Sorting out autism spectrum disorders: Evidence-based medicine and the complexities of the clinical encounter

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ABSTRACT
Autism spectrum disorders (ASDs) present particular problems for diagnosis, encompassing as they do communication difficulties, learning difficulties, social awkwardness, and severe disability, as well as some strengths and special skills (such as perfect pitch or artistic abilities). Hence ASDs have proven difficult to standardise, and evidence-based medicine (EBM) advocates deplore the absence of clean randomised control trial data for different approaches. This study explores the extent to which the drive for standardisation and statistical approaches to clinical medicine influence the ways paediatricians diagnose and treat ASDs. To this end, we interviewed nine paediatricians in private practice using a face-to-face, semi-structured approach. Three primary themes emerged from the interview data. First the essentially tacit, experiential nature of diagnosing autism, second the necessity of tinkering with and adapting existing diagnostic tools to particular patients and circumstances, and third, the influence of social constraints on the clinical encounter. This study demonstrates that the process of diagnosis and treatment recommendation involves constant negotiation between clinical experience, the evidence, and the family’s social situation. Furthermore, we find that statistical and EBM approaches are used most often at the margins of the clinical encounter to diagnose outlier patients, rather than the typical patient these approaches claim to describe.

KEYWORDS: autism; evidence-based medicine; sociology; diagnosis; paediatrics; standardisation; DSM

INTRODUCTION
The American Psychiatric Association is currently embroiled in an argument, both within its ranks and in the wider public domain, over the boundaries of autism. The Association is in the midst of revising its compendious Diagnostic and Statistical Manual, the authoritative and widely used classification system for mental health disorders, in preparation for its fifth edition. It proposes to roll Asperger’s syndrome, the diagnosis of choice for high-functioning, high profile individuals like designer Temple Grandin and artist Stephen Wiltshire, into a more general rubric, part of the autism spectrum, rather than leave it as a separate, special form of autism. The current version of the DSM-IV-TR lists five kinds of autism: autistic disorder, Asperger’s disorder, Rett’s disorder, childhood disintegrative disorders, and pervasive developmental disorder not otherwise specified (PDD-NOS). The psychiatrists embroiled in the DSM debate disagree about the evidence for classifying Asperger’s as a
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separate syndrome, arguing that research points to the continuity of high-functioning autism with the extreme impairment found at the other end of the scale. This claim is contested both by other psychiatrists and paediatricians, and by the advocates for the neuro-diversity movement, who claim Asperger’s as a positive identity rather than a deficiency, and oppose its assimilation into a spectrum disorder (see Baron-Cohen 2009; Grinker 2010; Hamilton 2010).

We draw attention to this DSM controversy not because we propose to take one side or other in the debate, but because it gives a strong flavour of the biomedical uncertainty that surrounds autism spectrum disorders (ASDs) more generally. Autism has widely variable symptoms which manifest differently in each individual, in highly unpredictable combinations (Grinker 2007). The autism spectrum encompasses communication difficulties, learning difficulties, social awkwardness, and severe disability problems that are sometimes combined with extraordinary abilities like those of Grandin and Wiltshire. The current version of the DSM-IV-TR defines autistic conditions as:

Characterized by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviours, interests, activities … These disorders are evident in the first years of life and are often associated with some degree of Mental Retardation. (American Psychiatric Association 2000)

Social impairments might include poor eye contact, uncommunicative gestures, a lack of friends. Communication impairments might involve a delay in or absence of (spoken) language, or repetitious or imitative use of language, as with echolalia for example, where the child repeats another’s utterances without reference to their meaning. Stereotyped behaviours, interests

and activities refer to ‘inflexible adherence to non-functional routines’ (such as lining-up toys and then throwing a tantrum when the line is interfered with), stereotyped body movements (such as hand flapping or rocking the body), and ‘preoccupation with parts or sensory qualities of objects’ (such as the sound an object makes, or squinting while holding an object up to one’s eyes; Ozonoff et al. 2005:523).

Autistic presentation in the clinic is thus highly idiosyncratic, and represents particular problems for diagnosis. The sheer heterogeneity of ASDs in terms of causes, age of onset, manifestation of symptoms, outcome and comorbidity with other disorders, means that the application of this label is broad and thus leads to indeterminate medical definitions of this disorder amongst practitioners (Bumiller 2008). There is a concern that some children diagnosed with an ASD have been misdiagnosed (Romanczyk et al. 1994). Unlike more straightforward childhood disorders like asthma or allergy, ASDs lack a biological marker or a set of pathology tests to aid in this diagnostic process. Hence the paediatrician cannot send off blood samples or use physiological measures like heart-rate to verify their intuitions about a particular child. Currently, diagnosis is based on the child’s developmental history, the presence or absence of observed behaviours, and ruling-out other medical conditions. A diagnosis can only be made once symptoms are frank, and sufficient data has been gathered on the behavioural symptoms exhibited by the child across at least two observational settings (Williams and Brayne 2006).

Overall then, ASDs are difficult to categorise. These classificatory problems are made more complex again by the wide variety of assessment approaches and diagnostic tools used amongst professionals. These include the autism diagnostic observation schedule (ADOS), the childhood autism rating scale (CARS) and the autism diagnostic interview-revised (ADI-R). While the

DSM aids the clinician in determining whether the patient is on the autism spectrum, the diagnostic tools produce a standardised score ‘that measures severity and numbers of symptoms’ (Grinker 2007:161). The ADOS takes approximately forty minutes to administer and consists of various activities that allow the clinician to interact with the patient and observe social and communication behaviours (Grinker 2007). In contrast, the ADI-R consists of a standardised interview with the parent or caregiver (Rutter et al. 2010), focusing on aspects of developmental history, language and communication, reciprocal social interactions, and repetitive, restricted, and stereotyped behaviours and interests. These domains are coded based on ‘highly standardized procedures’ (Rutter et al. 2010). The CARS consists of a rating scale of behaviours associated with autism and ‘measures the severity of a child’s autism by comparing a child’s behaviour to that of non-autistic children in fifteen different areas’ (Baker 2004:8). This brief outline of diagnostic tools only begins to capture the sheer variety in the ‘standardised’ approaches to this disorder’s assessment. There are at least 30 other diagnostic and treatment tools to be found in the field.

This heterogeneity is understood as a cause for concern among clinicians and professional medical bodies. It is frequently explained as the result of a lack of good, randomised controlled trial (RCT) evidence, supporting diagnostic techniques and the effectiveness of treatment interventions (Mesibov et al. 2006; Williams and Brayne 2006). The guidelines and tools used in the diagnosis of ASDs are based on what is considered weaker evidence, case–control studies and case series, which do not have the same statistical validity and reliability as RCTs in the current medical hierarchy of evidence. This has prompted calls from medical bodies, such as the Royal Australasian College of Physicians (RACP), for a ‘consensus approach to the diagnosis of ASDs’ (Silove et al. 2008). Other commentators have stressed the importance of taking a rational and standardised approach to the medical investigation of ASDs (Cass et al. 2006; Shattuck and Grosse 2007).

In short, these commentators blame the messiness of autism spectrum diagnosis on the absence of what counts as gold standard evidence, within the hierarchy set out by the evidence-based medicine (EBM) movement. EBM is essentially a strategy to standardise clinical practice, a movement which has been extremely influential in medical education and in health administration over the last 20 years, in part because it facilitates cost containment and simplifies state decision-making about the subsidisation of particular drugs and treatments. A commonly quoted definition in the literature describes EBM as ‘the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients’ (Sackett and Rosenberg 1995). EBM aims to optimise diagnosis and treatment through the use of statistical evidence for the effectiveness and efficiency of particular clinical interventions, measured ideally by randomised control trials. It promotes an epidemiological, population statistical approach to health and illness in the clinic, rather than the pathology–physiology approach historically associated with clinical case medicine and physician practice. Timmermans and Kolker summarise the assumptions about hierarchies of evidence at work in the EBM movement.

An understanding of pathophysiology is necessary but insufficient for the practice of clinical medicine. All pathophysiological inferences should be subordinated to the question of whether diagnostic or therapeutic interventions have been proven to be effective in sound empirical studies. (Timmermans and Kolker 2004:183)

Evidence-based medicine is most commonly disseminated through clinical practice guidelines and standardised tools, and through diagnostic databases like the Cochrane Collaboration. The rational behind such databases is that clinicians can check the RCT evidence for particular...
diagnoses and interventions, and hence bring such statistical knowledge to bear on their diagnosis and treatment of the patient before them in the surgery. Thus, for its advocates, EBM is understood as ‘a process by which clinicians translate clinical information needs into answerable questions, track down answers to those needs as efficiently and effectively as possible using the best evidence available, apply the information to patients and evaluate their performance’ (Sackett et al. 1997 in Phillips et al. 1999:163).

Timmermans and Berg’s (2003) examination of the political, ethical and practical aspects of the standardisation of healthcare provides an excellent platform from which to explore professionals’ ambivalent attitude towards EBM. Of particular interest to this study is their examination of the standardisation of clinical behaviour, conducted through in-depth interviews, participant observation, and documentary analysis. This research stresses the often creative and pragmatic way that clinicians interact with clinical guidelines and standardised tools to satisfy and advance their own ‘professional trajectories’ (Timmermans and Berg 2003:70). To what extent has this drive for standardisation and statistical approaches to clinical medicine influenced the ways paediatricians diagnose and treat autism? This question is posed in the study we present here. We set out to find if the EBM approach had made significant inroads into everyday clinical practice around ASDs. Autism is a telling case study here because of its sheer symptomatic variability, its associations with both genius and extreme impairment, its lack of an agreed biological marker or physical test, and, as we shall see, because of its complex entanglement with issues of family, capacity to cope. From one point of view it might appear in great need of improved standardisation, as some of the clinical commentators argue, but from another it might suggest the limits of standardisation, a residue of particularity that cannot be entirely eliminated from the clinical encounter.

Moreover, we are aware that, once on the ground, EBM may not function according to its stated intentions. This is certainly Timmermans and Berg’s (2003) findings, based on their empirical investigations of the impact of EBM on paediatric residents in a US hospital. They found that while most clinicians in their study were actively engaged with various EBM instruments, they did not necessarily submit to the tools, but ‘actively and deliberately make the guidelines work for them’ (Timmermans and Berg 2003:70). They further note:

For all those involved, the guideline is not a goal in itself but a means, acted upon in terms of their own aims and the local constraints structuring the situation in which the guideline happens to be placed. (Timmermans and Berg 2003:70)

Clinicians use EBM not to practice ‘better’ science but, more pragmatically, to ‘figure out what kind of evidence might be appropriate in dealing with patients’ (Timmermans and Berg 2003:165).

Nevertheless, they found that the introduction of standardisation tools into the clinical encounter was not neutral, but rather ‘mutually transforming’. Doctors used statistical evidence neither as a substitute for nor an extension of clinical experience and judgement, but in a dialogue where each modified the other. In particular Timmermans and Berg (2003) found that doctors ‘tinker’ with protocols to make them workable in practice, better suited to this particular patient with these particular problems and needs, rather than the probabilistic, statistical representation of a patient implicit in the guidelines. Their study thus breaks down the dichotomies set up in the EBM literature between the objective rationality created by tools and the creative instability of clinical experience and judgement. As Bowker and Star (1999) demonstrate in their more general study of classificatory practices, objective standards are necessarily modified and negotiated in practice because ‘people do not do the ideal job, but the doable job’ (Bowker and Star 1999:24).
So standards appear to lead a double-life: their function in theory, at the level of programmatic intention, and their function in practice, once they encounter the stickiness and obduracy of actual clinical encounters. Considering the difficulty of applying EBM to the diagnosis and treatment of ASDs, it seems logical to assume that much tinkering with the diagnostic tools and guidelines occurs, and likewise that particular experience may supersede the use of EBM and its instruments. However, sociological investigations of the subtleties and complexities involved in the clinical encounter when dealing with a heterogeneous disorder such as autism are scarce (see Rafalovich 2005).

This study does not endeavour to point out that the medical practice of diagnosing and treating ASDs lacks something; that if it were a truly ‘scientific’ practice one would see coherence, consensus and uniformity. Instead, it seeks to understand the incoherencies, complexities, and uncertainties faced by paediatricians in the clinic, and how these inform medical knowledge and practice. Furthermore, this study focuses on understanding the ways in which paediatricians reconcile the tensions between EBM approaches and the complexities surrounding ASDs. As Berg and Mol (1998) so aptly state: ‘medicine doesn’t fail to meet the standards: the standards fail to meet reality’.

**METHODS**

This study is based on interviews with private practice paediatricians who diagnose and treat children with autism in Sydney, Australia. Our study took helpful methodological guidance from Timmermans and Angell’s (2001) examination of paediatric residents’ use of EBM, particularly the way they identify different approaches to doing EBM. We took their interview questions as a starting point for designing the interview schedule for this study, although our study does not in any sense replicate theirs.

After ethics approval was secured from the Human Research Ethics Committee, clinicians were recruited using two different approaches. The first involved the publication of a recruitment notice in the Royal Australasian College of Physicians’ (Paediatrics and Child Health Division) e-bulletin. The second involved a recruitment letter posted to 22 paediatricians within the Sydney area.

In total, nine private practice paediatricians participated in a 25–40 minute semi-structured interview in 2009. Interviews were conducted face-to-face in the paediatrician’s place of work. Each interview was audio-taped and then transcribed verbatim. The number of years of experience practicing as a paediatrician ranged from 9 to 34. In fact, two clear groups were identified. Four participants had 16 years or less experience, and five participants had 30 years or more experience. This spread of experience points to different educational backgrounds and knowledge with regard to autism, for two key reasons. First, autism was only classified as a distinct disorder in 1980 in the DSM-III; and second, the ascendancy of epidemiology as the key to diagnosis only began in the late 1980s. Thus, clinicians with 30 or more years of experience, whose training and initial practice precedes the EBM movement, may be expected to have very different responses to clinicians educated and trained during the EBM movement.

The interviews explored: the process of diagnosing and treating ASDs within paediatric private practice; how clinical guidelines, tools and evidence are used in diagnosis and treatment; the benefits and challenges of the guidelines, tools and evidence within clinical practice; and clinicians’ understandings of EBM within the Australian and paediatric contexts.

Coding of the interviews was performed manually. Thematic headings were established after preliminary readings of the interview transcripts, and data was then sorted according to these pre-established codes. Where possible, quantitative data was calculated to provide information about trends in clinicians’ views. For example, responses to questions in which clinicians listed common
treatment interventions or diagnostic approaches were tallied. In doing so, we were able to distinguish salient themes and practices amongst the clinicians interviewed.

**FINDINGS**

Three primary themes emerged from the interview data. First the essentially tacit, experiential nature of diagnosing autism, second the necessity of tinkering with and adapting existing diagnostic tools to particular patients and circumstances, and third, the influence of social constraints on the clinical encounter, including on technical aspects of diagnosis and prescribed treatment. We will deal with these themes in turn.

**The role of the tacit and the experiential in diagnosis**

The clinicians indicated that the complexities and uncertainties surrounding diagnosis are sometimes addressed using standardised tools and guidelines, but mostly are managed using knowledge gained over many years of experience. This experiential form of knowledge is referred to throughout the interviews as a ‘gut feeling’ or a ‘sixth sense’. While it is difficult to accurately gauge what this ‘gut feeling’ entails due to the tacit nature of such knowledge, Wegner (1998:47) provides some insight into the experiential nuances involved in clinical practice:

... implicit relations, tacit conventions, subtle cues, untold rules of thumb, recognizable intuitions, specific perceptions, well-tuned sensitivities, embodied understandings, underlying assumptions and shared world views.

This aspect of diagnosis was discussed by clinicians in two key ways: the importance of observation, interaction and a ‘gut feeling’, and consensus among clinicians that the ADOS was the most useful tool.

Eight of the nine paediatricians ranked clinical experience and observational knowledge as the highest diagnostic competencies. Several of the more experienced clinicians stressed that being ‘old and grey’ (that is, having decades of experience behind you) meant that they were better equipped to diagnose subtler forms of ASDs, due to a heightened ‘sixth sense’. One clinician stated:

I do not use things like ... the ADOS; that’s not my cup of tea; to me, it is a clinical diagnosis, and of course, being old and grey, one can pick these things, because when you see lots and lots and lots of children, full-blown autism is not a difficult diagnosis. The more subtle ones, the Asperger’s – not quite that clear-cut – but in some respects, the combination of speech and language issues, socialisation issues, repetitive behaviours; it’s not too difficult to say well, this child fits into an ASD category, and then you just mentally classify is this severe, is this moderate or is this mild, is it just Asperger’s ...

The less experienced clinicians also stressed the superiority of clinical experience:

Well, I still think clinical diagnosis is the most important thing. I mean, I had access to all those tools when I started and yet, 10 years down the track I would actually prefer to go in there with no tools and 10 years of experience rather than all the tools and no experience. It’s that whole pattern recognition where they talk about expertise is being able to recognise patterns and it’s just getting out there doing it and seeing lots of it; and that to me is more important than the standardised tools.

Each of these quotes demonstrates the tacit nature of this ‘gut feeling’ knowledge. Phrases such as ‘one can just pick these things’, ‘you just mentally classify,’ and ‘expertise is being able to recognise patterns’, illustrate Wegner’s (1998) view of the experiential nature of the clinical encounter. These ‘gut feeling’ judgements are based on subtle cues, well-tuned sensitivities, embodied understandings, and recognisable intuitions that have been built up by diagnosing ‘lots and lots of children’ and ‘just getting out there doing it and seeing lots of it.’ The nature of this knowledge
depends upon the paediatrician learning the subtleties of interaction in the clinical encounter and recognising a pattern of symptoms. This type of knowledge is very difficult (and probably impossible) to standardise and make explicit. In particular, standardised approaches are difficult to apply to the relational dynamic evident among these practitioners. Autism is above all a disorder of social interaction, where the child fails to engage with others through self-expression, communication, empathy, play and the give and take of social belonging. Diagnosis thus involves relational assessments, where the doctor gauges the child’s capacity to exchange meaningfully with him/herself. The statistical approach of EBM simply does not apply to the intersubjective dynamics in play here.

Seven of the nine clinicians believed that the ADOS was the most effective/rigorous/accurate tool available to them in the diagnosis of ASDs. The ADOS stresses the importance of a lengthy observation of and interaction with the child (in comparison to other tools), which in turn allows more flexibility in the diagnostic process by drawing on the experience and judgement of the clinician (Grinker 2007). One of four modules of the ADOS is administered to the patient based upon their expressive language level and age (Lord et al. 2010). In light of clinicians’ responses regarding the centrality of interaction and ‘gut feeling’ in the diagnostic process, this attitude towards the ADOS is not surprising. One clinician stated:

ADOS has been shown to be a much more accurate tool than the CARS because it involves observation and history taking and other aspects of interaction with a child, and it’s much longer ... ADOS seems to be able to sort out [children on the spectrum] that are less clear-cut.

This result appears to support Timmermans and Berg’s (2003) finding that that medical practice ‘inevitably contain[s] a mixture of [EBM and clinical experience], albeit not necessarily in equal proportions’. Despite this preference for the ADOS, only three clinicians actually claimed they used it in the clinical encounter. One clinician offered a possible explanation for this result:

... there’s some evidence for the ADOS ... but it’s all based on a diagnosis which is a construct and so it’s like ADHD - we’ve got all this evidence but we’ve got this construct that is probably meaningless, so we’re trying to fit things into little boxes. So how you can have real evidence, I think, is very difficult when you really don’t have a genuine diagnosis ... because it’s a set of symptoms or whatever, so I think it’s very difficult to have genuine EBM under those conditions, until we get a better method, or dimensional tool.

This statement could explain the incongruence of many of the clinicians’ responses. While the ADOS may be the ‘gold standard’ of evidence for ASDs, essentially it is the best out of a bad lot. This could also explain why the use of clinical judgement, and basing diagnostic decisions on clinical experience, is such a common practice amongst the clinicians.

The quote above is also interesting as it highlights the tension between EBM as the gold standard and the difficulty of applying it to the ASD patient in the clinical encounter. However, this clinician, like Mesibov et al. (2006), illuminates the paradox of applying EBM to heterogeneous disorders. Despite the fact that ASDs do not fit the epidemiological mould, the medical profession continues to hope that EBM will develop a ‘better method or dimensional tool.’ This hope persists in spite of explicit explanations, whereby ASD is viewed as a ‘construct’ and the potential for ‘real’ evidence is questioned. It is interesting that even with the insights this clinician possesses, the power of EBM persists. This could be related to this clinician’s belonging to the less experienced group of interviewees, and thus her educational background. Educational and training norms are probably maintained throughout the physician’s career. Thus, this clinician was
educated and trained when EBM was an important part of the curriculum.

**The strategic use of guidelines: Adaptation and tinkering**

Most of the clinicians indicated that ASD is not difficult to diagnose if the child exhibits obvious symptoms. One clinician stated: ‘The diagnosis is pretty straightforward ... some of [the patients] are so obvious that the woman across the road could diagnose them.’ In such circumstances, clinicians emphasise that the use of diagnostic tools is pointless because it is a waste of time and money.

However, there is a clear trend in our data indicating that tool use is associated with difficult or uncertain diagnoses. If, for example, the doctor is unsure if the patient had attention deficit hyperactivity disorder (ADHD) or an ASD, or perhaps elements of both, tools were often used to alleviate this uncertainty. One clinician stated: ‘I might use an ADOS assessment at three years or four years if it’s not a straightforward diagnosis.’ Problems of comorbidity are quite common in ASD, which significantly complicates the clinical encounter.

So tools are used when a patient presents with symptoms that are hard to (tacitly) classify or tease apart from other disorders. This is a particularly interesting finding: the principles of epidemiology (and thus EBM) are based on probability and population statistics, yet it appears EBM is not applied to the probable ASD case. Instead, it is used at the margins to deal with improbable and ambiguous ASD cases. EBM literature searches are also used at the margins of the clinical encounter, when the physician has exhausted their clinical experience resources. One of the less experienced clinicians stated: ‘I do searches when there’s a reason to: when there’s something else going on; when there’s a question I don’t know the answer to.’

Another less experienced clinician discussed the reasoning behind using or not using the tools in the clinical encounter. Interestingly, her discussion seemed to establish a clear distinction between situations in which clinical experience is needed and situations that require the use of tools. She stated:

I think in some areas they are very valuable; at times I think they can try and oversimplify treatment; and I think at times, you’ve got to rely on your judgement and experience. But there are times when you’re going to find these tools very valuable; there are times when you feel they are not in the best interest of a patient or your judgement.

This quote illuminates the apparent tension between EBM and clinical experience. Yet most clinicians explained that medical practice was an act of negotiating in and between the tools, experience, and the patient. This negotiation process was justified by the heterogeneity (and thus uncertainty) of ASDs and inherent problems with the tools and guidelines. Thus, the tool requires ‘tinkering’ to make it functional in the clinical encounter.

Three main problems with the tools/guidelines were discussed by the clinicians. First, the inconsistencies between the diagnostic guideline (DSM-IV) and the tools (such as ADOS): ‘I might have a child who meets the ADOS criteria but doesn’t quite meet the DSM-IV [criteria].’ Second, clinicians discussed problems with the language and structure of the DSM-IV and that these problems made it difficult to apply and use in practice. One clinician stated: ‘What I think is one of the issues is there is so many different terms for the spectrum ... you can get caught in the semantics of it.’ Third, clinicians discussed the failure of the diagnostic tools to produce a definitive diagnosis of an ASD:

... like today, this little boy actually did really well, and I’m thinking has he or hasn’t he got the diagnosis of PDD(NOS) but then, as soon as I stopped and he wasn’t getting my attention, he’s spinning in circles and holding the
Do I practice evidence-based medicine? Well, obviously every doctor thinks he [sic] does, but the dilemma is that in behavioural medicine it is clear that some people respond to certain medications and some don’t; and so though the evidence says some don’t, the fact is that some do, and my role is to roll through certain therapies in an attempt to identify whether the patient responds to or benefits with what I am trying him on; if evidence says they don’t respond to x, but if one in ten does respond to x, is my patient that one in ten? So, I don’t dismiss therapies that are deemed not appropriate.

This response indicates, again, the problems associated with applying the construct of EBM and the ‘gold standard’ to the uncertain field of behavioural medicine. The point the clinician makes here is that while the evidence may say that a certain therapy or medication is ineffective in nine out of ten children, there is still one child that could benefit. Thus, it is important to ‘cover all the bases’, by ‘tinkering’ or negotiating in and between the tool, clinical experience, and the patient. One clinician claimed, in fact, that in such circumstances the diagnosis is so complex and uncertain that the diagnostic tools cannot be used:

There are a group of children who I just think have very severe ADHD ... so even the fact that they don’t respond to having their name called may simply be a concentration issue. And then there is another group who I find difficult again in that older age group where anxiety is such a component that what you perceive as poor eye contact in fact may be severe anxiety; and again if it is combined with ADHD I think it is very very difficult sometimes to tease those things apart and I’m not sure that any of our tools particularly help us with ... separating that, either. In some ways it doesn’t matter because I think the treatment is much the same.
Social constraints on diagnosis and treatment

This section explores the interactions between the situational or social constraints in which the paediatrician finds him/herself and the production of particular diagnoses and treatment recommendations. Many studies have examined the social shaping of the medical world, emphasising that physicians do not practice in a scientific vacuum (Hester-Moore 2005; McDonald et al. 2006; Timmermans and Angell 2001). For example, Rafalovich’s (2005) study shows that clinicians involved in the diagnosis and treatment of ADHD are often affected by the controversy that surrounds this disorder. Our research found that there were two main constraints identified by clinicians: the parent–paediatrician relationship and the impact of government funding.

The parent–paediatrician relationship

The parent–paediatrician relationship was discussed by seven clinicians. Two main issues were cited as affecting the role of the doctor in the clinical encounter: the parents’ emotional and financial capacity, and the parents’ agency in the treatment process.

Breaking the news to a family that their child is affected by autism requires empathy and sensitivity. Diagnosis and treatment recommendations are often modified to better suit the family capacity to cope with the consequences. This occurs in many ways. First, certain diagnostic tools and treatments may not be offered or mentioned to the family due to their expense. One clinician claimed that she believed it would be ‘cruel’ to discuss early intervention therapy with a low socio-economic status family, although she recommends such treatments to families with adequate financial means.

Second, clinicians sometimes use the diagnostic tools themselves to persuade parents to accept the diagnosis or to help them understand what the diagnosis entails:

As far as diagnosis goes, I think, parents like some criteria, they like to say they agree and it’s always a nice closure for the parents, this isn’t just a gut feeling – or this isn’t the doctor just trying to get the money and get me out of the office; they want something that says okay, this is the real thing, and this will push them on to therapies a bit harder and faster if they realise there is a definite diagnosis; and it’s not wishy washy – you have a diagnostic tool and you say, okay, tick, tick, tick, this is where we’re heading ... Parents like to have something in black and white.

So here standardisation tools are deployed to give the clinician leverage with the family and enrol their support for treatment, rather than to come to a statistically informed diagnosis. They function not as tools of rationalisation but rather as a means of reassurance and as rhetorical devices. EBM strategies were also drawn upon to recommend particular treatments. One clinician claimed she felt it was important to keep up-to-date with the ASD treatment literature for the sake of the parents, and that it was her role to direct parents towards treatments with an evidence-base to justify the time and money spent on them. She stated:

parents like evidence-based ... they want to know what’s best and what’s been proved ... they’re going to spend their time and their money in a wise fashion, for the better outcome ... one of our roles is to be able to provide that evidence-based research in terms of therapy.

Third, clinicians stated they will refer patients to treatments they do not necessarily believe to be effective because the parent expresses interest in them, or places pressure on the doctor:

I grew up under the influence of certain mentors who were sceptical of what those

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2 The term ‘parent’ will be used here for convenience, but it is important to note that not all caregivers are parents.
supportive measures [early intervention therapy] had to offer, and so I've always been somewhat hesitant about the effectiveness of those therapies. So I kind of live with that, but I still refer the children, because I think they certainly warrant assessment because the parents expect them and the parents certainly deserve a trial of those therapies, to see what outcome there is.

The other main issue that emerged in the parent–paediatrician relationship is the agency of the parents in the treatment process. One clinician reiterated the importance of the paediatrician working with the parent to help them understand the diagnosis and the treatment options. He describes his role as a ‘facilitator,’ whereby he provides preliminary assistance and then the caregiver takes over and makes the important decisions as to what treatment approach(es) to follow:

I think the role of the paediatrician, and my role, is a facilitator, to make the parents aware of the diagnosis, or to support their fears if a child has that; and then to try and steer them in the direction where they can get help; and to cut out things if they think it's not making any use; to let them know about things like respite care, which they may need if the child is extremely demanding and it's disruptive to the whole fabric of family life.

Another clinician highlighted his respect for the research and effort put in by parents in finding out about and trialling different treatment approaches. This respect was also translated to the belief that he had much to learn from these parents, and could use their knowledge to better his own practice. He stated:

I have two boys who I’ve looked after, whose mother has been absolutely fantastic in assessing every facility in the community. I’ve asked her ... would she write up a recommendation list of what she’s found most helpful.

Furthermore, several clinicians also down-play the role of the paediatrician in the treatment process, simultaneously highlighting the agency of the parent(s):

My experience is that, what the doctors say is really irrelevant to parents; what happens in the real world is the parents are given a diagnosis, we do the paper work, try to get as much financial help for the family ... and then in my case, you refer them to Aspect for the play intervention, I refer them to speech therapy; and then parents do their own thing, quite honestly.

**The impact of government funding**

In Australia, identification of autism needs to be made by a paediatrician, child psychiatrist or child psychologist in order for the child to be eligible for subsidised services, such as special education and funding (Bumiller 2008). Four clinicians commented on the implications of government funding and how this affected their recommendations of treatments. One clinician claimed she often recommended treatments based on therapies she could access through the community health centre and recommended preschool programs based on the funding that could be obtained. Another clinician mentioned that despite the lack of evidence supporting the effectiveness of early intervention programs, she recommended families get the ‘Helping Children with Autism Package’ (a government-funded initiative) to help meet the costs of treatments such as Applied Behavioural Analysis (ABA – an intensive early intervention therapy) and also recommended the ‘public ABA program’ which provides 20 weeks of free ABA. Furthermore, one clinician claimed that she does not like the drug Risperidone (used to treat hyperactivity and aggression) but is often forced to prescribe it because ‘it’s the only one on the pharmaceutical benefits schedule (PBS) available to me’. She goes on to state that she would prefer to prescribe other drugs (such as
Abilify), and in fact does, ‘if [the parents] can afford it’. Another clinician made the following comment:

… you will see the recommendation is 10 to 12 hours of direct therapy a week; it seems to be a magic figure and I think it has probably come out of the fact that the Americans were subsidising 12 hours a week and I think that’s become an administrative reality – it has become the folklore of what therapy is needed.

These comments provide important insights into the social motivations that affect paediatricians in the clinical encounter. These four clinicians’ statements illuminate the tensions that are created through the government involvement in medical practice. Medical judgement and decision making are not only affected by the medical ‘facts’ and ‘evidence,’ or what they believe is the right medical decision for the patient, but also by patterns of government subsidy. Thus, government subsidised treatments become the ‘right’ treatment options for the patient. The clinician responses indicate a concern that treatment norms or standards are being created by the government, and are having a significant impact on prescribing and recommendation behaviours.

**Conclusion**

We can see from our study that evidence-based medicine approaches are positive elements in the ASD clinical encounter. However they do not function programmatically, in the sense spelt out earlier by Timmermans and Kolker (2004:183), where:

All pathophysiological inferences should be subordinated to the question of whether diagnostic or therapeutic interventions have been proven to be effective in sound empirical studies.

That is, our paediatricians did not use EBM searches and guidelines to systematically shape their approach to diagnosis. Rather they were used strategically and residually. Paediatricians in the main relied on their own clinically informed embodied experience, their ‘gut-feeling’ capacity to tacitly recognise the particularities of autistic presentation and interaction, because they had already seen ‘lots of it’. Diagnostic tools like the ADOS were only pressed into service to sort out cases at the margins of the clinical encounter, where paediatricians found difficult to reconcile anomalies, or sensed issues of comorbidity, or where an initial diagnostic hypothesis was contradicted by the child’s subsequent development. So while epidemiologically driven EBM approaches purport to map optimum diagnosis and treatment, in our study at least it is used to identify outlier cases, those at greatest odds with the probable profile. The paediatricians also resorted to evidence-based approaches for rhetorical purposes, when they needed to persuade sceptical parents of the accuracy of the diagnosis or the advisability of a particular treatment. Here EBM furnishes evidence to a lay audience, rather than the expert clinical audience presumed in the diagnostic and treatment tools and databases. They gave paediatricians extra scientific leverage when their experiential knowledge did not carry sufficient weight with a family unwilling to accept a distressing diagnosis or a difficult course of treatment.

So we can see in the case of nosologically complex and contested disorders like those on the autism spectrum, guidelines and database searches may be used quite differently from the way they are used in diagnosing and treating say an infectious disease, where aetiology, treatment and prognosis hold a comparatively stable position in the array of biomedical classification. While our sample is comparatively small, our informants were remarkably consistent in their descriptions of the strategic and residual uses to which they put guidelines and diagnostic tools, and their counter-intuitive use of probabilistic data to diagnose outlier cases. We suggest that while the process of diagnosing ASDs may only be relevant in the ASD context, this study
may have implications for other heterogeneous disorders, such as ADHD and chronic fatigue syndrome. Moreover, difficult (that is, difficult to classify or diagnose) patients are encountered by medical practitioners on a daily basis, and it remains to be seen if here too we find strategic and residual uses of EBM.

References
for the paediatrician’s role in the diagnosis and assessment of autism spectrum disorders in Australia.


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FORTHCOMING

GOVERNMENT INTERVENTION IN RURAL AND REGIONAL AUSTRALIA AND BEYOND

Special issue of *Rural Society* – Volume 20 Issue 3

Editors: *Troy Whitford* (Charles Sturt University, Wagga Wagga NSW, Australia)

There is ongoing debate surrounding the level of government intervention required to assist rural and regional communities. Prior to the Global Financial Crisis, neo-liberal economic ideology dominated not only business but also government spending decisions. A rationale developed that markets could best decide what areas would economically grow.

- canvassing some of the central arguments for government intervention in rural and regional communities.
- applying a national and/or international context using comparative studies. Particular countries of focus will be Thailand, Great Britain and the United States.
- conducting a comprehensive examination of the Australian approach to rural and regional policy surveyed in a historical and contemporary sense.


ENERGY AND RURALITY: SOCIO-HISTORICAL PERSPECTIVES ON CHANGING PRODUCTION AND CONSUMPTION

Special issue of *Rural Society* – Volume 21 Issue 1

Editors: *Merrilyn Crichton and Catherine Strong* (Charles Sturt University, Wagga Wagga NSW)

Issues around energy are of central concern to people living in rural areas, especially as climate change increasingly forces us to ask questions about our energy consumption and needs. Answers to these questions could help to drive holistic, equitable and sustainable approaches to energy-related policy. To the frustration of many in public and private sectors, there is limited impetus on these matters. This may be partly due to the narrow evidence base and breadth of perspective available to policy makers.


MEDIATING RURAL AND REGIONAL SOCIETIES

Special issue of *Rural Society* – Volume 21 Issue 2

Editors: *Margaret Van Heekeren* (Charles Sturt University)

*Rural Society* is calling for papers for a themed issue for 2012 on the topic of mediating rural and regional societies. Rural and regional landscapes and the societies that live within them have long been represented in varied media forms, from the local paper to portrayals in art and film. These representations can take many forms, from matters of record to interpretations and even myth. Media representations play a major role in metropolitan and international understandings of rural and regional ways of life. The interaction of media with rural societies helps foster relationships and allows communities to express their environment in literary, creative and artistic forms.
