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McConachie, Helen, Parr, Jeremy R., Glod, Magdalena et al. (20 more authors) (2015) Systematic review of tools to measure outcomes for young children with autism spectrum disorder. Health Technology Assessment. pp. 1-538. ISSN 2046-4924

<https://doi.org/10.3310/hta19410>

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

Helen McConachie,^{1*} Jeremy R Parr,² Magdalena Glod,¹ Jennifer Hanratty,³ Nuala Livingstone,³ Inalegwu P Oono,¹ Shannon Robalino,¹ Gillian Baird,⁴ Bryony Beresford,⁵ Tony Charman,⁶ Deborah Garland,⁷ Jonathan Green,⁸ Paul Gringras,⁴ Glenys Jones,⁹ James Law,¹ Ann S Le Couteur,¹ Geraldine Macdonald,³ Elaine M McColl,¹ Christopher Morris,¹⁰ Jacqueline Rodgers,² Emily Simonoff,⁶ Caroline B Terwee¹¹ and Katrina Williams¹²

¹Institute of Health and Society, Newcastle University, Newcastle upon Tyne, UK

²Institute of Neuroscience, Newcastle University, Newcastle upon Tyne, UK

³School of Sociology, Social Policy and Social Work, Queen's University Belfast, Belfast, Northern Ireland, UK

⁴Guy's and St Thomas' NHS Foundation Trust, London, UK

⁵Social Policy Research Unit, University of York, York, UK

⁶Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

⁷National Autistic Society North East Autism Resource Centre, Newcastle upon Tyne, UK

⁸Institute of Brain, Behaviour and Mental Health, University of Manchester, Manchester, UK

⁹School of Education, University of Birmingham, Birmingham, UK

¹⁰PenCRU, Child Health Group, University of Exeter Medical School, University of Exeter, Exeter, UK

¹¹Department of Epidemiology and Biostatistics, VU University Medical Center, Amsterdam, The Netherlands

¹²University of Melbourne, Royal Children's Hospital and Murdoch Childrens Research Institute, Melbourne, Australia

*Corresponding author

Declared competing interests of authors: Ann S Le Couteur is one of the authors of the Autism Diagnostic Interview but receives no royalties; Elaine M McColl is a member of the NIHR Journals Library Editorial Group.

Published June 2015

DOI: 10.3310/hta19410

Plain English summary

Review of tools for autism spectrum disorder in children

Health Technology Assessment 2015; Vol. 19: No. 41

DOI: 10.3310/hta19410

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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.

ISSN 1366-5278 (Print)

ISSN 2046-4924 (Online)

Impact factor: 5.116

Health Technology Assessment is indexed in MEDLINE, CINAHL, EMBASE, The Cochrane Library and the ISI Science Citation Index.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: nhredit@southampton.ac.uk

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This report

The research reported in this issue of the journal was funded by the HTA programme as project number 11/22/03. The contractual start date was in June 2012. The draft report began editorial review in April 2014 and was accepted for publication in July 2014. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HTA editors and publisher have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HTA programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HTA programme or the Department of Health.

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