



The MeASURE project has been commissioned and funded by the National Institute for Health Research (NIHR). The purpose of the project is to review evidence about how best to measure the progress of young children with autism spectrum disorder (ASD) up to age 6 years. The project is led by Professor McConachie in Newcastle with a team of researchers and parents in Exeter and London.

The NIHR wants us to make recommendations about the best measurement 'tools', and also about what new research is required to improve what is available. By 'tools' we mean parent or teacher questionnaires or interviews, and assessments of children.

Stage 1

What did we do?

We developed a framework for the review based on

- How ASD is understood
- Areas to assess
- How children develop over time

We reviewed published papers about what parents have said about assessment of children's progress.

We consulted

- Parents about what areas are important to assess
- Early years professionals about which assessment tools they use most in monitoring children's progress
- Young people with ASD about the best way to carry out assessments

What did we find?

There was little overlap between areas that parents think are important to assess, and tools that are frequently used by Early Years professionals. Behaviour problems were the one exception to this. Overall, parents appear to prioritise children's relationships and general wellbeing, whereas professionals are keener on measuring change in ASD symptoms (see Table 1).

Table 1

Professionals: Areas measured	Parents: important areas to measure	Rank
90% social interaction with children	happiness	1
84% play skills	anxiety, unusual fears	2
79% attention	hypersensitivity to touch, noise, etc	3
76% amount of speech	positive views of self	4
75% understanding of language	distress	5
73% expressive communication skills	understanding visual information	6
72% pretend play	relationships with brothers and sisters	7
68% participation in activities	parent stress	8
68% challenging behaviour	fighting, hitting others	9
65% friendships	sleep problems	10

The young people with ASD recommended that assessments made simply observing children would show how they behave – such as whether they get angry easily, ability to sit still, how they respond to changes etc. But they also suggested children would be affected by where they were observed, so observation should be done in more than one place.

Tests might be alright if they are interesting, and given in manageable-length sessions. Testers should not assume instructions are clear and have the same meaning for a child with ASD.

People who do tests and assessments should find out about children before assessing them. Ask about special interests, motivators, sensory issues, where they would be most comfortable when being assessed, etc.

Stage 2

What did we do?

We searched systematically for all published research papers reporting

- Studies which track progress of children with ASD over time
- Studies which evaluate early interventions for children with ASD

What did we find?

From these we found 129 different measurement tools that had been used.

Stage 3

What did we do?

We then searched to find all published research examining the measurement properties of the 129 tools when used specifically with children with ASD.

We noted evidence about the measurement properties and whether the tools seemed to be working well, using a standard checklist (COSMIN – COnsensus-based Standards for the selection of health Measurement Instruments).

This checklist tells us:

- Whether tools are reliable (e.g. would show the same results if done again – test-retest reliability, inter-rater reliability)
- Whether tools measure what they say they measure (content validity, structural validity, internal consistency, criterion validity)
- Whether findings show expected patterns (e.g. young children with ASD are found to have more repetitive behaviours than children without ASD – hypothesis testing, convergent/divergent validity)
- Whether tools are able to measure change over time accurately

What did we find?

We found research papers examining only 52 of the tools (40%). Taking out those tools for which there was only poor quality or negative evidence, we were left with 46 tools for which there was at least some good evidence.

The most evidence has been gathered for tools that were developed especially for use with children with ASD. There are some recurring issues regarding evidence of test-retest reliability, either as this measurement property was not assessed or because the sample sizes in the studies were small.

There is hardly any evidence about which tools may have capacity to track children's progress over time, the main aim of the review.

In the case of tools such as the Autism Diagnostic Observation Schedule (designed to capture unusual quality of behaviours in order to aid diagnostic assessment) there is evidence of stability in assessment. In principle this would allow detection of unexpected change; however, the ways in which behaviours are measured may be insensitive to small changes in response to treatment.

There was only one tool included in the review that was designed explicitly for the purpose of measuring change, the Autism Treatment and Evaluation Checklist, and the evidence to support the measurement properties was thin.

Discussion of all tools, some only now in development, will be included in the report.

The review uncovered little evidence in relation to standardized assessments used with any children including those without ASD (e.g. to assess language, cognition and play) and for many questionnaire tools (e.g. assessing behavior, attention, and emotional regulation). The purpose of conducting some of these assessments may be to make comparison with patterns of typical development. Nevertheless, there is a need for evidence of their content validity for use with children with ASD. That is, any adjustments that may need to be made to tools to take into account the particular ways in which children with ASD think and behave. For example, if young children with ASD choose to play alone is this always a problem? Children with ASD may have more expressive language than would typically be expected for their level of understanding of language.

In the survey of professionals in stage 1, a number of tools were identified which are used in nurseries to monitor progress, such as the Early Years Foundation Stage Profile. The names of these were included in searches; however there appears to be no evidence about whether they have good measurement properties. The emphasis in such tools is to describe steps in building up skills, so that staff can plan learning activities for children – nevertheless it would be reassuring to know at least whether one staff member made similar ratings to another staff member (inter-rater reliability).

We have found no evidence concerning tools that can describe some of the aspects of children's social participation and wellbeing (valued by parents as important in Stage 1).

We do have evidence about some tools that measure behaviour problems and distress.

We have no evidence about measures of family quality of life, but some about measuring parent stress.

The issue of emphasis on measurement of 'problems' rather than 'abilities' and 'strengths' requires discussion.

Stage 4 (this is the stage of the project that we are now at)

What will we do?

We will present the evidence and information from the previous 3 stages to parents, young people with ASD, health and education professionals and researchers.

We will present examples of some of the better tools, so that participants at the Discussion Day and parent groups can discuss them. Issues we need feedback on are; the wording used, the time taken to complete questionnaire, and how they might be used in research or when families and professionals are working together.

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