# UK NATIONAL SCREENING COMMITTEE

## Screening for Autistic Spectrum Disorders in Children Under the Age of Five Policy Position Statement

**13 November 2012**

### Aim

1. This note provides background to the agenda item addressing the review of the evidence for screening for autistic spectrum disorders in children under the age of five.

### Current policy

2. The current policy is that screening for autism should not be offered.

3. The policy was developed by the former Child Health Subgroup following publication of Hall and Elliman's 'Health For All Children'.

### Review process

4. Solutions for Public Health were asked to review publications from January 2005 – November 2010. The review focused on issues relating to the test and the treatment.

5. The document was considered by the Fetal Maternal and Child Health Co-ordinating Group (FMCH) in July 2011. A three month consultation was hosted on the UK National Screening Committee (UK NSC) website and this closed in January 2012. The following stakeholders were contacted directly: British Psychological Society, Royal College of Paediatrics and Child Health, Royal College of General Practitioners, Royal College of Psychiatrists, National Autistic Society.

6. Two responses were received:

7. The British Psychological Society made some detailed points and the document has been amended to accommodate these where possible. However the Society agreed with the review's conclusion that, 'no approach to screening for ASD has demonstrated reasonable performance, in terms of both sensitivity and positive predictive value (PPV), in a general population screening study.'

8. The response from [redacted] focused on, and questioned, detailed issues relating to the review's assessment of the evidence on the effectiveness of interventions. These were addressed by the reviewer. The reviewer's main point was that the evidence of benefit from trials of interventions is insufficiently clear to support a national screening programme. This is particularly the case given the issues relating to the test. A National Institute for Health and Clinical Excellence guideline on the management of children with diagnosed ASD is being developed.

9. Both sets of comments are attached at Annex A.

**Recommendation**

10. The UK NSC is asked to agree the policy position on screening for autistic spectrum disorders in children under the age of five as follows:-

*A national screening programme for autistic spectrum disorders in children under the age of five is not recommended*

11. The UK NSC is asked to agree that the policy should be reviewed in three years' time unless there is significant new peer reviewed evidence in the meantime.

**Annex A**

**Response to document: Screening for Autism Spectrum Disorders in Children below the age of 5 years**

For expediency I will simply comment on specific points on a paragraph by paragraph basis.

**Paragraph 1:**

*"The appraisal stops short of most of the criteria for appraising the programme as a whole, because gaps in the evidence regarding the test and the treatment suggest that implementation of a screening programme would be premature."*

It is unlikely that anyone will ever agree that there are no longer gaps in the evidence, and it is unlikely that everyone will eventually agree on what the evidence actually suggests – this screening paper is a case in point. However, there is unequivocal evidence for the effectiveness of behavioural intervention for autism[1] as a treatment/intervention. Rather than supply hundreds of references at this point, I would refer you to the National Standards Project (2009) commissioned by the National Autism Centre in the US and involving hundreds of international experts (including renowned scientists, practitioners, researchers and clinicians). This is the most comprehensive review of autism treatments/interventions to date.

**Paragraph 2:**

Presumably the authors are referring to 'challenging behaviour' or 'problem behaviour' in the table's left column rather than just 'behaviour'. 'Behaviour' encompasses all of the activities people engage in (including actions, interactions, talking and thinking) so to use the single word in this context is rather strange and misleading.

**Paragraph 3:**

*"...there was insufficient evidence regarding the effectiveness of interventions (Williams and Brayne 2006)."*

Again, many would completely and utterly disagree (see comments about paragraph 1). Furthermore, the reference cited is from a very low impact factor journal, and just represents the views of these two authors. Again, there are hundreds of references (including those in high impact journals) that utterly refute this assertion, and, again, I would refer you to the National Standards Project (2009) as a starting point.

**Paragraph 4:**

*"This endorsement of universal screening for ASD is presumably [my emphasis] based on confidence in the effectiveness of early intervention, since the CDC webpage on treatments for ASD claims [my emphasis] that 'research shows that early intervention treatment services can greatly improve a child's development' (Centers for Disease Control and Prevention 2011b)."*

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[1] Behavioural intervention for autism is an intervention/treatment/educational provision that is based on the principles, and uses the methodology of, Applied Behaviour Analysis - ABA

This seems to be a rather derogatory paragraph. There is an implication that the CDC are in error in making such recommendations (the use of the words I have emphasized). More on RCTs below…

**Paragraph 28:**

Whilst everyone agrees that RCTs are the 'gold standard', there are other research designs that provide compelling evidence, and these should not be completely discounted with no further thought or discussion (again, see National Standards Project, 2009).
The heavy reliance on RCTS is a big problem because it is unlikely that there will ever be sufficient numbers of RCTs to satisfy an unequivocal recommendation for any one intervention. This is for two reasons, and these are both general reasons why RCTs are not satisfactory determinants of the scientific validation of autism interventions. First, all interventions for children with autism ought to be individualized according to the wide heterogeneity of assessed and expressed deficits. This is particularly true of behavioural interventions (and it ought to be true of all interventions). RCTs are designed to compare groups having one discrete intervention/treatment with another group (or groups) having something else (comparison), or nothing (control). This is perfect for testing a new drug where everyone gets the same drug and dose, but not practical or possible where each intervention is necessarily individualised: different tutors/teachers/therapists, different levels of experience and competence, different levels of intensity of the intervention, different levels of family involvement, children starting at different ages and with different developmental deficits, different levels of support from nurseries, schools etc. Second, it would be almost impossible to control for families rigidly and inflexibly adhering to the very precise independent variables described above and also not using/trying other sorts of interventions (e.g. diets, vitamin supplements, occasional access to any other of the thousands of treatments and interventions now available). Such confounds would not enable an accurate evaluation. Yes, ideally RCTs are a gold standard, but this is not an all or nothing scientific analysis, and studies that are not RCTs, but have experimental and comparison/control groups provide a level of evidence, as do the 100s if not 1000s of single-case study designs, and it has been argued by many, successfully, that these types of studies should be included in any sort of evaluation of the evidence, albeit not weighted as heavily as the gold-standard RCT. Thus, the whole 'treatment' section of this document is flawed by only relying on (a very limited number of) RCTs.

Furthermore, the authors of this document assert that:

*"...the only context in which non-randomised designs can produce very strong evidence of effectiveness is when the effect of treatment is large in relation to the effects of all the possible biases, and that is not the case with treatments for ASD"*

This statement is simply untrue. See, for example, Eldevik, Hastings, Hughes, Jahr, Eikeseth and Cross (2009), where extremely large effect sizes are reported (based on an extensive meta-analysis) supporting the efficacy of behavioural intervention for autism.

**Paragraph 30:**

The authors are suggesting that early intensive behavioural intervention (EIBI) and applied behaviour analysis (ABA) are synonymous. They are not. This is a persistent and intransigent

assertion that occurs as a result of not understanding what applied behaviour analysis actually is. Applied behaviour analysis (ABA) is an applied science and uses an understanding of why behaviour occurs to address a wide range of social issues, including helping individuals to learn. Like other applied sciences, ABA can be applied to a range of populations and settings (e.g. business and industry, education, gerontology, healthcare) and to a range of social concerns (e.g., anxieties, depression, phobia, addiction, behaviours associated with autism). Behaviour analysts use principles of learning and laws of behaviour that have been scientifically demonstrated, and use clearly defined procedures to specify how to change behaviour. The effectiveness of any behaviour change intervention is continually monitored and evaluated. The primary focus of ABA is on behaviour that is important to individuals, in terms of enabling them to lead more fulfilling lives. Practicing behaviour analysts work to achieve positive behaviour change for individuals, groups of people, and for organizations and society as a whole. Behaviour analysts might be involved in helping to make a positive difference to behaviour change in any context in healthcare, public health, social care, education, or business. Behaviour analysts work with people to help achieve behaviour change by using ABA-based intervention approaches. Behavioural intervention for autism is one such approach although it is not a clearly defined and prescriptive intervention, but one that is highly individualized and more accurately conceptualized in terms of how it is delivered, monitored and evaluated, not by what it comprises. Furthermore, one can only describe an intervention as one based on ABA if the intervention itself is directed by an individual with postgraduate training (in behaviour analysis) and sufficient supervised experience.

The authors' assertion that one of the RCTs of EIBI (Sallows & Graupner, 2005) concluded that the intervention made no difference is completely untrue, and suggests that the authors' did not read the Sallows and Graupner study at all. The Sallows and Graupner study compares two groups that were both receiving EIBI rather than a group receiving EIBI and a group that was not. The difference between the two groups was that one was described as a 'clinic-directed group' and the other as a 'parent-directed group'. Sallows and Graupner concluded that there were little differences between these two EIBI groups (in terms of outcome) after four years and grouped them for subsequent analysis. 48% of this larger EIBI group showed rapid learning, achieved average post-treatment scores, and at age 7, were succeeding in regular education classrooms. These results were consistent with those published by Lovaas (1987).

All three RCTs of EIBI highlighted by the authors of this report (including an accurate interpretation of Sallow and Graupner, 2005), therefore, suggest the efficacy of EIBI:

*"The first RCT (Smith 2000) concluded that EIBI was effective..." (paragraph 30)*

*"The third RCT of EIBI / ABA (Dawson et al 2010), published after all the systematic reviews cited above, found that intervention produced significant improvements in IQ and adaptive behaviour."*

The systematic review referred to by the authors (Blue Cross and Blue Shield Association, 2009) has been subsequently discredited and a number of families have successfully filed lawsuits against Blue Cross Blue Shield (BCBS) in order to claim funding for behavioural intervention for autism ('ABA'), an intervention that BCBS was judged to have wrongly described as investigative or experimental...The other review (Spreckley & Boyd, 2009) mentioned by the authors of this report is in direct contradiction with other meta-analyses...

**Paragraph 31:**

Here, at least, the authors acknowledge that other researchers have reached similar conclusions about the evidence for behavioural interventions:

*"Howlin et al (2009) concluded that 'there is strong evidence that EIBI is effective for some, but not all, children with ASD'"*

This is a strange an often used argument for not recommending behavioural interventions in the absence of any other intervention having anything like this amount of empirical support. It appears that behavioural intervention for autism is not judged comparatively with any other intervention. Not all children who have had (or are having) behavioural intervention make spectacular and significant gains. Of course that's true, but what other interventions can make any claims to even a moderate amount of progress and success relative to the plethora of studies supporting behavioural intervention. Eldevik et al. (2009) and Virues-Ortega (2010) are meta-analyses that conclude that such interventions do produce significant effects. There are no other studies that suggest that any other interventions (including the popularly recommended eclectic interventions that appear to be particularly favoured by many local authorities) have produced anything like these effects, but no one seems to be suggesting that these are not used and, moreover, they are often recommended. If the research question was framed simply as 'what intervention, or category of interventions has the greatest effect?' then the answer is simply, behavioural interventions. The question that seems to be asked is, 'do all children having behavioural interventions make progress' and because the answer is no, then that is sufficient justification for making no recommendations for behavioural intervention (whilst making recommendations for unsupported eclectic packages)…

**Paragraph 32:**

Here the authors point out that there has been disagreement amongst authors, published in the Lancet, about whether EIBI/ABA is highly effective. Notwithstanding the disagreements, and given the comments already made (above), it is unreasonable and inaccurate to conclude that claims about the effectiveness of behavioural intervention have "*no basis*". Even if one could make such an assertion, why are not similar assertions being made for other interventions? This seems to suggest a heavy bias against such interventions by the authors.

**Paragraph 33:**

See comments related to paragraph 30. The authors acknowledge that others (e.g. Eldevik et al., 2009) have explained that both groups in the Sallows and Grauper (2005) study received "a form of EIBI" but offer no defence of their own incorrect interpretation.

**Paragraph 34:**

The authors' implication, that the results of the third EIBI RCT by Dawson et al. (2010), may be an artefact of parental bias, is unwarranted, unnecessary and sounds biased in its own right.

**Paragraph 35:**

It is not at all clear why the authors should choose to discriminate between different sorts of behavioural interventions here, seemingly on the basis of intensity. Intensity is not a defining feature of any intervention based on the principles of ABA (see comments related to paragraph 30 above). It is also unclear whether the interventions/studies mentioned would meet the criteria for a behavioural intervention (to the extent that they would be guided by the principles of behaviour analysis). One could, I suppose, argue that any/all interventions for children with autism are essentially 'behavioural' in that they should be aiming to teach specific skills (behaviours) or reduce specific maladaptive problem behaviours. In any case, Yoder (2006) and Green et al. (2010) describe their interventions as communication specific ("communication interventions", "communication-focused treatment") so why is this section entitled "Focused behavioural interventions" rather than "Communication-based interventions"?
Paragraph 37 and 38:

The authors refer to the Scottish Intercollegiate Guidelines Network (SIGN) guidelines published in 2007, and mention that recommendations on clinical interventions are made within this document. This document is currently under review and the recommendations have been withdrawn, as a number of autism experts have agreed that the descriptions given about different clinical interventions (notably, but not exclusively, those described inaccurately as 'ABA') were woefully inaccurate. I was involved in these discussions (along with other colleagues) with Scottish ministers in 2009, and it is anticipated that the different sections on different interventions will be rewritten by those with the relevant expertise (e.g. the purely informational section on ABA will be written by behaviour analysts).

Having said that, the authors of this report still acknowledge that the SIGN guidelines do make one specific (grade B) recommendation for one type of intervention:

*"... 'behavioural interventions should be considered to address a wide range of specific behaviours in children and young people with ASD, both to reduce symptom frequency and to increase the development of adaptive skills'.*

**Paragraph 40 and 41:**

See comments about RCTs related to paragraph 28 (above). Again, why discount other research designs, even if they are not the 'gold standard'?

**Conclusion, paragraph 4:**

See earlier comments. This 'conclusion' is not even warranted based on this report and is extremely selective and inaccurate.

**Conclusion, paragraph 5:**

This is simply inaccurate (see comments about the Sallows and Graupner, 2005 study, related to paragraph 30).

**Conclusion, paragraph 6:**

It is not clear what is implied in this paragraph, although at least some of the studies mentioned should be more accurately referred to as communication-based interventions rather than behavioural interventions – given the definition of a behavioural intervention I have outlined.

**References:**

So many key references in the area of treatment/intervention are missing from this potentially important review…

Those mentioned in this response:

Eldevik, S., Hastings, R., Hughes, J.C., Jahr, E., Eikeseth, S., & Cross, S. (2009). *Meta analysis of early intensive behavioral intervention for children with autism*. Journal of Clinical Child & Adolescent Psychology, *38*, 439-450.

Lovaas, O.I. (1987). *Behavioral treatment and normal educational and intellectual functioning in young autistic children*. Journal of Consulting and Clinical Psychology. *55*, 3-9.

National Autism Center (2009). *National Standards Project*. National Autism Center: Massachusetts.

Virués-Ortega, J. (2010). *Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose–response meta-analysis of multiple outcomes*. Clinical Psychology Review, *30*, 387–399.

The British Psychological Society

# Screening for Autism Spectrum Disorders in Children Below the Age of 5 Years

British Psychological Society response to UK National Screening Committee

January 2012

## About the British Psychological Society

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of almost 50,000.

Under its Royal Charter, the objective of the British Psychological Society is "to promote the advancement and diffusion of the knowledge of psychology pure and applied and especially to promote the efficiency and usefulness of members by setting up a high standard of professional education and knowledge".

We are committed to providing and disseminating evidence-based expertise and advice, engaging with policy and decision makers, and promoting the highest standards in learning and teaching, professional practice and research.

The British Psychological Society is an examining body granting certificates and diplomas in specialist areas of professional applied psychology.

## Publication and Queries

We are content for our response, as well as our name and address, to be made public. We are also content for the UK National Screening Committee to contact us in the future in relation to this consultation response. Please direct all queries to:-

Consultation Response Team, The British Psychological Society,
48 Princess Road East, Leicester, LE1 7DR.

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## Response

The British Psychological Society (BPS) thanks the UK National Screening Committee for the opportunity to respond to this consultation.

### Overall

The draft report is written to headings from general criteria regarding screening, and the BPS finds the simplicity and discipline of this dispassionate approach helpful in some ways. However, we believe that the report would benefit from being edited by someone familiar in detail with autism. Subsequent revision(s) could further benefit from a cross-disciplinary approach as is more frequently practised within the field of ASD.

Overall we find the method, presentation and analysis of the published literature and the conclusions reached appropriate, easy to read and coherent. However, the draft report could be further enhanced if the authors were to address the specific issues outlined below.

### Introduction

**Para 2:**

The BPS finds the language used in this section confusing, as it mixes DSM (Diagnostic and Statistic Manual) and ICD (International Classification of Diseases) terminology. There is a need to refer to DSM-4, potential changes that will happen with DSM-5 and, more importantly, ICD-10. The latter might afford more internal consistency within the NHS as ICD categorisations are employed by the NHS's electronic Community Child Health Records (Community Child Health, 2000; CCH). The CCH database system, covering most of England & Wales, forms the basis of a regional ASD database currently being developed as a pilot for a national ASD database for Welsh Government (Wimpory and Leekam, in progress).

Whilst **Table 1** is adapted from Levy *et al* (2009), which itself was adapted from Volkmar & Pauls (2003), several of the statements are questionable. For example, the BPS does not consider that Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) has a 'fair to good' outcome (as opposed to autism with a 'poor to fair' outcome). We do agree that symptom severity (alongside IQ and language) is related to outcome but this does not cut down the middle of DSM-IV sub-classifications.

Asperger's syndrome excludes individuals with intellectual disability. With reference to possible causative factors for Autism, Table 1 states: "*More likely to establish genetic or other cause than in Asperger's syndrome or PDDNOS*". We would consider it much more useful to separate out the genetic from other aspects of causation. It seems likely that the heritability of these three conditions could then be stated without resorting to apparent speculation.

**Table 1.** The male:female ratio for Autism is usually presented as 3:1 so a reference would help support the reasoning for this being represented in Table 1 as 2:1. The male/female ratios for Asperger Syndrome should also be based on referenced epidemiological studies.

**Para 4.** The Centre for Disease Control (CDC) in the USA recommends universal screening for ASD. The draft report cites the CDC's website which apparently identifies early non-RCT (Randomized Controlled Trial) studies to justify this stance. However, our understanding is that the APA (American Psychological Association) position statement published in 2007 is the basis of the CDC's screening recommendation.

## The Condition

**Para 6.** Interesting points are made here regarding recognition of ASD prevalence; these concern changes in service provision and diagnostic practices (including diagnostic substitution).

**Paragraph 7+.** Whilst we understand protocol and definitions regarding screening have to be followed, we found the paragraph below **point 7** unhelpful:

> *"the epidemiology and natural history of the condition, including development from latent to declared disease, should be adequately understood and there should be a detectable risk factor disease marker, latent period or early symptomatic stage."*

Our concern is that if anyone with Autism, Asperger Syndrome (or their parents or carers) read this, it would be not only confusing but potentially distressing; we therefore suggest adding a footnote with particular regard to the term "disease"?

**Paragraphs 9 & 10.** The BPS endorses the points made here regarding the desirability and rarity of blind assessors for follow up assessments of children identified through early screening. However, we would query the origins of 33% stability for PDD-NOS in Para 10, page 5 (see comment on para 11 below).

**Table 2** refers to Lord 2005's study but this is not referenced at the end of the draft report (and therefore not referenced at the end of this consultation response). However, elsewhere in the text, the Lord *et al* (2006) study is mentioned with similar, but not identical, figures to those employed in Table 2. Unfortunately Table 2 (on pages 6 & 7) is presented with the last column spilling over onto the second page in both the pdf and printed versions. If it were more appropriately formatted to fit on one page this would enhance comprehension.

**Para 11.** The Lord *et al* (2006) paper itself does not show a stability of 30% for a PDD-NOS diagnosis. Table 3 (page 698 in their paper) shows that from 46 children with a PDD-NOS diagnosis at age 2 years 27 met criteria for autism at age 9 years (59%), 14 met criteria for PDD-NOS (30%) and 5 did not meet criteria for an ASD (11%). Most clinicians and researchers would accept that this is 89% stability since an autism outcome from an initial PDD-NOS diagnosis is not 'losing a diagnosis'. In the light of these issues, we recommend that every figure within the draft report is checked against the original publication to ensure that such errors are not made elsewhere.

## The Test

**Table 3** needs re-formatting to enable the references to be read alongside the studies to which they apply; this will save readers having to turn pages back and forth in order to read each line of the table. Unfortunately the conventions (a, b, etc.) for denoting more than one reference occurring by the same first author in the same year, have not been observed in the draft report and this may therefore lead to some confusion (e.g., Kleinman *et al,* 2008).

**Table 3**. We recommend making a distinction between the studies that screened a general population (e.g. Tebrugge *et al,* 2004, Dietz *et al,* 2006, Barbaro & Dissanayake, 2010 and Dereu *et al*, 2010), and those that screened a combination of general and high risk (referred for early intervention). For example, most of the M-CHAT studies are the latter. Positive predictive values will likely be higher in at-risk/enhanced samples. Positive predictive values should be initially presented within the draft report in both full wording and acronym form before being referred to as PPV in Table 3.

**Para 23.** The preliminary papers on the Q-CHAT (Quantitative Checklist for Autism in Toddlers) and FYI (First Year Inventory) (but not the papers on actual screening studies) have been published in the Journal of Autism and Developmental Disorders: Allison *et al* (2008); Reznick *et al* (2007); Watson *et al* (2007).

**Para 25.** The BPS would query the validity of using the drop out rates of those parents whose children fail initial screening tests for research as an indicator of the acceptability of a screen when used in clinical practice. Despite research practice having received ethical approval, it would seem unlikely to match the sensitivity expected from a screening service employing clinical staff rather than researchers/students etc.

**Para 26.** Following the September 2011 issue of The National Institute of Health and Clinical Excellence (NICE)'s clinical guideline, '*Autism spectrum disorders in children and young people: recognition, referral and diagnosis*,' (NICE, 2011), reference to this needs updating in the draft report with regard to tense etc.

## The Treatment

**Table 4**. We would prefer that Dawson *et al's* (2010) ESDM (Early Start Denver Model) study was not included with more conventional ABA/EIBI (Applied Behaviour Analysis/Early Intensive Behavioural Intervention) Random Controlled Trials (RCTs). Although it was relatively intensive and included behavioural methodology it also had a very developmental and relational focus which is different from more 'conventional' ABA/EIBI.

**Table 5: RCTs of Focused Behavioural Intervention.** Formatting criticisms of previous tables also apply to this one.

**Para 37.** "*The Scottish Intercollegiate Guidelines Network guideline 98 (SIGN, 2007) includes recommendations on clinical interventions for children and young people with ASD. Treatment is not covered in the forthcoming NICE Clinical Guideline on ASD in children and young people.*" The BPS suggests the draft report also cites the forthcoming NICE guidelines on intervention at this point, "*Autism - the management of autism spectrum disorders in children and young people*", due for publication in November 2013.

## Draft Report Conclusion

**Statement 1.** *"Studies of the natural history of these conditions indicate that about a third of children who are given a diagnosis of 'autism' at 20-23 months of age as a result of a screening programme, and up to a quarter of those identified as being within the broader category of 'ASD', are likely to lose these diagnostic labels by the age of four years. It is not clear whether these figures reflect the impact of early intervention (assuming it is effective) or over-diagnosis at 20-23 months of age."*

The BPS believes that this is inaccurate (see our earlier comments regarding 'The Condition, Para 11' above).

**Statement 2.** *"No approach to screening for ASD has demonstrated acceptable performance, in terms of both sensitivity and positive predictive value, in a general population screening study."*

Whilst we believe this statement is appropriate, it would be helpful to summarise the threshold for acceptability somewhere in the draft report. The NICE guidance (NICE 2011) sets Sensitivity and Specificity at 80% with lower Confidence Intervals (CIs ) not lower than 70% (see page 43 of the full guideline).

**Statement 3.** *"Approaches to screening for ASD used in recent studies are not accepted by a substantial proportion of parents. Parents of between one third and one half of all children who failed the initial screening test dropped out of the screening process before it had completed."*

The BPS recommends clarification of the research based context for the conclusions in this statement, as outlined in our earlier comments above regarding 'The Condition, Para 11'.

## Key Research Questions on Screening for ASD

**Point 2.** *"Why do so many parents of children who fail initial screening tests for ASD drop out of the screening process before it has completed, and can the process be refined so that the drop-out rate is reduced?"*

For reasons stated earlier, we believe this should be considered in a clinical context rather than being limited to research procedures and settings. Previous research looking at communication skills in health professionals could help at this point. An excellent resource is The Centre for Parent and Child Support website.

Autism and Asperger Syndrome are potentially life changing diagnoses for parents. The screening tools may also be picking up closely related conditions such as Dyspraxia and ADHD and these diagnoses may be more acceptable to parents, hence they may not return for further screening. It is also unclear whether there is any relevant epidemiology indicating which parents participate in the next stage and which parents fail to engage. For example, are there class or ethnic minority differences?

The way screening tools are delivered will either engage parents or frighten them away. These are more than checklists; they involve parents reporting on and considering aspects of their child's development, and may carry major implications for current and lifelong functioning. They have the potential to change the child's life and their family life. We therefore recommend that the professionals delivering them should be trained in (at the very least) basic communication skills.

There are several training programmes for professionals to enable them to engage with parents in respectful and empathic ways. The Partnership Model and Training Programme has been evaluated using randomised control trials and been shown to be effective (Davis and Rushton, 1991), particularly with regard to ethnic minority families. Practitioners capable of delivering this training can be found on The Centre for Parent and Child Support and the Axia-ASD websites.

## BPS Concluding Comments

Whilst we accept the conclusions of the draft review, given the criteria to which it must adhere, we suggest that a more positive approach to ASD screening of under-fives is considered. The context for this would be informed by a more detailed understanding of the prevalence figures for ASD and greater awareness of the need for trained clinical skills to be employed in the relevant screening/assessments.

In particular, we recommend that the value of skilled communicators/practitioners is emphasised for clinical screening. This would help establish mutual commitment between service and potential clients to help ensure retention of the latter.

*End*

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Wimpory, D., (PI) & Leekham, P., (Project in progress) "Development of an ASD Database"; matched-funded by Welsh Assembly Government & Betsi Cadwaldr University Health Board. November, 2010-May, 2012.