Sorting Out Autism Spectrum Disorders:
Evidence-Based Medicine and the
Complexities of the Clinical Encounter

by

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This thesis is dedicated to the wonderful children (and their families) I have worked with over the past three years who have been diagnosed with an autism spectrum disorder. To Riley, Ashton, Tom, Joseph and Tim: thank you for sharing your unique personalities with me and allowing me to be a part of your lives.

I wish to acknowledge the commitment of my supervisor Catherine Waldby whose extensive knowledge on the subject of my thesis and comments on my draft chapters were very valuable. I also wish to recognise the paediatricians who graciously gave up their time to be involved with this study.

I would also like to thank my Mum and Dad whose support and interest in my work has been unfailing, and my wonderful friends Chris, Hayley, Anna, and Amanda who were always there to listen and offer advice.
ABSTRACT

Clinical decisions regarding the diagnosis and treatment of Autism Spectrum Disorders (ASDs) are commonly based upon heterogeneous evidence and ‘expert opinion’. To date, research examining how paediatricians are using (or not using) evidence-based medicine (EBM) to diagnose and treat patients with an ASD has been absent within the literature across all disciplines. To understand how Australian paediatricians are using EBM to conceptualise, diagnose, and treat patients with an ASD, this study interviewed nine paediatricians in private practice using a face-to-face, semi-structured approach. Participants were asked questions about diagnosis and treatment of ASDs, and general questions about their attitudes towards EBM. Analysis of the interviews revealed four key factors affecting the clinical encounter with the ASD patient: the role of experience in the clinical encounter, the tacit and experiential nature of diagnosing and treating ASDs, skilful and creative interaction between the paediatrician and the diagnostic tools (tool “tinkering”), and the influence of political and social forces. This study contributes to sociological understandings of EBM and how it is used by paediatricians to diagnose and treat ASDs. It also demonstrates that this process involves constant negotiation between clinical experience, the evidence, intersubjective evaluation, and social forces.
# TABLE OF CONTENTS

Acknowledgements ........................................................................................................ 1
Abstract .......................................................................................................................... 2
Table of Contents ........................................................................................................... 3
List of Tables .................................................................................................................. 5
Table 1 ............................................................................................................................ 5
Table 2 ............................................................................................................................ 5
Table 3 ............................................................................................................................ 6
Table 4 ............................................................................................................................ 7
Table 5 ............................................................................................................................ 7
Table 6 ............................................................................................................................ 8
Table 7 ............................................................................................................................ 8
List of Graphs ................................................................................................................ 9
Graph 1 ......................................................................................................................... 9
Graph 2 ......................................................................................................................... 9

Abbreviations .................................................................................................................. 10

Chapter One: Forcing a Square Peg into a Round Hole: Managing Autism Spectrum Disorders within a Medical Context .................................................. 12
Introduction ................................................................................................................... 12
The autism spectrum: the savant to the severely disabled ......................................... 13
Diagnosing ASDs and the limitations of EBM ............................................................. 19
Evidence-based medicine: replacing mess with order ................................................. 22
The clinical encounter: a medicine full of tensions ...................................................... 26
Considering ASDs: Why they warrant investigation within the social sciences ......... 31
Research questions ...................................................................................................... 32
The structure of this thesis .......................................................................................... 33

Chapter Two: The Changing Knowledge Structure of the Medical Profession and the Impact of the Evidence-Based Medicine
Movement ...................................................................................................................... 34
Introduction: Engagement with theory ........................................................................ 34
Foucault and the medical “gaze” .................................................................................. 35
Standardisation in medicine ......................................................................................... 39
The evidence-based medicine movement: epidemiology in medical practice ............. 47
The reality of medical practice: a review of the empirical literature ......................... 51
The direction of this study..........................................................57

Chapter Three: Methodology...........................................................60
Methodological approaches of sociological literature addressing the field of paediatrics..........................................................60
Approach adopted for this study..................................................63
Human Research Ethics Committee (HREC)....................................65
Recruitment..................................................................................65
Interviews....................................................................................67
Limitations of this approach.........................................................71

Chapter Four: ASDs and the Clinical Encounter: Experience, Tacit Knowledge, Tool “Tinkering”, and the Influence of the Social World...73
Participants’ experience: an important independent variable...........73
Conceptualising EBM.................................................................75
Using tools/guidelines in the diagnosis of ASDs............................76
Prescribing medications...............................................................77
The tacit and experiential nature of diagnosing and treating ASDs......78
Observation and using a “gut feeling”............................................79
The ADOS as the most effective/rigorous/accurate tool...............81
Consensus about treatment recommendations..............................83
Autonomy in the clinical encounter.............................................85
Understanding tool and evidence “tinkering” in the diagnosis and treatment of ASDs..........................................................86
The political and social forces affecting medical practice..............91
The parent-paediatrician relationship...........................................92
The impact of government funding............................................96
Concluding Remarks..................................................................97

Chapter Five: Conclusion..............................................................102
Existing literature.......................................................................102
The impact of this study..............................................................106
Future directions of research.......................................................108

Bibliography..............................................................................113

Appendices..................................................................................120
Appendix 1 – Interview Questions.............................................120
Table 1: Duration of interviews

<table>
<thead>
<tr>
<th>Participant (in chronological order)</th>
<th>Interview duration (minssecs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>16.39</td>
</tr>
<tr>
<td>2</td>
<td>31.39</td>
</tr>
<tr>
<td>3</td>
<td>21.41</td>
</tr>
<tr>
<td>4</td>
<td>23.52</td>
</tr>
<tr>
<td>5</td>
<td>17.21</td>
</tr>
<tr>
<td>6</td>
<td>42.34</td>
</tr>
<tr>
<td>7</td>
<td>17.55</td>
</tr>
<tr>
<td>8</td>
<td>38.26</td>
</tr>
<tr>
<td>9</td>
<td>32.21</td>
</tr>
</tbody>
</table>

Table 2: Groupings of participants based on years of experience practising as a paediatrician

<table>
<thead>
<tr>
<th>Groups</th>
<th>Participant (numbers based on order of interview)</th>
<th>Years practising as a paediatrician (least to most)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3 4 1 6</td>
<td>9 10 15 16</td>
</tr>
<tr>
<td>2</td>
<td>2 7 9 5 8</td>
<td>30 31 31 32 34</td>
</tr>
<tr>
<td>Group</td>
<td>Participant</td>
<td>Diagnostic tools/questionnaires used</td>
</tr>
<tr>
<td>-------</td>
<td>-------------</td>
<td>--------------------------------------</td>
</tr>
</tbody>
</table>
| 1     | 3           | - ADOS  
- Griffith’s Mental Developmental Scales | ADOS |
| 4     | ADOS        | - M-CHAT  
- Attwood’s Oasis Questionnaire  
- Gillberg’s Autism Spectrum Screening Questionnaire | ADOS |
| 1     | ADOS        | ADOS, ADI-R |
| 6     | CHAT        | ADOS, SRS |
| 2     | 2           | - ADOS  
- M-CHAT  
- SCQ  
- Attwood’s Oasis Questionnaire  
- Gillberg’s Autism Spectrum Screening Questionnaire | ADOS, ADI-R |
| 7     | none        | ADOS |
| 9     | none        | Achenbach, SRS |
| 5     | none        | ADOS |
| 8     | none        | - |

Shaded rows indicate responses that illustrate consistency between columns 3 and 4.
Table 4: Various steps indicated by participants involved in the diagnosis of ASDs

<table>
<thead>
<tr>
<th>Steps involved in diagnosis</th>
<th>Number of paediatricians indicating they do this</th>
</tr>
</thead>
<tbody>
<tr>
<td>Observing the child:</td>
<td></td>
</tr>
<tr>
<td>general</td>
<td></td>
</tr>
<tr>
<td>triad – child playing alone, child-parent interaction, child-doctor interaction</td>
<td>5</td>
</tr>
<tr>
<td>Using experience or a “gut feeling”</td>
<td>8</td>
</tr>
<tr>
<td>Time spent talking with parents about their observations/concerns</td>
<td>7</td>
</tr>
<tr>
<td>Getting a medical history</td>
<td>6</td>
</tr>
<tr>
<td>Sending child off for other assessments</td>
<td>5</td>
</tr>
<tr>
<td>Using diagnostic tool(s)</td>
<td>5</td>
</tr>
<tr>
<td>Conferring with professionals who have interacted with the child (e.g. occupational therapist, speech pathologist)</td>
<td>5</td>
</tr>
<tr>
<td>Conferring with preschool/school child attends</td>
<td>4</td>
</tr>
<tr>
<td>Using research</td>
<td>3</td>
</tr>
<tr>
<td>Using questionnaires (administered to parents, preschool/school)</td>
<td>3</td>
</tr>
<tr>
<td>Ruling out other underlying problems that could be causing ASD</td>
<td>3</td>
</tr>
<tr>
<td>Using guidelines (e.g. DSM-IV-TR)</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 5: Problems identified by participants with clinical guidelines or standardised tools used to diagnose ASDs

<table>
<thead>
<tr>
<th>Group</th>
<th>Participant</th>
<th>Problem(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>- DSM-IV</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>- DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- tools do not produce definitive diagnosis</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>- DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- tools do not produce definitive diagnosis</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>- tools do not produce definitive diagnosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- costly: only wealthier families can afford them</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- user dependency</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- incorrect completion of tools</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>- DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- tools do not produce definitive diagnosis</td>
</tr>
<tr>
<td>7</td>
<td>7</td>
<td>- tools are too long</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- too much variation between tools</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- tools not well publicised</td>
</tr>
<tr>
<td>9</td>
<td>9</td>
<td>- DSM-IV</td>
</tr>
<tr>
<td>5</td>
<td>5</td>
<td>none – because states he does not use tools</td>
</tr>
<tr>
<td>8</td>
<td>8</td>
<td>none</td>
</tr>
</tbody>
</table>
### Table 6: Treatments recommended by participants

<table>
<thead>
<tr>
<th>Group</th>
<th>Participant</th>
<th>Treatments recommended</th>
</tr>
</thead>
</table>
| 1     | 3           | - early intervention programs  
|       |             | - speech therapy  
|       |             | - occupational therapy  
|       |             | - consultations with psychologist  
| 4     |             | - early intervention programs  
|       |             | - speech therapy  
|       |             | - occupational therapy  
|       |             | - consultations with psychologist  
|       |             | - physiotherapy  
|       |             | - help from community health centres  
| 1     |             | - early intervention programs  
|       |             | - speech therapy  
|       |             | - occupational therapy  
| 6     |             | - early intervention programs  
|       |             | - prescribing appropriate medications  
| 2     |             | - early intervention programs  
|       |             | - speech therapy  
|       |             | - occupational therapy  
| 7     |             | - early intervention programs  
|       |             | - prescribing appropriate medications  
| 9     |             | - early intervention programs  
|       |             | - speech therapy  
|       |             | - occupational therapy  
|       |             | - consultations with psychologist  
|       |             | - prescribing appropriate medications  
| 5     |             | - speech therapy  
|       |             | - consultations with psychologist  
|       |             | - prescribing appropriate medications  
| 8     |             | - speech therapy  
|       |             | - occupational therapy  
|       |             | - consultations with psychologist  
|       |             | - prescribing appropriate medications  

### Table 7: Learning about EBM in education and training

<table>
<thead>
<tr>
<th>Group</th>
<th>Participant</th>
<th>Did your education and training in paediatrics involve learning about EBM? (yes/no/unclear response)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3</td>
<td>Yes</td>
</tr>
<tr>
<td>4</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>6</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>7</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>9</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td>No</td>
</tr>
<tr>
<td>8</td>
<td></td>
<td>Unclear response</td>
</tr>
</tbody>
</table>
Graph 1: Treatments recommended by participants

Graph 2: Difficulties recommending treatments for children with an ASD
ABBREVIATIONS

ASDs
Autism spectrum disorders

ABA
Applied Behavioural Analysis

ADD
Attention Deficit Disorder

ADHD
Attention Deficit Hyperactivity Disorder

ADI-R
Autism Diagnostic Interview – Revised

ADOS
Autism Diagnostic Observation Schedule

CARS
Childhood Autism Rating Scale

CBCL
Child Behavior Checklist

CHAT
Checklist for Autism in Toddlers

DSM
Diagnostic and Statistical Manual

DSM-IV-TR
Diagnostic and Statistical Manual (4th edition, text revised)

EBM
Evidence-based medicine

ICD-10
International Classification of Diseases (10th Revision)
M-CHAT
The Modified Checklist for Autism in Toddlers

PBS
Pharmaceutical Benefits Scheme

PDDNOS
Pervasive developmental disorder not otherwise specified

RACP
Royal Australasian College of Physicians

RCTs
Randomised controlled trials

SCQ
Social Communication Questionnaire

SRS
Social Responsiveness Scale

WHO
World Health Organisation
CHAPTER ONE
FORCING A SQUARE PEG INTO A ROUND HOLE:
MANAGING AUTISM SPECTRUM DISORDERS WITHIN A MEDICAL CONTEXT

Introduction

Consider the following situation: A mother and father are concerned about their two and a half-year-old son’s development. He has no language, cannot play appropriately with his toys or other children, and will sit and stare out a window for extended periods of time. The parents take their son to their general practitioner (GP) seeking more information. Their GP refers them to a developmental paediatrician, who then confirms their suspicions with a diagnosis of autism spectrum disorder (ASD). The developmental paediatrician recommends several early intervention strategies (such as ABA – applied behavioural analysis), speech pathology, and pharmacological intervention (such as Naltrexone, Ritalin, or Risperidone), explaining to the family that these treatment interventions have had the most success based upon the limited evidence available.

The situation described above is typical of the process a family goes through when a child is diagnosed with an ASD. What is clear about this process is that ASDs are understood as a medical/psychiatric category and conceptualised within the deficit model (Molloy & Vasil 2002). The deficit model views behavioural symptoms as indicators of underlying
diseases, emphasises the individual origin of symptoms, and focuses on inherent flaws (D’Amato et al 2005; Zalaquett et al 2008). Discourse around ASDs has historically been dominated by medical and psychological models of deficit.

However, this study presents a complex and socially nuanced picture of ASDs within the medical context. It moves away from the deficit model’s conceptualisation of ASDs and focuses on understanding how the medical profession negotiates with and attempts to manage the complexities, uncertainties and difficulties associated with diagnosing and treating them. This chapter will firstly introduce the reader to the medical definition of ASDs and discuss the wide array of capabilities and areas of challenge present on the autism spectrum. Secondly, this chapter will demonstrate the complexity and uncertainty surrounding ASDs within the medical context. Thirdly, the concept and function of evidence-based medicine (EBM) will be discussed, as well as the tensions that emerge between clinical judgement and applying EBM to the heterogeneous disorder of autism. Fourthly, this chapter will outline the research questions to be addressed within this study.

*The autism spectrum: the savant to the severely disabled*

Within the health-care domain, ASDs are officially defined within standardised documents (referred to as guidelines within the health-care
profession) such as the International Classification of Diseases-10 (ICD-10) or The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR 2000). The DSM-IV-TR lists five autism spectrum disorders (also referred to as pervasive developmental disorders): autistic disorder, Asperger’s disorder, Rett’s disorder, childhood disintegrative disorders, and pervasive developmental disorder not otherwise specified (PDDNOS). These disorders are:

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 can include poor eye-contact and gestures, and a failure to develop relationships with peers. Communication impairments involve a delay in or absence of (spoken) language and repetition and imitation of language (for example, echolalia, whereby the child repeats vocalisations made by another person). Stereotyped behaviours, interests and/or 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 the eyes) (Ozonoff et al 2005: 523).
These symptoms manifest differently in every individual with an ASD. Even a non-autistic person may exhibit milder forms of autistic symptoms, such as exhibiting poor eye contact, craving structure and order, or tending to engage in obsessive behaviours (Durig 2005). A recent study investigating social and communication impairments in the general population of schoolchildren found that “traits resembling those seen in ASD are not confined to children with a clinical diagnosis” (Skuse et al 2009: 134) (emphasis added). The autism spectrum is truly diverse. It encompasses genius qualities (the savant), eccentricities and quirkiness, communication difficulties, learning difficulties, social awkwardness, and severe disability. The severely disabled autistic individual may not speak or may have a limited repertoire of expressive communication, may have limited understanding of spoken and non-verbal language, engages in self-injurious behaviours (such as head banging), usually has some form of intellectual impairment, and engages in sensory-related activities (self stimulatory behaviours, or “stimming”) such as rocking and hand-flapping. Some people on the autism spectrum may lead relatively normal lives with very few people realising they were diagnosed with an ASD as a child. Others may need ongoing full-time care and support. Some examples of these varied presentations of ASDs are discussed below.
For most people, conceptions of autism have largely been formed by the media, particularly by films such as *Rain Man* (1988) (Harwood & Jones 2009). This film depicts the autistic savant, a relatively rare condition involving unusual skills or abilities such as memorising maps or telephone books, or reading at an extremely rapid rate (Treffert 2009). For example, Stephen Wiltshire, referred to as “the living camera” and described as an “autistic savant,” is able to produce detailed and accurate representations of cities after having only viewed them briefly. In the documentary *Beautiful Minds: A Voyage into the Brain* (Höfer & Röckenhaus 2007) Wiltshire is taken up in a helicopter to view the city of Rome for forty-five minutes. He then reproduces, over three days, what he has seen with pencil and paper, right down to the minute details (for example, the number of columns or windows that make up each building).

However, as discussed above, ASDs are far more complex and varied than the picture painted by *Rain Man*. Temple Grandin presents another side of ASDs: that of the high-functioning autistic. She has obtained a PhD in animal science, published several books (see Grandin 1996a; 1996b; 2005), and regularly gives talks on her experiences with autism (see *My Experience with Autism* 2008), as well as in her academic field of agriculture and animal behaviour. She is intelligent, articulate, and an advocate for animal welfare and autistic movements. Grandin emphasises
that many people on the spectrum are capable of attaining success across a variety of fields, and that autism can be seen as a valued difference rather than a “disability” (1996b; Scully 2003).

One presentation of autism Grandin (1996a; 1996b) discusses in detail is the heightened sensory systems of autistic individuals. This is not a well-understood aspect of ASDs, but it is discussed by people on the spectrum and within much of the parent literature (see Isaacson 2009; Grinker 2007). Within this literature, explanations of the heightened sensory experience are often an attempt to give the non-autistic person a window into the autistic experience. For example, Isaacson (2009) provides the following description of mundane environmental experiences encountered every day by the “normal” person and how they affect his autistic son, Rowan:

> Autistic brains, it turns out, have a much greater number of nerve cells than “neurotypical” brains. The result can be extreme sensory overload. A breath of wind on Rowan’s cheek could feel like fire from a flame-thrower. The fluorescent lights of a supermarket or day-care facility could look like lights being strobed at one million times a second. His clothes or bedcovers could suddenly, if the wrong neurological switch was thrown, feel like lead weights or burning napalm (Isaacson 2009: 19).

Another conceptualisation of autism focuses on stereotyped and repetitive behaviours. In my language (2007) is a video that encompasses this side of the spectrum, referring to these behaviours as her “native language”. The viewer is told that engaging in these behaviours is about
“being in a constant conversation with every aspect of my environment, reacting physically to all parts of my surroundings...it is a way of thinking in its own right.” The behaviours include repetitive movements such as rocking the body backwards and forwards, repetitive hand gestures such as wiggling the fingers in front of the eyes, and repetitive sounds made through vocalisations (such as monotonous humming) or with objects (such as running a coat-hanger along a window shutter). This side of autism is also prominent in the Australian film *The Black Balloon* (2008), where Charlie, a low-functioning autistic teenager, will often sit in the back garden repeatedly banging a tin pot with a wooden spoon and making monotonous low-pitched noises.

Another very confronting aspect of ASDs is the ‘autistic meltdown’ (see Isaacson & Scott 2009). These tantrums demonstrate the lower-functioning side of autism (but are also manifest across the spectrum), where a child may be unable to communicate with others about what is upsetting or frustrating them, leading the child to exhibit severe short-term emotional and behavioural changes. The individual may scream, bite themselves and anyone attempting to interfere with their tantrum, kick, sob, bang their head repetitively against a wall, and throw things around a room. Each of these behaviours are shown in *The Black Balloon* during Charlie’s tantrums. Many of these tantrums are prompted by simple, everyday practices such as a caregiver taking something away
from a child. These tantrums are often violent, emotionally distressing for the affected individual and caregiver (and anyone observing), and can cause injury to the affected individual and anyone caught in the crossfire.

These examples provide a glimpse into the range of experiences and expressions of an individual affected by autism. The variety in symptoms and severity in each individual on the autism spectrum is just one of the complexities health-care practitioners face in the diagnosis of this disorder. Applying the statistical analysis and science of medicine to the disorder of autism is perhaps one of the biggest challenges faced by medical practitioners, and particularly paediatricians involved in the diagnosis and treatment of ASDs.

*Diagnosing ASDs and the limitations of EBM*

While the DSM-IV-TR (2000) appears to neatly categorise the symptoms of ASDs into distinct diagnoses, whereby a psychologist or paediatrician ticks boxes to demonstrate a child “fits the criteria”, the clinical reality is that the diagnostic process is far more complex and disordered. The examples above demonstrate a key part of this complexity: the sheer variety of symptoms exhibited by individuals on the autism spectrum. Grinker (2007) provides further insight into the complexities of diagnosis:
Most experts will agree that autism is a highly variable syndrome that resists easy definition. There is a multitude of symptoms, appearing in different constellations in different people, and most of these symptoms will also change in form or severity throughout childhood and adulthood. In addition, some people diagnosed with autism are much more affected by autism than others. “Autism” today is really an autism spectrum. The spectrum is broad enough to encompass both a severely mentally retarded autistic person without speech and a super-intelligent but socially awkward mathematician or physicist. (Grinker 2007: 10).

Diagnosis is an integral part of the medical process. In the case of ASDs, it needs to be carried out by a paediatrician, child psychiatrist or child psychologist in order for the child to be eligible for services, such as special education and funding (Bumiller 2008). According to the literature, there are three main factors contributing to the complex and disordered nature of diagnosing ASDs.

First, the diagnosis of ASDs within a medical context is seen as particularly problematic due to the lack of a biological marker or test to aid in this diagnostic process. Currently, diagnosis of this disorder 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 manifest, and sufficient data has been gathered on the behavioural symptoms exhibited by the child across at least two observational settings (Williams & Brayne 2006).
Second, the *heterogeneity* of ASDs in terms of causes, age of onset, manifestation of symptoms, outcome and co-morbidity with other disorders, means that the application of this label is incredibly 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 and consequently that medical understandings of ASDs are limited.

This limited understanding leads into the third difficulty: a *lack of “good” evidence* (that is, randomised controlled trials (RCTs)) supporting diagnostic techniques and the effectiveness of treatment interventions (Williams & Brayne 2006; Mesibov 2006). The guidelines and tools used in the diagnosis of ASDs are based on this “weaker” evidence (that is, case-control studies and case series which do not have the same validity and reliability as RCTs), and from a medical perspective: “such guidelines are only as robust as the evidence on which they are based” (Cass et al 2006). Furthermore, there is a wide variety of assessment approaches and tools used amongst professionals in the diagnosis of ASDs. 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 articles have stressed the importance of taking a “rational” and “standardised” approach to the medical investigation of ASDs (see Cass et al 2006;
Shattuck Grosse 2007). The focus of such literature lies with the hope of one day developing appropriate interventions and methods that meet the standards of “good evidence” (RCTs). This study, however, will explore this tension between applying statistical evidence versus the use of clinical judgement to diagnose and treat ASDs. Furthermore, it will concentrate on understanding the social and political forces that affect medical practice, especially the use of EBM and its instruments, when working with the ASD patient and their family.

**Evidence-based medicine: Replacing mess with order**

The uncertainty surrounding the diagnosis and treatment of ASDs within the medical arena has given rise to much debate within health-care literature as to how this disorder can be conceptualised and tested both theoretically and practically in a more rigorous, reliable, and valid manner (see McClure & Le Couteur 2007; Myers et al 2007; Rogers & Vismara 2008; Shattuck & Grosse 2007; and Mesibov et al 2006). However, uncertainty in medical practice is not only confined to heterogeneous disorders such as autism. Many articles (within the discipline of medicine and health care) criticising medical practice during the 1980s and 1990s, argued that there were large variations in the judgments and decisions made by clinicians (for example, Brook et al 1988; Eddy 1990; and Wennberg 1984). Clinicians, they argue, tend to rely on their clinical experience: a “notoriously misleading” resource
Evidence-based medicine is understood as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett & Rosenberg 1995). Proponents of EBM embrace an epidemiological model of medicine, rather than pathophysiological models which base claims on experience and expertise (this distinction is discussed further in Chapter Two). EBM is disseminated in practice through clinical practice guidelines and standardised tools. These media aim to describe and enforce “good clinical reasoning” as well as provide a “vehicle through which order can be brought to all those practices where messiness reigns” (Berg 1998: 227). Clinical protocols/guidelines, which are based on current scientific research, aim to bring about greater compliance and uniformity within medical practice. These changes to medical practice are thus seen as an “optimal solution to the ‘unscientific’ state of current medical practice” (Berg 1998: 227). The DSM-IV-TR is the diagnostic guideline most used to identify ASDs, and there are numerous tools used in medical practice to aid in the diagnostic process (for example, the Autism Diagnostic
Observation Schedule (ADOS), Childhood Autism Rating Scale (CARS) and Autism Diagnostic Interview-Revised (ADI-R)).

Using EBM in medical practice involves the evaluation and application of evidence. Evaluation of the evidence is based on the evidence hierarchy, which ranks research according to its validity (Evans 2003). The evidence hierarchy places randomised controlled trials (RCTs) above cohort studies, which in turn are ranked above case-control studies and case series (Borgerson 2009). At the very bottom of this hierarchy lies expert opinion. The ranking of evidence is based upon error and bias in results. RCTs minimise the risk of confounding factors influencing results, and as a result produce findings that are closer to the true effect than the findings generated by methods such as cohort studies or case series (Evans 2003).

Timmermans and Berg (2003) point out that discussions (see Gordon 1988; Willaims & Garner 2002; and Cabana et al 1999) regarding the introduction and use of EBM, tools and guidelines in medical practice “abound with images of domination and oppression” (69) due to these tools apparently usurping the determination of health-care workers’ paths of action. However, Timmermans and Berg (2003) highlight that, based on their empirical investigations of the medical profession,
Thus, health-workers are active in this process of engagement with the tools of EBM: they do not necessarily submit to the tools, but “actively and deliberately make the guidelines work for them” (Timmermans and Berg 2003: 70). According to this perspective, the tools of EBM are ultimately used to the health-care worker’s advantage and to advance their own “professional trajectories”. For example, Timmermans and Berg (2003) call attention to the real reasons clinicians use EBM: that is, not to practice “better” science but, more pragmatically, to “figure out what kind of evidence might be appropriate in dealing with patients” (165). In Timmermans and Angell’s (2001) study involving interviews with paediatric residents, we see that:

The proposed problem for which EBM is the solution does not match the reality of learning to doctor. Residents generally do not agonize as much about variability or dehumanizing care as they worry about getting through the residency without killing patients, completely exhausting themselves, accumulating negative evaluations, or getting sued. (Timmermans & Berg 2003: 165)

However, this process of “standards-tinkering” does not imply that health-care workers are necessarily resisting their presence. Rather, interactions between health-care workers and standards are “mutually transforming,” whereby elements of evidence and medical expertise are used in the clinical encounter (Timmermans & Berg 2003: 76). This
examination of the role of clinical tools and guidelines within the medical profession breaks down traditional dichotomies set up in the literature between the efficiency and rationality created by tools and the creativity of clinical experience and judgement. The two are presented as mutually exclusive in medical practice. Timmermans and Berg (2003) instead argue it is a process of active negotiation and interaction between guidelines/tools and the health-care worker.

*The clinical encounter: A medicine full of tensions*

This process of “standards-tinkering” is particularly interesting when dealing with ASDs. Physicians must attempt to manage the tension between pressures to apply evidence in practice and the intersubjective, experiential-based evaluation of a heterogeneous disorder. This is a difficulty that is explicitly discussed by health-care workers in the literature (see Mesibov et al 2006; Dawson et al 1998). Despite this understanding of the complexity of medical practice, health-care professionals treat this tension as a problem that must be addressed and rectified. Mesibov and colleagues (2006) claim:

…the traditional research methods emphasizing randomized assignment to groups, stringent control groups, and blind evaluations of treatment progress just don’t fit as neatly into autism treatment research as they do for biomedical or pharmacological interventions. My hope for the next decade is that we will develop more appropriate and responsive treatment intervention approaches that will meet the standards for scientifically rigorous research on treatments and autism. (Mesibov at al 2006: 7).
This “hope” is conveyed in much of the health-care literature cited above, yet Mesibov and colleagues (2006), in the quote above, unconsciously illuminate the very paradox or tension that exists within the medical profession. ASDs do not fit the mould of “traditional research methods” due to the nature of the disorder: it has no biological markers, it is a heterogeneous disorder, diagnosis is based on observed behaviours, and its treatment is usually therapy-based. The medical profession’s solution to the problem—developing better and “more appropriate” evidence—is the very reason the tension exists. Dawson and colleagues (1998) explain this tension, demonstrating that doctors are conscious of the complexity and uncertainty of much medical decision making. Thus, it is difficult for doctors to apply EBM in circumstances where they are dealing with heterogeneous conditions and comorbidity, and are compelled to consider socio-economic factors affecting the patient. One of Dawson and colleagues’ (1998) participants argues:

I think [EBM] is a complete hoax personally...trials are done on such specific, clean questions but they never quite apply to the patient in front of you...I think that is the problem with practice at my level – it is very individual. That is why I don’t agree with EBM: there isn’t any evidence to help you deal with the difficult patient. (Dawson et al 1998: 21)

This quotation provides an apt example of the difficulty of using EBM in the clinical encounter. EBM is described as a paradigm shift in medicine because it is about “creating a culture where medical practitioners automatically think in an ‘evidence’-based way every time they see a
new case, where it becomes instinctive to seek out research evidence and base treatment decisions on that evidence” (Dopson et al 2003). Thus, health-care workers seeing patients on a daily basis are expected to embrace this paradigm, even when dealing with a “difficult patient”. Despite health-care professionals’ overt recognition and understanding of these perceived problems that are inherent to autism itself, the square peg of disorders such as ASDs continues to be forced into the round hole of EBM. It is therefore important to understand how these clinicians justify such practices and reconcile these tensions.

Berg and Mol (1998) further illuminate this tension. They state that academic discussions surrounding the health-care domain often take unity to be the norm against which variety must be measured and discarded. They take diversity to be a temporary state that may be overcome through such things as evaluation studies, protocols, and the standardization of terminology. (Berg & Mol 1998: 7)

Berg and Mol (1998) suggest instead that diversity—whether it is problematic or non-problematic; good or bad—is stable and is an inevitable part of any complex practice. They suggest it is futile to try to counter this diversity, and practitioners instead should try to understand the “politics inside medicine”. They state: “A medicine full of tensions contains politics, in the way that disease is established, the body is touched, patients are treated, cells are counted, and problems are solved” (Berg & Mol 1998: 8). Thus, the differences that exist in medicine can be
seen as distinctly social: the medical world is a *social* world, even the rational, scientific knowledge that forms the basis of its epistemology is subject to the political and social forces present within the boundaries it has established for itself.

A satirical article titled ‘Seven alternatives to evidence based medicine’ by two Australian physicians further contributes to the social nature of medical practice (Isaacs & Fitzgerald 1999). It may also provide insight into the attitudes of Australian developmental paediatricians towards the use of EBM in the diagnosis and treatment of ASDs. The article outlines seven competing motivations (and personalities) in decision-making that EBM must contend with (see table below) based on what their colleagues would do when “faced with a clinical problem for which there are no randomised controlled trials and no good evidence” (Isaacs & Fitzgerald 1999: 1618).

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<td>Confidence*</td>
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*Applied only to surgeons
This is exactly the problem faced by medical practitioners dealing with ASDs. While the article is a spoof, it does have a serious message: “There are plenty of alternatives for the practicing physician in the absence of evidence. This is what makes medicine an art as well as a science” (1618). When dealing with disorders such as autism where there is no clear professional consensus as to how to diagnose and treat patients, it is important to understand how physicians proceed with diagnosis and treatment in the clinical encounter.

This tacit nature and socially-affected view of medical practice is perhaps best summarised by Wenger (1998):

[Practice]...includes all the 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. Most of these may never be articulated, yet they are unmistakable signs of membership in communities of practice and are crucial to the success of their enterprises. (Wenger 1998: 47)

Thus, this study seeks to make sense of the tacit and experiential nature of the clinical encounter with regards to ASDs. It also aims to understand at what point, and to what extent, the tacit and experiential nature of medical practice and the use of clinical tools and guidelines interact.
Considering ASDs: Why they warrant investigation within the social sciences

This thesis 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. This study instead seeks to understand the incoherencies, complexities, and uncertainties faced by Australian paediatricians in private practice 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” (10).

As it stands, the practice of diagnosing and recommending treatments for ASDs within the field of Australian paediatrics in a private practice setting (that is, the medical setting in which most children with an ASD are diagnosed) does not necessitate the use of any particular tools or protocols. While paediatricians are expected to be familiar with the DSM-IV-TR and its diagnostic categories, they are not required to use any formal tools or guidelines (Silove et al 2008). Many ASD diagnostic tools have been developed, such as the ADOS and ADI-R, and are presumably used by paediatricians to aid them in the diagnosis of ASDs. However, how they are used, to what extent they are used, when they are
used, *why* they are used, and *whether* any are more consistently used are all questions that are yet to be addressed within the literature. Likewise, understandings of the motivations and clinical reasoning behind the recommendations made by paediatricians in regards to ASD treatment approaches to use are limited.

*Research questions*

The overall aim of this study is to understand the ways paediatricians reconcile the tensions between evidence-based medicine approaches and the complexity of identifying and treating autism spectrum disorders.

This study specifically aims to:

- Understand how Australian paediatricians within a private practice setting use evidence-based medicine, standardised tools, and practice guidelines in the diagnosis and treatment of autism spectrum disorders;
- Understand Australian private practice paediatricians’ attitudes towards evidenced-based medicine in both a theoretical and practical sense;
- Determine whether EBM and its associated tools are in fact regularising or standardising the diagnosis of, and recommendation of treatments for, ASDs; and
• Determine whether there is consensus among Australian paediatricians in private practice as to the diagnosis of, and recommendation of treatment for, ASDs.

**The structure of this thesis**

The second chapter summarises the extensive field of literature within which this study is situated. It reviews key theoretical and empirical investigations of evidence-based medicine and examines absences in the literature. The third chapter discusses how this study will proceed and outlines the methodology of this analysis. Chapter four discusses the significant trends and issues that emerge from the interviews conducted with nine Australian paediatricians and links these findings with the theoretical work discussed in chapter two. In doing so, this chapter develops a sociological picture of the clinical encounter within the Australian paediatric private practice and its negotiations with EBM and its associated tools. The conclusion explores the implications of this study for research into paediatrics, evidence-based medicine, and private practice within Australia and suggests how this research might proceed.
CHAPTER TWO
THE CHANGING KNOWLEDGE STRUCTURE OF THE MEDICAL PROFESSION AND THE IMPACT OF THE EVIDENCE-BASED MEDICINE MOVEMENT

Introduction: Engagement with theory

The literature examining evidence-based medicine is diverse and interdisciplinary. It delves into a range of academic disciplines, including medicine, anthropology, sociology, information technology, psychology, public administration, business, government policy and management; and deals with issues such as quality and safety, objectivity, mediating cultural boundaries within hospitals, legal and political considerations, autonomy, and bureaucratic accountability. This variety indicates the complex nature of medical practice when it comes to EBM: It appears that medicine as a profession is not only answering to the bureaucratic structures within its boundaries, but that these boundaries have broken down and the medical profession must now answer to a plethora of different groups each with their own interest in how medical practice should be carried out. This has interesting implications for sociologists interested in understanding and investigating the complexities of medical practice today.

This chapter will begin by examining Foucault’s (1975) Birth of the Clinic and his concept of the medical “gaze,” and will demonstrate that these ideas provide an interesting framework through which to
conceptualise epistemological changes in medicine. Secondly, this chapter will present a historical overview of the changes that have occurred in the knowledge-base and epistemology of the medical profession. This will include an examination of the rise of standardisation in medical practice, and the rise of evidence-based medicine. Thirdly, this chapter will consider the implications of sociological empirical contributions to the literature examining the place of EBM within medical practice. Finally, these discussions will be drawn together to explain the importance of investigating autism spectrum disorders within this context.

**Foucault and the medical “gaze”**

Foucault’s (1975) *Birth of the Clinic* presents the clinic not only as a place where medicine is practiced, but also a discursive practice: “because it is a set of rules and procedures within a field of inquiry that make possible a link between health and knowledge” (Long 1992: 119). For Foucault, the birth of modern medicine in the eighteenth century was not “an act of psychological or epistemological purification” whereby a linear progression in knowledge led to a true understanding of the nature of body and disease; rather, it involved a “syntactical reorganisation of disease” whereby a shift in the structure of medical knowledge led to an “epistemological rupture” (Foucault 1975 in Long 1992: 120).
This epistemological rupture involved “scientific medicine” or a “medicine of tissues” replacing a “medicine of symptoms” (Long 1992: 119). The medical practice of the autopsy made the previously invisible visible and allowed doctors to describe and express this knowledge. Thus, the “code of knowledge changed” and in doing so determined what could be seen by the medical profession (Long 1992). This notion of what doctors see or a way of seeing is referred to as the medical “gaze” (Foucault 1975). It could be argued that this way of seeing within the medical profession has undergone another recent change, with the epistemological shift from pathophysiology to epidemiology. Pathophysiology refers to the changes in the physical and biochemical functions of the body that are associated with a disease or syndrome, whereas epidemiology refers to the study of factors affecting the health and illness of populations. This epidemiological “gaze” entails the use of tools or guidelines based on statistical evidence to justify medical practice.

While Foucault (1975) stresses that the clinical “gaze” moved from “the symptomatic surface to the tissual depth” (135) with the birth of modern medicine, it is important to recognise that the medicine of tissues sometimes does not apply to certain disorders or illnesses. For instance, doctors’ “tissual gazes” cannot be applied to patients with disorders (such as chronic fatigue syndrome) that lack a biological marker or test to aid
in their diagnosis and treatment. This too is the case in the apparent shift from pathophysiology to epidemiology: if there are no biological markers or tests it becomes more challenging to carry out empirical investigations using randomised controlled trials (RCTs) (the ‘gold standard’ in the hierarchy of evidence). As discussed in Chapter One, ASDs are a case in point. Arnold and colleagues (2000) explain this difficulty of applying RCTs to research involving patients with an ASD as follows:

The broad spectrum of pathology encompassed and the wide individual variation in symptomatic expression (sample heterogeneity) and treatment response challenge the sensitivity, psychometric properties, and/or assumptions of most instruments and assessment strategies commonly used in RCTs. (Arnold et al 2000: 100)

Thus, ASD is described as a heterogeneous disorder due to the inter-subject or inter-patient variability (that is, the wide array of ASD symptoms that can present differently in each patient) in genetic, neurobiological and clinical characteristics as well as in the response to treatment (Arnold et al 2000; Drew 2002). Furthermore, RCTs are difficult to apply to ASD research due to the heavy emphasis placed on direct observation in studies examining both diagnosis and treatment. Attempts to standardise observational practices, however, are largely ineffective (see Arnold et al 2000). Thus, empirical investigation into the way in which paediatricians direct the medical “gaze” towards patients whom they suspect are on the autism spectrum would provide further
insight into this Foucauldian concept as well as the management of heterogeneous cases within clinical practice.

Foucault’s (1975) ideas regarding the medical “gaze” provide an interesting framework through which to examine the epistemological changes that have taken place within the medical profession. Chapter One demonstrates that the medical “gaze” encompasses the complexities of, and tensions within, medical practice. Not only does this medical “gaze” incorporate the epistemology of epidemiology, where standardisation and scientific rigour are upheld as ideal medical practice, but also elements of the social world, such as the uncertainties, complexities and incoherencies of medical practice. Understanding the nature of this epistemological change in medicine will provide a clearer picture of what entails the medical “gaze” within the medical profession today. However, before examining epidemiological medical practice (that is, EBM), it is necessary to first consider the founding ideas of this paradigm. Classification and standardisation provide an interesting backdrop to discussions regarding evidence-based medicine and represent an important change within scientific and medical knowledge structures.
**Standardisation in medicine**

Classification, objectification and standardisation have made the practice of modern medicine possible, shaping it into the discipline it is today. According to Bowker and Star (1999), the term *classification* refers to a “spatial, temporal, or spatio-temporal segmentation of the world,” while a *classification system* refers to a “set of boxes (metaphorical or literal) into which things can be put to then do some kind of work—bureaucratic or knowledge production” (10). *Standards* endeavour to make actions comparable over time and space and are described as “mobile and stable” (Timmermans & Berg 1997: 273). Bowker and Star’s (1999) definition of the term *standards* is more complex and involves six elements: they are a set of agreed upon rules; they transcend place and time; they operate within and between different contexts (for example, the creation of a link between the phone and the computer); they are often enforced by the law; standards in use do not necessarily represent the ‘best’ standards; and they are often difficult and expensive to alter.

More specifically, within a contemporary medical context, Timmermans and Berg (2003) distinguish *four* ideal typical categories of standards. The first category is labelled *design standards*, which are “structural specifications”, such as “the properties and features of X-ray devices” (24). The second category is *terminological standards*, which “ensure stability of meaning over different sites and times” and include
documents such as the International Classification of Diseases (25). The third category of standards is performance standards, which regulate professional work by “setting outcome specifications”. The fourth category is referred to as procedural standards, which take the form of clinical practice guidelines and “delineate a number of steps to be taken when specified conditions are met” (25).

The key ideas forming the foundations of standardisation (that is, predictability, accountability, and objectivity produce universality) date back to the Enlightenment, and the notion that development and evolution of knowledge goes hand-in-hand with increased rationality and control (Timmermans & Berg 2003). But the beginnings of standardisation in medicine are pin-pointed to have taken place during the early twentieth century. At this time, the medical curriculum was changed and minimum standards were created, and these developments affected all hospitals across the United States (Timmermans & Berg 2003). Several factors are cited for these changes. Firstly, care of patients became more complex because treatment was managed not only by the patients’ primary physician but also medical specialists. Secondly, the standardisation movement was fuelled by fears that if efficiency standards were not created within the profession, public officials would do it for them. Thirdly, there was a desire to make hospitals more financially responsible institutions (Timmermans & Berg 2003).
Following World War Two, standardisation in general established itself as a useful tool to “avoid direct political conflicts about barriers, inequities, and asymmetries in international trade and so a focus on standardization reemerged as the ‘product of a global economy’” (Timmermans & Berg 2003: 12). Interestingly, Timmermans and Berg (2003) point out that the historical motivations behind standardisation within the medical profession differed. At the beginning of the twentieth century, standardisation was aimed at the skills, tools, and facilities required by clinicians: “the content of the work itself was left unaddressed: to decide the proper course of action for a given solution was the unique prerogative of the individual professional” (Timmermans & Berg: 13). However, during the 1980s, standardisation or evidence-based medicine, focused on the content of the work itself – it aimed to regulate medical expertise and medical decision making (Timmermans & Berg 2003). The focus of standardisation in the medical profession today, in the form of EBM or clinical practice guidelines, is to “delineate what sequence of activities constitutes a professional response to a given situation” (13). Timmermans and Berg (2003) state:

of all the kinds of standardization attempts that have affected medicine in the twentieth century, evidence-based guidelines represent the farthest-reaching and most direct attempt to prescribe and preset the actions of health care professionals. (Timmermans & Berg 2003: 14).
In recent times, standards remain central to the production of knowledge, with significant resources allocated to creating and maintaining standards (Latour 1987). The concept and process of standardisation is most commonly associated with scientific practice, and is one of the key criteria used to distinguish between scientific and non-scientific knowledge (Gottweis, Salter & Waldby 2009). Within the field of medical science, it is believed that to reliably build upon this scientific knowledge, uniform conditions need to be implemented across laboratories, researchers and technologies to ensure the credibility and stability of discovery (Gottwies et al 2009). Timmermans and Berg (2003) similarly emphasise the centrality of standardisation to scientific practice. They highlight that without agreed-upon rules, systems and benchmarks shared by various work environments, adequate comparisons cannot be made, rendering such work useless in terms of building scientific knowledge through collaboration. As Gottweis and colleagues (2009) state: “Standards bind communities of practice across space” (170) and thus allow consistency across geographical location and cultural context.

However, it is important to recognise that standards cannot just be analysed as “technical artefacts” (Gottweis et al 2009). Rather, according to Gottwies and colleagues (2009), they are the product of negotiation, debate and compromise between bureaucratic bodies, scientific
communities, community groups, and the private sector. Therefore, they are always affected by the interests of these groups (Gottweis et al. 2009). Within the medical profession, there is a particularly strong administrative focus and reliance on standards. Yet, Bowker and Star (1999) emphasise that medicine as a science has not developed as a linear progression of ideas resulting from increasing consensus due to this reliance on standards. Instead, they state that it has developed as a “panoply of tangled and crisscrossing classification schemes held together by an increasingly harassed and sprawling international public health bureaucracy” (Bowker & Star 1999: 21).

Young (1995) (in Bowker and Star 1999) emphasises the complex nature of categories within medicine and psychiatry. He highlights that while psychiatrists communicate with each other using the language and categories of the Diagnostic and Statistical Manual (DSM), many do not believe in the categories they are using. Bowker and Star (1999) demonstrate how the objectivity of classifications and standards are often compromised within the medical profession due to, for example, human limitations—that is, “people do not do the ideal job, but the doable job” (Bowker & Star 1999: 24). Therefore, standards appear to lead a double-life: their function in theory (that is, how they are discussed within the literature from a theoretical, versus empirical, perspective) and their function in practice. This study seeks to elaborate on this disparity.
between the theoretical/discursive stance of the medical profession and the actual practice of medicine in the clinical encounter.

Further adding to the complexity of standards and their use in medical practice, Timmermans and Berg (1997) introduce the idea of the “ universality” of standards. They illustrate that it is the extension and transformation of networks already firmly in place that act as the essential ingredients to allow universality. The term “ universality” within the context of medicine refers to the ability to apply, for example, a diagnostic test, across different hospitals and even countries without practice variation. The term “ network” within this context refers to a means through which medical knowledge and practices can be made universal. Latour (1983) explains his conception of networks using the railway as an analogy: “Scientific facts are like trains, they do not work off their rails. You can extend the rails and connect them but you cannot drive a locomotive through a field” (in Timmermans & Berg 1997: 274). Thus, the rails (networks) are the means through which trains (scientific facts) are made to work across different settings (universality). An example of a network is clinical practice guidelines.

This process of extending and transforming networks will of course create tensions as past infrastructures, procedures and practices are challenged. Timmermans and Berg (1997) emphasise that while
standards (such as clinical practice guidelines) are often portrayed as changing and replacing old practices, it is also important to see them as incorporating and extending already existing practices and routines. Furthermore, these authors stress that the universality of standards does not depend upon the presence of “centralized (scientific) control” (275), meaning that a standardised network does not require a “central actor” but rather “distributed activity” (275). This idea is illustrated through Timmermans and Berg’s (1997) analysis of an oncology protocol and the CPR protocol, in which they demonstrate that the origin of universal standards “is the result of historically situated, distributed work of a multitude of actors” (288). Thus, the concept of universality, as used by Timmermans and Berg (1997), emerges as quite precarious and uncertain, leading them to use the term “local universality” to address this ambiguity. They define local universality as follows:

Local universality emphasizes that universality always rests on real-time work, and emerges from localized processes of negotiations and pre-existing institutional, infrastructural, and material relations. ‘Universality’, here, has become a non-transcendental term – no longer implying a rupture with the ‘local’, but transforming and emerging in and through it. (Timmermans & Berg 1997: 275).

Timmermans and Berg’s (1997) work marks a significant contribution to discussions surrounding the use of standards within the medical profession, as it provides a practical critique of the notion of total bureaucratic supervision and control, such as “protocols render physicians’ skills superfluous”, “protocols can become a form of
‘tyrannical domination’”, and that doctors are reduced to “mindless cooks” (287). Their work emphasises that “it is the protocol’s trajectory which is secondary and which is aligned to [the physicians’] goals and trajectories” (Timmermans & Berg 1997: 288) and that “many years of experience or a strong familiarity with the literature supersedes following the protocol to the letter” (289). The agency of the patient in the clinical encounter further adds to this complex view of clinical guidelines and tools. Timmermans and Berg (2003) claim that sometimes the patient’s hopes and goals will affect the clinician’s use of the guidelines and tools: “patients will often negotiate their eligibility for a protocol” or skip elements of it “when they no longer see a meaningful link between their own future and the protocol’s trajectory” (71).

Thus, to reconcile the patient’s wants and needs, the bureaucratic pressures to use EBM, and the physician’s own agenda, it is common for the physician to “tinker” with the protocol to make it workable in practice. Timmermans & Berg (1997) conclude that this is an acknowledged and accepted practice within the medical profession, stating: “Leaving the enrolled actors some leeway or discretion is often the preferred way to ensure their cooperation” (291). 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 experience may supersede the use of EBM and its instruments.

*The evidence-based medicine movement: Epidemiology in medical practice*

Timmermans and Berg (2003), amongst a plethora of other researchers (see for example: Aveyard 1997; Eddy 2005; Marshall 1997; Timmermans & Mauck 2005), identify three key figures as forming the foundations of what is now widely known as EBM: Archie Cochrane (1972), John Wennberg (1984) and David Sackett (1995). Archie Cochrane (1972) argues against the overuse of medical techniques that were not supported by reliable and valid evidence, that is, the RCT. He advocates the use of systematic reviews of RCTs on a given topic by clinicians so that they could have quick access to evidence supporting or negating a certain intervention. This evidence is based upon a hierarchy, as outlined in Chapter One. Such a database now exists and is called the Cochrane Collaboration. The second key founder of the concept of EBM is John Wennberg (1984), who demonstrates that medical interventions often vary according to geographical location. Reasons given for this variation are: inadequate medical knowledge, physician practice styles, patient preferences, over-reliance on inadequately verified diagnostic tools, and basic inequities in the health care system (Timmermans & Berg 2003). Ultimately, Wennberg’s contribution to the EBM movement
was the establishment of “optimal treatment levels”, which allowed government agencies and medical organisations to check treatment outcomes and allocate financial resources appropriately (Timmermans & Berg 2003: 15). The third figure discussed by Timmermans and Berg (2003) is David Sackett (1995), whose definition of EBM is most commonly quoted in the EBM literature (see Chapter One). Sackett contributed to methodological approaches to analysing data, and evaluating the scientific validity and merit of medical interventions, as well as coining and promoting the term “evidence-based medicine” and articulating its principles (Timmermans & Berg 2003). However, what brought about this need within the medical profession, during the late 1980s, to change its epistemological framework from pathophysiology to epidemiology?

This is a critical question that Timmermans and Berg (2003) address. The key response they give relates to society’s scepticism, at this time, towards the professional expert and the privileged power and knowledge that they hold. Essentially, the position of the autonomous medical professional had come under pressure due to rapidly escalating health care costs, an increasing awareness of practice variations, vast amounts of data generated by evolving technologies, and a general dissatisfaction within society regarding the role played by experts and professionals (Timmermans & Berg 2003). Thus, the medical profession realised the
need to act on these general feelings that were developing to maintain their status as professional experts and the “wielders of medical knowledge” (Timmermans & Berg 2003: 16) and ensure their professional survival.

However, it has not just been the medical profession that has influenced the development of EBM. Four key groups are often identified as having an interest in the development of clinical guidelines: the medical profession, business or the private sector, the government, and insurance companies (Timmermans & Berg 2003). These four groups are also responsible for propelling the EBM movement forwards. The converging interests of these four parties have seen economic evaluations applied to the evidence, the results of which go on to affect the guidelines. For example, different interventions are not only judged based on their medical effectiveness but also on their financial cost. This can be seen in Australia through doctors prescribing medications listed under the Pharmaceutical Benefits Scheme (PBS). Medications listed under the PBS are subsidised by the Australian Government—for example, Risperidone is listed under the PBS and is often used in the treatment of behavioural symptoms of ASDs (such as aggression). However, the drugs listed under the PBS are arguably there due to “legal and political maneuvering” on the part of pharmaceutical companies (Rennie & Luft

Pharmaceutical companies can be expected to continue to fund analyses of the cost-effectiveness of their products, and, as legal and political maneuvering in the United Kingdom, Canada, and Australia has shown, to continue to bring great political and legal pressure on the organizations responsible for deciding the relative merits of their products. (Schuchman 1999 and Wilkinson 1999 in Rennie & Luft 2000: 2158).

Much of the literature addressing what is sometimes described as a “paradigm shift in health care” (Timmermans & Berg 2003) has been divided into supporters (see Sackett et al 1996; Rosenberg & Donald 1995) and critics (see Mykhalovskiy & Wier 2004; Smith & Pell 2003; Timmermans & Kolker 2004) of EBM. The supporters of EBM claim that standardisation is essential for effective communication and collaboration within the medical profession as it assists transparency in practice and moves medicine in the direction of an “exact science” (Rosoff 2001 in Timmermans & Berg 2003: 19). The critics of EBM claim that it turns medical practice into “cookbook” medicine, reducing practice to simple rule-following and thus undermining the experience and clinical expertise of each individual physician. A frequently discussed issue that has arisen from such debates relates to medical professionals’ compliance with clinical practice guidelines and thus the overall aims of EBM. Timmermans and Berg (2003) state:

One of the great attractions and weaknesses of evidence-based medicine is that while experts might have decided what is best, it
remains up to the professionals to acquaint themselves with the clinical guidelines and follow the consolidated advice. (Timmermans & Berg 2003: 21)

These ‘pro’ and ‘anti’ EBM discussions are played out predominantly in the medical literature, whereas sociological examinations of EBM focus on explaining the processes that have caused this ‘paradigm shift’ in medicine, and understanding how (and whether) this ‘paradigm shift’ has changed the practice of medicine. Some of these sociological studies are discussed in Chapter One. The following section discusses five exemplary qualitative studies in varying contexts and within different sub-disciplines (for example, general medicine doctors, nurses, paediatric residents) examining the use of EBM in the clinical encounter.

**The reality of medical practice: A review of the empirical literature**

The recent empirical research within the sociology of the medical profession demonstrates that clinical practice is a complex and disorganised affair. This complexity is evidenced by many empirical (sociological) investigations of a variety of medical specialisations as well as general medical practice. This discussion concentrates on recent (post-2000) sociological contributions to understandings of EBM. Five exemplary studies are evaluated: two examining general perceptions and opinions of medical staff; one investigating perceptions and opinions of medical staff within an Australian context; and two illustrating the perceptions and opinions of paediatricians.
McDonald, Waring and Harrison (2006) provide an examination of the attitudes of hospital doctors and managers to the implementation of rules in the context of patient safety. Their findings suggested a clash between the values of managerialism and medicine, highlighting that the doctors’ narratives were centrally concerned with the rejection of the discourse and rules of standardisation: “doctors’ accounts suggest that the rule is ‘there are no rules’” (McDonald et al 2006: 194). McDonald and colleagues (2006) point to social norms and values present both within and outside of the medical world as causes of these attitudes. Thus, within the context of medicine:

The unwritten rules of medical practice suggest that doctors whose practice is closely governed by guidelines, or who comment critically on the work of other medical professionals, will no longer be regarded as doctors, since autonomy and a refusal to judge others are key elements of the medical identity. (Hunter 1991 as cited by McDonald et al 2006: 198);

And within the broader social context:

The fact that doctors command greater popular support and enjoy much higher levels of trust amongst the general public than do hospital ‘bureaucrats’ contributes to their ability to resist challenges to their autonomy. (McDonald et al 2006: 198)

Furthermore, in another study conducted by McDonald and colleagues (2005), in which the perspectives of nurses and doctors regarding clinical guidelines were compared, it was found that doctors and nurses adopt
and promote the collective values of the particular profession in which they have been *socialised*. Thus, while nurses emphasised the importance of following guidelines and standardised approaches to ensure patient safety, doctors stressed the need for flexibility in the face of unpredictability and emphasised the tacit nature of their knowledge through experience. In fact, doctors claimed that they did not “identify with” certain standards, nor regard them to be “legitimate,” and thus did not follow them. Here, again, one sees the distinctly social-side of medical practice emerging, as well as the process of “standards tinkering”.

Hester-Moore (2005) interviewed fourteen health practitioners (10 doctors, 4 nurses) about their management of decreased libido in her exploration of the tension between the use of standards/guidelines and the requirements of clinical practice. She demonstrates that both the guidelines and practitioners’ experience are involved in a “transformative process” while clinical decision-making is enacted (184). She highlights that the *guidelines* and the health practitioners’ *translations* of the guidelines into “‘doable’ everyday practice” are “mutually shaped and shaping, constructed by and constructing, social phenomena.” (184) This notion of negotiating or tinkering with EBM and its instruments appears to be a theme within sociological examinations of EBM. Additionally, Hester-Moore’s study, as well as the other studies discussed in this
section, avoid a conceptual difficulty that Timmermans and Berg (2003) discuss with reference to theoretical examinations of EBM. This conceptual difficulty reinforces the distinction between experience (or clinical judgement) and the use of EBM and its instruments (Timmermans & Berg 2003). Perpetuating this binary avoids recognising the true complexities and intricacies of medical practice: the act of negotiating in and between guidelines, experience, and clients.

Rafalovich (2005) interviewed twenty-six clinicians (including paediatricians) about their diagnosis and treatment of attention deficit hyperactivity disorder (ADHD) in children. He claims that clinicians have reservations about the diagnostic validity of the DSM-IV, highlighting that the application of this guideline in the clinical setting requires negotiation on the part of the clinician in terms of using clinical judgement to aid in decision-making. Furthermore, the study stresses that the clinicians are not practicing in a vacuum, but are instead largely affected by the scepticism (and thus subjective interpretations) that surrounds ADHD, both within the medical community and expressed in society at large (for example, in the media). Rafalovich states:

Hence, the ambivalence elucidated in this study may demonstrate the reflexivity between clinical realms and the broader discursive contexts that affect, and are affected by, such realms. As the diagnostic category of ADHD and its most conventional methods of treatment remain mired in debate, the many points of contention that characterise the modern discussion of ADHD may become visible in the way clinicians realise their professional aims. (Rafalovich 2005: 318)
Again, this study accentuates the role of the social world in affecting the clinician in the clinical encounter. It is also particularly valuable as it examines the application of the DSM-IV in the clinical encounter – the guideline used by paediatricians to diagnose ASDs. Furthermore, ASDs and ADHD can exist simultaneously in one patient (comorbidity), and thus children diagnosed with an ASD will sometimes also be affected by ADHD. These results, then, could have implications for this study.

Timmermans and Angell’s (2001) study (also discussed in Timmermans & Berg 2003), in which paediatric residents are interviewed about their use of EBM in clinical decisions, aims to empirically investigate the extent to which EBM has altered medical training. Ultimately, it shows that “the political and ontological effects of EBM...subtly change the interrelationship between people and their tools of knowledge” (Timmermans & Berg 2003: 143). Timmermans and Berg (2003) state:

An EBM medical practice will differ depending on what kind of research qualifies as evidence and the different clinical situations it pertains to. In order to qualify as EBM, should the resident reserve literature consultations for rare, difficult, and new cases, or especially for routine patient actions? What literature qualifies as solid evidence, and how should it be read? When can a resident who believes in EBM assume that he or she knows the evidence and skip consulting the literature? (Timmermans & Berg 2003: 145)

Timmermans and Angell’s (2001) research, in which these questions are addressed, show that there are at least two very different ways of “doing
EBM”, and these are embodied in the “librarian” and the “researcher” approaches (345). The majority of the participants in their study fulfilled the criteria of librarian, with the main difference between the approaches relating to researchers evaluating the literature based on randomised controlled trials and librarians consulting any literature. Thus, a key factor in doing EBM involves awareness of the evidence hierarchy. This distinguishing factor between participants could have implications for this study. The Australian paediatricians interviewed could have differing conceptions as to what constitutes EBM based on independent variables such as length of time practicing as a paediatrician (that is, clinical experience).

A further finding of Timmermans and Angell’s (2001) study is the power of clinical experience in the clinical encounter. Resident physicians (that is, people that have received their medical degree but are still involved in training) reported that in circumstances where they believe the attending’s (that is, a physician that acts as a supervisor to residents) clinical decision is at odds with the literature, and they approach the attending with the relevant evidence to discuss the case, the literature would likely lose out: “The attending would qualify the study’s findings with some reason why the recommendations did not apply in this particular case” (Timmermans & Berg 2003: 159). Timmermans and Berg (2003) go on to state:
Not only did residents confirm that their superiors’ institutionalized power advantage and accumulated experience trumped any knowledge they might have gleaned from the literature, but they also admitted that they would act similarly when others challenged them...[they would] “likely stick with experience”. (Timmermans & Berg 2003: 160)

However, the conceptual difficulty of evidence and experience being viewed as distinct, even opposite, entities, as discussed above, does not apply to Timmermans and Angell’s (2001) study. The authors qualify that the participants ultimately indicate that medical practice “inevitably contained a mixture of the two, albeit not necessarily in equal proportions” (Timmermans & Berg 2003: 163-4). Thus, they state:

The quality that guides clinical decision making is not the tradition-bound experience put up as a straw person in the medical and sociological literature, but a mixture of skills and uncertainties grounded in medical knowledge. (Timmermans & Berg 2003: 163).

**The direction of this study**

In this chapter, I have discussed the paradigmatic shift that has taken place in the medical profession and how this has affected medical practice. This shift from pathophysiology to epidemiology, however, has not been a simple process. Three key factors are outlined as contributing to the complexity of medical practice today. *First*, the notion that standards lead a double-life, in that there is a disparity between the motivations of administrative and bureaucratic bodies developing standards/guidelines and the motivations of those that must apply them in
practice. *Second*, the idea that health-care workers do not do the ideal job, they do the “doable” job. This often involves “tinkering” with standards to make it workable in practice. Thus, the trajectory of a standard is second to the clinician’s goals. *Third*, the idea that standards and guidelines are affected by the interests of many groups external to the medical profession, such as government and industry. These factors suggest that the medical epidemiological “gaze” is not as rigorous, standardised, nor scientific as it often purports to be. In fact, the medical “gaze” appears to be affected by many political and social forces at work within the medical profession and outside of it.

Investigating this complex conception of the medical “gaze” within the context of a disorder such as autism, surrounded by scientific uncertainty and medical complexities, therefore makes for an interesting study. Autism spectrum disorder, as discussed in Chapter One, is a *heterogeneous* disorder. Thus, ASDs’ causes, age of onset, symptoms, comorbidity with other disorders (such as ADHD), and patients’ responses to treatment all differ according to each patient. This sheer variability makes ASDs particularly difficult to test under the epidemiological paradigm, particularly using a RCT. Diagnosing and treating ASDs, as demonstrated in Chapter One, is carried out at an individual, case-by-case level and heavily relies on the clinician’s observation of the patient. While standardised tools and guidelines that
aid in the diagnosis of ASDs exist, it appears paediatricians are critical of their functionality in practice and that sometimes they are used incorrectly (Symons 2008). 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).

Thus, an investigation of the paediatricians’ “gaze” and how it is applied in the clinical encounter to autism spectrum disorder will shed light on the inter-subjectivities, subtleties and complexities involved in medical practice. Such an investigation will provide greater understanding of what the “doable” job entails in the diagnosis and treatment of ASDs, the role standards play in the clinical encounter, and whether internal and/or external political and social forces affect the “gaze” of the paediatrician. In doing so, this study will hope to show that:

The difficulty for medicine as a discipline is maybe not that this subjectivity is happening, but that the medical research tradition lacks strategies for the study of interpretive action, its dynamics and its consequences. (Malterud 2001: 397).
CHAPTER THREE
METHODOLOGY

Methodological approaches of sociological literature addressing the field of paediatrics

To ascertain the scope and depth of sociological research within the field of paediatrics, and to shed light on the process of conducting interviews with medical professionals about the practice of medicine, a Sociological Abstracts (CSA) database search was performed early in the research process. The terms “paediatric” OR “pediatric” OR “paediatrician” OR “pediatrician” were searched within abstracts. This database search revealed that the field of paediatrics, whilst a popular topic of interest for sociologists in general, has not been properly explored in terms of understanding the practice of paediatrics and conducting field research with these professionals. Three studies investigating the way paediatricians practice within the hospital setting provided good examples of conducting field research within a paediatric clinical setting.

In Fortin’s (2008) sociological examination of a paediatric clinic in Montreal, Canada, a “triple research method” is used. This research method is described as an “ethnographic approach” and involves observations of clinical work over a one year period, individual in-depth interviews with clinicians, and case studies of patients and their families.
This research approach was interested in discovering more about the dynamics of the clinical encounter within a hospital setting.

In Hunter and colleagues’ (2008) sociological examination of critical incidents within a major paediatric hospital in Australia, the ethnographic approach is also embraced. The authors claim that “an anthropological ethnographic research approach enable[s] the researcher to observe, document, interpret and make sense of the activities of clinicians...[it] significantly exposes and highlights hospital dramas and shows the effects on clinicians’ everyday lives” (91).

Timmermans & Angell’s (2001) study (see Chapter Two), involving in-depth interviews with seventeen paediatric residents, aims to understand how the standardisation of medicine through the implementation of EBM and its instruments affects knowledge acquisition and medical practice. Of particular interest for Timmermans and Angell are how these paediatric residents are managing clinical uncertainty and whether this paradigm shift within the education setting is translated to the clinical practice setting. The interview questions used within this study were aimed at generating detailed stories, and the interviewers probed repeatedly for specific instances of clinical problem solving. Each respondent was asked similar questions, but not necessarily in the same wording and sequence. Timmermans and Angell (2001) claim that they
would have preferred to observe their participants while involved in clinical decision-making and during contact with patients. Importantly though, they stress that obtaining participants for the interviews was cumbersome enough: “Even with the blessing of the attending physician, it remained difficult and time-consuming to access the residency programs” (344). The recruitment process was also quite challenging in this study and will be discussed at length later in this chapter. Thus, this generation of stories and probing for detailed clinical examples approach was an attempt to compensate for the limited methodological framework within which they were forced to work.

Whilst these studies all contribute important empirical observations to sociological understandings of the field of paediatrics within the hospital setting, it is also important to understand the nature of paediatric clinical practice within a private practice setting. As discussed in Chapter One, children diagnosed with an ASD in Australia are usually diagnosed by a private practice paediatrician. However, there is a gap in sociological understandings of the paediatric private practice, as well as sociological understandings of how patients with an ASD are managed in the clinical encounter. Another trend that emerges within this literature is the research method of ethnography and observation, as well as the use of in-depth interviews. This methodological consistency is important to
consider when formulating a research approach for sociological empirical investigations into the practice of medicine.

**Approach adopted for this study**

The observational and ethnographic approaches within health care settings have been described as “insightful and illuminating” (Mays & Pope 1995: 182). Mays and Pope (1995) claim that such an approach side-steps the discrepancy between what people say they do, and what they actually do: it “circumvents the biases inherent in the accounts people give of their actions caused by factors such as the wish to present themselves in a good light, differences in recall, selectivity, and the influences of the roles they occupy” (182). Furthermore, Polanyi’s (1983) work emphasises the tacit nature of human knowledge, that is, we know more than we can impart. Polanyi examines the “art” of the medical diagnosis as an example of this tacit knowledge. He describes the skilful testing and expert observation involved, yet doctors’ inability to explicitly explain the process. Whilst this approach clearly has many benefits, it is important to point out that the studies making use of this methodology are conducted within large-scale settings, such as hospitals. The scale of this study is far more modest due to time and resource limitations, and is interested in individual clinicians in a private clinical setting. Thus, it was decided that interviews would be an adequate methodological approach to gain the information needed for this study.
However, Mays & Pope’s (1995) point regarding the biases inherent in people’s accounts of their own actions will certainly be taken into account as a methodological weakness of this study.

Timmermans and Angell’s (2001) methodological approach in their examination of paediatric residents’ use of EBM in the management of clinical uncertainty provided a good model for this study. Their work is a vital contribution to the sociological literature dealing with EBM, as it ties together the ideas of uncertainty in medical practice, differences in practice based on the experience of the doctor, and different approaches to doing EBM. Through their methodological approach, they were able to convey the complexities, subtleties and uncertainties encountered in medical practice. As outlined in Chapter One, the aims of this study are similar, and therefore Timmermans and Angell’s (2001) methodological approach appears to be a good way to test these objectives. As a result, the interview questions used in Timmermans and Angell’s (2001) investigation were used as a guide for this study. These existing questions, and their investigation more generally, gave the researcher insight into paediatric practice through a sociological lens and provided a starting point in regards to the relevant questions to ask.

The formulation of the interview questions for this study was thus based upon the information obtained from the Timmermans and Angell (2001)
study, a variety of articles examining the diagnosis and treatment of ASDs, and personal contact (through the researcher’s work with children diagnosed with an ASD) with parents of children diagnosed with an ASD and professionals diagnosing and treating ASDs.

**Human Research Ethics Committee (HREC)**

Two ethics applications were submitted to the HREC. The first application required amendments to the recruitment process (that is, to provide a more detailed explanation as to how the study would recruit participants), the Ethics Administration telephone number, and some formatting details. The second application was submitted in the form of a letter that addressed the requested amendments. Ethics approval for this study was granted on 15 May 2009. The approval period to conduct this study was May 2009 to May 2010.

**Recruitment**

Participants were recruited using two different approaches:

1. The publication of a recruitment notice in the Royal Australasian College of Physicians’ (Paediatrics and Child Health Division) e-bulletin on 29/05/2009. The recruitment notice requested interested persons to contact the researchers (whose details were provided) if they wished to participate in the study. Interested persons were then sent a ‘Participant Information Statement’,
‘Participant Consent Form’, and a self-addressed stamped envelope to be read, signed and returned to the researchers.

(2) A recruitment letter posted on 22/06/09 to twenty-two paediatricians listed on the Yellow Pages website under “paediatric medicine” and “paediatricians”. This letter consisted of a ‘Recruitment Letter’, ‘Participant Information Statement’, ‘Participant Consent Form’, and a self-addressed stamped envelope: potential participants were told that if they were interested in participating in the study, to read, sign and return the relevant documents to the researchers.

In accordance with ethical guidelines, no pressure was placed on the paediatricians to respond. Paediatricians were also made aware that they could withdraw from the study at any time.

The lack of response was not surprising given the caution in the literature that access to the ‘powerful’ or ‘elites’ can be difficult (Sarantakos 2005). Due to the lack of respondents three weeks after recruitment approach (1), the researcher used recruitment approach (2) to increase the chances of obtaining interviews. This approach was more personal and had a greater likelihood of receiving the attention of the respondent as a result. Of the two recruitment methods used, two participants responded to the recruitment notice in the RACP’s e-bulletin, and eight responded
to the recruitment letter. Of these ten respondents that initially expressed interest in participating in the study, only one did not participate in the interviews because they did not respond to the researcher’s attempts to organise an interview time. This was a common problem with all of the respondents: once they had given their permission to be contacted by telephone to organise a time to be interviewed, each participant was contacted at least three times before a response was received. Interestingly, most participants spontaneously indicated to the interviewer that they participated in the study out of a sense of obligation (to the profession of Australian paediatrics, claiming this research was “relevant” and “important”) and/or interest in the research topic. Overall, the recruitment process took place over a period of eight weeks.

*Interviews*

Data collection took place over a period of seven weeks, beginning on June 29 2009 and ending on August 19. Interviews were audio-taped, conducted face-to-face in the paediatrician’s place of work. The average length of interviews was 26 minutes 56 seconds: with the shortest interview 16 minutes 39 seconds in duration; and the longest interview 42 minutes 34 seconds in duration (see list of tables, Table 1). Each interview was transcribed verbatim.

The interviews took the following structure:
The interviewer was greeted by the paediatrician in their reception/waiting area and then ushered into their office. The interviewer presented herself to participants formally, but also in a friendly and open manner. The paediatrician was provided with a consent form, participant information statement and a list of the questions to be asked in the interview (this provided them with a visual copy of the questions to refer to if they were side-tracked or went ‘off topic’ while answering) (see appendix 1). The interviewer then gave a brief outline of the research and its purpose and provided a brief outline of the interview structure. The interviewer also demonstrated her knowledge of, and interest in, the topic when introducing the interview, outlining her three years of experience working with children diagnosed with an ASD. By providing this information, the interviewer wished to convey her knowledge base within the area.

The interviewer then presented the audio-recording device and again confirmed that it was okay for it to be used. The audio-recording device was switched on and the questions were asked in order. Six of the nine interviews were conducted without interruption, three however were interrupted by phone calls. In these cases the audio-recording device was switched off during the phone call and switched-on again at the phone call’s conclusion and the paediatrician’s confirmation that the interview could once again progress.
The interview schedule (see appendix 1) contained questions in relation to:

(1) *The paediatrician’s experience*

(2) *The diagnosis of ASD:*

(a) at varying ages

(b) problems encountered with the use of guidelines in diagnosis

(c) whether a particular diagnostic tool was preferred over others.

(3) *The treatment of ASD:*

(a) the clinical process a paediatrician goes through in recommending treatments

(b) difficulties encountered when recommending treatments

(4) *The use of EBM in paediatrics and in the diagnosis and treatment of ASD*

(a) defining EBM

(b) education

(c) the use of literature searches in diagnosis and treatment

(d) the importance of EBM within Australian paediatrics

The interviews conducted for this research can be described as semi-structured (Sarantakos 2005): while a structured list of questions was followed in a certain order, probing was often used when the interviewer felt something interesting was mentioned and needed elaboration; when
something needed clarification; or if the interviewer felt that the question was not answered or understood by the interviewee. In the case of a question not being answered or understood the question was rephrased. All questions were “open” and the interview schedule was therefore “unstandardised” (Sarantakos 2005).

The interviewer’s experience in working with children diagnosed with an ASD, as mentioned above, was very valuable during the interview process for two of reasons. Firstly, many of the standardised tools used to diagnose ASDs, as well as the treatments, are commonly discussed in acronym form. Thus, this experience over the years has brought the researcher into contact with such terminology, allowing the interview to progress without interruptions on the interviewer’s part for the interviewees to clarify acronyms and their meanings. Secondly, probing questions in semi-structured interviews is an important tool. The interviewer’s experience aided her background practical knowledge of ASDs and allowed her to formulate probing questions that drew on real-life experiences of families with a child on the spectrum, health-care professionals diagnosing and treating ASDs, and children themselves on the autism spectrum. This certainly contributed to a more in-depth level of probing.
However, these ‘probing questions’ also improved as the researcher interviewed more paediatricians. Due to the marked absence of literature examining the use of EBM in the diagnosis and treatment of ASDs, the interview data provided many novel insights and raised many new questions in the mind of the interviewer. Thus, as the interviewer learnt more about the paediatricians’ roles in the diagnosis and treatment of ASDs through each interview, she was able to probe the paediatricians with a stronger knowledge base. This technique is known as ‘explication’ whereby “findings emerge through the study and are interpreted during the process of interviewing” (Sarantakos 2005: 270).

**Limitations of this approach**

There are some limitations in the data obtained from the interviews. Firstly, the small sample size of the study means that it is difficult to make inferences from the interviews extending beyond the interviews themselves. Timmermans and Angell (2001) similarly identify their small sample size as a significant limitation in their research approach: “[it] does not allow us to make fine distinctions along the lines of gender, race, medical sub-discipline, and year of residency—all potentially relevant independent variables” (345). This too is an important factor to consider within this study: because the sample size is nine, independent variables such as the paediatricians’ experience, where they were educated and trained, and their gender and race, cannot be adequately...
examined and generalised. Secondly, the interviewees are considered “elites” and it is possible that they were guarded in their responses because they mistrusted how the responses would be used (Sarantakos 2005). Thirdly, a common problem with interviews and any self-report data is the truthfulness of the answers (Sarantakos 2005). Within the context of this study, the interviewer was aware of relevance of the ‘social standards’ bias, whereby respondents provide answers that may have been adjusted to conform to social standards, resulting in the researcher receiving answers that are socially desirable but not necessarily correct or accurate. Unfortunately, it is unclear within the literature what the cultural norms and values are within the context of the private paediatric clinic, thus it was hard to “ensure sensitive questions [were] formulated in a manner that neutralis[ed] external factors in interviewing” (Sarantakos 2005: 284). An important aim of this study is to address this gap in the literature, thus shedding light on the cultural norms and values that exist within this context.
Analysis of the interviews revealed a number of issues, many of which have been discussed in the existing literature, but have yet to be understood within the context of private practice paediatrics and the diagnosis and treatment of ASDs. These issues include: the role of experience in the clinical encounter, the tacit and experiential nature of diagnosing and treating the heterogeneous condition of autism, the necessary practice of tool “tinkering” and tool negotiation, and the influence of political and social forces in the clinical encounter.

**Participants’ experience: an important independent variable**

The interviews in this study began by establishing the experience of the participants in terms of how many years they had been practicing as paediatricians. Due to the changes in medical epistemology (that is, the shift from pathophysiology to epidemiology and evidence-based practice) during the 1990s, the researcher anticipated that experience may be a crucial independent variable affecting participant responses. For instance, a participant with thirty or more years of experience, and therefore someone that conducted their training and initial practice prior to the EBM movement, may be expected to have very different responses from a participant that was educated and trained during the EBM movement.
Two clear groups were identified: four participants had 16 years or less experience, and five participants had 30 years or more experience (see list of tables, table 2). Furthermore, all of the less experienced participants are female, and all of the more experienced participants are male. Unfortunately, the independent variable of gender cannot be explored in this study due to the small sample size.

According to the Royal Australasian College of Physicians (RACP) (Paediatrics Division), the number of Paediatric Fellows that are members of the RACP in Australia is approximately 1500. Considering the specificity of this study, in that the paediatricians interviewed are practicing in the Sydney area, are developmental paediatricians, and have to have experience working with an autistic population; it is fair to say that the number of paediatricians meeting this criteria would be quite small. Unfortunately, this figure could not be obtained from the RACP.

These divisions between less and more experienced participants will be discussed in this section to determine any differences in data based on this independent variable. Three key differences between groups one and two were identified: conceptualising EBM, using tools/guidelines in the diagnosis of ASDs, and prescribing medications. However, as discussed with regards to the independent variable of gender, due to the small sample size, any variation in data between less and more experienced
participants must be discussed cautiously and cannot be extrapolated to
the larger Australian paediatric population.

Conceptualising EBM

Throughout their interviews, two of the more experienced participants
conveyed an anti-EBM attitude when questioned specifically about EBM.
Additionally, they did not mention EBM in general diagnostic and
treatment questions. Upon further questioning, it was discovered that this
attitude was related to the participants’ conceptualisations of EBM. They
stated, respectively:

I’m a book person, rather than a computer person – I prefer what’s in
front of me than what’s on the screen...It’s just an age thing.

...it just wasn’t necessary; it’s just a personal thing; we weren’t really
taught much about autism when I was training in paediatrics, and it’s
something I and my colleagues have had to pick up along the way. So
the way it’s just happened for me, is through the reading of journal
articles mainly, going to conferences, going to lectures and then, more
or less, formulating my own approach, based on that information; and
it’s an ongoing thing...

Both these responses conveyed, in this researcher’s eyes, a
misunderstanding about what is meant by the term EBM. Both
participants appear to assume that EBM is specifically a computer
resource, and seem to discount reading journals in a hard-copy format as
forming part of EBM. From both these participants’ previous responses,
it is fair to assume they do practice EBM, just not necessarily on a
computer. This resistance to, and discomfort with, the use of computers
to conduct EBM literature searches could be a widespread phenomena amongst physicians educated and trained prior to the 1990s. These physicians may not be as competent, nor familiar, with the Cochrane data-base and other computer-based EBM search tools as physicians who have been educated and trained over the past twenty years (that is, when EBM formed an important part of medical training and education). Thus, further investigations need to examine this possible discrepancy.

*Using tools/guidelines in the diagnosis of ASDs*

To ascertain whether there were educational differences between participants with regards to EBM, participants were explicitly asked about their education and training. While all four of the less experienced participants indicated that their education and training had involved learning about EBM, only one of the more experienced group claimed this was the case (see table 7). This data could account for differing responses between the two groups in terms of the use of EBM in the clinical encounter. All of the less experienced participants cited one or more diagnostic tool(s) used in their diagnosis of ASDs, whereas just one of the more experienced group mentioned the use of diagnostic tools or guidelines (see table 3). Thus, if the less experienced participants have been specifically educated and trained to use EBM, they will likely be more confident making use of it in medical practice and understanding its deficiencies. One of the more experienced participants, when questioned
about the importance of EBM and its instruments to the practice of paediatrics in Australia, stated:

I know the answer to that is ‘very important’, because my daughter has just finished her post-graduate medical course and I’ve seen what she does with this stuff; I think it’s just a generational thing now; it’s just the way medicine is changing; and is it important? Of course it’s important. Do I use it? No! (laughs in a self-deprecatory manner)

This quote illuminates a generational gap that appears to exist in medical practice. While the participant admits EBM is an important change that has affected medical practice, he matter-of-factly states that he does not use it. This attitude could be explained by McDonald and colleagues’ (2006) discussion of the social norms and values that exist within the medical profession (as discussed in Chapter Two).

Prescribing medications
Another trend that emerged between the two groups was the tendency of the more experienced participants to use pharmacological interventions in the treatment of ASDs than the less experienced participants (see table 6). Four of the more experienced participants stated that they prescribed medications, whereas only one of the less experienced participants stated she did this. In fact, one of the more experienced participants stated: “I use a lot of pharmacological intervention, and I think I’m one of the biggest prescribers of Risperidone.” This represents an interesting trend in the data and warrants further investigation to ascertain whether doctors
with more experience are more likely to use pharmacological intervention compared to less experienced doctors. Such a result could relate to differing educational or training practices across time within Australian paediatrics. The following quote from a more experienced participant may provide further insights into why this trend exists:

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

Favouring the practice of medicating patients over other treatment approaches, such as early intervention therapies, relates perhaps to educational and training norms prevalent during the 1970s and 1980s. Thus, physicians educated during this period probably carry these norms with them throughout their careers.

**The tacit and experiential nature of diagnosing and treating ASDs**

The tension that exists between administrative goals of applying EBM to heterogeneous disorders such as ASDs, and the actual practice of applying EBM in the clinical encounter is examined in Chapter One. The idea that evidence produced by “specific” and “clean” trials can be applied to the ASD patient is to underestimate the complexity, uncertainties and difficulties faced by paediatricians. Every individual diagnosed with an ASD, it is claimed, is affected differently (Grinker 2007). The participants interviewed for this study demonstrated that these
complexities, uncertainties and difficulties 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) 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. (Wegner 1998: 47)

The tacit and experiential nature of diagnosing and treating ASDs was discussed by participants in four key ways: the importance of using observation and a “gut feeling” to diagnose ASDs, consensus among participants that the ADOS was the most effective/rigorous/accurate tool, consensus among the participants regarding treatment recommendations, and the maintenance of autonomy in the clinical encounter.

**Observation and using a “gut feeling”**

If we consider the steps that are used by participants in the diagnosis of ASDs, experiential and observational knowledge are the most highly ranked (see table 4). Both of these steps are discussed by eight of the nine participants. The experience gained from practicing as a paediatrician is
stressed as “the most important thing” by the majority of participants.

Several more experienced participants stressed that being an “old and grey” paediatrician (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 participant 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...

Interestingly though, and consistent with Timmermans and Angell’s (2001) study discussed in Chapter Two, less experienced participants also stressed the essential nature of clinical experience. In Timmermans and Angell’s (2001) study, paediatric residents claimed that if they were faced with a decision where the evidence conflicted with their experiential knowledge, they would “likely stick with experience” (160). A less experienced participant made a very similar statement:

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.
Both of these quotes demonstrate the highly 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” highlight 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. The statistical approach of the epidemiological “gaze” simply does not apply to this type of recognition.

The ADOS as the most effective/rigorous/accurate tool

Seven of the nine participants believed that the ADOS is the most effective/rigorous/accurate tool available to them in the diagnosis of ASDs (see table 3). The ADOS stresses the importance of a lengthy observation of 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. In light of participants’ responses regarding the essential nature of using observation and a “gut
feeling” in the diagnostic process, this attitude towards the ADOS is not surprising. One participant 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” (163-4). Despite this preference for the ADOS, only three participants actually claimed they used it in the clinical encounter (see table 3). One participant 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 participants’ responses. While the ADOS may be the “gold standard” of evidence for ASDs, essentially it is the best out of a bad lot. This also could explain why the use of clinical judgement, and basing diagnostic decisions on clinical experience, is such common practice amongst the participants.
The quote above is also interesting as it highlights the tension between the epidemiological “gaze” and the difficulty of applying it to the ASD patient in the clinical encounter. However, this participant, like Mesibov and colleagues (2006) (see Chapter One), illuminates the paradox of applying the epidemiological “gaze” to heterogeneous disorders. Despite the fact that ASDs do not fit the epidemiological mould, the medical profession continues to apply the epidemiological “gaze” in the hope that one day they will develop a “better method or dimensional tool.” This hope persists in spite of explicit explanations, such as Mesibov and colleagues (2006) and the participant’s comment above, whereby ASD is viewed as a “construct” and the potential for “real” evidence is questioned. It is interesting that even with the insights this participant possesses, the power of the epidemiological “gaze” persists. This could be related to the participant’s classification as a less experienced participant, and thus her educational background. As discussed in the previous section, educational and training norms are probably maintained throughout the physician’s career. Thus, this participant was educated and trained when EBM was an important part of the curriculum.

Consensus about treatment recommendations
Surprisingly, there was a significant amount of consensus amongst participants regarding the recommendation of treatments for children
diagnosed with an ASD (see list of graphs, graph 1). Most participants recommended *early intervention programs* (which focus on improving the child’s educational, behavioural and communication abilities) and/or *speech therapy* (which focuses on improving the child’s language skills) and/or *occupational therapy* (which focuses on improving the child’s gross and fine motor skills). Considering the variety of treatment approaches available to children on the spectrum and the difficulty of finding evidence to support most of the treatments, this consensus amongst participants presents as an interesting trend in the data. One participant provided an explanation as to how he believed paediatricians go about recommending treatments:

> I guess I’m just a simple clinician, and I use what I think works...I guess the approach [paediatricians] take is that if we notice the child has a weakness in an aspect of his or her development...we will try to plug it...that’s how I think a clinician approaches it. It’s not very scientific, is it?

Here, the importance is identifying the weaknesses in the patient through clinical judgement and addressing each perceived weakness with approaches the paediatrician believes are effective: “I use what I think works.” Thus, there appear to be shared underlying assumptions as to what works in the treatment of ASDs amongst the participants.
Autonomy in the clinical encounter

All nine participants indicated that they did not feel that their autonomy as a doctor was threatened by EBM or clinical practice guidelines. Several participants also pointed out that the field of developmental paediatrics is an inherently uncertain field. This allows clinicians much leeway in decision-making because guidelines, tools and treatment approaches are based on “weaker” evidence and are difficult to apply in practice due to the heterogeneous nature of many of the presenting conditions. One participant stated:

It’s such an airy fairy area, developmental paediatrics; there’s no blood test or brain scan to prove it, so it’s such a clinical diagnosis; and so really...the management is therapy.

Thus, maintaining autonomy within the field of developmental paediatrics seems to be a characteristic of this type of medicine due to the uncertain status of evidence and difficulty applying it within this field. Most participants suggest that while taking the evidence into account is important, at the end of the day it is clinical judgement or experience that has the “final word” and it ultimately overrides EBM and the tools associated with it. Furthermore, two more experienced participants reiterate this notion of autonomy through their suggestion that epidemiology is not an essential, nor stable, part of medicine. These participants stress that EBM is an “adjunct,” and that ultimately they practice medicine the way they want to:
I know that these things are the times, but one swims with the tide and one does what one does, and people come and see me and I guess that’s okay.

**Understanding tool and evidence “tinkering” in the diagnosis and treatment of ASDs**

As discussed in Chapters One and Two, tool “tinkering” appears to be a common practice amongst physicians and other health care workers. This study also demonstrates that tool “tinkering” occurs amongst the participants in the diagnosis and treatment of ASDs. A physician that partakes in tool “tinkering” views the tool or guideline as a means, to be acted upon with their own clinical judgement, goals and constraints of the situation in mind. Constraints within the clinical encounter could involve, for example, the socio-economic status of the patient or the complexities/difficulties of the condition being diagnosed and treated. Thus, a tool or guideline will be used by the physician when they deem it to be appropriate and when they see a need for it.

In the case of diagnosing ASDs, most participants indicated it is not a “difficult” disorder to diagnose if the child exhibits “obvious” symptoms. One participant stated: “The diagnosis is pretty straight forward...some of [the patients] are so obvious that the woman across the road could diagnose them.” In such circumstances, participants emphasise that the use of diagnostic tools is pointless because it is a waste of time and
money. However, if the diagnosis was not straightforward and the participants were unsure, for example, if the patient had ADHD or an ASD, or perhaps elements of both, tools were often used to alleviate this uncertainty. One participant 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 a disorder such as ASD which significantly complicates the clinical encounter. One participant 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.

Thus, there is a clear trend in the data indicating that tool use is associated with “difficult” or “uncertain” diagnoses. Tools are used in situations where there is uncertainty and complexity, and these situations exist at the margins of the clinical encounter. Uncertainty and complexity in the clinical encounter are experienced when a patient presents with symptoms that are hard to (tacitly) classify or tease apart from other disorders. This is a particularly interesting trend in the data: the principles of epidemiology (and thus EBM) are based on probability and
population statistics, yet it appears EBM is not applied to the probable or obvious ASD cases. Instead, it is used at the margins to deal with improbable and ambiguous ASD cases. This finding illuminates a paradox that exists when applying EBM to ASDs and will be discussed in more detail in Chapter Five.

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 participants 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 participant 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, presenting them as if they are mutually exclusive entities in
the clinical encounter. In Chapter Two, this distinction or tension is described as a “conceptual difficulty,” in that it oversimplifies the clinical encounter by producing an either/or situation. However, most participants described the tool “tinkering” process in similar terms when compared to the five studies discussed in Chapter Two. Participants 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 (see table 5). Thus, the tool requires “tinkering” to make it functional in the clinical encounter.

Three main problems with the tools/guidelines were discussed (see table 5). 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, participants 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 participant 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, participants 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 plane up to the corner of his eye, that didn’t come out on the ADOS; and I noticed a few times as soon as I stop interacting with them and they have a bit of free play just completely unstructured sometimes I will see things, or they will pick all of the cars out of this box and then line them all up; and I’ll go mmmmmmmmm!

Furthermore, the tools can altogether miss a diagnosis:

There’s really no ideal screening tools...as far as I’m concerned, they all give you some help, but none of them is diagnostic as such...it’s not uncommon for me to see kids who’ve been through various assessments...and they say ‘this kid hasn’t got autism’, but, in fact, the child has autism.

These three problems provide insight into why the tools and guidelines are rarely sufficient on their own in the diagnosis of ASDs. Seven of the nine participants explicitly stated they had one or more difficulties with the tools and guidelines (see table 5). These difficulties justify the practice of tool “tinkering” and highlight that this is an essential practice if these standardised tools are expected to be used in the clinical encounter. Thus, an ideal tool for diagnosing ASDs does not exist: “medicine doesn’t fail to meet the standards: the standards fail to meet reality” (Berg & Mol 1998: 10).

The use of EBM in the treatment of ASDs also requires manipulation and “tinkering”. Many participants indicated they experienced difficulties using the evidence to aid in the recommendation of treatments. They claimed that due to the heterogeneous nature of ASDs, it was difficult to
“put in a good study” (that is, a RCT), that there was a “genuine lack of evidence” for most of the therapy-based interventions, and that “there is very limited good research on which [treatment] is better and which is more appropriate.” One participant discussed the evidence “tinkering” he used in the treatment of his patients with an ASD:

Do I practice evidence-based medicine? Well, obviously every doctor thinks he does, but the dilemma is that in behavioural medicine it is clear that some people respond to certain medications and some don’t; and 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 participant 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”, whereby covering all the bases involves “tinkering” or negotiating in and between the tool, clinical experience, and the patient.

The political and social forces affecting medical practice

As discussed in the previous section, tool “tinkering” is often motivated by certain situational constraints placed on the physician in the clinical
This section will explore the situational constraints that participants felt affected their clinical “gaze”. The five studies reviewed in Chapter Two examine the impact of the social world on the medical world, emphasising that physicians do not practice in a scientific vacuum but are affected by the social phenomena that surrounds their work. For example, Rafalovich’s (2005) study highlights that clinicians involved in the diagnosis and treatment of ADHD are often affected by the controversy that surrounds this disorder. The research discussed here found that there were two main themes discussed by participants: the caregiver-paediatrician relationship and the impact of government funding.

**The parent-paediatrician relationship**

The parent\(^1\)-paediatrician relationship was discussed by seven participants (see graph 2). Two main issues were cited as affecting the role of the doctor in the clinical encounter: the parents’ wants and needs and the parents’ agency in the treatment process.

Conveying the diagnosis of an ASD to the parent of the child is a complex and challenging task. According to the participants in this study, breaking the news to a family that their child is affected by autism requires empathy and sensitivity. Thus, medical practice is often altered

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\(^1\) The term “parent” will be used here for convenience, but it is important to note that not all caregivers are parents.
to accommodate the needs and wants of the family. 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 participant claimed that she believed it would be “cruel” to discuss early intervention therapy with a family of a low socio-economic status, although she recommends such treatments to families with adequate financial means. Second, as discussed in the previous section, diagnostic tools are usually only used at the margins, when the paediatrician faces uncertainties in the clinical encounter. However, some participants mentioned that they will also use diagnostic tools if the parent(s) is having difficulties accepting 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.

Third, participants 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 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. (emphasis added)

Fourth, one participant 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.

Fifth, participants indicated they follow an empathetic approach when discussing the diagnosis and treatment options with the patient’s parent(s). A common difficulty faced by the participants in the recommendation of treatments to the family was communication with the parents (see graph 2). Participants expressed an awareness of the stress and anguish involved (for the family) in receiving a diagnosis of ASD, and thus the difficulties that follow from this when explaining to the parent(s) that most of the treatments available are expensive and take place over many years. One participant claimed that “some of these parents are just running themselves ragged” in the process of finding appropriate treatment interventions for their child. Communication with parent(s) was therefore described as difficult due to the participants’ emotional discomfort explaining that the treatment process is arduous, long, and does not guarantee success. One participant stated:
The other main issue that emerged in the parent-paediatrician relationship is the *agency of the parents* in the treatment process. One participant 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 participant 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 participants 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**

Four participants commented on the implications of government funding and how this affected their recommendations of treatments. One participant 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 participant 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 ABA and also recommended the “public ABA program” which provides twenty weeks of free ABA. Furthermore, one participant 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 PBS (Pharmaceutical Benefits Schedule) 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 participant 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 participants’ 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 participant 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.

**Concluding remarks**

This study demonstrates that evidence-based medicine and its instruments are used by paediatricians in the diagnosis and recommendation of treatments for patients with an autism spectrum disorder. However, their use is varied and complex, and is affected by
factors such as the paediatrician’s experience, the tacit and experiential nature of diagnosing and treating ASDs, the uncertainties inherent to the disorder of autism, and the influences of political and social forces in the clinical encounter.

Discussions about the use of experience versus EBM and its instruments were referred to in matter-of-fact terms, with some participants explicitly stating that this was the only way to practice in the field of developmental paediatrics because it is such an “airy fairy” field. Tool “tinkering” was a common practice amongst the participants to reconcile the tension between using the evidence and the difficulty of applying it in the clinical encounter. This seems to suggest that paediatricians practicing in this field are socialised to accept the scientific limitations of developmental paediatrics.

Thus, the use of EBM in the diagnosis and treatment of ASDs is selective: the participants in this study suggest that they use it when they see a need for it (for example, to address uncertainty in diagnosis or to help explain the diagnosis to the family). This study highlights that EBM’s functionality in the diagnosis and treatment of ASDs lies at the margins of the clinical encounter. This is a particularly interesting finding because it contradicts the fundamental meaning and purpose of EBM. EBM is based on statistical or probability science, in that it identifies
optimal treatment approaches to, and common risk factors for, various conditions. Thus, EBM indicates approaches the physician should take based on the *typical* patient. However, this study shows that experiential and tacit knowledge tends to be used when a patient presents with obvious or typical ASD symptoms, and that EBM is used when dealing with outlier cases and ambiguities in the clinical encounter. Thus, a paradox exists when it comes to using EBM in clinical encounter with the ASD patient: the probability data of EBM is applied to the improbable cases. This finding will be discussed in more detail in Chapter Five.

In terms of the diagnosis of ASDs, there appears to be much variability in the steps used in the diagnostic process as well as the diagnostic tools used. It does not appear that the tools and guidelines developed to aid in the diagnosis of ASDs are having a regularising or standardising effect. This could be due to the many factors affecting the motivations of the clinician in the clinical (diagnostic) encounter (see diagram 1 below).
Diagram 1: The reality of the use of EBM and its instruments in the (diagnostic) clinical encounter: Factors that affect the negotiation between experience and the evidence.

**Social Factors**
- Use of tools to help the family understand/accept the diagnosis – clinician being sensitive to the family’s needs
- Tools used based on financial means of family, i.e. ADOS cannot be used in many instances due to the expense
- Belief that clinical experience overrides the use of tools
- Use of evidence a “personal thing”, dependent on socialisation in education/training

**Functional Factors**
- Tools do not distinguish between comorbid disorders e.g. anxiety and ADHD
- Semantics/wordiness of DSM-IV make it difficult to apply
- Categories in DSM-IV difficult to apply in the clinical encounter (e.g. PDD(NOS) and Asperger’s)

**Evidence-based medicine, clinical guidelines & tools**

**Clinical Factors**
- Used of tools to confirm clinical judgement
- Sometimes tools help to resolve uncertainty about diagnosis
- Evidence as a default when clinical experience cannot provide the answer
- Tools are utilised on the diagnostic margins

In terms of recommending treatments for patients with an ASD, there appeared to be consensus amongst participants both in the treatments recommended and the difficulties experienced in the process of recommending treatments. This is an interesting result when one considers the varying motivations affecting the clinician in the clinical encounter (see diagram 2, below).
Diagnosis 2: The reality of the use of EBM in the recommendation of treatments in the clinical encounter: Factors that affect the negotiation between experience and the evidence.

**Clinical Factors**
- Clinical judgement or experience important in decisions about treatments: “I use what I think works”
- More experienced clinicians tend to prescribe medications – Educational/training differences?

**Social Factors**
- Agency of parents in the clinical encounter
- Sympathy expressed by the clinician regarding the family’s plight
- Using/not using EBM seen as a “personal thing” or “generational thing”
- Cost of treatments
- Bureaucratic bodies creating treatment ‘norms’ – i.e. prescribing a drug/therapy because family receives compensation for it, not because it is the ‘best’ drug/therapy
- Use of EBM based on differing educational/training experiences

**Functional Factors**
- “gold standard” of EBM does not apply to ASDs
- Lack of “good” evidence
- EBM oversimplifies the treatment of ASDs

The overwhelming theme of these interviews is the profound effect the social world has on the medical world. The doctor is not only negotiating a relationship between clinical experience and the evidence, but is also affected by social and political factors. These factors include the values and norms established in their education and training, the families’ financial constraints, being sympathetic to the families’ acceptance and understanding of the diagnosis, and the involvement of bureaucratic bodies within medicine and the effects this has on the treatment process.
I think [EBM] is a complete hoax personally...trials are done on such specific, clean questions but they never quite apply to the patient in front of you...I think that is the problem with practice at my level – it is very individual. That is why I don’t agree with EBM: there isn’t any evidence to help you deal with the difficult patient. (Dawson et al 1998: 21)

**Existing literature**

The above quote from a doctor interviewed in Dawson and colleagues’ (1998) study captures the quandary facing paediatricians in the clinical encounter with the ASD patient. In the diagnosis and treatment of ASDs, every patient is a “difficult patient.” ASDs are heterogeneous, there is no biological marker or test to aid diagnosis, and there is a lack of RCTs supporting diagnostic techniques and the effectiveness of treatment interventions. Consequently, it is difficult to *produce* “clean” and “specific” research questions, and then *apply* the research in the clinical encounter. While the medical literature acknowledges these difficulties, the medical profession continues to advocate the application of EBM and its instruments to the diagnosis and treatment of ASDs. As demonstrated by this study, the process of applying EBM and its instruments to this heterogeneous disorder is a negotiated and complex process; full of tensions, paradoxes and ambiguities.
The findings of this study contribute to a socially nuanced view of Foucault’s medical “gaze”. The medical “gaze” of the participants interviewed for this study is made up of a complex interaction and negotiation between clinical experience, EBM, tacit evaluation, and social motivations affecting the clinical encounter. Whilst epidemiology is portrayed as the new paradigm that has engulfed medical epistemology, the reality of medical practice within developmental paediatrics, as indicated by the participants in this study, is that the clinician determines the direction of the clinical encounter through the interplay of various factors. Ultimately the path taken will coalesce with their “professional trajectories” (Timmermans & Berg 2003), and will involve “tinkering” with the tools to make them work in practice.

The participants do not follow the epidemiological paradigm by trying to force the square peg of ASDs into the round hole of EBM. They fashion a hole themselves, slowly shaping it over many consultations with the patient (taking months, even years, if need be) until the peg fits, or until the doctor has exhausted all of their resources. An example of this shaping process includes “tinkering” with the tools and evidence. During this process, EBM and its instruments are often used, but they are used in a way that coalesces with the paediatrician’s motivations. These motivations include social factors such as educational norms, and clinical uncertainties such as the inability to distinguish between an ASD and
ADHD (comorbidity). This notion of the social nature of medical practice is supported by the empirical literature discussed in Chapter Two.

This socially nuanced picture of the clinical encounter with the ASD patient is made more complex by the role of the patient’s family. Several participants discussed the agency of the parents during the clinical encounter, as well as in their pursuit of treatments for their child. For example, several participants commented that as a paediatrician recommending treatments for ASDs to families, ultimately their role was to act as a “facilitator”. They explain the options, describe and evaluate the evidence, make recommendations; but in the end, the parent makes the decision as to whether the evidence is applicable to their child. Furthermore, many of the participants indicated that the parents are often the deciding factor as to whether they will use a diagnostic tool or not. These results are consistent with Timmermans and Berg’s (2003) findings regarding the agency of the patient in the clinical encounter (see Chapter Two).

This study also explored the participants’ clinical experience as a factor affecting the use of EBM and its instruments in the clinical encounter. The literature highlights that one of the objectives of introducing EBM into the hospital environment, and medical practice more generally, was
to ‘level the playing field’ between the attending and the resident, or the more experienced doctor and less experienced doctor. Thus, physicians are increasingly expected to base medical decisions on the evidence, rather than experience or authority (Timmermans & Berg 2003).

However, this study and Timmermans and Angell’s (2001) study (see Chapter Two), highlight that EBM does not appear to ‘level the playing field’ in practice. In this study, most participants indicated the necessity of the use of a “gut feeling” to aid them in the diagnosis of ASDs: “because ASD is such a clinical diagnosis”. Furthermore, they emphasised that while they take the evidence into account, clinical judgement or experience has the ‘final word’ in clinical decision-making.

This study also found that the use of diagnostic tools occurs at the margins of the clinical encounter. This finding is particularly interesting for two reasons. First, it illuminates a paradox that exists in the diagnostic practices of the participants interviewed for this study. Data based on typical ASD cases (EBM) is applied to the ambiguous and difficult to classify cases. Second, this paradoxical use of EBM is yet to be discussed in the literature. This finding will be discussed in the following section as an important impact of this study.
The impact of this study

This study demonstrates that the focus of existing research neither captures nor reflects the complexities, subtleties and uncertainties of diagnosing and treating ASDs in the clinical encounter. The sociological literature’s silence on the role of EBM in the diagnosis and treatment of ASDs is surprising and significant given the medical uncertainty surrounding these disorders: ASDs provide an ideal framework through which to explore the limitations of EBM. This study demonstrates that the use of EBM in the diagnosis and treatment of ASDs is affected by four key factors: experience and education, the tacit nature of the clinical encounter, tool “tinkering,” and social and political factors. While sociological investigations of medical practice have examined these factors, they are yet to be understood in relation to Australian paediatrics and ASDs.

However, the paradoxical nature of the use of tools in the clinical encounter has not been explored in any of the literature to date. This study, therefore, illuminates a function of EBM that has previously gone unrecognised, and consequently, raises some important questions that warrant further investigation. Two questions that I will address in this section relate to why this paradox exists when diagnosing ASDs, and how this paradox could be applicable to other areas of medicine.
As discussed throughout this thesis, diagnosing and treating ASDs within a medical context is a difficult and complex process. This study demonstrates that experiential knowledge is usually the primary resource paediatricians draw on to diagnose a patient with an ASD. Participants indicated that they use a “gut feeling” to form an initial hypothesis about whether the child has an ASD or not. In many cases, this initial hypothesis, based on experiential knowledge, is enough to form a diagnosis. However, it is when the participant is unable to form a certain hypothesis that they seek out other resources to alleviate their uncertainty. The use of diagnostic tools, therefore, appears to be motivated by a need to provide a definitive diagnosis. The parent comes in with a question: “does my child have an ASD,” and the paediatrician is expected to provide and explain this answer. Thus, diagnostic tools are used at the margins of the clinical encounter to perhaps provide the definitive diagnosis that the paediatrician is unable to offer the parents using just their experiential knowledge. Furthermore, the diagnostic tools provide a justification for this diagnosis, and as one participant stated: “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.” Deferring to the tool in difficult or complex cases perhaps highlights the medical profession’s attitude to EBM: it allows health care workers to sort things out when they are difficult to sort out; it provides a way to proceed when all other ways have been barricaded. However, as
discussed above, EBM’s claimed functionality lies with the majority of medical cases, not the minority.

Thus, understanding *whether* and *how* this paradoxical use of EBM exists in other medical contexts is important. While it may only be relevant in the context of this study, that is the diagnosis of ASDs by paediatricians in private practice, it may have implications for other heterogeneous disorders, such as ADHD and chronic fatigue syndrome. Physicians diagnosing and treating these disorders probably share the same difficulties in applying EBM in the clinical encounter that the participants in this study discussed. Furthermore, this finding could also have implications for medical practice in general. “Difficult” (that is, difficult to classify or diagnose) patients are encountered by medical practitioners on a daily basis. These patients also seek to be “sorted out” with a diagnostic categorisation. It remains to be investigated whether doctors in *other fields* are deferring to tools at the margins of the clinical encounter.

**Future directions of research**

As illustrated in Chapter Three, some important limitations exist in the interview format. It has been suggested in the literature that interviewing “elites” (Sarantakos 2005) can be problematic as they can be guarded in their responses due to a mistrust in how their responses may be used.
Furthermore, as interview data is self-report data, one cannot guarantee the truthfulness or accuracy of responses. A problem that may be particularly relevant in regards to the context of this study is the ‘social standards’ bias, whereby participants provide answers that may have been adjusted to conform to social standards. For example, a study conducted by Hunter (1991) (as cited by McDonald et al 2006) suggests that doctors practice according to an unwritten code that holds that if their practice is closely governed by guidelines or tools they are no longer regarded as doctors. However, it is important to keep in mind this study was conducted 18 years ago, and thus its applicability to this study is questionable. Yet the point remains that medicine is made up of socially motivated beings, and thus the truthfulness of their answers is a factor to consider. Furthermore, it is suspected that due to the time constraints of the interview (thirty minutes), participants were unable to discuss in much detail the steps and processes used in medical practice to diagnose and recommend treatments for patients with an ASD. This means that some of the data could be incomplete, in so far as it does not cover the true complexity and detail of the clinical encounter and the clinical process.

An adequate way to overcome such critiques would be to actually observe the participants in the clinical encounter, or medical practice more generally; as well as interview the participants. This technique was
also identified by Timmermans and Angell (2001), in their study of paediatric residents, to be the most favourable in this form of research. Both Fortin (2008) and Hunter and colleagues (2008) conducted ethnographic research in paediatric settings, illustrating the feasibility of this approach. Thus, using an ethnographic approach to address the issues examined in this study would provide more detailed, and therefore more accurate, data.

In regards to the findings of this study, several areas warrant further investigation. First, the tacit and experiential nature of the clinical encounter is difficult to explore in an interview format. This study provides the groundwork for exploring these factors more fully. Due to the tacit and subtle nature of the clinical encounter, the most appropriate methodological approach involves ethnographic research. Second, the role of experience and education in determining diagnostic and treatment practices with regards to ASDs needs to be investigated using a larger sample size. This warrants investigation not only due to the paradigm shift from pathophysiology to epidemiology within medicine, but also because ASDs are a relatively new category in the DSM. Some of the more experienced paediatricians interviewed for this study indicated that their education did not involve learning about ASDs and that they have had to “make it up as we go along.” Third, this study investigated the social and political forces affecting the decision-making of paediatricians.
involved in the diagnosis and treatment of ASDs. Two are discussed in
detail, however, it is probable that there are many more affecting clinical
judgement, such as the role of industry and medical administrative
bodies. Fourth, the paradoxical use of EBM in the clinical encounter
requires further investigation. This practice of applying probability data
to outlier cases has not yet been examined in the literature. Future studies
need to examine why this trend exists, whether it extends into other
medical fields, and whether it is unique to certain medical conditions or
disorders.

Another research question raised by this study involves the investigation
into the motivations of the ASD tool and guideline creators. Berg’s
(1998) examination of the socially and politically-charged nature of the
process of creating tools and guidelines, as discussed in Chapter One,
could provide further insight into the ASD diagnostic and treatment
process, as well as the medical management of heterogeneous disorders
more generally.

It is evident that there are many directions future research can take in the
sociological investigation of the medical management of ASDs. This
thesis draws on extensive empirical work examining EBM in medical
practice, but provides the first glimpse of how EBM is used in practice
when applied to ASDs. It has contributed to the sociological EBM
literature by analysing the key factors that influence and affect the clinical encounter with the ASD patient. This study not only fills a void in sociological understandings of ASDs, but also provides useful insights for the medical literature and the caregivers and families of children on the autism spectrum.
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APPENDICIES

Appendix I – Interview Questions

(1) How long have you been practicing as a paediatrician?

(2) Diagnosis

(a) What steps are involved, for you as a paediatrician, when diagnosing a two year-old child with Autism Spectrum Disorder (ASD)?

(b) What steps are involved, for you as a paediatrician, when diagnosing a three year-old child with Autism Spectrum Disorder (ASD)?

(c) What steps are involved, for you as a paediatrician, when diagnosing a four year-old child (or older) with Autism Spectrum Disorder (ASD)?

(d) In your experience, have you encountered any problems with the clinical guidelines or standardised tools that are used to diagnose ASD?

(e) There are a variety of diagnostic tools/guidelines that paediatricians are able to use in the diagnosis of ASD (for example, I know of the ADOS, CARS, GARS).
   (i) Could you estimate how many guidelines and tools are available to you as a paediatrician when diagnosing ASD.
   (ii) Do you believe one of the diagnostic tools is more effective/rigorous/accurate etc. than the others? If yes, why?

(3) Treatment

(a) What steps are involved, for you as a paediatrician, when recommending treatment(s) for a child diagnosed with ASD?

(b) Have you experienced any difficulties when trying to recommend treatments for a child diagnosed with ASD?
(4) Evidence-Based Medicine (EBM)

(a) Please define the term ‘evidence-based medicine’

(b) Did your education and training in Paediatrics involve learning about EBM?

(c) Do you conduct (EBM) literature searches to aid you in the diagnosis of ASD?

(d) Do you conduct (EBM) literature searches to aid you in the recommendation of treatments for patients diagnosed with ASD?

(e) If you do not use EBM, why not?

(f) Do you feel your autonomy as a doctor is threatened by EBM, clinical practice guidelines (CPGs), or tools?

(g) How important do you think EBM, CPGs and standardised tools are in the field of paediatrics in Australia?