Background

National guidelines for diagnosing autism in the UK state that developmental history-taking and direct observation of the child and should be carried out in all cases of suspected autism.1,2

The National Autism Plan for Children, covering England and Wales, states that every child with suspected autism should be assessed by a multi-agency team, and that at least one member of that team should be trained in the use of standardised instruments.1

The gold-standard observation instrument is the Autism Diagnostic Observation Schedule (ADOS). There are several standardised instruments for history taking, e.g., the Autism Diagnostic Interview – Revised (ADI-R), and the Diagnostic Interview for Social and Communication Disorders (DISCO).

Objectives of this study were to investigate:

- The extent to which the various standardised instruments are used in clinical practice in Wales.
- Clinicians’ attitudes toward these instruments.

Method

A structured questionnaire was sent to professionals involved in autism diagnosis across Wales. The response rate was 57% (estimated), with 118 respondents, representing clinical psychology, paediatrics, psychiatry, educational psychology, and speech and language therapy, among other disciplines.

Ten professionals were invited to take part in a focus group. The professionals were selected to represent all geographical regions of Wales, and senior members of the full range of disciplines named above.

Questionnaire study results

On average, respondents estimated that:

- A standardised developmental history-taking instrument is used in 63% of the cases they see (M = 63, SD = 43, range 0 - 100).
- The ADOS is used in 57% of the cases they see (M = 57, SD = 39, range 0 - 100).

There was much variation, with many respondents indicating that standardised instruments were used either for all cases or for no cases. For example:

48% of the respondents reported using the ADOS. The most popular history-taking instruments are shown below:

- ADOS (32%)
- ADI or ADI-R (21%)
- DISCO (7%)
- DAISI (4%)

Of those who indicated that they use a standardised instrument, around 2/3 had attended a training course, but most had not completed the post-course assessment:

- ADOS: 22% had completed training course + post-course assessment
- ADI-R: 20% had completed training course + post-course assessment
- DISCO: 12% had completed training course + post-course assessment
- DAISI: 13% had completed training course + post-course assessment
- 3di: 33% had completed training course + post-course assessment

Focus group findings

How do you use diagnostic instruments?

Some participants reported using diagnostic instruments in the first instance in all cases, whereas others would use an instrument only in complex cases.

Several participants reported taking items from diagnostic instruments to create their own unique assessment, whereas others reported using the instruments in full, exactly as described in the manuals.

What is the value of using diagnostic instruments?

Participants valued diagnostic instruments in terms of:

- The level of standardisation, objectivity, and robustness they provide.
- Their usefulness for profiling children’s strengths and needs.
- The value to parents, who find it reassuring to see “something structured and rigorous” being used.

However, participants emphasised the primary importance of a sound, broad knowledge of both autism and typical development, and said that, “In the end, whilst the instruments help structure thinking, it comes down to your professional judgement.” The group reported that instrument trainers were right to stress this.

The participants noted with some concern that in many cases the results of the ADOS and ADI do not agree and in their view this calls into question the validity of these instruments.

What are the barriers to using diagnostic instruments?

Participants felt that uptake of diagnostic instruments was limited by shortages in financial resources for:

- The equipment (the initial outlay, the forms, and videoing facilities)
- The training, which is often several days, involving travel and accommodation costs.
- The time required for maintaining fidelity in the months and years after initial training.

Some members of the group felt that the length of time needed to use diagnostic instruments can be somewhat prohibitive, although one participant commented on the value of such instruments in streamlining the diagnostic process.

The availability of training courses was also mentioned as a limiting factor.

Summary

There is significant variation in the extent to which standardised instruments are used in the diagnosis of autism in children in Wales.

Professionals also varied in the manner in which they use standardised instruments, and their level of training. The study showed that diagnostic instruments, alongside sound clinical judgement, are valued by professionals.

The study highlighted some of the barriers that are likely to limit uptake of standardised instruments in clinical practice.

References:

1. National Autism Plan for Children (2003). Published by the National Autistic Society for the National Initiative for Autism: Screening and Assessment (NIASA) in collaboration with the Royal College of Psychiatrists (RCPsych), the Royal College of Paediatrics and Child Health (RCPCH), and the All Party Parliamentary Group on Autism (APPGA).


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