The autism spectrum: the changing context of diagnosis, research and practice

Ken Aitken

Editorial comment

Dr Ken Aitken is Chair of the research sub-group of the Scottish Government's ASD Reference Group. The landscape of autism is changing in ways that have important implications for diagnosis, research and practice. A key focus of the Scottish Strategy for Autism is its commitment to evidence-based practice (Scottish Government, 2011). It stated that 'it is essential that the findings from quality research are disseminated and put into practice' and that there should be 'a clear conduit for feeding in research information that updates, endorses and improves clinical practice' (p 30). In addition, it recommended that an evaluation of existing research should be commissioned by the ASD Reference Group as well as consideration given to what further research is necessary 'with a view to disseminating what is available and to the commissioning of some pieces that would be of particular practical value to people with ASD and their carers' (p 14). This paper examines current developments relating to research and evidence-based practice within the changing context of autism definition and diagnosis.

Address for correspondence
E-mail: *drken.aitken@btinternet.com*

Acknowledgements
I would like to thank Scottish Autism who commissioned the piece of work on which this paper is based and in particular to thank Alan Somerville, CEO, and Charlene Tait, Development Director, at Scottish Autism for setting me the initial brief for this project.

Introduction

Those commissioning and monitoring autism services across the UK have various expectations of the services they fund across both the public and independent sectors. One is that health, education and social services will increasingly and explicitly incorporate evidence-based approaches to best practice, where available, in all aspects of their work. While service users should be entitled to expect that their education, care, support and treatment conform to the highest standards, implementing the processes required to achieve these goals is far from automatic and requires a range of factors to be addressed.

In order to develop and implement an evidence-based approach to working and to incorporate its implied standards, several features are required:

- A clear understanding of what evidence-based practice is and what the expectations are of what is being commissioned. This needs to be clear to service providers and users and to those commissioning the services
- Ready access to up-to-date evidence for all (service providers and their front-line practitioners, commissioners, and those independently monitoring and accrediting services)
- Maintaining 'treatment fidelity', that is, accurate implementation and appropriate training and accreditation of provision to ensure that practices that are developed on the ground mirror what has been evidenced (see: Lawton and Kasari, 2013; Mandell et al, 2013)

- Meaningful data collection. This requires the use of tools that are available, affordable, relevant and sensitive to change in the issues or problems they are being used to assess
- Data analysis that helps to inform and improve services, collated so that service outcomes can be compared both with those expected from the literature and across provisions using a comparative effectiveness research (CER) model, as discussed below.

The above five points cover the minimum requirements for monitoring, for comparison, for valid evidence on level of service provision, for ensuring adherence to agreed standards, for implementation of evidence-led new service developments and for progress in service implementation. These should also be linked to CER-derived best-practice recommendations.

The information generated from such a system needs to be accessible and analysable. This will require the use of methods that are transparent (clearly specified and repeatable by anyone), valid (using accepted techniques and statistics) and adequate both to allow comparison across alternatives and to gauge efficacy against predicted outcomes based on the literature (see Aitken, in press). Where such data are needed but no adequate assessment measures are available, these may need to be developed from scratch. If this is the case, robust evidence will not be available until the tools required have been developed and validated.

No changes to practice are resource neutral. Where this general approach is to be adopted and is not currently in place, there would be various structural and financial implications: initial staff training in implementation of approaches, reliable data collection, understanding the basics of evidence-based practice and the ongoing costs involved in revalidation and initial training of new staff; any increases to staffing required for implementation; independent monitoring of practice; and equipment and proforma budgets and additional secretarial support. All of the above will have some level of impact if such systems are required, as will increased staff turnover, ongoing changes to diagnostic and clinical practice, requirements for bioinformatics support for data analysis and changes to client population.

There needs to be an organisational climate that accepts both the utility of moving to such a model and the need for refinements to practice to be informed and guided by the outcomes generated. In order for this to be achievable and successful, any such developments must be adequately supported and resourced (see Aarons et al, 2011). The resulting framework would need to be 'fit for purpose'. It would also need to be reflexive, ensuring that it incorporated the implementation of the best approaches currently available and was able to adapt to enable incorporation of findings indicating the need for alterations in practice. Flexibility is fast becoming a critical component of any such framework.

Such developments should be needs-led – 'What is the minimum acceptable level of profiling required to develop and refine an evidence-led service for this client group now?' – rather than starting from budgetary constraint – 'What is the best service we can provide within a recurrent budget of £N?'. Within reason, cost should only be a secondary consideration – 'Given the minimum acceptable level of provision required, how can this be configured and resourced within current budgetary constraints?'.

It is important that the process is capable of generating data allowing the salient aspects of service provision to be evaluated, that it provides demonstrable results and that it is sensitive to the implications of changing evidence. Once in place, such a system would enable the generation of 'practice-based evidence' to evaluate the implementation of 'evidence-based practice' (Green, 2006). It would thereby complete the audit cycle by driving the commissioning of relevant research in areas identified as requiring improvement and testing out the predictions from research evidence in real-life situations.

Evidence-based practice (EBP)

Evidence-based practice in the context of health interventions implies:

> *'… the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research.'* (Sackett et al, 1996)

Evidence-based practice has been advocated as the best approach to assessing performance and effectiveness across a wide spectrum of areas of work and across a range of specialisms, therapies and professional groups. It has been recommended as the approach of choice across many professions including general medicine (Sackett et al, 1996), clinical psychology (Beidas and Kendall, 2010), speech and language therapy (Roddam and Skeat, 2010), occupational therapy (Holm, 2000), education (Horner et al, 2005), social work (Webb, 2001) and government administration (Davies, Nutley and Smith, 2010).

Evidence-based practice relies on the availability of robust published evidence in the peer-reviewed literature. One recent review (Carrasco, Volkmar and Bloch, 2012), has highlighted evidence of publication bias by comparing registered trials of medications used for repetitive behaviours in autism against subsequently published evidence. The authors showed that research publication was highly selective and suggested greater benefit than was actually found when taking all funded trial results as a whole.There is an inherent bias in the clinical literature to publish positive results (see Easterbrook at al, 1991). This strongly suggests that as well as literature searching it is important when reviewing work in an area to identify ongoing studies, studies which have been published but not picked up by electronic search, research approved and completed but not published and discontinued research. In the USA, the requirement that funded studies are now registered once approved allows searching for ongoing work and for studies that have been completed but not published. These can be located through sites such as NDAR (the National Database for Autism Research) and *clinicaltrials.gov.*

In the UK, a Behavioural Insights Group has been established by the Cabinet Office to encourage and disseminate comparative evaluation and to monitor and evaluate changes to practice. This group's initial work on methods for the evaluation of new developments shows a clear intention to develop this model of assessment and the relevant infrastructure across UK public services (see Haynes et al, 2012).

Gaining access to relevant evidence

Different professions have different resources to help with the process of locating and evaluating evidence of best practice, and different approaches to evaluating evidence. In general, PubMed *(www.ncbi.nlm.nih.gov/pubmed)* and PsychINFO *(www.apa.org/pubs/databases/psycinfo/index.aspx)* are perhaps the best for accessing information on evidence relevant to autism. The relative increase in research in this field outside of Europe and North America (see Interagency Autism Coordinating Committee and Office for Autism Research Coordination, 2012), particularly in South America, Western Asia and China, makes it increasingly important to search on other platforms such as Scielo *(www.scielo.org/php/index.php?lang=en).*

There are many gaps in the autism literature. One recent review showed, for example, that the majority of autism research is with young children. A review of data from three years of publication in three of the main journals, indicated that 98 per cent of published work was on people under 20, and over 50 per cent of this was on children aged four to eight years (Edwards et al, 2012).

The changing ethnodemographic makeup of populations may also be important as a number of refugee and immigrant groups appear to have an increased prevalence of autism or different patterns of presentation (Barnevik-Olsson, Gillberg and Fernell, 2008; Minnesota Department of Health, 2009). After a long period when racial differences were sidelined as 'politically incorrect', there is increasing recognition that population differences in the frequency of certain genotypes may be important in both clinical presentation and in optimising treatment approaches (Sontoredjo, de Boer and Maitland-van der Zee, 2013), but without racial differences in themselves having importance for treatment (see Kahn, 2013).

Ensuring 'treatment fidelity'

Treatment fidelity is fairly straightforward to ensure when training and accreditation are available and materials can be purchased in a standard format. It is important to have a system in place to ensure that all staff using an assessment instrument are consistent in administering and scoring it, are able to generate comparable results and are regularly re-accredited to ensure there is no significant change in how they rate over time (an issue referred to as 'inter-observer drift').

With many autism assessment materials no resources for training or re-accreditation are readily available, and for some there is no ready source for the materials required. In these circumstances it is important to develop training to ensure that staff who are using a specific measure are consistent both with each other and over time to ensure that results are reliable and replicable.

Collecting robust information

The assessment instruments used, whether questionnaires, rating scales or more formal tests, need to be appropriately standardised. They should ideally have been recently norm-referenced on a comparable population. Initial assessments will typically be more extensive, and might depend on the individual complying with activities or requests. The methods used and the practicability of information collection can be heavily affected by context. Once an approach to working has been established it may be unduly disruptive to use assessment tools requiring a high level of directed compliance (this can be the case with some of the more intensive early intervention approaches).

Tools that require training and demand a significant amount of staff time to complete are only useful if staff are given adequate time to implement them and are appropriately trained and supported to comply. The question then becomes whether the additional time and resources required are justified by the information generated and whether the additional costs to the organisation make this feasible.

Analysing the information collected

The analysis of information depends in part on why the information is being collected. There are several possible questions that would require different types of analysis. Is this approach producing the expected results with this client? Are we achieving treatment fidelity? How do the results we are getting compare with those predicted from the literature? How does this approach compare with others?

The move from EBP to comparative evaluation research (CER)

Most people working in the health sector have become familiar with the idea of evidence-based practice. Using EBP criteria only clears the low hurdle of showing that using a particular approach is better than doing nothing at all (this is the evidence of effectiveness generated by waiting-list studies and placebo-controlled trials).

Comparative evaluation research (CER) takes the idea of evidence-based practice to a further level, by using similar methods in comparing different approaches, and it is beginning to be adapted further to investigate which treatment or approach will be likely to be best for a given individual (see Basu, 2011). The CER model (see Olsen, Grossmann and McGinnis, 2011; Sox, Greenfield, and the Committee of Comparative Effectiveness Research Prioritization, 2009; Sox et al, 2010) was introduced in the USA because a significantly larger proportion of the population was given access to wider choices in healthcare through private systems and a way needed to be found to ensure greatest benefit and value for money. A system with comparable scope and aims may be required in the UK, particularly if non-governmental organisations and private initiatives take on an increasingly significant component of service provision to this population and various competing models of provision are readily available.

CER directly compares the implementation and outcomes with different approaches. It does this by carrying out 'head-to-head' studies where the relative benefits of two or more approaches can be tested using the same evaluation methods in comparable populations. This has required the setting up and central financing of an independent body to undertake and evaluate patient-centered outcome research (PCOR). PCOR is another term introduced

alongside CER which is starting to appear more in the literature (see Olsen, Grossmann and McGinnis, 2011).

The Patient Centered Outcome Research Institute (PCORI) was established under the US Patient Protection and Affordable Care Act 2010 with ongoing funding as an independent nonprofit organisation 'to assist patients, clinicians, purchasers and policy-makers in making informed health decisions' (section 1181(c)). PCORI is government funded but independent and tasked with oversight of CER studies. These studies use the same assessment methods to compare and contrast the outcomes achieved with different practices and approaches in comparable populations. This change in emphasis provides a clearer way to investigate the relative benefits and the cost-effectiveness of differing approaches and of different models of service delivery. The major difficulty at present is that it requires a change to and harmonisation across the methodologies both for data collection and its subsequent analysis.

Much of what is currently being produced within the CER framework is identifying the gaps – the lack of good studies to inform and guide clinical practice. To take two examples, CER studies of interventions for children (Warren et al, 2011) and for adolescents and young adults (Taylor et al, 2012) on the autism spectrum have identified 9,005 papers of potential relevance. Of these, only 191 unique studies were identified as adequate and reviewed in detail. None of these was of adequate quality to generate best-practice recommendations.

Changes to diagnostic practice and classification

Assessment of individuals and comparison with reference standards relies on agreement both on the diagnosis of the individuals being assessed and on their comparability with the populations on which those standards were developed. This is a possible issue for many measures as the diagnostic criteria for the various terms used such as 'autism', 'autistic disorder' and 'autistic spectrum disorder' have differed and typically broadened slightly with each revision to the major classification systems. The concatenation of autistic disorder, Asperger syndrome and PDD-NOS into a single condition – autism spectrum disorder – and a weakening of the requirements for current presentation is the greatest change to date. It is necessary to consider diagnostic classification systems as they are likely to affect our practice in the near future.

DSM-5 (The American Psychiatric Association's classification system)

In North America, the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM) is typically used for clinical diagnosis (American Psychiatric Association, 1994). This is not, strictly speaking, used in the UK. However, as most published research that forms the evidence-base for best clinical practice has to date used samples diagnosed on DSM criteria this is *de facto* the basis for best-practice evidence. There was little practical difference between the previous DSM classification (DSM-IV) and the World Health Organization's (1992) current International Classification of Diseases (ICD-10). Both introduced Asperger syndrome as a diagnosis for the first time.

The biggest practical changes introduced with the recent fifth revision of the DSM criteria (American Psychiatric Association, 2013) for ASD are:

- There has been a move from the 'triad of impairments' (social impairment, communication impairment and repetitive behaviours and restricted interests) with difficulties in all areas having to be present at time of diagnosis, to a 'dyad of impairments', by combining together the social interaction and social communication impairments into one category, with only these difficulties needing to be present at time of diagnosis (see Lord and Jones 2012). The criteria for repetitive behaviours and restricted interests may be met currently or historically
- Asperger syndrome disappears as a diagnostic category, becoming subsumed as part of ASD. Some people with a current Asperger diagnosis, particularly if high-functioning and independent, will be unlikely to fit the new ASD criteria
- For the first time, ADHD is diagnosable in people on the autism spectrum, opening up the possibility of treatment for ADHD in this overlapping group (around 40 per cent have co-morbid diagnoses, but ADHD could not be treated in someone with a DSM-IV diagnosis of autistic disorder) (Grzadzinski et al, 2012)

- Adult diagnoses will be easier to make as there is a reduced reliance on obtaining a detailed early developmental history
- Some disorders, particularly Rett syndrome, will no longer be seen as a part of ASD
- A severity rating has been introduced, allowing ASD to be graded.

There has been a heated debate about the impact that these changes to diagnostic criteria will have (see, for example, Buxbaum and Baron-Cohen, 2013; Grzadzinski, Huerta and Lord, 2013; Volkmar and Reichow, 2013). The view of the DSM-5 Workgroup on Neurodevelopmental Disorders is that if the new criteria are used as they are intended, this will not change the numbers who receive a valid diagnosis (Swedo et al, 2012). However, some have predicted a substantial decrease in overall autism prevalence (Matson, Hattier and Williams, 2012). On the other hand, reduced reliance on early developmental history may lead to increases in adult diagnosis.

Controversy around DSM-5 has also arisen over conflict of interest issues that have had to be declared publicly for the first time. Many of those involved in developing the revision have declared conflicts, primarily due to pharmaceutical research sponsorship (see, for example, Cosgrove and Krimsky, 2012).

ICD (the World Health Organization's International Classification of Diseases)

The next ICD revision, ICD-11, is currently projected to be submitted for approval and adoption by the World Health Assembly in May 2015. There is no indication of whether the ICD changes will mirror those that have been made to the DSM or will be modified to reflect the issues and concerns discussed below. Preliminary papers from Professor Rutter who is likely to chair the update group suggest that it will take some of the concerns expressed by the US National Institute of Mental Health (NIMH) over the DSM into account (see Rutter, 2013; Rutter and Uher, 2012; Uher and Rutter, 2012).

The ICD system has a much longer history than the DSM and is broader in scope, as it deals with all aspects of medicine and not just with mental health. Using ICD it is relatively simple to look for possible comorbidities, such as with neurological conditions, cardiac issues, immune problems and gastrointestinal issues. Since on the ICD all clinical specialities use the same diagnostic system and the same coding structure case recording is much simpler. This is why many US private healthcare systems use ICD instead of their own DSM system.

Research domain criteria (RDoC)

The concept of RDoC has been introduced to try to direct US clinicians to incorporate research evidence from neuroscience, genetics and other areas into clinical research and practice. This year the US administration launched the BRAIN Initiative (Brain Research Through Advancing Innovative Neurotechnologies) as a joint initiative of the National Institutes for Health and the National Science Foundation. In his opening speech on the project President Obama highlighted autism as one of a number of conditions at the centre of this new and substantial public-private funding initiative.

There has been increasing frustration at the limited impact and role that biological advances have had on mental health practice (Kapur, Phillips and Insel, 2012) despite their expanding profile and funding. The United States National Institutes for Health (NIH) Director Tom Insel has made explicit statements to the effect that NIMH research funding is moving away from using DSM classification as a basis for funded research to the use of RDoC (Cuthbert and Insel 2013; Insel et al, 2010). He said of DSM-5:

> *'Patients with mental disorders deserve better. NIMH has launched the Research Domain Criteria (RDoC) project to transform diagnosis by incorporating genetics, imaging, cognitive science and other levels of information to lay the foundation for a new classification system. That is why NIMH will be re-orienting its research away from DSM categories. Going forward, we will be supporting research projects that look across current categories – or sub-divide current categories – to begin to develop a better system.'* (Insel, 2013)

This will represent difficulties for the DSM system and for ongoing reliance on DSM as a diagnostic framework. The evidence-base emerging from NIH-sponsored RDoC-based studies will progressively diverge from the DSM model and be difficult to interpret within it, increasing public expectations of a more clearly differentiated view of the autism spectrum and of targeted treatment implementation.

NIH is the largest funding agency for healthcare research in the World. Their critical influence on the research agenda ensures that most future published research will be required to conform to their new classification model. They have effectively declared that through failing to integrate genetic, neuroimaging and other recent developments into the DSM-5, it is no longer fit for purpose and that future NIH sponsored work will need to conform to the RDoC classification that will supercede it. In future, evidence-based practice will be dictated by a literature using a comparative evaluation research model with samples on which the comparisons are based using RDoC criteria and not those found in the DSM. It remains to be seen whether ICD-11 will conform to RDoC or not, but this is likely to be the driving force that influences and changes our everyday practice.

Concluding comments: changes in research emphasis and what these will mean

Above I have indicated the recent and impending changes in diagnostic practice and have given a brief indication of the reasons that research funding for autism is likely to take a different direction in the coming decade, rather than sticking to evaluating treatments and approaches using traditional diagnostic groupings. These changes will provide an increasing evidence-base to support the differentiation of practice on the basis of differentiation of subgroups or of individual differences that will not conform to the current monolithic psychiatric groupings in DSM-5.

Now, more than ever before, it is important to keep abreast of the changes to clinical and research diagnosis and of how these can affect practice. Developments and changes to definitions, diagnoses and assessment processes alter the relevance of specific assessment tools and can invalidate normative samples. The flexibility to develop and evidence innovations will be increasingly important in bridging the increasing gaps between the available evidence and practice needs (see Wandersman, Chien and Katz, 2012).

References

Aarons, G, Hurlburt, M, and Horwitz, S (2011) Advancing a conceptual model of evidence-based practice implementation in public service sectors *Administration and Policy in Mental Health* 38, 4–23.

Aitken, K J (in press) *Evidence-based assessment in ASD: What is available, what is appropriate and what is 'fit-for-purpose'?* London: Jessica Kingsley Publishers.

American Psychiatric Association (1994) *The diagnostic and statistical manual of mental disorders, 4th edition* (DSM-IV) Washington, DC: American Psychiatric Association.

American Psychiatric Association (2013) *The diagnostic and statistical manual of mental disorders, 5th edition* (DSM-5) Washington, DC: American Psychiatric Association.

Barnevik-Olsson, M, Gillberg, C and Fernell, E (2008) Prevalence of autism in children born to Somali parents living in Sweden: A brief report *Developmental Medicine and Child Neurology* 50, 598–601.

Basu, A (2011) Economics of individualization in comparative effectiveness research and a basis for a patient-centered health care *Journal of Health Economics* 30, 549–559.

Beidas, R S and Kendall, P C (2010) Training therapists in evidence-based practice: A critical review of studies from a systems-contextual perspective *Clinical Psychology* (New York) 17, 1–30.

Buxbaum, J D and Baron-Cohen, S (2013) DSM-5: The debate continues *Molecular Autism* 4 (11) available at *www.molecularautism.com/content/4/1/11* (accessed 3 October 2013).

Carrasco, M, Volkmar, F R and Bloch, M H (2012) Pharmacologic treatment of repetitive behaviors in autism spectrum disorders: Evidence of publication bias *Pediatrics* 129, e1301–1310.

Cosgrove, L and Krimsky, S (2012) A comparison of DSM-IV and DSM-5 panel members' financial associations with industry: A pernicious problem persists, *PLoS Medicine* 9 (3), e1001190.

Cuthbert, B N and Insel, T R (2013) Toward the future of psychiatric diagnosis: The seven pillars of RDoC *BMC Medicine* 11 (126) available at *www.biomedcentral.com/1741-7015/11/126* (accessed 3 October 2013).

Davies, H T O, Nutley, S M and Smith, P C (2000) *What works?: Evidence-based policy and practice in public services* Bristol: Policy Press.

Easterbrook P J, Berlin J, Gopalan R and Matthews, D R (1991) Publication bias in clinical research *Lancet* 337, 867–872.

Edwards, T L, Watkins, E E, Lotfizadeh, A D and Poling, A (2012) Intervention research to benefit people with autism: How old are the participants? *Research in Autism Spectrum Disorders* 6, 996–999.

Grzadzinski, R, Huerta, M and Lord, C (2013) DSM-5 and autism spectrum disorders (ASDs): An opportunity for identifying ASD subtypes *Molecular Autism* 4 (12) available at *www.molecularautism.com/content/4/1/12* (accessed 3 October 2013).

Grzadzinski, R, Di Martino, A, Brady, E, Mairena, M A, O'Neale, M, Petkova, E, Lord, C and Castellanos, F X (2012) Examining autistic traits in children with ADHD: Does the autism spectrum extend to ADHD? *Journal of Autism and Developmental Disorders* 41, 1178–1191.

Green, L W (2006) Public health asks of systems science: To advance our evidence-based practice, can you help us get more practice-based evidence? *American Journal of Public Health* 96, 406–409.

Haynes, L, Service, O, Goldacre, B and Torgerson, D (2012) *Test, learn, adapt: Developing public policy with randomised controlled trials* Cabinet Office Behavioural Insights Team available at *www.cabinetoffice.gov.uk* (accessed 5 September 2013).

Holm, M B (2000) Our mandate for the new millennium: Evidence-based practice, 2000 Eleanor Clarke Slagle lecture *American Journal of Occupational Therapy* 54, 575–585.

Horner, R H, Car, E G, Halle, J, McGee, G, Odom, S and Wolery, M (2005) The Use of single-subject research to identify evidence-based practice in special education *Exceptional Children* 71, 165–179.

Interagency Autism Coordinating Committee and Office for Autism Research Coordination (2012) IACC/OARC *Autism spectrum disorder research publications analysis report: The global landscape of autism research* Washington, DC: IACC/OARC.

Insel, T (2013) Transforming diagnosis NIH Director's Blog, 29 April available at *www.nimh.nih.gov/about/director/index.shtml* (accessed 5 September 2013).

Insel, T, Cuthbert, B, Garvey, M, Heinssen, R, Pine, D S, Quinn, K, Sanislow, C and Wang, P (2010) Research domain criteria (RDoC): Toward a new classification framework for research on mental disorders *American Journal of Psychiatry* 167, 748–751.

Kahn, J (2013) *Race in a bottle: The story of BiDil and racialized medicine in a post-genomic age* New York: Columbia University Press.

Kapur, S, Phillips, A G and Insel, T R (2012) Why has it taken so long for biological psychiatry to develop clinical tests and what to do about it? *Molecular Psychiatry* 17 (12), 1174–1179.

Lord, C and Jones, R M (2012) Annual research review: Re-thinking the classification of autism spectrum disorders *Journal of Child Psychology and Psychiatry* 53, 490–509.

Lawton, K and Kasari, C (2013) Teacher implementation of joint attention intervention in preschool classrooms: Fidelity and context, *Autism – Open Access* 3 (1), 1000108.

Mandell, D, Stahmer, A C, Shin, S, Xie, M, Reisinger, E and Marcus, S C (2013) The role of treatment fidelity on outcomes during a randomized field trial of an autism intervention *Autism* 15, 281–295.

Matson, J L, Hattier, M A and Williams, L W (2012) How well does relaxing the algorithm for autism affect DSM-5 prevalence rates? *Journal of Autism and Developmental Disorders* 42 (8), 1549–1556.

Minnesota Department of Health (2009) *Autism spectrum disorders among preschool children participating in the Minneapolis public schools early childhood special education programs* available at *www.leg.state.mn.us/docs/2009/other/090520.pdf* (accessed 3 October 2013).

Olsen, L-A, Grossmann, C and McGinnis, J M (2011) *Learning what works: Infrastructure required for comparative effectiveness research – workshop summary* Washington, DC: National Academies Press.

Roddam, H and Skeat, J (eds) (2010) *Embedding evidence-based practice in speech and language therapy: International examples* Chichester: John Wiley and Sons.

Rutter, M (2013) Changing concepts and findings on autism *Journal of Autism and Developmental Disorders* 43 (8), 1749–1757.

Rutter, M and Uher, R (2012) Classification issues and challenges in child and adolescent psychopathology *International Review of Psychiatry* 24, 514–529.

Scottish Government (2011) *The Scottish strategy for autism* Edinburgh: The Scottish Government.

Sackett, D L, Rosenberg, W M C, Gray, J A M, Haynes, R B and Richardson, W S (1996) Evidence based medicine – what it is and what it isn't: It's about integrating individual clinical expertise and the best external evidence (Editorial) *British Medical Journal* 312, 71–72.

Sontoredjo, T A, de Boer A and Maitland-van der Zee, A H (2013) Etnische farmacogenetica [Ethnicity in pharmacogenetics: English abstract] *Nederlands Tijdschrift Voor Geneeskunde* 157, A6118.

Sox, H C, Greenfield, S and the Committee of Comparative Effectiveness Research Prioritization (2009) *Initial national priorities for comparative effectiveness research* Washington, DC: National Academies Press.

Sox, H C, Helfand, M, Grimshaw, J, Dickersin K, Tovey D, Knottnerus J A and Tugwell P (2010) Comparative effectiveness research: Challenges for medical journals *Cochrane Database of Systematic Reviews* 27 (8), ED000003.

Swedo, S E, Baird, G, Cook, E H, Happé, F G, Harris, J C, Kaufmann, W E, King, B H, Lord, C E, Piven, J, Rogers, S J, et al (2012) Commentary from the DSM-5 Workgroup on Neurodevelopmental Disorders *Journal of the American Academy of Child and Adolescent Psychiatry* 51, 347–349.

Taylor, J L, Dove, D, Veenstra-VanderWeele, J, Sathe, N A, McPheeters, M L, Jerome, R N and Warren, Z (2012) Interventions for adolescents and young adults with autism spectrum disorders *Comparative Effectiveness Review* 65, AHRQ Publication No. 12-EHC063-EF.

Uher, R and Rutter, M (2012) Basing psychiatric classification on scientific foundation: Problems and prospect *International Review of Psychiatry* 24, 591–605.

Volkmar, F R and Reichow, B (2013) Autism in DSM-5: Progress and challenges *Molecular Autism* 4 (13) available at *www.molecularautism.com/content/4/1/13* (accessed 3 October 2013).

Wandersman, A, Chien, V H and Katz, J (2012) Toward an evidence-based system for innovation support for implementing innovations with quality: Tools, training, technical assistance, and quality assurance/quality improvement *American Journal of Community Psychology* 50, 445–459.

Warren Z, Veenstra-VanderWeele J, Stone W, Bruzek J L, Nahmias A S, Foss-Feig J H, Jerome R N, Krishnaswami S, Sathe N A, Glasser A M, et al (2011) Therapies for children with autism spectrum disorders *Comparative Effectiveness Review* 26, AHRQ Publication No. 11-EHC029-EF.

Webb, S A (2001) Some considerations on the validity of evidence-based practice in social work *British Journal of Social Work* 31, 57–79.

World Health Organization (1992) *The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines* Geneva: World Health Organization.