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Systematic review of tools to measure outcomes for young children with autism spectrum disorder

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Plain English summary

Review of tools for autism spectrum disorder in children

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Plain English summary

The MeASURe (Measurement in Autism Spectrum disorder Under Review) project aimed to find the best tools, such as tests and questionnaires, to measure the progress of children with autism up to the age of 6 years.

First, we asked people what they thought it was important to measure. Parents, and children and adults with autism, told us that happiness, anxiety and sensory overload were most important. Health and education staff said they needed tools to measure areas of difficulty. This was because these are important when deciding whether a child has autism, and in finding out what things help them.

Next we found all of the published studies that tracked the progress of children with autism, to find out what tools researchers had used. Between them, these studies used 131 tools, so we then looked for studies that told us how good these tools were when used with children with autism.

We found tools that could be used to monitor some aspects of the progress of young children with autism but not all. There was little or no evidence about whether tools that describe children's social participation and well-being are useful for children with autism. We found good evidence for the usefulness of a small number of tools that measure autism characteristics and behaviour problems. When we showed these to parents and professionals at a Discussion Day, they pointed out flaws, such as unclear wording and crowded presentation of questionnaires.

New research is needed to improve this situation. Valued outcomes to assess include social communication skills, well-being and quality of family life.

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