increase waiting times, c) significant overlap in content between QDS, SIGN and NICE.
- 🌀 Based on the findings from this study, if the Quality Diagnostic Standard is to be retained and used to understand if services are meeting this standard then some of the items need to be more specifically worded.

What can be done to reduce delays?

- 🌀 We conducted focus groups with each of the diagnostic services to review their specific data, co-examine their wait issues and co-identify specific solutions.
 - This resulted in the development of local action plans, focused on redesigning pathways and processes to reduce waits for diagnosis within current resources.

⁵ except for setting the expectation that a report be written stating diagnosis, criteria and tools

- The Autism ACHIEVE Alliance synthesised these into an 'Aggregated Action Plan for child services' and an 'Aggregated Action Plan for adult services'.
- These key solutions were identified by services as follows:
 - To develop efficient working and communication by:
 - speeding up administrative processes, for example by using report-writing proformas
 - collecting and reviewing information to support forward planning of the service having a multi-disciplinary team with dedicated time for ASD assessment and diagnosis
 - carrying out reviews and succession planning of training needs for each service, and opportunities for continual professional development (CPD).
 - To reduce non-attendance rates by:
 - implementing a pro-active attendance policy as part of the care pathway, relevant to the client group.
 - To reduce inappropriate referrals by:
 - providing training and information for referrers, multi-agency partners, families etc.
 - To improve effectiveness of care pathways by:
 - establishing clear pathways and detailing constructive use of time and tools at each stage of the ASD diagnostic process
 - utilising structured processes for requesting and gathering relevant contextual information prior to attendance for diagnostic assessment.

Phase 2: Reducing Waits in Adult Services

Who did we work with?

All adult ASD diagnostic services identified at phase 1 of the project (30), plus an additional 2 newly configured services, were invited to participate. Of these 32, 19% (6/32) were unresponsive and of the 26 remaining, 42% (11/26) chose to participate. Of these 73% (8/11) were Learning Disability Services, 18% (2/11) were Mental Health Services and 9% (1/11) was a specialist ASD services. 46% (5/11) services had participated in phase 1 of the research and 54% (6/11) were new to the initiative.

In phase 2 we, therefore, worked collaboratively with 42% (11/26 adult ASD diagnostic services) of the responsive adult service from 43% of Health Boards to introduce changes in practice to reduce waits.

🌀 The 11 adult teams sampled averaged 5.5 MDT members per service (range 1-11 members).

The following professionals were included in the teams:

- 73% had a Clinical Psychologist
- 64% had a Speech and Language Therapist
- 36% had an Adult Psychiatrist
- 27% had a Specialist Nurse
- 27% had an Occupational Therapist
- 9% had a Physiotherapist.

Inclusion criteria

The inclusion criteria for Phase 2 data was:

- 🌀 The individual had been referred for an *assessment* of ASD⁶.
- 🌀 The individual had been referred to the service within the past 24 months or within the past 6 months if the service had previously participated in phase 1.
- 🌀 The individual had been assessed by the service participating in the Autism ACHIEVE Alliance research.

The quantitative data therefore gathered in phase 2 involved the analysis of 155 case notes (71 before wait reduction intervention, 84 after wait reduction intervention).

What did the sample look like?

- 🌀 As with the phase 1 sample, there were more males with ASD in the phase 2 sample than females
 - The pre-intervention sample comprised 54% males and 35.2% females (data were missing for 10%).
 - The post-intervention sample comprised 69% males, 26.1% females and 1.1% transgender (data was missing from 1.1%).
- 🌀 The average *referral* age for the pre-intervention sample was 31.3 years (SD=11.7) and for the post-intervention group 30.2 years (SD=10.5).

⁶ This differed from phase 1, where the individual had to have received a *diagnosis* of ASD to be included.

- 🌀 In the pre-intervention sample, the mean *age of diagnosis* of ASD was 31.6 years (SD =11.7) and 30.8 years (SD = 10.6) for the post-intervention sample.
- 🌀 There were no significant differences in age of referral or diagnosis between the pre and post -intervention samples.
- 🌀 77.5% of the pre-intervention and 52.3% of the post-intervention samples were considered to be at increased risk for ASD.

Analytic method

The aim of phase 2 was to work alongside participating services to develop and implement interventions to reduce waiting times for those referred for assessment and diagnosis of ASD.

Descriptive statistics were used to determine the demographic profile of the sample and participating services. A multi-level modeling approach was used to determine if overall waiting times had significantly reduced as a result of the intervention.

What was the wait reduction intervention?

The wait reduction intervention was based on Flight Gate methodology (Forsyth et al, 2014) and had two streams of activity:

- 1) *Developing a community of practice*
 - a. This involved a series of face to face change workshops
 - b. Autism ACHIEVE Alliance team visits to services to support change
 - c. Creating a “virtual hub” online resource to allow community to have active discussion and share resources.
- 2) *Developing and re-implementing assessment proformas & diagnostic pathways*
 - a. This involved the community building proformas and pathways based on evidence
 - b. Each service implemented pathways through specific diagnostic targets
 - c. AAA reviewed the targets and provided services with specific feedback
 - d. Development of post diagnostic intervention manual.

How long did it take?

- 🌀 The intervention took place over a 12 month period, with 6 months of this comprising the intervention phase.
- 🌀 In the pre-intervention phase, services were recruited and data was collected (data collected from 71 cases).
- 🌀 Participating services attended
 - “Committing to Change” workshop in month 1
 - “Driving Change” workshop in month 4 &
 - “Sustaining Change” workshop in month 9.
- 🌀 Months 1-3 were focussed on sharing information; building shared resources; building a community of practice and developing local action plans for reducing waits.
- 🌀 During months 4-9 (the intervention phase) the action plans were put into place.
- 🌀 During months 4-9 the services returned data on all cases(n=84) referred for ASD diagnostic assessment whose assessments were completed in this time period.

- Services were supported by the research team via weekly contact and case by case feedback on the data returned, with solution focussed discussions which gave particular reference to duration of assessment. Adjustments to practice were planned based on feedback and discussion.

What did services think about the interventions?

Feedback obtained from the participants at the end of the workshops showed that:

- Workshops were rated as *moderately useful* to *extremely useful* by 100% of respondents.
- 87.5% of respondents rated the workshops as *very good* to *excellent*.
- 100% of respondents considered the ASD Diagnostic Pathway and Proformas to be *very useful* to *extremely useful*.
- 82.5% of respondents reported being *moderately confident* to *very confident* their service can reduce wait times before intervention.
- 75% of respondents felt *very supported* to *extremely supported* by the Autism ACHIEVE Alliance in reducing wait times for diagnosis.
- Workshop presenters were rated as *very skilled* to *extremely skilled* by 100% of respondents.

Did the intervention reduce waits?

Yes, the statistical analysis indicated that:

- The longest service wait was reduced by 52 weeks (12 months).
- The average amount of time an individual waited for diagnosis across all services prior to the intervention was 149.4 days (21.3 weeks). The average wait after intervention was 119.5 days (17 weeks).
- And therefore, there was an average reduction of 29.9.days (4.3 weeks) decrease in overall waiting times between pre and post intervention for the period between referral and sharing the diagnosis.
- This reduction was statistically significant, based on a multi-level model analysis ($B=-28.31$, $p<.05$).