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The autism diagnostic encounter in action

Using video reflexive ethnography to explore the assessment of autism in the clinical trial

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Declaration

This is to certify that to the best of my knowledge, the content of this thesis is my own work. This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Brydan Sarah Lenne, June 2018

Abstract

Despite the increasing visibility of autism, this disorder has resisted a consistent and stable diagnostic definition, treatment approaches, and biomedical and genetic attempts to make sense of how it manifests within the body. That this confusion remains despite the enormous biosocial productivity of the category indicates that there is likely a unique set of circumstances, an "epistemic murk" (Eyal et al 2014), in which autism exists, and perhaps thrives.

Given there is limited understanding of how clinicians diagnose ASD in practice, especially within the diagnostic encounter of the clinical trial, this thesis focuses on the contention and "epistemic murk" that surrounds autism as the object of the clinical trial and the paradoxical attempts by medicine and the psy-sciences to codify, standardise and quantify this heterogeneous disorder. Using a video-reflexive ethnographic (VRE) approach, I observed and videoed 22 diagnostic sessions with parents and children over two years as part of a randomised double blind placebo-controlled drug trial in a children's hospital in New South Wales, Australia. Edited clips from these videos were later played back to the clinician in reflexive one-on-one feedback sessions with the researcher, allowing the collaborative analysis of complex diagnostic data.

This video data provides a rich, negotiated, embodied and socially nuanced picture of the autism diagnostic encounter in action within the clinical trial. In this context, autism is no longer perceived solely as a set of observable behaviours, but rather a disorder that is firmly located within the brain and its processes. ASD medication, the disorder itself, and the individual ASD brain cannot be properly conceptualised without each other, with each element feeding into a classificatory loop. This data also demonstrates how participants must constantly negotiate between the inherently qualitative nature of the diagnosis in practice and the standardised agenda of the clinical trial, which views disorder as a quantitative deviation from a statistical norm. The thesis argues that during the diagnosis, the clinician must filter, categorise and quantify this complex, inter-subjective, experiential knowledge to fit with what counts as measurable evidence. However, it is behind the scenes that the real labour of the clinical trial occurs. This labour generates data through participants' value-orientation, their experiences, stories, and corporeal translation of knowledge. This diagnostic work is above all complex, value-laden and qualitative.

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ACRONYMNS USED IN THIS THESIS

ABA	Applied Behavioural Analysis
ABC	Aberrant Behavior Checklist
ACC	Agenesis Corpus Callosum
ADHD	Attention Deficit Hyperactivity Disorder
ADI-R	Autism Diagnostic Interview—Revised
ADOS	Autism Diagnostic Observation Schedule
AS	Asperger's Syndrome
ASD	Autism spectrum disorder
ASPECT	Autism Spectrum Australia
CAN	Cure Autism Now
CARS	Childhood Autism Rating Scale
CDD	Childhood Disintegrative Disorder
DD	Developmental Disability
DSM	Diagnostic and Statistical Manual
DSM-III	Diagnostic and Statistical Manual (3rd Edition)
DSM-III-R	Diagnostic and Statistical Manual (3rd Edition, revised)
DSM-IV	Diagnostic and Statistical Manual (4th Edition)
DSM-IV-TR	Diagnostic and Statistical Manual (4th Edition, text revised)
DSM 5	Diagnostic and Statistical Manual (5th Edition)
EBM	Evidence-based medicine
GP	General Practitioner
ICD-10	International Classification of Diseases (10th Revision)
IQ	Intelligence Quotient
NHMRC	National Health and Medical Research Council
NSAC	National Society for Autistic Children
PDD	Pervasive developmental disorder
PDD-NOS	Pervasive developmental disorder – not otherwise specified
RCTs	Randomised controlled trials
SPD	Semantic pragmatic disorder

SSRIs	Selective Serotonin Reuptake Inhibitors
WHO	World Health Organisation
WISC-IV	Weschler Intelligence Scale for Children (4th Edition)

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INTRODUCTION

Autism spectrum disorder as a "moving target"

(Kenyon 2011)

It is 3pm and I am halfway through my ABA [Applied Behavioural Analysis] session with Rowan [pseudonym], a four year old boy diagnosed with autism spectrum disorder (ASD). I am sitting on the floor in a room with toys, a table and chairs, puzzle pieces and toys strewn about, and Rowan having a meltdown on the floor next to me. Rowan is considered "non-verbal" and has quite severe tantrums and inflexibilities. But in the year that I have worked with him I have come to know him by his joy when he is around his brothers and the family dog, his huge grin, his excitement when he watches or plays with Thomas the Tank Engine, and his love of rough and tumble play with his family.

This is Rowan's second ABA session for the day: six days a week he has two three-hour ABA sessions per day. Today's session got off to a rocky start. Even before our session, during lunchtime, Rowan's mum – Eve – accidentally tripped over his perfectly lined up Thomas the Tank Engine and train-themed line of toys that stretched from one end of the house to the other (much like the image above). It took him a day to construct it. Each item in the line had been perfectly placed in a certain order and orientation that made complete sense to him, but no one else. By tripping on the toys, Eve had disrupted the carefully constructed line and sent many of the toys flying across the floor. The meltdown that ensued went for over half an hour: screaming, biting (his own hand), and tears.*

By the time I arrived at their house he had calmed somewhat, but I knew to adjust my expectations for the session ahead. Today we are working on his speech (although considered "non-verbal", we are helping Rowan develop some sounds and functional words, like "more", "open", "up"), receptive language (like recognising and pointing to colours and objects from pictures in a children's book) and some gross motor activities (such as jumping, balancing, throwing a ball). As a break between activities, Rowan selects some toys from my ABA toy bag – a Thomas the Tank Engine puzzle and some trains – and begins lining them up along the floor. I sit with him, intending to complete the puzzle with him and to practice working on turn taking.

This does not go down well: at my request to place the puzzle pieces into the puzzle frame, Rowan flings and kicks the puzzle pieces and toys in frustration, and spends the following 10 minutes in meltdown. I wait patiently for him to calm, letting him know I am there ready to play when he is ready. I talk quietly about the puzzle and how I would love his help, as it is very tricky. Eventually, Rowan begins watching what I am doing and slowly makes his way over to my side, and then calmly begins slotting-in pieces of the puzzle.

At the end of our session we go downstairs to chat with Rowan's Mum. I often carry Rowan down the stairs at the end of our sessions and play a game where we jauntily go down a few stairs, then back up a couple of stairs backwards, then down again and up, pairing each movement with the appropriate word "up" or "down". This often provokes a fit of giggles. On this occasion, we are standing nearly at the bottom of the stairs and Rowan is still in my arms. Our session finished on a good note and I am telling Eve how well he did and how well he recovered from his meltdown. As we are standing there, Rowan excitedly wriggles in my arms and exclaims suddenly and clearly, "Up, up". We both stand looking at each other, mouths open in shock, and Rowan's mother breaks out into an enormous grin as her eyes well with tears. This is Rowan's first word.

Introduction

The passage above describes one of my most memorable moments working with a child with autism in my six years as an ABA therapist. Rowan was the first child I got to know on the spectrum, and I was lucky enough to get to know seven other children with autism and their wonderful families. It was through working with these eight very unique children that I began to appreciate and understand the famous saying in the autism community often attributed to Doctor Stephen Shore: **"***If you've met one person with autism, you've met one person with autism***".**

I have shared this recollection to draw attention to two important aspects of autism that will feature prominently in this thesis. The first is what clinicians would call Rowan's "restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association 2013), that is, lining up Thomas the Tank Engine trains and other train-related toys. For clinicians, the way Rowan lines up toys is "problematic" because he does this in a repetitive, restricted, excessively circumscribed and ritualistic way, and shows extreme distress when asked to change or move these toys. As I have stressed above, Rowan's restricted and repetitive activities are unique to Rowan, and for other individuals diagnosed with autism, these activities may be similar, or they may be vastly different. It is these behaviours that this thesis will focus on, particularly in the context of the diagnostic gaze and the way they are standardised, quantified and coded. The second aspect of autism that this memory addresses is what I will refer to later in the thesis as "competence". The significance of Rowan's first word – "up" – is two-fold. Not only has he clearly communicated an intention beyond clinical expectations of him, but he has done so outside of the confines of the standardised and prescribed ABA therapy session. This is an important theme in this thesis: understanding the competence, strengths and abilities of children on the autism spectrum outside of the confines of prescribed medical and psychological norms of the standardised clinical encounter.

The ambiguity of autism spectrum disorder and its diagnosis

In the eleven years that I have been working with children with autism and/or researching autism, I have witnessed increased visibility and major shifts in the way that autism is studied, funded, talked about, portrayed in the media, diagnosed and treated. The focus of this thesis is the way in which autism has been redefined, tweaked and tinkered with since being coined as a diagnostic concept in 1943 by Leo Kanner. This process is crucially influenced by medicine and the psy-sciences' drive to standardise, quantify and categorise. This is in spite of the heterogeneous nature of autism spectrum disorder: autisms' causes, age of onset, symptoms, comorbidity with other disorders (such as attention deficit hyperactivity disorder (ADHD) or anxiety), and patients' responses to treatment differ from individual to individual. For diagnostic practices, this translates to clinicians relying on interpretive work to reach a diagnostic decision. This involves observing the child's behaviour directly, speaking with parents about their child, and/or using standardised diagnostic tools (such as the Autism Diagnostic Interview-Revised (ADI-R) or the Autism Diagnostic Observation Schedule (ADOS)). The information is then matched to the diagnostic criteria stipulated in the DSM 5. Thus, diagnosing and treating autism is carried out at an individual, case-by-case level and heavily relies on the clinician's observation of the individual's behaviour and speech (Silove, Blackmore, Warren, Gibbs, and Roberts 2008).

This sheer variability makes autism particularly difficult to test under the epidemiological paradigm, particularly using the gold standard of randomised controlled trials (RCTs). Yet, it seems that this ambiguous and elusive status of autism in fact fuels scientists' and researchers' efforts to represent it categorically and concretely in the biomedical sciences and diagnostic documents. In her book *Constructing Autism*, Majia Nadesan (2005) explains this medical drive for discovery of the "truth" about what autism is:

> Although present-day researchers represent autism as a continuum or as several continua of communicative and cognitive impairments, and pay lip service to the idea these impairments may stem from different etiologies, autism continues to be implicitly and explicitly theorized as a definitive entity whose origins can be found in faulty, neurological impairments (e.g., of the amygdale), or impaired biochemistry. The implicit but dominant model seems to be that there is a visual-spatial-topological autistic center that will ultimately be discovered. This view of autism implicitly invokes a model of medicine in which disease is ontological, *a thing in itself*, which can be distinguished from the afflicted patient whose ontological status is unrelated to the disabling disorder. (Nadesan 2005: 20)

This thesis is concerned with teasing out and distinguishing between this medical model that views autism as ontological in nature, and the conception of autism as a nominal

category – subject to a vast array of social, political and cultural factors. As Nadesan (2005) explains:

> Perhaps it is the case that the etiology of autism lies in a multitude of mutually entwined biological and cultural/social factors, including the very standards of normality used in the determination of the disorder. Put another way, perhaps autism is not a *thing* but is a nominal category useful for grouping heterogeneous people all sharing communication practices deviating significantly from the expectations of normalcy. These communication practices are becoming, increasingly, standardized, codified, and widely distributed. (Nadesan 2005: 9)

Of particular interest is the way that clinicians reconcile these two perspectives in the diagnostic encounter, and how they must juggle this epistemological struggle. This is significant too in the context of applying standardised assessment tools in the autism diagnostic encounter. As Nadesan (2005) suggests in the quote above, the key identifying autism "symptoms" are becoming increasingly quantified and standardised, with this approach growing in popularity amongst practicing clinicians. For example, in a recent survey of Australian clinicians (paediatricians, psychiatrists, psychologists, and speech therapists) involved in the diagnosis and treatment of autism, 82% of respondents reported that they either frequently or always administer standardised assessments in diagnostic evaluations for ASD (Taylor et al 2016). A key aim of this thesis is to understand how these tools are operationalised in practice in the clinical encounter, especially given that in this same survey, 48% of respondents indicated that they have made provisional diagnoses (these are made when ASD is suspected but not confirmed) and 17% indicated they have diagnosed ASD when an individual does not meet criteria for the disorder (called diagnostic "upgrading") (Taylor et al 2016). As John Ellard (1992) points out, applying standards and classifications within the psy-sciences comes with a set of assumptions about how these documents operate and the nature of the disorder being diagnosed, and how these standards do not match up with the reality of practice:

> The first error is to believe that the phenomena of every field of study can be laid out in a matrix, like the periodic table of elements. Many of the things which interest social and psychological scientists are not readily collapsible into neat entities, ready for categorisation. ... The act of observation is likely, or certain, to alter what is being observed, which means that different observers attending to the same phenomena may come away with different data, quite legitimately. If these and other more subtle problems are to be found in the hard world of physics, how can we assume that we have been presented with an orderable world? (Ellard 1992: 547)

> A further error is to believe that a diagnostic classification, through intuition, successive reviews, logic or the invention of new machines will slowly advance towards and finally achieve an unquestionable truth...Look about you and ask which other branch of science has achieved this happy state, or is about to do so, and yet the pursuit continues. It is a fallacy which has been with us for thousands of years and yet its attractiveness has never diminished. (Ellard 1992: 548)

Given this ambiguity around the classification and diagnosis of autism, prevalence studies similarly and unsurprisingly reflect this uncertainty. For example, finding consensus on current prevalence of ASD in Australia is subject to debate: the Australian Medical Association (AMA) states on their website that currently, "there is no reliable data on the prevalence of ASD in Australia". Over the past decade, study after study has whittled prevalence rates down further and further. Internationally, estimates range from one in 100 children affected by ASD in the UK (Brugha et al 2011), one in 68 children in the US according to the Centers for Disease Control and Prevention (Christensen et al 2016), and the astonishingly high rate of one in 38 children in a South Korean study (Kim et al 2011). The more conservative UK estimate is often cited in Australia, and based on data from the Australian Bureau of Statistics (ABS) this equates to approximately 230,000 children in Australia meeting diagnostic criteria for ASD. Currently, the most widely recognised and quoted estimate in Australia is around one individual with autism in every 100 people (1% of the population). This "increase" in diagnostic rates of autism has led many researchers and educators to refer to an "autism epidemic". To unpack this notion of an autism epidemic in Australia, however, we need to take a closer look at autism in the clinical setting, and autism in a research or clinical trial context.

Autism in the clinic

My introduction to the world of autism was in a clinical setting, and thus, this thesis has been motivated by two important factors: my clinical work as an ABA therapist with children on the autism spectrum; and a pilot study for this thesis (see Lenne & Waldby 2011) exploring diagnostic and treatment practices of Australian developmental paediatricians in the clinic.

My work as an ABA therapist threw me into the world of autism as an undergraduate psychology student wanting to learn more about the practice of child psychology. Through this clinical work, I became aware of the extreme highs and lows experienced by a child with autism and their family, as outlined in my interaction with Rowan and his mother Eve at the beginning of this chapter. I also learnt about the highly stressful and confusing nature of the autism diagnostic session, and how this process could be a relief to one family, devastating to another, and completely avoided by others. Parents often spoke of it as a baffling experience, and also gave me highly varied accounts of the approaches used by the paediatricians to reach the diagnostic label. This experience as an ABA therapist has placed me in a unique position as a social researcher who is interested in exploring the diagnostic clinical encounter and the people involved in this session: the clinician, the child and the parent.

My clinical work provided me with six years' experience working with families and their children with autism, and the clinicians involved in the diagnosis and treatment of this

disorder. I worked alongside clinicians to develop strategies and techniques to help the child and parent perform everyday activities and learn from their environment and peers. I then implemented these strategies and techniques in one-on-one and group settings (in the family home, preschools, schools and social settings) with the child on the autism spectrum for many hours each week. I worked closely with the parent to communicate the child's progress and incorporated their ideas into the child's program. This experience has given me invaluable insight into problems faced by each of these groups, pressing research questions that need to be explored, and perhaps most importantly, sensitivity and understanding when undertaking research with these groups.

The pilot study, in which nine private practice paediatricians were interviewed about their experiences diagnosing and providing treatment plans for children with an autism spectrum disorder (Lenne & Waldby, 2011), raised many questions about how clinicians manage clinical uncertainty, and how they use diagnostic tools in practice when confronted with different cases. The pilot study examined the complexities and messiness facing clinicians who diagnose and provide treatment plans for children on the autism spectrum. The paediatricians interviewed for the study worked in private practices across Sydney, Australia and saw a wide cross-section of the community. These initial interviews provided me with important insights into the various clinical approaches to the diagnosis of autism and the role EBM and standardised diagnostic tools play in the clinical encounter. Three key findings emerged from these discussions:

(1) The tacit and experiential nature of diagnosing and treating ASDs;
(2) The skilful and creative interaction between the paediatrician and the diagnostic tools (tool "tinkering"); and
(3) The paradoxical way in which the paediatricians use diagnostic tools: Paediatricians use these tools (which are based on statistical/probability data) when dealing with an outlier patient, that is, one that is difficult to categorise (such as children with a suspected co-morbid disorder, like anxiety or ADHD) (Lenne & Waldby, 2011).

Autism in the clinical trial

On the flip side, I would like to turn the focus of this thesis towards the field of clinical research, and more specifically the randomised controlled clinical trial (RCT). The uncertainty and ambiguity experienced in diagnosing and treating autism in clinical practice has its foundations in the way that research, evidence, standards and guidelines – that is, evidence-based medicine (EBM) – are created and disseminated in the fields of medicine and the psy-sciences. Dealing with an abstract concept such as autism, which has no known single, identifiable biological cause, marker or descriptor of its core symptoms, makes this

disorder incredibly difficult to fit into RCT and EBM paradigm. As Laura Schreibman (2005) points out:

> The field of autism is littered with the debris of dead ends, crushed hopes, ineffective treatments and false starts. This has been frustrating and discouraging for everyone, including parents and professionals…The field is susceptible to all sorts of false beliefs, snake-oil treatments, and potential "cures" because we are dealing with a devastating disorder for which we have few answers to date. Ignorance provides a vacuum that sucks in all kinds of ideas – some right, some irrelevant, some dead wrong, and some even harmful. (Schreibman 2005: 7)

Understanding the challenges involved in the production of EBM in the field of autism research is thus a fascinating area of inquiry. Interestingly, the direction of my research and focus on the clinical trial for this thesis was shaped by the recruitment process: a paediatrician that was engaged in my original round of recruitment of private practice clinicians invited me to embed my study within a larger RCT he was overseeing at an Australian metropolitan children's hospital which was testing the use of a drug to treat children diagnosed with ASD (the diagnostic sessions were conducted as part of the trial). So what initially began as a focused study of the private practice clinic and ASD diagnostic practices, developed into a study of the ASD diagnostic practices embedded in a clinical trial in a public hospital and the associated practices that take place within a clinical trial involving children with an ASD.[1]

The clinical trial studied for this thesis is described in the protocol as a randomised double blind placebo-controlled trial, funded by the National Health and Medical Research Council (NHMRC) and run by a not-for-profit Australian children's research institute. The trial aims to test the efficacy of the drug Fluoxetine (an antidepressant known as a selective serotonin reuptake inhibitor (SSRI)) in treating targeted symptoms including repetitive behaviours, anxiety, irritability, aggression, and self-injury. In my description of my ABA session with Rowan at the beginning of this chapter, I outline many of the symptoms that the Fluoxetine would target: his repetitive lining up of trains, distress when the line is disrupted, inflexibility in the way that he plays with the trains, and engaging in self-harm through biting his hand.

It is important to clarify here what an RCT is, as it is crucial to understanding the process of this trial, as well as to demonstrate why it is so difficult to force the square peg of autism into the round hole of the RCT or EBM. Lock and Nguyen (2010) explain that the RCT is:

[1] Importantly, given the clinical trial studied for this thesis began its data collection in 2012, the trial protocol is tied to the DSM-IV-TR. However, the timeframe of this thesis (2010-2017) situates the production of knowledge about autism diagnosis at a significant crossroads where the medical and paraprofessions, and the research community, were gearing up for the shift from the DSM-IV-TR to the DSM-5. Thus, this thesis examines the influence and impact of both the DSM-IV-TR and the DSM-5.

> [T]he pinnacle of biomedical research design because, by incorporating technologies of randomization, placebo-control, and blinding, it appeared to be impervious to bias, and the most objective of clinical research methods to date. In RCTs, the intervention to be studied is allocated to one group to which a control group is compared. To eliminate the placebo effect, the control group receives a proxy for the intervention: if it is a drug that is being evaluated, individuals who are controls receive a pill (the placebo) that appears identical to the drug under investigation but contains a biologically inert substance…this is why evidence from RCTs is considered to be the most valid, because the effects produced by therapeutic agents can be rigorously separated from the background "noise" of placebo effects, biased observers and subjects, and chance events. The RCT has become the gold standard for proving that a new drug or intervention is indeed effective. (Lock & Nguyen, 2010: 183)

Bishop, Snyder, Aligna & Leite (2016) also identify that RCTs provide *estimates of average causal effects,* which implies that the intervention/drug etc. works better for some participants than others: "Establishing an average causal effect does not preclude the possibility that the intervention does not affect some participants and may have a negative effect on others" (502). This is particularly difficult when it comes to autism research due to the problems associated with diagnosing this disorder and establishing what "average" is in this heterogeneous population. Further, the absence of biological markers or tests to aid in producing a diagnostic outcome makes it more challenging to carry out empirical investigations using RCTs. 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)

RCTs are difficult to apply to ASD research due to the heavy emphasis placed on direct observation in studies examining both diagnosis and treatment. Thus, attempts to standardise observational practices are essentially ineffective (see Arnold et al., 2000).

This study

Sociological investigations of the subtleties and complexities involved in the diagnostic clinical encounter when dealing with a heterogeneous disorder such as autism are scarce (Rafalovich, 2005). Given the emphasis on observable behaviours as the key indicator of autism during the diagnostic encounter, I argue that for my research to properly capture these subtleties and complexities of diagnosis, a visual ethnographic approach is needed. Accordingly, I have employed a video-reflexive ethnographic (VRE) approach (Iedema, Mesman & Carroll 2013) to study the diagnostic practices of clinicians involved in the diagnosis of autism in the clinical trial setting. In Chapter Three I provide further details on the significance and background of this approach.

This thesis, through the methodology of VRE, allows me to fully embrace the "mess", uncertainty and enigma surrounding autism and its classification and diagnosis. This thesis explores how creative collaborations with clinicians, parents and their children open up new ways of conceptualising and classifying autism, and reveals otherwise tacit practices that are brought forth through the visual and reflexive nature of this methodology.

The aims of this study

(1) To form a more complete, complex and nuanced picture of how evidence-based medicine and standardised tools are used in the ASD diagnostic/assessment process
(2) To understand how clinicians reconcile the uncertainties and ambiguities of autism within the standardised, quantified and codified ambit of the clinical trial
(3) To investigate the potential of video reflexive ethnography (VRE) and video technology to shape and change diagnostic practices

The research questions for this study

(1) To what extent does the drive for standardisation and statistical approaches to clinical medicine influence the ways clinicians diagnose and assess autism spectrum disorder?
(2) How do the individual preferences and opinions of clinicians diagnosing/assessing ASD affect and interact with the process of labelling a child with ASD?
(3) How do clinicians negotiate the problems of standardising the diagnosis of ASD in the clinical trial to ensure that the participants meet the RCT criteria?
(4) Do video reflexive ethnography (VRE) and video technologies have the potential to significantly change what evidence "counts" towards ASD diagnosis and treatment?

CHAPTER ONE

From "The Minus Children"[2] *to Epidemic: A History of Autism Spectrum Disorder (ASD) in Australia*

Introduction: the uncertainty and instability of the diagnostic label

> Mentally defective, mentally retarded, developmentally disabled, dementia praecocissima, childhood schizophrenia, atypical child, symbiotic psychosis, brain damage syndrome, negative elective mute, developmental aphasia, schizophrenic syndrome in childhood, infantile psychosis, semantic pragmatic disorder (SPD), Deficits in Attention and Motor Perception (DAMP), infantile autism, pervasive developmental disorder (PDD), Asperger's Syndrome (AS), pervasive developmental disorder – not otherwise specified (PDD-NOS), childhood disintegrative disorder (CDD), autistic disorder, high functioning autism, low functioning autism, autism spectrum disorder (ASD)....?

The list of diagnostic terms above illustrates the vast array of terms that have been used to describe a set of behaviours that have puzzled researchers and clinicians for nearly a century. Listing these various diagnoses is not an attempt to engage in retroactive diagnosis. However, it does convey that "for contemporaries it was plain that autistic children passed undetected through the custodial sieve and disappeared among residential populations" (Eyal, Hart, Onculer, Oren, and Rossi 2010: 77). What is particularly telling about these diagnostic labels is that they are a product of their time; they reflect the understandings and beliefs about "mental disorders" in that era, and they therefore change as these understandings and beliefs change. As Shirley Ferguson (2012), an Australian child and family psychologist, states: "The history of autism is written in its revisions and redefinitions. DSM 5 is where current thinking is at, DSM 6 will likewise be a totally different document." The question mark at the end of the above list of labels conveys the historically contingent and fluid nature of the formulation of diagnostic criteria. Furthermore, it demonstrates, as Ferguson (2012) points out, the uncertainty surrounding the list of symptoms we identify as representing autism today, and what it will be labelled and what will constitute this label in future diagnostic documents.

This chapter will present an historical analysis of the instability and uncertainty surrounding the labels "mental retardation," "developmental disability" and "autism," and their continuing volatility in the world of genetic science, biomedicine, psychiatry and psychology. While it is important to explore the evidence and key findings of scientists, researchers, and

[2] "*The Age* reporter, John Larkin, stated, 'We called them The Minus Children, not to downgrade them, not to imply they were lesser beings, but because they were behind, in everything from esteem to opportunity'" (Manning 2008).

clinicians that have advanced naturalist conceptions of this disorder, these perspectives will be explored alongside the social forces that have produced and perpetuated the changes and instability in the diagnosis, treatment, and the very conception and definition of this disorder. The associations that are formed between the various interested groups in the field of autism are key to understanding how parents and therapists have become formidable forces, and how the field of medicine, particularly psychiatry, has taken a back seat. This analysis will track how this label has transformed from Leo Kanner's (1943) description of a rare subset of childhood schizophrenia to today's apparent autism epidemic, and from Kanner's very specific criteria to explain the behaviour of a small proportion of children to today's diagnostic mess.

Further, this chapter will explore the fluidity and historical contingency of this cultural category we label as autism today. It will show how and why this label is subject to change, controversy and resistance, thus leading to its constant revision and reconstitution. As Rutter (1978) states:

> [T]he question is not "What is autism?" but rather "To what set of phenomena shall we apply the term *autism*?" There is no point in starting with the word *autism* and then defining it. It is merely a word and like any other word it means just what we want it to mean – no more and no less. In short, the word *autism* is merely a convenient substitute or shorthand term for Kanner's long prose description, and no information is to be gained by analyzing it. (141)

At present, there is no historical examination of how autism diagnosis and treatment evolved within the Australian context. As demonstrated above, this disorder has been labelled variously according to medical/psychiatric knowledge at the time, and perhaps even according to the whims of individual clinicians. This has made the researcher's task a little more complicated, requiring the net to be cast a little further and wider to include research on individuals classed in the categories of "mentally retarded" (mental impairment), "feebleminded" and "developmentally disabled." This chapter draws on a variety of resources to explore this subject, including some first-hand accounts of institutions in Australia during the 1960s and 1970s through interviews with two Australian psychiatrists (Doctor P and Doctor C), an Australian psychologist (Mr A) – all of whom have practised both before and after deinstitutionalisation – and the father of an individual diagnosed with autism in the early 1970s in Sydney, Australia (Mr D)[3].

[3] To conduct these historical interviews, ethics approval was sought from the University of Sydney HREC (Reference: MF/PE, Project No: 2012/2065) and Autism Spectrum Australia (ASPECT) (Reference: 1114). Participants were recruited via ASPECT through an email circular (outlining my study and interest in the history of autism in Australia) sent out by administrative staff. Three clinicians and one parent expressed interest in participating via email directly to me: Doctor P, Doctor C, Mr A and Mr D. All participants were sent participant information statements and consent forms, and interviews were organised to take place at a time and place of their convenience. Interviews lasted approximately 1 hour each and were audio-recorded. The purpose of the historical interviews was to capture the voices of clinicians and parents that had experienced "autism" in a very different historical context. Recruitment proved to be a challenge given the small number of clinicians that had practiced and specialised in "autism" during the 1960s to 1970s, and that most had retired from

It is posited by two US-based authors (see Eyal et al. 2010; Shattuck 2006), two of the most influential observers of autism (Kanner 1948; Rimland 1964) as well as an Australian psychiatrist and psychologist (interview data) that those individuals we now label today as "autistic" were likely institutionalised as "mentally retarded" up until a few decades ago. Indeed, it was not until deinstitutionalisation came about that there was even a need for these specific subsets of diagnoses – the umbrella term of "developmentally disabled" within the institutional setting sufficed. Thus, this chapter will be divided into two major sections which will each explore institutionalisation and deinstitutionalisation in Australia. As Eyal et al (2010) demonstrate, these two historical periods provide crucial insight into how autism spectrum disorder came to be labelled as such and how this diagnostic label snowballed to become the "epidemic" that it is today.

Section 1: Institutionalisation in Australia

Introduction

Historical explorations of education, psychiatry, welfare and childhood in Australia have all but disregarded an examination of developmental disabilities and intellectual disabilities as a part of this inquiry. When mentioned in these historical texts, the very concept of intellectual disability is discussed as natural and fixed, and certainly not an idea or label to be challenged or questioned (see Garton 1988). However, scholars such as Corinne Manning (2008) and David Earl (2011) are beginning to explore the ebbs and flows that this category has experienced within Australia, and also the changing fortunes of those that have been labelled under this umbrella category of intellectual disability. This section will examine, within the Australian context, the institution itself and classification systems within the institution for individuals falling broadly under the label "developmentally disabled" or "mentally defective", as well as explore mentions and cases of autism. An influential framework embraced at this time, particularly within the institution, was the controversial science of eugenics. Many psychiatrists in Australia were enthusiasts of eugenics, and advocated the use of practices aimed at improving the genetic composition of the

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practice. Similarly, recruiting parents of children that had received an "autism" diagnosis during this historical period was challenging for the same reasons. Importantly, these interviews are here to provide insights into the personal experiences of the clinicians and parent who were grappling with what was then considered a very rare condition. The experiences of these interviewees are not intended to be interpreted as the universal experience of these cohorts, but simply provide some personal narratives to interweave throughout the researched historical data presented in this chapter. I recognise, particularly in the case of Mr D's testimony, that the reality of life within institutions for those with disability is a hugely contested space. I also recognise that this thesis has not provided historical testimony from those diagnosed with autism – particular in regards to disability activism and advocacy, and that this is a gap that warrants further investigation. Thus, it is important to acknowledge that while parents and carers may be supportive of new "community villages," given the history of institutionalised care facilities and the relative dominance of parents and carers' voices over those of people with disability themselves, a lot of care needs to be taken in reporting parents' views as a comprehensive account. Thus, the historical interviews presented in this chapter need to be read with this in mind.

population (Carman-Brown and Fox 1996). Thus, they opted for the prevention of disabilities through programs of sterilisation or segregation (that is, institutionalisation).

Early classification: "idiots," "imbeciles" and "the feebleminded"

Children and adults with a developmental or intellectual disability in Australia went largely unnoticed until the *early twentieth century* (Earl 2011). At this time, the British Government's Royal Commission on the Care and Control of the Feebleminded (1904-1908) graded those considered "mentally defective" into three classes: idiots (lowest functioning), imbeciles, and the feebleminded (higher functioning) (Garton 1988). As is the case today, it was the higher-functioning classification that was the most difficult to assess. This presented problems from the point of view of eugenics, because the "feeble-minded" could slip between the diagnostic cracks and thus avoid the scrutiny and gaze of the state. The surveillance of children was therefore a priority, as it was believed that the application of IQ tests within schools would allow the success of eugenic reforms. As Harvey Sutton (1911), Director of the Victorian School Medical Service, declared:

> Normal physical defects and anthropometrics were inadequate for the proper testing of the capabilities of children. They needed more precise forms of intelligence testing ... the extension of surveillance into schools and the extensions of the concept of hereditary deficiency beyond that which is physically apparent. (904)

These three grades of "mental deficiency," and the psychiatric legitimacy associated with them, redefined the conception of the "dangerous classes". As Garton (1988) outlines, this allowed psychiatrists and eugenicists to justify their arguments and ideas within the realm of science and rationality, rather than morality. Thus:

> The older philanthropic categories of 'deserving' and 'undeserving' often meant that those who were thought most dangerous to the social order were ignored or only came within the ambit of state control after they had committed a crime. The 'science' of IQ tests allowed for the determination of the 'dangerous' or 'deficient' classes before they had committed anti-social acts. The replacement of a discourse of 'badness' and 'morality' by one of 'deficiency' and 'illness' favoured the intervention of the state to prevent social problems, rather than having to wait until offences had been committed. Doctors had new power to define which social groups required preventative social intervention. (Garton 1988: 59)

Thus, diagnosis and categorisation acted as a way of seeking out the deviant members of the population and was often carried out in schools by general practitioners (Carman-Brown and Fox 1996). Those classed as "feebleminded" (that is, individuals with mild impairment) would have been taken care of in the home with their family, perhaps even taking up some form of unskilled employment in adulthood or assisting the family with the day to day tasks of maintaining the home. Individuals with more severe impairment, those classed as "idiots" and "imbeciles", were certified by physicians and taken in at institutions (known as lunatic asylums at the time) such as Kew Idiot Asylum (later renamed Kew Cottages), which opened

in 1887 (Earl 2011; Manning 2008). However, these gradations or classifications of deviant members of the population were by no means stable categories with clear-cut boundaries. The particular point that Manning (2008) and Earl's (2011) research makes on this issue, rather, is that rather than the myriad of developmental diagnoses at the clinician's disposal today, psychiatrists at this time were able to categorise patients using a simpler classificatory system that was focused on institutionalisation.[4] Accordingly, the development of classification systems for the intellectually disabled appeared to provide the justification for this institutionalising zeal. Williams' (1996) exploration of the definition and diagnosis of intellectual disability in New South Wales between the late nineteenth century and early twentieth century delves into the social motivations behind this classificatory drive. She highlights that as early as the late nineteenth century the rise of classification systems, spurred on by the "scientific" endeavour in the field of medicine, demonstrated the allure of numbers and the conviction that meticulous measurement could ensure "irrefutable precision" (Williams 1996: 254). With regards to intellectual disability, a rise in state intervention and surveillance, evidenced by the work of constables, magistrates, legal guardians, superintendents and directors of state institutions, led to a greater regulation of childhood and those classed as "feebleminded" during the early twentieth century (Van Krieken 1991; Williams 1996). Thus,

> In the area of intellectual disability or "feeblemindedness", the drive to quantify and classify was at first an intellectual endeavour to understand and therefore control "deviance" and later a response to contain what was seen as incurable. In essence, that which could not be cured could at least be contained. This notion of containment associated with surveillance is evidenced in court proceedings of persons admitted to institutions under *The New South Wales Lunacy Act* of 1878, where under the omniscient legislative and medical gaze, patients were variously charged with offences such as "wandering at large", "Not fit to be at large" and "not under proper care and control". Furthermore, a belief in the incurability of those deemed to be "mentally enfeebled", was to have a profound influence on approaches to management. (Williams 1996: 255)

Australia and the eugenics movement: assessment and surveillance

Psychiatry played a dominant role at this time because it supplied "plausible explanations for a variety of social problems" (Garton 1988: 188). Through the expansion of its treatment facilities and the diversification of its patient populations, psychiatry's gaze and jurisdiction widened. Significant also to this professional dominance in Australia was the wider interest in eugenics, evolution, heredity and social progress:

> A broad range of groups was concerned with the prospects for social progress in Australia, and a number feared the erosion of living standards by the proliferation of the 'unfit' in the

[4] It is important to note that people currently diagnosed with autism today may have been categorised within this context as "mad," or "idiots," and some would not have registered as anything other than "normal." As I emphasise later in this chapter, and thesis, for the category of autism, this relationship of interconnected factors such as experience, classification, management and support is complicated and mutually constitutive.

> community. Science was seen as the way out of many social policy dilemmas, and psychiatry, as the science of mental defect, was a favoured solution. (Garton 1988: 188)

Harvey Sutton, a public figure and Australian professor in medicine during the early twentieth century, was also a strong supporter of the eugenic movement. For Sutton (1911), it was of the utmost importance for experts to decipher who was "hereditarily unfit" and segregate this group so as to "eliminate many undesirables from the community, and diminish the intensity of many social problems" (Sutton 1911: 905):

> One of the principles of eugenics is to eliminate in ideal fashion stocks definitely undesirable. It has been shown that the families of feeble-minded are large, and often mentally defective. Their numbers exceed the average number in the ordinary family, so that our problem increases with each generation. Again, the economical side presents itself, for if you do not help to check their increase you and your children will have to pay for their support. (Sutton 1911: 905)

Similarly, psychiatrists were concerned with separating the curable from the incurable. Furthermore, Garton (1988) notes that the medical classification of "mental defectiveness" allowed social problems to be redefined and reconceptualised by psychiatrists as medical problems. For both eugenicists and psychiatrists at this time, mental capacity as measured by the intelligence quotient (IQ), was considered to be a "fixed potential" and therefore determined their educability. Thus, the psychiatric/eugenic division between the curable (educable) and the incurable (in-educable) defined whether a child would receive medical supervision in special institutions or education in the community (Lewis 1988: 144). The measurement and definition of "mental deficiency" therefore became a priority for researchers, both overseas and in Australia. To this end, in 1905 Binet and Simon developed the first IQ test which they claimed could accurately measure intelligence; classifying individuals that performed below certain scores into varying grades of impairment (Garton 1988: 58).

This overarching eugenic concern also began to manifest itself through increasing government intervention and surveillance of childhood. This was achieved through censuses, as well as testing in schools, baby clinics and child guidance clinics, which served in alerting professionals to the "existence of a group of children who developed at rates far below the expected statistical average" (Earl 2011: 87). These classificatory measures led to a greater interest in the care and placement of the feebleminded, and resulted in the passing of the *Mental Deficiency Act* in Britain in 1913 which "provided for the identification and compulsory detainment of feebleminded citizens" (Earl 2011: 88). This prompted Australian eugenic reformers over the next three decades to campaign for similar legislation to be passed in each of the states, arguing that the hereditarily feebleminded posed a threat to the nation (Garton 2010; McCalman 2009; Thomson 2010; Watts 1994). Despite this pressure from the eugenics movement in Australia, they were unsuccessful in their bid for the compulsory "care" of "mental defectives", largely due to concerns surrounding

sterilisation clauses as well as cost issues. This absence of legislation meant that care of these individuals fell to their families, and this care was *private* and in some respects, *silent*. Because hereditary feeblemindedness was linked to social problems such as prostitution, alcoholism, and juvenile delinquency, mental deficiency became a problem to be dealt with "out of the public eye" (Earl 2011: 88). Such individuals were institutionalised when families were deemed to be unable to cope any longer.

However, the scope of this early surveillance of the intellectually disabled was limited by the enormity of this task, the biggest issue being that consensus could not be reached amongst the experts. According to Williams (1996), this was due to: (1) the contentious nature of taxonomy; (2) the attempt to set up a homogenous classification of mental deficiency; and (3) the inconsistent, ambiguous and confused nature of the classificatory definition and terminology, particularly with regards to "feeblemindedness" (255-6). For example, while some doctors attributed the label of "feeblemindedness" to higher-functioning individuals (that is, a "high grade mental defective"), others applied it generically to all those with an intellectual disability (Williams 1996). Sutton (1911), in an address to the Australasian Medical Congress, also emphasised the perplexing nature of classifying individuals with mental impairment: "In introducing the subject of the classification of the feeble-minded, I do so with some trepidation, seeing that so little agreement exists even among the expert and experienced" (894). Additionally, he critiques the output of clinical measurement through standardised tests, claiming that "the clinical type gives us no real idea of their mental quality" (Sutton 1911: 894).

Thus, the use of a "classificatory" schema (for example, a diagnostic checklist) when dealing with intellectually disabled populations during the early to mid-twentieth century was rare. Doctor P and Doctor C (interview data) both attest to this, stressing that in practice these standardised tools were not useful and in most cases, impractical. Instead, clinicians "depended almost entirely on observable and reported physical and behavioural phenomena and [were], to an extent, influenced by factors which fell outside the dominant medical paradigm, including an increasing drive to institutionalise deviance" (Williams 1996: 253). For example,

> the most prevalent diagnostic indicator of feeblemindedness for admitting physicians was appearance. "Has a fatuous expression", "a frightened idiotic expression", and "expression shows signs of wanting of intelligence", were common statements made in the records as factors observed indicating insanity. The second most prevalent diagnostic indicator was the inability to speak coherently, and the third, descriptions of physical impairment or deformities, for example; shape and size of the head; palate high, arched, of the gothic type; size of tongue; strabismus [eyes not properly aligned with each other]; and deformity and spasticity of limbs. (Williams 1996: 263-4)

Similarly, clinicians in the US in the early 1900s working with individuals with intellectual disability relied on observed and reported phenomena as opposed to a clinical diagnosis (Scheerenberger 1987). Thus, subjective factors such as the child's appearance, their age (for example, "the child is eight years old, yet acts like he is three"), their performance at school, and general coordination (Williams 1996: 258) were the focus of the diagnostic encounter. In fact, Alfred Frank Tredgold, the infamous American eugenicist, argued that the medical and psychological professions lacked relevance in matters of the committal of an individual deemed mentally defective (Tredgold 1947 [1908]). Instead, the decision whether or not to institutionalise an individual was a social and legal assessment which served to identify those who were socially incapable. Eyal et al (2010) confirm this view, explaining:

> In reality, medical or psychological expertise was called upon mostly to provide a seal of approval for a pre-existing social mechanism of exclusion. Any relative or even "any reputable citizen" could apply to the court to have somebody committed (...). The application would typically need to be verified by a three-person panel, only one of whom was a medical doctor or psychologist. Typically, the panel's examination was brief and the whole procedure took only one day. (78)

Williams (1996) argues that, despite the first mentions of the use of IQ tests as diagnostic aids amongst the intellectually impaired in 1909 in Newcastle Hospital, Australia, the real focus of diagnosis lay with the doctor's decisions which led to an individual being institutionalised or permitted to live under the care of their family. Analysis of these same records showed that intellectual disability and mental illness (or "insanity") were very closely linked and identified from an (institutional) administrative and diagnostic standpoint (Williams 1996). According to Australian psychiatrists Doctor P and Doctor C (interview data), once institutionalised, children and adults diagnosed with "mental retardation" were often grouped with those classed as "mentally ill" and received many of the same treatment approaches. Manning (2008) notes that in the Kew Asylum medical professionals tried to group the residents according to their intellectual and physical disabilities, and that this practice was motivated by the desire to put forth an image of Kew as an ordered institution that "catered for the specific needs of residents" (20-21).

In reality, individuals assigned the label "mentally retarded" often faced a great deal of stigma with regards to their treatment within the institution. As Williams (1996) emphasises, there was "a sense of inevitability concerning the fate of those deemed to be afflicted, and institutionalisation, labelling, and treatment nihilism [were] a feature of management in the first two decades of the twentieth century" (268). Built into this label was the assumption that all individuals with some form of mental impairment fall within the same diagnostic category and should thus be treated in a streamlined fashion. This suited the diagnostic and treatment practises of the time: there was no need for delineated and specific diagnoses which would serve in grouping certain symptoms together in some semblance of order because the attitude towards these individuals at that time in Australia,

as in other parts of the world, was that they were a social problem that needed to be dealt with en masse in the institution.

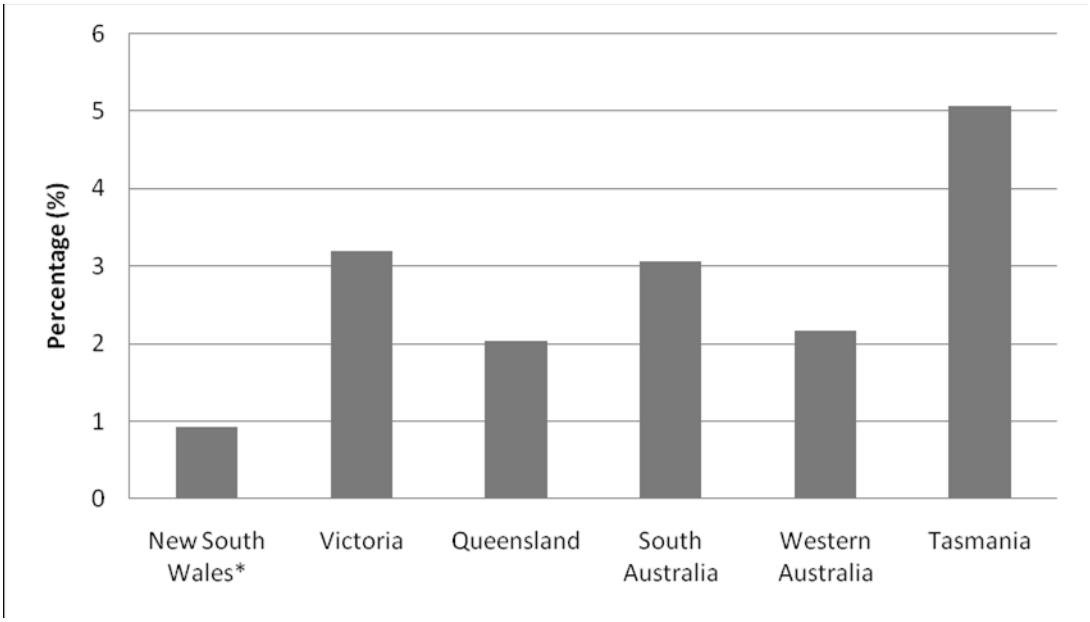
Large scale standardised testing in Australia

Larger-scale efforts in Australia to measure the rates of "mental deficiency" amongst the population took place in the 1930s. McIntyre's (1938) book *The Standardization of Intelligence Tests in Australia* explores the difficulties encountered in standardising IQ tests within Australian schools. His exploration of the *Report on Mental Deficiency in the Commonwealth of Australia*, an enquiry whose purpose was to determine the extent of "mental deficiency" in Australia (McIntyre 1938: 15), provides insight into the logistical problems encountered in the standardisation process. Investigation took place in "mental homes" and through a census of children attending state and private schools. Figure 1.1 (below) records estimates of the number of "idiots, definite mental deficients and border-line cases" for the age band 6 to 14 years in each state on the basis of returns from schools and institutions (see McIntyre 1938: 15).

Interestingly, NSW's figure is substantially less than the other states, and the Tasmanian figure is significantly higher. McIntyre (1938) notes these discrepancies arise from difficulties encountered in the standardisation process, such as imprecise instructions sent out to schools involved in the classificatory procedure. For example, he states:

> The preliminary notice provided the criterion of two or more grades retardation at age 10, and three or more grades at age 14, without defining the normal grade for 10- and 14-year-old children...Starting age and amount of retardation from grade to grade as well as from state to state, and the margin of uncertainty thereby introduced into the criterion, may well account for the interstate difference between the states other than New South Wales. (McIntyre 1938: 15)

Figure 1.1 (McIntyre 1938): Australian survey conducted in the 1930s – Estimates of the number of "idiots, definite mental deficient and border-line cases" for ages 6 to 14 years



*According to McIntyre (1938) the NSW figure is abnormally low and should be discounted due to problems with the collection of data.

McIntyre (1938) discusses the lack of clinicians in Australia that had been trained to accurately administer standardised tests, such as IQ tests: "The application of intelligence tests, either group or individual, as a regular practice, is confined to a very few specialists and enthusiasts in Australia, and any test demanding familiarity with a complex technique is certain to be faultily applied by a considerable percentage of teachers" (McIntyre 1938: 18). He also notes the inconsistencies that exist between the different tests administered by teachers (the criterion of "scholastic retardation") and psychologists (mental tests, that is, IQ tests). McIntyre (1938) cites two studies, both conducted by H.T. Parker (unpublished) – a psychologist for the Tasmanian Education Department – which demonstrate vastly different categorisations made by teachers compared to psychologists. In one study, Parker found that after classifying the same population of Tasmanian school children, teachers classified 207 children as "mentally deficient", whereas the psychologists found only 102 cases with an IQ below 70 (the cut off for "mental deficiency"). In the second study, while the teachers found that the percentage of "defect" was greater for boys than girls, the psychologists found no significant difference between the sexes. McIntyre (1938) explains:

> The excess of boys in the whole group is due to the inclusion of a considerable number of dull boys, a percentage of their counterparts among the girls being regarded by the teachers as normal...it is likely the that greater conformability of girls than of boys to school organization is responsible for some of the disproportion in the Commonwealth Survey. (16)

The suggestion is that different cultural expectations of girls and boys within Australian schools played a subjective role in the classificatory process. Another of the difficulties

associated with categorising individuals with an intellectual disability is that individual differences, requirements and social needs lose their importance and meaning through the intelligence test. In the early twentieth century, testing of individuals with mental impairment produced scores which allowed clinicians to group similarly scoring individuals, and then compare the higher and lower scoring groups (Lewis 1988: 144). This methodology failed to capture and explore the uniqueness of each individual and their strengths and difficulties.

It appears that differentiation between individuals in the institution was not a focus of clinical concern. In fact, the category of mental retardation during the first half of the twentieth century was closely associated with the domain of "abnormal individuals" – with links to danger and criminality – which therefore placed it within the jurisdiction of psychiatry (Eyal et al. 2010). Importantly, Eyal et al (2010) explore, within the US context, the socioeconomic status of these individuals deemed "socially incapable" and find that they were disproportionately likely to come from what some considered at the time to be the "lower rungs of society": immigrants, African Americans , or lower-class whites. This too, it seems, was the case in Australia, with Australian eugenicists (as discussed earlier) proclaiming that feeblemindedness was a problem of the "lower classes" and "lower races". The concept of autism, of course, could not develop within such a homogenous setting – that is, the institution – but instead, it emerged on its margins as a "residual and rare category" (Eyal et al. 2010: 80). At the institution's margins were upper- and middle-class families – families that contested the categorisation of their child as "feebleminded" and resisted their institutionalisation (Kanner 1943).

The alliance between the paraprofessions and parents

In 1943, Leo Kanner, a child psychiatrist, published his landmark article "Autistic Disturbances of Affective Contact" in which he described his diagnosis of the first eleven cases which he labelled with the term "autism." Kanner argued that these eleven children (all from white and upper- or middle-class families) represented a subtype of childhood schizophrenia: they were distinct from children diagnosed with schizophrenia due to early onset, lack of hallucinations, and family histories. He also identified three key defining characteristics of autism: social isolation, language impairments, and insistence on sameness (Kanner 1943). Today, these remain defining characteristics of the disorder (see DSM5: American Psychiatric Association 2013). Kanner asserted that social isolation seemed to be the most salient of these characteristics, and consequently used the label "autism" to describe the disorder. Kanner (1943) wrote: "There is from the start an extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside" (Kanner 1943: 242). He also noted that the condition existed amongst children diagnosed within the broader frameworks of "schizophrenia" and "feeblemindedness":

> These characteristics form a unique "syndrome," not heretofore reported, which seems to be rare enough, yet is probably more frequent than is indicated by the paucity of observed cases. It is quite possible that some such children have been viewed as feebleminded or schizophrenic. In fact, several children of our group were introduced to us as idiots or imbeciles, one still resides in a state school for the feebleminded, and two had been previously considered as schizophrenic. (Kanner 1943: 242)

Given Kanner was working with white upper/middle-class families, the very "discovery" of autism can be derived from a social need pushed by these parents in the mid-twentieth century. While the category of feeblemindedness continued as a widespread phenomenon among the lower classes, the label of autism served to initially differentiate the wealthier classes through clinical professionals (whose services were expensive) applying a "rare" label to middle- and upper-class children (Eyal et al 2010). Meanwhile,

> Within the institution, autism was completely below the radar, undifferentiated from an inchoate mass of institutional residents. Childhood schizophrenia was able to thrive during this period...precisely because it lost the delicate balance and swung all the way into the domain of mental illness, the domain of the psychiatric hospital and electroconvulsive treatment. (Eyal et al. 2010: 56)

In practice, it appears that the professional and societal treatment of those classed as developmentally disabled or feebleminded in Australia continued to be dominated by the belief that little could be done for such individuals. Diagnostic and assessment practises continued to perpetuate the undifferentiated "inchoate mass" that existed within the institution. This situation in Australia during the 1950s to 1970s was discussed by two of the interview participants – Mr A (child psychologist) and Doctor P (psychiatrist):

> [Autistic children] would have fallen into the DD [Developmentally Disabled] category. Almost invariably. Some of the higher-functioning people...I dunno, they might have found themselves in other areas, but I think DD would have swallowed most of them...we had the DD services in the psych hospital, and initially, as I said, they were mixed up a bit. But then they got separate wards for them. But we also had DD services outside the psych hospital, and they varied a lot. (Doctor P (psychiatrist) – interview data)

> [T]he old style Royal Derwent [psychiatric] Hospital, where I did my prac placement in 1974; it had something like 2000 patients, but very few of them were identified with autism...basically, back then, the awful terms 'mentally defective' or 'with psychotic illnesses' [were used]. (Mr A (psychologist) – interview data)

> People were referred to as 'retarded,' it wasn't even 'intellectual disability' back then. The categories were 'Moron' – a whole lot of inappropriate labels were used to describe people. I suppose it was a hangover from the 1960s, that institutions were where people who weren't managing well in the mainstream went. For some it was tragic, as their main issues were not their intellectual disability, or even mental illness, but a combination of learning difficulties and hearing impairment, visual impairment: [disorders] that people in those days just understood as something that needed to be shut away. Terrible! (Mr A)

Throughout the first half of the twentieth century in Australia, medical practitioners often placed pressure on parents to place their developmentally disabled child in institutions like Kew Asylum. These societal attitudes towards children with developmental disabilities were fuelled by eugenics, the medicalisation of treatment approaches (centred within the institution), and the failure of governments and medical practitioners to recognise the differences between the care needed for the mentally ill and the intellectually disabled (Gillgren 1996). The intellectually disabled child was viewed as a "hopeless case," incurable and therefore unworthy of Government funding: a population that, in the eyes of the authorities, was entirely expendable. In some cases, parents were told by doctors to "'forget' about their newborn, to go home and have another baby, or devote themselves to their other child or children" and most parents did as they were told (Manning 2008: 30). This often unquestioning acceptance of medical judgement reflects the popular attitude held amongst Australians at that time that medical specialists "knew best" (Manning 2008: 31).

However, during the 1950s in Australia, it was the paraprofessionals (that is, psychologists, dedicated educationists, occupational and speech therapists) united alongside parents and medical personnel that began to bring about changes in attitudes towards the feebleminded as well as altering the lives of individuals with mental impairment. The most powerful tool used by these united groups was research: through this medium they were able to show that learning for handicapped children seemed to follow a similar sequence as for "normally" functioning children; it simply occurred at a slower rate (Lewis 1988). This shift in attitude towards the "mentally retarded" also affected how it was socially and medically perceived. Whereas in the pre-war period, mental retardation was conceived of as a physiological condition and thus dealt with via segregation and prevention of reproduction, in the 1960s the notion that mental retardation was linked with lower socio-economic status (that is, those living in urban and rural slums) brought about a shift in social and cultural explanations. In Australia, this led to the formation of parents' bodies such as the Australian Council for the Mentally Retarded – which did much to improve the facilities for those individuals during the 1950s and 1960s (Lewis 1988) – and the Slow Learning Children's Group (SLCG) in Western Australia – which formed in 1951 and led to the establishment of residential facilities for children with intellectual disabilities, speech and occupational therapy clinics, and diagnostic and testing centres. This growth was driven by a string of highly successful publicity and fundraising campaigns – led by parents – which aimed to not only provide these groups with some much needed funding, but also to convince governments and the Australian public that children with intellectual disabilities deserved the community's attention and the government's support (Earl 2011). Furthermore, the emergence of the Australian Group for the Scientific Study of Mental Deficiency, established in the 1960s by professionals in the field, demonstrated the

optimism surrounding the capabilities of those with mental impairment in their education, training, socialisation and rehabilitation (Lewis 1988).

When one examines the accounts of hospital staff and doctors describing the conditions of institutions housing children with intellectual disabilities, it is not surprising that such action was taken by parents. In an interview with Doctor Guy Hamilton (Gillgren 1996), the former senior medical officer at Claremont – an institution in Western Australia for children with intellectual disabilities – the reality of institutional life during the early 1960s is revealed:

> The care was appalling. In the male children's ward, J Block, there were people who lay in bed with bed sores until they died; there were cot cases for whom little but basic nursing was provided; there was no policy of training and the care of 40 people in a ward by two or three rostered staff was inadequate. At meal times, they were seated at arm's length from each other, so that they couldn't grab each other's food, which I suspect they did simply because they were hungry. Many who were incontinent were often hosed down outside, even in winter in the so-called airing court. There was no individual care, there was no love, there was no care at all and all bad behaviour was coped with in the medical fashion, using what some used to call 'chemical warfare' against them. This was a medical response to abnormal behaviour; there was little psychological treatment or training. It was the only place in the world that I have found children as young as two years being referred to simply by their surnames...They were receiving worse treatment than animals and most certainly were not being treated as children. (Gillgren 1996: 78-9)

During the mid-1960s, parent groups began campaigning for real change via a new approach to the needs of the mentally impaired who were housed in psychiatric hospitals. Many hospitals set up training and re-education programs and the general process of moving the mentally impaired (residing in institutions) into special units where adequate attention could be provided took place (Earl 2011; Lewis 1988). The law was also updated to reflect the changing philosophy at the time. For example, the repeal of the *Lunacy Act 1903* and enactment of the *Mental Health Act 1962* in Western Australia represented the modernisation of law towards mental disorders (Rayner and Cockram 1996). Most importantly, the *Mental Health Act Amendment Act 1965* (WA) introduced the word "intellectual" into the definition of mental disorder, thus separating mental illness ("a psychiatric or other illness that substantially impairs mental health") from the "intellectually defective" ("suffering from arrested or incomplete development of mind").

Indeed, Carman-Brown and Fox (1996) argue that these changes were the first steps towards deinstitutionalisation within Western Australia, and this action challenged the fundamental conceptions about what intellectual disability was and how it should be treated. This opened up fertile new ground for the paraprofessions, particularly psychologists, to lay claim to. While psychiatrists remained tethered to institutional practices (psychotropic drugs, incarceration, and clinical interaction with and treatment of their patients, whom psychiatrists believed to be predominantly the mentally ill rather than

people with intellectual disabilities), psychologists had a new tool that, when wielded within the community setting, completely altered disability services (Carman-Brown and Fox 1996). Behaviourism represented a new path for Australian psychology due to its focus on observable behaviours rather than the unobservable and un-quantifiable inner-workings of the mind. Thus, it was measurable, efficient, useful, and had "scientific" status. The impact that behavioural psychology had on the developmentally disabled population, and particularly those labelled autistic, will be addressed in more detail in the next section.

Funding for the intellectually handicapped increased substantially in the 1970s when the Whitlam Government introduced two Bills – the Sheltered Employment (Assistance) Bill and the Handicapped Children (Assistance) Bill – which provided funds for sheltered workshops, residential accommodation, training centres and training equipment (Lewis 1988). Allowances were also paid to parents of children who received care within the family and invalid pensions were paid to handicapped people sixteen years and older who were classed as 85 per cent incapacitated (Lewis 1988).

It is evident that the rise in paraprofessions, and their alliance with parents, had a very important impact on the conception of autism in Australia in the mid to late 1960s. The formation of not-for-profit organisations by parents, such as the Autistic Children's Association of South Australia (now known as Autism SA) – which provided services to individuals with autism and their families – began to emerge in Australia during the 1960s. This effort culminated in the organisation of the first conference on autism ever to be held in Australia in 1967 – *Autism: Cure Tomorrow, Care Today*. This conference saw the gathering of professionals and government officials from around the world to discuss topics of diagnosis, psychological assessment, therapeutic techniques and educational techniques for the autistic child. The presentations are peppered with hope – that science will provide the answers as to how to better diagnose and treat autism – but also tempered with the realisation that the condition itself is inherently enigmatic. Some examples of this optimism and realism are conveyed below by the Minister for Health at the time, the Honourable A.J. Shard (1967), a professor of child health at the University of Queensland, T.J. Rendle-Short (1967), and a professor of clinical psychology at Monash University, E. Morey (1967):

> It has been said that generally autistic children are perfect physically and if we could only find the key to unlock them from their detached state we would uncover perfectly normal children. I realise that such a golden key will not be immediately produced at this conference. However, I am confident that this first Australian conference on autism will provide useful guidelines to the ultimate design of such a key. (Shard 1967: 11)

> When a new disease is recognized the pattern of events is usually as follows: At first all we have is a conglomeration of apparently unrelated symptoms. Later this group of symptoms is found to have a certain pattern and we give the new disease a name. The next stage is to find out the causation and if possible to the treatment of this new disease.

> With Infantile Autism we are really only just past stage one: that is to say, we have some knowledge of the signs of and symptoms but we do not yet know which are most important. We do not know the cause and the treatment is largely symptomatic. We are not even agreed upon the name of the condition. (Rendle-Short 1967: 35)

> The psychological assessment of autistic children is no easy matter...As Edith Meyer-Taylor writes, 'Not only may the whole of the psychological examination resemble a psychological experiment, but also each individual test situation. The child himself, rather than the test that is being administered, is the subject of experimentation...' If our techniques are inappropriate and unsuited to assess a child, then he may well be 'untestable' and it is better to observe his behaviour rather than to attempt an assessment...[Autistic children] present us, both as psychologists and educators, with a tremendous challenge. (Morey 1967: 108-9)

These quotes provide insight into professional attitudes towards the newly emerging condition of autism within Australia during the 1960s. While Shard, the politician, conveys the hope that many parents and professionals have invested in the world of science and medicine – that the right combination of early recognition, therapies and education will "unlock" the autism to reveal the "normal" child within – Rendle-Short and Morey, the doctor and psychologist, present the clinical reality of the practising professional. Rendle-Short is concerned about what symptoms should make up autism, what causes it and how should we treat it, while Morey poses questions about whether autism can be diagnosed within the standardised paradigm of psychology. It is important to recognise that these questions, particularly those regarding the very act of defining and construing autism, were being raised at this time in Australia and that they were a point of contention for many clinicians, before the formal inclusion of autism in the DSM-III in 1980.

The Australian parental experience of autism during the 1960s and 1970s: pioneers, advocates, experts

The *Autism: Cure Tomorrow, Care Today* conference had a very clear, clinical focus – its aim was to provide professionals and families with information on the diagnosis, treatment and education of the autistic child. However, one perspective it failed to incorporate was that of the parents. It is appropriate therefore, at this point, to explore the diagnostic testimonies of some parents of children labelled with a developmental disability (including autism) during the 1960s and 1970s in Australia. What is clear from personal accounts provided by parents about their child's diagnostic experience is that it was not a simple, straightforward process of going to the doctor and receiving a label. In Manning's (2008) *Bye-Bye Charlie*, the reader is given a rare glimpse into the world of Kew Cottages, an institutional setting for individuals with an intellectual disability. Through the combination of oral testimony from a range of people including residents, families, staff, policy makers, and visitors, as well as documentary evidence, the book provides insight into institutional living. Manning (2008) references two cases of autism (probably diagnosed in the late 1960s to early 1970s, although she does not specify any dates) in *Bye-Bye Charlie*, quoting the mothers' experiences of diagnosis and treatment in Australia:

> As a little fellow, of say three, Stephen wasn't talking, and we thought he must be deaf. I knew of the Princess Elizabeth Kindergarten for Deaf Children...so I took Stephen up there ... At the end of six months the Directress ... called me in and she said: 'No Rosalie, Stephen isn't deaf, I don't know what his problem is.' Then came the search. I got a lot of literature from America, there was this strange thing called 'autism'. Autism just wasn't a word in Australia. ('Rosalie' in Manning 2008)

> Who is to blame? What is to blame? These are questions that many parents of children with intellectual disability desperately seek to answer. Sometimes, however, there is no immediate explanation. This was the case for Rose and Martin Miller and their son, Sean. Rose explained: 'we really don't know what happened... He was born perfectly normal ... [When he was] about a year old ... He just stopped developing like a baby does. He was tested for all sorts of things and nothing showed up.' The local doctor referred Rose to a paediatrician who coldly told her that Sean would not develop any further. Unhappy with this doctor's attitude and prognosis, she sought a second opinion and was sent to Elizabeth Turner at the Children's Hospital. Sean underwent a battery of tests including those to determine if he had encephalitis, phenylketonuria or deafness. All tests were negative. Without a definitive diagnosis, and with the behaviours Sean was exhibiting, autism appeared a possibility. (Manning 2008: 48-9)

From these accounts, it appears autism was a default diagnosis. When all other diagnostic options were exhausted through negative results, autism may have been the diagnostic fallback. Autism remained an unknown entity, a label attributed to enigmatic cases and a label that certainly did not provide any answers in terms of treatment approaches. These accounts are consistent with Lurline Morphett's (1986) experience of receiving a diagnosis of autism for her son during the 1960s, outlined in her book *Face to Face.* She discusses taking her son to her general practitioner, a paediatrician, a psychiatric social worker, and finally to a psychiatrist. What is most striking about her account is how little information and explanation she is given by most of the clinicians she came into contact with: "There seems to be something wrong...but I don't know what it is" (32); "From [the paediatrician's description], I came to the conclusion that this was a severe mental illness" (34); "[The paediatrician] referred me to a child psychiatrist who, he said, was better equipped to deal with such problems and would confirm whether the diagnosis was correct" (34); "having been interviewed by the psychiatric social worker who asked a host of questions, and answered none" (36); "[The psychiatrist] did not realise we had never been exposed to the technical terms which were commonplace to him" (36). The general attitude toward children with a developmental disability at this time appears to have been medically oriented, focused on the incurability of intellectual disabilities:

> Certainly [the psychiatrist] was saying that the chances of Simon ever being normal were negligible, and that even if he made good progress he was likely to spend most of his life in a mental institution. (Morphett 1986: 37)

However, from Morphett's discussion of the recommendations made by the Australian child psychiatrist, it is evident that parent advocacy and community service provision were certainly underway – the essential ingredients for the changes to later come with deinstitutionalisation:

> We were to write to England for a small booklet by Lorna Wing, a British authority on autism. In it were the answers to many of our queries. We were to contact the president of the state's Autistic Children's Association, of which the inaugural meeting had been held just a week before. By this means we could come into contact with other parents of autistic children, though, being a rare and recently recognised condition, there were not many children in our city as yet diagnosed. The final suggestion was aimed at providing our family with some relief from Simon's persistent, irrational demands and in familiarising him with a different environment. We were to add his name to the waiting list of those seeking admission to a day school for seriously mentally handicapped children. We later carried out each of these suggestions, though the third one was not followed through to its conclusion. (Morphett 1986: 37)

Similarly, Mr D's son's ("Joe") diagnostic story follows a similar path to Morphett's (1986) account:

> I don't know how early we began to think we needed help because it takes quite a while to realise something more serious is happening and probably he was a bit under two [years old] when we felt he wasn't developing normally. He hadn't learnt things like feeding himself...So we saw our GP and said he doesn't seem to be developing properly, and our GP said the Department of Health has a paediatric service in Parramatta and he referred us to them. We made an appointment. They brought in external specialists, one was a leading Sydney paediatrician to help assist families. I can't give you an exact sequence of events; at first they just said, "he's a slow developer, he'll come good in time." And so some time went by and he didn't come good and we went back to them...at one stage they suggested psychoanalysing his mother – they suggested it, we declined. We had two daughters, we'd raised children before. We knew we were rational people – (laughs) I do have a University degree, I might come in the category of being suspected of being distant but his mother didn't come into this category....They still persisted with the belief that he would come good...but sometime when he was about three to four [years old], the *Readers Digest* published a list of the attributes of autism...there were twenty different aspects of autism and he scored in our view, thirteen of them...autism is just like that, no one person will have all twenty, but some will have these and some will have those. So, we asked through this service was he autistic and they said, "No, he's definitely not autistic." Had we not been given that incorrect advice, we would have looked to the Autistic Children's Association earlier. Whether that would have made a difference or not, I don't know. They said he's "negative-elective mute." That is a way of saying [it] medically. (1)

After four years of not receiving a diagnosis through the public system, other than the term "negative-elective mute," numerous failed attempts to attain treatment services such as speech therapy, and placements in preschools and schools, Mr D took Joe to a paediatric

specialist, who then recommended they see a Professor of paediatric psychiatry – Julian Katz[5]:

> [Katz] took [Joe] aside into his office, leaving us for about ten minutes; and he came back and he said: "there's autism there and he needs to get to an appropriate facility." At that time the Autistic Children's Association was based at Belrose in a cottage, which was full; but the new facility at Forestville was just completing and there was hope that we could get him in there when it was completed. That would probably be 1971 – Katz had a social worker who got Joe into [A facility]...The Principal of [the facility]... took him in and I went to see them one day – there was a group of children with the teacher and they had a picture of a dog; they were going round saying "d" for dog; what was [Joe] doing? – He was wandering round the room taking no notice. He just didn't stay sitting with the group. This is characteristic of autism and the reason for the one to four ratio of teachers, because they do not concentrate in the normal way – you can't get a group of them to work together. You have to work one to one at that early stage...he was there for a year and then the opportunity came to go to the Autistic Children's School – this would have been [19]71-72 and he would have been six [years old].

It is evident from Mr D's account of this consult with Katz that diagnostic tools (such as an IQ test) were not used (due to Katz's short interaction with Joe), and it is most likely that his diagnostic approach was consistent with earlier approaches (outlined above) that focused on subjective factors and observable phenomena.

Furthermore, it is also apparent that Mr D played an active and informed part in obtaining the best diagnostic services and treatment for Joe. Yet many of his concerns and queries were dismissed throughout the diagnostic process. While it is widely accepted today amongst clinicians that parents coming to them with concerns about their child have an important and powerful role in the assessment and management of the child, it is important to realise that such an attitude was somewhat of an anomaly amongst clinicians before the 1990s. An infant welfare nurse presenting at the *First Twenty-Four Months in the Life of a Mentally Retarded Child and its Family Conference* in Victoria in the 1970s, however, cautions clinicians against dismissing the parent's gut instincts:

> However frequently we see a baby and however closely we have observed his progress we are not seeing him as his parents see him. When parents express concern there are almost always grounds for that concern, and there is always a need for careful investigation and consultation with the parents. (Morris 1977: 21)

The difficulties experienced by families in researching, resourcing and locating treatments for those with mental impairment or developmental disabilities was a major discussion point at the *First Twenty-Four Months in the Life of a Mentally Retarded Child and its Family Conference* in Victoria in 1977. The Director of the Mental Deficiency Services, Doctor

[5] Julian Katz was appointed as the first Professor of Child Psychiatry in Australia in 1963 at Sydney's Royal Alexandria Hospital for Children and the University of Sydney.

Barlow, highlights the "tremendous fragmentation" that characterises service provision for children with mental impairment and developmental disabilities. He states:

> there is a complete lack of co-ordination. This stands out as probably one of the greatest handicaps to progress in the field of mental retardation in the State. The fragmentation and lack of coordination means, too...that even when services are available they are not necessarily *known* to be available. The mother who spoke used the term "stumbled into" – she *stumbled into* a number of services and sources of information, almost by accident. There is something terribly wrong when this has to happen. When services are so light on the ground anyway, we suffer in addition from the fact that nobody knows about half of them and what they're doing. (Barlow 1977: 78)

Mr D outlines the various schools his son Joe attended from preschool to primary school to special education providers during the late 1970s. The Autistic Children's School was where he spent most of his primary school years (six to twelve years old). This school represented a leap forward in service provision for children with autism at the time given they were using ratios of 1 teacher to 4 children, with additional teacher's aids. Significantly, Mr D explains, this was brought about by campaigning by both parents and Dr Katz (paediatrician).

From a clinical perspective, Mr A (psychologist, interview data) discusses the very limited clinical knowledge with regards to treatment approaches for children diagnosed with a developmental disability or autism during the 1970s. He emphasises that schools would have been the main environment that children with a developmental disability or autism diagnosis received some form of therapeutic attention, however, he qualifies:

> [T]here weren't so many special ed [education] teachers, there certainly weren't speech pathologists or psychologists who specialised in intervention back in the 60s; that began to occur in the 70s certainly; so sadly, there weren't a range of [clinical] disciplines involved; often parents were told this is how your child is, the outlook is pretty grim; the child won't be able to do this or that; and it was a bit of a death, outcomes limiting sentence that they got from the diagnosticians. (Mr A – interview data)

The various people (such as family and treatment providers) and situations the parent has to deal with and manage post-diagnosis creates a highly stressful and emotionally charged period in their life. Coupled with lack of services, lack of treatment, lack of funding, and the inevitability of institutionalisation in childhood or adulthood, parents had very little hope and expectations for a child diagnosed with a developmental disability in Australia prior to the 1980s. However, it is clear from Earl's (2011) research – exploring the development of parent advocacy groups for children with intellectual disabilities in Australia – that post-World War II, parents and the community took on an increasingly active role in the care and assistance of children with an intellectual disability. This gradual growth in parent involvement from the late 1940s to the 1980s in Australia, along with the growth in the

paraprofessions, set the stage for a new network of expertise to develop in the wake of deinstitutionalisation. The removal of the institution as *the* "treatment facility" and the formation of an alliance between parents and therapists heralded new ways of treating this "undifferentiated inchoate mass" of institutionalised children within the home and the community (Eyal et al. 2010). The changes brought about in Australia (and worldwide) during the late 1960s and early 1970s by parent advocacy, the principle of normalisation, changes to the law and other classificatory devices, and an increase in government funding were all vital to the reshaping of the Australian public's attitudes towards people with intellectual disabilities and how they should be treated and supported (Rayner and Cockram 1996). The growing strength of these attitudes was a strong catalyst for change: replacing the medically-dominated custodial and institutional approaches to services with a community-based treatment program – deinstitutionalisation.

Section 2: Deinstitutionalisation in Australia: from "undifferentiated mass" to "autism epidemic"

Section 2 of this chapter will examine the process of deinstitutionalisation in Australia, the effect it had on diagnosis, treatment, and service provision for children and adults with a developmental disability, and how Eyal et al's (2010) historical analysis of how the autism spectrum became the preferred way to represent and intervene in childhood disorders. While Eyal et al's (2010) work is rooted in the US context, this section will demonstrate the ways in which it converges and diverges with the Australian context. Crucial to this discussion is the rise of the paraprofessions, particularly psychologists, in the classification, diagnosis and treatment of intellectual and developmental disabilities in Australia. This section will shed light on how autism came to be the paradigmatic childhood disorder – emerging in the void between mental illness (that is, childhood schizophrenia) and mental retardation – and how it has come to hold an "epidemic" status in Australia and many other parts of the world today. As indicated in the introduction to this chapter, an important source of information for this section has been obtained through interviews with two Australian psychiatrists (Doctor P and Doctor C), an Australian psychologist (Mr A) – all of whom have practised both before and after deinstitutionalisation – and the father of an individual diagnosed with autism in the early 1970s in Sydney, Australia (Mr D).

It is important to point out that while much has been achieved in Australia through the process of deinstitutionalisation, the transition has been far from smooth, unproblematic, and preordained. In fact, deinstitutionalisation has taken somewhat of an uncertain and halting path:

> Deinstitutionalisation and normalisation proceeded almost by trial and error, structured by imperfect and contradictory understandings of their meanings; changes in their meaning through elaboration and experience; the influence of new professions 'on the make'; decidedly

> ambivalent public understandings of disability itself; and constant constraints on funding. (Stella 1996: 93)

Normalisation

Before exploring what deinstitutionalisation means within the Australian context, it is necessary to briefly examine the philosophical underpinnings of this movement. The terms *deinstitutionalisation* and *normalisation* often appear together, and are even used synonymously sometimes to describe the policy and philosophy of moving formerly institutionalised individuals out into the community. The publication of *Changing Patterns of Residential Services for the Mentally Retarded* in 1969 saw the articulation of the principles of normalisation by key thinkers such as Bengt Nirje and Wolf Wolfensberger. For Nirje, normalisation involved establishing a quality of life for the intellectually disabled that was equal to the patterns and conditions of the everyday life of mainstream society (in President's Committee on Mental Retardation 1969). This definition was further elaborated upon by Wolfensberger:

> Use of culturally normative means (familiar, valued techniques, tools, methods), in order to enable persons life conditions (income, housing, health services, etc.) which are at least as good as that of average citizens, and to as much as possible enhance or support their behavior (skills, competencies, etc.), appearances (clothes, grooming, etc.), experiences (adjustment, feelings, etc.), and status and reputation (labels, attitudes of others, etc.). (Wolfensberger 1980: 80)

Wolfensberger (1983) also proposed the term *social role valorisation* to describe the development of the normalisation principle. This term explains the phenomenon of social devaluation – whereby individuals who are seen as socially deviant both lose valued social roles and are given devalued roles – and the need to counteract this process by supporting processes which enable devalued individuals to attain and keep valued social roles (such as "employee" and "friend") and avoid negative roles (such as "patient" and "deviant") as they move out into the community. Thus, Wolfensberger (1983) argued that institutions breed attitudes of social devaluation through the practise of grouping devalued individuals together and isolating them from the community. Thus, social role valorisation is dependent upon discontinuing the practice of institutionalisation.

Embracing the Principle of Normalisation: Deinstitutionalising Australian Facilities

When defining the term "deinstitutionalisation," it is important to differentiate between the individual and the institution itself, because the term has different meanings for these different entities. Thus, for Doctor P, institutionalisation of an individual within Australia means

> [Y]ou take away a person's independence and you make them dependent on you as the treating or controlling person...in doing so...you take away their daily living skills, because they cease to have to do things for themselves: all their meals are supplied, in some cases clothing is supplied,

> all medical care/dental care is automatic, they don't do shopping, excursions (if there are any they're organised by the treating team), and so on and so on. So you take away a person's ability to be independent. In addition, you expose them to a regime, which is very controlling and determines exactly how they're going to spend most of their day, and most of their life in fact.

Thus, to *de*institutionalise an *individual*, one must address all of these factors that have contributed to their identification with an institutionalised individual. People must be re-taught daily living skills, interacting in the community, carrying out tasks independently, making independent judgements about their lives and daily activities. All the abilities that have been stripped from the individual must be replaced. To *de*institutionalise the institution/hospital itself the structure and function of the hospital needs to be changed. Doctor P claims that before the 1961 Royal Commission in NSW, headed by Justice McClements, which set out some fundamental human rights for the mentally ill and mentally impaired, "some wards in psychiatric hospitals built for about 60 patients housed 100 patients." Thus, deinstitutionalising the structure of the psychiatric hospital involved housing patients in more appropriate conditions. Changing the function of the hospital involved altering treatment practices and staff practices/routines. Here, the aims of deinstitutionalising the individual were operationalised with the provision of patient autonomy through enabling patients to make decisions about their own treatment.

The next step in the process of deinstitutionalisation is the movement or placement of individuals out into the community. This is distinguished from *community care* and is the subject of much debate when discussions around the effectiveness of deinstitutionalisation take place. According to Doctor P, community placement of individuals in institutions was taking place as early as the 1960s, long before the Richmond Report. He explains:

> One of the major reasons was that in...1955 we actually got tranquilisers...we didn't have medications before that that were in use, apart from trying to control aggression basically – sedating people. We got the modern tranquilisers and the anti-psychotic drugs and we started using them in Australia in 1955. Within a matter of a year, the medical superintendant at Gladesville Hospital was writing his annual report to the Inspector General for the Insane (as it was in those days) that this had made a dramatic difference, patients who were uncontrollable were now controllable, patients who we thought would never move out into the community were now moving out into the community.

Doctor P references a hand-drawn graph throughout the interview that charts the numbers of patients in residence at the Gladesville Hospital, Sydney, from 1958 to 1990 (unfortunately I am unable to provide a copy of the graph as Dr P's ethics approvals and data sources were unknown). This graph shows the dramatic drop in patients from 1958 to 1980s. Thus, physically emptying out the institutions – one component of the deinstitutionalisation definition – took place in Australia between the late 1950s to the early 1970s, according to Doctor P. Once physically outside of the institution, the former patients were: "more or less on [their] own. If you wanted ongoing treatment you came back to an

outpatient department, generally inside a hospital somewhere and you give them a script for drugs and send them away, that was it" (Doctor P). Prior to 1967, former institutionalised patients were released into the community without any financial aid or support. This, according to Doctor P, caused huge problems for these individuals and psychiatrists: patient numbers built up in outpatient departments, leaving many individuals stranded, helpless and homeless. However, in 1967 the Commonwealth Government extended invalid pensions to developmentally disabled individuals, and later further extended this pension to mentally ill individuals. This pension was known as a "Sheltered Employment Allowance" (Department of Family and Community Services 2001; Department of Social Security 2009). Doctor P claims that the Sheltered Employment Allowance brought about "enormous changes" because it meant that "patients could save money, they had money for rent and bonds, they could go out into the community – so it meant that giving patients pensions made a *huge* difference."

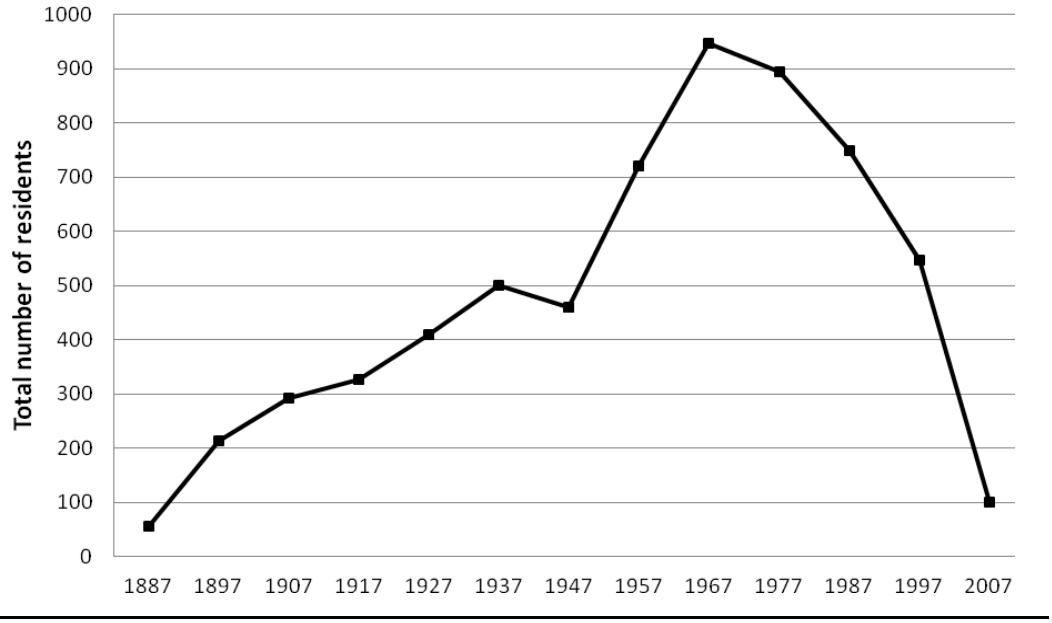
While community placement was underway from the late 1950s onwards, community care was not implemented in earnest until the 1970s. Doctor P believes that community care was taking place, on a very small scale, in the 1960s through the staff of hospitals going out to visit discharged patients to check up on them. With the election of the Whitlam Government in 1972, there was a significant rise in funding for community care and community health. Doctor P states:

> A part of their funding was community health funding, and that funding enabled the development, for the first time, of comprehensive community care services (instead of just community placement, which is just bunging people out there)...[so] you now have community care, which means adequate follow-up, proper intervention, and other forms of care quite apart from just popping in and saying, "How're you going? Here's your tablets, blah!" and that's it.

However, this initial funding was steadily cut back: "initially it was Commonwealth funding, then it became Commonwealth-State funding, and of course the States jacked-up, and so it has taken a long while for it to develop where it is" (Doctor P).

Dr P's data source relates to the "mentally ill" population. However, the graph below (Figure 1.3) shows the Kew Cottages – Australia's largest institution for people with an *intellectual disability* – population peaked at 948 residents in 1968, with a rapid decrease in residents from 1977 up until its closure in 2007. Thus, comparison of the figures from Gladesville Hospital and Kew Asylum (Cottages) indicates that deinstitutionalisation of the intellectual disabled population began roughly twenty years later than the deinstitutionalisation of the mentally ill. This is probably due to impact of antipsychotics on the mentally ill population during the 1960s, whereas medication would have played less of a role for those with an intellectual disability.

Figure 1.3 (Manning 2008: 20): Kew Cottages Population Statistics by Decade from 1887-2007



In their report, *Children with Disabilities in Australia*, the Australian Institute of Health and Welfare (AIHW) (2004) demonstrates that the impact of deinstitutionalisation on children with disabilities occurred primarily during the 1980s, with 9% of children with a severe disability living in cared accommodation in 1981, compared with 0.4% in 1998. The AIHW (2004) also points out that for children with intellectual disabilities the term *non-institutionalisation* is perhaps more fitting than *deinstitutionalisation*, as this process of change has tended to be more about these younger individuals staying in the community in greater numbers, rather than moving out of institutions. For children with intellectual disabilities, the changes in attitudes, legislation and government involvement in Australia resulted in an improvement in access and availability of services, the introduction of income support for their carers, and more support from the mainstream education system. However, with the majority of these children now residing in households, provision of care rested mainly on the shoulders of family care givers. This has led to adverse health effects for the caregivers (that is, focusing on the health of the child has led to the caregiver ignoring their own health) as well as relationship strain and stress (30% of children with a disability live within a single parent family, compared to 18% of children without disabilities) (Australian Institute of Health and Welfare (AIHW) 2004).

When consulting Australian policy documents formally outlining the process and aims of deinstitutionalisation, such as the *Richmond Report* (New South Wales Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled 1983) and *Policies for Developmental Disability Services* (NSW Department of Health 1985), it is evident that the principles of normalisation have been formally acknowledged and upheld. For the NSW Department of Health (1985), normalisation:

> advocates that the ways in which services assist persons with a developmental disability and the lifestyles which these services support should be valued by society in general and perceived as being as normal as possible within a local community and culture. (2)

This philosophy is enacted by providing children and adults with a developmental disability with care, support, opportunities and agency in their everyday life. Thus, deinstitutionalisation or non-institutionalisation means not only being out in the community, but promoting dignity and independence, enhancing self-respect, encouraging and assisting the individual to lead a productive and satisfying life, ensuring the individual receives remuneration for productive work activities, encouraging and assisting individuals to make their own decisions, and having the opportunity to participate in community life (NSW Department of Health 1985: 2).

The Richmond Report (New South Wales Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled 1983) also made a very important distinction between the nature and needs of mental illness in comparison to the intellectually disabled. The separation of these two categories is an important feature of Eyal et al's (2010) autism matrix theory, which will be discussed in the following section. In Australia, this separation meant the following:

> (a) The identification of two separate and distinct client groups
> (b) The establishment of two distinct management structures
> (c) The separation of budgets
> (d) The total physical separation of the two services
> (e) The employment of distinct client-specific categories of staff in each of the two service areas (NSW Department of Health 1985: 6)

Hand in hand with the process of deinstitutionalisation was the considerable legislative development within Australia from the mid 1980s onwards which empowered the disabled through anti-discrimination and protective legislation. This legislation is vitally important in ensuring the rights of the intellectually disabled as well as determining what and how much help individuals may receive. Prior to this, the Australian Federal Government's involvement in disability policy was limited to provision of pensions, some funding, benefits and direct services controlled by the Commonwealth Rehabilitation Service. By establishing and sponsoring some important initiatives in 1983, such as the Disability Advisory Council of Australia – consisting of people with disabilities and their advocates – and the Handicapped Programs Review, the Federal Labor Government at the time was able to make its mark and have a profound effect on disability service delivery throughout Australia (Rayner and Cockram 1996). These changes – that is, the emptying out of institutions, the changes in legislation, the changes in societal attitudes towards the intellectually disabled and mentally ill – are all the more impressive when one considers the group at the heart of this movement:

> New services and legislation for people with intellectual disabilities did not arise because the medical professions decided they should. The response by the law in the late twentieth century to intellectual disability is a success story for families and ordinary citizens who formed interest groups, demanded government action, and who were prepared to go out and start the service themselves. They should not be left unresourced and excluded as 'volunteers' or clients. They should be a part of the rule-making, service development process. (Rayner and Cockram 1996: 162)

The Autism Matrix – differentiating the mass post-deinstitutionalisation

The key question that must be asked now is: How did these shifts within the Australian context in terms of the *professional/clinical domain* (from medical model and dominance of psychiatrists and doctors to the developmental model with power ascribed to the paraprofessions, particularly psychologists), *legal documents* (changed legislation embracing the principles of normalisation), *advocacy groups* (the rise of parent activism) and *social attitudes* (for example, the Year of the Disabled in 1981 (Goddard, Davidson, Daly, and Mackey 2008)) affect the individuals who were formally institutionalised based on their status as mentally ill or developmentally disabled? This chapter has explored each of these elements separately, but this section will consider how their interaction created a unique space for the emergence of a disorder, autism, and how it was able to take on epidemic proportions.

In the first section of this chapter, classification within the institutional setting was explained as a eugenic means of separating the "fit" from the "unfit", the "educable" from the "ineducable", and those to remain in society or be removed from it and housed within the institution. Within this context, classification was not required – differentiation between "abnormal individuals" would have been pointless when, in the majority cases, individuals received very similar treatment in institutions that only began to differentiate between the mentally ill and the intellectually disabled in the mid-to late-twentieth century. With the process of deinstitutionalisation beginning in earnest in the late 1970s in Australia, combined with the release of the DSM-III in 1980 (which essentially saw a paradigm shift in the way that psychology and medicine went about diagnosis and treatment), it is logical to assume that these changes would have brought about a shift in classificatory, diagnostic and treatment practises. Thus, the deinstitutionalisation of the mentally disabled meant that

> [A] large number of children, who previously would have been institutionalized as mentally retarded, were now to be treated in the community at the earliest age possible, it also meant that the categories employed by the institutions to distinguish and diagnose children became meaningless and blended together into an ill-defined mass of "atypical children". Here the ideology of "normalization" that guided much of the deinstitutionalization movement played an important role. It involved a thoroughgoing reorganization and democratization of the relations of expertise, by breaking the monopoly enjoyed by psychiatry over administrative power in the

> field of retardation, and by empowering more peripheral professions as well as patients and parents. (Eyal et al. 2010: 56).

As this chapter argues in the previous section, during the 1960s in Australia a shift began to take place within the institution, as well as professionally, with regards to the issues of assessment, treatment and care of individuals with an intellectual disability. This change was spearheaded by parent groups and psychologists, two groups that were highly motivated by the promises and outcomes suggested by the principle of normalisation. For parents, deinstitutionalisation promised better care and support for their child and a brighter future. For the paraprofessions and psychologists, community care brought power and professional dominance as they became the overseers of treatment programs and service provision. This hand-over of professional power to the paraprofessions also brought with it increased agency ascribed to parents in their ability to act like consumers and pick and choose the therapies and treatment approaches that best suited their child. For Eyal et al (2010), these factors were crucial in the shaping of autism spectrum disorder and the creation of the autism matrix.

Eyal and colleagues' (2010) book, *The Autism Matrix,* explores the history of autism, and its current status as an "epidemic," through its connection with the deinstitutionalisation of mental retardation, which the authors claim began in the late 1960s in the United States. The desinstitutionalisation of individuals with an intellectual disability in Australia also appears to have begun in the late 1960s (see Figure 3), but did not begin in earnest until the 1980s. Deinstitutionalisation acted as what Eyal et al (2010) term a "moral blender" (3). Old categories and labels that were mobilised within Australian and American institutions, such as "feebleminded," "moron," "mentally retarded," "idiot," "psychotic," "schizophrenic child," were apparently scrambled through the process of deinstitutionalisation. As a result, the boundary between mental illness and retardation was blurred. This, in turn, led to a "great undifferentiated mass of 'atypical children'" which were then gradually sorted into new categories within a "new institutional matrix" (Eyal et al. 2010: 3). It is interesting to note that the Australian and US contexts appear to diverge at this point. As previously discussed in this chapter, the boundary between mental illness and intellectual disability appears to have always been blurred within the Australian institution. According to Australian and NSW Government documents and policies, it was not until the 1980s and deinstitutionalisation that any formal distinctions were made between these two categories (see NSW Department of Health 1985). However, as Figures 2 and 3 indicate, there was some separation between these categories at the institutional level.

The new institutional matrix replaced the custodial institution with community treatment, special education, and early intervention programs. Furthermore, this mental health reform allowed new professional jurisdictions to open up and broaden their scope and significance (such as psychology and speech therapy). Whilst this process of deinstitutionalisation of

course demonstrates a major shift in the philosophical underpinnings of the treatment of individuals with an intellectual disability or a mental illness, Eyal *et al* (2010) point out that it should not be seen as a complete break from institutional ideas, but rather, a transference of duties to the family, whereby a new vision of systematising the comprehensive surveillance and placement of atypical children can take place. These factors, Eyal et al (2010) claim, have led to a "spectrum of autistic-type disorders that [straddle] an indeterminate terrain between mental illness and retardation, thereby laying the groundwork for the epidemic" (9). Thus,

> The issue is not whether the rise in the number of diagnoses is due to vaccinations, pollution, or diagnostic substitution, whether it is "real" or fabricated. The issue is that our practices for representing and intervening in childhood disorders are no longer constrained by the opposition between retardation and illness, but proceed as if they can ignore it (Eyal et al. 2010: 8-9)

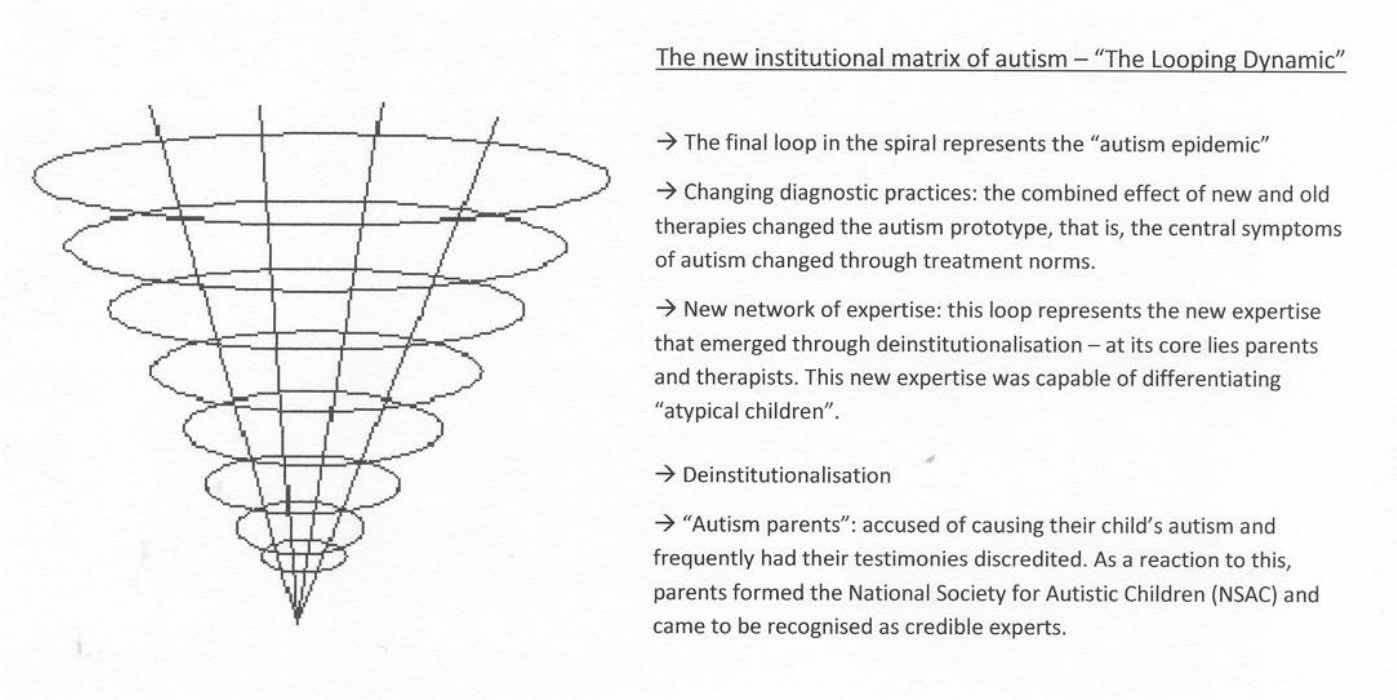
In terms of the treatment of ASDs today, psychiatrists have essentially taken a back seat. ASDs are notoriously difficult to diagnose because they resist medical classification. While psychiatrists and paediatricians commonly diagnose ASDs and prescribe medications (which do not treat the core of the disorder, but rather manage or control problematic behaviours), paraprofessionals have deployed behavioural, speech, occupational, and other therapies to address the core problems associated with this disorder. Eyal et al (2010) emphasise that these therapies date back to the mid-1960s, where they played a fairly marginal role and had little association with the discipline of psychiatry. As discussed earlier, behavioural psychology was being practised in Australia from the 1960s and was a key tool utilised by psychologists to demonstrate the practicality, measurability and scientific-nature of their profession. With deinstitutionalisation and the opening up of professional jurisdictions that came with it, a space opened up for these paraprofessionals to establish a legitimate place within the field. Thus, deinstitutionalisation allowed a "massive change in the social organization of expertise" (Eyal et al. 2010: 4).

The parents of children diagnosed with autism played a key role in this change. Eyal et al (2010) claim that through the formation of parents' groups such as the National Society for Autistic Children (NSAC) and National Association for Retarded Children (NARC), parents sought to undermine the dominance of the psychiatric profession, which had, in the past, frequently disregarded and belittled their perspective. In Australia, it was the formation of parent groups such as the Australian Council for the Mentally Retarded, the Slow Learning Children's Group, and the Autistic Children's Association of South Australia that fought hard to obtain services and rights for their children. Indeed, these groups united alongside the paraprofessions and even some medical professionals to raise awareness, change the law, and change professional opinions about the intellectually disabled. These Australian parent groups also used research and science to gain the respect of Government, and ultimately obtain funding (Earl 2011; Lewis 1988). A key research initiative was the formation of the

Australian Group for the Scientific Study of Mental Deficiency during the 1960s, which subsequently demonstrated that children with intellectual difficulties do in fact benefit from socialisation, education and training (Lewis 1988). It is findings like this, and the power and hope that they gave to parents, that demonstrates precisely why the label of autism became so popular and resonated so strongly with parents. Eyal et al (2010) explain that the appeal of the category of "autism" to parents is that it, above all, offers hope: while it removed the stigma attached to the category "mentally retarded" in the institution, it simultaneously opened up a large array of previously unavailable therapies and services that thrived on the idea that autism had a potentially transformative "critical window of opportunity" that may result in the child's "cure."

Eyal and colleagues (2010) argue that the widening jurisdiction of paraprofessionals and the therapies they promote have had an important impact upon the diagnosis of autism, particularly upon the DSM. The creation of the identity "autism parents" together with deinstitutionalisation created the need for "a new type of expertise, capable of sorting and differentiating the 'atypical children'" (Eyal et al. 2010: 23) Thus, at the core of this "new expertise," according to Eyal et al, are the parents and therapists. They have been fundamental in the definitional and diagnostic shift that has occurred over the past twenty years. Eyal et al (2010) refer to all of the changes affecting autism's diagnosis and definition as a "new institutional matrix" which can be thought of as a "looping dynamic". The looping dynamic is made up of spirals in an "increasingly widening vortex" (23). The "autism epidemic" represents a final spiral in this vortex of looping processes (see Figure 1.4, below).

Figure 1.4: The new institutional matrix of autism based on information presented in Eyal et al (2010: 23-24)



The looping dynamic is described as open and permeable, and therefore the entry of new therapies into this new institutional matrix is relatively easy. As new and old therapies interacted and combined, the experience of autism and its presentation in the clinic began to change. Eyal et al (2010) highlight the role of Applied Behavioural Analysis (ABA) and Sensory Integration Therapy in changing the focus of diagnostic practices and standardised documents. For example, self-mutilation and self-injurious behaviours used to be a central criterion in the diagnosis of childhood-onset Pervasive Developmental Disorder (PDD) in the DSM-III (1980). However, in the 1970s this behaviour began to be targeted through behaviour modification (such as Applied Behavioural Analysis) and was seen as treatable or controllable through these therapies. As a result, these behaviours came to be seen as marginal in clinical presentations and were discounted as outside the core symptoms of autism. In the DSM-III-R (1987), self-injury became an "associated feature" in the criteria for PDD. In the DSM-IV (1994) there is no mention of self-mutilation or head-banging. While behaviour modification eliminated criterion from diagnostic practices, Sensory Integration Therapy appears to have added to the criteria. Such approaches have "established both sensory hypo- and hyper-sensitivity firmly as a core feature of the autistic prototype, and arguably provided language and practices to give meaning and shape to autistic experience not as aloneness but as neurodiversity" (Eyal et al. 2010: 24) This continuing overhaul of the autistic prototype has been reinforced by the heterogeneity of the population captured through diagnosis. As it stands now, the DSM-IV-TR allows the diagnosis of a PDD to include both the intellectually disabled and "higher functioning" individuals. Thus, one can see how

these processes and their consequences led to the "autism epidemic," which represents the final loop in the looping dynamic (see Figure 1.4).

While Eyal et al's (2010) work focuses on the US context, it is clear that many of the historical and philosophical underpinnings of the autism matrix are shared by the Australian context. The way that parent groups and the paraprofessions (mainly psychology in the Australian context) fought to secure community care and rights for the intellectually disabled, changed the way intellectual disability was perceived in Australia so that individuals were no longer deemed "hopeless" or "incurable," and developed treatment approaches that created optimism amongst parents and professionals was crucial to the harnessing of this label and its epidemic status within Australia today.

However, through the research conducted for this chapter, an absence in the literature was noted. There appears to be very few accounts of adults with autism living out in the community post-deinstitutionalisation. While it could be argued that autism was essentially unheard of only thirty years ago, it seemed to be an issue that required further investigation. This is what prompted an interview with Mr D, the father of Joe – a man in his late 40s who was diagnosed with autism in the early 1970s.

Deinstitutionalising autism in Australia: Invisible adults?

Central to the concept of this thesis is the idea that autism resists definition and classification. This is a consistent theme throughout this chapter also, and is evident too in the way that deinstitutionalisation has been applied to adults on the autism spectrum: autism never seems to fit neatly into the categorised or defined spaces set out for it. Deinstitutionalisation, of course, comes in many different forms. However, the reality in Australia, according to Mr D, is that adults with a diagnosis of "low functioning" or "moderate functioning" autism (as well as other more severely affected individuals with a developmental disorder) remain in a kind of limbo: residing in facilities that are somewhere in between an institution and a community cottage. For Mr D's son – Joe – as well as some of his other fellow residents with a diagnosis of autism, the prospect of "deinstitutionalisation" did not become a reality until 2010 (and there is even contention still as to whether the facility he resides in now constitutes an institution or not). The proposal was for him, and many others his age or older and with similar diagnoses, to be transferred from Macquarie Hospital, where he had spent the majority of his life, to community cottages. This proposal was originally made in the early 2000s. Macquarie Hospital continued to hold the status of "institution" and the movement of its residents to community cottages was a step towards meeting the commitment made to have all residents moved out of institutions and into the community. Mr D explains, however, his objections to this proposal based on the needs of individuals with an ASD:

> I led a group to see the Minister to inform her that community cottages were not the right answer.... If someone is sick or behaving badly, the rest of the cottage is grounded, as they don't have sufficient staff to deal with this; there is a level of disability which does not benefit from being stuck in an isolated cottage. So we saw the Minister (…) who said the money is available and it's going to happen anyway and I can't do anything about it. We went down the process of looking at service providers and defining what was needed. Now some of our folk are profoundly disabled, needing very special cottages; all need a big room and no two stories, as this presents problems....I wrote a submission saying, first of all, we're quite happy to stay where we are, but if that's not acceptable, because it's in the middle of a psychiatric hospital, what we need is a community village – cottages together in a group; they are benefitted by being able to share, if someone is sick in a cottage, the adjoining cottage can work with them, and they can go out; if there is violence in a cottage there is staff on site who can come and help; a whole lot of reasons like that. I got word from the Minister's office that he had opposition from all the advocacy groups, which is because they don't know anything about [autism] – the groups are dominated by physical disability advocates... In the end, the Minister approved the idea of a community village, against all the opposition... So we won the battle and they all moved into the village in December (2010), which is located in the [Hospital] grounds, as the hospital had a lot of ground, but not up where the wards of the hospital are, but at the back of the hospital which fronts a domestic road. (8-9)

Thus, deinstitutionalisation did not occur for these individuals with a diagnosis of ASD until 2010. Furthermore, most other major facilities in NSW housing residents with some form of developmental disability/learning disability (such as Rydalmere, Marsden and Stockton) have yet to be "deinstitutionalised" according to Mr D. Yet crucially, many of the disability advocacy groups are critical of these newly set up community villages, arguing that they still resemble an "institution." Mr D, who has had numerous dealings with these groups, elaborates on the debate that he and these groups are currently embroiled:

> I consider we have deinstitutionalised the Lachlan Centre [now known as the Norton Road Specialist Supported Living] with the village, but the advocacy groups don't think so. People with Disabilities (Peak Advocacy Group) are taking the Department to court on that issue, saying it doesn't comply with the Disability Services Act; and I think they will lose, because it is a valid defence to say we have residents with five residences; they will argue because they are side by side, it constitutes an institution. So, there is a big argument going on at the moment. It's been in court for over a year on procedural arguments...We've got the village and I have not been daunted by the law, and I can tell you there will be more villages.

Mr D explains that for many individuals with developmental disabilities, and particularly autism, the routine and security of the hospital or "institutional" environment has become a way of life for the residents, and to suddenly uproot them, especially those that have resided in such a setting for forty years or more, would be very distressing:

> They...have some residents who have been there a lot longer, [Rydalmere] is older [than other hospitals]; and so they have some residents who would probably be all right in the community; but, they've been there now for perhaps 40 years and they are into their late 60s - 70s, I believe one is 90; and the feeling is, that's their community, and it would be very traumatic for them to

> be transplanted into a community cottage and try and make contacts there. So there's an argument that there is a group who ought to be kept together, because of their affinity to the others, as in a way that is their community; and then that raises the possibility of not just building accommodation but what we need is a geriatric facility.

Mr D's beliefs have also been expressed by other parents of individuals residing in an institutional setting. For example, Manning (2008) quotes the mother of an resident with autism, Rosalie, who supported the proposal to relocate the Kew Cottages residents to a cluster-style housing estate. While this idea was rejected by the Government and advocacy groups on the basis that such a development would perpetuate the segregation of Kew residents from mainstream society, Rosalie argued that a strong sense of "community" existed amongst the residents and staff at Kew and that this was worth preserving: "there's a great deal of talk around these days...about developing communities, *this was our community*, and it's all taken away from us now and it's very sad" (Manning 2008: 232).

These accounts demonstrate that while the discourse of "hope" and "cure" surrounds the classification and understanding of autism in *childhood*, and has made possible the formation of the autism matrix, the reality of conceptualising, treating and caring for individuals with autism and developmental disabilities in adulthood remains very much below the public radar.

Conclusion

This chapter tells the Australian version of the story of how the category of mental retardation was transformed into a label – autism – that embodied a discourse of hope and created a new space in health care provision which brought with it a group of re-invented therapies and treatment approaches. It demonstrates that the development of a disorder or a label such as autism is historically contingent, subject to revision, redefinition and reconstitution, and above all, is a highly messy process.

CHAPTER TWO

The "seeable" and "sayable" body: The changing knowledge structure of the medical profession and the impact of the evidence-based medicine movement

> A classification is a way of seeing the world at a point in time...No classification is ever perfect. (World Health Organization 1993: vii)

Introduction

The statement above captures the imperfect, unstable and evolving nature of diagnostic categorisations. Since the first descriptions of "early infantile autism" in 1943 by Leo Kanner, the diagnostic category of autism has been reworked and redefined to reflect "this year's shorthand for this year's hypotheses about the nature of the things that interest us" (Ellard 1992: 548). This literature review provides important background on medicine's preoccupation with standardised diagnostic practices and the "gold standard" of evidence-based medicine (EBM) and randomised controlled trials (RCTs), shedding light on how this reductionist biomedical practice came to be and outlining some of the key problems associated with it.

From bedside medicine to the birth of the clinic: "What is the matter?" becomes "Where does it hurt?"

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 can also be described as when *hospital medicine* (or a "medicine of tissues") replaced the long-practiced *bedside medicine* (or a "medicine of symptoms") (Armstrong 1995; Long 1992; Peerson 1995; White 2002). *Bedside medicine* reigned during the period from the Middle Ages to the eighteenth century and was characterised by a dependent doctor seeking the patronage of the socially superior patient within the family home (Pickstone 1993). Doctors heavily relied on their reputation and were therefore motivated by their need to retain favour with the patient (White 2002). During this time, medicine was a:

> dialogue with 'the sick man' – a discussion of his or her 'total symptom complex' in a language shared by the patient. The aim was prognosis and therapy, reached by the exercise of 'judgement'. (Pickstone 1993: 436).

Armstrong (1995) refers to bedside medicine as a *two-dimensional model of illness*: the patient describes their symptoms, such as a headache or abdominal pain, which are then viewed as the illness to be treated. This model of medicine was favourable due to the minimal cost to the state and the reduced spread of disease (Peerson 1995). However, with the Industrial Revolution and urbanisation that came with it during the nineteenth century, the number of sick or destitute people without families to house them and take care of them rapidly increased. The focus therefore turned to the need to house these individuals in hospitals where they could receive more equitable health care. This marked the turn to *hospital medicine* or the "birth of the clinic" (Peerson 1995; White 2002). Armstrong (1995) refers to hospital medicine as a *three-dimensional framework*, whereby symptom, sign and pathology are involved in the diagnostic process. While the patient identifies their symptom(s), as they did within the bedside model of medicine, the doctor, through their clinical examination of the patient, adds to this information by providing an "intimation of disease," that is, a sign (394). Armstrong (1995) explains further:

> For example, the patient's symptom of abdominal pain might be linked to the sign of abdominal tenderness that the physician could discover; but neither symptom nor sign in itself constituted illness: both pointed to an underlying lesion that was the disease...the 'clinical picture' as drawn by both symptom and sign enabled the pathology that existed beneath experience to be inferred. (394)

Thus, this three-dimensional approach allowed the medical ideology of the time to change profoundly in this shift from the "medicine of symptoms" to the "medicine of tissues". Under this model, colleagues and medical teachers were the key source of prestige for doctors; and the patient-doctor dynamic changed, whereby the patient became dependent upon the "professional doctor" (White 2002). Where previously the doctor had been concerned with the "sick person" as a whole, doctors were now interested in an "object-centred medicine"(Pickstone 1993: 436): where disease was conceptualised as "a problem of the pathology of a specific organ, distinct from the whole existence of the individual" (White 2002: 121). This objectification of the patient replaced the former element of subjectivity present in bedside medicine (that is, the attention to the patient's personality, culture, beliefs and their own perception of their illness) (Peerson 1995). Thus, patients, dependent upon the expertise and skills of the doctor, became the guinea pigs under the clinical gaze: "available in life for new kinds of clinical examination, and available in death for post-mortem examinations on an awesome scale" (Pickstone 1993: 436).

Central to this objectification of the patient is the clinical "gaze". For Foucault, the gaze relates to the idea that knowledge is constructed at the intersection of seeing, speaking, touching, hearing and knowing (Long 1992; Osborne 1992). Foucault (1973) stresses in the preface to *The Birth of the Clinic* that the ideological rupture in medicine that occurred in the early nineteenth century was above all tied to the "*qualitative* precision of description",

rather than the "rationalization, scientization or even the...quantification of medical discourse" (Osborne 1994: 34). Foucault states: "the precise, but immeasurable gesture that opens up the plenitude of concrete things, combined with the delicate network of their properties to the gaze, has produced a more scientific objectivity for us than instrumental arbitrations of quantity" (Foucault 1973: xiv). The concept of gaze was also brought on by medicine's interest in autopsy during the eighteenth century: seeking an "explanation for the nature of disease that occurred within the body, but which was not apparent on the surface" (Peerson 1995: 109). Thus they became concerned with making visible the invisible; changing the focus of medical thought from the living to the dead (Peerson 1995). In *The Birth of the Clinic,* Foucault (1973) demonstrates that by the early nineteenth century medicine was focused on this "clinico-pathological correlation" and embraced a "three-dimensional probing from symptomatic surface into diseased interior" (Armstrong 1995; Long 1992: 137). Importantly, this medical and scientific knowledge can be worked and manipulated so that the diseased body can be both "seeable" and "sayable":

> At the beginning of the nineteenth century, doctors described what for centuries had remained below the threshold of the visible and the expressible, but this did not mean that, after over-indulging in speculation, they had begun to perceive once again, or that they listened to reason rather than imagination; it meant that the relation between the visible and invisible—which is necessary to all concrete knowledge—changed its structure, revealing through gaze and language what had previously been below and beyond their domain. A new alliance was forged between words and things, enabling one to *see* and *say*. (Foucault 1973: xii)

Thus, the "gaze" is made up of the tools and techniques of clinical examination: "inspection, percussion, palpation and auscultation" (Armstrong 1995: 394), that is, examining the body through observation, tapping or striking its surface, touching, and listening. This gaze has allowed the mapping of the human body, and through the post-mortem, has led to identifying "the exact nature of the hidden lesion" (Armstrong 1995: 394).

While Foucault (1973) acknowledges that this rupture in medical ideology led to a more enlightened form of health care delivery, he also recognises that, through epidemics, doctors began to cast a "multiple gaze" upon populations which "brought power to the medical profession on a scale not previously experienced" (Peerson 1995: 112). This epidemiological gaze ensured medicine had a wider jurisdiction, enabling vast surveillance and control over society. Armstrong (1983) outlines how this epidemiological gaze persisted through to twentieth century medicine in Britain. *First*, health became a social concern, rather than a private one. *Second*, national registers were created in which information about births, deaths, marriages and notifiable diseases were documented (such as tuberculosis). *Third*, in-depth patient medical histories began to be documented for the purposes of monitoring mortality and morbidity rates. *Fourth*, surveys were deployed by medical researchers to collect information about the population – statistics, randomised

controlled trials and placebos all became commonplace techniques. *Fifth*, notions of "normal" and "healthy" versus "abnormal" or "pathological" were included in checklists, criteria, diagnostic tools to aid in classification of the patient. Foucault outlines the beginnings of this notion of medical normality in the nineteenth century:

> Medicine must no longer be confined to a body of techniques for curing ills and of the knowledge that they require; it will also embrace a knowledge of *healthy man*, that is, a study of *non-sick man* and a definition of the *model man*. In the ordering of human existence it assumes a normative posture, which authorizes it not only to distribute advice as to healthy life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives. (Foucault 1973: 39-40)

The diagnosis of autism spectrum disorders (ASDs) is very much reliant on concepts of normalcy and comparisons to "the norm". The standardised tools used in the diagnosis of ASDs, such as the Autism Diagnostic Interview-Revised (ADI-R), involve the observation of behaviours which are then scored against a checklist of what is considered normal and abnormal behaviours. For example, in the DSM-III(R) (American Psychiatric Association (APA) 1987) the criteria for autistic disorder states: "Consider a criterion to be met *only* if the behavior is abnormal for the person's development level".

Georges Canguilhem: The normal and the pathological

Georges Canguilhem's (1989) distinction between the normal and the pathological, on the one hand, and the norm and normativity, on the other, are central concepts used in this thesis to make sense of the autism diagnostic process. Canguilhem observes that medicine's perspective on health is based on the notion that disease is a quantitative deviation from a fixed norm (a constant) and to return a patient back to health, medicine must focus on re-establishing the norm from which the patient has strayed. However, Canguilhem (1989) argues that this distinction cannot account for the lived experience of health. A norm, within Canguilhem's qualitative conception of health, instead represents a desired situation rather than a statistical average. Here, the *norm* is the condition of the organism at any one time, and it is *dynamic*: it actively maintains its balance and is continually adjusted (Zajicek 1995: 333). This ability to adapt and change is described by Canguilhem (1989) as being "normative". Thus, *normativity* is the historical and evolutionary rejection of abnormal states and depends upon the adjustment and maintenance of norms. For Canguilhem (1989), health is characterised by flexibility, mobility, variability, and normativity; disease is characterised by intolerance, stasis, conservativeness, and rigidity. Normal, therefore, is not the statistical average, but rather the creative ways that organisms adapt to their environments.

Canguilhem (1989) stresses the importance of context and qualities of individual feeling when examining illness, rather than medicine's preoccupation with quantitative expressions

of biological, biomechanical, chemical or genetic abnormalities. Context is central to his argument, given health and illness are defined by the organism's ability to adapt to new environments, and thus establish new norms. Significantly, Canguilhem delineates between two types of norms: vital (biological) norms and social norms. For an organism, vital norms come inherently with it and the environment in which it lives. Social norms, in contrast, are actively set:

> In a social organization, the rules for adjusting the parts into a collective which is more or less clear as to its own final purpose – be the parts of individuals, groups or enterprises with a limited objective – are external to the adjusted multiple. Rules must be represented, learned, remembered, applied, while living in an organism the rules for adjusting the parts among themselves are immanent, presented without being represented, acting with neither deliberation nor calculation. (Canguilhem 1989: 250)

Canguilhem emphasises, however, that despite this distinction, vital norms and social norms are inextricably intertwined. For example, Canguilhem (1989) uses the case of height – something one would assume to be firmly classed as a vital norm – to demonstrate how vital and social norms are in fact interlinked. In some populations, average height may reflect societal preferences for a certain height: for instance, extremities in height may be devalued leading to these people being isolated and finding it more difficult to reproduce. Food habits and lifestyle habits can also impact height: studies have demonstrated that in cultures where smoking is widely practiced, average heights are impacted. These factors then play a role in affecting the statistical average of what appears to be a biological fact.

This distinction between, and simultaneous entanglement of, vital norms and social norms is important because it demonstrates that the creation of new norms is not just a biological process, but rather a complex interaction of social, biological, cultural, historical and political processes going on within an individual's environment. Thus, when distinguishing between normal and pathological states, we must also take into account this complex environmental and contextual milieu in which the individual exists.

Later in this thesis I will demonstrate the utility of Canguilhem's (1989) qualitative reconceptualisation of the normal and the pathological in the way that it allows us to rethink the current medical approach to the diagnosis of autism in the clinical encounter. However, to achieve this, we must first understand the drive to standardise that dominates medical approaches, particularly when it comes to diagnosis and medical research. It is this movement away from the individual towards the social; the movement away from a medicine concerned with "a body of techniques for curing ills" towards a medicine of "normal" versus "abnormal" that the discussion now turns. It is through Foucault and Canguilhem's work that one can understand the shift towards classification and standardisation within medicine, and see the foundations laid for the use of diagnostic tools and EBM.

Standardisation in medicine

As outlined above, early nineteenth century medicine was characterised by a clinical gaze that penetrated beneath the surface of the visible (that is, the body of symptoms) to the inner workings of the invisible body. The knowledge created by this probing gaze prompted the conscious and unconscious creation of a system of order, a way of understanding, manipulating and applying this new information. Thus,

> ...a ubiquitous set of tiny, invisible things were being negotiated and sewn into the social fabric. These were formal, commodified classifications and standards, both scientific and commercial. People classified, measured, and standardized just about everything – animals, human races, books, pharmaceutical products, taxes, jobs, and diseases. The categories so produced lived in industry, medicine, science, education, and government...Most of these [standardizing] activities became silently embodied in the built environment and in notions of good practice. (Bowker and Star 1999: 17)

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 and 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). These standards make up what is today known as *evidence-based medicine* (EBM). Within medicine, EBM is understood as "the conscientious, explicit, and judicious use of current

best evidence in making decisions about the care of individual patients" (Sackett, Rosenberg, Gray, Haynes, and Richardson 1996: 71). It is disseminated through clinical practice guidelines and standardised tools which aim to "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).

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 and Berg 2003). But the beginnings of standardisation in *medicine* are said to have begun 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 and 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 and 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 re-emerged as the 'product of a global economy'" (Timmermans and Berg 2003: 12). Yet Timmermans and Berg (2003) note a divergence in the historical motivations behind standardisation within the medical profession. 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 and Berg 2003: 13). However, during the 1980s, standardisation or EBM, focused on the content of the work itself – it aimed to regulate medical expertise and medical decision making (Timmermans and 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. (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, and 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 (Gottweis, Salter, and Waldby 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, Salter, and Waldby 2009). Rather, according to Gottweis 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. 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 and 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 and 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. Indeed, in chapters four, five and six I elaborate on this disparity between the *theoretical/discursive* stance of the medical profession on the diagnosis of autism and the actual *practice* of diagnosing autism 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 and 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 and 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 and 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 and Mauck 2005), identify three key figures as forming the foundations of what is now widely known as EBM: Archie Cochrane, John Wennberg and David Sackett. 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 and 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 and 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. 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 and 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 and 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 and 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 and 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 and Luft 2000: 2158), rather than their scientific merit. Rennie and Luft (2000) state:

> 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 and Luft 2000: 2158).

Much of the literature addressing what is sometimes described as a "paradigm shift in health care" (Timmermans and Berg 2003: 18) has been divided into supporters (see Rosenberg and Donald 1995; Sackett et al. 1996) and critics (see Mykhalovskiy and Weir 2004; Smith and Pell 2003; Timmermans and 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 and 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. (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. 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. Six 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 three illustrating the perceptions and opinions of *psychiatrists* and *paediatricians*.

McDonald, Waring and Harrison (2006) provide an examination of the attitudes of hospital doctors and managers in the UK towards 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, Waring, and Harrison 2006: 194). They 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 in McDonald, Waring, and Harrison 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, Waring, and Harrison 2006: 198)

Furthermore, in another study conducted by McDonald and colleagues (2005), in which the perspectives of UK 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 Australian health practitioners (ten doctors, four 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 discusses 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 and 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 (2005) 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. (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.

Similarly, Whooley (2010) draws on in-depth interviews with 21 US psychiatrists to explore how the DSM is used in practice, and demonstrate the contradictions and negotiations involved in the psychiatric diagnostic encounter. Whooley found that a tension exists for psychiatrists between "the desire for autonomy in practice and the professional goal of legitimacy within the system of mental health professions" (452). Thus, to establish autonomy within their profession, psychiatrists develop what Whooley terms "workarounds" to essentially undermine the DSM in the diagnostic encounter. Workarounds include using alternative diagnostic classifications, tinkering with diagnostic coding (numbers) on paperwork, and engaging in diagnostic negotiations with patients. Importantly, these findings raise questions about the supposed monolithic and powerful status of the DSM in medicine and psychiatry, and the notion of formal, standardised diagnoses that go hand-in-hand with this document. Whooley's (2010) study provides important evidence that the application of the DSM, in everyday practice, is complicated, negotiated and contested.

Another important finding of Whooley's (2010) study is the way that psychiatrists invert the reductionist biomedical model of "first diagnose, then treat". In reality, the psychiatrists apply their own classification system, essentially whittling down 300 diagnoses into two categories: mood disorders (axis 1) and personality disorders (axis 2). Significantly, the purpose of this binary distinction is not diagnostic classification, but rather "reflects different emphases determined by the psychiatrists' interpretations as to what the proper focus of the therapeutic intervention should be" (Whooley 2010: 459): For mood disorders, medication; for personality disorders, psychotherapy. These psychiatrists discard the standardised diagnostic criteria in favour of "exercising professional discretion as to the type of treatment the patient may need" (Ibid: 459), and thus "treatment does not follow diagnosis; diagnosis follows treatment" (Ibid: 459). Here, psychiatrists are able to exercise their clinical autonomy and judgement, and prescribing medications plays an important role

in enabling this autonomy. This treatment-centric approach practiced by psychiatrists is also the focus of patients. Whooley (2010) explains:

> Because the DSM is a public document, patients also draw on it. Patients periodically come to the clinical interaction with a DSM diagnosis in mind. The increase in internet-based resources and direct-to-consumer drug advertising allows patients to be more proactive with their doctors. Because these resources tend to present mental disorders as diseases with specific cures, patients come to expect their psychiatrist's orientation to conform to this view. (458)

In Chapter Six I extend these ideas by exploring the role of the pharmaceutical industry in promoting the off-label – that is, "for medical indications that have not yet been tested" (Cooper & Waldby 2014: 215) – use of SSRIs for repetitive behaviours in autism. I examine how this use of off-label drugs is extremely lucrative for pharmaceutical companies – the way they are able to create and expand their markets via "making allusions…to nonapproved uses" (Rosewarne 2013: 136). By linking the off-label uses with the drug's side effects, the pharmaceutical company is legally able to indirectly promote the drug for other uses. In doing so, they are able to include more and more indications under one standardised treatment, thus getting the most out of the evidence-base, and allowing the drug's extension at the fringes (de-standardisation) through practice rather than "evidence". In fact, one could argue that doctors' reluctance to completely conform their practice to EBM is leveraged by the pharmaceutical industry. This analysis sheds light on the way that we view the clinical trial studied for this thesis, and the labour that is being carried out within it by both clinicians and parents.

The final empirical study I would like to examine highlights the important interplay between using diagnostic tools and drawing on clinical experience. Timmermans and Angell's (2001) study (also discussed in Timmermans and 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 and Berg 2003: 143). They 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 and 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. 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 and 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". (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 and 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 and Berg 2003: 163)

These studies provide important context for this thesis, indicating that within medicine there exists an established research-to-practice disconnect. While EBM, guidelines and standardised diagnostic documents are presented within the medical context as the gold standard of clinical practice, their application in the everyday clinical encounter tells another story. In reality, these documents, while still used and referred to, are also tinkered with, worked-around, manipulated and negotiated with to fit with the "do-able" job. This is highly relevant to the diagnosis of autism given the heavy emphasis within medical, psychological and psychiatric research on the DSM and standardised diagnostic tools such as the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS).

Diagnosis as an apparatus: Labelling theory and the "looping effects of human kinds"

Given the emphasis of this thesis on the use of standardised tools in the diagnostic process of labelling a child with autism, it is important to explore this notion of labelling and what it means within a sociological context. Labelling theory holds that if you attribute the label of "autism spectrum disorder" to a child and then institutionally confirm that label, then the labelled individual will adopt stereotypical patterns or key characteristics of "autistic behaviour". This theory is applied to individuals. This work sits within the field of the sociology of diagnosis, with particular focus on the psy-sciences and psychiatric diagnoses and their interaction with changing norms and classifications (Jutel & Dew 2014; Nettleton 2013; Pickersgill 2011). A key focus of the sociology of diagnosis is the way in which diagnostic categories are made up through professional, patient and political claims making and debate. Thus, notions of "normal" and "pathological" become distinguishable to individuals and society, and in turn play an important part in shaping the way that society relate to various treatments (such as medicating or therapeutic approaches) and negotiate situations such as institutionalisation, discharge and access to services (Hacking 1995; Pickersgill 2011). The DSM demonstrates an important example of a diagnostic text containing many contested categories and has come to shape, and be shaped by, a wide range of social actors and institutions. Especially relevant to this thesis, Annemarie Jutel and Kevin Dew (2014) point to the role of the pharmaceutical industry as an "engine of diagnosis" which helps to fuel changes to the American Psychological Association's (APA) nosology and then becomes further entangled in the medicalisation processes that back "pharmaceuticalisation." As a result, diagnostic focus shifts to a reframing of categories or pathologies in terms of the brain and pharmaceutical intervention – a theme I explore in more depth in Chapter 4.

Hacking's extension of labelling theory through his notion of "the looping effects of human kinds" provides an important foundation for understanding the key arguments within the field of the sociology of diagnosis. For Hacking (1995) "human kinds"[6] are:

> [K]inds about which we would like to have systematic, general, and accurate knowledge; classifications that could be used to formulate general truths about people; generalizations sufficiently strong that they seem like laws about people, their actions, or their sentiments. We want laws precise enough to predict what individuals will do, or how they will respond to attempts to help them or to modify their behaviour. (352)

Importantly, Hacking (1995) distinguishes between the classification of *human kinds* and the classification of *natural kinds*. Hacking explains that for natural kinds, if one were to call a

[6] In his later works, Hacking (2007) distances himself from the term "human kinds" claiming it was confused and unhelpful. He clarifies that the "kinds of people" he discusses are those studied by the "human sciences," that is, social sciences, psychology, psychiatry, and clinical medicine (Hacking 2007: 293).

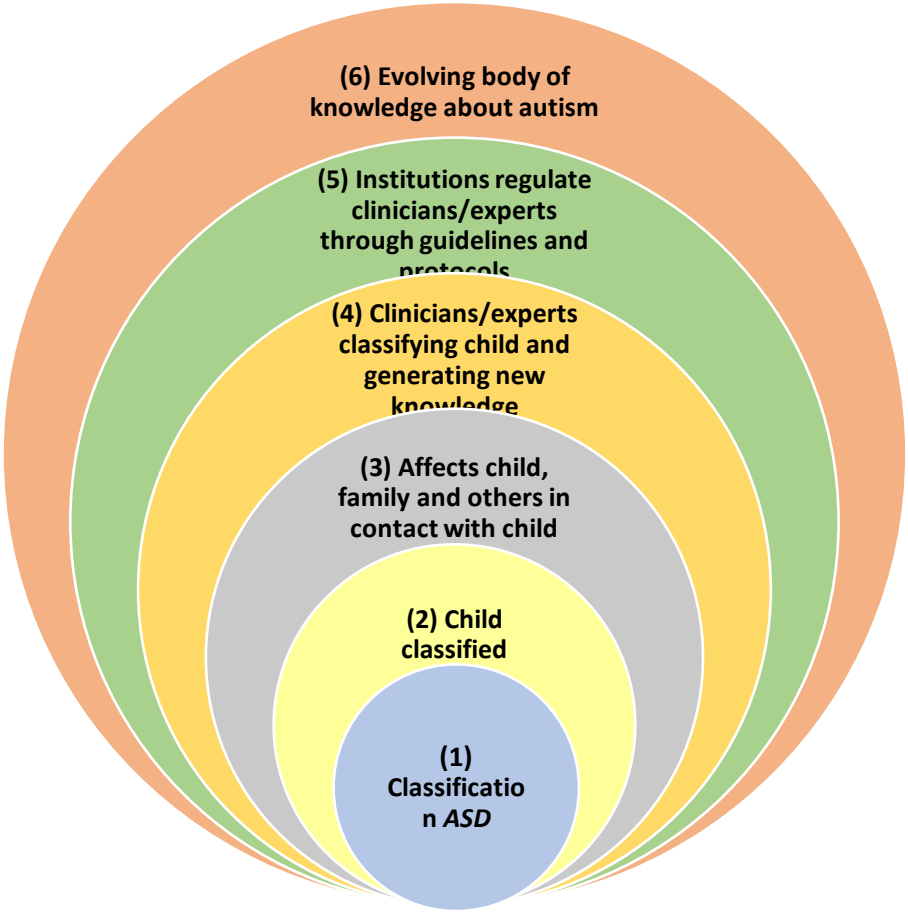
red, round, edible and crunchy object an apple, and they were to class this as a fruit, it would make no difference to the object itself what it is labelled or how it is classified. It would, of course, make a difference to us in terms of how we treat the object: whether we eat it or not, what other food it compliments, how to eat it and so on. Alternatively, for human kinds, if one were to label a child "autistic," a variety of reactions are likely. First, the label of "autism" may make the child's family, other children, teachers, clinicians and so on treat and relate to the child differently. Second, the label of "autism" may also affect the child's perception of him or herself due to the often morally loaded nature of human kinds. Both of these factors can contribute to changes in the definitions of the label or "kind" itself.

For Hacking, once individuals have been classified or labelled, they are in turn changed by this label or "kind" due to its effect on and interaction with them. This can, in turn, change the very characteristics and essence of the label or classification itself. Thus, professionals/clinicians are then forced to adapt and evolve these classificatory categories. Interestingly, even the causal relationships between the individual and the label can be adapted, forming new "essential definitional connections" (Hacking 1995: 369). This process of changing categories/labels can also change how society thinks about those that are labelled. This is what Hacking calls the "looping effect": labelled individuals rethink who they are and what their label means, the label/category changes as a result forming new "causal knowledge" and jettisoning "old causal knowledge" (Hacking 1995: 369). Hacking (2007) goes on to explain:

> We think of these kinds of people as given, as definite classes defined by definite properties. As we get to know more about these properties, we will be able to control, to help, to change, or to emulate them better. But it is not quite like that. They are moving targets because our investigations interact with the targets themselves, and change them. And since they are changed, they are not quite the same kind of people as before. The target has moved. That is the looping effect. Sometimes our sciences create kinds of people that in a certain sense did not exist before. That is making up people. (Hacking 2007: 293)

Importantly, the label attributed to the individual forms only one part of the complex dynamic involved in the diagnostic process. The diagnosis of autism, for example, involves many actors (moving from the specific – the child and his/her family – to the more general – the bodies of knowledge about autism itself) that contribute to this looping effect (see Figure 2.1). The *classification* of a child within the autism spectrum disorder (ASD) category leads to the label of autism with a severity ranking between 1 (requiring support) to 3 (requiring very substantial support) for social difficulties and repetitive behaviours (see circle 1, Figure 2.1), which in turn can *affect the child* classified (see circle 2), as well as their *family* and those that interact with the child (see circle 3). I have added the family of the child, as their role in the looping effect of the classification of ASDs is a crucial one, as will be discussed in chapters five and six (see for example Eyal et al. (2010)). The *clinicians or*

Figure 2.1: The Looping Effect of Classification - Formulated from information provided in Hacking (1995; 2007)



experts (see circle 4) who classify, study, and treat those labelled with autism also affect this diagnostic dynamic through their own backgrounds, interpretations, and interests which shape their clinical gaze. These experts generate knowledge through discovery, judge its scientific rigour, and then apply it in practice. Thus, they routinely contribute to, and act on, circles 1, 2, 3, 5, and 6 in Figure 2.1. Furthermore, the *institutions* (see circle 5) producing standardised tools and practice guidelines implement limitations and regulations which these clinicians and experts are expected to comply with. Hacking clarifies that by "institutions" he means formally organised, structured entities. Enveloping all of these actors is the "*evolving body of knowledge*" (Hacking 2007: 295) (emphasis added) (see circle 6, Figure 2.1) about autism which comes from a vast variety of scientific groups, as well as popular science, and the media. This evolving body of knowledge can be seen through Latour's black boxes and the many examples of these black boxes within the field of understanding autism spectrum disorders. Thus, "names of classes, and the people who fall under them, interact through larger interactions in the thriving world of institutions, experts, and their knowledge" (Hacking 2007: 297). The six elements illustrated in Figure 2.1, below, are all interactive and play an active and crucial role "in looping effects and making up people" (Hacking 2007: 298).

Kanner (2007) uses the example of how the *autism spectrum* came to be through the classification of Asperger's Syndrome (AS), which today no longer exists as a diagnostic category in the DSM 5. Despite the fact that Hans Asperger, a German Paediatrician, first described Asperger's Syndrome in 1944 (in German), AS remained largely unknown until Lorna Wing introduced it to the English-speaking world in 1981. AS was then officially included as a diagnostic category in 1994 in the DSM-IV (American Psychiatric Association 1994), and then removed in 2013 from the DSM 5. Thus, Hacking (2007) explains:

> We have *(a)* a new classification, a new kind of person whom it is possible to be. *(b)* Individual people themselves change, as they are recognised to be of that type, or see themselves as high-functioning autists. *(c)* All of this requires institutions, including schools, social and health services, which disseminate and revise the current *(d)* knowledge. And there are *(e)* experts, including Lorna Wing. The institutions are vastly...ramified and the experts from...diverse fields... (304).

Hacking (1995) goes on to explain:

> Responses of people to attempts to be understood or altered are different from the responses of things. This trite fact is at the core of one difference between the natural and human sciences, and it works at the level of kinds. There is a looping or feedback effect involving the introduction of classifications of people. New sorting and theorizing induces changes in self-conception and in behaviour of the people classified. Those changes demand revisions of the classification and theories, the causal connections, and the expectations. Kinds are modified, revised classifications are formed, and the classified change again, loop upon loop." (Hacking 1995: 370)

Hacking (2007) lists ten "engines of discovery" which he describes as imperative to the practice and progression of science today: (1) *counting* – for example, comparing rising rates of autism cases; (2) *quantification* – for example, while autism resists quantification it is believed by clinicians that the autism spectrum is comprised of a "quantitative range of disabilities" (Hacking 2007: 308); (3) *creating norms* – for example, standardised tools and guidelines which measure the child being diagnosed against "normal" data; (4) *correlation* – for example, "We try to correlate autism with everything....The less we know, the more we search for correlations in the hope that they will direct us to something important." (Hacking 2007: 309); (5) *medicalisation* – for example, autism was originally defined by a child psychiatrist and is therefore considered to fall within the domain of medicine; (6) *biologisation* – for example, autism is today understood by the scientific community as originating from biological and neurobiological problems which in turn provides families with a legitimate mental disorder that needs to be treated; (7) *geneticisation* – for example, the drive to link the biological with the genetic can be seen in the vast body of literature in search of the "autism gene." Interestingly, this research in which deviance is linked to genetics has been explored over the past century, notably through the search for the gene that produces criminal behaviour; (8) *normalisation* – for example, behavioural therapies for autism aim to shape autistic behaviours into more socially appropriate or "normal"

behaviours; (9) *bureaucratisation* – for example, screening for developmental delays occurs early on in a child's life through visits to the doctor, at pre-school and school. Once identified as developmentally delayed, children are assigned to special services. Hacking (2007) states, "Autism is among other things a bureaucratic concept, used in the administration and management of awkward schoolchildren" (311); and (10) *reclaiming one's identity*, that is, "resistance by the known to the knowers" (Hacking 2007: 305-6) – for example, the formation of autism liberation groups, known as the neurodiversity movement, have reacted to this medicalisation, normalisation, and bureaucratisation of their difference and have accordingly tried to reposition themselves as experts and reformulate new institutions. All of these engines impact upon the looping effect described above. Indeed, it is because of these engines that the interactions between the elements of the looping effect framework have evolved so rapidly.[7]

Latour and the "construction of scientific facts"

Bruno Latour's work provides an apt starting point to examine the relationship between science, technology and society, and the drive for standardisation within this milieu. Latour's work can best be described as the ethnographic study of practices: he is not interested in searching for explicit knowledge already in the minds of the subject, rather, he is interested in locating knowledge "primarily in activities, events, buildings, instruments, procedures, and so on" (Mol 2002: 32). Latour's work seeks to describe the diversity of practices and the complex relationships involved in what he called "the construction of scientific facts" through direct observation of the scientific laboratory (Latour and Woolgar 1986).

Central to Latour's work is the idea that the natural and the social are intertwined and are difficult to differentiate and separate. In *Science in Action* (1987) Latour breaks down traditional divides between science, society and technology, as well as the notion of something "inner" and "outer." For example, Latour (1993) (in Mol 2002) examines several versions of the natural/social distinction, one of which is the subject/object divide. The subject, a social entity, "actively knows," and the object, a natural entity, is "known". Latour places these concepts can be seen as two poles on a spectrum, "which have many quasi subjects and quasi objects, mixtures, in-between them" (Latour 1993 in Mol 2002: 31). Latour holds that instead of jumping between the poles on the subject/object spectrum (that is, "jumping between the ideas that reside in the minds of subjects and some objective

[7] The recent work of Daniel Navon and Gil Eyal (see Navon 2011; Navon & Eyal 2014; Navon & Eyal 2016) provides an explanation of looping genomes and the diagnostic change and generic makeup of the autism population. Their work builds on Hacking's framework of "dynamic nominalism" to demonstrate how knowledge about biological etiology can interact with the "kinds of people" set out by diagnostic categories in ways that "loop" or modify each element over time. Their historical analysis demonstrates how "geneticisation" played an important role in bringing together autism as a biosocial community and how evidence from genetics research later made an important contribution to the diagnostic expansion of autism.

reality *out there*") one should recognise the interaction and interconnectedness of the natural and the social, the subject and the object, and of the persistent uncertainty when practising in this milieu (Mol 2002: 31). In Latour and Woolgar's (1986) *Laboratory Life*, reality or nature does not have fixed traits. For them,

> Scientific activity is not 'about nature,' it is a fierce fight to *construct* nature. The laboratory is the workplace and the set of productive forces, which makes construction possible. Every time a statement stabilizes, it is reintroduced into the laboratory (in the guise of a machine, inscription device, skill, routine, prejudice, deduction, program, and so on), and it is used to increase the difference between statements. The cost of challenging the reified statement is impossibly high. Reality is secreted (243).

Furthermore, Latour and Woolgar (1986) argue that the notion of "scientific discoveries" is in fact misleading, claiming that these discoveries have been constructed through social processes and that before these causal social processes these discoveries or facts did not exist.

The importance of the social in the practice of science is discussed at length by Latour (1988) through the example of the pasteurization of France. This example illustrates how a scientific discipline changed a society, however, Latour simultaneously makes the point that no matter how influential a structure may be (in this case, vaccination), "science does not have the power to impose its order on society" (Mol 2002: 62). Thus, Pasteur's work did not change society through its power or scientific rigour, but through a process of "association" (Latour 1988). For Latour, all the actors involved in this process of change were active entities. From the laboratory, Pasteur's vaccination practices spread throughout French farms quite quickly due to his own movement between the lab and the farms. Pasteur, in doing so, had established a strong alliance between the lab and farmers, highlighting that they had much to gain through this alliance: through vaccination their cows would be protected from anthrax (Mol 2002). However, this new scientific discourse was unable to penetrate the clinic. Doctors in private practice did not stand to gain anything through this alliance with Pasteur's lab because they stood to lose professional territory by handing over patients to other professionals to be vaccinated. As Mol (2002) points out, "Private doctors only started to "believe" in serums once the Pasteur laboratory put these on the market, and the doctors were free to use them in their own surgeries when they considered it appropriate" (64).

This example clearly highlights Latour's key argument: science does not possess the power to impose itself; change that comes about through a new scientific idea is driven by actors outside the laboratory who "associate" themselves with this idea. These actors form "chains of associations" which in turn comprise networks. The networks may be long or short, strong or weak, yet the strength of the network depends on what sustains the associations (Mol 2002). By Latour's (1987) account, when one follows scientists and engineers through

society, one can find a network of alliances that involve more than people and societies. These alliances can include machines and devices created by the scientists, or perhaps the disorder, disease or microbe they discover. These discoveries or creations, for Latour (1987), are also actants that play a vital role in these alliances or associations.

This notion of associations, chains and networks fits in particularly well with Eyal and colleagues' (2010) conception of the "looping dynamic" (see Figure 1.4, discussed in Chapter One). The spirals in this looping dynamic can be seen as associations made between actors outside of the clinical paradigm (essentially, those clinicians or researcher creating the standardised documents used to diagnose autism) and those within the clinical paradigm. These associations between actors have become quite strong over the past two decades: the alliance between parents, therapists, and now clinicians involved in the diagnosis of this disorder has had an enormous impact on the field of autism.

Latour and the permanently opened "black box" of autism

In *Science in Action*, Latour (1987) uses the metaphor of a "black box" to describe the inner workings of science and technology. A black box in this instance denotes an unquestioned fact. However, Latour is not interested in the black box *product*; rather, he is concerned with the *process* of how the fact became fixed knowledge, or a *closed* black box. He claims that it is through the resolution of controversy and the accumulation of support from colleagues that these scientific facts are made. Importantly, for Latour, nature (or the external world) itself is not of consequence in this process because throughout the controversy it is used to argue both the claims and counter-claims. Thus, for Latour (1987), "all science is artificial in the sense that it is an object of investigation malleable within the bounds of its literature; it constitutes a universe of discourse, not a social institution mediating physical reality and biological processes" (Etzkowitz 1987: 696).

Latour is centrally interested in "science in the making": the *open* black boxes characterised by their uncertainties, controversies, and the various alliances that take place between actors (both things and people). All of these activities find expression through research in the laboratory, the production of scientific papers, and the development of networks. Busfield (2006) highlights that Latour (1987) provides a number of strategies and techniques used in the process of fact creation: "skilfully analysing the rhetorical devices used in academic papers, the use of citation, the creation of allies, as well as the "trials of strength" between the different protagonists that can lead to the closure of a black box." (300). Furthermore, the black box's status of open or closed is dependent upon the people that encounter it: "Do we take it up? Do we reject it? Do we reopen it? Do we let it drop through lack of interest? Do we make it more solid by grasping it without any further discussion? Do we transform it beyond recognition?" (29). Thus,

> Buying a machine without question or believing a fact without question has the same consequence: it strengthens the case of whatever is bought or believed, it makes it more of a black box. To disbelieve or, so to speak, 'dis-buy' either a machine or a fact is to weaken its case, interrupt its spread, transform it into a dead end, reopen the black box, break it apart and reallocate its components elsewhere." (Latour 1987: 29)

Thus, the study of autism spectrum disorders can be seen as a field filled with open black boxes. It is a field that is constantly in a state of flux: whether it is diagnostic research, genetic research, pharmaceutical research, therapeutic research, research regarding the causes of ASDs and so on. Furthermore, it is not only clinicians that are keeping the black boxes of autism research open: parents play a vital and powerful role in this questioning process, as outlined by Eyal et al. (2010) in their book *The Autism Matrix*. The important point to make here, with regards to ASDs, is that "the scientific facts contained in the black box are not well established" (Busfield 2006: 303) and are therefore constantly being re-worked, tinkered with, misused, or misunderstood.

Diagnostic research: The changing categories from the DSM-II to DSM 5

As discussed in Chapter One, the black box of psychiatric/psychological/medical classifications of ASDs through the Diagnostic and Statistical Manual (DSM) has been, and still is, a highly contested, messy and uncertain space. Scientific controversy and the accumulation of research have gone hand-in-hand with the development of the DSM. From the DSM-II, when autism was included within the diagnostic category of childhood schizophrenia, to the DSM-5 (published in 2013), the term "autism" has been re-defined, re-conceptualised and re-arranged within different classificatory categories. Even after all of this "tweaking," the DSM's diagnostic status is far from being a closed black box. As Volkmar and McPartland (2014) point out:

> Concerns about the impact of DSM changes should be considered in the context of sweeping changes occurring in psychiatric research. The director of the National Institute of Mental Health has expressed the organization's intention to move away from research based on diagnostic categories toward emphasis on biological processes that can be applied transdiagnostically (Insel 2013). It is possible that DSM-based groupings may become decreasingly relevant in federally sponsored research. (207-8)

From a medical/positivist perspective, this is perhaps the most fundamental problem with ASD: lacking a consistent and stable definition means that any research involving its causes and treatment will be difficult to test under medicine's hierarchy of evidentiary support. Without this fundamental stability in conceptualisations of its diagnosis, these uncertainties simply get passed on to subsequent research involving the category.

Genetic research: The elusive goal of finding "autism genes"

Despite the many technological and analytical advances in the study of genetics over the past decade (such as the HapMap project and the sequencing of the human genome), there

has yet to be "successful disease gene discovery in psychiatric diseases" (Gupta and State 2007; Losh, Sullivan, Trembath, and Piven 2008: 1-2). This research is often described as "long and arduous,"(Gupta and State 2007) "sparse," "lacking," and "not well documented," (Lichtenstein, Carlstrom, Rastam, Gillberg, and Anckarsater 2010), "fuzzy" and "unstable" (Rabeharisoa and Bourret 2009), while the subject matter is described as "elusive" (Gupta and State 2007; Losh, Sullivan, Trembath, and Piven 2008). Over 30 years ago the first study demonstrating "compelling evidence for a genetic etiology to autism" was published (Folstein & Rutter 1977). Subsequent studies have provided "strong but indirect evidence [supporting] the role of genetic factors in the etiology of autism" (Losh, Sullivan, Trembath, and Piven 2008: 2). Other methods such as genome screens, candidate gene association, examination of structural variants, and studying autism endophenotypes have all been "fraught with several methodological and analytic challenges," which have led to a "scarcity of hard replicated findings to date" (Losh, Sullivan, Trembath, and Piven 2008: 8). Some of these challenges include: "limited power, varying designs, genotyping and analyses, and imprecise phenotypic definitions" (Losh, Sullivan, Trembath, and Piven 2008: 8).

One of the biggest challenges facing these geneticists is that the definition of autism is so wide and varied. Thus, autism presents differently in every child, that is, each individual on the spectrum can potentially display a unique cluster of symptoms. Geneticists' jobs are, therefore, very difficult because of the "phenotypic and etiologic complexity of [autism] itself, which may be compounded by varying phenotypic definitions used across studies" (Losh, Sullivan, Trembath, and Piven 2008: 3).

However, some genetic studies remain optimistic that persistence will lead to "dramatic advances" in this area in the future (see, for example, Gupta and State 2007: 429; Losh, Sullivan, Trembath, and Piven 2008). But for now, according to Rabeharisoa and Bourret (2009) the work of psychiatric genetics,

> Remains (almost) entirely in the future, for current knowledge is far less developed and stabilized, and persistent uncertainties and controversies weigh on the role of mutations and the relevant models of disease. (707)

Pharmacological research: The case of varied medication use among children with ASDs

Medication use amongst children diagnosed with an ASD is substantial. For example, Oswald and Sonenklar (2007) found in their study of 2390 individuals diagnosed with an ASD that 83 per cent of the sample were prescribed drug(s). The seven most frequently prescribed classes of psychoactive drugs were antidepressants, stimulants, tranquilizers/antipsychotics, anticonvulsants, hypotensive agents, anxiolytic/sedative/hypnotics, and benzodiazepines. They found that individuals were prescribed, on average, drugs within 4 different classes (e.g. antidepressants,

anticonvulsants, stimulants and benzodiazepines) over the course of a year. Furthermore, over the course of a year, individuals submitted claims for up to six drugs in the same class. Thus, children with an ASD are "increasingly likely to be treated by a wide range of psychotropic and other medications" (Oswald and Sonenklar 2007: 353). One of the key reasons given for this variety is that "there are no clear guidelines regarding psychopharmacologic treatment of individuals with autism spectrum disorders" (Filipek et al. 2006 in Oswald and Sonenklar 2007: 348). I provide more detail about this pharmacological variety and use of medication amongst children diagnosed with ASD in Chapter Four.

"What causes ASDs?" research: The case of the MMR vaccine

Scientific and medical discussions about the cause(s) of autism always attract media attention: they are often controversial, represent a scientific breakthrough, and have important consequences for how autism is perceived by clinicians, therapists, parents and the lay public. One very controversial "scientific breakthrough" was that the measles, mumps, rubella (MMR) vaccination causes autism. This idea had prevailed within communities made of up families with children on the autism spectrum, such as Generation Rescue, before it entered the domain of science. A common story told amongst these parents went as follows: "My son was a bright, precocious, healthy two-and-a-half-year-old child in 1980 when I took him in for his fourth DPT shot....after that, he regressed physically, mentally and emotionally and became a totally different child" (in Palfreman 2010). These stories became widespread and easily accessible due to the "radically changed social media environment, where YouTube videos spread virally across the Internet" (Palfreman 2010). However, groups such as Generation Rescue did not effectively "get off the ground" until the infamous article, written by Andrew Wakefield – a British gastroenterologist, was published in 1998 in *The Lancet*. His study looked at 12 children with gastrointestinal problems and an autism spectrum disorder, 8 of which developed symptoms of autism *following an MMR shot* (Bedford and Elliman 2010): "Wakefield's theory was that the measles vaccine inflamed the intestines, causing harmful proteins to leak into the bloodstream, eventually damaging the brain and causing autism" (Palfreman 2010). Within the scientific community, it was quickly pointed out that this paper had some fairly fundamental limitations when measured up to the "gold standard" of evidence: it was based on a small case series (only 12 participants), there were no controls, the paper linked three common conditions, and it relied on parental recall and belief (Godlee, Smith, and Marcovitch 2011: 64). Regardless, this article had a dramatic effect on vaccination rates across the world: in some places vaccination coverage fell to as low as 70 per cent (Ireland), and in parts of the U.S. it fell from 92% in 1995-6 to 80% in 2003-4 (Bedford and Elliman 2010).

The reasoning behind these parents' concerns was simple enough: the child was fine, then they got the MMR vaccine, then they developed symptoms of autism. The two events

happen closely together, so it is reasonable to ask whether the two are causally related. However, it is also important to point out that this vaccination is given at an age (15 to 18 months of age) when the first symptoms of autism also begin to appear: when the child is beginning to walk and develop language (Palfreman 2010).

This controversy is particularly interesting because it involves a dialogue between the media, lay persons (active in movements such as Generation Rescue), and scientists. As Finn (2010) points out:

> The publication of [Wakefield's] study, and the controversy and criticism that followed it, coincides with the rapid growth in the scope of Internet information resources and the number of Internet users (Madden 2006), and represents a unique opportunity to explore the intersection of expert and non-expert conversations about an issue of health, science, and public policy, mediated, in part, by a digital information environment.

What is particularly interesting is that this dialogue between experts and non-experts has revolved around the scientific research that was carried out relating to the MMR link to autism. For some health professionals, non-experts have "tainted" the science and its understanding amongst lay persons: "Politicians, lawyers, and journalists have weighed in on the discussion and have confounded the science with emotion, belief systems, and the legal system" (Goldson 2009: 198). The impact of these non-expert views have bled into *what* scientists should study, and in Wakefield's case, *how* they should study it. The black box of "do vaccinations cause autism?" was continually forced open by determined parent groups who suggested different hypotheses when the black box appeared to be closing. Thus, as Doctor Paul Offit, a paediatrician in Philadelphia, points out in the CBS documentary "The Vaccine Wars":

> The hypotheses continue to shift. The first hypothesis, which, you know, people bought into long and hard, is that the combination measles, mumps, rubella or MMR vaccine cause autism. Twelve epidemiological studies showed that that wasn't true. Then the hypothesis shifted to thimerosal, an ethylmercury-containing preservative that was in vaccines, that's no longer in vaccines except for some multi-dose preparations of flu vaccine, that that caused autism. And that clearly has been shown not to be true....So now this is classic for pseudo-science, is you just keep moving the goal posts. So now the goal post is, "No, we didn't mean actually MMR caused autism or thimerosal caused autism, we just meant vaccines in general cause autism." (Palfreman 2010)

Over time, a large body of epidemiological and virological evidence failed to show a link between receiving the MMR vaccine and developing symptoms of autism. This led to *The Lancet's* retraction of Wakefield's 1998 article, claiming it was scientifically flawed. Furthermore, it transpired that some of the 12 children that had participated in his small study were referred to him through a lawyer involved in suing the pharmaceutical manufacturers on the children's behalf (Palfreman 2010). This lawyer allegedly paid

Wakefield more than 435,000 pounds (Cohen and Falco 2011). Thus, we can see here how non-experts, such as lawyers, can affect the scientific process on a fundamental level.

The role of parents in keeping the black box of ASD open

As discussed above, parents played a key role in directing the research on the vaccination-autism link and also keeping this black box open by generating further hypotheses through the movement Generation Rescue. While this is a fairly controversial example, where parents seem to be pitted against clinicians and scientists, another example, discussed at length by Eyal et al (2010), highlights how parents, through the National Society for Autistic Children (NSAC), also paved the way for the parent-activist-therapist-researcher as a new type of expert. This has been a slow and gradual process, evidenced by the shift in practice and ideology of the therapeutic and diagnostic professions, "towards a partnership model which values the clients' perspectives and emphasizes respectful collaboration between professionals and their clients" (Avdi, Griffin, and Brough 2000: 327).

A key achievement of the NSAC was that they "invented and disseminated a new style of being a parent – "autism parenting" as a vocation, as the "expert on your own child" and "a credible source of knowledge" (Eyal et al. 2010: 172), and were viewed as being key players in the implementation of interventions (Marcus & Schopler 1987). Indeed, Silverman and Brosco (2007) detail how parents of children with an ASD have organised research funding, founded clinical research networks, and even suggested new avenues for research. For example, since the early 1970s, a subset of parents have described how their child developed normally up to a between 1-2 years of age, after which they began to regress, and were subsequently diagnosed with an ASD. Yet, only recently, researchers have begun to investigate these claims of regression, and a study conducted by Werner and Dawson (2005), confirmed these parental claims through the observation of birthday videotapes between these crucial years. Another example drawn upon is the Cure Autism Now (CAN) foundation. Two parents from CAN "understood that if autism were a complex and etiologically heterogeneous genetic disorder, a large sample of genetic material was necessary to understand the disorder" (Silverman and Brosco 2007: 394). Thus,

> Because researchers did not seem to be sharing genetic samples, these parents contacted families and enrolled them in a new gene bank organized through CAN, the Autism Genetic Resource Exchange. To prevent needless reproduction of results, CAN made the publication and sharing of data conditions of use. The Cure Autism Now Foundation was able to amass data and samples from more than 400 families at an initial cost of more than $6 million in private donations. (Silverman and Brosco 2007: 394)

Why study autism? The direction of this project

Recent work in the fields of sociology, anthropology and science and technology studies have begun to focus this interest in diagnosis, classification, diagnostic practices and

treatment to the understanding of autism, particularly its historical evolution and the role of various key social forces in bringing about its epidemic status today. Berend Verhoeff's (2014) work on the stabilisation of autism as a category, for example, explores the drive of autism research to account for persistent uncertainties and conflicts in scientific understandings of autism, namely its heterogeneity and a failure to identify disease specific biomarkers. Verhoeff (2014) argues that the "reframing of autism as a neurodevelopmental spectrum disorder satisfies the scientific, institutional and socio-political needs for stability and homogenization" (65). Additionally, and of particular interest to this thesis, is the work of Jennifer Singh (2015) and Chloe Silverman (2011) who explore research programs and interests in autism, and highlight the crucial role parents play in the affective and personal choices they make, and the passion and hope they bring to the clinical encounter, that in turn shape the discourses of developmental psychology, psychiatry and even genetics and biology. These authors, among others (see for example Fitzgerald 2017 and Hollin 2017) explore the way that this affect and passion is also a key part of the way clinicians and scientists in the field of autism practice, diagnose, treat and research.

Thus, the fundamental aim of this project is, as Latour (1987) states, "to be there *before* the box closes and becomes black" (21): "Apart from those who make science, who study it, who defend it or who submit to it, there exist, fortunately, a few people, either trained as scientists or not, who open the black boxes so that outsiders may have a glimpse at it" (Latour 1987: 15). As an early intervention therapist that works with children on the autism spectrum, as well as a sociologist, I have a unique opportunity to enter this clinical world simultaneously as an insider and an outsider. I enter as an insider due to my own clinical background, as an applied behavioural analysis (ABA) therapist, a treatment approach frequently approved and recommended by clinicians. I enter as an outsider with the ability to approach the clinic with an analytical and critical sociological eye and thus open the black box of ASD assessment practises.

As outlined in this chapter, three key factors contribute 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 is shrouded in scientific controversy and uncertainty due to its medical status as 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 individual. This sheer variability makes ASDs particularly difficult to test under the epidemiological paradigm, particularly using the gold standard of randomised controlled trials (RCTs). Diagnosing and treating ASDs is carried out at an individual, case-by-case level and heavily relies on the clinician's *observation* of the patient's behaviour and speech (Silove, Blackmore, Warren, Gibbs, and Roberts 2008). While standardised tools and guidelines that aid in the diagnosis of ASDs exist, it appears clinicians are critical of their functionality in practice and that sometimes they are used incorrectly (Symons 2008). Clinicians are constantly trying to force a square peg into a round hole:

> According to the federal [US] legislation, children are developmentally disabled if they have diagnoses that are known to result in disability or because they have documented developmental delays. Yet, as Zola (1993) noted, the dichotomisation of disability is problematic. It imposes an artificial structure of categories that are not consistent with individuals' experiences of their bodies and assumes that disability is static, while children's development is dynamic...In EI [early intervention], the developmental guidelines serve as a template for normalcy. That template fits some children well but does not fit others. (Leiter 2007: 1636)

However, sociological investigations of the subtleties and complexities involved in the clinical encounter when dealing with a heterogeneous disorder such as autism are scarce (Rafalovich 2005). Thus, an investigation of a variety of clinicians' "gazes" and how they are applied in the clinical encounter to autism spectrum disorder will shed light on the inter-subjectivities, subtleties and complexities involved in clinical assessment. Such an investigation will provide greater understanding of what the "doable" job entails in the assessment of ASDs, the role standards play in the clinical encounter, and what internal and/or external political and social forces affect the "gaze" of the clinician. 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

Video-reflexive ethnography and the study of the diagnosis of autism in action

> —We study science *in action* and not ready made science or technology; to do so, we either arrive before the facts and machines are blackboxed or we follow the controversies and reopen them.‖ (Latour 1987: 258, italics in original)

Introduction

In the previous two chapters, I examined the history of developmental disabilities and autism spectrum disorder in Australia – including the ways they have been defined and treated over the past 100 years, and the increasingly prominent role standardisation and evidence-based medicine (EBM) have come to play in this process. I explored the difficulty of applying EBM to developmental disorders such as autism, as well as medicine's relentless pursuit of the "gold-standard" of evidence: that is, how it seeks to bring order and structure to what is inherently messy and disordered.

Autism spectrum disorder is a *heterogeneous* disorder – there is a lack of scientific certainty around its causes, age of onset, symptoms, comorbidity with other disorders (such as ADHD and anxiety disorder), and patients' responses to treatment. This variability makes ASD particularly difficult to test under the standardised epidemiological paradigm, particularly using the gold standard of randomised controlled trials (RCTs). Accordingly, ASDs are diagnosed and treated at an individual, case-by-case level, drawing upon the clinician's *observation* of the patient's behaviour and speech (Silove, Blackmore, Warren, Gibbs, & Roberts, 2008).

While standardised tools and guidelines that aid in the diagnosis of ASD are promoted by the Australian medical community (Silove et al., 2008), clinicians are reportedly critical of their functionality in practice (Lenne & Waldby, 2011; Symons, 2008). This was the key focus of the pilot study[8] to this thesis, which found that to reconcile this tension, clinicians use clinical creativity through the process of tool tinkering to do the "doable job". This also means that sometimes these tools are used in circumstances in which they are not intended to be used (for example, with individuals that are outlier cases due to possible co-morbid disorders) (Lenne & Waldby, 2011). Following on from this pilot study, this thesis seeks to explore the nuances and complexities around how these standardised tools are being used,

[8] Interviews were conducted with nine Australian private practice developmental paediatricians in 2009 (Honours thesis).

negotiated, interpreted, tweaked and analysed in practices that constitute the ASD diagnostic encounter.

Thus, this chapter extends upon this theoretical discussion by presenting the guiding methodological approach used for this thesis – video-reflexive ethnography (VRE) – which enables me to engage with and capture the messiness, complexity, indeterminacy and flux of the autism diagnostic encounter within a clinical trial. In explaining and justifying this approach, I will consider the methodological literature around video ethnography and VRE, and the ways that other medical and health issues have been previously dealt with "in the field." I examine key studies and examples in the fields of sociology and medicine that have used video data and VRE within the clinical/healthcare setting and within the context of working with children with autism. Finally, I outline the setting, design and analytical approach of this study and the relative unchartered territory that was embarked upon when developing the project.

Guiding principles and background

In formulating my methodological approach for conducting research, developing methods and gathering data, I found the work of Charmaz (2011), Glaser and Strauss (1967), Latour (1987) and Law (2004) particularly helpful. This approach aligns with the key concepts laid out in Grounded Theory (Glaser & Strauss 1967; Charmaz 2011) whereby "data collection and analysis reciprocally inform and shape each other through an emergent iterative process" (Charmaz 2011: 360).

As I have discussed in Chapter Two, Bruno Latour's ethnographic work on the study of scientific practices presents an insightful theoretical framework that directs my methodological approach. Just as Latour focuses on procedures, relationships, activities, machines and events in the "construction of scientific facts" (Latour and Woolgar 1986), this thesis also investigates the interactions, procedures, inscriptions and notes, standardised tools and body language central to the process of reaching an autism diagnosis in the clinical encounter. Latour's (1987) work highlights the *active* nature of investigating "science in the making" through the notion of "black boxes." Open black boxes represent fields of inquiry that are characterised by uncertainties, controversies, and various alliances that take place between both things and people. A researcher that wants to explore open black boxes must take on a malleable and dynamic approach that is able to cope with this constant state of flux. I will argue that the approach I have used in this thesis to explore the construction of autism diagnosis, or autism diagnosis in the making, within a clinical trial echoes Latour's own theoretical approach regarding the construction of scientific facts and the study of "science in action."

For this study, I began with some research questions that originated from a 2009 pilot study in which I conducted semi-structured interviews with nine developmental paediatricians. These research questions focused on understanding the tacit and experiential nature of the ASD diagnostic process in more detail, and how and why standardised tools were used in the clinical encounter. Coupled with a review of studies examining the diagnosis of ASD, I established that there was a need for the use of a set of methods that would enable access to this knowledge (beyond the approach of interviews). Additionally, I also revised and re-worked my research questions and themes as the research progressed. The pilot study also established the need for a set of flexible methods that, in the field, can adapt to/complement the notion of "science *in action*" (Latour 1987: 258) and the background messiness, flux and indeterminacy (Law 2004) of the clinical encounter:

> events and processes are not simply complex in the sense that they are technically difficult to grasp (though this is certainly often the case). Rather, they are also complex because they *necessarily exceed our capacity to know them*. No doubt local structures can be identified, but…the world in general defies any attempt at overall orderly accounting. (Law 2004: 6)

Thus, the point of the methodological approach taken in this thesis is not to "uncover," "objectify," "know," or "unlock" the diagnosis of ASD and the various practices associated with the diagnostic clinical encounter, but rather to study diagnostic practices as they occur *in action* – embracing their messiness, unpredictability and uncertainty – and reflexively make sense of these alongside the clinician with the aim of encouraging dialogue about tacit and experiential knowledge and practices. Methods that remain removed or stay at a distance from the complexity of the clinic *in action* (such as interviews and focus groups) do not seek to understand the nuances of medical practice, and in the case of this study, tell us nothing new about the diagnosis of ASD.

The approach of conducting ethnographic fieldwork was therefore very appealing, as I was drawn to the way that it would enable me to fully immerse myself in the clinic and its day-to-day practices. The following passage from Bosk's (1985) account of his ethnographic fieldwork with genetic counsellors highlights the richness and complexity of the data available when conducting this type of research:

> [F]ieldwork puts us directly in touch with the human dimensions of social life in a way that no other method of inquiry does…Full understanding involves an intimate contact and this is what fieldwork provides. It allows us to describe a set of fundamental life experiences as they occur – it provides us with the words to inscribe the arc of human experience…it allows us to see the human conflicts that lie beneath the surface of an advancing and dazzling medical technology…Fieldwork supplies precisely what other methods of research drop out – the experiencing individual as a member of community and the set of shared meanings that sustains that individual's action in an uncertain world. Fieldwork allows us to see social life as we live it…it allows us to examine the fit between principles and practice. (Bosk 1985: 14)

In the following sections I will detail the effectiveness of video-reflexive ethnography (VRE) as a collaborative qualitative methodology used to improve the quality of care in healthcare settings and as a tool to enact change. I will also draw on both medical and sociological studies and examples to highlight the power of video when engaging in research with children with autism and their families.

Video ethnography and video-reflexive ethnography: collaborative research in the health-care setting

> Far from being a research style of representativity, measurement, or proof, Video Ethnography is a soft procedure characterised by gaze-seeking and experimentation, by plausible suggestions and possible views, one whose strength and effectiveness seems to lie precisely in the fact that even well focused pictures can provide material for discussion and provoke a need for communicative validation. It is not the fixation of a fact, but the onward goal of movement of thought which becomes the goal of ethnographic research by means of motion pictures. (Mohn, 2009: 179-180)

The quote above emphasises three key strengths of the video-reflexive ethnography (VRE) approach that are central to the data collection process used for this thesis. The first is the ability of an image to "provide material for discussion" and "provoke a need for communicative validation." The second is the way that VRE enables us to examine practices *in action* (Latour 1987) by focusing on "the onward goal of movement of thought." The third is the way that VRE produces important discussions between clinicians, and between clinicians and researchers, thus allowing the key findings of this study to be brought forth. This section will explore the significance and importance of using the dynamic, visual, adaptable, flexible and active techniques of VRE to explore the diagnosis of autism within a clinical trial.

At its very foundations, the purpose of video ethnography is to focus on and capture the *audiovisual aspects of people in action* (Knoblauch, Schnettler, & Raab, 2009), allowing the researcher to document the intricacies, intimacies and complexities of day-to-day life. There is a strong emphasis on the *naturalness* of the data gathered in this way: individuals or groups that are being studied are expected to go about their daily routines and work as if they were not being observed or filmed (Knoblauch et al., 2009). The ethnographic approach used *alongside* the video-recording is crucial to this notion of capturing "natural" data – that is, it is necessary for the researcher to spend time with and build rapport with the participants to achieve this naturalness, and for the researcher's presence to be accepted (Knoblauch et al., 2009). However, this is not to say that ethnographic observations and video data are "neutral" documents – they are produced with a focused, and somewhat predetermined, scope and therefore should be seen as having an author (Mohn, 2009). For Mohn (2009), the camera is used in the field as a "Caméra Stylo" (a

picture-pen) whereby "[d]esigning the moving image articulates the focus of observation" (175) as opposed to recording and/or transcribing and analysing any and every situation.

Lomax and Casey (1998) extend this perspective, arguing that the *process* of filming and observing as a researcher helps to "socially construct and produce the data that is collected" (1.4). Thus, rather than treating video data as a duplication of the unrecorded event, or claiming that the video camera distorts the research process, Lomax and Casey (1998) contend that:

> The activity of data collection is constitutive of the very interaction which is then subsequently available for investigation. A reflexive analysis of this relationship is therefore essential. Video generated data is an ideal resource in as far as it can provide a faithful record of the process as an aspect of the naturally occurring interaction which comprises the research topic. (1)

The video-*reflexive* ethnographic approach combines two innovative methodologies: "video-ethnography" and "video-reflexivity." The process of video-reflexivity involves ethnographic video footage of clinical practices being played back to the clinician(s), patient(s), and/or patient's family involved for review, discussion and analysis. Studies have demonstrated that through this reflexive process, clinicians learn, develop and even change their practices after developing this new awareness (for example, Carroll 2009; Carroll et al 2008; Iedema & Carroll 2010; Iedema et al 2006). The reflexive component of the research relies on video-recording the diagnostic sessions and playing-back these clips to the clinician involved for their analysis, alongside the researcher. Video-reflexive ethnography allows the researcher and clinician to engage with messiness, complexity, indeterminacy, flux and the clinic in action.

These methodologies have been used within hospital settings to facilitate clinician-learning and clinician-led practice redesign (see Carroll 2009; Carroll, Iedema, & Kerridge 2008; Collier, Sorensen & Iedema 2015; Collier & Wyer 2016; Iedema, Long, & Forsyth 2006; Wyer, Iedema, Jorm, Armstrong et al. 2015; Wyer, Jackson, Iedema, Hor et al. 2015). Iedema and colleagues (2006) highlight the usefulness of this methodology in the health-care setting, claiming that the challenges facing contemporary health-care work involve "constantly confronting new evidence, different viewpoints, diverging interests and unpredictable emotions. This produces processes which are not linear and mechanical, and which therefore demand reflexive conduct" (164).

Video-reflexivity is above all an interventionist approach, providing a "powerful form of feedback, enabling people to confront and intervene in everyday complexity" (Iedema et al. 2009: 133). In contrast to studies using observational, ethnographic and interview approaches, video-reflexivity enables a more dynamic approach: real-life clinical situations are videotaped by the researcher who later plays back segments of this video to the clinicians involved for their analysis and discussion (Iedema et al. 2009), while the

researcher simultaneously makes sense of the video alongside the clinician. This collaborative and reflexive approach between researcher and clinicians enables a mutual and dialogic relationship (Iedema & Carroll, 2010) to form: "Video-based research can facilitate a crossing of the divide between data and analysis, and instead produce a 'data-in-analysis', where participants account for, and explain, their practices as they are performing them for the camera" (Forsyth, Carroll, & Reitano, 2009: 215-16). It is a way to negotiate and cross the boundaries "between researchers and researched and between knowing and doing" (Juhasz, Heath, & Iedema, 2009: 323). An important effect of the practitioner/patient being involved in the research process and participating in this self-reflection and collaboration is the direct impact on practice and the way practitioners and/or patients "are enabled to articulate changes to better suit their contexts and purposes" (Iedema 2014: 196).

The video-reflexive approach is best suited to unpacking the complexities of medical practice and unspoken rules, behaviours and individual idiosyncrasies of the clinicians being studied. It provides an opportunity for insights to be shared across disciplines, and for new meaning and practices to be created by the clinician alongside the researcher. It is above all a *collaborative approach*: allowing researcher/clinician/patient to collectively negotiate and determine what issues are important, what data to collect, how to collect this data, and how to use the data (Iedema 2014). Thus, it has a direct impact on those involved in the research, "because they have been given a stake in it and its outcomes." (Iedema 2014: 197) Iedema and colleagues (2009) contend that two important and contrasting realisations are reached by clinicians when watching-back video-clips of their practice:

> First, they realise the extent to which their practices embody their own peculiar logic – a logic they have often learned *no longer* to see. This logic harbours a regularity that has become second nature, thereby slipping from conscious view. Second, the footage reveals for them the complexity and indeterminacy of what they do. It reveals their practical wisdom, or phronesis, which they had equally come to take for granted (Dreyfus 1979). They observe themselves making on-the-spot decisions, acting on hints and intuitions, sharing tasks with colleagues in ways they could not have described beforehand nor afterwards, displaying knowledge they gained in unexplained ways, and so forth. (293)

Iedema, Mesman and Carroll (2013) elaborate further on another complex dimension of what clinicians "see" when watching their video footage – rather than just focusing on what appears before them on the screen, participants draw on knowledge and experiences within their organisation, take into account things that have happened in the past, and look forward to possible future occurrences – thus they are "linking what was shown to what was known" (Iedema 2014: 198). Here, video images can be seen as multi-layered, allowing participants in the reflexive session to variously interpret the data in what Iedema and colleagues (2013) refer to as the "hologrammatic" effect of VRE.

I would like to turn the discussion now to two key studies, conducted over the past two years, which have used VRE with patients and families to explore issues around patient safety within the context of the Australian hospital. These two studies represent important contributions to the VRE literature as their findings have important implications for practice redesign within the healthcare setting. By outlining the methodology and findings of these studies, I want to demonstrate the potential of VRE to enact real change in medical and organisational practice. Further, these studies demonstrate the insight and knowledge that patients and families have to offer within the clinical domain, and how this knowledge can be used to enact changes to the social-emotional practices within the clinic as well as clinical and standardised practices.

In Collier et al. (2016) VRE is used to explore patients' and families' perspectives on patient safety within end of life care. The researchers point out that current organisational definitions of harm and safety fail to take into account the socio-cultural aspects of healthcare delivery and are determined exclusively by researchers, policy-makers and clinicians. Using VRE over a period of 18 months in an Australian tertiary acute hospital, Collier et al. (2016) worked with patients with an advanced life-limiting illness and their family members. Through this research they demonstrate that patients at the end of life have unique perspectives and experiences of safety and harm, and that these patient and family-defined concepts are not always acknowledged, defined or addressed by clinicians or hospitals. Some of the interpersonal concepts of harm and safety that they raised included compassion, effective interdisciplinary communication and continuity of care, focus on the person not disease, dignity and the act of listening and then acting. Addressing these patient and family definitions by incorporating them into current guidelines and practices will have important implications for the way that patients experience safety and harm within the context of dying in the future.

In Wyer et al. (2015), VRE is used to examine patients' understandings of hospital infection control in a metropolitan teaching hospital in Sydney, Australia. They note that research to date has focused on top-down approaches that address frontline clinician practices, namely the expertise and insights of people providing and receiving care with regards to patient safety. Wyer and colleagues (2015) offer an alternative approach by using VRE with patients during their experiences of care to explore patients' understandings and enactments of infection prevention and control. Using VRE was vital to this study's success as it enabled the researchers to engage with patients at the frontline of care and reveal, through reflexive viewings of their video data, patient-identified infection prevention control practices and roles that patients can play to contribute to their own safety. This demonstrates the valuable contribution that patients can make in achieving patient safety in the clinical setting, and emphasises that clinicians should be supporting, consulting and engaging with patients to achieve safer care.

Thus, the video-reflexive component of this approach is advantageous for numerous reasons within the context of healthcare: it allows the researcher to capture fast-paced, complex and multifaceted clinical processes as they unfold, thus providing a rich record of the clinical encounter (Iedema et al. 2013); it frames the clinical encounter in a "'visual language' that is more easily accessible" (Iedema 2014: 196) to clinician/patient/researcher; and perhaps most importantly, it dismantles the notion of the *research subject* through the act of playing-back video footage to those who appear in it and making sense of it together as a "deliberate democratic strategy and ethical act" (Iedema 2014: 196). These features are highly relevant to researching the autism diagnostic encounter embedded within a clinical trial given that this endeavour involves: complex and multi-faceted diagnostic processes that are framed within standardised tools (WISC-IV/WAIS-IV and ADI-R) and must answer to the broader framework of the clinical trial protocol; collaboration with, and the important role of, parent and child in the ADI-R and WISC-IV/WAIS-IV respectively; focusing on the predominantly visual aspects of diagnosing autism given that assessment of this disorder is reliant on observable behaviours; and working alongside the diagnosing clinician in a collaborative way to understand the complexity and uncertainty involved in this practice, and how standardised tools are enacted, interpreted and tinkered with in this clinical trial space.

Using video with children and children with autism: research in medicine, psychology and social sciences

One of the key factors that motivated my use of video as a tool to collect data for this thesis was my frequent exposure to the video camera during my ABA therapy sessions with children with autism. Video is often used during these therapy sessions to monitor, analyse and improve the performance of the therapist. In many early intervention approaches, like ABA and Floor Time, videoing the child during their session is also a common way for supervising clinicians to keep abreast of the child's progress or any problems parents and other therapists are struggling with. I also found in my own practice as a therapist that many of the children enjoy watching themselves in these videos made during their therapy session, and will in fact learn from this process in a kind of self-reflexive practice. For example, video is a common tool used in the various treatment approaches to ASD. The use of a technique called "video modelling" involves the child observing a video of peers/siblings/themselves demonstrating specific skills and then imitating the observed behaviour. This well-established technique aims to improve skills such as toileting, socialisation/play skills, communication and so on (Cardon & Wilcox 2011; Keen, Brannigan, & Cuskelly, 2007; Mechling & Moser, 2010; Nikopoulos & Keenan, 2004; Sherer et al., 2001).

In recent years, research in experimental and clinical settings in fields such as psychology, education and medicine often portray video as a tool used to "unlock" or "solve" the mysteries and complexities of clinical practice to produce new ways of quantifying or

categorising individuals or conditions. James et al (2012) suggest that this use of video footage in clinical assessments and diagnosis is increasingly common due to its ability to predict a range of developmental outcomes. For example, in two studies exploring using retrospective video analysis, home videos of infants with autism are analysed and coded into categories to determine the usefulness of sensory-motor measures and social behaviors as early predictors of autism during infancy (Baranek, 1999; Baranek et al., 2005). These studies advocate the use of computer-based coding technology in the retrospective analysis of video (Baranek et al., 2005), and claim that this analysis provides "a window into the earliest manifestations of autistic symptomology within a naturalistic paradigm" (Baranek, 1999: 223). Other studies focus on filming the child in their *everyday environment* to provide more "accurate" information to the health care provider about the child's symptoms and their responses to therapy (Jones & Schwartz, 2009; Oberleitner et al., 2006).

Furthermore, an "App" – *ASDetect* – launched in 2015 and developed by La Trobe University, Melbourne, uses a series of videos and questions to guide parents through the identification of potential "red flag" signs of ASD (Barbaro & Dissanayake 2010; 2013). It gives parents access to video footage from clinical assessments with children with and without ASD, and clearly identifies the context and expected key behaviours of children at each age. This demonstrates the use of video in the screening process on a large scale, and the way in which video is being harnessed in the clinic to capture more ASD diagnoses.

These examples of the use of video in the clinical setting are an important illustration and acknowledgement of the very established role that video plays within the autism clinical setting and the way that video can be used as a means of reaching diagnostic decisions. Given the reliance on observable behaviours to diagnose this disorder, it is perhaps unsurprising that video has come to play such a significant role in the clinical and therapeutic setting. However, research that directs the lens of the video camera towards the diagnostic encounter with children, and the *autism* diagnostic encounter specifically, is limited.

In recent years, two researchers at the University of Wisconsin, Jason Turowetz and Douglas Maynard, have begun using audio and video data to explore how clinicians diagnose children with autism. Using this data – which spans two eras (1980s and 2010s) and is derived from a larger project examining the testing and diagnosis of autism at an interdisciplinary developmental clinic – these researchers explore a variety of issues such as category attribution as a diagnostic device (Turowetz & Maynard 2016) and the use of narrative and storytelling in clinical settings (Maynard & Turowetz 2017). Their findings offer an important contribution to the sociology of diagnosis literature, and clinical understandings of how autism is diagnosed in practice. For example, Turowetz and Maynard (2016) demonstrate that reaching a diagnostic label involves piecing together information about the patient, then fitting that information into a diagnostic category, and then

providing adequate justification to the parent as to why the child fits/does not fit the category of autism. Maynard and Turowetz (2017) argue in a later paper that for clinicians to arrive at a diagnosis of autism they must build a narrative case, that is, they use stories and test performances as evidence to support or negate a diagnosis of autism. These researchers use conversation analysis procedures to analyse the audio and video data, and thus the focus of this research is predominantly on these conversational interactions, rather than the visual and embodied nature of the interactions. For example, the transcribed quotations included in their papers (see Maynard & Turowetz 2017; Turowetz & Maynard 2016; Turowetz 2015) are focused on patterns of speech – such as intonation, pauses, emphasis – and what is said. This is a significant point of divergence from my own research and data collection approach for this thesis.

Grant and Luxford's (2009) exploration of the intercultural communication between child health nurses and parents in Australia presents a unique example of the use of VRE in child and family health settings. Their research focuses on understanding the intercultural communication issues that vulnerable migrant families experience in the clinical setting. During their three stages of data collection, Grant and Luxford (2009) focus on developing trust with the child health professionals (child and family health nurses, social workers, doctors, physiotherapists and administrative staff) through participant observation, making visual recordings of practice during consultations between child health professionals and parents, and reflecting on practice through the use of in-depth interviews with the child health professionals after viewing their video recordings. Grant and Luxford's (2009) study is particularly pertinent as a resource for this project as it outlines some important benefits of the VRE methodology when working in a clinical setting with families (who are discussing their children) and clinicians. Using VRE allowed the researcher to identify "differences between what participants said in the field and what they did in practice...Without video, this depth of critique would not be possible. Major areas of incongruence included professional knowledge, identity and relations of power." (228) One of the examples Grant and Luxford (2009) provide regarding this incongruence in professional knowledge relates to one of the clinicians claiming that her decisions and recommendations are based on NHMRC guidelines, yet later clarifying (after watching a video clip of herself) that most of her practice is based on life experiences. This process allows for reciprocity, self-determination and self-understanding (Grant & Luxford, 2009) for the clinician, because the clinician and researcher work side by side in a mutually beneficial relationship. Iedema and colleagues (2006) point out that this approach is "participative, dynamic (as in ongoing and iterative), and protective of individuals" (164). This is described as an *endogenous* approach – that is, relying on "cooperation and negotiation among practitioner-clinicians and hospital researchers as the bases upon which meaning and significance are constructed" (164).

This study seeks to reimagine the way that video can be used in the autism clinical encounter, establishing it as a useful research tool to help "sort out" – by making visible and

overt – the tacit practices and diagnostic messiness that constitute the autism diagnostic encounter. Video, in the context of this study, is used not as a tool to structure, codify, "more accurately diagnose" or treat autism, but rather as an illuminating device to closely understand, analyse and make sense of autism diagnostic practices. The video-reflexive ethnographic approach offers a further layer to this analysis: it allows me, as the researcher, to build up a rich observational account and experience of the autism diagnostic process, and the opportunity to reflexively engage the diagnosing clinician in discussions about her own unique insights about her practice.

By playing back video clips of significant moments/incidents to clinicians, they are given the chance to identify and explain the often tacit, difficult to articulate, or complex details of the diagnostic encounter alongside the researcher. As Schubert (2009) explains:

> Video recording and analysis in videographic research should be considered focusing devices which are embedded within a larger context of multiple methods, ranging from participant observation to interviews and producing very detailed accounts of selected phenomena in the field. Using video equipment as a sociological instrument, one has to keep in mind that it does not produce or reproduce 'reality' but that it consists of an array of artefacts which aid in the sociological reconstruction of practices by distorting our perceptual habits and exempting us from some restrictions of space and time. (124)

This use of video-reflexivity to transform the previously tacit and implicit into something that is visible, explicit and able to be challenged and analysed, demonstrates the innovative and unique nature of this methodological approach. The philosophical principles underlying the methodology align with the key arguments of this thesis: video reflexive ethnography is not fixated on "producing or reproducing 'reality'" nor is it fixated on facts, the purpose is rather "the onward goal of movement of thought…by means of motion pictures" (Mohn, 2009: 179-180).

Setting: The autism diagnostic encounter nested within a clinical trial

This study was nested within an NHMRC-funded randomised double blind placebo-controlled trial, conducted within an Australian metropolitan children's hospital[9]. The trial investigates the use of a Selective serotonin reuptake inhibitor (SSRI) in the treatment of anxiety in children with an autism spectrum disorder (ASD). As I have argued in the preceding chapters, applying a randomised controlled trial (RCT) design to investigate the effectiveness of a drug in children with a diagnosis of autism presents numerous challenges, particularly the problems associated with diagnosing this disorder and establishing what is deemed "average" within this heterogeneous population. The absence of biological markers

[9] Ethics approval was sought from the University of Sydney HREC (Reference: MF/PE, Project No: 2012/2065), Autism Spectrum Australia (ASPECT) (Reference: 1114), and the Australian Metropolitan Children's Hospital where my research was conducted (HREC approval number 11/SCHN/156 and SSA/12/SCHN/158)

or tests to aid in producing a diagnostic outcome makes it more challenging to carry out empirical investigations using RCTs:

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

This study, nested within the clinical trial, therefore presents a unique opportunity to observe and record EBM in practice, and the various social, political, medical, and interpersonal factors that play a role in this process. Understanding how clinicians address the problem of working within the paradigm of an RCT with a population of children on the autism spectrum will also provide valuable insights into how clinicians work within and between the confines of the standardised world of the clinical trial. Nesting this study within this drug trial provides a valuable opportunity to investigate not only the ASD-specific aims and research questions outlined above, but also to turn the sociological gaze on the practices and rules that make up a clinical trial.

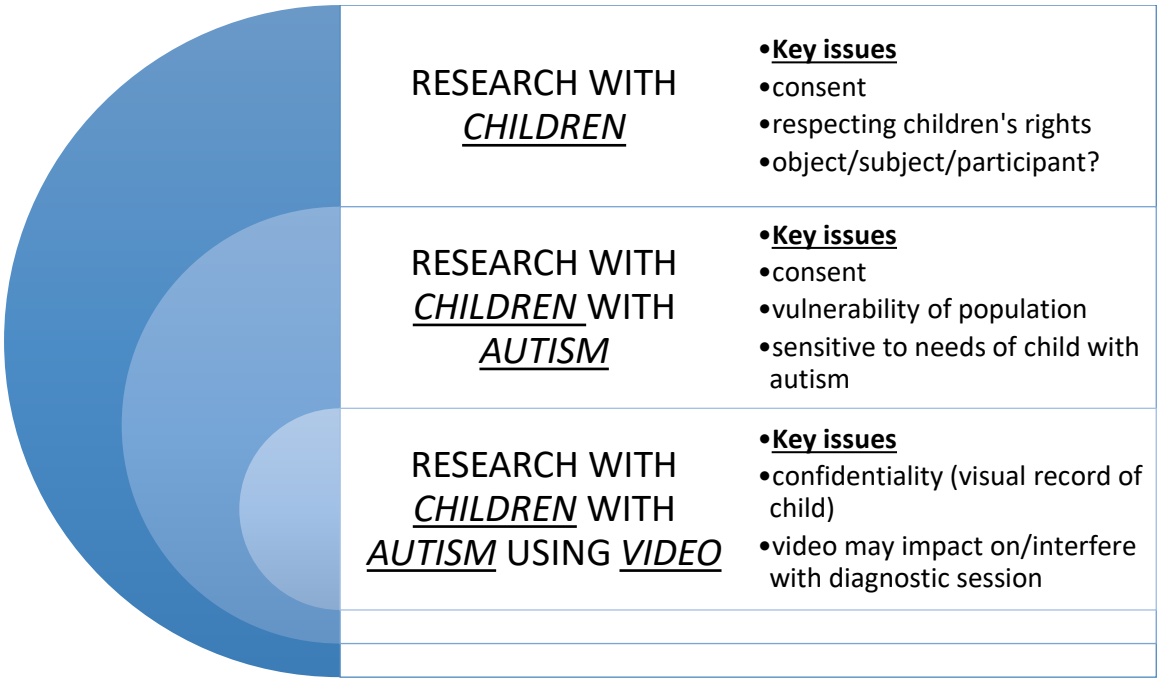
Ethical and practical implications of working with children with autism

When embarking on this thesis, I knew that I wanted to explore the complexities of the autism diagnostic clinical encounter using video, and this required navigating three layers of methodological and ethical challenges: working with *children*; working with children with *autism*; and working with children with autism *using video*. Each layer (see Figure 3.1) raised its own methodological, ethical and practical implications that required consideration. Importantly, these issues were not simply addressed in the ethics application and then ignored, but rather dealt with and re-visited throughout the entire methodological development, ethics, data collection, data analysis, and writing up process. From the outset, I knew that finding participants would be challenging given that I wanted to work with not only children, but children with a potential autism diagnosis. Further, I planned to video the intimate and emotionally charged setting of the diagnostic clinical encounter for this ostensibly sensitive and vulnerable population.

Alderson's (2000) work was helpful in navigating the ethical, methodological and practical issues outlined above. The importance of recognising children as *participants* in the research, rather than *objects*, was key to my approach in working in this field. I recognised that children with a possible ASD diagnosis could "speak 'in their own right' and report valid views and experiences" (Alderson 2000: 243). For children with autism, "speaking" may also involve sign language, body language, facial expressions or sounds. It was therefore important to respect and attempt to record and document the varied forms in which these children communicated their thoughts and ideas within the diagnostic encounter. While the children were not included in the reflexive interviews, their "voices" (including body

language, facial expressions and sounds) within the video data are an important part of this thesis, especially the proceeding chapters.

Figure 3.1: Methodological, ethical and practical implications of the research



Alderson (2000) also stresses the importance of informed and voluntary consent for children in research and points out the danger in researchers assuming that the consent of the parent/guardian will suffice and that children are incapable of expressing their consent or refusal to take part in a research project. A concerted effort was made prior to each diagnostic session with the child to not only ask for the parent/guardian's consent, but also to seek the child's approval on the consent form (name, signature and date). Additionally, before each diagnostic session began, the clinician would explain to the child (while with their parent(s)) that a researcher would be videoing the session, and sought confirmation that this was something the child was comfortable with. When the child came into the room for the diagnostic session, I would show the child the camera and let them examine it and show them where it would be set up in the room. Two of the ten children that participated in the diagnostic session (the WISC-IV) opted to not be videoed (despite their parents' consent), but consented to my presence throughout the session, and this decision was of course honoured.

One further point made by Anderson (2000) that will be discussed in detail in Chapter 5 is the issue of "infantilising" children that participate in research:

> [P]erceiving and treating [children] as immature and, in doing so, producing evidence to reinforce notions of their incompetence. This can include 'talking down' to children by using over-simple words and concepts, restricting them into making only superficial

> responses…researchers' over-complicated or poorly explained terms, topics and methods can also misleadingly make children (and some adults) appear to be ignorant or incapable. (243-4)

In Chapter Five I will discuss how, within the context of the WISC-IV/WAIS, the children's competencies/strengths/skills/quirks were often overlooked or ignored within the confines of the standardised questions presented in this "diagnostic test." The WISC-IV/WAIS was part of a battery of standardised tools that were administered as part of the clinical trial and thus the clinicians were bound by the trial protocol with little room to maneuver. While the clinicians did not have control over the questions asked of the child, they were able to find moments and ways to creatively engage with the children during the standardised diagnostic encounter.

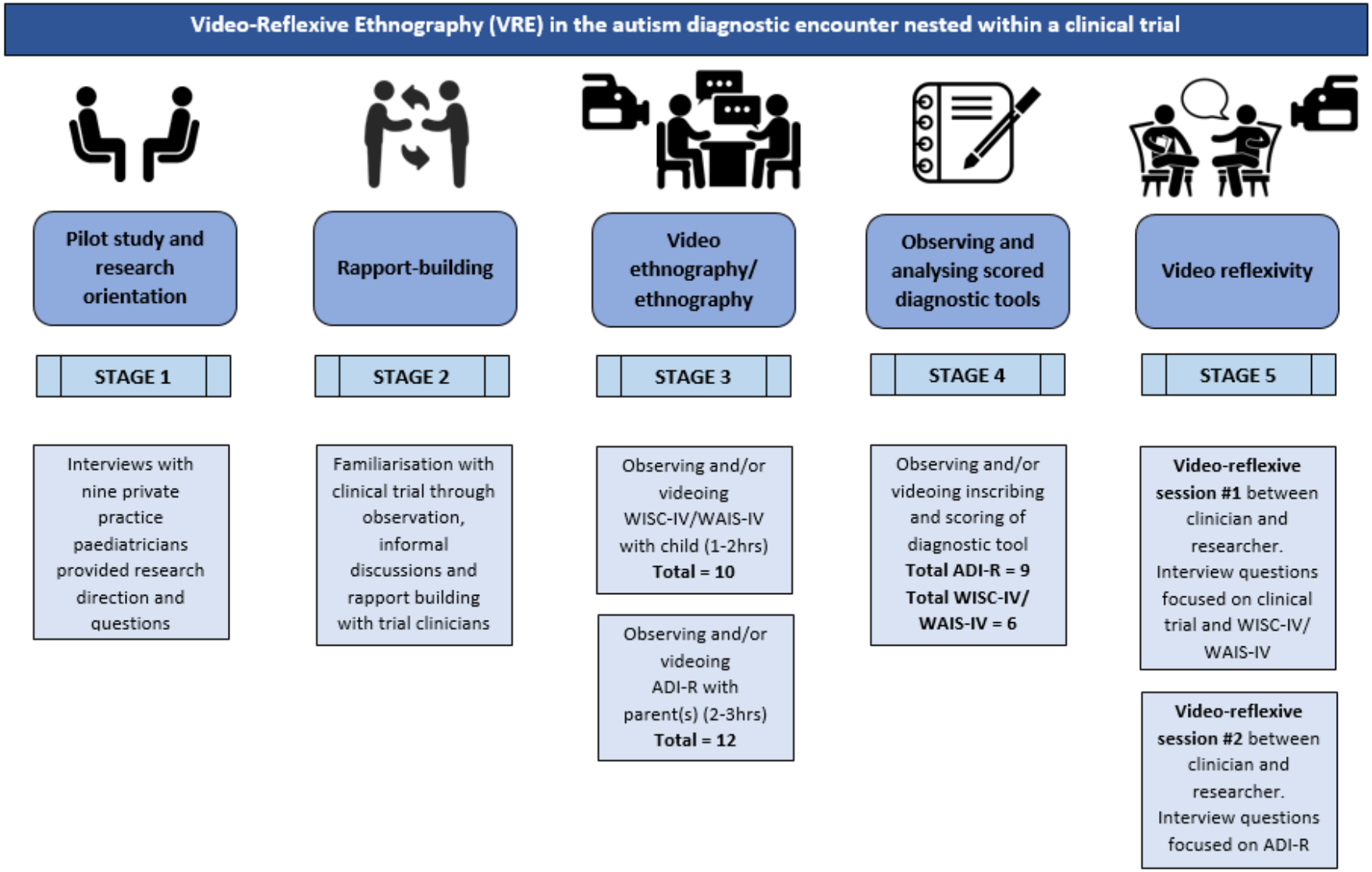
Study design

Figure 3.2 outlines the five stages of data collection that make up the study design. This design was developed through close consultation with the video-reflexivity and video-ethnography literature. Collier and Wyer (2016) offer a similar summary of their approaches to VRE through Collier's end of life study, and Wyer's inflection control study (see Collier & Wyer 2016: 983). The video camera was used in the formal assessment stages involving the WISC-IV/WAIS-IV and ADI-R (stage 3) as well as the reflexive interviews with the clinician (stage 5). Observational field notes were taken when video was deemed inappropriate to use.

Stage one outlines the pilot study, which involved discussions and interviews with nine private practice paediatricians specialising in the diagnosis of autism spectrum disorder (details discussed above). As outlined in Iedema et al. (2009), these initial discussions with clinicians orient the researcher and provide engagement with and insight into the problems and complexities of clinical practice. This is the beginning of the "alongsider" approach taken in video-reflexivity. By allowing researcher and clinician to develop this knowledge alongside each other, and thus including the research participants in the methodological process, a mutual respect is obtained. While Iedema and colleagues (2009) use the same participants throughout their study, the initial phase of my study draws on a different group of clinicians (private practice paediatricians) compared to stages two to five (clinical trial psychologists), outlined above in Figure 3.2.

Stage two builds upon the knowledge obtained in stage one through time spent with the clinicians involved in the assessment process of the clinical trial. During this time, I familiarised myself with the clinicians through observation, asking questions, engaging the clinicians in discussions about various aspects of the trial, and general rapport building. This occurred for three months prior to stage 3, but continued throughout stages 3 to 5.

Figure 3.2: The five stages of the video-reflexive ethnography process nested within the clinical trial



Stage three involves observing and videoing the diagnostic sessions between clinician-child and clinician-parent. Both of these sessions were structured by standardised tools: an intelligence test (WISC-IV/WAIS-IV) with the child, and the Autism Diagnostic Interview-Revised (ADI-R) with the parent(s)/caregiver(s). The WISC-IV/WAIS-IV takes roughly one to two hours to administer, and the ADI-R takes two to three hours. Later in the chapter I will detail the procedure I used to transcribe and analyse this video data. I observed and/or videoed a total of 10 WISC-IV/WAIS-IV sessions and a total of 12 ADI-R sessions (see Table 3.1 for more detail).

Stage four includes observing the psychologist during the WISC-IV/WAIS-IV and ADI-R sessions making notes and scoring the responses onto the respective standardised tool answer booklets. After the conclusion of some of the sessions, I was able to go through the inscribed and partially scored answer booklets and film/make notes on key sections of particular interest. I was able to observe and make notes on 9 ADI-R scored booklets and 6 WISC-IV/WAIS-IV scored booklets (see Table 1 for more detail).

Stage five comprises the reflexive part of the methodology. Here, one-on-one interviews (both around 90mins in length) between myself and the clinician take place in which video clips of the diagnostic sessions with both the child (WISC-IV/WAIS-IV) and parent (ADI-R) are played-back. The reflexive sessions are structured loosely around interview questions that I developed during the analysis of the ADI-R and WISC-IV data. These questions are linked to the video clips that are played back to the clinician. The detailed process of analysing, coding and selecting these short video clips is discussed later in the chapter (see Table 3). The video clips are played back to the clinician for her insights, analysis and general comments. While I selected the video clips and formulated questions about these clips from my own analysis of the data and using my "researcher's gaze," the focus of this stage of the methodology is to make sense of the video-clips and the data gathered in "*stage three" alongside* the clinician. The clip was played to the clinician during the one-on-one interview (and sometimes played again for follow-up) and then the psychologist was given the opportunity to provide thoughts, feedback, and analysis about the clip before I asked any further questions.

Recruitment

Given that my study was nested within the clinical trial, participant recruitment for the clinical trial itself was carried out independently by the clinical trial clinicians. Therefore, my study recruitment took place within the group of participants that had already agreed to take part in the clinical trial through this initial recruitment process. In the sections below I detail these two recruitment processes.

Recruitment for clinical trial participation

Participants for the clinical trial were mostly recruited by paediatricians connected with the hospital, as well as by some private practice paediatricians. Information was given to participants about the trial, and they were given time to consider the trial and their child's participation. The trial recruited participants with the following characteristics:

1. Aged between 7 and 17 years;
2. Has a known diagnosis of an autism spectrum disorder; and
3. Has troublesome restricted, repetitive and stereotyped behaviours

Both the child and their parent(s) were required to participate in the trial. After contact was established and consent obtained, two diagnostic sessions were used to confirm the ASD diagnosis for the trial. First, the psychologist administered the Wechsler Intelligence Scale for Children (4th Edition) (WISC-IV) for children aged between 7-16 years, or the Wechsler Adult Intelligence Scale (4th Edition) (WAIS-IV) for those aged 17 years, in a one to two hour diagnostic session with the child. The WISC-IV is an individually administered intelligence test for children between the ages of 6 to 16. It can be completed without requiring the child to read or write, and requires the clinician to record and code the child's responses, which then allows the clinician to calculate a score which represents the child's cognitive ability. The WISC-IV is sometimes used to diagnose attention deficit hyperactivity disorder (ADHD) and learning difficulties. The WAIS-IV is very similar but has been adapted for an adult population. Second, parents underwent a two-hour diagnostic interview – the Autism Diagnostic Interview-Revised (ADI-R) (a standardised diagnostic tool) – with the psychologist. The interview is described as employing highly standardised procedures and requires the interviewer to record and code the informant's responses, whereby a score is generated and allows the interviewer to indicate whether or not the child is on the autism spectrum.

Recruitment for my study

Two female clinical psychologists were involved in conducting the assessments as part of the clinical trial and both were employed by the hospital. Psychologist 1 (shortened to "psych" in the transcriptions of the video data) – the main trial clinician – conducted all of the sessions except for the WISC-IV with Nikolas (see Table 3.1), which was carried out by Psychologist 2 (shortened to "psych#2" in transcriptions of the data). Both clinicians were sent an information statement and consent form requesting their participation in the filming of the assessment consultation with parent and child, and an interview with the researcher.

Table 3.1: List of participants (pseudonyms) and participation checklist

Participant Child (pseudonym)	Sex (M/F)	Age (yrs)	Participant(s) Parent(s) (pseudonym)	ADI-R			WISC-IV/WAIS		
				Observed	Video length Hrs, mins (‘), secs (“)	Analysed scored tool	Observed	Video length Hrs, mins (‘), secs (“)	Analysed scored tool
Ian	M	12	Kate	✓	2hrs 21’53”	✓	✗		✗
Gil	M	9	Sarah	✓	2hrs 54’49”	✓	✗		✗
Leo	M	13	Alice	✓	2hrs 54’35”	✓	✓	1hr 18’18”	✗
Paul	M	7	Teleri	✓	1hr 58’26”	✓	✓	1hr 21’24”	✓
Rupert	M	11	Sophie & Stewart	✓	1hr 31’48”	✓	✗		✗
Nikolas	M	8	Siobhan	✗		✓	✓	1hr 19’00”	✓
Michael	M	13	Teneale	✓		✓	✓		✓
Patrick	M	8	Laura & Tom	✓	3hrs 23’55”	✓	✗		✗
Des	M	17	Brienna	✗		✗	✓ (WAIS)		✓
Lorna	F	13	Alison	✗		✗	✓		✓
Brendan	M	15	Tim & Lena	✓	1hr 48’34”	✗	✓	1hr 33’44”	✓
Daniel	M	9	Hayley	✓	2hrs 19’32”	✗	✓	1hr 23’42”	✗
Manahil	M	13	Hana	✗		✓	✓		✗
David	M	7	Abigail	✓	2hrs 13’49”	✗	✓	0hr 26’00”	✗
Stephen	M	7	Jenny & Matthew	✓	3hrs 02’03”	✗	✗		✗
Harvey	M	12	Bronte	✓	1hr 57’48”	✗	✗		✗
Simon	M	16	Jacob	✓	1hr 50’45”	✗	✗		✗

Psychologist 1 then helped with recruitment of the parents and children by sending out the information statement and consent form to all the parents of the children participating in the clinical trial, requesting their permission to allow the researcher to video their child during the ASD assessment process as well as video the parent-clinician assessment process. A section requesting the consent of the child, where appropriate (in terms of the child's comprehension and writing abilities), was also included. A total 13 ADI-R sessions were observed and 12 of these were videoed. A total of 17 parents consented to be videoed and/or observed during the ADI-R session: 9 of the ADI-R sessions took place with one parent present, and 4 took place with two parents present. A total of 10 children were observed during the WISC-IV/WAIS-IV diagnostic sessions, and of these, 6 sessions were given permission to be videoed (see Table 3.1).

As discussed earlier in the chapter, I was very aware of the importance of being respectful of, and sensitive to, the context of the diagnostic encounter. Therefore, the following steps were taken to ensure that my presence, the use and purpose of the video, and the purpose of my study were made clear to participants:

- In the weeks prior to the scheduled date of assessment (ADI-R or WISC-IV) the clinician emailed the parent/caregiver the Recruitment Package for my study, as well as telephoned the parent/caregiver to speak about any questions or concerns they may have about my study;
- The clinician would speak privately to the parent(s)/caregiver(s)/child *in person* immediately prior to the assessment session to confirm they were comfortable with the use of the camera and my presence. During this time I would wait separately in the room where the session would take place;
- The clinician introduced me to the parent(s) and child and they were given the opportunity to ask any further questions they had about my study, after which the signed consent forms would be handed over;
- I stressed that the video could be switched off at any time if they wished; and
- I then confirmed with the parent(s)/caregiver(s)/child whether it was okay to begin filming. The duration of the session was then filmed until the participant(s) left the room at the conclusion of the clinical encounter (usually around 1-2 hours for the WISC-IV/WAIS-IV and 2-3 hours for the ADI-R).

Context – the clinic room

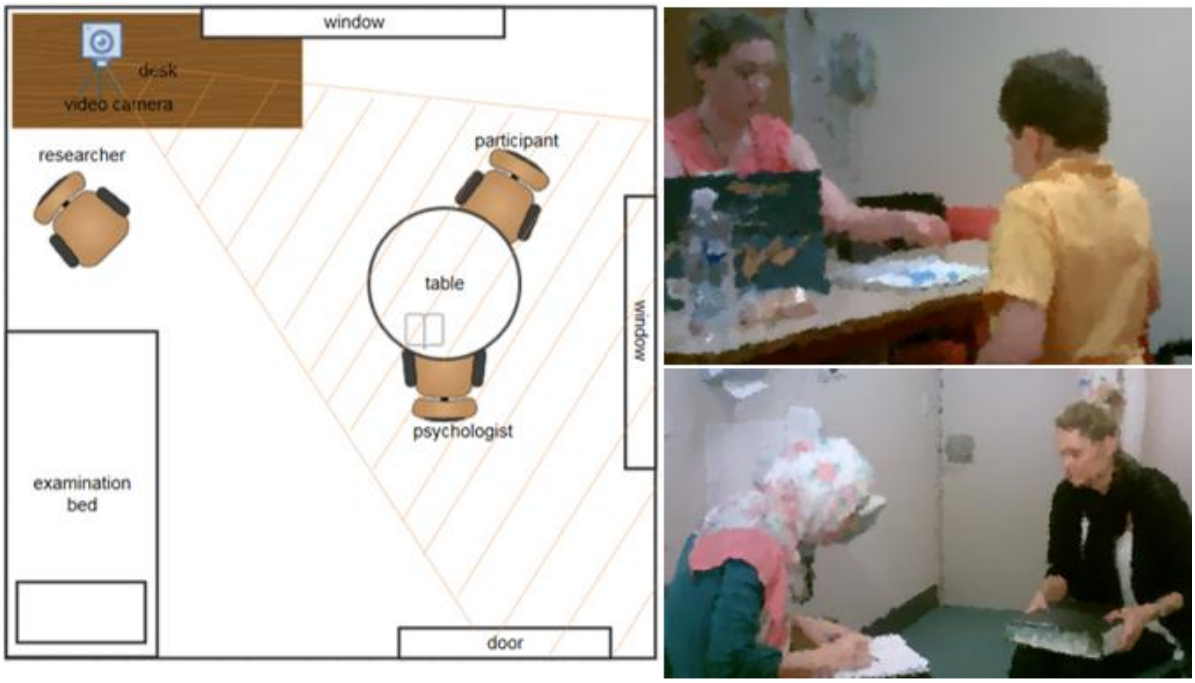
Unlike Lomax and Casey's (1998) description of their dilemma in setting up the camera, and negotiating the social complexities and nuances of determining the appropriate time to switch the camera on and off, my study was situated within "the clinic" rather than "the home" and so the camera was set up prior to the consult starting (and participant entering the room), and then switched off once the consult had ended and the participants had

departed the room – thus there were clear boundaries around the start and end of the filming period.

The camera took the form of a small, unobtrusive device, about the size of an iPhone, and was set up on a small tripod in the corner of room (see Figure 3.3, below). Figure 3.3 roughly illustrates the field of vision captured by the camera in the shaded area of the diagram, and the two images next to the diagram demonstrate the actual video image captured: the face and upper half of the body of the child or parent and psychologist, but I do not appear in the frame. This was a logistical decision – the rooms that the diagnostic sessions were conducted in were quite small and the researcher's priority was to capture the participant, the psychologist and the materials used in the assessment, which often meant that the researcher was cut out of the shot. The participants' attention was sometimes drawn to the camera, but given that the camera was left to run for 2-3 hours at a time, and effectively ignored by the psychologist and researcher, it did not feature as an object of much interest throughout the sessions. This is evidenced by how few times it is mentioned in conversation throughout the clinical encounters, and the infrequency of eye-gaze directed toward the camera. This lack of interest in the camera may in part be explained by the cognitively demanding nature of the diagnostic sessions for the parents and children, with the participants becoming quite absorbed in the questions/tasks. However, as discussed earlier in this chapter, it is important to stress that I do not consider this video data as a "neutral document" (Mohn 2009). I consider myself the author of this video data, given I have chosen and directed the angle of the camera, and thus the focus of observation, so that the viewer attends to certain components of the room and interaction being studied and analysed.

An important issue to consider in discussions about camera placement and angles is the way that these video recording practices impact and influence the way that myself, and the clinician, then go on to understand and analyse this video data. Being aware of the power of the camera and where it is placed, how it is focused, and why it is directed at such an angle are all important considerations when orienting an analytical gaze to the video data produced and then later reflexively engaged with. Mengis, Nicolini and Gorli (2016) argue that the practice of conducting video research is not simply an objective experience in which we record activities, conversations and interactions, but rather is has a "performative effect on the object of inquiry" (1). In this way, they explore how both camera angle and movement make up different forms of spatial understanding, orient the analysis, and foreground different dimensions of spatiality (Mengis et al. 2016: 2). Importantly, these researchers point out that the researched space, such as the clinic room illustrated above that the autism diagnostic sessions take place in, must be seen as a social space which comes with its own inherent values, power relations and aesthetics.

Figure 3.3: Typical room set-up for the ADI-R and WISC-IV and camera views



Based on the definition and explanation provided by Mengis et al. (2016), the configuration of camera angle and movement used for my own video research for this thesis is classed as the "American-Objective View," which sees space as "experienced and interpreted" (13). Here, the camera is fixed at a medium shot distance at eye level: it shows the clinician and parent from above the knees (as opposed to an all-encompassing shot of the room) from a fixed vantage point (as opposed me moving, directing, or zooming-in the camera lens to focus on people or objects). Mengis et al. (2016) argue that this type of video apparatus allows for the analysis of meaningful interactions: the audience is able to observe/hear dialogue, body language, gestures, facial expressions, and the way that the bodies occupy the physical elements of space (affectively and relationally given the small space that the camera angle focuses on). Thus, "the American-Objective View makes us focus on the experienced and the interpreted space…the relational space created between clinicians and patient" (14). The camera shot is fixed and continuous, which in turn means that what is recorded and then played back represents a continuity of place and time, suggestive of: "a sense of a coherent scene to which we have access from the beginning to the end and from which we can thus draw a meaningful conclusion (and a morale)." (14) Mengis et al. (2016) caution that:

> The apparatus of the American-Objective View positions us as onlookers, witnesses of something that unfolds in front of our eyes and thus still performs a space that is objective in character. It generates objects and subjects as distinct entities, a strategy that reflects not only the traditional composition of naturalistic iconography but also puts us into the position of traditional ethnographic observers. (14)

While the gaze of the camera in my study appears to de-emphasise the contextual space of the clinic room, Mengis et al. (2016) point out that the apparatus of the American-Objective View privileges interactional accounts and an understanding of space as experienced and interpreted. This approach is appropriate for my study given the key focus of the videos is on the verbal and non-verbal interactions between the psychologist and parent(s) or psychologist and child, and the way that the diagnostic tool (and its associated materials for the WISC-IV/WAIS) is read from, interpreted, manipulated and inscribed upon. The spatial relationships that exist within these interactions are focused and directed within a defined, small space. An important element of Mengis et al's (2016) critique of the American-Objective View is the way that it perpetuates the notion of the objectified participants. However, an important strategy of the VRE approach is to dismantle the concept of the *research subject* by playing-back video footage to those who appear in it and making sense of it together in what Iedema (2014) describes as a "deliberate democratic strategy and ethical act" (196). By playing back edited video clips to the diagnosing psychologist in my study, I hope to subvert these traditional ways of objectifying participants and contribute a new approach to research within the field of the sociology of diagnosis.

The researcher's presence during the clinical encounter

Lomax and Casey (1998) make the point that when conducting video ethnography, the researcher *appears* to be "doing nothing" in comparison to, for example, a field-note observer who is busily taking notes and therefore "*observably* and accountably engaged" (19). This can present an interesting situation for the researcher, as it leaves more scope for them to engage with the interaction they are studying and become an *active participant*, as compared with the field-note observer. Carroll (2009) suggests that in conducting VRE, this notion of the participating researcher manifests through the considered application of researcher reflexivity. This researcher reflexivity involves managing and negotiating the ethical challenges that arise when both the participant and researcher view the video data, such as ensuring the participant feels comfortable in embracing the vulnerability and openness that comes with viewing and critiquing one's own practices. Carroll (2009) also discusses the tendency in VRE research publications to write-out the researcher, minimising or completely erasing the valuable contribution that they make in producing and reflexively engaging with the video data.

Extending upon Carroll's (2009) work, I discuss my involvement, below, in the diagnostic encounters with the parents, children and clinicians. While I was generally not physically present in the recorded video data, conversations sometimes take place between myself and the psychologist, myself and the parent(s)/child, as well as all people present in the room. Additionally, it is clear from the videos that I participate non-verbally in the sessions as evidenced by the occasional glances/changing facial expressions made by the psychologist and participants in my direction. I found that visual (non-verbal)

acknowledgement was sometimes expected of me with, for example, what I interpreted as a querying look (eyes wide, raised eyebrows) from the parent. In hindsight, I regret that I did not manipulate the room/camera placement prior to the beginning of the session to ensure that I was also captured in the camera shot. As a participant, at times, throughout the clinical encounter, I believe I have missed out on some valuable data by not including myself – the researcher – as a participant in this complex, socially-nuanced clinical encounter. For example, in my field notes – jotted down as reflections after each session – I talk about my reactions to:

- a mother crying during a diagnostic session and how difficult it was for me to not be able to comfort her;
- a parent telling a funny story about her child, and the beautiful shared experience between myself, the psychologist and the parent laughing alongside each other;
- not being able to understand what a child is saying, and the psychologist looking towards me for clarification to see if I could decipher what was being said;
- a child making a clever joke that the psychologist did not understand, and my reaction as the researcher – trying to stifle my laughter so as not to disrupt the flow of the session, but giving the child a small grin to let her know that I had "got the joke."

These moments offer valuable insights into how all parties intersubjectively negotiate the complex terrain of the ASD clinical encounter.

A further layer to this researcher involvement is of course the reflexive session. Given the sheer amount of time spent at the field site over the course of many months, it was inevitable that I formed a friendship with the main psychologist conducting the diagnostic sessions as part of the clinical trial. Not only were we a similar age, but we had a similar clinical background in that we were both originally trained as Applied Behavioural Analysis (ABA) therapists. Thus our interactions in the reflexive interviews took on a multilayered form: at times we would embrace a colleague-to-colleague dialogue in our discussions around clinical and therapeutic aspects of autism; at other times we would joke and speak as friends, sharing stories about our everyday lives; when asking a predetermined question within the interview, we would defer to the researcher-participant dialogue; and finally, when explaining a particularly complex aspect of the diagnosis or clinical trial to me, the psychologist would adopt the "expert" role. Like Collier and Wyer (2016), I consider my role in this research to be participatory and active – whether it is through intersubjectively negotiating these emotionally-charged moments in diagnostic sessions or engaging in very frank and open reflexive sessions in which both the psychologist and I must manage the shifting relations of researcher-participant, colleague-colleague, friend-friend, or expert-student.

Transcription and analysis of data

One of the biggest problems facing researchers who work with video data is how to transcribe the data, or at least make it accessible for analysis. Transcription, in this context, therefore forms a central part of data analysis because what is transcribed "generates observations that are fundamental to analytical inferences" (Knoblauch et al., 2009: 15). While visual forms of representing data are becoming possible – Knoblauch et al (2009) discuss "visual mentality" as a mode of analysis that focuses on visualising and imagining as opposed to the written word – current technology only allows the researcher to create frame grabs and themed clips, which are then translated into some form of textual representation (photo stills are also used in some representations). The dilemmas that are faced by the researcher in this transcription process are explored in the following two accounts:

> Even before we start to search for the 'right semantics' for the actions, gestures, bodily and facial expressions, articles of clothing, etc. we observe, we are faced with the dilemma that total and simultaneous perceptions must be brought into a succession of written thoughts. (Soeffner, 2009: 208)

> [T]he relative neglect of video in the social sciences is sometimes attributed to its complexity and abundance. A few minutes of recording produce a large quantity of visual, kinaesthetic, and acoustic data that must be transcribed and prepared for analysis. Video data is certainly among the most complex data in social scientific empirical research. It is multi-sensual and sequentially ordered, enclosing both diachronic and synchronic elements, e.g. speech and visual conduct, gesture, mimic expressions, representation of artefacts and the structure of the environment, as well as signs and symbols…Hence, video recording generates an extraordinary abundance of data, confronting the researcher with the problems of data management, retrieval and selection. This may not only cause the problem of data overload, but also raises the question of how to select sequences appropriate for further scrutiny…[T]he methodological problem of what constitutes the unit of analysis and how to assure a balance between time-consuming microanalysis and an overview over the whole data corpus remain open questions for future methodological debates. (Knoblauch et al., 2009: 14).

Given the sheer number of hours of data collected for this study (approximately 45hrs), as well as the richness and complexity of this data (as described above and in the table below), the analysis process required a systematic and organised approach that would enable the researcher to make the most of this data. The complexity of the data gathered in the diagnostic sessions with both the parents and children that participated in the clinical trial is conveyed in Table 3.2, below, where three important features of the data are examined:

Table 3.2: Textual, audio and visual features of data

Feature of data	**Examples**
Textual content	Content of what is said and the meaning behind these words.
Audio	Overlapping speech, emphasis on certain words, pausing,

	raising/lowering of pitch or intonation, speaking or muttering quietly, raising voice, and imitation.
Visual	Nonverbal gesture or action (hands), body language (for example, turning towards/away from someone), facial expressions, gaze, posture, touch, and spatial behaviours. The visual features are transcribed using square brackets and italics, for example [*shakes head*].

Accordingly, to make this data accessible for analysis, I used an approach loosely based on McNaughton's (2009) analysis of video recordings of classroom interactions during a series of educational drama lessons. Her paper outlines five key steps in this analysis process – which I have adapted to suit my data – and are described in Table 3.3, below (McNaughton, 2009):

Table 3.3: Video-reflexive ethnography analysis process (adapted from McNaughton (2009))

	Steps of analysis	**Description**
Step 1	***Familiarisation and Initial impressions: descriptive notes of the video data***	This step initially involved watching each video clip one to two times and taking general, descriptive notes about the diagnostic sessions as well as the general structure of the sessions. The purpose was to familiarise myself with the data so that I could begin to make connections between the different diagnostic sessions and participants.
Step 2	***Developing analysis tables*** ***(See Tables 3.4 and 3.5, below)***	From the notes taken in step 1 about the structure of the diagnostic sessions, I developed analysis tables for both the ADI-R sessions with the parents and the WISC-IV sessions with the children (see Tables 3.4 and 3.5). These tables acted as a template for any subsequent analysis that took place. The *ADI-R analysis table* comprised three columns (see Table 3.4): (a) *Video number and time interval* (for example, video 1, 09'28"-11'56" – this would mean that the clip came from video 1 (often there were three videos per diagnostic session), and the significant clip runs from 9 minutes (') and 28 seconds (") to 11 minutes and 56 seconds); (b) *Theme* (classificatory categories that were used to group, link and make associations between the data); and (c) *Examples/quotes* (under this column significant clips would be described or transcribed to add further explanatory detail).

		The *WISC-IV analysis table* took on a similar structure, but included an extra column that delineated the ten tasks that make up the WISC-IV (for example: perceptual reasoning, verbal comprehension, working memory and so on) (see Table 3.5).
Step 3	***Initial identification of significant clips and initial coding of themes***	Videos of each diagnostic session were re-watched, with detailed notes taken on video number and time interval, theme, and notes taken in the examples/quotes column about the clip. Refining of themes occurred in this stage of the analysis process, as well as initial identification of key clips that would need to be transcribed for further analysis. Additionally, clips that may require further reflexive feedback from the psychologist are highlighted in yellow in the analysis tables.
Step 4	***Transcription/video stills of clips for close analysis***	Each analysis table is consulted and significant clips that have been documented in step 3 are then re-watched, transcribed – taking into account the textual, audio and visual features of the data, as outlined in Table 3.2, above – and/or edited at key moments as video stills. All transcriptions and video stills are edited to ensure anonymity of participants through the use of pseudonyms (for text) and blurring of faces (for images).
Step 5	***Selection of clips to play back in reflexive session with psychologist***	Analysis tables are consulted to determine which of the clips initially marked in step 3 as requiring reflexive feedback should be shown to the psychologist. For example, sometimes up to twenty clips under the same code/theme are marked to be shown to the psychologist for reflexive feedback. One to three clips are selected based on the sub-themes present, or to provide a contrast between videos. These videos are transferred to the Apple iMovie program which provides facilities for stopping, reviewing, and isolating (cutting) clips into "episodes". Subtitles can be added to difficult-to-hear episodes.
Step 6	***Reflexive interview with psychologist video – repeat steps 1-4*** ***(See table 3.6,***	Two reflexive interviews with the psychologist were conducted using some predetermined questions to structure the interviews. These questions were developed based on the analysis tables from the ADI-R and WISC-IV (see Tables 3.4 and 3.5). The video data from the reflexive

	below)	interviews were treated similarly to the ADI-R and WISC-IV video data. Each video clip is viewed one to two times and general notes and observations are made. An analysis table is developed with the same structure as the table used for the ADI-R (see Table 3.6). Significant clips are then identified and aligned with existing themes, and any new themes are identified in this reflexive analysis. Step 4 (transcription) is repeated as described above.

The development of the analysis tables (see step 2, Table 3.3) was also based on McNaughton's (2009) study. She describes her approach as an *Analysis Matrix* in which she records the clip time, description and interpretation of verbal and non-verbal language, and theme codes in a table structure. Each ADI-R, WISC-IV and WAIS-IV that I observed had a separate table with observational and analytic notes, transcriptions of key interactions, and thematic coding (see tables 3.4, 3.5 & 3.6, below). I found this a very useful way to structure and easily access my analysis. The three tables below illustrate snapshot examples of the analysis tables for the WISC-IV, ADI-R and the reflexive interview with the psychologist:

Table 3.4: Adapted Example Analysis Table WISC-IV/WAIS-IV (McNaughton, 2009)

Section of WISC-IV	**Video # and time interval**	**Theme (derived from my analysis)**	**Significant quotes and researcher notes**
Perceptual Reasoning Index (PRI): Picture Concepts - children are provided with a series of pictures presented in rows (either two or three rows) and asked to determine which pictures go together, one from each row.	Video 1 34'05" – 34'46"	Abstract competency vs. concrete competency	Example here of ability of child to construct story around his real-life experiences and relate to the pictures. Explains why these images are salient to him. Paul points to the picture of the leaf and the skateboard (correct answer is glove and shoe) Paul: because when you ride a skateboard there's all these leaves on the ground [smiles] Psych: [laughing] is that what happens to you, is it? Paul: [*Nodding and smiling*] and sometimes there's lots of leaves and they get…and my skateboard gets stuck in them. Psych: Oh no! Paul: And sometimes I ride my […?] and it gets stuck on…my ground is like [*shows psych by drawing with finger on table*], and it gets stuck in those and I go flying off! [*smiles*] Psych: [laughs] Oh no! You have to be careful! This interchange, which displays "concrete

			competency" is ignored and not recorded on the test, other than an incorrect answer.

Table 3.5: Adapted Example Analysis Table ADI-R (McNaughton, 2009)

Time interval	**Theme (derived from my analysis)**	**Significant quotes and researcher notes**
Video 2 21'35" – 22'30"	Parents as experts: Insight of parents into their child's behaviour	Tim: He's very immersed in media. He loves songs, he loves rap… Psych: [*Laughing*] He told us! Tim: …all that sort of stuff. Heaps of that, he loves all that. Lots of videos and things like that, and he will listen and re-listen to stuff, I think, until he *gets it*… Psych: OK. Tim: Ahh, actually. He just keeps going until…then one day he'll say something that he could've said twenty times ago, but he says it then and indicates his understanding. That's due to the immersion he's given himself.

Table 3.6: Adapted Example Analysis Table for Psychologist Reflexive Interview (McNaughton, 2009)

Time interval	**Video analysed**	**Theme (derived from my analysis)**	**Significant quotes and researcher notes**
58'00"	Brendan (PAR11) Video 2: 10'26" – 11'59"	Rigidity of test/ standardisation	Researcher: So, there's 1-2 minutes there where he's just like [*pretends to be distracted by looking around room*]… Psych: You know what, they're not listening to your verbal instruction because it's too much language for them. And, I mean, that's the tool! There's too much language, but if you just give them an example, they draw on what they're supposed to do based on the example – like the pattern, they're looking for a pattern. So the minute I said the example, he came up [*demonstrates regaining of attention with clear eye-contact*]. Researcher: Yeh, interesting…just to clarify, so with the tool, you *have* to [provide] that explanation, so you kind of, I guess, are sitting there kind of going "blah blah blah" (I have to say this) and then you're like, 'OK, let's get to the examples [laughs] so I can get [their attention] back!' Psych: Yes! [Very emphatic in response] Exactly! You've got it one-hundred percent! I feel like that *all the time*!

Schubert's (2009) approach to the process of analysing video in the form of "content logs" (120) also provided a helpful guide for theme/code development within the context of my

study. Schubert stresses that the content logs are not complete transcripts of video, but rather may contain rough descriptions, transcripts of segments of the video, and may contain references to analytic concepts/themes. Importantly, and in accordance with Grounded Theory methodology of conducting research,

> The content logs change as the research progresses: they become more detailed when sequences are analysed…The role of theoretical saturation in the process of identifying ethnographic chunks and creating content logs is that an analysis is always conducted with respect to the progress of the research…i.e. the researcher starts coding with theoretical sensitivity, continues to refine the categories by theoretical sampling and the process comes to an (sometimes tentative) end, when theoretical saturation is reached. In the practice of video analysis, this process resolves into the multiple steps and iterations of analysing videographic data, which are oriented towards the relevance of the material for the research questions: a) selecting key sequences…, b) repeated viewing…, c) systematically comparing different cases… (Schubert, 2009: 120-1)

The process undergone for the analysis in this study is outlined in detail in Table 3.3 (above) and highlights the refining, coding and reaching theoretical saturation methods. Another layer of the development of themes in the analysis process is the large pool of data that the themes were developed from. Figure 3.4, below, illustrates the sheer variety of data drawn upon during the analysis process, while Figure 3.5 demonstrates an example of how I directly applied this approach to a theme I draw on in Chapter Six.

Figure 3.4: Illustration of theme development (adapted from Balmer, Master, Richards, Serwint, & Giardino, 2010)

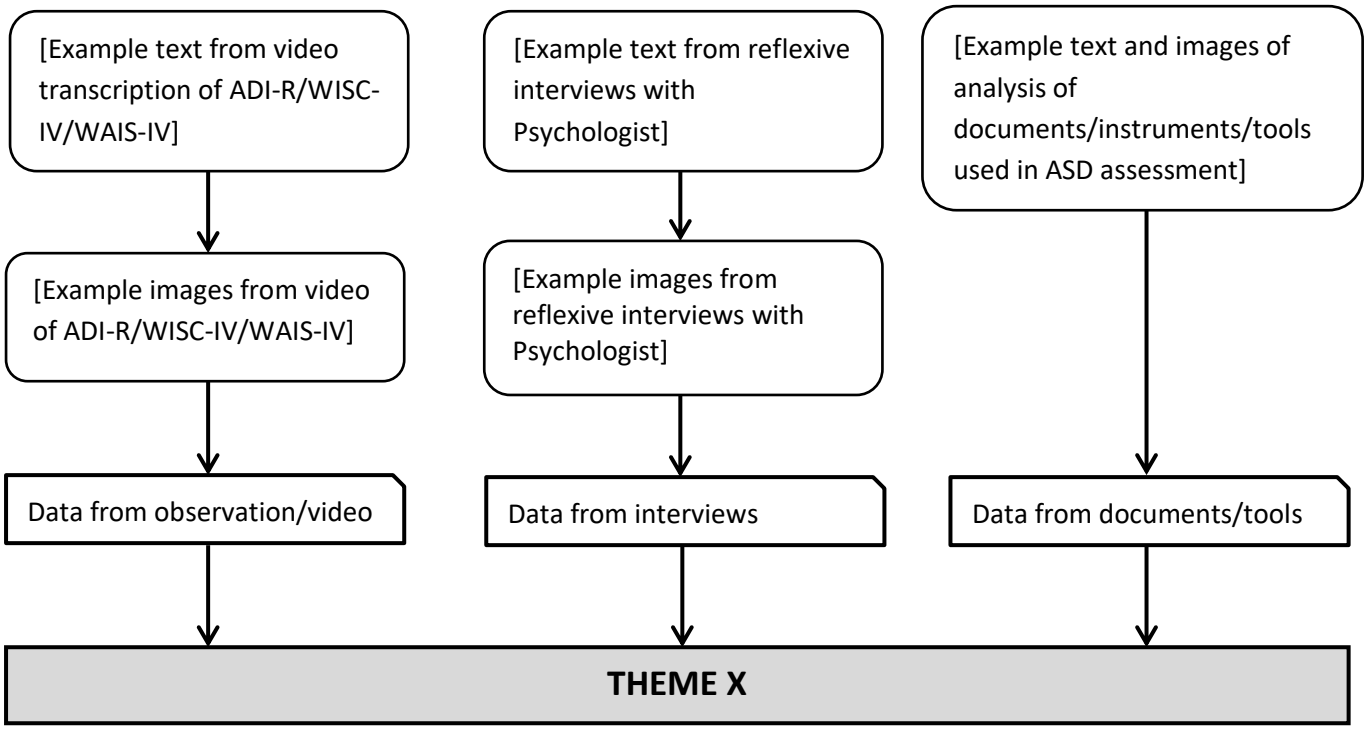


Figure 3.5: Example from my analysis of how I used the various forms of data for theme development

Transcribed text from Rupert's ADI-R with Sophie and Stewart

Sophie: I took him back to home and I saw how he...[*demonstrates by raising her hands to her eyes*]

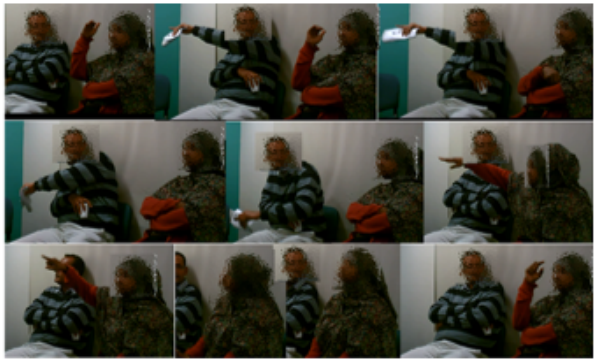
Stewart: [*gesturing towards the blinds in the clinic room*] He saw, like, lines... [*tilts head to the side with arm outstretched, moving head and arm simultaneously as if following an object moving along a straight trajectory*] and goes like that [*whips his head to the side*]

Psych: Ahhh, I know what you mean!

Sophie: [*pointing at the blinds*] This window, now, these lines [*gestures by pointing and drawing a line with her finger in the air*] when he comes, straight away he will: [*tilts her head to the side and then begins rolling head around in circles repetitively whilst looking at the blinds from the corners of her eyes*] look at it this way.

Stewart: He just look and look [*demonstrates by tilting head to the side and looking out of the corners of his eyes*]

Corresponding video stills from ADI-R

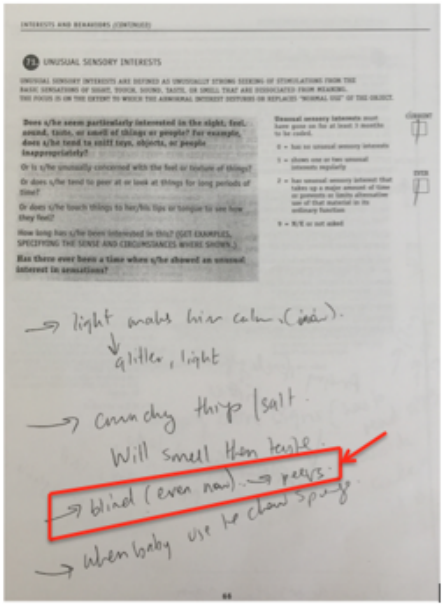


Transcribed text from reflexive interview with psychologist after playing back this video clip of Sophie and Stewart's ADI-R

Researcher: How do you deal with, you know, working with families where there is a little bit of a language barrier, or there is a bit of, you know, a lack of understanding – how does that work for you [with] diagnosing and coming to that...

Psych: Usually with families with a language barrier, because they don't understand, umm, often you let them talk first and then you'd ask the same type of question but in a different way. Like, for example, it's very clear – there are repetitive behaviours and stimming [*points at computer screen where video has been paused*] – [the parents] don't understand that, they actually don't understand what the concept of autism is. So, just collect the data and then go through [it] with them. So, sometimes I have families like that and I'll say, 'Well, actually...we call that sensory stuff, so it just means, you know, impulsivity, and he can't control it, and he enjoys it.' And I always give an example, I'll say, 'You know how you click a pen [*demonstrates curving fingers around pen and moving thumb up and down rapidly as if clicking the top of a pen*] – it's like that! And he needs to do that.' Umm, so with a family like that, I would normally, yeh, break it down. I know the questions are standardised, but, families like that, they don't understand those standardised questions, and they don't even understand - this family specifically – they don't understand what autism is...

Image of Rupert's scored ADI-R reflecting the response conveyed by Sophie and Stewart



THEME (discussed in Chapter 6) >> "Rendering" (Myers 2015) ASD diagnosis through the translation of knowledge using corporeal labour

Figure 3.5 (above) provides an example of how this approach adapted from Balmer and colleagues (2010) was applied in practice to my various modes of data. Using the example theme of "Rendering" and ASD diagnosis, which I discuss at length in Chapter Six, I show how I use transcribed text and corresponding video stills from the videoed ADI-R between the psychologist and the parents (Sophie and Stewart), as well as the corresponding transcribed text from the reflexive interview in which I ask the psychologist about this specific interaction, combined with the scored and inscribed page from the ADI-R answer booklet in which the psychologist's notes about this interaction are recorded. The cumulative power of this data, combined with my knowledge and analysis of the literature (see Chapter Two), enables me to develop themes in this complex analytic process.

Conclusion

The focus of this thesis is the use of video-reflexivity to analyse clinical encounters within a randomised control clinical trial. The subjects of that clinical trial were children who had a known diagnosis of an autism spectrum disorder, and their parent(s) or caregiver(s).

Autism spectrum disorders are experienced differently by each individual – ie. each person has different symptoms, responds differently to treatment, and often has varied co-morbidity with other disorders. Accordingly, the interaction between this infinitely varied disorder and a randomised control trial which sought to categorise how those individuals [insert] provided a fascinating backdrop for the video-reflexive methodology of this study.

I used a video-reflexive approach in which as researcher I both filmed clinical encounters and sat in on those encounters, with the intention of being an "alongsider" in the study, and the natural consequence that at times I was also in limited ways a participant. Approximately 45 hours of data (observed and the majority video-recorded) was collected for this study, which provided rich and complex data for analysis. I then transcribed the data and categorised it by theme, before engaging in a "reflexive" session with the clinician to consider the clinical encounter. In this reflexive session, the clinician initially provided unprompted analysis of the data, before more directed discussions took place, in particular reflexive analysis of the observations I had made.

In the following three chapters, I explore the key findings of this incredibly rich and unique data. Chapter Four will explore how the "autism" of the diagnostic encounter in the clinical trial differs in some fundamental ways from the "autism" diagnosed in the paediatrician's or psychologist's clinic. I will consider: how the context of the

clinical trial directs the diagnostic gaze of the psychologist in the clinical encounter; how this diagnostic gaze is directed towards the paediatric body and mind; and what factors motivate this diagnostic difference.

Chapter Five will examine the physical diagnostic tools themselves as artefacts of the diagnostic process: the wording of the questions; the way that they are read out; the inscriptions of the psychologist on the tool itself; and how the handwritten diagnostic notes – taken throughout the clinical encounter – are filtered by the psychologist into a single number placed in a box on each page underneath each question. I will argue that this can clearly be seen in the administration WISC-IV/WAIS-IV whereby responses from the child are scored based on their competence in various tasks, while the test simultaneously ignores or minimises other competencies. The labour involved in *achieving* an ASD diagnosis will be explored through the rigid way the trial requires diagnosis to fit within the narrow parameters of what counts as "evidence". The diagnostic session must be conducted in a certain way to fit the ambit of the clinical trial and the drug to best tested.

Chapter Six will contrast the diagnostic practices of the psychologist during the child WISC-IV/WAIS-IV session versus the parent ADI-R session. I focus on the way that corporeal labour is used in the ADI-R diagnostic encounter, that is, the way that clinicians use bodily gestures to encourage the compliance of their patients during assessments and examinations. Crucially tied in with this discussion is the emphasis the methodological approach of this thesis has on the *visual* – that through the use of video I have been able to capture and analyse the significance of this corporeal labour in the clinical encounter and demonstrate how it is often used by both psychologist and parent to convey and in fact *translate* significant clinical information that may have been invisible or misunderstood otherwise.

CHAPTER FOUR

Autism in the clinic, autism in the clinical trial: Refocusing the diagnostic and treatment gaze in the clinical trial

> There is a yawning gap between, on the one side, the prominence of autism as a clinical, epidemiological and social force, and, on the other, what can be said with certainty about autism as a neurological, genetic or diagnostic object. (Fitzgerald 2014: 244)

Introduction: ASD, medication and the clinical trial

This thesis has argued that the category of autism is uncertain, controversial, ambiguous and heterogeneous. In this chapter I will focus on the contention and "epistemic murk" (Eyal et al 2014: 236) that surrounds autism as the object of the clinical trial. Autism has resisted a consistent and stable diagnostic definition, treatment approaches, and biomedical and genetic attempts to make sense of how autism manifests within the body. That this confusion remains despite the enormous "biosocial productivity" of the category indicates that there is likely a unique set of circumstances, an epistemic murk, in which autism exists, and perhaps thrives.

The clinical trial is an example of this biosocial productivity, motivated by the drive to make sense of this disorder. In particular, recent years have witnessed a rapid increase in the publication of randomised, double-blind, placebo controlled clinical trials assessing psychoactive medications for the treatment of autism to guide clinical practice (Hollander et al 2004; Hollander et al 2012; Myers & Johnson 2007).

However, issues of contention, heterogeneity and "epistemic murk" remain relevant within this ASD clinical trial setting too. These trials are steeped in uncertainty, and the results are frequently subject to debate and critique. As Elizabeth Wilson (2008) explains with respect to the placebo-drug relationship in antidepressant clinical trials:

> The conclusions drawn from the data, the suggestions for further research, the criticisms about methodology and design, and the data themselves are extraordinarily heterogeneous. The variables that ought to characterise the placebo response in depressed subjects seem unruly or profligate; over time they have not settled into reliable patterns from which judicious treatments or reliable clinical designs could emerge. For example, the location of treatment (in or out of hospital), the age of the

> trial participants, the length of the trial, and the mode of psychological assessment, all generate patterns of placebo response; and all of these variables can change with different antidepressant medications. (33)

I will use Wilson's exploration of the placebo response and the drug-placebo relationship to reimagine the way that we understand the clinical trial and the placebo-drug relationship. For Wilson (2008), it is about understanding how "ingestion, physiological activity and therapeutic alliance might be aligned" (38). This argument has much relevance to the fluoxetine clinical trial studied for this thesis, particularly the notion that a participant's response to the active drug is intimately tied up with, and inextricably linked to, being *in the clinical trial itself*.

But before delving straight into an exploration of the inner workings of a clinical trial assessing the effectiveness of the drug fluoxetine on repetitive behaviours in children with ASD, it is important to reflect on the context surrounding the medication of children on the autism spectrum. This includes a brief consideration of the important period of deinstitutionalisation in Australia. Current treatment practices of medicating children with an ASD will also be considered, with an exploration of why the use of drugs such as antidepressants, stimulants and antipsychotics have become established and common-place in the treatment of ASD given the lack of evidence supporting this approach.

Then, by exploring Dick Willems' (1998) ideas around the potential for medications to "reorganise the body by creating new identities for it" (118), I will consider the ways in which the mechanisms of these "autism drugs" may be understood as feeding back into and altering conceptualisations of autism, its categorisation, and its diagnosis.

This chapter will go on to consider the context of the clinical trial and examine how the diagnosis of autism is marked by some key differences in this specific clinical encounter. A key distinction made in this chapter is the differences between "autism in the clinic" and "autism in the clinical trial." In analysing this difference I examine: how the context of the clinical trial directs the diagnostic gaze of the psychologist in the clinical encounter; how the diagnostic gaze is directed towards the paediatric body and mind; and what factors motivate this diagnostic difference. By using some key examples from my filming of ASD clinical trial diagnostic sessions, I will argue that the autism of the diagnostic encounter in the fluoxetine clinical trial differs in some fundamental ways from the autism diagnosed in the paediatrician's or psychologist's clinic.

By drawing on Nikolas Rose's work on psycho-pharmacological societies and the neurochemical self, I hope to shed light on this re-focusing of the diagnostic gaze.

This analysis raises broader questions about the way in which the medical profession has come to code children's quirkiness, "reduced emotions", "abnormal eye contact", difficulty in "making friends", "fixated interests" and "lining up toys" (American Psychiatric Association 2013) as autism spectrum disorder, treatable by drugs such as fluoxetine.

Historical considerations: drugs as an enabler for non-institutionalisation

In Chapter One, I explored the historical underpinnings of autism spectrum disorder and presented an historical analysis of the instability and uncertainty surrounding the labels "mental retardation", "developmental disability", and "autism", and their continuing volatility in the world of genetic science, biomedicine, psychiatry and psychology. In particular, in Chapter One I argued that the individuals we now label today as "autistic" were likely institutionalised as "mentally retarded" up until a few decades ago. Indeed, it was not until deinstitutionalisation came about that there was even a need for these specific subsets of diagnoses – until then, the umbrella term of "developmentally disabled" within the institutional setting sufficed.

As discussed in chapters one and two, the dominant treatments available for children on the autism spectrum are behavioural and psychological in nature. With the rise of the paraprofessions between the 1970s and 1990s in Australia and worldwide, as well as the availability of certain drugs such as tranquilisers, anti-psychotics and antidepressants, the scene was set for deinstitutionalisation. In an interview with an Australian psychiatrist, who practised during the deinstitutionalisation period in Australia, Dr P speaks of this deinstitutionalisation-enabling environment created by the introduction of these drugs:

> One of the major reasons was that in...1955 we actually got tranquilisers...we didn't have medications before that that were in use, apart from trying to control aggression basically – sedating people. We got the modern tranquilisers and the anti-psychotic drugs and we started using them in Australia in 1955. Within a matter of a year, the medical superintendant at Gladesville Hospital was writing his annual report to the Inspector General for the Insane (as it was in those days) that this had made a dramatic difference, patients who were uncontrollable were now controllable, patients who we thought would never move out into the community were now moving out into the community.

Interestingly, some of the earliest studies involving children with autism and medication involved the hallucinogen lysergic acid diethylamide (LSD). These studies were conducted by a United States psychiatrist named Lauretta Bender during the 1960s. In her most frequently cited 1963 study titled, "LSD and UML treatment of

hospitalized disturbed children" (Bender, Faretra & Cobrinik 1963), Bender and colleagues state that:

> The heightened perceptual awareness, increase in rapport, and breaking through of repressive ego defenses suggested a possible use of the drug as an adjunct psychotherapy, especially of neurotics, and has led to considerable experimentation in this area. In all of these studies LSD was usually given in single doses of 30 to 400 μg at weekly intervals, for varying periods of time, generally in conjunction with individual or group therapy. (Bender, Faretra & Cobrinik 1963: 84)

Bender et al (1963) identify many of the core symptoms we identify with autism today. Social impairment is discussed in terms of isolation and solitary behaviour: "Rarely did one child play with an adult, and even then the play was momentary, returning a ball thrown to them once and then losing interest" (86) and "Many were completely unresponsive to their environment, sitting or standing alone" (86). Examples of speech and communication deficits were identified as:

> Many of these children had not spoken any intelligible words; some made guttural sounds, screamed, or uttered other noises. Some had one or two words which were used rarely for communication; some seemed to understand directions and to be on the verge of speech; a few hummed or sang commercials, or bits of nursery rhymes. (86-7)

And notably, she singles out *anxiety* and *repetitive behaviours* as the final key symptoms:

> The autistic children showed all degrees of severity of symptoms and anxiety. Many were…rocking, whirling, and staring at their fingers. Others made contact only by excessive clinging, pulling, and biting or scratching. […] A boy, one of twins, avoided contact with other persons by covering his eyes or ears with his hands, or turning his back when approached, occasionally darting anxious fleeting glances at the person addressing him. Another boy beat his cheeks and forehead violently with his fists, or banged his head against the wall, so that his face was continually bruised and a football helmet had to be worn for protection. (86-7)

Bender et al (1963) are hesitant in their recommendations regarding the effectiveness of the drug, stating that, "[i]n general, we have not yet distinguished important characteristic differences in the clinical response to either LSD or UML, although there seems to be moderately greater excitability with LSD, especially early in treatment." (87) However, they go on to claim that when half of the children were taken off the medication for a period of four weeks, a short time afterwards many of the children regressed and lost previous gains that had been demonstrated whilst on the drug.

Understanding the role of medication in the deinstitutionalised landscape is key to understanding the success of the paraprofessions at this time, and how their

therapies and educational and psychological treatment approaches were able to flourish. In their report *Children with Disabilities in Australia* (2004), the Australian Institute of Health and Welfare (AIHW) demonstrates that the impact of deinstitutionalisation on children with disabilities occurred primarily during the 1980s and 1990s, with 9% of children with a severe disability living in cared accommodation in 1981, compared with 0.4% in 1998.

The AIHW (2004) also points out that for children with intellectual disabilities the term non-institutionalisation is perhaps more fitting than deinstitutionalisation, as this process of change has tended to be more about these younger individuals staying in the community in greater numbers, rather than moving out of institutions. For children with intellectual disabilities the changes in attitudes, legislation and government involvement in Australia resulted in an improvement in access and availability of services, the introduction of income support for their carers, and more support from the mainstream education system. However, with the majority of these children now residing in households, provision of care for them rests mainly on the shoulders of family care givers. This has led to adverse health effects for the caregivers (that is, focusing on the health of the child has led to the caregiver ignoring their own health) as well as relationship strain and stress (30% of children with a disability live within a single parent family, compared to 18% of children without disabilities) (Australian Institute of Health and Welfare (AIHW) 2004).

Consistent with this idea of deinstitutionalisation (or non-institutionalisation) and the push for psychological and educational treatment approaches in the community, drug research during the late 1970s and 1980s focused on medications that could work hand-in-hand with therapy. A good example of this is Haloperidol, an antipsychotic medication, which was believed to make children more amenable to behavioural therapy (Feinstein 2010). In a placebo-controlled and double-blind study, Campbell and colleagues (1978) critically assessed the interaction of the two treatments – Haloperidol and behaviour therapy – with regards to their effects on symptoms and language acquisition in 40 autistic children aged 2.6 to 7.2 years. They concluded that: “Haloperidol was found to be significantly superior to placebo in decreasing certain symptoms, depending on the age group” (640). Thus, from the late 1970s, research into the collaboration between drug and therapy in the treatment of autism was well under way.

The rate of prescribing these types of medication in children in general continues to rise. During the late 1980s and early 1990s, there was a dramatic increase in the use of psychotropic medications by children and adolescents in the United States. The increase cut across age, racial/ethnic, geographic, gender, and insurance groups and included stimulants, antidepressants, and other psychotropic medications (Olfson et

al 2002: 518). Olfson and colleagues' (2002) US-based study demonstrates, for example, that children were 3.56 times more likely to use an antidepressant in 1996 than in 1987. Indeed, fluoxetine was actually approved by the Food and Drug Administration (FDA) in late 1987, and was marketed in the US in 1988. This is unsurprising given that during the 1980s, childhood and adolescent depression became a topic of considerable clinical and research interest (Angold 1988), with studies demonstrating an apparent increase in the number of depressed children and adolescents (Weissman et al. 1984; Ryan et al. 1992).

Recent studies also show that, despite this ambiguity and uncertainty, medication use amongst children diagnosed with an ASD is substantial (Oswald & Sonenklar 2007). Spencer et al (2013) report in *Pediatrics* that among 33,565 children in the US with ASD, 64% had a filled prescription for at least one psychotropic medication (Spencer et al. 2013: 833).

In a study of 2390 individuals diagnosed with an ASD, Oswald and Sonenklar (2007) found that 83 per cent of the sample were prescribed drug(s). The seven most frequently prescribed classes of psychoactive drugs were antidepressants, stimulants, tranquilizers/antipsychotics, anticonvulsants, hypotensive agents, anxiolytic/sedative/hypnotics, and benzodiazepines. This study found that individuals were prescribed, on average, drugs within four different classes (that is, antidepressants, anticonvulsants, stimulants and benzodiazepines) over the course of a year. Furthermore, over the course of a year, individuals submitted claims for up to six drugs in the same class. Thus, children with an ASD are "increasingly likely to be treated by a wide range of psychotropic and other medications" (Oswald and Sonenklar 2007: 353). One of the key reasons given for this variety is that "there are no clear guidelines regarding psychopharmacologic treatment of individuals with autism spectrum disorders" (Filipek et al. 2006 in Oswald and Sonenklar 2007: 348). It is also worth mentioning that several studies have demonstrated a correlation between psychotropic medication and geographic characteristics, such as increased medication use in lower socioeconomic and rural areas in the US (Farmer et al 2009; Rosenberg et al 2010).

It is not surprising, therefore, given this propensity for medicating without scientific evidence, that today children's behavioural problems constitute a growing market for psychotropic drugs. Regardless of the benefits or risks, this has become big business for the pharmaceutical industry. According to a recent survey conducted by Medco Health Solutions (a pharmacy benefits management company) which looked at prescription purchases in the US, spending on behaviour drugs for children and adolescents rose 77 percent from 2000 through 2003. These classes of drugs – SSRIs,

antipsychotics, and stimulants – are now the fastest growing type of medication taken by children, eclipsing antibiotics and asthma treatments (Freudenheim 2004).

However, the medical literature remains cautionary about the benefits of psychoactive drugs in the treatment of ASD. For example, a study in *Pediatrics* in 2011 performed a systematic review of medical treatments available to those on the Spectrum, and found that, "although many children with ASDs are currently treated with medical interventions, strikingly little evidence exists to support benefit for most medications" (McPheeters et al 2011: 1318).

Furthermore, medical literature offering clinical recommendations to practitioners regarding the treatment of autism spectrum disorder often contains cautions and caveats in its assessment of the use of psychoactive drugs. Behavioural and educational therapies are usually discussed first, and are portrayed as preferable (see for example Scahill 2008; Myers & Johnson 2007). In Myers and Johnson's (2007) review of ASD treatment options, for example, not only do they begin the discussion of treatment options with a comprehensive look at the various behavioural and educational approaches available, but when they do eventually begin their discussion of psychopharmacological options they preface the discussion with warnings that: "treatable medical causes and modifiable environmental factors" must be first ruled out; the clinician may actually be dealing with a co-morbid disorder which is separate to the symptoms of ASD; and that "there is currently insufficient literature to establish consensus regarding an evidence-based approach to pharmacologic management" (1170-1). It is therefore clear that the medical literature is upfront in addressing the uncertainty and murk that surrounds autism treatment approaches.

Selective Serotonin Reuptake Inhibitors (SSRIs): fluoxetine, autism, and the anxious/obsessive brain

Of specific interest to this chapter is the class of psychoactive drugs known as antidepressants (selective serotonin reuptake inhibitors – SSRIs), and more specifically, a type of SSRI called fluoxetine. Aman and colleagues (2005) have shown that between 1993 and 2001, antidepressants showed the largest increase compared to other classes of psychoactive drugs amongst children with autism, with reported use rates tripling in this time. Fluoxetine is often cited as the third most commonly prescribed antidepressant, sitting behind paroxetine and sertraline (Oswald and Sonenklar 2007).

Fluoxetine – which is also known by the trade names Prozac, Sarafem, Ladose and Fontex, among others – was approved by the US Food and Drug Administration

(FDA) for use in the treatment of major depressive disorder in December 1987. The US fluoxetine patent expired in August 2001, with generic formulations available in the US and elsewhere. Fluoxetine is commonly associated with treatment of major depressive disorder (including paediatric depression), obsessive-compulsive disorder (in both adults and children), bulimia nervosa, panic disorder and autism. However, no drug authority has specifically approved the use of SSRIs for the treatment of autism. Thus, the prescribing of SSRIs and fluoxetine for autism is either "off label" or related to an "associated indicated disorder such as obsessive compulsive disorder (OCD) or depression" (Williams et al 2013: 3). "Off label" indicates that a medication is being used in a manner that is not specified by the FDA's approved packaging label, for example: it is being used in an unapproved age group, at an unapproved dosage level, or an unapproved form of administration. In Australia, to date, only fluvoxamine (an SSRI) has been given a specific indication of OCD in children eight years and over, "while prescribers are urged to exercise caution in prescribing other SSRIs for children under the age of 18 years" (Williams et al 2013: 3).

In clinical trials in which SSRIs are tested within a population of people diagnosed with an ASD, Nikolas Rose's (2003) notion of the "neurochemical self" helps to explain this reconceptualisation of autism as a "brain problem". According to Rose (2003), neurochemical selves operate within psycho-pharmacological societies as we "have come to understand our minds and selves in terms of our brains and bodies". Rose (2007) suggests that everyday emotions and conduct are being reconceptualised in terms of neurological theories and neurochemical deficiencies, which require treatment through pharmaceutical products and psy-expertise. There is also a "wider shift in which such drugs are becoming central to the ways in which our conduct is governed, by others, and by ourselves" (Rose, 2007: 223). For example, in Hollander and colleagues' (2012) double-blind placebo-controlled trial of fluoxetine in adults with ASDs we can see the use of this neuro- and bio-medicalised language in the description of the disorder, firmly locating autism within the brain:

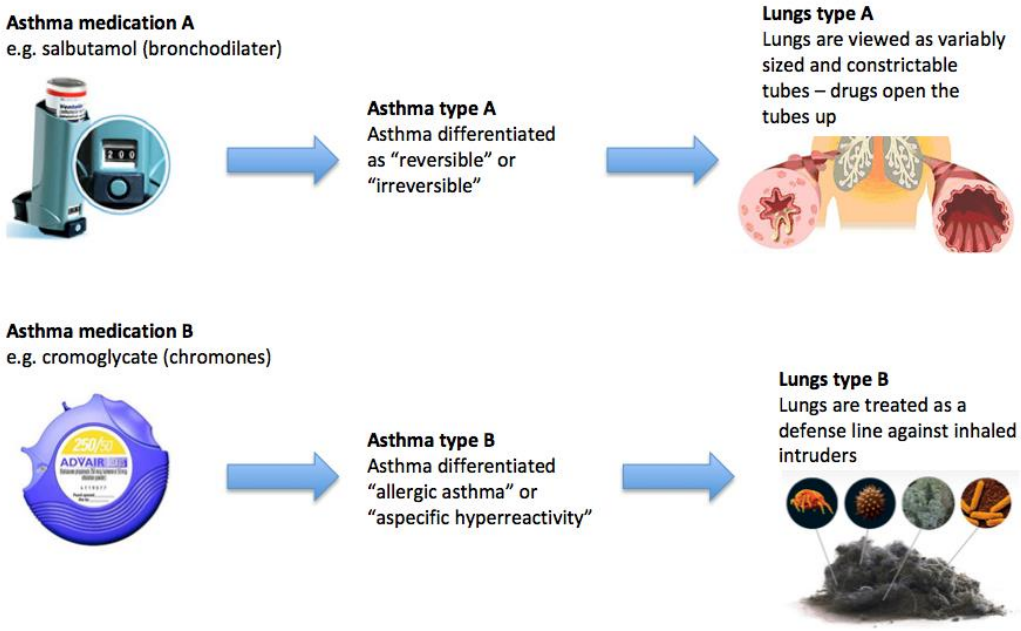
> The interest in SSRIs for the treatment of ASDs stems from a hypothesized role for serotonin (5-HT) in the pathophysiology of ASDs and the similarities between repetitive behaviors in ASDs and obsessive-compulsive disorder (OCD), a condition for which SSRIs are a first-line treatment. It has been hypothesized that dysfunction of 5-HT regulation in ASDs occurs during early developmental periods, results in cortical morphogenetic abnormalities and altered 5-HT neurotransmission, and influences symptom domains such as anxiety and rigidity. (Hollander et al 2012: 292)

I will explore the way that Rose's concept of neurochemical selves is enacted in the clinical trial studied for this thesis in detail later in the chapter.

Reorganising the autistic body through treatment

In Willems' (1998) exploration of the narratives of asthma patients and the way that clinical practice is shaped by the different medications available to asthma patients, we are shown that these differences in drugs are what generates a division of the disorder, in classificatory terms, into "subclasses fitting these treatment possibilities" (109). In other words, the different medications become the negotiator and mediator in debates about how to classify patient X or Y. Figure 4.1, below, illustrates Willems' (1998: 105-118) argument in his chapter "Inhaling drugs and making worlds".

Figure 4.1: Diagram representing Willems' (1998) ideas on different drugs-different asthmas-different lungs



Willems (1998) observes that in the clinical encounter, asthma medication A – salbutamol – is administered in situations when the clinician is trying to distinguish between two subclasses of asthma: "reversible" and "irreversible". When the asthmatic patient has their lung function tested, the clinician takes a measurement before inhaling the bronchodilator, and after. The asthma is classified as "reversible" if lung function significantly improves after inhalation. Thus,

> as therapeutic agents, [bronchodilators] also diagnose…without the existence of bronchodilators it would be impossible to reverse the airway obstruction, and thus it would be impossible to sensibly differentiate between reversible and irreversible asthma. Drugs construct the division in a very down-to-earth sense: they enter the lungs and physically produce a reversal of the obstruction of the airways – in "reversible" cases, that is, not in "irreversible" ones. (110)

Similarly, medication B – chromones – demonstrates a second distinction within the classification of asthma: "mainly allergic asthma" and "mainly aspecific hyperreactivity". Chromones are often the first step in diagnosis *and* treatment of the patient. If the use of the drug chromoglycate reduces complaints and the need for bronchodilators (medication A), then the patient is classified as having an allergic form of asthma. Alternatively, the patient will receive treatment of inhaled steroids, and they are diagnosed with a nonallergic form of hyperreactivity. Thus, we can see from these different medications – A and B – different forms of asthma are constructed and diagnosed with these treatment possibilities. Willems (1998) also highlights that the drug itself is not the only actor in this creation of difference and reordering of bodies. Other actors include the measurement devices, obedient subjects, epidemiological researchers, laboratory researchers, the clinicians who prescribe the drug, and so on.

Taking these ideas one step further, Willems (1998) points out that this reordering of asthma classification through different medications also creates a reordering of the body, or more specifically, the lungs. Thus, as Figure 4.1 demonstrates, with medication A, asthma is conceptualised as a problem of constricted tubes, with the bronchodilators opening up these tubes to clear the airways. Medication B, on the other hand, is concerned with protecting the lungs against allergens. The lungs are treated as a defence line against inhaled intruders. As Willems (1998) explains:

> In all asthma practices, airways are treated – but they are treated as *different* airways. Some drugs strengthen entrance barriers, others open up constricting tubes, and yet others treat inflammatory membranes. If these were all "aspects" there would have to be one underlying or overarching unity: "the lungs." But if different practices each treat different lungs, and each of them defines its own *ontology of the airways*, then the answer to the question what kind of object "the lungs" *are* starts to look quite different. (113)

Different Treatments, different autisms, different brains

Having explained the key ideas behind Willems' (1998) argument, I will now seek to apply these concepts to the practice of prescribing medicine to children on the autism spectrum. Firstly, however, it is important to recognise that the above examples analysing the treatment of asthma are based on known and established physiological mechanisms that take place in asthma sufferers. The underlying causes of these different types of asthma have been established, with drugs treating these specific conditions. On the other hand, the diagnosis and causes of ASD are shrouded in far more controversy, uncertainty and complexity.

In Figure 4.2 I apply Willems' (1998) ideas to the highly complex and uncertain practice of prescribing medications to children on the Spectrum. I have used the

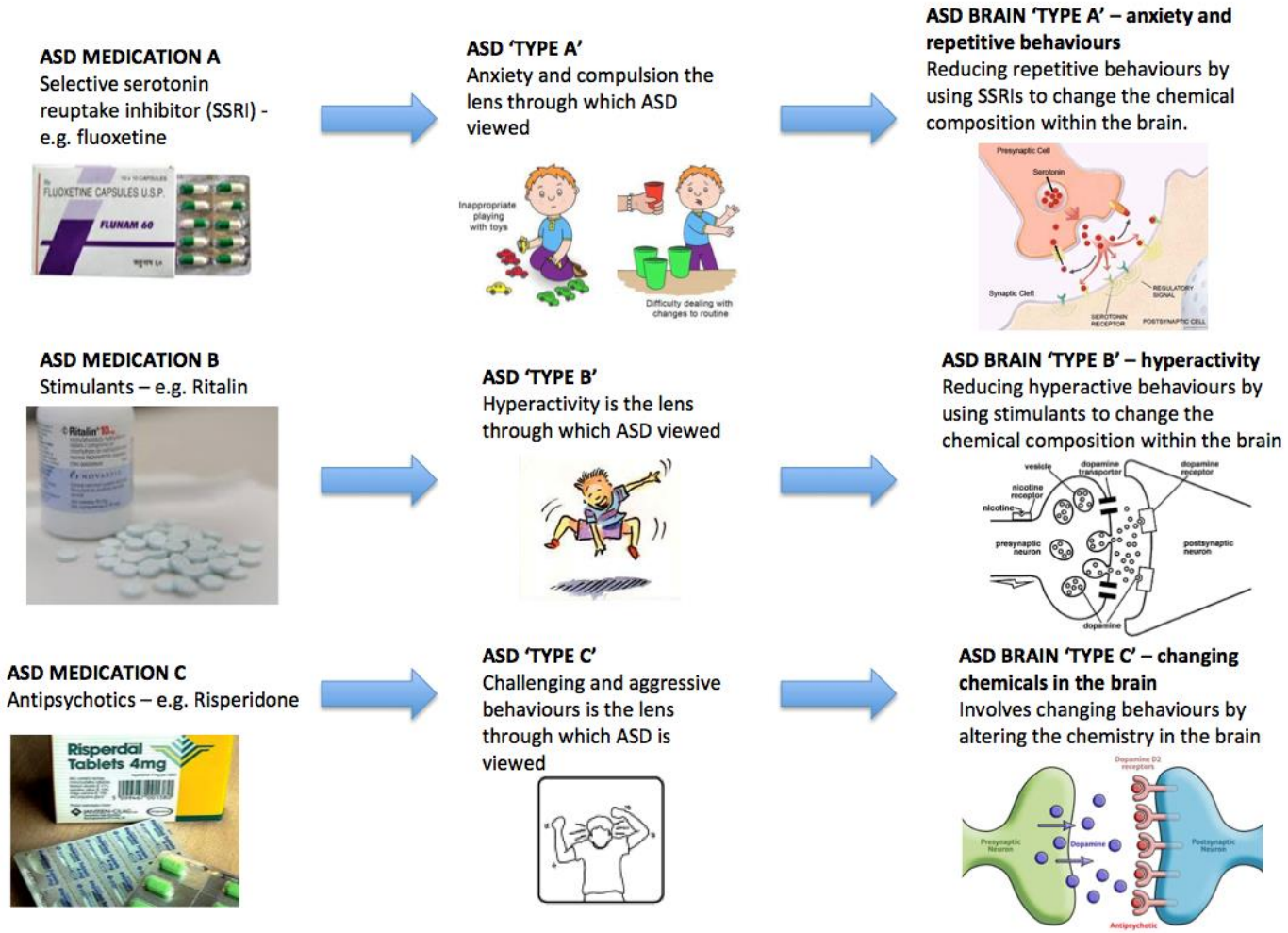
example of three commonly prescribed medications for ASD, and illustrated the way that these different approaches reorder or reframe conceptualisations of the classification of autism. Thus, for ASD medication A – fluoxetine (SSRIs) – autism symptoms are seen through the lens of anxiety as indicated by the child's symptoms of repetitive behaviours. If the child's manifestations of anxiety – repetitive behaviours – decrease with the use of fluoxetine, the link between autism and anxiety is strengthened. From a clinical trial point of view, the effectiveness of this drug in the sample of children tested provides evidence for the targeted nature of this drug in treating repetitive behaviours in children with ASD. Importantly, it also provides evidence for FDA (or Therapeutic Goods Administration (TGA) in Australia) approval for the drug to be used in ASD-symptom treatment. Furthermore, this sort of drug research is also seen as a way of getting closer to understanding the autistic brain. As Figure 4.2 demonstrates, the effectiveness of "ASD medication A" also feeds into the classificatory loop by providing information about how an "autistic brain" reacts to fluoxetine (SSRIs).

The same is true for medication B – Ritalin (stimulants) – and medication C – Risperidone (antipsychotics). To prescribe Ritalin is to see autism through the lens of hyperactivity and attention deficits, and thus to reorder autism in the child as defined and treatable by drugs and therapies that target these hyperactive behaviours. Likewise, if this drug is deemed effective, it informs clinicians about the mechanisms of the autistic brain through the addition of stimulants.

The important point here is that the ASD medication, the disorder itself, and the individual ASD brain cannot be properly conceptualised without each other. The brain and the medication do not precede medical practice, but instead, they follow from them (Willems 1998). As ASD medical practice, research and knowledge shifts and evolves, the essence of the ASD brain will alter with them.

Thus, the action and agency of these medications, and the various actors crucial to their administration, are a vital part of understanding how conceptualisations of ASD are established, critiqued, and developed:

Figure 4.2: Different treatments – different autisms – different brains (adaptation of Willems' (1998) work)



> Drugs, then, are therapeutic agents, but as a part of their therapeutic action, they produce differences and similarities, divergences and connections. They do not merely help the body, or body parts, to resume old functions that are hampered by disease. They also define diseases and reorganise the body by creating new identities for it. (Willems 1998: 118)

Fluoxetine and autism in the clinical trial: refocusing the diagnostic gaze

The clinical trial examined for this dissertation was particularly interested in one of the three core areas of impairment in children with autism: stereotyped behaviours, interests and activities[10]. These behaviours are the focus of the fluoxetine trial, because research suggests that they are linked to anxiety (that is, children with high anxiety tend to have more repetitive behaviours than those without anxiety) (Rodgers et al 2012) and are therefore a visual way of identifying and "measuring" anxiety in children with ASD.

Children were often sent to participate in this trial by their paediatrician, and in many cases had previously *received a diagnosis of autism*, or were *believed to have autism* by their paediatrician. Thus, the diagnostic session in the trial was often just a formality to "confirm" the paediatrician's diagnosis or instincts. The trial was able to offer families, in turn, a free diagnostic report via the Autism Diagnostic Interview-Revised (ADI-R), an intelligence test for the child via the Wechsler Intelligence Scale for Children (WISC-IV), as well as the possibility of free medication and thorough monitoring by clinicians for the sixteen-week clinical trial period.

To begin the diagnostic encounter (which was often the first point of contact between parents and trial staff) in this fluoxetine trial with children with ASD, the psychologist would explain the purpose of the study to the parent(s) and what the study was hoping to achieve. Unlike a private practice diagnostic session, the fluoxetine-focused nature of this trial (and diagnosis) directs the clinician and parent gaze towards the child's anxiety, and the behavioural manifestations of this anxiety ("repetitive and/or stereotyped behaviours"). Thus, in the following exchange with the mother (Laura) and father (Tom) of Patrick (see *Table 1* – at end of document – for more information about participants), an eight-year-old boy with a suspected autism diagnosis, we can see how attention is shifted towards these key components of the clinical trial:

[10] These may include: (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus; (2) Apparently compulsive adherence to specific non-functional routines or rituals; (3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or rocking back and forth); (4) Persistent preoccupation with parts of objects. (American Psychiatric Association 2000)

Psych: So, basically, with the study, before we start, it is for kids with autism. So, they're looking at all those behaviours that Patrick shows, so doing this [*demonstrates Patrick's behaviour of rubbing/picking at hands*], breaking the pencil… the goal of this study is to look at the medication to see if it reduces that behaviour. So the medication that we use – it's been around for a long time – but they've never actually looked at it with kids on the Spectrum, and all those repetitive behaviours. So, it's an anxiety-based medication. But we're looking at controlled doses, because what we've been finding is that a lot of paediatricians, they either give you too much, or too little; and that dosage effects kids on the Spectrum in terms of: does it make them do those behaviours more; is it effective at all? And what we're finding is that it's not, that's why this trial is looking at a specific dosage. And at the moment, what I find in a lot of the kids that we've looked at is that it has had an effect on the kids that *do* have the medication.

The psychologist makes direct reference to the *specific* repetitive behaviours exhibited by Patrick – picking and rubbing at hands and breaking pencils – and immediately establishes a link between repetitive behaviours, anxiety, and fluoxetine. Not only is the parents' gaze directed toward links between behaviour-brain-drug, but also the apparent agency of this drug through its *action* and *effect*: the fluoxetine *targets* the anxiety, and we see a *reduction* in the behaviour. The agency of the drug, however, is tempered somewhat by this clarification from the psychologist a few minutes later:

Psych: The goal of the medication is not to cure something like that [aggressive behaviour], but it should help him to cope a little bit better. So, if it was a situation like that, you'd hope the medication would just make him cope a *little* bit more than what he normally does.

In the case of Brendan, a fifteen year-old boy who is described by his mother (Lena) and father (Tim) as having "compulsive tendencies", the psychologist references behaviours Brendan exhibited during his WISC-IV consultation with her, and uses these to illustrate this link between brain-behaviour-drug and the specificity and agency of the fluoxetine in targeting the anxious behaviours:

Lena: I think that the other, probably obsessive, tendency that he has is he could become a bit of a hand-washer. You know, he spends a lot of time going in and out of the bathroom and washing his hands.

Psych: So they're the types of behaviours that we're going to look for when we are starting the medication – so, how compulsive is he when he's washing his hands [whilst on the medication]. And, you know, he does that pop pop pop [psych raises her index finger and gestures to her cheek] with his mouth. These are the types of behaviours to look for – so less of these [while on the medication]. Even for when he rocks [back and forth] more, or when he gets quite worked up and you can see he is getting quite anxious. Any of those mannerisms that he does. I noticed [in the WISC-IV] when he was getting

frustrated on one of the tasks he was getting quite worked up he'd rock a little bit more.

Lena & Tim: Yes [*both nodding*].

Similarly in the case of Stephen, a seven year-old boy who has received a myriad of labels from various clinicians over the years (for example, he was diagnosed with Agenesis Corpus Callosum (ACC)[11] at birth, and later received diagnoses of Attention Deficit Hyperactivity Disorder (ADHD), and ASD), we can see through his mother's explanation of his current situation that his anxiety is mixed in with the "murk" of his condition(s). For example, Jenny, Stephen's mother, explains the complexity of Stephen's diagnostic and treatment situation to the psychologist in the process of telling her son's story:

Jenny: So he went to Dr X, and he mentioned that he might have ADD, and I think that was over the three year period he was [being treated by] him. So, then we came here and saw Dr Y, and Dr Y said: 'Look, to me he's got some autism spectrum disorder items there,' which the psychologist who we saw – I think one of the things she said was that he displays bizarre behaviours, which yeh, he did…So I said, 'yes, look, bits of his behaviour that I look at, and I look at what autism is, [the behaviours] do display on the autism spectrum. Certainly with areas of play that he does – it's very ordered, very specific – and his routine stuff…So, Dr Y said, 'His anxiousness could be, with the behaviour he showed here, Asperger's Syndrome.' He said, 'I can sit here and just reel all of it off [different diagnoses] and it's kind of there in one big ball.'

Jenny: Stephen's got a myriad of things: ACC, ADHD, ASD – there's a million other ones [labels] the doctor said we could give him. So, he's been on Risperdal for a long time, and I think when we moved over here, there were questions as to why he had been on it for such a long time. So we've taken him off that and we just wanted to try to look at alternative solutions. He's tried Tegretol, Ritalin – Ritalin sent him the other way: he's quite anxious, which is part of his Asperger's, so it actually made him focus on his anxiety…so that didn't last for long at all. So I think it was to look at fluoxetine as another method to try to, sort of, contain his anxiety and his anxiousness and all of that.

The psychologist then goes on to explain how the medication will work by targeting his specific anxious, repetitive behaviours, while also cautioning that the actual role of the medication is not to cure, but to help with the "regulation" of behaviours:

[11] Agenesis Corpus Callosum (ACC) "is a rare congenital abnormality in which there is a partial or complete absence of the corpus callosum. This is the area of the brain which connects the two cerebral hemispheres…The first symptoms of ACC are usually seizures, which may be followed by feeding problems and delays in holding the head erect, sitting, standing, and walking. The seizures may be caused by a very common disorder called infantile spasms, which is associated with ACC. There may be impairments in mental and physical development, hand-eye coordination, and visual and auditory memory. Hydrocephalus may also occur. In mild cases, symptoms such as seizures, repetitive speech, or headaches may not appear for years…There is no standard course of treatment for ACC. Treatment usually involves management of symptoms such as hydrocephalus and seizures if they occur."(Brain Foundation 2014)

Psych: So, the only thing with the study is that it's blinded, so I don't know if he's going to have fluoxetine or not. There's a possibility he'll be on placebo. But it will be good as well, because then we can see what's working and what's not, and then, based on that, we should know. So the study finishes at the end of the year, so we'll know most likely next year what he was on. And then, based on that, you can work out if it's something you want to use long-term. So it's an SSRI, it's quite a good medication – just watching the kids that I've seen in the study (it's gone on for three years now). So, you know, we're looking at repetitive behaviours, so all his anxious behaviours

Psych: The fluoxetine, the goal of that, I mean, it's not going to cure his routines, but it should help him to regulate himself just a little bit better. So they're the changes that you're looking for: is he crying longer, is he getting so worked up so quickly…

Stephen's case is particularly interesting given his diagnosis of ACC and the comorbid conditions that are associated with his primary diagnosis of ACC. His case illustrates Willems' (1998) ideas shown in Figure 4.2 (as discussed earlier in this chapter) in terms of the way that medications feed back into how clinicians understand, make sense of, categorise and treat disorders. Stephen has been given a cocktail of drugs over the years in what appears to be a trial and error process in coming to decisions about how to categorise and define his condition. In the following discussion between the psychologist and Stephen's mother, Jenny, below, we can see how this has clearly been a problem for Stephen throughout his life, and the psychologist's recognition that this is quite common for children with ASD in general:

Psych: With these kids it's hard as well. I can see why he's had so many diagnoses. The kids on the Spectrum, because they're so inflexible and show a lot of symptoms that the kids with ACC, ADHD and so on show, they all show similar stuff. All the kids that come in, they've got this label, this label, this label, this label [laughs as she counts on her fingers].

Jenny: He was born, obviously, with Agenesis Corpus Callosum, so everything else is just associated with that. I think he's had autism [diagnosed] at one point with one psychologist that we went to see, and I was like, 'No, he isn't autistic, he's just born with ACC, which will then potentially show you: autistic spectrum, anxiety, all those things, and they're all associated with ACC.'

Psych: Yeh, I mean, that's probably why you've had a hard time trying to find something conclusive [laughs]. Yeh, and the meds!

In the reflexive interview with the psychologist, we discussed the difficulty of including children in the trial with comorbid disorders. Interestingly though, while Stephen's ACC was acknowledged as an added complexity, the psychologist kept returning to the idea that as long as the diagnosis established that ASD was "the core thing" then the child was included in the trial. Thus, as long as the medication was able to address those "core" ASD symptoms, the psychologist was satisfied that it

was the ASD that was being "treated." Here we can see Willems' (1998) ideas played out in the way the psychologist justifies Stephen's inclusion in the trial:

> Psych: With the ACC, it's still clear that even though he's got this other neurological condition, he's still presenting with features of ASD [slaps hand on table to emphasise]. [Jenny and Matthew] even said it themselves, "All kids with ACC are different and they have a bit of this and a bit of that, whereas Stephen has all the of [the ASD symptoms]", so all the autism stuff.
>
> Psych: With the trial, we have to rule out specific diagnoses – only the mental health ones though, because I think they show similar symptoms. In terms of other things, we haven't screened. As long as they have ASD. And I can only think of three kids [with comorbidities]: Manahil, who had deafness; Stephen who had [ACC]; and [new participant, not participating in my study] who had a family history of sensitivity to the medication. I haven't seen it as an issue. I mean, you always want to screen for comorbidities. In our trial we made sure that ASD was the core thing. With stuff like that it's hard, because ASD is neurodevelopmental, and ACC is neurological as well, so, it could be both. It's hard to say.
>
> Me: So, participants like that are still included in the trial, even if there is some question mark [over the diagnosis]…?
>
> Psych: Yeh, because we're still looking at the autism symptoms, right! So with the autism symptoms, we still want to make sure that the medication's helping those symptoms.

This cocktail of drugs and diagnoses, as the psychologist recognises, is quite common amongst the population of children with ASD. For Lena and Tim, Brendan's parents, Brendan's experiences with the stimulant-classed drug Ritalin demonstrated that this was not the right approach for him, and led to their participation in the fluoxetine trial as they try to come to terms with how to manage his behaviour:

> Lena: When he was on Ritalin, and one of the reasons for us deciding to stop was, he became quite a compulsive picker, and picked at himself, bit his fingers and nails back to the quick, and was picking at his skin, that kind of thing.
>
> Lena: This was another reason why we stopped Ritalin, because I felt that he was becoming too melancholy and he became very delicate, emotionally, and would just snap. He would hit his head on the wall, or pull his hair, or threaten self-harm, that kind of thing.

Again, here we see Willems' (1998) notion of the role of medications in the reorganisation of the body, and how they create new identities through the action of the medication. Brendan's paediatrician had a certain idea about his condition, or his autism, and prescribed a drug he thought *might* alleviate some of his "problem behaviours". However, the drug produced certain side-effects that made its use

untenable, and so Brendan's autism was reordered as a disorder that may be altered using the SSRI fluoxetine.

Likewise, for Daniel, a nine-year-old boy with high-functioning autism, anxiety is still a significant problem for him despite the cocktail of medications he is on. His mother, Hayley, discusses his current dosages of Ritalin and Risperdal and how he has stopped taking these medications for the purposes of the study. She expresses concerns about the potential for Daniel to receive the placebo (in-active drug), and what this will mean. However, the psychologist explains the benefits of taking part in the trial:

> Psych: So hopefully, at least we know then that the extra medication that we are adding is definitely working.
>
> Halyley: Well, if it's worked for the other kids [in the trial], I don't see a reason why it shouldn't work for him. Especially if he's in their category [autism with anxiety].
>
> Psych: Ohhh, he fits, he is the biggest match. So, it's really good – the SSRI will be perfect for him. At least we'll know that that is the medication he's been needing.
>
> Psych: Like I said, it's good [taking the fluoxetine and going off the other medications]: because then we'll know the Ritalin is definitely working; the Risperdal is definitely making a difference in his behaviour; and if he needs an SSRI – so it's good to see.

Thus, using Willems' (1998) theory, we can see that the psychologist is positioning the fluoxetine as a potential third element in this drug cocktail to help the child's behaviours. By not taking the other two drugs – Ritalin and Risperdal – they are also able to confirm if these medications are "definitely making a difference to his behaviour". Thus, taking these medications/not taking these medications feeds back into decisions about what sort of behaviours make up Daniel's brand of autism.

Another key difference between autism diagnosed in the *clinic* and autism diagnosed in the *clinical trial* is the *way* that the child is diagnosed. This difference is perhaps most obvious through the complete reliance on the Autism Diagnostic Interview-Revised (ADI-R) – the diagnostic tool that structures, directs and essentially standardises the whole of the psychologist-parent interview – throughout the clinical trial. In contrast, the diagnosis in the clinic is often more dynamic, experiential and nuanced, as evidenced by interviews I conducted with Australian private practice paediatricians in 2009. Eight of the nine paediatricians interviewed indicated that they ranked clinical experience and observational knowledge as the highest diagnostic competencies. Using phrases such as: "one can just pick these things," "you just mentally classify," and "expertise is being able to recognise patterns"

illustrates this preference for the "gut feeling" approach to diagnosing autism spectrum disorder (Lenne & Waldby 2011: 75).

Diagnosis in the clinical trial, on the other hand, needs to be specific, documented, transparent, and scientific. The focus is on distinguishing between "the patient meets the trial criteria" and "the patient does not meet the trial criteria." As Fitzgerald (2012) explains, this transparency and "rigour" is vital for the clinical trial:

> But perhaps more interesting, in this case, is what marks the difference: for inclusion in the clinical trial, participants will have to pass a given cut-off on at least one, and preferably both, of the 'gold standard' quantitative scales. This is a requirement of publishing in a good journal – and is obviously governed by concerns about the homogeneity of participant populations across different studies. But for the clinic, where this kind of specificity is less of a concern, there is a different solution, and this is to cede some epistemological space to whether autism is actually 'felt' by the clinician in the course of the encounter. (Fitzgerald 2012: 80)

Thus, the motivation behind diagnosis in the clinical trial is also fundamentally different when compared to the clinic, or private practice, as explored in the following exchange between the parents of Patrick and the psychologist:

> Psych: So, what this assessment is, so the one I am doing now… I mean, if you go to any private clinic we use the same type of assessment. So it's to confirm if he is or isn't on the Spectrum. And it sounds like he is quite, I mean, he *is* on the Spectrum.
> Laura: Yeah, I have no doubt.
> Psych: If you did want a thorough, thorough, thorough assessment, there is another assessment that we also use, but, I mean, if you *know* he's on the Spectrum, you're looking at, you know… do you see the diagnosis in terms of [a means to getting] extra funding, extra help; or do you want a more thorough diagnosis which…
> Tom: Is for treatment mostly…
> Psych: Yeah, exactly!
> Laura: And he needs that funding for school and stuff.
> Psych: And that's what I say to a lot of families: there's no point in spending all the extra money on…
> Laura: To tell us what we already know.
> Psych: Exactly! So this [*gestures at ADI-R booklet*] is good because it will just tell us if he is or isn't. I'll be able to give you a report, you can use that report for what you need, and hopefully it will help him a little bit more. And also, maybe I can give you some suggestions of what else to do, and we can go from there.

We can see from this dialogue that while the focus of diagnosis in the clinic/private practice is to identify whether the child has autism, it is predominantly motivated by the steps that come *after* this diagnosis. Thus, diagnosis in the clinic is about establishing areas that the child needs help with, their strengths and weaknesses,

and how to get funding so that the child can participate in therapies, go to school, and so on. In the clinic, diagnostic and treatment recommendations are often mediated, not by "science" or "facts", but by socio-political factors, such as patterns of government subsidy (Lenne & Waldby 2011), whereas, in the context of the clinical trial, the diagnostic focus is more immediate: the ADI-R "will tell us if he is or isn't [on the Spectrum]". Furthermore, the diagnosis in the clinical trial is presented by the psychologist as concrete and stable – he *is* or he *isn't* – with the psychologist stating at the beginning of this extract that, "it sounds like he is quite, I mean, he *is* on the Spectrum". This certainty is echoed by the mother too: "Yeah, I have no doubt". Yet, this child is eight-years old and has resisted any sort of diagnostic category since his behaviour was deemed "problematic" by his parents at the age of three or four. This certainty around diagnosis presents a stark contrast to the picture of autism painted in the literature review of this thesis, as well as by the paediatricians in the clinic (for example, one paediatrician in my pilot study refers to the field of developmental paediatrics as "airy-fairy").

Dealing with "epistemic murk" in the clinical trial: the "psyche-neuron-pharmaceutical" alliance

Nikolas Rose's work on psycho-pharmacological societies and the neurochemical self is particularly helpful in understanding how this shift in diagnostic gaze occurs within the clinical trial. As explained earlier, Rose (2007) suggests that everyday emotions and conduct are being reconceptualised in terms of neurological theories and neurochemical deficiencies, which require treatment through pharmaceutical products and psy-expertise.

Thus, individuals diagnosed with ASDs, their parents, and the various therapists involved in their diagnosis and treatment are all reconceptualising the symptoms of ASD in terms of the functioning of their brain chemicals. In the case of this fluoxetine trial, autism is no longer perceived as *just* a set of *observable behaviours*, but rather a disorder that is firmly located within the *brain*, and its processes. The drug, fluoxetine, is not only presented as a substance relieving the symptoms of anxiety (the repetitive behaviours), but is also a way of "modulating and managing these neurochemical anomalies" (Rose 2007: 223). The key goal of the medication is not to cure, or even to "normalise," but is rather to "adjust the individual and restore and maintain his or her capacity to enter the circuits of everyday life" (Rose 2007: 210). This is highlighted in a statement made by the psychologist as she discusses the medication with the parents of Patrick:

> Psych: The goal of the medication is not to cure something like that [aggressive behaviour], but it should help him to cope a little bit better. So, if it was a

situation like that, you'd hope the medication would just make him cope a *little* bit more than what he normally does.

This adjustment and restoration of the self, according to Rose, occurs alongside, and as part of an alliance with, "the doctor and the molecule" (2007: 211). This notion of an alliance with the doctor, and the "patient's" (and/or parents') use of, and engagement with, the language around the "molecule", "neurochemistry", and "psy-jargon" is particularly evident in these clinical trial diagnostic encounters, and demonstrates an extension of this concept of the "self" in the diagnostic encounter.

This doctor-pharma alliance is also heavily dependent on the cooperation of the participant in the trial (or in the majority of cases, the cooperation of the parent). We can see in many cases that the parents are often critical of, and hesitant about, the medication and its potential benefits or effects. In the following interaction between Patrick's parents and the psychologist, we can see Laura and Tom advocating for the individuality and uniqueness of their son, and their concern that they would rather he not take the medication if these qualities will be affected:

Tom: I wouldn't want him to be a zombie, but!
Laura: Yeah!
Psych: No!
Laura: This is the one thing I am worried about, as difficult as Patrick can be in situations, I would rather change his *situations*, than change *him*. If he's going to be on the ADD or ADHD medication…
Psych: It's different…
Laura: If he's going to be mute…
Psych: It's different…
Laura: I want that spunky little boy…

Likewise, for Bronte, the mother of Harvey – a twelve-year-old boy who will be attending secondary school the following year – there is a process of negotiation that goes on between parent and psychologist. In many instances throughout the diagnostic interview, the mother stresses the improvements her son has made through psychological intervention, and through the use of techniques she has developed herself at home. In the interchange below, the mother is filling out a rating scale to obtain a baseline measurement of her son's repetitive behaviours that will be addressed by the medication. We see her challenge the psychologist's assumptions (that her son has ASD) behind giving her this rating scale to fill out:

Bronte: With the compulsions, he's fixed it up himself!
Psych: Well…is there anything that you want to see with the medication? Like, does he bite his nails, or pace up and down…?
Bronte: Constant things in his hands…
Psych: Even touching himself at home, maybe a little bit less, or…?

Bronte: You see, it's amazing how even that has improved!
Psych: OK, because he's got the awareness now.
Bronte: Maybe just the constant things in his fingers.
Psych: Because I think that's something we'd be able to see from the medication.

At the end of the diagnostic session with Bronte, Harvey's mother, we see the psychologist provide both a psy- and neuro- explanation to justify why Harvey is on the Spectrum and why medication will be helpful for him:

Bronte: So, does it look as though he is on the Spectrum?
Psych: It sounds like he is, yeah. It sounds like he's on the Spectrum. His repetitive…I have to look a little bit more at the scoring…it still sounds like it's very borderline, because a lot of it's anxiety as well. So, with kids that are anxious, they show some symptoms as kids on the Spectrum. But all the other things: the hand flapping is such a big thing; the fact that he's very socially behind, you know, it's been quite consistent since he was a child; these are the signs that we're looking for.
Bronte: I mean, I just don't want to put him on a medication…although, I guess he needs it for his anxiety anyway.
Psych: Yeah, yeah. So, SSRIs are used for kids that are quite anxious these days. But what they're finding with kids on the Spectrum is that it's helping with these repetitive mannerisms a little bit more. And, because their serotonin is not balanced, it's supposed to just help balance it a little bit more. It's just; there's never been a consistent dosage before, so paediatricians have been giving whatever they think. So it hasn't been standardised yet. So, this trial, hopefully, will [provide] that.

The limitations in the solely neurological explanation for autism can be seen here. The psychologist draws on behavioural language to explain the diagnosis to the mother, and then switches to the neurological language to rationalise the need for the medication. Yet, even in this brain-based description, we can see the "epistemic murk": on the one hand, the psychologist reassures the mother of the widespread nature of the use of fluoxetine among children with anxiety and autism; yet paradoxically highlights that there is a lot of uncertainty around what dosage to give to children, and that ultimately this is based on the discretion of the treating paediatrician.

The ability of these families to think critically about, and debate the effectiveness of, this neurochemical re-shaping of their child demonstrates that clinical trial participation, and the diagnostic encounter within this context, is a negotiated space. It also highlights that the clinician-pharma alliance in the clinical trial is in fact actually a clinician-*parent*-pharma alliance. This is particularly evident in the following exchange between Patrick's mother, Laura, and the psychologist, in which Laura demonstrates her knowledge about how clinical trials work with relation to testing the effectiveness of the medication when there are confounding

environmental variables present. Within the trial protocol, there are very strict guidelines around controlling the use of other *medications* the child may be taking (that is, they are not allowed to participate in the trial if they are taking any other psychoactive medications). However, there are no guidelines around whether the child is participating, or about to begin participation in, behavioural, speech, or occupational therapies, or if the child will be undergoing any environmental changes that might significantly affect their anxiety levels (such as a change in school). Both mother and psychologist recognise this limitation, yet the psychologist stresses, at the end of the interchange, that the medication will lead to noticeable, positive changes in the child's behaviour:

> Laura: Will environmental changes affect the results? Because, I have always strongly believed that Patrick is a product of his environment, and we are looking at putting him in [a new public school] which has only got 120 students, so having a different environment…I mean, he's still going to be an autistic kid in a main-stream system – which is a challenge in itself – but I think it will help reduce those high level sort of [behaviours]…
>
> Psych: It will, and all the environmental factors… I mean, the problem with all these studies is you can't just pin-point that it is the medication. I mean, it could help a little bit, but the fact that he changed schools; even […] if you change something at home; you know, the fact that he's going to OT; if he's had his therapy; or whatever he's doing – that's all going to play a role.
>
> Laura: But all those things are changing, because all those things are targeting the autistic spectrum.
>
> Psych: Yeah, because now you *know*.
>
> Laura: Yeah, so his OT – we're going back to OT now – but it's to target what we now know his condition is.
>
> Psych: And you'll see changes, you really will. Give it about eight weeks and you'll see changes in terms of his anxiety, inflexibility, his behaviour…

This conversation provides valuable insight into the very nature of this "epistemic murk" of ASD. We already know that there is no causal, linear pathway that can be traced between pill and mind. As explained by Elizabeth Wilson:

> The pill does not act directly on the brain – it has to be ingested, absorbed, transmogrified and transported via the bloodstream to the liver; in the liver it is metabolized and then dispersed through the entire body (fat, muscles, skin, blood brain barrier); once in the brain the SSRI arrives at the cerebral synapse and modulates the uptake of one neurotransmitter out of the scores of peptides, amino acids and monoamines that regulate chemical traffic in the human central nervous system (CNS). (Wilson 2011: 286).

The complexity of the biological mechanisms involved in the workings of an SSRI demonstrates the whole-of-body approach that is taking place. Taking this one step further, we can recognise that this body exists in an environment that acts on it in

profound and significant ways, and that we therefore need to look at the drug as a "modulator within a complex system" (Wilson 2011: 286), as well as *modulated by* the environment the body exists within.

Thus, the neurochemical re-framing of autism is always kept in check by the "epistemic murk" (Eyal et al 2014) that engulfs autism, and the entanglement between the key actors or paradigms in this context: the drug (fluoxetine); the neurosciences (explanations about how fluoxetine works); the psy-sciences (treatment therapies such as Applied Behavioural Analysis (ABA) and occupational therapy (OT)); the parent (as the key provider of information in the diagnostic encounter, they direct the gaze of the clinician); and the child. This "epistemic murk" manifests itself in these ASD diagnostic encounters by the inability of neurological theories or the drug itself to dominate the diagnostic discussions due to the many uncertainties around them. This is demonstrated by obvious gaps and limitations in the "evidence" or "explanations" offered to the parents during discussions about the drug or the trial itself, as well as the way that the parents try to make sense of their child's behaviour. For example, there are numerous instances of parents querying, "I don't know what's going on up there" (gesturing to the head/brain) or "he/she is in his/her own world" when they are explaining behaviours their child exhibits (for example, losing their temper/throwing a tantrum or engaging in repetitive behaviour such as rocking or picking at hands).

This "epistemic murk" is also evident in the heavy emphasis on the "psy-sciences" and "psy-therapies" throughout the clinical encounter. Much of the language that both the parents and psychologist use is heavily reliant on a behavioural (and mainly "visible") understanding of autism: (e.g. mentions of the child's "sensory processing difficulties", "inflexibilities", "repetitive behaviours"). Additionally, the psychologist constantly refers the parents to psychological techniques (using "social stories" to alleviate anxiety) or therapies (the "Cool Kids Program" – run by the Department of Psychology at Macquarie University) throughout the diagnostic session, to provide the families with strategies to manage the child's autism and anxiety.

Wilson (2011) talks about a "coalition between psyche and neuron and pharmaceutical" in her analysis of neurological and clinical trial data on the use of SSRIs in depressed paediatric populations. She claims that these "depressive states are neither caused nor cured by singular events (a gene; a pharmaceutical); rather they are complex, non-deterministic sedimentations of phamaco-affective, ideo-chemical and neuro-social affiliations" (277). I argue that this trial seems to demonstrate the beginnings of this kind of psyche-neuron-pharmaceutical alliance, where drug and therapy are presented as working hand-in-hand. This is particularly

evident in the following conversation between Laura, Patrick's mother, and the psychologist:

> Psych: This medication makes you more aware. So, you know how these kids, they can't express themselves – so kids on the Spectrum, they can't express themselves – so what I've found with a lot of the kids that I've had, is that they actually express themselves more. So, you'll see more emotion because they don't know how to express themselves. So, with the medication, it's making everything more clear. So, once he's expressing himself more, it's about intervention, and strategies that [child's psychologist] is using. Because, he should be able to, not digest, but just understand a little bit more, and by understanding a little bit more – it sounds like he understands…he doesn't *understand*, but he's *aware* of what he's doing. So we want that awareness.
>
> Laura: Yeah [*nodding*], he's very aware, he doesn't *want* to be like that, he's knows it's not right.
>
> Psych: So what we want is, we want him - because he's more aware - to start using the tools that he's been given. So, you know, if it is the 'traffic light system', if it is 'breathing', if it is – whatever they gave him…and that's what the goal of the medication is: to help him stop for a sec, so that he can use those tools, and so he does regulate himself a little bit more. So you have to give it at least six weeks – it won't take effect immediately.

Here we can see that the fluoxetine is presented as an enabler: by taking the medication, the child's mind will be altered to make him more "aware" and in doing so, will make his uptake of therapy or intervention more effective. According to the psychologist, the fluoxetine will allow him to "regulate himself a little bit more" which, in turn, will allow him to effectively use the "tools" he has been given in the psychological interventions. Both components work hand-in-hand, in an alliance; the child's anxiety cannot be addressed without both elements.

Relationship between placebo and drug

Given that this trial is a "double-blind placebo controlled trial", the participants, their parents, nor the clinicians, know who has received the active (fluoxetine) or placebo medication. Thus, the primary aim of most clinical drug trials is to separate the drug-response from placebo-response. Wilson (2008) claims that it is the "political imperative" of the clinical drug trial to "render drug and placebo distinct events" (35), and that clinical literature actively dismisses the idea that a drug-placebo relationship has co-evolved to "exist in a mutually beneficial alliance" (35). She draws on two key meta-analysis studies published in the journal *Prevention and Treatment* to demonstrate the difficulty in separating the placebo from the antidepressant medication. In the first study, which collated data from 47 clinical trials, "80 per cent of the improvement in patients taking the drugs was also seen in patients in placebo control groups; and the mean difference in improvement

between patients taking the drug and those in the placebo group was only a few points on the Hamilton Depression Rating Scale" (31). In the second study, a meta-analysis of 19 clinical trials demonstrated that "placebo response accounted for about 75 per cent of the response to active antidepressant medication" (31) (this included SSRIs).

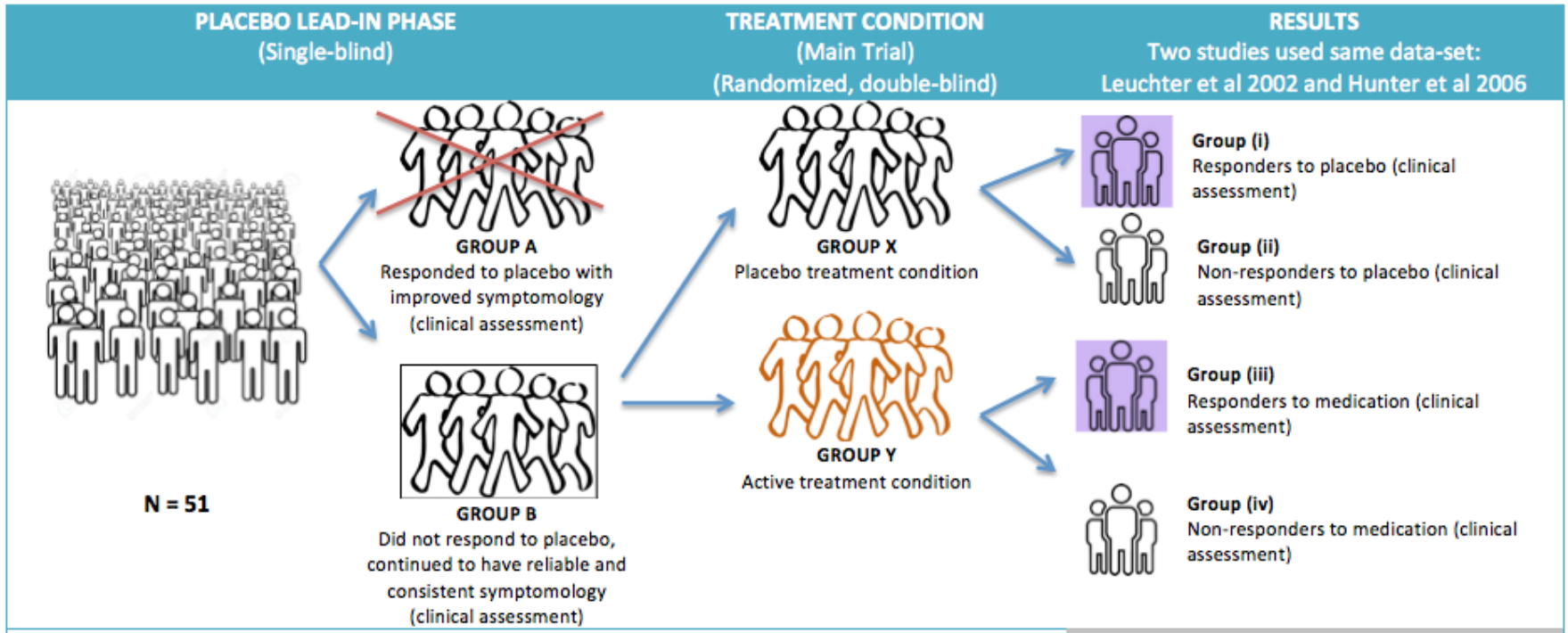
Wilson (2008) argues that instead of focusing on whether the drug or placebo are the sole author of antidepressant effects, or whether we reject the drug or the placebo as a clinical hoax, we should be turning our attention to modelling "a system of efficacy in which drug and placebo are properly, happily entangled" (33). Thus, Wilson argues that there is actually "a fundamental affinity between these events" (34):

> Every new antidepressant finds its identity in relation to placebo, and it is now an industry requirement that in order to measure medication effects accurately we must also measure placebo…these circumstances are not simply convention and sound methodological design but are also an unformulated recognition that the response to medication and the response to placebo are parasitic on each other. (34)

Wilson (2008) points to a now obsolete definition of placebo to further reinforce this notion of the *parasitic relationship* between drug and placebo – in the fifteenth, sixteenth and seventeenth centuries the term placebo was used descriptively to infer that someone was a flatterer, a sycophant or a parasite. Wilson (2008) describes several clinical trial studies in her paper that point to this parasitic relationship. She explains that given the difficulty in differentiating between drug-responders and placebo-responders in clinical trials of antidepressants, researchers struggle to justify the addition of the new drug to the market. The focus therefore turns to finding a "reliable biological marker" that allows the researchers to differentiate between placebo-response and drug-response, thus isolating what is referred to in the clinical literature as a "true drug response" (Wilson 2008: 36). Wilson (2008) stresses that these trials push for the drug response to be "freed from its contaminating relation to placebo" (36), yet paradoxically, she points out, the "antidepressant drug is most clearly itself – indeed can only fully be itself – when it is under the influence of placebo" (36).

Wilson (2008) examines two studies (Leuchter et al 2002 and Hunter et al 2006) conducted by a UCLA research group that are interested in showing a particular biological marker (cerebral perfusion – blood flow in the brain) can differentiate between placebo-response and drug-response (antidepressant). The studies, both using the same data-set, involved two phases (see Figure 4.3): phase one involved a 1-week placebo lead-in where participants were told they were receiving the active medication (an antidepressant), but were in fact given a placebo and then had EEG

Figure 4.3: Diagrammatic representation of the Leuchter et al (2002) and Hunter et al (2006) antidepressant clinical trial



measures taken at the start and end of the week; and phase two involved the 8-week treatment condition, whereby only participants that did not respond to the placebo in the first phase (group B) were then randomly spilt into two groups that either received the placebo (group X) or received the active medication (group Y) and EEGs measures were taken at regular intervals. While both studies used the same dataset, they focused on the EEG results taken from different groups of participants and at different times (see Figure 3), and accordingly had very different findings.

Leuchter et al's (2002) study focused on the EEG results from the 8-week treatment condition of the responders to placebo (group (i) in Figure 4.3) and the responders to medication (group (iii) in Figure 4.3). They found that there was a biological difference between the two groups, with group (iii) demonstrating a decrease in prefrontal perfusion (an indication of good medication response). Hunter et al's (2006) study focuses on the EEG results from the 1-week placebo lead-in phase for the participants that received the active treatment (group Y in Figure 4.3). They found that the decrease in prefrontal perfusion (indication of good medication response) emerged in Group Y (those receiving the active treatment condition) in the placebo lead-in phase – *before the active drug is administered*. Importantly, they also discovered that the brains of Group (iii) – the responders to medication – *pre-empts this "reliable biological marker"* that will develop once they have been given the active medication. The brains of Group (iv) – the non-responders to medication – show no changes during the lead-in phase. Wilson (2008) points out the significance of these findings:

> On the basis of these data, it seems that being a good medication responder means being a good placebo responder: having a good drug response seems to go hand in hand with having a good placebo response, and, likewise, the less well you respond to placebo the less well you respond to the drug. (37)

Wilson's (2008) analysis of these two studies provides a compelling argument for reimagining the way that we understand the clinical trial and the placebo-drug relationship. For Wilson (2008), it is about understanding how "ingestion, physiological activity and therapeutic alliance might be aligned" (38). Wilson (2008) posits that for Group (iii) – the drug responders (see Figure 4.3) – "the active medication harnesses a capacity for improvement (an antidepressant potential) that is catalysed first by being in the trial itself" (38). Thus, one could argue that in the placebo lead-in phase, Group (iii) have already taken the "antidepressant" and "ingested the treatment" via the hope and exposure to "the clinic" that is attached to being in the trial itself:

> It seems that, for the drug responders, the active medication harnesses a capacity for improvement (an antidepressant potential) that is catalysed first by being in the trial itself. In the placebo lead-in phase, the drug responders have already taken the antidepressant: before they

> have taken the active medication they have ingested the treatment. The drug they are given in the weeks following the lead-in phase is a *condensed, pharmaceutical dose of a treatment that has begun with the exposure to placebo pills, clinical staff, and hope* [emphasis added]. (Wilson 2008: 38)

This argument has much relevance to the fluoxetine clinical trial studied for this thesis, particularly the notion that a participant's response to the active drug is intimately tied up with, and inextricably linked to, being *in the clinical trial itself*.

Before examining Wilson's (2008) arguments around how the anticipation of clinical care and the hope that comes with it affects the participant's "drug response", I would like to draw attention to the fact that the clinical trial studied for this thesis was very preoccupied with the separation of placebo and drug. When introducing the parent(s) to what participating in the clinical trial will entail, the psychologist does so by presenting the placebo and the drug as very distinct entities. Furthermore, she presents the drug as having a quantifiable and determinable effect that will allow both the clinicians and the parents to *know* whether the child is on the active medication. Similarly, when the placebo is mentioned, the psychologist always speaks with certainty about both herself and the parents *knowing* that the child is on the inactive medication. In the following exchange between Patrick's parents, Laura and Tom, and the psychologist during the diagnostic encounter, we can see this immediate distance set up by the psychologist between the active drug (fluoxetine) and the placebo:

> Laura: That's why I'm keen to do this trial, because hopefully, when he gets to that point…
> Psych: Yeah, I think the medication will help him if he's at that point…
> Tom: But we don't know if he's going to get the medication.
> Psych: That's the other thing as well, yeah.
> Laura: I think we'll know. If there's no change, if he's still reaching that red line…
> Psych: Yeah, yeah.
> Tom: But it depends on each person too, it depends on the effects.
> Psych: I think you'll be able to tell, I really do.
> Laura: I think we will.
> Psych: Because, I've been on this trial for two years now – you can tell! So I think you'll be able to tell.
>
> Tom: What have been the results so far with this trial?
> Psych: I mean, we can see that there has been an effect with kids that have been on the medication. I mean, *I* can see, just comparing all the kids, the ones who are on the medication and the ones who aren't, but I still haven't had any confirmation yet and we won't know until the end of the trial.

The psychologist's assurances to both parents that they will *know* whether the child is on the medication are based on her two years' of experience on the trial ("you can tell") – despite the fact that the trial is double-blinded and the results are not released until the trial has reached completion.

In some cases, the psychologist establishes which participants present as being "perfect" for the clinical trial during the ADI-R interviews. These participants have "obvious" or easily identifiable anxious behaviours (specifically described as repetitive or stereotyped behaviours in the context of ASD) which makes them "easy to quantify" and thus clear whether the medication is having an effect. The following extracts from the ADI-R interviews with Leo's Mum (Alice), Daniel's Mum (Hayley), and Patrick's Mum (Laura), demonstrate this apparent certainty around the ability to determine the effectiveness of the active drug:

Psych: I actually think…he's perfect for this trial. Just meeting him, without doing the assessments.
Alice: [laughs] Why…? Why's that?
Psych: Just because his behaviours are quite…they're *there*, so at least it's quite easy to quantify, you know, if the Fluoxetine is working or not.

Hayley: Well, if it's worked for the other kids, I don't see how it shouldn't work for him. Especially if he's in their category. [laughs]
Psych: [smiling] He fits! He's the biggest match! So it's good, the SSRI will be perfect for him. So then we'll know that's the medication he's been needing.

Psych: Yeh, and you'll see changes, you really will! Give it about 8 weeks and you'll see changes in terms of his anxiety, his inflexibility, his behaviour…

We can see from these examples that this clinical trial is still firmly attempting to project the scientific endeavour to separate drug response from placebo response. While they do not go as far as Leuchter et al (2002) to use a biological marker to distinguish between drug and placebo responders, there are numerous references throughout my data where the psychologist talks about the ease of measuring the effectiveness of the fluoxetine by quantifying children's anxious behaviours. This is a key focus of the ADI-R assessment, and much time is spent detailing each child's repetitive and stereotyped behaviours for the purposes of measuring the effectiveness of the drug.

As illustrated earlier in this chapter, the focus of the ADI-R and the WISC-IV during the clinical encounter is to direct the clinical gaze towards the repetitive and stereotyped behaviours that the medication will target. Another important consideration here is the responsiveness of *both* the *child* and the *parent(s)* to the medication/placebo. While the child *ingests* the drug, and *experiences* the "physiological effects", the parents *observe* (as well as experience) the external, behavioural effects of the medication, and are asked to *report* on these "positive or negative side effects" weekly in a "trial diary". Thus, part of the aim of these "diagnostic" sessions is to educate the parents about what they need to focus on and look for in their child's behaviour to accurately measure and quantify whether the medication is having an effect. The examples below demonstrate this directed focus:

Psych: OK, so basically with the study, before we start, it is for kids with autism. So we're looking at…so all those behaviours that Patrick shows: so, doing this [*gestures rubbing hand up and down arm*], breaking the pencil [*mimes both hands in fists as if holding pencil and snapping hands apart and upwards*]. The goal of this study is to look at the medication to see if it reduces that behaviour. So, the medication that we use – it's been around for a long time – but they've never actually looked at it with kids on the Spectrum, and all those repetitive behaviours. So it's an anxiety-based medication. Ummm, but we're looking at controlled doses, because that's what we've been finding: that a lot of paediatricians, they either give you too much, or too little; and that dosage affects kids on the Spectrum in terms of: you know, does it make them do those behaviours more; is it effective at all…and what we're finding is that it's not. And that's why this trial's looking at a specific dosage, and at the moment what I've found with the kids we've looked at is that it has had an effect on the kids that do have the medication. So, Melbourne Hospital are using it, WA are using it, and it's the first study in Australia to do this kind of stuff.

Psych: So, you know, we're looking at the repetitive behaviours – so all of his anxious behaviours. So, what does he normally do? Is he constantly checking [things], walking around…?

Jenny: Routine is a big thing. So, we weren't at work this morning, so [that generated] a bit of anxiety: "I'm not in my normal going to school time" – so anything outside of his normal routine or the way we do things. So anything that's outside the norm, it just chucks him.

Matt: He hates anything…just doing something off the cuff. Everything has to be planned. He likes to know in advance what we're doing. If we're going to stop him doing something, we have to say, "In five/ten minutes time, we're going to be doing this." You've always got to break everything to him gently.

Psych: The fluoxetine, the goal of that, I mean, it's not going to cure his routine changes, but it should help him to regulate himself just a little bit better. So, they're the changes you're look for: is he crying longer, is he getting so worked up so quickly…

Psych: Well, it's just basically if he did any of those things [*points at scale*] and he does some of these [*points at items on scale*], I noticed, you know, he shakes his legs and he clenches his hands, so these are all the things…

Alice: Oh! [*smiles and looks surprised*]

Psych: Oh, [laughs] just from watching him!

Alice: I know he flicks his fingers [*demonstrates each finger joining with thumb and flicking*]

Psych: Yeh, he does that as well. These are all the things we want to look out for when he's on the Fluoxetine – to see if it's decreased, OK?

Psych: And then also, with his blinking, so with a lot of the repetitive behaviours, it is the autism, and it could be exacerbated by anxiety. And a lot of kids on the Spectrum are quite anxious. And then the other thing, as well, it could be a tic. I mean, I don't know, because I am not assessing him for that, but all it is, it's just stress-related, so if he's anxious, it makes sense. Umm, so all you've got to do is the Fluoxetine – if it is not placebo – you should see a change. And the other thing is, if you end up seeing a psychologist, to focus on those types of stress management.

Returning now to Wilson's (2008) scepticism of the possibility of there being a "true drug response," I would like to draw attention to what Wilson calls the pill-clinician-assessment-hope matrix:

> The 2006 study [conducted by Hunter at al] casts doubt on the idea that there can be any such thing as a true drug response, *elicited independently of anticipation or clinical care* [emphasis added]]. In this sense, Hunter et al.'s data show that what is ingested in a clinical trial is not an isolated pill but also a wide set of expectations delivered through intensive clinical attention. I swallow the pill, I ingest the clinicians, I incorporate confidence in measurement and cure. It may be this capacity to ingest more than just a pill that marks the difference between a drug responder and a drug non-responder. Perhaps the drug non-responder takes in too little or (paradoxically) is too drug focused, remaining sequestered from the broader therapeutic milieu. Perhaps the drug responder takes in just enough of the *pill-clinician-assessment-hope matrix* [emphasis added] to catalyse a sustainable antidepressant reaction. (Wilson 2008: 38)

In the clinical trial studied for this thesis, there is evidence in every ADI-R that I observed and/or filmed of a genuine concern for each participant's care and wellbeing. This is a prominent theme throughout the ADI-R sessions and is worth noting given Wilson's (2008) argument that a drug response is likely tied up with the participant not only ingesting a pill, but also the hope and care that comes from interacting regularly with clinical staff and benefitting from their advice and expertise, as well as the hope associated with taking the active medication. While my study was not privy to the results of the fluoxetine clinical trial (still running) and thus I am unable to follow-up or draw any conclusions about the fluoxetine reactions of participants, there are certainly many examples throughout my data to suggest that the pill-clinician-assessment-hope matrix was at work in this clinical trial.

I will explore these ideas later in the thesis (Chapter Six) in the form of the care work performed by the psychologist during the ADI-R diagnostic encounters. The following example from the ADI-R session with Patrick's parents, Laura and Tom, highlights this care work embedded within the psychologist's "coaching" of the parents as to how they can identify whether the medication is effective for their son Patrick:

> Psych: This medication makes you more aware. So, you know how these kids, they can't express themselves – so kids on the Spectrum, they can't express themselves – so what I've found with a lot of the kids that I've had, is that they actually express themselves more. So, you'll see more emotion because they don't know how to express themselves. So, with the medication, it's making everything more clear. So, once he's expressing himself more, it's about intervention, and strategies that [child's psychologist] is using. Because, he should be able to, not digest, but just understand a little bit more, and by understanding a little bit more – it sounds like he understands…he doesn't *understand*, but he's *aware* of what he's doing. So we want that awareness.
>
> Laura: Yeah (nodding), he's very aware, he doesn't *want* to be like that, he's knows it's not right.

Psych: So what we want is, we want him - because he's more aware - to start using the tools that he's been given. So, you know, if it is the 'traffic light system', if it is 'breathing', if it is – whatever they gave him…and that's what the goal of the medication is: to help him stop for a sec, so that he can use those tools, and so he does regulate himself a little bit more. So you have to give it at least six weeks – it won't take affect immediately.

Conclusion

This chapter orients this broader thesis, and my video-reflexive ethnographic fieldwork examining the diagnosis of autism, within the space of the *clinical trial*. I explore the way that the clinical trial studied for this thesis deals with medical uncertainty around medicating children with autism by using various techniques such as Rose's concept of the "neurochemical self", establishing a clinician-parent-pharma alliance, and the way that the clinical trial itself feeds into the autism classificatory loop by providing "data" and "evidence" as to how an "autistic brain" reacts to fluoxetine. I also explore how the clinicians and parents involved in this clinical trial must refocus their diagnostic gaze and conceptualisation of autism to fit with the ambit of the clinical trial: that is, autism symptoms are seen through the lens of anxiety as indicated by the child's symptoms of repetitive behaviours. This anxiety/repetitive behaviours-focused gaze is key to understanding the diagnostic process that is discussed in the following two chapters, in which I explore the use of the two standardised diagnostic tools (as stipulated in the clinical trial protocol): the Wechsler Intelligence Scale for Children (WISC-IV) and the Autism Diagnostic Interview-Revised (ADI-R).

CHAPTER FIVE

Observing, constructing and achieving autism through diagnostic tools

Introduction

In this, and the following chapter, I will explore the different ways that quantitative and qualitative notions of the normal and the pathological are utililised in the clinical trial during the ASD diagnostic sessions with both the children (WISC-IV) (this chapter) and the parents (ADI-R) (Chapter Six). In particular, I will examine how these approaches are in constant tension: while the *quantitative* approach to diagnosis is presented as a governing and overarching presence – a rule to be followed to fit the paradigm of the scientific clinical trial, the *qualitative* approach is often viewed as the practical, ethical and necessary way to conduct the diagnostic sessions. These diagnostic tools, particularly the WISC-IV, tend to generate a very scientific and quantitative understanding of ASD, shaping diagnostic conversation, stories and behavioural observations into "data" and "evidence" to support criteria of what is normal and pathological to fit the ambit of the clinical trial.

I will consider how prescribed values of normality and pathology embedded in the diagnostic tool give rise to a dichotomy between what Maynard (2005) describes as "abstract competence" and "concrete competence." Most tests used in the assessment of ASD measure abstract competence, that is, "the ability to answer questions in general, theoretical terms independent of any particular context," whereas concrete competence is "experience-based, tied to specific contexts, and exhibited in the performance of everyday actions, such as issuing and following directives, turn-taking, making and responding to requests, engaging in play, and so forth" (Turowetz 2015: 58). We can see these concepts played out in the WISC-IV, where responses from the child are scored based on whether their competence in various tasks aligns with standardised criteria, while any competencies not stipulated in the criteria are ignored or minimised.

The chapter will draw on Georges Canguilhem's (1989) distinction between the normal and the pathological, on the one hand, and the norm and normativity, on the other, to help illuminate the distinction between these two ways of diagnosing. Canguilhem observes that the development of science as a positivist, objective enterprise required the ability to make a quantitative distinction between the normal and the pathological. Thus, medical views about health are based on the notion that disease or malfunction are a quantitative deviation from a fixed norm – taken to be constant – and that to return a patient back to health, medical practice must focus on re-establishing the norm from which the patient has strayed. Yet this distinction cannot account for the lived experience of health since there is a

value attached to this medical concept of the normal (representing a fixed entity): that is, the normal is linked to an "ideal" state. This attachment of value takes place through a shift from the normal to the norm, whereby the concept of normality bridges the gap between description and value. The term normality is thus simultaneously used for objective descriptions and to make value judgments or establish rules/principles. Thus, the pathological state is qualitatively different from the healthy state because it holds a fundamentally different value for the organism. This dimension of value, established by the nature of the organism, cannot be reduced to a numerical quantity. Here Canguilhem mobilises the concepts of norm and normativity to designate the ability of living subjects and organisms to adapt to change. For Canguilhem (1989), a norm represents a desired situation rather than a statistical average. The *norm* is the condition of the organism at any one time, and it is *dynamic*: it is continually adjusted in order to actively maintain its balance (Zajicek 1995: 333). *Normativity*, on the other hand, is the historical and evolutionary rejection of abnormal states and depends upon the adjustment and maintenance of norms. For Canguilhem (1989), it is this distinction between the normal and the normative that is fundamental to his concept of what defines health – "health is a margin of tolerance for the inconstancies of the environment" (Canguilhem 1989: 197). Health is characterised by flexibility, mobility, variability, and normativity, that is, the ability to create and maintain new norms through adaptation to a given environment; disease is characterised by intolerance, stasis, a tendency towards conservation, and rigidity. Consequently, what counts as normal is not the statistical average, but rather the creative ways that organisms adapt to their environments.

Using diagnostic tools in the diagnosis of ASD: The WISC-IV and ADI-R and their historical roots

This chapter, and Chapter Six, focuses on the use of standardised diagnostic tools**,** the Wechsler Intelligence Scale for Children – 4th Edition (WISC-IV) and the Autism Diagnostic Interview-Revised (ADI-R)**,** to categorise individuals as "on the autism spectrum." To understand why these diagnostic tools are used in the assessment of ASD, I consider their historical roots as well as how they are administered in the clinical setting.

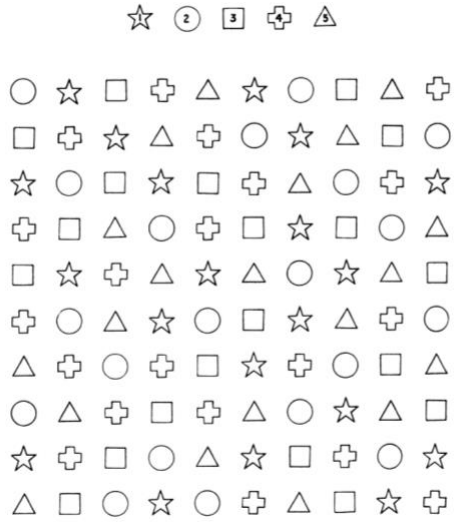
The stark difference between these two tools and the way they are administered (setting aside the obvious difference that the WISC-IV is administered to the child and the ADI-R to the parent) can largely be traced back to the two different epistemologies influencing the origins and evolution of these tools. These two histories stem from: (1) on the one hand, the normative positivist emphasis that drove much of psychological thought from the mid-twentieth century and onwards, whereby standardised and metrically-oriented processes were preferred and concepts of children and their development were embedded in a cognitive notion of the subject; and (2) on the other, a developmental paediatric approach that was striving for standardisation, but also sought to accommodate the complexities and

uncertainties surrounding the current knowledge of the disorder of autism by allowing the development of a tool with flexibilities.

The Wechsler Intelligence Scale for Children

Despite the rapid development in science and technology in medicine over the past century, the Wechsler Intelligence Scale for Children (WISC) and intelligence tests, more generally, have been subjected to only minor changes over this time. The test continues to be administered in the same way and includes tasks dating from the 1800s and early 1900s. For example: the "block design" task, developed by Samuel Kohs in 1923, was based on a commercially-available game of the time called "Color Cubes"; the substitution test (coding) was introduced in 1911 by Robert Woodworth and Frederic Lyman Wells was designed to measure the ability to learn new associations (see Figure 5.1, below); and the digit span test, which was developed by Joseph Jacobs in 1887 and is designed to test working memory (Boake 2002). As Boake (2002) points out, the Wechsler scales contain mental tests from a period before the concept of psychometric intelligence was even developed.

Figure 5.1: Substitution Test (Woodworth & Wells 1911 in Boake 2002: 385)



The Wechsler scales were developed between the 1880s and the First World War. The popularity of intelligence tests was cemented as a result of an intelligence-testing program carried out by the US Army during the First World War. The 1920s-1930s saw the development of a new group of intelligence tests, which led to a dramatic rise and expansion in the use of these tests, especially within the context of schools. The Wechsler-Bellevue scale was published in 1939 and quickly gained prominence due to its use of familiar tests that psychologists viewed as "valid", its ease of administration and statistical interpretation, and the large standardisation sample (Boake 2002). In 1949, a revision of Wechsler-Bellevue Form II was published as a children's scale, the Wechsler Intelligence Scale for Children:

> The WISC introduced the basic standardization procedure to be followed by later Wechsler intelligence scales. The sample consisted of 100 male and 100 female subjects at each age from 5 to 15 years. The subjects, who were all white, were selected to represent the proportions of the U.S. population residing in four geographical regions, as well as the proportion of parents working in various occupations. (Boake 2002: 400)

In Donna Varga's (2011) critical examination of "scientific child study" within the field of psychology, it is evident that the study of children changed quite dramatically during the twentieth century. Scientific procedures were privileged, whereby environments were controlled, conditions were replicated for comparisons, stimuli and variables were managed and manipulated, processes were standardised, and results recorded, scored and compared. For Varga (2011), this final process of recording and scoring characteristics of the child to "obtain a summary of the person's self" was also about transforming something dynamic, individual and complex into a static form – a statistic – which "produces an individual that can be measured, compared and acted upon" (148). Thus, for Varga (2011):

> this era [beginning of the 20th century] invented and disseminated processes of child study for the rational organization of child development. What a child is and can be, and the meaning of childhood, was disembodied through scientific observation processes that abstracted time and space from behavior, and categorized children's development into progressive stages to symbolize a universal ideal. (Varga 2011: 140)

In her historical examination of the transformation of autism in Britain, Evans (2013) notes that, during the 1960s, British psychologists challenged the dominant notion of the 1950s that "autism" referred to excessive hallucinations and fantasy in infants. Most of the psychologists – pre 1960s – derived these theories from their study of individual cases that they had observed and/or treated themselves. Evans (2013) emphasises that:

> Their understanding of autism was framed by a broader disciplinary-wide agreement that developmental psychology was a science that tracked the emergence of subjectivity. If they did employ basic statistical methodologies, these were used as an adjunct to these theories. (13)

From the late 1950s, however, psychologists began to turn to epidemiological studies to radically challenge this old model of child development, and the concept of autism that was built upon it. Epidemiology was seen as a method of validating psychology as a science, and thus:

> 'Autism' was then completely reformulated as a new descriptive category to serve the needs of this new model of child development. From the mid-1960s onwards, child psychologists used the word 'autism' to describe the *exact opposite* of what it had meant up until that time. Whereas 'autism' in the 1950s referred to excessive hallucinations and fantasy in infants, 'autism' in the 1970s referred to a complete lack of an unconscious symbolic life. (Evans 2013: 4)

Evans (2013) argues that a big part of this radical reformulation of the label "autism" was intricately intertwined with the more "general shift in Anglo-American psychiatric reasoning which sought to understand psychological problems through epidemiological studies rather than individual cases" (4).

Furthermore, this emphasis on epidemiological methods had strong roots in the practical endeavours of advocacy groups to campaign for the provision of schooling and education to children with autism. For example, the Society for Autistic Children, which began to set up schools exclusively for children with autism in Britain in the 1960s, was keenly aware of the need to provide education and other services to families after deinstitutionalisation occurred (Evans 2013). Thus: "The need to integrate all children within the same educational framework also encouraged their integration in a unified theoretical framework concerning the development of their thought" (17). Indeed, Mr L. S. Piddington, a psychologist for the department of education in South Australia, speaking at the *Autism: Cure Tomorrow, Care Today* conference in Adelaide, Australia in 1967, shares his beliefs regarding the necessity of providing *early* assessment and treatment services through child guidance clinics and kindergartens:

> One of the great difficulties concerning this whole problem of autism has been that a number of children that we have had to deal with have been fairly old when first discovered and early treatment had not been possible…These are the children that have been posing a colossal problem to us all and do continue to do so in any education system. We can only suppose and hope that such children…would have been entirely different had they had early treatment and diagnosis as suggested by Professor Rendle-Short or if they had the treatment that I suggested in the Kindergarten or Lady Gowrie [child guidance clinic]…May I comment in passing about a point raised by Professor Morey in her discussion concerning Intelligence Tests and assessments. I cannot help feeling that if it is possible to obtain a reasonable accurate assessment from the child in a test situation, that he is well on the way to being accessible to the sort of treatment that I am indicating here. (115)

From the 1960s onwards, researchers such as Mildred Creak, Beate Hermelin and Neil O'Connor began developing diagnostic features common to childhood schizophrenia to enable statistical, population-based studies. Hermelin and O'Connor were particularly interested in the use of statistical analyses centred on behavioural measures (Evans 2013). Michael Rutter, likewise, saw the importance of the application of epidemiological methods to all childhood psychiatric disorders. Rutter (1965) was convinced the need to classify these disorders, and argued that they needed to be identified and characterised before meaningful studies could be conducted about such disorders.

Similarly, in the Australian context, while there appeared to be some hesitation amongst psychologists regarding the applicability of IQ tests when working with autistic children, there is a strong push within the field of psychology to use a variety of standardised assessments and tools in the diagnostic process. Professor E. Morey, a Victorian clinical

psychologist, discusses the various assessment tools used within her practice at the *Autism: Cure Tomorrow, Care Today* conference in Adelaide, Australia in 1967:

> Autistic children do not all present the same problems as to the techniques [of assessment] to be used. Some older children, and indeed some of the younger ones who are not severely handicapped, may well be able to undertake a formal psychological examination such as Merrill Palmer, a Revised Stanford Binet or a Wechsler Test for Children. This is useful because some of these children may be helped in a normal school setting and it is useful to have an assessment which can compare them with their classmates. (106)
>
> …any plan for the education of an autistic child must also consider his social and emotional development. These aspects usually must be assessed by report (usually from the parents) and observations of the child at play. Report techniques such as the Vineland Social Maturity Scale and the Bristol Adjustment Guides have been used with autistic children with success. Play observation and interpretation is also used, but full understanding of the autistic child's fantasies and play activities is very difficult. (108)
>
> The foregoing discussion has made it clear that the psychological assessment of autistic children is no easy matter. The psychologist must have a great variety of skills and techniques available, and must be able to use these with flexibility without entirely invalidating his findings…Wherever possible, each item is presented in standard form first. This is a prerequisite wherever scoring with available norms is aimed at. Then the examiner introduces modifications, partial solutions, questions…The skilled examiner avoids arbitrary modifications but manipulates with psychological insight. (108-9)

It is clear from these quotes that Morey (1967) is aware of the challenges of standardising the assessment of autism, yet these quotes also represent the ever-looming push for the quantification of the field of psychology. By using scales, standardised reporting measures, and cognitive tests, the child undergoing assessment can be plotted on a graph, compared, and measured against the "norm". By shifting the focus of diagnosis from the mind to more observable qualities like behaviour and communication, measurement and standardisation of assessment became possible.

Evans (2013) observes that in the late 1960s there was a key shift in conceptualisations of autism from a disorder defined by hallucinations, to one that focused on deficits in communication. Thus, she summarises: "These language abnormalities or differences then came to be a defining feature of the new concept of "autism" in its new psychological metamorphosis, which followed its radical strip-down to behavioural measures in the 1960s" (19). These changes eventually translated to categorical changes in the form of the *Diagnostic and Statistical Manual of Mental Disorders Third Edition* (DSM-III) (1980), where the category of childhood schizophrenia (and reference to hallucinations) was completely written out and replaced instead by the category of "pervasive developmental disorders," under which "infantile autism" was included as a sub-category.

Given the strong focus of IQ tests on observable behaviours and the quantification of cognitive abilities, it is unsurprising, therefore, that the WISC was used in diagnostic tests with children with possible autism. Indeed, the continued popularity of today's use of the WISC in the assessment of neuropsychological disorders is often cited in the literature (Camara, Nathan & Puente 2000). Yet it is interesting to note that Wechsler himself did not specifically develop the scale to measure cognitive deficit (Boake 2002). As Boake (2002) demonstrates through the following insightful quote from British psychiatrist Andrew Patterson[12] in 1944, the key problem for the WISC and other intelligence tests aligns very closely with Canguilhem's (1989) arguments regarding the loss of the complex, rich, functional, contextual and qualitative:

> On the outbreak of war there was a clamour for tests for intellectual impairment. The academic psychologists through no fault of their own were encouraged to produce tests for conditions of which they had little knowledge and no clinical experience. This is the very opposite of the clinical approach where close observation should lead to the formulation of a test. In no other sphere of clinical science are tests devised before the phenomena have been studied. Such tests devised *a priori* tie nature down to a certain pattern of breakdown and such an assumption has always hindered progress. It also leaves out of account the variety of ways in which interference with cerebral function may express itself in the field of performance. There is more than a danger that the stereotyping of modes of investigation will force us to think along those lines only, and to close our eyes to and cease investigation of the breakdown which the hard facts of clinical observation present. (Paterson 1944, in Boake 2002: 402)

Over the years, subsequent WISC revisions have been based on standardisation samples that are considered larger and more racially and ethnically representative. The WISC-IV (2003) is the current version that was administered as part of the clinical assessment in the SSRI clinical trial studied as part of this thesis. It takes approximately 1½ hours to administer and consists of ten tasks that test a child's perceptual reasoning, verbal comprehension, working memory, and processing speed.

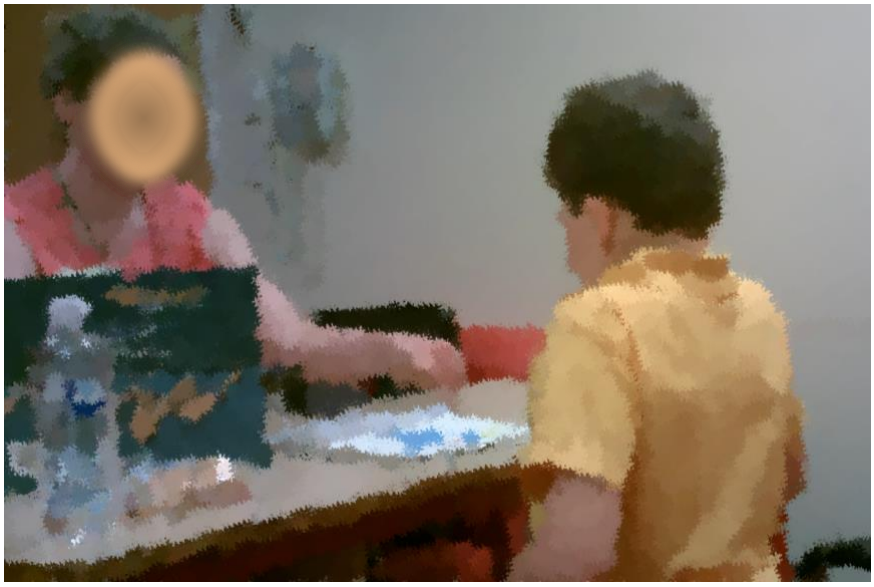
A psychologist conducts the test one-on-one with the child. Before beginning the assessment, the psychologist must configure the room and materials as prescribed by the WISC-IV manual and are therefore (ideally) standardised across all assessments. Figure 5.2, below, provides an indication of what this configuration looks like.

The role of the psychologist is to ensure that the child attempts each of the tasks prescribed by the WISC-IV within this standardised space she has created. This is achieved through verbal standardised instructions prescribed by the WISC-IV manual. The exact delivery of these instructions is considered important to ensure comparability between each case. The importance placed on this *sameness* or standardisation is particularly evident in the digit span task where the reading of the digits is expected to be carried out in a *monotonous*

[12] I was unable to access these primary documents as they were obtained by Boake (2002) in his historical research within the Archives of the History of American Psychology.

tone, avoiding any accent or rhythm which will assist the child in the degree of ability that they will be able to repeat what has been said. The emphasis and focus on standardisation, and the effect this has on the administering clinician are the key points of difference between the WISC-IV and the ADI-R.

Figure 5.2: WISC-IV room and material configuration (during a perceptual reasoning task)



The Autism Diagnostic Interview-Revised (ADI-R)

It is interesting that this epidemiological-influenced redirection of the clinical gaze towards the autism diagnostic encounter not only shaped the practice of psychology, but has also filtered into medical practice. Over the past fifty years, a large variety of standardised scales, checklists and questionnaires have been developed to assess the symptoms and behaviours of autism – as aligned with the diagnostic criteria set out in the various versions of the DSM. These tests were developed to serve a variety of purposes, such as: diagnostic screening, describing behaviours and their severity, and charting behaviour change as a result of therapies (Matson 2008: 12). Matson (2008) points out that due to the uncertainty surrounding autism's etiology, there was little consensus on which assessments should be used:

> Early theoretical perspectives regarding causal mechanisms in autism differed markedly with no consensus regarding whether autism was a biological or a psychogenic disorder; and thus, no consensus about assessment tools. The tendency of differing perspectives to focus on particular features of autism to the exclusion of others meant that comprehensive assessment related to all areas of the children's functioning was often not achieved. These factors then influenced assessment processes – whether it was essentially qualitative or quantitative and whether or not it was derived primarily from naturalistic observation, interview, observation within a clinical setting, using standardized measures, or some combination of these. (10)

One of the earliest autism diagnostic questionnaires that can be found in the literature is Bernard Rimland's E-2 Checklist which was developed to measure Kanner's description of autism, known as "classic autism" (Rimland 1964). Turning to the Australian context, T.J. Rendle-Short, a University of Queensland professor of child health and medical doctor, speaks about his development of a standardised checklist through his work with autistic children at the *Autism: Cure Tomorrow, Care Today* conference held in Adelaide in 1967. Rendle-Short's (1967) paper, entitled "The diagnosis of infantile autism," begins by establishing the profound uncertainty surrounding the diagnosis and definition of autism. He also, crucially, identifies the tacit quality of a medical diagnosis and the role of experience in the clinical encounter and how this plays out when dealing with a case of autism:

> What a doctor really does when he makes a diagnosis is to compare the child before him with his memory of previous children he has seen and also of check-lists recorded in the literature. If a previous child was called a case of autism and the present case has the same signs and symptoms, the he too is likely to be a case of autism. But the real trouble is that no two children are identical, and really all we can say therefore is that this child is more or less like a child we saw before whom we call autistic, who in turn was like another child, and so on. (35)

For Rendle-Short, this presents a key problem for the clinical identification of autism, and has led him to conduct his own research in an attempt to produce a standardised checklist to be used in the diagnosis of autism. Using the method of "Numerical Taxonomy," a method he states that is "used for many types of scientific classification, for instance trees and insects," the researchers compared 25 autistic children with "50 normal children, 50 children with Rubella deafness and 30 Cerebral Palsied children." As a result, they came up with 13 items, which they have called "the major manifestations of Infantile Autism" (Rendle-Short 1967: 36).

It was through the development of the Autism Diagnostic Interview (ADI) in 1989 by Le Couteur and colleagues that a "gold standard" approach to autism diagnosis began to emerge. The ADI-R, a structured parent or caregiver interview, was developed to probe the child's developmental history and current behaviour centering on autism diagnostic criteria (Matson 2008). The ADI was written and developed by two medical professionals (as opposed to psychologists) Michael Rutter (a child psychiatrist) and Ann Le Couteur (a developmental paediatrician). The questions it poses focus on how the child would act in typical situations, particularly in terms of social reciprocity, communication, and repetitive behaviours, as well as what the child was like during preschool years (Feinstein 2010). The ADI-R requires extensive training for the clinician and the actual administration lasts two to three hours. It is appropriate for use regarding individual ages 1½ years to adulthood.

This first version of the ADI was mainly used for research purposes. In Le Couteur and colleagues' (1989) paper, in which they report on the reliability and diagnostic validity of the

ADI, we are provided with an outline of the two key factors that led to the development of this diagnostic tool. First, they identify the acknowledged need within the disciplines of psychology and psychiatry for the development of standardised diagnostic instruments that allow clinicians to compare diagnostic information from patient to patient and clinic to clinic, thus making the diagnostic process explicit and operational. Second, while Le Couteur and colleagues (1989) recognise the importance of observational diagnostic tools (such as the ADOS) in the assessment of ASD, they point out that they can only access behaviours at a static point in time and do not take into account the course of development.

The Autism Diagnostic Interview (ADI) was designed to be administered to the child's principal caregiver (see Figure 5.3, below, as an illustration of the interview set up) and "aims to provide a lifetime assessment of the range of behaviors relevant to the differential diagnosis of pervasive developmental disorders" (Le Couteur et al 1989: 365). Thus, the ADI was designed to distinguish between autism and other developmental comorbid disorders that present with similar symptoms such as ADHD, anxiety disorder, OCD, Tourette's syndrome and so on. The ADI is a standardised interview and is classed as such for two main reasons: first, it specifies the range of behaviours to be covered; and second, there is a predetermined coding system for each behavioral item:

> Each coding is intended to specify some particular type of abnormality. A coding of 2 or 3 is made when that specified abnormality is present (the 2/3 distinction, when that is provided, being made on the basis of its severity). A 1 coding is used when it is clear that the subject has exhibited behavior of the type specified in the coding, but when it is not severe, frequent, or marked enough to warrant a 2 coding. It is *not* used to reflect vague, dubious, or uncertain abnormalities (these are coded 0). The 0 coding mean that the behavior specified in the coding was not present. This does not necessarily mean that the behavior was fully normal, but it does mean that any departures from normality were not of the kind specified in that particular coding. (Le Couteur et al 1989: 369)

The interview consists of 93 questions and takes the following structure:

(1) Opening questions: general orienteering questions, when and how the parents first became aware that something might be wrong with the child, and key developmental milestones;
(2) Communication questions;
(3) Social development and play questions;
(4) Repetitive and restricted behavior questions; and
(5) Questions about general behavior problems.

The questions ask for information about when the child was four or five years old, as well as current behaviour over the twelve months before the interview. The tool developers specify that:

Figure 5.3: The typical room set up for the ADI-R interview with the caregiver

> For each behavioral item, there is an initial compulsory probe and also a coding with instructions on the detail required in order for the investigator to decide whether or not the specified behavior is present. The interviewer is expected to be fully familiar with the conceptual distinctions and differentiations required for each coding, and with the specific aspects of behavioral information that are necessary in order to decide on each rating. Guidance is provided in the interview schedule in the form of suggested supplementary probes but the onus is on the interviewer to ask whatever questions are required in order to clarify precisely which behaviors were manifest. The basic interviewing task is to obtain detailed *descriptions of actual behavior* with particular reference to the differentiations required for each coding. The standardization of the interview, therefore, lies in the specification of the behavioral criteria used for each rating. Interviewers are guided in their questioning not just by the probes provided but, more particularly, by knowledge on just what information is required for each rating. (Le Couteur et al 1989: 367)

There are some key techniques used by the ADI that have been included for the purposes of improving retrospective recall. This is clearly a difficulty for any interview requiring someone to recall information and examples that occurred up to ten years ago. Le Couteur et al (1989) point out that this is because we do not encode memories in terms of dates, or ages, but rather, associate them with significant personal events. The first of these techniques is called a "trigger" event: the parent is asked about a significant event that occurred between the ages of four and five, such as a birthday, moving house, Christmas, or holiday, to help them remember this time in the child's life. Thus, "the objective is to trigger memories of what the child was doing at some personally memorable period or occasion, which can be, dated according to external temporal landmarks" (Le Couteur 1989: 368-369).

An example of how the clinical trial psychologist achieves the narrative behind this trigger event is demonstrated in the following extract from an ADI-R in which she questions Bronte,

the mother of Harvey (a 12 year-old boy who has had problems with anxiety and was referred to the trial when his paediatrician recently mentioned that he may have ASD):

Psych: So, what we're going to do…with this assessment it goes back normally to about the fourth and fifth birthday. So, is there anything significant that happened around that time to help you remember Harvey back then?

Bronte: [laughing] remembering Harvey when he was four…[*crosses arms and looks thoughtful*]

Psych: Anything major happen…?

Bronte: Nothing major happened…I mean, he didn't talk 'til he was…I can go back even further [*gestures by moving finger in an arc*] [laughs] – he didn't talk until two and two months. We remember this very well because we were like, 'He's not talking! He's not saying anything!' and then at two and two months he's just talk, talk, talk [gestures with hand to mimic mouth opening and closing]. And then he got absolutely fascinated with numbers – numbers in Coles' aisles (which made shopping interesting). Numbers on clocks – highly fascinated with numbers. And then at around four it was electronic games, so he became really fascinated with electronic games…

Psych: Was there any games that you remember that he was absolutely *obsessed* with?

Bronte: No, but he's obsessed with Animal Crossing now! [laughs]

Psych: [laughing] Oh dear! So then maybe if I say the electronic period, that's when you can remember the behaviours specifically around four and five?

Bronte: Yeh! I was pregnant with [sibling] and I remember waiting in the obstetrician's office and he was playing his games [*gestures with both hands to indicate playing with game console*]

Psych: All right, so you were pregnant [*writing in ADI-R booklet*] OK!

By allowing Bronte to talk through her memories of Harvey from the age of two, Bronte is able to picture certain key events, or obsessions in this case, that interested Harvey. Bronte recalls Harvey's interests in electronic games, which then prompts her memory of being pregnant and being in the obstetrician's office watching him entertain himself by playing an electronic game. The psychologist now has a specific memory that she can use throughout the diagnostic interview that conjures up an *image* in the mind of the mother of this time in Harvey's life.

Interestingly, in one ADI-R with Laura and Tom, parents of trial participant Patrick (an eight year-old boy who struggles with social interaction and aggression), Laura acknowledges the usefulness of this technique in the way that it helps her to remember back to Patrick at the age of four:

Psych: All right, what about when he was four or five?

Laura: [*nodding*]

Tom: [mutters] Can't remember.

Laura: [*Turns to Tom*] Don't you just go back to the home? I always go back to – when we're talking about him now – I envisage myself in *this* house, and when we talk about four years ago, I picture myself in the house at [suburb].

Psych: Yeh, that's why we have to pinpoint that area…
Laura: It's good! It's a good technique! [laughs]
Psych: Yeh [laughing], otherwise you'd be thinking, hmmm, OK…?
Laura: There's too many things that have happened in the last, you know, eight years – so I just think about that home and how our life was.
Psych: Exactly, because it's so specific as well, it helps! It's good!

The second technique is the use of *specific occasion questioning style*: the interviewer is expected to elicit a sequential account of the child's behaviour – what they *actually do* – by focusing on a specific occasion, and ideally prompting the parent to "recreate a picture in their minds of a sequence of behavior that they have observed, rather than report a general impression" (368). The following example from one of the clinical trial ADI-R videoed sessions with the parents (Jenny and Matthew) of Stephen, a seven year old boy who has also been diagnosed with Agenesis Corpus Callosum (ACC), shows how the psychologist must use prompts to determine whether Stephen displays joint attention (that is, the ability of one individual to alert another to an object by means of eye-gazing, pointing or other verbal or non-verbal indications):

Psych: But it's quite consistent? He points quite a bit?
Matthew: Yeh [*shrugs*]
Jenny: Does he? I'm going to have to have a look now when I go back. I don't know if he does! Think of him pointing specifically to stuff?
Matthew: [*Hand on chin, thinking*]
Psych: So, if he sees something in the shop, "Mum, I want the Oreos" [*demonstrates with arm outstretched and index finger clearly pointing*] or whatever. "Hey, let's go over there" [*demonstrates with vaguer gesture – arm and hand are floppy, hand is curled over*], or…
Jenny: I don't think he does
Matthew: He'd just walk over. He'd just go there.
Psych: [*writing in ADI-R booklet*] so he does some…
Jenny: I'm trying to think now, but…
Matthew: I'm sort of second-guessing myself…
Jenny: Yeh, it's a bit like that.
Matthew: It's probably because he *doesn't* point that you don't always get it. So, you end up looking around thinking, "well where are you looking?"
Psych: But he'll still do that [*demonstrates with index finger extended, with arm close to body*], he'll do the [*vague gesture with hand*], whatever it is?
Matthew: He might just say, "Look at the car" and you'll be like [*looks over both shoulders as if confused and searching*], "Where?" So yeh, he probably doesn't when I think about it because that's probably part of the problem, where I can't see it half the time.
Psych: Ah, OK. And I'm assuming it was the same when he was younger?
Jenny & Matthew: Yeh.
Psych: [*Changes answer in ADI-R booklet by crossing out and writing new response*] OK, let's go with that.

In the following chapter, I will draw on Gardner and Williams' (2015) work to explore how the psychologist uses another technique, one that is not explicitly discussed or specified in the ADI-R, regarding the use of corporeal labour to generate responses and conjure images in the parent's mind.

From these examples we can see that the ADI-R relies on experienced and skilled interviewers who have been highly trained both in how to question parents to elicit the responses required by the tool and in the practice of making conceptual distinctions involved in coding. It is important to note that during one of my reflexive interviews with the psychologist, she mentioned that when conducting her first two ADI-Rs, she was required to video them for "research reliability." This involves another psychologist watching the videos back and conducting their own coding and scoring of the ADI-R separately. The two scored documents are then matched up to ensure "inter-rater reliability," that is, ensuring consistency between the ways that assessors/administrators score the tool.

The ADI (1989) was modified and renamed the Autism Diagnostic Interview-Revised (ADI-R) in 1994. The revised interview has been reorganised, shortened, and modified to be appropriate for children with mental ages from about 18 months into adulthood and linked to ICD-I0 and DSM-IV criteria (Lord et al 1994). Video data of the ADI-R sessions with parents gathered during this clinical trial will be discussed in detail in Chapter Six.

Using diagnostic tools in the clinical trial: Why use the ADI-R and WISC-IV?

This was one of the first questions as a researcher that I pondered as I began filming the diagnostic sessions with the trial participants. In a review of other clinical trials involving testing medications for children on the autism spectrum, I was interested in whether there was a set precedent or an established protocol with regards to what tools to use to determine an ASD diagnosis. Eleven studies were reviewed in which children with autism participated in a randomised controlled clinical trial testing either a Serotonin Reuptake Inhibitor (SRI) (DeLong et al 2002; Hollander et al 2005; King et al 2009; Owley et al 2010; Henry et al 2006), such as fluoxetine, or a stimulant (Jahromi et al 2009; Nickels et al 2008; Posey et al 2004; Posey et al 2007; Research Units on Pediatric Psychopharmacology Autism Network 2005; Stigler et al 2004), such as methylphenidate. While all studies required the diagnosis to be consistent with the Diagnostic and Statistical Manual (4th Edition) (DSM-IV-TR), the way that these diagnoses were reached was incredibly varied. Some studies required the presence of an existing diagnosis of ASD (meaning that some form of assessment had been carried out externally to the trial) (For example, Owley 2010, Henry 2006 and Research Units on Pediatric Psychopharmacology Autism Network 2005); some studies required one diagnostic tool or a combination of diagnostic tools (For example,

DeLong 2002; Hollander 2005; Jahromi 2009; King 2009; Owley 2010; Posey 2007); others provided only a vague account of diagnostic requirements, such as "diagnoses were made using the DSM-IV" (Posey 2004; Stigler 2004); while another study required participants with "research-identified autism" which was based on the child's medical records, developmental, neurological, psychological and psychiatric assessments, as well as reports on school visits (Nickels 2008). The different tools used across these studies varied from the ADI-R (*n* = 4), Autism Diagnostic Observation Schedule (ADOS) (*n* = 3), Childhood Autism Rating Scale (CARS) (*n* = 1), and the Aberrant Behavior Checklist (ABC) (*n* = 1). Six out of the eleven studies reviewed used one or more diagnostic tools. No studies reported using the WISC-IV.

What was most surprising about this review of RCTs for ASD drug trials was the complete lack of justification in these articles as to *why* a certain diagnostic approach had been taken, thus providing no insight or logic behind this quite fundamental selection criteria. Similarly, the clinical trial psychologist (psych) that took part in my study was also blind to the justifications behind why certain diagnostic tools had been written into the trial protocol. As a clinician with a background in private practice diagnosis and treatment of ASDs, her thoughts regarding this issue were particularly illuminating:

> Psych: So, I guess the point of [the WISC-IV] is just for reconfirmation of the diagnosis [from the ADI-R] in the trial. But in private practice, for example, we would not rely on this at all. At *least* we use the ADOS and the ADI-R, and observation.
>
> Me: And why are you using the intelligence test? Why is that used and not an ADOS or something?
>
> Psych: To be honest, I ask myself the same question, because regardless of the IQ…I mean, we use cognitive testing as well for a diagnosis but that's just to see where they're at in terms of cognitive functioning and where to diagnose them [on the spectrum] – because, you know, your Asperger's have a higher IQ.

And later in the interview, the psychologist goes on to elaborate how diagnosis works in the private practice setting:

> Psych: That's why the best practitioners of a lot of studies are using more than one diagnostic tool. I know ASPECT [Autism Spectrum Australia] do. I mean, a school observation will tell you so much in two hours, of where that kid is at in terms of functioning.
>
> Me: Sure, sure. That's really interesting.
>
> Psych: It *is* interesting! I honestly wish they had the ADOS in this trial…
>
> Me: Do you know why it isn't? Was it just a time thing?
>
> Psych: I think it was a time thing; and I think [the ADI-R] is just easier to score, especially because it's hard to find people who are trained in [the ADOS]. But I would prefer ADOS for this [trial] assessment [of ASD], and I asked myself the same question when I first started [working on the trial]: "Where's the ADOS and why do we need the cognitive testing?"

This ambiguity and messiness of diagnostic practice pervades all elements of autism work: whether it is diagnosis in the clinic, recommending treatment practices, prescribing medications, or conducting clinical trials, the elusive nature of ASD is inherent to all aspects of its study and practice. ASD clinical trials are not immune, despite the seemingly protected and legitimised scientific space of the randomised controlled trial (RCT).

The diagnostic tool as a "list": shaping the gaze through a point of reference

Just like studies using the RCT and clinical trial approach, using standardised assessments and checklists in the diagnosis of ASD gives the impression, to the uncritical eye, of validity, stability, visibility, and certainty. The standardised diagnostic tool is an important artifact of the clinical trial procedure for this very reason: in theory, it allows other clinicians and researchers to trace the line from diagnostic label back to the start of the assessment process. This section will consider the work involved in abiding by the rules and directions set out by the tools: the wording of the questions; the inscriptions made by the psychologist on the tool itself; and the scoring process whereby the psychologist must filter the "mess" of their notes into scores placed in boxes. These inscriptions and scores are of course informed by prescribed ideas (as dictated by the DSM) of what counts as normal and autistic, and are dictated and enforced by the instructions in the tool, as well as the training that the psychologists must complete to conduct the assessments. The quantitative notions of what the average child is capable of are the underlying basis of cut-off scores in the WISC-IV and the ADI-R. Likewise, for the ADI-R, scores not only indicate whether the child is "normal" or on the autism spectrum, but also delineate an average for autism itself – indicating where on the Spectrum the child can be placed based on this number. Thus, it is important to consider how these criteria work or act upon the clinician, and how in turn, the clinician works or acts upon the criteria (that is, tinkering with the tool). This latter point will be explored later in the chapter.

Law and Lynch (1990) point out that criteria or "lists" impact profoundly upon one's perception and how they perceive and observe what is in front of them. They describe this as a reflexive relationship:

> "Perception" is list-driven in the sense that the current state of the list provides motives for: searching the environment; regarding, disregarding and selecting among potential experiences; remarking upon or saying nothing about an observed event; and treating an announced sighting as a notable, doubtful or unremarkable claim. There is thus a reflexive relation between the literary phenomenon of the list and the embodied and interactional performance of observation and representation. (Law & Lynch 1990: 270)

This reflexive relationship is further articulated by Latour (1999) and can be extended to the process of diagnosing ASD. The diagnosis, via the diagnostic tool, is a construction, a

discovery, an invention and a convention. As Latour (1999) would have it, the diagnosis is: *constructed* by the work of the psychologist and by applying the construct of the diagnostic tool; *invented*, because without the work of the trial psychologist, and other psychologists in developing the diagnostic tool, as well as the psychiatrists that originally created the label "autism", there would be no diagnosis, no autism; *discovered*, because the diagnosis has been "hidden" or previously "missed" – "it *discovers* a form that until now has been hidden but that we retrospectively feel was already there beneath the visible features" (67); and *conventional*, because without the psychological conventions of coding, standardising and labelling behaviour, these children would be considered "quirky" or "mentally impaired" and so on (66-7). Thus, the point of this process is to:

> establish a reversible route that makes it possible to retrace one's footsteps as needed. Across the variations of matters/forms, scientists forge a pathway. Reduction, compression, marking, continuity, reversibility, standardization, compatibility with text and numbers – all these count infinitely more than *adequatio* [the correspondence of the mind and reality] alone. (Latour 1999: 61)

The way that the psychologist records much of what is said by the parent(s) in the ADI-R in written form on the tool itself, and then uses these notes to justify the codes/scores she eventually records for each question is an example of how this diagnostic tool attempts to align itself with the scientific notions of replication – the ability for another psychologist to retrace these steps and to reach the same diagnostic conclusions (Latour's (1999) "reversible route"). This process, using the videoed interviews with the psychologist conducting the ADI-R as part of the clinical trial, can best be represented in Figure 5.4, below. Through this process, the psychologist first observes and listens, often simultaneously transcribing and forming initial opinions based on experience. Then, later, while "scoring" the ADI-R, the psychologist shapes and constructs the reported symptoms, anecdotes, stories into a numerical value, until a final numerical value is reached or "achieved." This score is compared to population data, whereby the psychologist is able to compare these scores with norms based on the "average" or "neurotypical" child and determine whether this child falls above or below certain cut-off criteria that deem them to be on the Spectrum or not on the Spectrum. Based on these scores, the clinician can then develop a report in which this numerical value translates back into a compatible and comparable diagnosis with a body of evidence behind it, thus fulfilling the needs of the clinical trial. The diagnosis is then translated or articulated into a report for the parent. Thus, the process, as outlined in Figure 5.4, is as follows:

- Step A shows the multi-faceted and complex context of the child's everyday life: interacting with family, going to school, playing, watching TV, interacting with peers, struggling with challenges within their environment.
- Step B indicates the diagnostic interview – the ADI-R – with the parent/caregiver where the psychologist asks the parent a series of questions about the child's life,

how the child would act in typical situations (for example, in terms of social reciprocity, communication, and repetitive behaviours). This step also incorporates the psychologist's inscription of this information in hand-written note form onto the tool (see Figure 5.4, below)

- Step C illustrates the point of reference that is used to make sense of, and ultimately "score," each response given by the parent using the criteria that assigns a numerical value of 0, 1 or 2 based on conceptions of what is normal and abnormal behavior. The psychologist's written records of the parent's answers are converted into numbers (see Figures 5.6 and 5.7). As Figure 5.6 shows, however, these scores are interpretive and can create confusion, as illustrated by the scribbled out score in one of the boxes.
- Step D details how these numbers are then manipulated to produce a "score" which has been fed through a statistical equation. Through this number or "score", the child is placed on a spectrum or bell curve – directly comparing them to thousands of other children of their age (see Figures 5.6 and 5.7).
- Step E indicates the final step in this decontextualisation whereby the "score" and bell curve are translated into a report that is provided to the parent/caregiver (see Figure 5.8).

Figure 5.5, below, outlines the basic steps involved in the translation of observed behavior, to written text, to numerical value, to the use of norm values in the WISC-IV. While steps C to E remain essentially the same between the two tools, it is the first two steps that differ most markedly, and produce a very different diagnostic encounter for the subject of the test (that is, the child in the WISC-IV and the parent in the ADI-R). Steps A and B in the ADI-R involve drawing on information from the parent about the child's everyday life – what they were like as a young child, how they interact with their family and friends, what they know about their child's school-life, their child's likes and dislikes, how they deal with change, and numerous other contextual aspects of the child's life. Steps A and B in the WISC-IV, however, is completely removed from the contextual factors of the child's everyday life – the child is asked highly rigid questions, some of which are directed to be read in a "monotonous tone", to determine their cognitive capacity within a test-like environment.

Figure 5.4: The process of decontextualisation in the diagnosis of ASD using the ADI-R

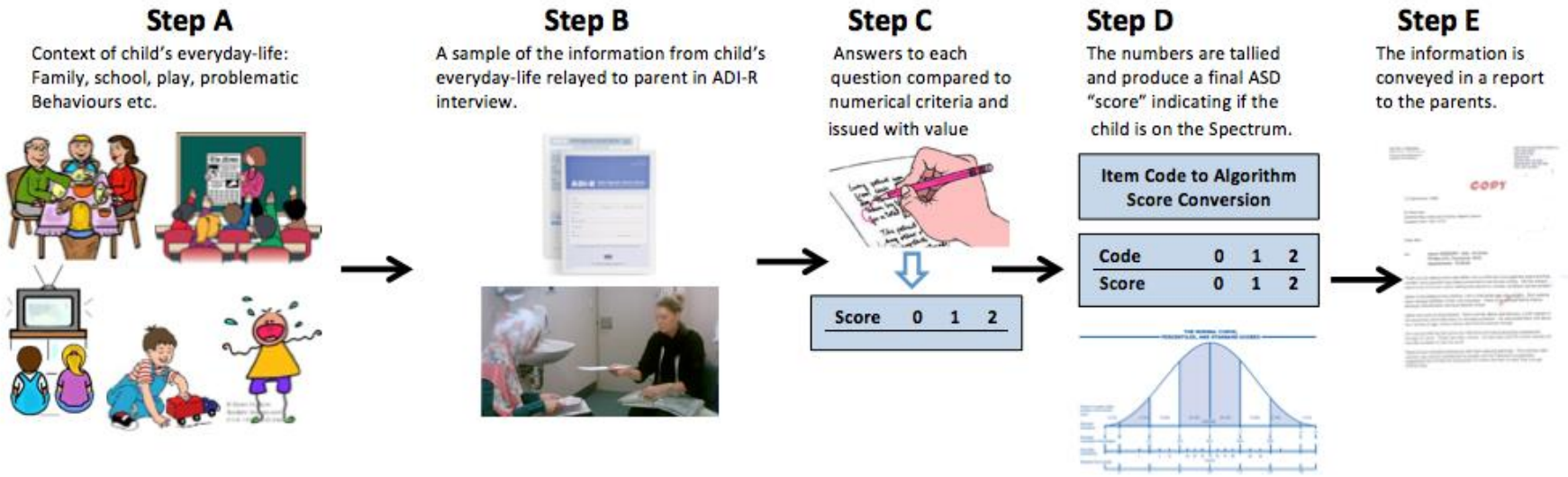


Figure 5.5: Administering the WISC in the clinical trial

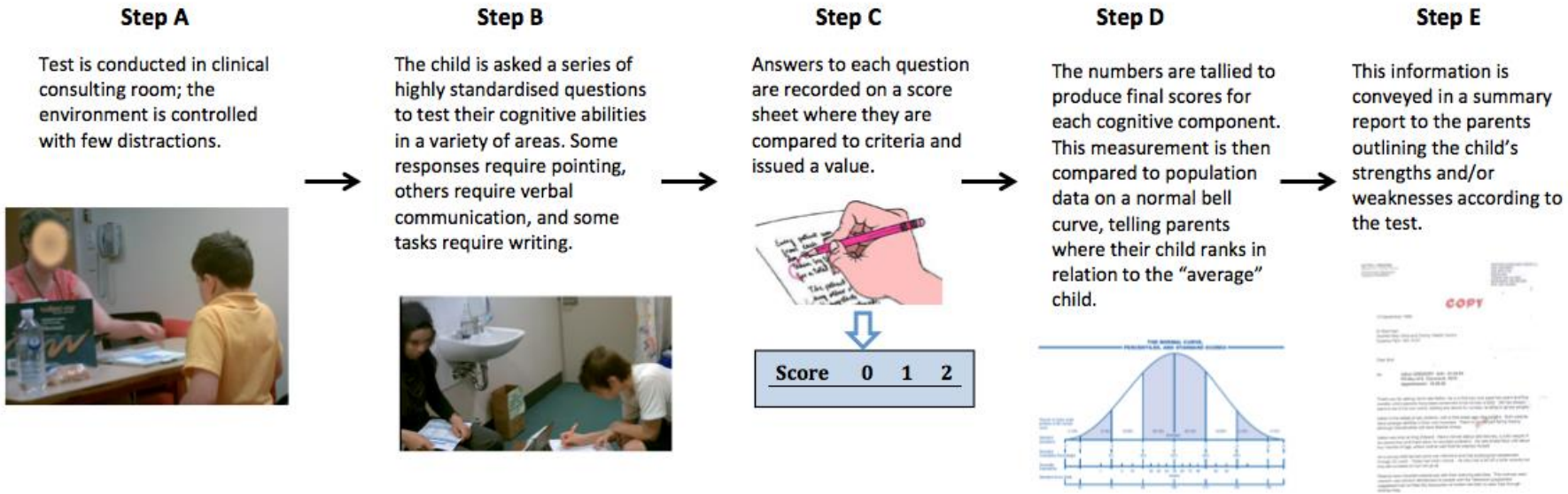


Figure 5.6: Hand-written notes made by the psychologist during the ADI-R (see Step B, above)

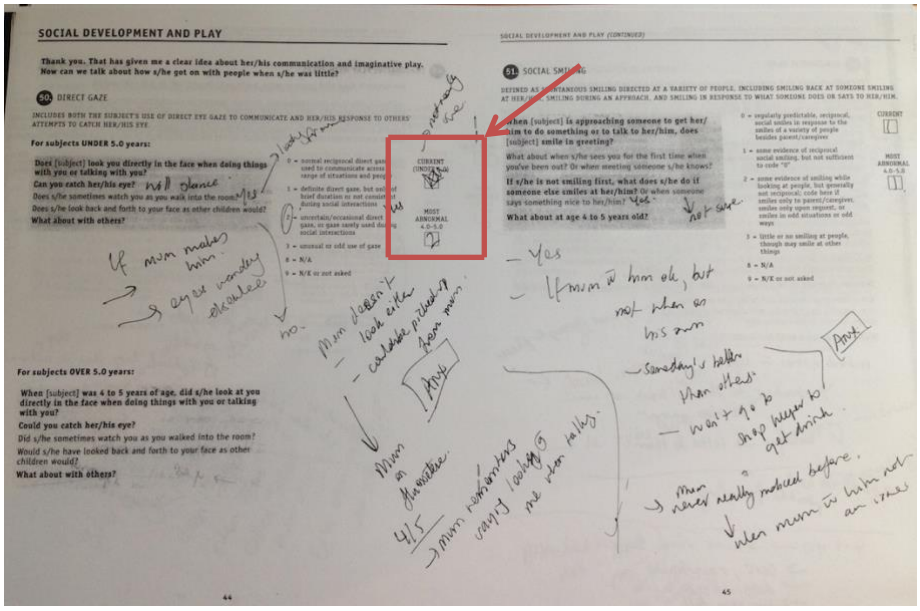
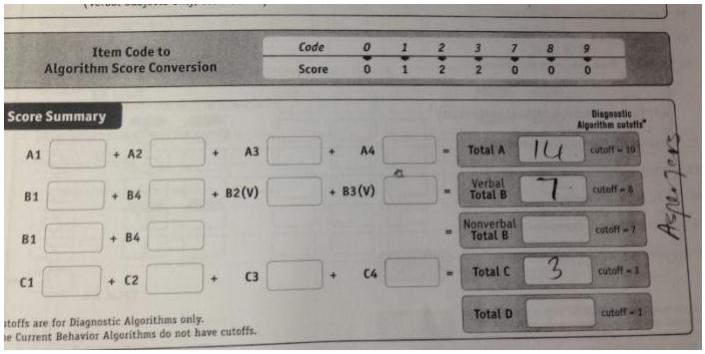


Figure 5.7: Score sheet with final cumulative scores on the ADI-R (see Step D, above)

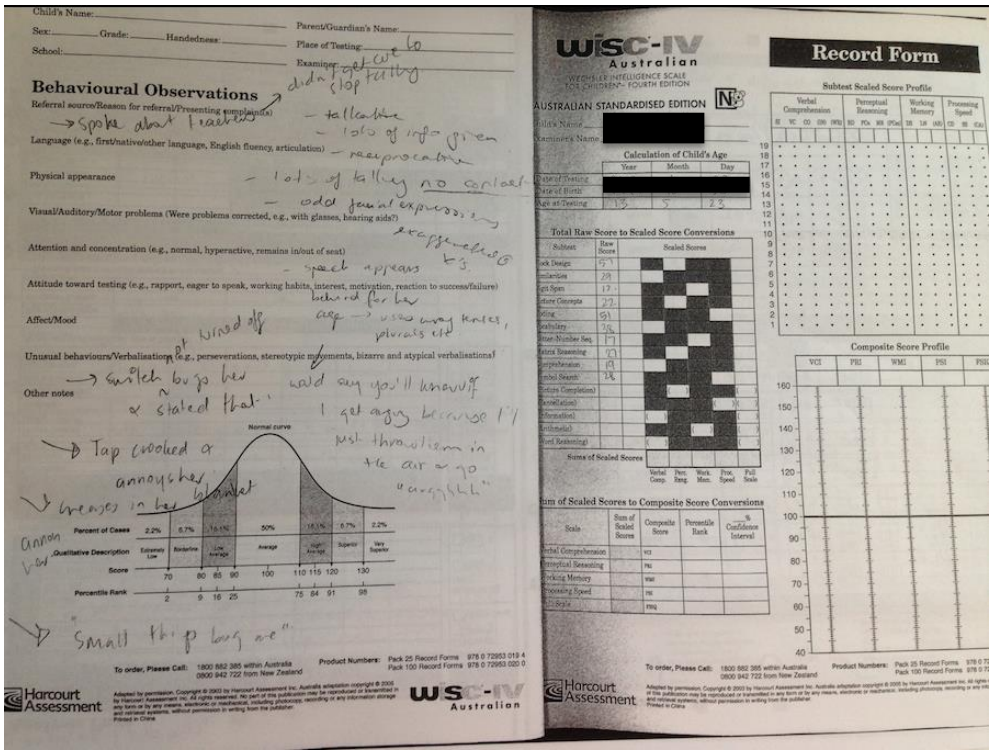


The “mess” of this contextual information that is provided by the parents in the ADI-R, and through observation of the child’s behaviour in the WISC-IV (See Figures 5.6 and 5.8) presents particularly strong visual imagery of the disordered way in which this information is often conveyed to the psychologist. During the ADI-R, for example, the parent is asked to remember back to a period when their child was four to five years old (for some of the parents, this meant trying to conjure up memories from up to 12 years ago). As a result, the parent often jumps from one memory to another, requiring the psychologist to transcribe examples of behaviours and events that can often be disjointed, occurring at different ages, and sometimes relating to questions that are asked further on in the manual.

While this mess and scrawl, as a product of fragmented memory recall, is inherent to the ADI-R approach, the free observations of the psychologist during the WISC-IV are very much on the periphery. These observational notes are certainly not the focus of the test, and are usually scribbled hurriedly by the psychologist during the few moments within the structured test that she is able to take a moment to watch the child. These moments are

infrequent given the rigid structure, time-sensitive nature, and normative focus of the test. The interactions that take place between child and psychologist are generally drained of inter-subjectivity and creativity.

Figure 5.8: Handwritten notes made by the psychologist during the WISC-IV



Crucially, in the clinic, this apparent "scribble" and mess is in fact a highly ordered and important recording of salient occurrences throughout the diagnostic encounter. While these scribbled notes may appear haphazard and disordered, they are in fact a record of the visible and important facts they have observed throughout the session, and form a crucial part of the knowledge and diagnostic process. These notes are used in reports written to schools or other clinicians, and to aid in justifications of treatment approaches recommended to families. Whereas, in the clinical trial setting, this complexity and detail is invariably lost and rendered superfluous given that the focus of the diagnosis is to produce the comparable "score" – deeming the child to be on the Spectrum or not on the Spectrum, with the overall focus being eligibility of the child to participate in the clinical trial. Thus, this textual knowledge – while important – is ultimately trumped by the norm values or score in the hierarchy of knowledge production of the clinical trial.

Emphasising deficits and eliding strengths: The case of abstract competence versus concrete competence

Canguilhem's (1989) definition of the scientific understanding of the normal and the pathological pervades this clinical trial. Not only are the very notes that the psychologist jots

down turned into a “score”, but also conversations, body language and behaviors are scrutinized through this quantified gaze. Manyard (2005) and Turowetz’s (2015) work is helpful here in exploring how the diagnostic tools focuses the quantified gaze to ignore the “concrete competence” of the child in favour of “abstract competence”. They demonstrate how questions in standardised tools are often targeted towards testing abstract competence, and in doing so, misinterpret, misunderstand, or sometimes altogether ignore concrete competencies possessed by the child. I will explore the ways in which the WISC-IV (administered to the child by the psychologist) fails to recognise many strengths of the child being assessed due to the rigid way that the tool is administered and the rules around scoring responses.

Manyard’s (2005) work uses conversation analysis to examine the performance of children diagnosed with an ASD in a videoed Brigance Diagnostic Inventory of Early Development standardised test (this test uses questions like: “what do you do when you’re hungry?”). His analysis distinguishes between “commonsense” and “autistic” intelligence, highlighting that children with an ASD answer in a way that reverses a “structural preference for gestalt or global interpretation of utterances” (abstract competency) and instead favours a “stimulus-bound, local understanding” (concrete competency) (Manyard 2005: 499).

Similarly, Turowetz’s (2015) work uses a conversational analysis approach to a videoed case-study assessment of a child with a possible ASD, combining this with group diagnostic meetings about the child’s diagnosis with other clinicians and the mother. In this examination, the various *perspectives* are considered whereby different interpretations arise about what certain behaviours the child exhibits *mean*. In a specific task, in which the child is being asked to reference a picture of two cups, one empty and one full, the psychologist asks: “this is empty, this one is….” The child, in response, tries to “pick up” the cup (although of course he cannot, because it is a picture) and pretends to drink from it, and then pretends to hand it to the psychologist. The psychologist interprets this behaviour as the child confusing image with reality, which has serious implications for determinations around how high or low-functioning an autistic child he was considered to be. However, in the diagnostic meeting in which the parent was present, the mother reinterprets this behaviour based on her knowledge of her child. For her, this is her child demonstrating a problem-solving strategy in which he attempts to distinguish between empty and full by physically picking up the cup to see which is heavier. The researcher then adds his own interpretation of the incident through his viewing and analysis of the video (interestingly, this is not discussed in the meeting, and the video of the incident is not replayed at the diagnostic meeting): for him, the incident with the cup demonstrates the child attempting to initiate play with the psychologist.

This example highlights the highly interpretative nature of diagnosis, and how three different perspectives all produced conflicting explanations for a behaviour. The

interpretation of this behaviour was key in determining important aspects of the child's diagnosis. These ideas are summarised, below:

> A clinician's emphasis on abstract competence may lead her to assess a child's performance in terms of whether or not he measures up to the standards of the tests he is given. This may cause her to miss or ignore the various kinds of concrete competence the child could be displaying, as Tony did when he engaged in play with Laura—play that, as we saw, he may have been trying to initiate even before the clinician "redirected" him. While this is problematic for any child being assessed, it is especially so for autistic children. As Maynard and Turowetz (2014) have shown, such children tend to be so oriented to concrete activities, like giving directions or repeating phrases, that these may interfere with the child's ability to demonstrate the abstract competence a given instrument is designed to measure. This is not to say that measures of abstract competence are (or should be considered) inappropriate or irrelevant to diagnosing autism, but that features of their design and implementation can diminish or obscure certain competencies a child displays in interaction. Accordingly, it is important to identify and recover forms of concrete intelligence a child may exhibit in order to offset and balance assessments of his abstract intelligence, as well as to discern whether and how the former may have affected the latter. This, in turn, could provide a more nuanced picture of the child's strengths and limitations. (Turowetz 2015: 74)

For the children participating in the clinical trial studied for this thesis, demonstrations of this preference for abstract versus concrete competence are evident in the videoed WISC-IV assessment between the psychologist and child. In the case of Brendan, a fifteen year-old boy who loves action movies, video games and rap music, there were several instances of this concrete competence. For example, as discussed in Manyard's (2005) explanation of autistic intelligence, concrete competence favours a "stimulus-bound, local understanding," and this localised stimulus-specific knowledge is conveyed in the following exchange:

> Psych: What does absorb mean?
> Brendan: Absorb?
> Psych: Yeh, absorb.
> Brendan: Absorb means to take something from someone, a lot like a monster's case they would need…ummm…for example, when human beings need energy to survive that would be absorbed, or to take something and to take it, eat it, drink it, etc.

Brendan is scored "0" for this response (that is, according to the WISC-IV manual, he did not provide an answer that was correct or partially correct). He has clearly used examples that are salient to him in his response, drawing on his interests in television shows, movies and video games. The way that the WISC-IV has devalued this response, and ignored potential strengths in his answer (the way that he has drawn on examples to process and articulate his response) means that his overall performance on this task is significantly undervalued.

Interestingly, the psychologist's notes on the WISC-IV score sheet also demonstrate the way in which her emphasis on abstract competence creates a kind of "tunnel vision" in the way that she goes about assessing the child in the diagnostic process. Thus, not only does the

test, with its limited questions and rigid scoring criteria, use narrow categorisation techniques, but so too does the psychologist through the way that she views the child's behaviours. In her notes on the score sheet she has written that Brendan engages in "atypical verbalisations" through the "repetition of words". However, my notes as a researcher observing the session (in person, and via video analysis later) provide further context to these "atypical verbalisations". I note that Brendan's repetition of words occurs during the verbal comprehension task, and to me, seem like an effective technique to help Brendan process the word, giving him time to think about its meaning and sound. Brendan's dad, Tim, confirms this in the ADI-R interview, explaining that repetition and immersion is Brendan's way of making sense of things:

> Tim: He's very immersed in media. He loves songs, he loves rap…
> Psych: [Laughing] He told us!
> Tim: All that sort of stuff. Heaps of that, he loves all that. Lots of videos and things like that, and he will listen and re-listen to stuff, I think, until he *gets it*…
> Psych: OK.
> Tim: Ahh, actually. He just keeps going until…then one day he'll say something that he could've said twenty times ago, but he says it then and indicates his understanding. That's due to the immersion he's given himself.

Similarly, the observed WISC-IV session with Lorna, a 13 year-old girl who was very talkative and made many jokes throughout the diagnostic encounter, is another example of the psychologist using this "abstract competence tunnel vision". In the psychologist's notes on the WISC-IV score sheet, she has written that Lorna displayed "odd facial expressions" and "exaggerated expressions" and that there was "lots of talking – no context". In contrast, the notes that I made as the researcher throughout the session focus on the way that Lorna builds rapport with the psychologist and researcher. Her "exaggerated gestures" seem to reflect her sense of humour: she is very expressive (making comic angry faces as she tells a story); at the completion of each block task she makes comic celebrating gestures (hands up in the air with clenched fists – as if standing on a podium accepting applause); when a task becomes too hard she throws her hands up to her face dramatically and says "I give up!" (while smiling). These behaviours all generate laughter from both psychologist and researcher. Yet they are interpreted and inscribed by the psychologist as abnormal.

Creativity in responses to some of the WISC-IV questions are also quite insightful in terms of understanding the ways that concrete competence emerges in the diagnostic encounter. The following exchange between Lorna and the psychologist during the verbal comprehension vocabulary task further highlights Lorna's quick wit, yet also the inability of the psychologist to comprehend the significance of her response and the creative way in which she has answered the question:

> Psych: What does mimic mean?
> Lorna: What does mimic mean [*looks directly at psych, smiling*]

Psych: [*Distracted, checking manual*] Yes, what does mimic mean?
Lorna: [*Looking disappointed*] To copy someone.

Likewise for Michael, a 13-year-old boy who was alert and eager to do well throughout the task, asked the psychologist, in response to a question about what should you do if you find a wallet in a supermarket: "Can there be a right or a wrong answer? Because there's a difference between what you *should* do and what you might *want* to do?" While the psychologist has given Michael the maximum 2 points for this question, for his answer she has only written down his response after this clarification, "give it to the shopkeeper or manager". The WISC-IV manual does not contain criteria for scoring an answer that demonstrates capabilities outside of the rigid objective of the question. Each question's purpose is clearly demarcated and scores must correspond to the parameters set out in the manual.

David, a 7 year-old boy who was previously diagnosed with ASD, dyspraxia and language delays, similarly demonstrates some creative interpretations to questions. The examples discussed below, both within the context of the ADI-R interview with David's mother, Abigail, highlight the complexities of the English language at times for children on the Spectrum, and the humorous ways that language can be interpreted. The first excerpt from the ADI-R interview involves the psychologist questioning Abigail about how David responds to "simple" instructions or requests; the second excerpt involves David's comprehension of instructions and his literal interpretations:

Psych: So, is there an example? For example, what about if you said, "David, go get my purse from my bedroom"?
Abigail: Oh no, do you want to laugh! [*Claps hands in exclamation*] OK! I go, "David, can you get me the straw broom [*laughing, bent over*] I need to sweep the floor". OK, he went and got me a straw [plastic drinking straw], cos he only heard straw [*gestures with both palms straight and flat, facing each other – as if indicating a segment*] [laughing]
Psych: [*laughing, head back*]
Abigail: …and [pauses while laughing] he came to blow [*demonstrates as if blowing through straw*] [laughing] with the straw [*rocking back and forth with laughter*]
Psych: [laughing loudly]
Abigail: Yeh, so that was like…I thought, "Oh, I should have said…" instead of using "straw broom" – because I've never used those two words together – I always say, "Go get the broom". But I don't know what made me, because I try to…like, I use simple sentences, but I just said, "Go get the straw broom" [laughing].
Psych: That is *so* funny! It was like that when we did the assessment and I said, "Oh, we're going to say [the numbers] backwards now," so he turned around [*draws circle with finger in air*] and sat backwards [laughing]
Abigail: [laughing] But, like, he takes literal [*gestures with both palms straight and flat, facing each other – as if indicating a segment*]…so I was in stitches. I can't laugh at him, but it was so hilarious. I'm like, "Oh no!" [laughing]

Psych: OK, so we're going to go back and look a little bit more at his language. So, how much language do you think David understands, now, if you don't gesture at all?

Abigail: If I talk to him, and even if he's not looking at me, he understands everything – if he *wants* to listen…

Psych: Yeh, that's fine…

Abigail: …if he's engaged, umm [pause] Like yesterday I said, "David, there's money in your front pocket of your school bag". And he wasn't showing me that he [was listening] and I looked at him and I go, "Look at me! Where's your money?" and he goes, "In the front pocket of my school bag". So he knew exactly, but he looked like he was completely zoned out. So yeh, I think he *understands* everything, umm, he does take things literal. Like, when I say, "Hold your horses mate", he goes, "I got no horses!" [*mimics a perplexed look*] [laughs]

Psych: [laughing, a lot]

Abigail: So, his *comprehension* is another thing: he understands everything, but he doesn't understand slang, he doesn't understand sarcasm…

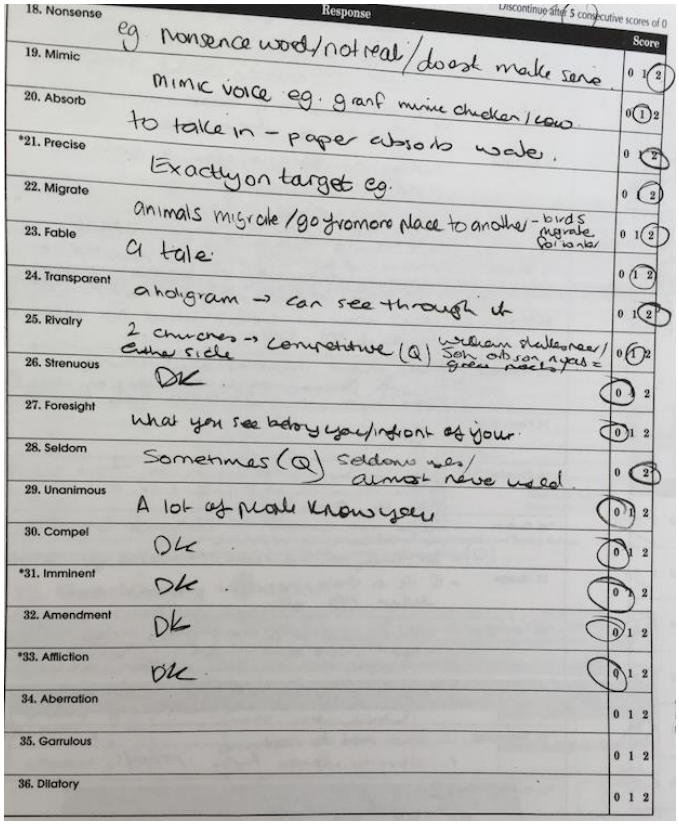
Psych: Yeh.

Abigail: Umm, he understands what you're saying, and he's also got to be in the right frame of mind to.

I would argue that these four creative examples of Brendan, Lorna, Michael and David's responses reflect concrete competencies. If reconfigured in this way during the diagnostic encounter, one could also argue that these responses align with Canguilhem's (1989) qualitative notions of norm and normativity and the ability of living subjects to adapt to change. By exercising flexibility and applying a dynamic approach in these situations, more strengths and skills would be acknowledged and recognised in these children within the WISC-IV tool. The responses in the examples above demonstrate a remarkable aptitude in these children to use creative ways to adapt to their environments. In Brendan's case, using his specialised interests in television, movies and video games to provide a definition for a word; in Lorna's case, using humour to engage with the psychologist within the context of a (fairly boring) assessment; in Michael's case, understanding the nuances of human behaviour when it comes to desires versus social expectations; and in David's case, interpreting instructions in a literal, but novel way by: (1) getting the straw to blow the dust on the floor into a pile to be collected up, instead of sweeping; (2) turning his chair around backwards instead of listing the numbers backwards; and (3) being puzzled by his mother's request to "hold your horses" and responding indignantly, "I got no horses!"

Sometimes basic competencies and skills are altogether overlooked. During the verbal comprehension vocabulary task, 9 year-old Daniel and the psychologist engage in some confused exchanges, which ultimately lead to Daniel completing this section of the test before he should have. This is based on a rule in the test that stipulates that if the child provides five incorrect answers in a row (indicated by scoring the child 0 on the score sheet) then the task will end at that point (see Figure 5.9, below). This means that his score for that component of the test is recorded as significantly less than his actual capabilities.

Figure 5.9: WISC-IV score sheet for the Verbal Comprehension Vocabulary task



	Response	Score
18. Nonsense	eg nonsence word/not real/doesn't make sense	0 1 2
19. Mimic	mimic voice eg. grandf mimic chicken/cow	0 1 2
20. Absorb	to take in - paper absorb water.	0 1 2
*21. Precise	Exactly on target eg.	0 1 2
22. Migrate	animals migrate/go from one place to another - birds migrate for winter	0 1 2
23. Fable	a tale.	0 1 2
24. Transparent	a hologram → can see through it	0 1 2
25. Rivalry	2 churches → competitive (Q) [illegible]	0 1 2
26. Strenuous	DK	0 1 2
27. Foresight	what you see before you/in front of your	0 1 2
28. Seldom	Sometimes (Q) Seldom was/ almost never used	0 1 2
29. Unanimous	A lot of people know you	0 1 2
30. Compel	DK	0 1 2
*31. Imminent	DK	0 1 2
32. Amendment	DK	0 1 2
*33. Affliction	DK	0 1 2
34. Aberration		0 1 2
35. Garrulous		0 1 2
36. Dilatory		0 1 2

It is important to mention that for this WISC-IV session with Daniel, the psychologist was recovering from a cold and visibly and audibly displays symptoms of congestion (blowing nose, coughing and affected speech). In the following two examples, we can see that Daniel is initially confused by the word he is asked to define (probably due to the psychologist's problems with articulation given her congestion), and once he has understood what was asked of him and is trying to process an answer, he is cut off and unable to pursue a certain line of thinking that may have produced a "correct" answer. In the second example, we can see a very clear example of how sometimes a complete breakdown in communication can occur, with neither party aware that it has happened:

Psych: What does "ancient" [sounds like "agent" due to psych's blocked nose] mean? [*turns head away to cough*]. An-cient [pronounced "agent"]. [*looks at Daniel*]

Daniel: Agent…? [*trails off looking puzzled, furrows brow*]. Agent. [*Looks at psych, as if to clarify*]

Psych: What is it?

Daniel: Did you mean a-*g*ent, or an-*cient*?

Psych: An-*cient*

Daniel: Oh! Like the Ancient Pyramids! [*smiles in recognition*]. A pyramid is like a square-based pyramid…

Psych: [*Cutting Daniel off, writing in book, not looking up*] So, what does the word *ancient* mean?

Daniel: Spooky?

Psych: Spooky. Anything else? [*Writing in book, not looking up*]

Daniel: [*Puts head down*] That's it.

Psych: What about obey? [pronounced "a-bay" due to the psych's blocked nose] What does obey [pronounced "a-bay"] mean?
Daniel: Like, a bay is a place where, umm…island… [*looks up, thinking*]
Psych: Yeh, anything else?
Daniel: [*shakes head*]

Daniel is cut off by the psychologist when he begins to explain what a pyramid is, and re-directed to the word ancient. His next response is to link the word "ancient" with "spooky". Daniel is never given an opportunity to fully explain his knowledge about pyramids, nor justify why he thought pyramids were "spooky". The WISC-IV does not allow the psychologist to delve deeper, to prompt, to follow-up, to clarify. This example highlights the complete disregard the WISC-IV has for the process of thought, creativity and intersubjectivity. In the second example, the complete lack of follow-up, or even clear repetition or clarification of the question means that Daniel is scored "0" on the score sheet. As I watched this situation unfold during the session with Daniel, I could clearly see the miscommunication that had occurred, and yet I was not able to intervene and disrupt the session to explain to the psychologist what had happened. These situations were common throughout the WISC-IV and I found them ethically challenging: while I wanted to observe the way that these tools are administered in the clinic in a natural, everyday basis, I felt conflicted by the knowledge that I could have helped the child perform better on the test.

The focus of the WISC-IV is to get through the questions before the child becomes too fatigued; therefore, the psychologist often shuts down any perceived divergences from the question and attempts to constantly refocus the child on the task at hand. However, when we consider that the psychologist is not only working with children, but also those with an ASD, the normative and rigid focus of the WISC-IV is amplified further. In the reflexive interviews with the psychologist, we discussed the problems associated with applying the WISC-IV to this group of children in the clinical trial. One of the key problems the psychologist identified was the wordiness and length of the instructions she must read out to the children:

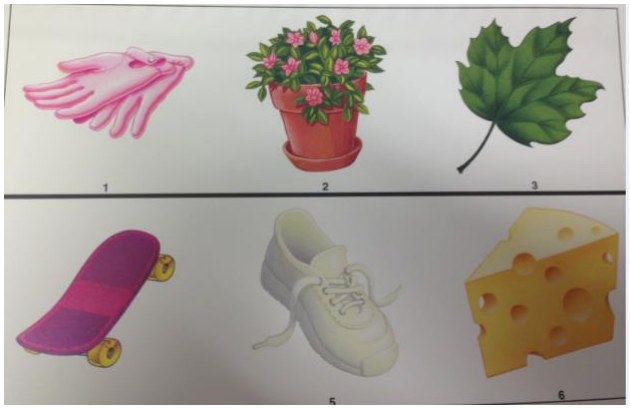
Psych: Well, the instructions are really long, and look…remember we're…remember the tool is comparing typically developing kids of *all* ages – so a six year old, or what you'd expect a six year old to do. So, it'd expect [the clinician] to say, "Ah, you know, pick one from here that goes with one from here" – and you're just pointing – so they should be able to pick that up straight away. With the kids with autism, you need limited language, you need to get their attention, you need to prompt them visually in terms of what to do and you might need to give the example again because they're not understanding. So, I think that would be the difference in terms of the two.

The psychologist identifies four key ways that the tool fails to accommodate for children with an ASD, and techniques that she would use to help the child understand when reading out the WISC-IC instructions: (1) the language in the instructions needs to she shortened and limited; (2) gaining the child's attention (for example, using rewards such as, "let's do X first, then we can play with Y [showing a toy/game that the child enjoys]; (3) using visual prompts to make the question clearer; and (4) repetition of the question or the example question at the start of each task to ensure the child understands what is expected of them.

The clearest examples of the way that concrete competency is altogether ignored in the WISC-IV is through the Perceptual Reasoning task involving "picture concepts". In this task, the child is shown rows of pictures where they must pick which pictures are associated with one another. The children are required to point to the pictures that they think "go together" but they are explicitly told that they are not required to explain *why* they go together (and of course, the scoring for this test is either right or wrong – if the child selects the predetermined associated pictures as set out in the manual, they achieve points). Thus, in the following examples, we can see how Paul (a seven year-old boy who told stories about his family throughout the diagnostic interview and talked about his favourite books by Roald Dahl) and Nikolas (a nine-year-old boy who was highly focused throughout his test and very compliant) use creativity, story-telling and contextual, stimulus-specific examples to explain their selected pictures (even though they are told by the psychologists that they do not need to):

Paul:	[*points to the picture of the leaf and the skateboard* [see Figure 5.10, below] ("correct" answer is glove (1) and shoe (5))]
Paul:	because when you ride a skateboard there's all these leaves on the ground [*smiles*]
Psych:	[laughing] is that what happens to you, is it?
Paul:	[*Nodding and smiling*] and sometimes there's lots of leaves and they get…and my skateboard gets stuck in them.
Psych:	Oh no!
Paul:	And sometimes I ride my […?] and it gets stuck on…my ground is like [*shows psych by drawing with finger on table*], and it gets stuck in those and I go flying off! [*smiles*]
Psych:	[laughs] Oh no! You have to be careful!

Figure 5.10: Image from Perceptual Reasoning (Picture Concepts) Task (Paul)



Nikolas: [Nikolas selects the windmill, the key and ladder (see Figure 5.11). "Correct" answer is windmill (3), merry-go-round (5) and world globe (12)]

Nikolas: The windmill, the ladder and the key go together because you use them all for something I don't know [laughs], but you would definitely use the key to get into the windmill and I think you'd use the ladder to get up to higher places in the windmill.

Figure 5.11: Image from Perceptual Reasoning (Picture Concepts) Task (Nikolas)

Through these examples we can see the importance of context-specific information and creativity in forming responses. For Paul, the skateboard and the leaf trigger happy and exciting memories of him playing on his skateboard. He uses the pictures to tell the psychologist a story about something he enjoys doing, demonstrating other skills (such as language, sense of humour, affect and so on) that are not recognised by the WISC-IV. In Nikolas' response we can recognise his ability to construct a kind of narratival logic within the pictures that is salient to him. Yet, this response is simply marked incorrect and the concrete competence displayed here – creativity, narrative construction, logic – is omitted.

When I discussed the Perceptual Reasoning (picture concepts) task with the psychologist in the reflexive interview, I played her some of the videos discussed above. It was interesting to understand how she grappled with and reconciled the competing notions of acknowledging the value of each child's concrete competency (their creativity and ability to piece together information in a novel and unique way), yet also her deference to the standardised, clinical privileging of abstract competencies. The quotes below highlight the way that the psychologist contends with these conflicting views, and the way that she "thinks out loud" as she processes these new ideas, and ultimately why she defaults to the normative and clinical approach:

Psych: Yeh, no, it's interesting you say that, because I had a kid the other day, umm – literally the other day – who every single one he was giving me his logic as to why [the pictures] went [together]. And yeh, you can see the pattern that they're thinking in their head in terms of why it associates with that [picture] – I mean, that's their thinking – but again, ***remember we are comparing…[autistic] kids to all levels, so they're just trying to find out the average with that***. Which is a shame! But, like I said, this isn't a *diagnostic tool*, so you wouldn't use that, but for observations, you'd put

that as part of [the report] – I mean, it depends on the purpose of the report. ***For this [clinical trial], we only needed IQ***, but if we're doing an autism assessment, but we're also unsure of the cognitive stuff, you'd write all this information down.

Psych: But remember, as well, ***because it's a testing tool, they always go by numbers…in terms of scoring*** and because then if we use the descriptors…it's like when you're coding your own stuff, right? You have to come up with a code and you don't know how subjective or standardised it is. But yeh, you're right – I agree….And remember the question though *is*, at the end of the day, [Paul] has to find the most common [association between the pictures]…even though that's *his* experience, ***he's not generalising to what it should actually be***[13] …you know what I mean?

While the psychologist acknowledges the value in the experience-based knowledge and thought processes the child goes through to produce a creative and unique response, her training in the rigorous, standardised and normative world of psychological testing, RCTs and EBM trumps all else. In the clinical trial they must "always go by numbers", "try to find out the average", and "compare" with the average. The clinical trial necessitates culling any information that cannot be reduced down to a number – "we only needed IQ" – and reduces information down to a binary of "right" and "wrong" – "he's not generalising to what it should actually be". This final statement (the last bolded sentence in the quote above) highlights the language that is commonly used by the psychologist when discussing the tools and their function. There is an assumption being made here that what is "average" is correct and fixed, that these tools provide the parameters of what counts as "the way that we should think." Here, the psychologist clearly defers to Canguilhem's definition of the scientific understanding of the normal and the pathological.

In the next example, I would like to demonstrate what can be achieved if the codified, rigid, statistical-norm based approach of the WISC-IV is relaxed and a more qualitative, experiential-based style is embraced with the child. This in turn allows for these concrete competencies to be demonstrated by the child. This approach would align with Canguilhem's use of the concepts of norm and normativity to designate the ability of living subjects to adapt to change.

Daniel, a 9-year-old boy whom the psychologist has previously worked with, was very quiet for the first forty minutes of his WISC-IV assessment. He spoke minimally, and only when required to – not wholly unsurprising given he has already been diagnosed with an ASD, but noteworthy given his already built-up rapport with the psychologist. In my notes I have recorded that he was "very shy" and "quiet". However, when the psychologist begins asking Daniel questions as part of the "Verbal Comprehension Index – Vocabulary" task, in which the child must provide a definition of a word, Daniel begins to open up as the psychologist engages him in conversation about his little brother Charles (whom the psychologist also

[13] When the psychologist says "he's not generalising to what it should actually be," she is referring to Paul's interpretation of how the pictures in the Perceptual Reasoning (picture concepts) task are associated.

knows). This conversation is generated through one of the questions – "What is a pest?" – during which Daniel relates a story to the psychologist, which helps him to ultimately answer the question. The quote below, extracted from this conversation, demonstrates the naturalised, contextual and experiential way in which the child generates this answer, outside of the confines and rigid structure of the parameters and rules set out by this tool:

Psych: All righty, you ready for the next one? What is a pest?
Daniel: Oh, what do you mean, "a pest"?
Psych: Yeh, what's a pest? [*Looking down at the WISC booklet and writing in the score sheet*]
Daniel: What's a pest anyway? [*Smiling, confused*]
Psych: [*Trying to hide a smile*] You tell me!
Daniel: I think it's my brother! My brother's a pest! [*Smiles*]
Psych: [Laughing]
Daniel: He just annoys me – I get cranky! He just teases me and he gets up on the couch and then goes around trying to smack me, and then he laughs [*Smiling*]
Psych: [*Smiling and writing in WISC-IV score sheet*] Oh no!
Daniel: Once, I was trying…running upstairs to watch a movie and I had chocolate in my hand [*demonstrates as if holding chocolate in outstretched hand*]…
Psych: Yeh…
Daniel: …and I was running up, falled on the stairs…I had this thing [*pulls up sleeve on shirt to his elbow*], on here [*shows Psych spot on arm just near elbow – looks at her as he is telling her*] – I had a cut…
Psych: Oh noooo! [Sympathy in tone]
Daniel: …and then when Charles' iPad – he just dropped that, like about two times, there's the sharp bit [*show's psych his fingers, which are fanned out, pointing at a spot between his fingers*] and he put his finger…I saw it was bleeding there [*rubs spot on finger while looking at psych*]
Psych: So, the iPad broke as well and [Charles'] finger was bleeding?
Daniel: [*Gestures by rubbing at spot between fingers again*] Over here. And then he was OK [*shrugs*].
Psych: Ohh, ouch! So you had to get a new iPad did you?
Daniel: Nah! I just sticked it with sticky tape [*gestures as if placing pieces of tape on the iPad with his fingers*] […]
Psych: So, based on that, what do you think a pest is?
Daniel: A pest is something that bothers you.
Psych: They bother you, don't they! [Upbeat and encouraging tone]

Not only is Daniel able to generate a "correct" response to this question at the end of this conversation (after initially struggling to comprehend the question), but he also demonstrates some key skills that are highly relevant to an ASD diagnosis. For example, Daniel is able to use gestures effectively to help him convey meaning (this is perhaps something he has learned to do to help others to understand him given his language delay), he demonstrates the core skill of joint attention (often lacking in children diagnosed with an ASD) whereby he shows the psychologist where he fell on his elbow and makes sure she is engaged by looking up into her eyes, and he shares in a joke with the psychologist about his

younger brother who "annoys" him. Daniel can only demonstrate these skills as a result of the psychologist's deviation from the rigid structure of the WISC-IV, whereby she engages in a conversation with Daniel about how his brother is a pest, and what this means for him. It is here that we can see that the fixed, statistical norm-based quantitative conception of the normal and pathological, as critiqued by Canguilhem (1989) – discussed earlier in this chapter – forms the theoretical underpinnings of the WISC-IV. Yet, it is this (rare) moment in which the psychologist (unknowingly) embraces Canguilhem's (1989) alternative *qualitative* conception of the normal and the pathological, allowing the child to demonstrate his "health" and "normal functioning" through relaxing the rigid rules around administration of the standardised WISC test and allowing him to express himself through stories and experience.

"You're not supposed to, but…": Making allowances, tweaking words, altering tone and honing-in on questions

In this chapter, I have focused on the strict structure of the WISC-IV and the rigid parameters around its administration. I have drawn on examples to demonstrate how this has a profound impact on a child with autism and their ability to achieve within the confines of this test. A key focus of the reflexive interviews with the psychologist was this rigidity of the WISC-IV; and how this impacts the psychologist's ability to perform her job, whether the child's full potential is captured by this test, and whether the test is useful in determining whether the child is on the autism spectrum. A key theme that emerged from these discussions was the creative ways that the psychologist manipulated or subtly adjusted the tool so that she could achieve the result she needed. There were two key motivators behind this approach: (1) to provide opportunities for the child to succeed – "we have to get the best out of [them]"; and (2) to draw out ASD symptoms, thus making autism visible, within a test that is not an ASD diagnostic tool.

The first subtle adjustment is the way the psychologist makes allowances throughout the assessment by tweaking words and phrases, and slightly varying her tone as she reads out questions and responds to their answers. In the exchange below, the psychologist explains to me the necessity of using positive words and an elevated tone after the child gives a response to each question, regardless of whether they are marked right or wrong:

> Psych: So, you're not supposed to give positive praise – just so you know!
> Me: Yeh? It's interesting…
> Psych: But, I have a tendency to give it because I feel like with these kids, I *know* them…
> Me: Yeh!
> Psych: …and they struggle when they think they are [giving] the wrong answers. So, you're supposed to…I would say, "Good, good, good, good, good" [elevated tone] – even when it's wrong!

Me: Yep, yep, exactly! And that's how you've been trained, you know, through your work at [the private practice early intervention clinic] as well?

Psych: Yep! Yep! Exactly! I had a very very low-functioning boy at the hospital – he didn't understand half the stuff – so it was literally, every single question: [puts on excited voice] "'Yay, good job,' next [question], 'Yay, good job,' next [question]" – even though he was getting them wrong [laughs, good naturedly].

Me: Yeh, yeh. That's really interesting!

Psych: Because you *have* to!

Me: So, you're sort of feeling like, if you don't give them that reinforcement, you'll "lose them" [lose their attention] completely, is that right?

Psych: Yeh, yeh, exactly! Exactly! You've got it!

Me: …that they need some sort of…

Psych: …they need some sort of motivation!

The psychologist talks about the necessity of this adjustment in tone – "because you *have* to" – drawing on her many years of experience working as a therapist with children with an ASD – "I feel like with these kids, I *know* them…". Without this praise and variation in tone, the psychologist talks about losing the child's attention and the child struggling to complete the task. By adding some words of encouragement after the child's response, the psychologist is making a small adjustment to encourage the child to continue to attend to the questions and participate in the test.

Another allowance the psychologist makes is the simplification of the instructions read out to the child. In the example below, the psychologist reflects on a video clip of 15 year-old Brendan losing focus, and then regaining his interest when the psychologist provides an example of how to complete the task at the end of a long, read-out explanation. She discusses how she must read out the standardised words first, but after this, she simplifies the instructions by editing them down to the key terms and relaying these in a clear, emphatic tone:

Psych: You know what, they're not listening to your verbal instruction because it's too much language for them. And, I mean, that's the tool! There's too much language, but if you just give them an example, they draw on what they're supposed to do based on the example – like the pattern, they're looking for a pattern. So the minute I said the example, he came up [*demonstrates regaining of attention with clear eye-contact*] […]

Me: Yeh, it's hard because I can see you sometimes…like, you're changing your tone, you're trying to say the…

Psych: …key words!

Me: …the *key words* and everything, yeh – you can see the kids are just like errrgh [*demonstrates loss of attention by looking away, turning head*]

Psych: Because I would have just said [for the WISC task instructions], "Say numbers then letters. Numbers in order, letters in alphabetical order" [says this in an emphatic way, clear way]. So I'd say that first.

Me: So, you are still able to break it down in your own way, before or after you've said the "standardised"…

Psych: Yeh, I do! Whether you are supposed to or not, that's another whole debate. But, like I said, you're looking at the reason why you're using it in the first place…

The psychologist acknowledges that this might not be common practice to summarise the instructions into key words and relay this edited version to the child, but she points out that this is an essential practice to maintaining the child's interest and focus to obtain a snapshot of cognitive functioning for the clinical trial – "you're looking at the reason why you're using [the WISC] in the first place." The psychologist has used her experiential knowledge and "feel" for autism to subtly alter the test, yet simultaneously remain within its parameters by continuing to read the standardised instructions and maintain the overall structure and integrity of the test. She goes on to clarify:

Psych: The experience and the training…and, I mean, I'm not "experienced" [changes tone to indicate self-deprecation] you know, in terms of *age*, but in terms of seeing these [autistic] kids everyday, you know, you do learn how to adapt for them. And, because, like I said, this is an *IQ* test: to get the best out of them, you need to try to cater for their own inflexibilities and then you write in the report whether it's a true reflection or not, we don't know, but we've got what we can out of it […]. The report's really important.

The last part of this quote, however, demonstrates again how the psychologist will always defer to the scientific method of clarity and making ones work transparent and replicable. She uses the psychological report – a diagnostic summary that is written by the psychologist after the test results have been analysed – as a way to justify and validate these small deviations from the standardised WISC-IV manual. Thus, the appearance of a subtle rebellion against the rigidity of the tool by way of making the WISC a little less alienating and confusing for the child is justified, minimised, and explained away by their documentation in the diagnostic report. The psychologist qualifies these amendments with frequent references to the diagnostic report throughout the reflexive interview:

Psych: So, with the cognitive assessments, they're not tailored for kids that have got difficulties. So, when you have a kid with these difficulties, you need to adjust. So, there's no set protocol. You *have* to follow the standardised method, but with kids like this, they're not going to follow-through at all if you [use] that standardised method. So, in the [diagnostic] *report*, we mention that we had to use x, y and z, or adjust for x, y, z. But, as long as the instructions are the *same*, umm, I mean…because you're trying to get the most out of the child as well, right! So you're looking for a baseline. So, as long as it's clear in the report, so that people know...

Psych: Yeh! But remember as well, we have to be careful – that's why you write in the report what you *do*. Because it's not really then a reflection of say, "low-average" – it might be an over-estimate because you inflated [the child's score], because you helped them a little bit…

The second key creative technique the psychologist uses while administering the WISC-IV is to identify and pinpoint certain questions that draw out ASD symptoms, thus making autism visible and explicit within the clinical encounter. It is important to remember that the WISC-IV is not an autism-specific tool, so the questions are not designed to help the clinician diagnose this disorder. In the following two examples, the psychologist discusses two different occasions in which symptoms of autism became clear to her in the child's responses to the test questions. The first example is drawn from the reflexive interview with the psychologist after playing back a video clip of 15 year-old Brendan providing a definition of the word absorb, in which he references superheroes to explain its meaning:

Me: So, the main [example] I wanted to talk about was "absorb," which was at the beginning…

Psych: Yeh! The superpowers! That was how he associated it. (…) That's part of autism! That's part of the *actual* diagnosis where [the child] takes something out of context to *explain* the world or whatever it is…

Me: And so, that's a key marker for you of: "this is autism?"

Psych: Yes.

Me: So, a kid that isn't on the Spectrum will maybe just draw from their own personal experience, versus using a movie or…?

Psych: So, even if [a child not classified on the Spectrum] used a movie, for example, they'd use it differently, because they might say, "Oh, in the movie the character does blah blah blah blah," or, "Skeletons are real because it was in the movie blah blah blah blah." These kids are actually using the *rules* or the *context* to *add* to their meaning. So, like, for Brendan, it was, well, he thinks about the movies and the superpowers, or whatever it is, and he applies it – he *fits* it in – whereas the other kids, they don't *fit* it in, it *comes* as an example, these [autistic] kids *fit* it in. Maybe that's a good way to put it?

By asking Brendan a seemingly simple verbal comprehension question, the psychologist is able to extrapolate from his response a key indicator of ASD. While watching the video clip in the reflexive interview, the psychologist immediately reacted to Brendan's response when he began talking about superpowers. Her response above draws upon her experiential knowledge of how a child with autism talks about movies – "for Brendan…he thinks about the movies and the superpowers, or whatever it is, and he applies it – he *fits* it in." For a clinician that knows what to look for, and draws on their experience administering a tool with a certain population, a seemingly straightforward IQ test can in fact reveal symptoms of a disorder such as ASD.

The second example is also drawn from a video clip of 15 year-old Brendan providing an answer to a question about a social scenario: "why should you say sorry?" I asked the psychologist what her impressions were about his response to this question, which was "That's what you're supposed to do":

Psych: Yeh, that's an autism one. So, normally we do – you're not supposed to, but – sometimes when I go look at the…I'll go to the emotional questions [in the WISC] just to see how they respond, because that's part of the autism and usually you'll find that they don't know what to say. [Their response] is just very rule-focused.

Me: So, yeh, what was it about that made you go, "Oh, that's autism!"

Psych: Because he said, "That's what you're supposed to do" and he couldn't understand the reasoning behind it – *why*! He could only understand the context, what you *should* do.

Me: Yes. And in terms of *that* response being scored in the WISC, is that…

Psych: He wouldn't get it!

Me: So that question is specifically looking at, you know, that theory of mind-type response – being able to put yourself in someone else's shoes?

Psych: Umm…I'm pretty sure he might have got one [point] because he [mentioned] the context, but I think the [complete] answer is "because it makes them feel better."

Me: So, he's just giving rule-based kind of responses…

Psych: A *learned* response.

Me: …this is what you're *supposed* to do, but because he can't sort of say, "Because, if that was me, and someone did that to me, I would feel much better if someone said sorry" etcetera, etcetera.

Psych: Yeh, he doesn't get that.

Me: Yeh, and so that's a common theme in all [children with ASD]? That they're giving you a rule-based response and that's a key kind of [indicator] [*clicks fingers to emphasise*]

Psych: Autism! Yeh! And you can use that in your observations.

The psychologist concedes at the beginning of this quote that "you're not supposed to, but – sometimes…I'll go to the emotional questions [in the WISC] just to see how they respond." This admission highlights the way in which the psychologist manipulates the questions in the WISC-IV to serve her own (or the clinical trial's) purposes – that is, to determine if the child has an ASD. Again, we can see here how the psychologist uses her experiential knowledge to draw inferences about the child outside of the parameters and intended purpose of the WISC-IV. She interprets Brendan's response as a "learned response," emphasising that "he couldn't understand the reasoning behind it – why! He could only understand the context, what you *should* do."

Conclusion

This chapter has examined the labour involved in reaching an ASD diagnosis through the rigid way the trial requires diagnosis to fit within the narrow parameters of what counts as "evidence". The WISC-IV sessions are focused on what counts as normal and pathological, and they are constrained – drained of intersubjectivity and creativity. These sessions embody Canguilhem's critique of the quantitative distinction between the normal and the pathological that drives science as a positivist, objective enterprise. Unsurprisingly, and as Canguilhem points out, this quantitative distinction does not hold up in practice, because it cannot account for the lived experience of health. This chapter has drawn on numerous examples to demonstrate the possibilities of acknowledging and recognising concrete competencies in a more qualitative approach to the assessment of children with ASD. In the

following chapter I will discuss the use of the Autism Diagnostic Interview (ADI-R) with parents as an ASD diagnostic tool in the clinical trial, and examine how this tool, while still standardised, provides more scope for clinical creativity and interpretation.

CHAPTER SIX

Performing, translating and feeling autism through clinical labour: Invoking images, triggering memories and creating evidence

Introduction

I have demonstrated that the prescribed norms and standardised nature of the diagnostic tools used in the clinical trial studied for this thesis have a rigid and limiting impact on the diagnostic process. This is evidenced by their deference to quantitative or statistical conceptions of what is normal and abnormal, the way that they elide complexity and messiness through the process of reducing experiences, stories and examples to numerical scores, and the way in which the tool privileges abstract competence at the expense of concrete competence (or autistic intelligence). This chapter, however, will focus on how the complex and visually rich data that is gathered during the Autism Diagnostic Interview-Revised (ADI-R) allows the diagnostic encounter to be conducted as a more negotiated and information-seeking enterprise between the psychologist and parent(s). Key to this approach are the techniques used by the psychologist within the ADI-R interview to (1) trigger memories through invoking images and specific events in the minds of the parents, and (2) use one's body to act out what I am calling "corporeal labour" in the diagnostic encounter. This chapter will also explore how the parents use their own form of corporeal labour to translate their knowledge about their child, which is often the only way that they can convey this knowledge due to their lack of a clinical vocabulary that would enable them to communicate verbally the complexity of some of their child's behaviours and mannerisms (such as repetitive and stereotyped behaviours, "stimming," complicated movements of the body and so on).

As discussed in the previous chapter, the ADI-R is classed as a standardised interview because: it specifies the range of behaviours to be covered and there is a predetermined coding system for each behavioural item. However, the ADI-R includes two key techniques for improving retrospective recall that offer the potential for a more creative, visual and embodied approach to the diagnostic encounter: (1) Using a *trigger event* to create a specific memory that conjures up an image in the mind of the parent – for example, the parent is asked about a significant event that occurred between the ages of four and five, such as a birthday, moving house, Christmas, or holiday, to help them remember this time in the child's life; and (2) Using a *specific occasion questioning style* – the interviewer is expected to elicit a sequential account of the child's behaviour – what they actually do – by focusing on a specific occasion, and ideally prompting the parent to "recreate a picture in

their minds of a sequence of behaviour that they have observed, rather than report a general impression" (Le Couteur et al 1989: 368).

These two techniques are crucial for a tool that relies on the parent recalling information and examples from up to 12 years ago. Interestingly, the developers of the tool – Le Couteur et al (1989) – point out that we do not encode memories in terms of dates, or ages, but rather, associate them with significant personal events. Thus, the emphasis of the ADI-R is on momentous personal events – images, smells, feelings, sounds – and these form the foundation of the ADI-R, and set the tone for this standardised assessment.

Crucially tied in with this discussion is my use of video-reflexive ethnography (VRE) to collect data during these diagnostic sessions, and the emphasis this approach has on not only on recording what can be seen, but the active and dynamic nature of this data. Through the use of video, I have been able to capture and analyse the significance of the visual, emotional and corporeal elements of the ADI-R in the clinical encounter, and demonstrate how they are often used by both psychologist and parent to convey, and in fact *translate*, significant clinical information that may have been invisible or misinterpreted otherwise. I will examine how clinical labour – involving both corporeal and emotional work – is performed by the parents and psychologist to embody the ADI-R. I will explore how these forms of emotional and corporeal labour are used variously to translate the complexity of autism symptoms and clinical language, as well as to explain behaviour, bodily movements and expressions in a way that language cannot, and how these forms of knowledge are sometimes considered the most valuable form of evidence. I will also explore the ways that Hochschild's (1983) emotional labour is enacted and the significant care work that the psychologist performs during the diagnostic encounter.

Clinical labour as the creation of a form of value

This chapter relies heavily on the concept of labour and is used to describe the work performed by parents and the diagnosing psychologist throughout the ADI-R clinical encounter. However, embedded in this concept of labour within the clinical trial is the idea that this work involves the creation of a form of value: labour in this context is a social relation and involves the production of scientific knowledge/data (Cooper & Waldby 2014).

The clinical trial studied for this thesis is described as a randomised double blind placebo-controlled trial, interested in testing the efficacy of the SSRI Fluoxetine in the treatment of repetitive behaviours in children with autism. This Australian trial is NHMRC-funded and run by a not-for-profit Australian children's research institute. The protocol for the trial explains that the evidence for the use of SSRI medication for repetitive behaviours is inconclusive, and that the Therapeutic Goods Administration (TGA) in Australia, and the Food and Drug Administration (FDA) in the United States are yet to approve the use of SSRIs for repetitive

behaviours in autism. And yet, over the past decade in Australia, the "off-label" – that is, "for medical indications that have not yet been tested" (Cooper & Waldby 2014: 215) – use of Fluoxetine and other SSRIs in children with autism has become increasingly common. Thus, the key aim of the trial is to test the efficacy and safety of low dose fluoxetine in the treatment of repetitive behaviours in children with autism.

Particularly relevant to this study is the fact that few prescription drugs have been tested on children, meaning that the majority of drugs taken by children are prescribed off-label. Melinda Cooper and Catherine Waldby (2014) explore this off-label use of drugs in the context of the US, explaining that:

> The consumption of drugs "off-label"…is a widespread and not formally regulated, practice. The FDA has little jurisdiction over the actual practice of medicine, leaving the doctor free to make decisions with regard to how drugs should be consumed once normal standard-of-care options have been exhausted. It appears, in fact, that off-label indications constitute a huge proportion of overall prescriptions in the United States, with some estimates suggesting that over 60 per cent of legal drugs are prescribed for nonstandard use. (215)

In light of the above, it appears that the use of off-label drugs both in the US, and here in Australia, is extremely lucrative for pharmaceutical companies. Cooper and Waldby (2014) explain the very calculated process by which pharmaceutical companies conduct clinical trials, seeking approval for just one medical indication (for example, an indication that is either easy to prove or the most remunerative in terms of its patent life) and then once approved, promoting the off-label use of its drug for untested indications. Lauren Rosewarne (2013) similarly argues that the truly lucrative market emerges through the off-label use of a drug. Rosewarne (2013) uses several examples to demonstrate the ways that pharmaceutical companies create and expand their markets via "making allusions…to nonapproved uses" (136). By linking the off-label uses with the drug's side effects, the pharmaceutical company is legally able to indirectly promote the drug for other uses. Thus, an important element to understanding the clinical trial studied for this thesis, and the labour that is being carried out within it, is the idea that through this clinical trial a market-oriented form of value is being created for the pharmaceutical industry.

The OECD points to life sciences research as contributing to advances in healthcare and biotechnology at a pace more rapid than ever before. This is significant because this research is also driving large sectors of the global knowledge economy (OECD 2000). However, few researchers have focused on the forms of embodied labour – such as the contribution made by participants in drug trials – that are necessary to sustain such an economy. Cooper and Waldby's (2014) innovative examination of clinical labour provides a theoretical foundation for the way that I will talk about the work carried out by the parents and psychologist throughout the ADI-R diagnostic encounter. Cooper and Waldby (2014) argue that participation in clinical trials should be regarded as "labour" when:

> The activity is intrinsic to the process of valorization of a particular bioeconomic sector and when therapeutic benefits to the participants and their communities are absent or incidental. Indeed, much clinical labor consists precisely in the endurance of risk and exposure to nonpredictable experimental effects that may be actively harmful, rather than therapeutic. We also include the situation where clinical labor is performed in exchange for health care, reconfigured as an "in kind" compensation for service, comparable to "workfare," where the payment of welfare benefits is made contingent upon the obligation to work. (8-9)

They go on to explain how this clinical labour relates to the clinical drug trial:

> Human research subjects…occupy a liminal but critical position in the postindustrial biomedical economy…their labor is *fully internal* to the value chains of the pharmaceutical and biomedical industries. The data generated by human research subjects is incorporated, in an immediate sense, into the investigational new drug application that needs to be submitted to regulatory authorities before a drug is approved for marketing. (9)

Importantly, Cooper and Waldby (2014) explain that the work performed by the participant in the drug trial "does not figure in the economic analyses of labor in the life sciences" (9). Of more concern are notions of professional divisions of labour, with particular focus on "the cognitive labor of the scientist as the technical element necessary to the establishment of intellectual property in living matter" (Cooper & Waldby 2014: 9). While the child is the consumer of the active medication or placebo for the drug trial studied for this thesis, the parent also plays a crucial role in providing the data. This, of course, is due to the fact that the symptoms of interest in this trial must be observed and recorded by the parents – there is no biological test or scan that the trial clinicians can complete to determine the efficacy of the medication. This parent-provided data is then "incorporated…into the investigational new drug application that needs to be submitted to the regulatory authorities before a drug is approved" (Cooper & Waldby 2014: 9). In this trial's case, the aim is for the drug to be approved for use in the treatment of repetitive behaviours in children with autism. The parent not only administers the fluoxetine to their child, and observes and records the child's behaviours during the trial period, but also provides essential "baseline" information about the child's functioning prior to taking the medication via the ADI-R assessment. Therefore, the labour performed by participants in this clinical trial involves "compliance with often-complex medical regimes of dosing, testing, appointments and self-monitoring", with non-compliance rendering these carefully developed clinical protocols, standards and procedures useless (Waldby & Cooper2008: 59).

This chapter will focus on two circuits of value production taking place within the trial: the first involves the clinical outputs of the trial that need to meet the rigours and standards of the Therapeutic Goods Administration approval process; and the second involves the care being offered to the patient (both parent(s) and child) at the point of the trial, whereby the patient receives "free care" or "treatment" (such as behavioural tips and clinical care

suggestions) in exchange for participation in the fluoxetine trial. In exploring these forms of value production, I will draw on the embodied work of the parent and the psychologist and show how the process of performing, translating and feeling autism constitutes a uniquely collaborative form of "clinical labour."

Achieving autism through corporeal labour: invoking images and triggering memories

The following section draws on the work of Gardner and Williams (2015) and Natasha Myers (2015) to explore the way that corporeal labour is used to enhance the ADI-R techniques of triggering memories through invoking images and specific events in the minds of the parents, and further, how the parents use corporeal labour as a translation device to convey their expert knowledge about their child. In this way, parents are able to bypass clinical vocabulary and communicate their knowledge in a way that clinicians perceive to be a more valuable and accurate form of evidence. Significantly, this finding was accomplished through my use of the VRE methodology: identifying parents' bodily movements as a key component of building a case for a diagnosis of autism was brought to the fore for the psychologist by watching back edited video clips of her ADI-R interactions with the parents.

Specifically, when using the term corporeal labour, I refer to John Gardner and Clare Williams' (2015) conceptualisation of "clinical work involving the body" which enables the "generation of understanding within such consultations" (2). Thus, this labour involves clinicians using their body as a "communicative apparatus within a carefully constructed material terrain" (Gardner & Williams 2015: 2); yet the knowledge required to conduct these diagnostic sessions is also *embodied*: "clinicians possess a body that has learnt to be sensitive to, and moved by, a set of contrasts that many other bodies would fail to register" (2). The clinician's gaze is guided and channelled within this diagnostic space: their embodied knowledge and experience of autism is activated within the diagnostic encounter. Gardener and Williams' (2015) study is particularly relevant in the context of my own study, as their work focuses on how bodily gestures are used to encourage compliance from their patients and to generate clinically relevant data during multidisciplinary clinical team diagnoses with children affected by a movement disorder called dystonia.

Moving away from the specific context of the diagnostic space, and to the area of the laboratory where protein molecules are studied, Myers' (2015) innovative work explores the way that molecular protein modellers engage their bodies actively in their work. Her study examines the ways that these scientists "get entangled – kinesthetically and affectively – in their modeling efforts" and the way that they "confront the limits of what they can see and what they can know" (1). Her work challenges assumptions about what counts as the kinds of labour that constitute scientific research, and how scientists work with and relate to their objects of inquiry. Myers (2015) stresses:

> Scientific objectivity is conventionally understood as neutral, rational, and so disembodied practice. Scientists are expected to dissociate their cognitive activities from their bodies' complicating passions and proclivities… the practitioners documented in this book reveal that life science research is a full-bodied practice. (2)

Myers highlights the important combination of knowledge about chemical laws and physical properties of proteins obtained from books, and a kinesthetic and affective sensibility that forms an integral part of their scientific inquiry. This chapter extends this perspective to demonstrate the integral role that the body plays in making sense of ASD and the questions in the ADI-R assessment tool through acting-out and using gestures to make ASD visible and translatable during the diagnostic clinical encounter. The full-bodied labour performed by both parent and psychologist during the ADI-R is essential in formulating a diagnosis. It is also highly collaborative: the body here emerges as a way to share, reason, negotiate and translate knowledge. As Myers (2015) highlights, protein modellers:

> engage their entire bodies, including their hands, arms, shoulders, heads, necks, torsos, and even legs in model building…they practice a kind of "molecular calisthenics" as they figure out (for themselves) and relay (for others) their intimate knowledge of molecular forms and movements. While this is a practice that both enables and constrains how they imagine molecular worlds, their bodies provide a pliable, readily available medium for reasoning through the specificities of protein structure and sharing their insights with others. (18)

Similarly, in the ADI-R interview, both the parent and psychologist *engage their entire bodies* – eyes, mouth, head, neck, shoulders, arms, hands, fingers, legs and feet – in the collaborative and negotiated process of acting out and making sense of autism. These movements and gestures act as common ground, or a common language, for the parent and psychologist. Sometimes there may be clinical language to describe the gestures or movements that the parent acts out, and in such cases, the psychologist is able to transform and translate the physical into words on paper. However, in some cases, there are no standardised clinical words that can describe these "kinesthetic sensibilities" and the psychologist must improvise and think creatively to translate this knowledge into a "useable" standardised form. As Myers (2015) observes in the quote above, "bodies provide a pliable, readily available medium," thus allowing the parent and clinician to effectively share their knowledge and work together and alongside each other to produce a diagnosis.

In the following sections, I will draw on my observed and videoed data of the ADI-R sessions involving the parents and psychologist to explore various ways in which corporeal labour is enacted. First, I will explore how the psychologist embodies the ADI-R and its clinical language to translate standardised questions to the parents, thus demystifying the often technical language that surrounds autism and enhancing the parent's understanding of not only the question being asked, but also their overall knowledge of autism. Second, I will demonstrate the power that comes with the parent's use of corporeal labour during the

ADI-R, and how this in fact aligns with a key technique that the ADI-R uses in the generation of evidence. In this way, embodying or performing autism becomes a sign of the "expert parent." Third, I will explore the way that corporeal labour is employed throughout the ADI-R to translate, explain and decipher symptoms and behaviours. In many cases, language is an insufficient tool to convey or describe autism, and without corporeal labour, there would be no shared understanding and no evidence.

Embodying the ADI-R: Using corporeal labour to translate standardised questions

The psychologist frequently embodies the ADI-R text in the way that she acts out certain behaviours, or uses her body or voice to "perform" autism, to prompt the parent(s) to remember behavioural features of their child and to translate, or transform, the text-based manual into a more relatable form. Just like in Gardner and Williams' (2015) exploration of the diagnostic practices of physiotherapists for children with a movement disorder, we can see how corporeal and verbal communication are used simultaneously and complement one another throughout the diagnostic encounter:

> In the process, bodily movements and words acquire specific meaning within the assessment. Indeed, verbal utterances are indexical to the [physiotherapist's] body movements and the material and discursive elements that constitute the diagnostic space. (Gardner & Williams 2015: 8)

Successful communication of the ADI-R questions/items is paramount in the "generation of sought after clinical information" (Gardner & Williams 2015: 8). The work involved in eliciting this clinical information is substantial for the psychologist: the parent(s) are prompted to respond to carefully-worded questions, paired with bodily movements and gestures, generating key diagnostic information that the psychologist goes on to code and quantify. The entities that constitute this diagnostic space (predetermined, of course, by the diagnostic tool) shape and amplify these interactions so that they are easily recognised by the psychologist's diagnostic gaze. In the example below, the psychologist asks the parent(s) whether the child has any odd mannerisms, such as flicking their fingers near their eyes, flapping, fixating on their fingers, or rubbing their hands together. For every ADI-R I observed and filmed, the psychologist asks the following question and embodies each description with the accompanying gestures illustrated in Figures 6.1 and 6.2 below:

> Psych: Does he have any, umm, mannerisms that are odd? So, like, umm with his hands: so, flicking his fingers near his eyes [*demonstrates by flicking thumb and forefinger very close to eyes*], flapping [*demonstrates with both hands flat and to the side of body, moving up and down repeatedly*], or…any of those hand mannerisms at all [*demonstrates by moving fingers near eyes and rubbing hands together*]? Or anything a bit strange that you've noticed?

Figure 6.1: Psychologist displaying gestures associated with "odd mannerisms"

Figure 6.2: ADI-R with Abigail, mother of David – demonstration of "odd mannerisms"

In the following exchange between the psychologist and Simon's (a 17 year old autistic teenager who has previously been diagnosed with ADHD) father, Jacob, we can see how the psychologist uses both the specific occasion questioning style that is characteristic of the ADI-R, as well as her body to indicate a visual demonstration of what she means:

Psych: What about that time, going back to when [Simon] had little speech, and used to do everything himself, do you remember him, like, ever pulling you [*demonstrates reaching out and pulling father*] to the door to get you to open something, or taking your hand [*holds out hands and pretends to place on door handle*] and putting it on the door, or standing there screaming to get something because he couldn't reach?

Jacob: No, well see, what it is, is we had one kid, then we had another kid, then another kid, and – it's sort of not *not* taking notice of the other one, but, you know what I mean, trying to care…I just can't remember always, you know. I haven't got the best memory either.

Psych: That's OK. Yeh, yeh. Just remember what you can.

Jacob: Yeh, I sort of can't remember.

Psych: OK [*writing in ADI-R booklet*].

This interaction is particularly interesting given the age of Simon who is undergoing diagnosis: because Simon is 17 years old, Jacob is required to remember back over 12 years to produce examples of Simon's behaviour in question, as required by the ADI-R. As he

reiterates, this is incredibly difficult. By using gestures the psychologist tries to create an image in the mind of the father of Simon performing that behaviour 12 years ago.

Another example of this display of corporeal labour is evident in the ADI-R conducted with Hayley, the mother of Daniel: a nine year-old boy whom the psychologist has actually worked with for years in the private practice she works for. Not only does the psychologist use gestures to convey meaning in this exchange, she uses these gestures to legitimise Hayley's response to a question about sharing through the psychologist's own experience with the child:

Psych:	Does he ever offer to share with you now, so…
Hayley:	[emphatically] Yes! Now, Yep! Like, you have to ask, but he will!
Psych:	Actually, you know what, I've seen him at school, and he'll *voluntarily* say, "Here, do you want…" [*gestures with hand as if giving*], or the kids will just [*gestures as if grabbing*]…
Hayley:	Kind of grab…[laughs]
Psych:	Yeh [laughs]
Hayley:	And then he'll say, "Yeh, you can have it." But before, he'd be like, "No! It's mine!" [*gestures with hand as if protecting object*]
Psych:	All right. So when he was four or five?
Hayley:	No [*shakes head*], no chance!

Thus, as we can see from the interaction between the psychologist and mother Hayley, above, some ADI-R questions, as text read out to the parent, can be confusing and unclear. Yet, when paired with "specific corporeal form and movement," these ADI-R questions "acquire specific referents within the assessment" (Gardner & Williams 2015: 8). Through the pairing of bodily movements with verbal standardised questions, the psychologist is participating in "the production of a meaningful semiotic world: the material terrain is interactionally-transformed via an interplay of physical enactment and verbal instruction into a diagnostic space, which will subsequently enable the production of diagnostic knowledge." (Gardner & Williams 2015: 8-9).

This use of gestures throughout the ADI-R by the psychologist presents an obvious contrast to the complete lack of gestures used in the WISC-IV with the child. While children often use gestures throughout the WISC-IV to convey their meaning, or to translate an answer, or to help explain a story, the psychologist's behaviour, in comparison, is regulated, her gaze channelled in a "non-negotiable transfer of knowledge" from subject to observer (Varga 2011: 138). Unless the child's gestures are seen to represent examples of repetitive, unusual, quirky or problematic behaviour – and thus transcribed by the psychologist in the "behavioural observations" section of the WISC-IV score sheet – they are rendered invisible under the psychologist's gaze which remains within the parameters of the highly standardised tool.

The coding process for these interactions and responses, both corporeal and verbal, is just as nuanced. Some responses to questions in the ADI-R are quite lengthy and highly negotiated by both psychologist and parent(s). This is often clear in the sections of the ADI-R in which the psychologist asks about the child's ability to point things out to their mother or father using gestures and gaining attention, as well as questions relating to any unusual or repetitive mannerisms the child may exhibit. For example, in the following exchange between the psychologist and Alice, the mother of trial participant Leo (a thirteen year old boy who has previously been diagnosed with ADHD and Oppositional Defiance Disorder (ODD)), we can see how complex and nuanced a gesture as seemingly simple as "pointing" can be (see Figure 6.3), and the work that is required by both psychologist and mother to ensure that this knowledge is accurately translated and understood by both parties:

Psych: What about in the past? Did he used to point when he was four or five? Did he say, "Mum, look!" [*demonstrates by pointing with arm and index finger outstretched*].

Alice: Yeh, there'd be tractors – he'd notice all the trucks and tractors.

Psych: So, he's go, "Oh, this tractor is…" [*demonstrates by pointing with arm and index finger outstretched*]. Now, how would he point? Would he go like that [*demonstrates with outstretched flattened hand*], or would he go like this [*demonstrates arm outstretched with index finger pointing*], or would he just [*demonstrates hand raised straight up in the air*]…?

Alice: Yeh, sometimes he wouldn't even point, because I'd be like, "Where? Where?" [*turns head right and left, looking around, as if puzzled and searching*] you know.

Psych: Yeh, OK. So, sometimes he did, sometimes he didn't.

Alice: Yeh, if he did, it'd be like [*demonstrates with just index finger pointed, but arm remaining close to body*]

Psych: So, minimal maybe?

Alice: Yeh, he'd just assume you know.

Psych: [*nodding*] Yeh, these are all the types of things we are looking for.

Alice: Oh, OK!

Psych: Because a lot of kids on the Spectrum, I mean, they don't use all the social overtures. They either verbalise or they don't use that contact with your language, with your gesturing, so…these are all the things we are looking for.

Alice: Oh wow, there you go!

Psych: Yeh, it's very interesting!

Figure 6.3: Psychologist's demonstration of pointing during ADI-R with Alice (mother of Leo)

This is issue of "pointing" is similarly negotiated between the psychologist and Laura, the mother of trial participant Patrick (an eight year old boy who struggles with social interaction and aggression). In the exchange below, it is evident how important these gestures are for the psychologist to clarify exactly the kind of pointing behaviour she is looking for, and for Laura to translate the subtle ways that her son, Patrick, communicates and gestures to direct attention:

Laura: I'm pretty sure that he has that finger pointing ability [*demonstrates pointing with index finger*], but it's not something that I can say he does all the time. It would be seldom. He, like that [*gestures with definitive point*], it's not really… [*shakes head*]

Psych: Because, I mean, I guess the purpose of the finger point is that you have intent. So, I mean [*demonstrates by pointing upwards and following direction of the point*], you know exactly what you're looking at, what you're directing at. Whereas, a lot of kids, you know, do it like [*gestures with flat outstretched palm*]…it's more [*gestures vaguely with palm flat*].

Laura: [*shakes head*] I'd say Patrick would be more vague with that – not as direct [*demonstrates with definitive pointing action*]. He's more…he uses his gestures more [*uses hands to indicate bringing something towards her*] to come in, to say, "Here I am," rather than what's outside of him [*gestures with hands away from self – as if pushing something away*]. Does that make sense? Like, he does a lot of this [*turns to Tom and places hands on his leg, and then moves her hands towards herself*]. And if he sits next to me, he's got to put his foot like that [*places her foot on top of Tom's foot*]. He's got to be touching me, like, to bring you next to him [*brings hands towards herself*]. But, to say, "There's the bottle of water" [*points finger at hypothetical bottle of water*]; he'd just go [lowers tone to a mumble] "There's the

bottle of water" [*slightly inclines head to indicate direction of hypothetical bottle of water*], like that [*slightly inclines head*] [laughs].

The psychologist must ensure that she communicates the question in the correct wording, and then determine if the question has been understood by the parent(s) – she must gauge this based on how the parent(s) responds, and measuring this against what she already knows about the child (from previous reports from other clinicians, or previous interactions with the child). If the question has not been understood, or there is doubt in the psychologist's mind regarding the parent's answer, then the psychologist must find a way to reframe the question, or make its meaning clearer through the use of corporeal form and movement. The psychologist will often provide a clinical "summary" or "interpretation" of what the parent has said to ensure that there is consistency between what the parent has communicated and how the psychologist has understood the response. Thus, as Gardner and Williams (2015) argue, the body is used to generate understanding and to translate complex clinical ideas. The psychologist uses her body as a "communicative apparatus" (Gardner and Williams 2015: 2) that has been honed and trained, through years of experience working with children with autism and their families, to not only perform autism, but also to recognise it in the bodily performances of others.

The psychologist also stresses another important dimension to this corporeal labour, relating to the way that it can provide the parent with a moment of realisation or understanding about their child. The psychologist emphasises, throughout the reflexive interview, the difficulty some parents have coming to terms with, or understanding, their child's autism symptoms. In the following three quotes from the reflexive interview, the psychologist argues that using her body to demonstrate examples of autistic behaviours can sometimes help families to "see for themselves," to "understand," and to "realise":

Psych: Often families over-estimate what their child does, and then, when you break it down for them, they realise they don't, and you know if they do or don't based on if the families, again, can give examples – and Mum, straight away says, "Well, actually, now that I think of it, he can't [point things out to his parents]" [*gestures definitely by tapping the table with her hand*]. So, then we use that [*points at paused video on computer screen*] because that's giving you an indication. And if…if you're unsure, the scoring is good because you don't have to score it, or you can put it in the middle, because a lot of the scoring is like, "[does] that [go] there?" but it might be limited. And normally, because – if they can't give an example – [the behaviour] is either not an issue [that is, it's not present], or they actually haven't noticed [the behaviour] before, because they're so used to it. So, that's when you try and ask for specific examples, or give them examples. Yeh, and when I had to use the gestures, *then* they seemed to understand a little bit more. Like I said, what you were talking about before in terms of the norms – they don't know what's "normal" [*makes scare quotes with fingers*], so they just go based on what they know, and I know Stephen was an only child…

Psych: Like I said, you validate…to, you know, validate their thoughts and their beliefs. But then you try and counteract that belief by…and this is where the examples [in the ADI-R] come in, when you try and say, "Well, is this happening? Is this happening? Is this happening? Is that a problem now?" So they can see for themselves, that realisation. It's problem solving with the client. You're formulating together.

Psych: I feel like families that don't understand [ASD diagnosis], so for example, I'll say, "Will he peer at things?" They'll say, "No". So then I'll go, "OK, does he do this?" [*demonstrates with mobile phone by turning it so the screen faces downwards and moving it towards and away from her eyes*] "Oh, yes he does!" "Does he do this?" [*stretches out arm with fingers apart and stares at fingers as she moves arm in a horizontal arc*], "Yeh, he does!" "Does he do this?" [*demonstrates bending down and staring underneath table*] "Oh yeh, he does!" This is what it is. [The parents] don't understand [*scrunches up nose and shakes head*]. So, gestures in that context – to explain to families – it helps as well. You can use [the gestures] in examples. (…) And then you say, "Yeh, I get what you mean because I know exactly what you're looking for" – because there are specific gestures that are specific to autism [*emphasises point by tapping table*]. Like, some kids do, you know, this [*stretches out arm and spins around*] and spin, but autistic kids do it [*stretches out arm with fingers slightly apart, body crouched over, staring fixedly at fingers as spins body around*]. So, I think it's a good way to differentiate

Through these interactions between the psychologist and parent(s), we can see how this negotiated process unfolds, and how the psychologist relies on demonstrations and performance to clarify her meaning. It is clear that to successfully administer the ADI-R the psychologist must draw on her years of experience working with children on the Spectrum to produce relevant and meaningful actions and performances capable of translating the ADI-R questions into a form that is intelligible to parents.

The power of corporeal labour as evidence: Performing autism as a sign of the "expert" parent

A particularly complex example of this use of corporeal work and the need to transcribe this knowledge into textual form to produce a definitive answer and allow the question or item to be "scored" is evident in the ADI-R interview with Patrick's parents, Laura and Tom. This ADI-R was particularly interesting because it involved two parents who had separated, and thus spent time with Patrick in their respective homes. In the ADI-R diagnostic encounter, there was often disagreement between Laura and Tom when answering the psychologist's questions. In the interaction below, we see how the psychologist must mediate between the parents and negotiate an answer that she can later score:

Psych: What about when he's younger? When he was younger, looking at when he was four. Umm, did he ever, ahh, you know, if you had the cars, did he ever, you know, play with them properly [*moves hands around as if pushing toy cars*]

Laura: No, he'd smash them into each other. Or fling it [*swings arm, pretending to fling toy car into the wall*] and see how fast he could smash [the car] into the wall.

Psych: OK, when he's smashing them, was it quite repetitive? In that it's [acts out banging cars together over and over again] smashing, OK, let's do it again, smashing.

Laura: Yep [nodding]. In the kitchen, remember the kick boards in the kitchen [*looks at Tom for acknowledgement*]? He'd just ram them in [*swings arm as if throwing cars at wall*] – all of them!

Tom: [*looking sceptical and talking over Laura*] I don't know that that's repetitive [muttered in lowered voice]. It's just normal play! Just normal kids play, that's all!

Laura: [talking over Tom] …and he'll get them all together [*uses arms and hands to act out gathering objects together*] and line them up nice and neatly, and then…[*moves hands rapidly to indicate messing objects up*].

Tom: [talking over Laura] …we all played cars, and we all played the same way…

Psych: OK, and we all do that, but kids on the Spectrum, what they do it that, the way they play is exactly the same. So, you know, even if it is the, you know, the diagonal on the table [*pretends to move cars diagonally on a flat surface*], it could be the same – so, just going like this [*moves hands back and forth in the same way as if pushing car on diagonal trajectory*].

Tom: No, nah. He wasn't doing that. [*shakes head*] Never done it like that. He doesn't play…he doesn't play the game for long, he doesn't play it…

Psych: See, it looks like play…but it's always the same type of play.

Tom: [*shrugs*] But you only play a car one way. You've got to hold it and you've got to go like this [*moves hand backwards and forwards as if moving a toy car*]. It's not going to continue going on its own!

Laura: Like, we had the mat [*draws a big square with finger*] that had a track on it. He didn't get the car and drive along the track [*moves hand as if driving a toy car in an orderly way along the road*] and go visit someone…

Psych: So that's what we're looking at…

Laura: …he would just get the cars and smash them [*uses hands to demonstrate cars being smashed together*]

Psych: See, that's repetitive, because, like, you know, it's the same type of movement with the hands: that way [*moves hands to the right*] and that way [*moves hands to the left*] and that way [*moves hands to the right*].

Laura: That's why he never plays well with other people: because it interrupts the way that he wants to do something. See, he doesn't want to go and drive around, you know, race, and do all of that. He just wants to smash them up [*acts out smashing cars with hands*].

When this clip was played back to the psychologist in the reflexive interview, she discussed the difficulties involved when two parents disagree. When asked how she resolved this in terms of transcription of her notes and then coding/scoring the response, she specified that she privileged the knowledge of the parent who was able to provide specific and multiple examples of the behaviour in question. In the quote below, the psychologist outlines the reasons why her intuition tells her to trust the mother as a "more reliable source":

Me: So, obviously you have Mum going, "No he doesn't do that", and Dad going, "Yeh, he does". What do you do in terms of taking notes [in the ADI-R booklet] and who do you listen to? How do you score that?

Psych: So, with umm…look you can see, like, for example, Dad's in denial because he keeps on going back and saying, "All children do that, kids do that". So, when that happens, you *know* the parent that's a little bit, maybe, less reliable, than the parent that is [more reliable]. But, with autism assessments, you're always looking at if it *happens*, or if it *doesn't* [*emphasises by tapping edge of hand on table*]. So, Dad's saying, "No no yeh he does, no he doesn't, yeh he does", so, it's not consistent. Whereas Mum is more adamant and, you know, "*No*, he *doesn't"*. So, you can see that that's the more reliable source [*points at video still of Mum on computer screen*]. So then, when you're scoring, you can either, like, work out the middle or the threshold, or you can go based on where you've got more evidence. And we're looking at consistency across contexts as well. But yeh, Dad's in denial and he keeps on using…he keeps on referring it back to other kids, rather than telling me if it happens or doesn't happen – that's all I need to know.

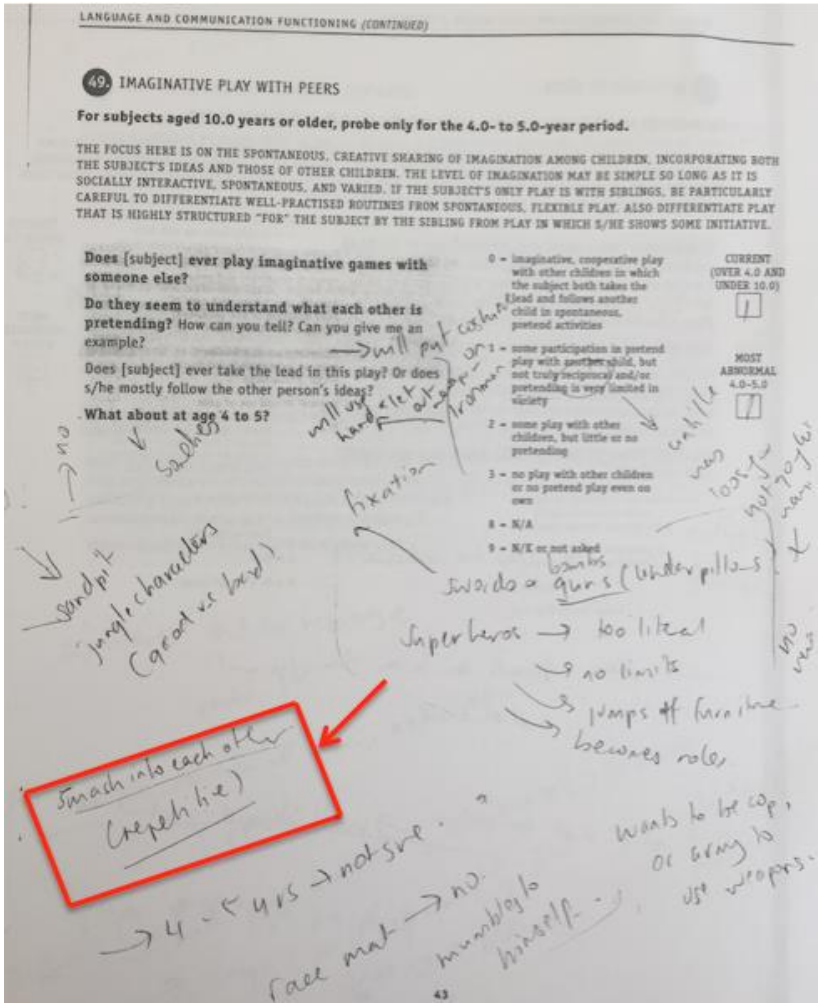
It is clear from the quote, above, that the psychologist, throughout this ADI-R, must make value judgments about which of the parents is providing the reliable source of information. Laura describes her experiences with her son, Patrick, referencing and acting out behaviours that he exhibits (or does not exhibit) based on the question asked by the psychologist. Laura uses specific, concrete examples based on what she has seen her son do. Tom, Patrick's father, on the other hand, makes generalised statements about how all children play and is not able to provide specific experiential examples that the psychologist can record as "data" or "evidence" that can then be used to generate a score.

The psychologist, meanwhile, must take notes about the interaction. Answers generated by the ADI-R questions, and further shaped and amplified by clarifications and corporeal prompts, are "captured and translated into more durable modes of representation such as text" (Gardner & Williams 2015: 9). The psychologist must go through a process of deeming what counts as evidence to be recorded in the ADI-R booklet, determining how to translate complex bodily movements and/or facial expressions, inscribing this in the ADI-R booklet in clear shorthand notes (so that she can later return to the data to verify the scores), and finally, to attribute a number from 0 to 3, based on the inscribed data, to indicate the presence and severity of the symptom.

What is particularly interesting about this example is the way that Laura is able to establish herself as the "reliable" source of information in this interaction through her use of gestures. The psychologist states that the most important part of an autism diagnosis is being clear about "if [the behaviour] *happens*, or if it *doesn't* [*emphasises by tapping edge of hand on table*]" – she even emphasises her point by tapping the table as she says this. As I have stressed throughout this thesis, this is important because all that we really know about autism (in terms of diagnosis) is what can be *seen* and *observed* – that is, behaviours, communication, and social interaction. In Figure 6.4, the red box around the inscription: "smash into each other (repetitive)" on the ADI-R booklet highlights that it is Laura's ability

to act out Patrick's "smashing up" of the cars to indicate repetitive play that provides the psychologist with reliable evidence that can be "counted" by the ADI-R tool.

Figure 6.4: Psychologist's inscriptions on the ADI-R for "Imaginative Play with Peers"



During the reflexive interview, the psychologist also makes an important point about what a parent's corporeal labour means to her, and why she counts it as evidence:

> Psych: And then, with this one, as well, Mum's use of gestures – it was like she was replaying the stuff in her head. So, it was like her way of remembering. That's how I saw it.
>
> Me: Can you talk a bit more about that?
>
> Psych: It shows that she's got more concrete, clear ideas in terms of what [the behaviour] is, but maybe it's hard to put a label to it. I mean, she's not a clinician, so she doesn't know what it is. Umm, so that, for example [*points to paused video on computer screen*] to Stephen's family, where their gestures, when I gave the gestures, they couldn't give [the gestures] back, whereas [Daniel's] Mum was able to give [those gestures] back, so she's a more reliable source.

For the psychologist, Daniel's mum's gestures demonstrate that she is acting out a clear memory of Daniel performing that behaviour – "it was like she was replaying the stuff in her head" – and this performance cements her as a reliable source. This labour performed by Daniel's mum is then transcribed onto the ADI-R scoring booklet and incorporated and counted as evidence towards Daniel's diagnosis of ASD and his ultimate participation in the drug trial.

Most importantly though, this performance or translation of ASD symptoms enables the psychologist to exercise her clinical judgement, her gut feeling, within the diagnostic encounter. In the following exchange, which takes place during the video-reflexive interview, the psychologist reveals the flexibility available to her in the scoring of the ADI-R, and how she uses her clinical instincts to evaluate the evidence (in this case, examples via gestures) presented to her by Stephen's parents, Jenny and Matthew:

Psych: I think, yeh, I think the good thing about the assessment process is, because you're asking so many questions, families start to think about things themselves, and then they start to realise. And, as well, when you go through, again, the autism spectrum, you explain the high functioning… and then they seem a little less resistant, as well. Yeh, this was an interesting family [referring to an ADI-R clip we had just watched of Stephen's parents, Jenny and Matthew]. They changed their answer fifty times! [*smiles*] I think you've got to go by your gut sometimes.

Me: OK, OK. And, what does that entail for you – going by your gut?

Psych: So, for example, with this family, right – they straight away said, "yes" [in response to a question regarding whether Stephen could point out things to the parents using gestures and eye contact], but again, when I started to ask for examples, they couldn't […] So, for example, with this family, you could tell straight away that, like, they didn't really get it. So, because they didn't really get it, and they had no evidence, you could kind of tell that, well, I think he doesn't – because it would be very obvious [if Stephen was able to point things out to his parents using gestures and eye contact]…Yeh, sometimes I think you just have that feeling, like, "Oh, I think they're wrong." But, like I said, at the same time, the ADI-R is very specific, where it's all about evidence to reduce that subjectivity. Sometimes I put a question mark if I'm not sure.

Me: And then, how does that work when you're going back and scoring it if there's a question mark there?

Psych: So, when I score it, like I said, normally, because they're like severity-type levels [holds hands horizontally at different heights to indicate different levels], so if it's there…and then [the ADI-R always specifies], "Is the skill there, but is it limited?" [*emphasises point by tapping open palm with side of hand*]. I normally put that one, or I put "unclear"…you can put one where it's like "unsure" or…

Me: OK, so there's a bit of flexibility within the tool? It's not so definitive – like it has to be yes or no?

Psych: No, no. So there's four [*holds up four fingers*] rating scales – I can't remember off the top of my head, I might be wrong. There's always a zero, a one, a two [*indicates by tapping finger on table for each number as if drawing out a scale*], a three, and then I think four and five are "non-applicable"-type. So you just tick if they've got no language. So, with zero, it's like you're typically functioning […] So that one is always, you know, that's typical, no problems, whatever…number one [*holds up index finger*]

is the one where it is a bit unclear [*holds hands up at chest level, facing palms down, and alternates them up and down*] – so it sounds like he does, but then it sounds like he doesn't – so it's enough to code there [*draws circle with finger on table*], whereas two and three are quite sure…So it's good in that aspect.

Me: So, it gives you a bit of flexibility?

Psych: Yeh, I think so.

Given that Jenny and Andrew were unable to provide clear examples of Stephen exhibiting (or not exhibiting) pointing behaviour, the psychologist uses her clinical instincts – based on this diagnostic interaction with Matthew and Jenny, and a short interaction with Stephen during the WISC-IV, as well as her many years of experience working with children on the Spectrum and their parents – to form a judgement about whether the parents have provided an example that counts as evidence in the ADI-R. From the psychologist's perspective, the ability to produce the examples, and act these out as if replaying a memory, is the key to producing significant, usable evidence: "the ADI-R is very specific, where it's all about evidence to reduce that subjectivity." The psychologist also details the scoring mechanisms the ADI-R tool has in place to account for uncertainty, and the flexibility afforded to her if there is any doubt she may have with regards to scoring.

When language fails us: Using corporeal labour to translate knowledge

A key element in enabling this flexibility in the ADI-R is the way that the psychologist allows and relies upon the body as a vehicle to collaborate, share, negotiate and translate knowledge. Myers' (2015) work is pertinent here, in particular her observation that the protein modellers "do not 'see' molecules or produce 'images' of biological phenomena rather, they *make* models to *render* the molecular world visible, tangible, and workable" (18). Likewise, for the psychologist and parent, they do not "see" or "know" an ASD diagnosis, but rather construct it together via their gestures and actions to render the diagnosis *visible, tangible and workable*. The diagnosis is a "rendering" because it is a representation of ASD, created through the labour performed by the parent and the psychologist during the clinical encounter. This labour is performed through the *lens of the ADI-R*. Just as a scientist looks through a microscope at a cell and manipulates what they see through the application of dyes or adjusting the light source, the ADI-R similarly manipulates and directs the gaze of the psychologist to see autism under certain standardised conditions.

The example transcribed below, which takes place during the ADI-R with Kate, Ian's mother, highlights this rendering process through the overall structure of the ADI-R, and the way that the psychologist and parent work together to frame a response to the question "What kinds of things make Ian happy?" Here we can see Kate's intuitive, or tacit, knowledge about her son Ian's expression of emotions, and how the psychologist helps to draw out a

concrete and clinically relevant example of Ian's display of emotion to count as evidence in the context of the ADI-R. Kate and the psychologist, by working together, are able to render Ian's expression of happiness visible and tangible by conjuring up a memory and acting this out. As a result, an anecdote is produced that can be recorded as evidence on the ADI-R score sheet:

> Psych: What kinds of things make Ian happy?
> Kate: If I buy him a new art book. He likes that. If I buy him art supplies and things like that, that makes him happy. But he doesn't really show it, he'll just go, "thanks mum" [in a monotone]. But I know, I *know* he's happy.
> Psych: So how does he show these feelings? So, you said he says, "thanks mum".
> Kate: Yeh, that's about it, it's like he's embarrassed to show that he's happy. Sometimes I find… I know he was really happy about it, but there was no, like…most people would be like, "Yessss! Thanks Mum!" [excited tone] [*fists clenched impersonating excitement*] But there's none of that with him, it's still always very flat [*gestures with palms flat*].
> Psych: OK, I noticed that yesterday….Does he ever seem to want to share in his enjoyment of something?
> Kate: Oh yeh! …My mum came over this morning…and it was like, "[Grandma] come and have a look at my lizard, come and have a look at my lizard!" So then my mum's there on the floor [*imitates grandma's posture lying on the floor eagerly looking at the lizard*] – my 73 year old mum! – on the floor looking at this lizard [*smiling*]. So yeh, he was very excited [*emphasises with hands splayed out*] and that was *his* way of being excited.

The excerpt from Kate's ADI-R, above, demonstrates another dimension of this concept of corporeal labour: one which privileges parents' knowledge and intuition because they are "experts about their own children". Parents find themselves in a unique position during the ADI-R where they must frequently draw on their intuition and gut feeling about their child, but also translate this gut feeling into something meaningful and reasoned that can be used as evidence by the psychologist. These meaningful examples are built on an accumulation of the unique and privileged knowledge that only a parent can have about their child: their sensitivities to their child's quirky behaviour; an understanding of when, where, why and how these behaviours manifest; and their ability to make judgements and evaluate what constitutes normal behaviour based on their observations of other children. Relevant here is Myers' (2015) observation of the way that protein modellers use their bodies in their work, describing them as being "contoured by a kinaesthetic and affective sensibility" (4). Myers argues that this kinaesthetic and affective sensibility is about feeling and embodying the work, and cannot be learned by consulting books. Likewise for autism diagnosis, the parents are able to embody and perform their children's behaviours because they live with them and experience them on a daily basis. Similarly, clinicians who see autistic children day-to-day in their practice hone a kind of "intuition", a "sense of things" or a "gut feeling" through the quantity of cases they see. So much of what we know about autism is restricted to what we can *see* – behaviours, language, social interaction. Thus, the importance of using the body to translate and explain – for both parents and clinicians – becomes a vital source of communication during the clinical encounter.

A section of the ADI-R involving questions about repetitive behaviours and stereotyped movements of the body holds key relevance to the clinical trial studied for this thesis given the fluoxetine effects are measured based on the presence or absence of these behaviours. Examples of repetitive behaviours and stereotyped movements can include hand-flapping, rocking, eye twitching, lining up toys and so on. However, this section of the ADI-R is also important because my video data shows that this is a key instance where parents rely heavily on corporeal labour to communicate their knowledge. Through their gestures and actions, the parent(s) and psychologist grapple with complex gestures, movements and expressions to render the diagnosis visible, tangible and workable. The four groups of video stills (see Figures 6.5, 6.6, 6.7, and 6.8) from four different ADI-Rs I discuss, below, demonstrate the immense variety as well as complexity of the gestures involved in conveying these behaviours, the full effect of which is hard to convey without seeing the video clips themselves. The images below show that the way that the parents use their hands, faces and bodies to perform their child's unique version of autism, differs profoundly; and yet they all defer to this corporeal labour as their "communicative apparatus" (Gardner & Williams 2015: 2).

For Gil's mother, Sarah, these behaviours take the form of hand movements in front of the eyes, twisting and playing with fingers, placing objects in certain orders and lining objects up, smelling fingers, and hands over ears (see Figure 6.5). For Stephen's mother, Jenny, such repetitive behaviours are evident in the highly symmetrical worlds her son has constructed with Lego, the ordered way in which he plays with his Star Wars characters, and the way he recreates a mental picture that he has in his head through his physical play (See Figure 6.6).

Figure 6.5: Video stills of Sarah demonstrating her son Gil's repetitive behaviours

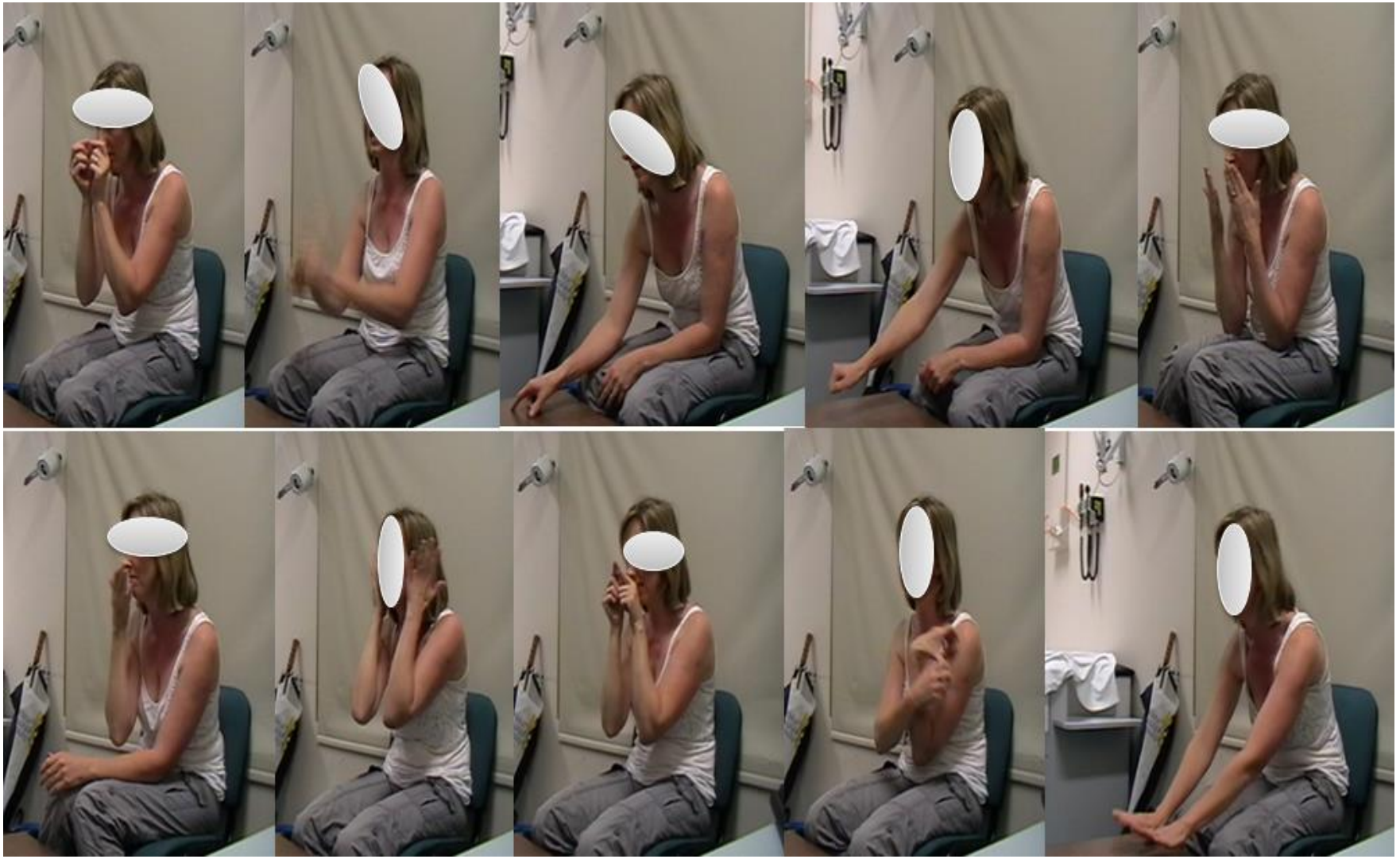


Figure 6.6: Video stills of Jenny demonstrating her son Stephen's repetitive behaviours during the ADI-R

Figure 6.7: Video stills of Hayley demonstrating her son Daniel's repetitive behaviours during the ADI-R

The following extract from Daniel's ADI-R with his mother, Hayley, paired with the video stills (see Figure 6.7), demonstrates the complexity of the verbal and corporeal "evidence" presented by Hayley. The nuances of Daniel's lining-up behaviours would be lost without the accompanying visual clarifications and demonstrations: not only do Hayley's actions generate understanding (Gardner & Williams 2015), she is also rendering these complex symptoms

visible and tangible (Myers 2015), allowing the psychologist to gather evidence, build a representation of autism, and justify the score she ascribes to that section of the ADI-R:

Psych: Did he ever line up things the same way over and over?

Hayley: [*nods emphatically*] *Always*!

Psych: So, what are some examples? I know you said the figurines and cars and stuff…

Hayley: There'd be like, the hot wheels – he'd line them all up [*gestures with fingers indicating a line*]. And then I bought the figurine set of Ickle Pickle and he'd kind of line the up [*gestures as if placing figurines in a row*]. Ummm, even now with the Skylanders, cos he'll put them kind of in order. And with the Lego – he's got a couple of little displays and he'll line them up and he'd always make sure they're in a line and straight [*squints eyes and gestures as if adjusting object to make straight*]. [*Smiles*] And books! Books! [*points at psychologist to emphasise point*] Big thing! Like, they all had to be… [*gestures with both palms flat facing each other*] and if they fell down he'd get the shits and put them back up because he wanted them all straight…in order [*gestures with palms straight, indicating precision*].

Similarly, during David's ADI-R with his mother Abigail, we can see how important the use of hand gestures are in Abigail's account of David's specific way of holding hands with her. Pairing the transcription of this exchange with the video stills (see Figure 6.8) highlights the very precise sequence of movements that David uses to hold hands with Abigail in a particular way:

Psych: Did he ever, umm, show you what he wanted by taking your hand, or your wrist, and using it as a tool…

Abigail: [*nodding*] But he…[*uses hand to demonstrate – interlaces fingers*] when he grabbed my hand it was in a certain way, like, you know, he would never grab me there [*demonstrates by clasping at her wrist*] because we can't, even to this day, grab him by the wrist. He'd like grab…[*holds out hands flat and begins to carefully interlace fingers*] he'd set his hand perfectly into mine [*shows hands clasped together with fingers interlaced*] and it would have to be comfortable, and then drag me along – like, it would have to be…he does it a certain way.

Psych: OK [*writing the entire time, but also looking up to watch Abigail's gestures*]

Figure 6.8: Video stills of Abigail demonstrating her son David's specific way of holding hands during the ADI-R

This translation process through corporeal work is regularly carried out when language and words fail to articulate and capture the complexity of these "autism" behaviours. In fact, I would suggest that this corporeal work is *essential* to the ADI-R's effectiveness as a diagnostic tool, and any diagnostic tool hoping to assess a parent's account of their child's possible autism. Both the psychologist and parents use this visual technique to explain, make sense of, translate and codify knowledge.

Additionally, the other vital factor involved in this corporeal demonstration of the repetitive symptoms of ASD is that, in many cases, these behaviours may be unique, or essentially different, to each child diagnosed with ASD. While the psychologist may be able to group various unique behaviours into a category such as "hand flapping" or "stereotyped movements of the body," the parents may not be able to recognise or identify such categorisations. Thus, the parents' ability to act out these qualitatively different mannerisms, quirks and behaviours, and for the psychologist to then categorise and codify this knowledge, demonstrates the experiential, naturalised and qualitative way in which the two parties generate and formulate the diagnosis together. This would seem to confirm Canguilhem's (1989) argument, discussed in Chapter 5, which posits that disease and disorder cannot be reduced to a quantitative deviation from a statistical norm, but instead must be understood as a qualitative difference based on the patient's value-orientation and experience.

The unique, qualitative dimension of each child's diagnosis with ASD manifests itself in each of the ADI-Rs observed and/or filmed for this thesis. By using video-reflexive ethnography not only to collect data, but also to actually experience the autism diagnostic encounter, alongside the psychologist I was afforded a rare opportunity to witness and articulate the highly qualitative, dynamic, collaborative and corporeal nature of diagnosing autism. Corporeal collaboration involved the psychologist and parent working alongside one another to find a common understanding through synonymous (body)language. The following three examples highlight this collaborative endeavour between parent(s) and psychologist.

In the ADI-R excerpt, below, Laura offers an account of the quirky behaviour of her son Patrick (an eight year old boy who struggles with social interaction and aggression) (see Figure 6.9). Here, Laura struggles to articulate the behaviour she has observed and uses her hands and whole body to perform and try to make sense of it. After going through this process of demonstrating Patrick's behaviour, the psychologist is able to recognise, understand and categorise this behaviour into a broader group of "sensory" ASD symptoms. She goes on to validate and reflect the behaviours Laura mentions by linking them with other "sensory" behaviours she has seen displayed by children diagnosed with ASD:

Laura: It's like he's readjusting [by peering at his hand]. [To dad] Have you noticed it yet?

Tom: [*shakes head*]

Laura: Always! Always, always! [*demonstrates stretching out arm and forming a circle between index finger and thumb, and then peering at the circle out of the corners of eyes*]. And then look away. Sometimes he'll do it when he's talking. He's talking to you and then he goes like that [*demonstrates peering/hand gesture again*] out of the corner of his eye.

Psych: And it's only those two?

Laura: Yeh, it's hard to explain [*demonstrates peering/hand gesture again – as if trying to make sure she has got it right*]. And I tried to film him one day. It's really bizarre what he does, and I think, "What the..?! What are you doing?" [*furrows brow in puzzlement*]. I asked him about it once and he was *so* uncomfortable, so I thought, "I'm leaving that alone!"

Psych: It's a sensory thing that he does. I've had a lot of kids that do it. It's the peering and the way that they position their hand. Some kids it's like this [*peers at flat hand on lap*], some kids it's like that [*hand up to face peering through cracks in fingers*]

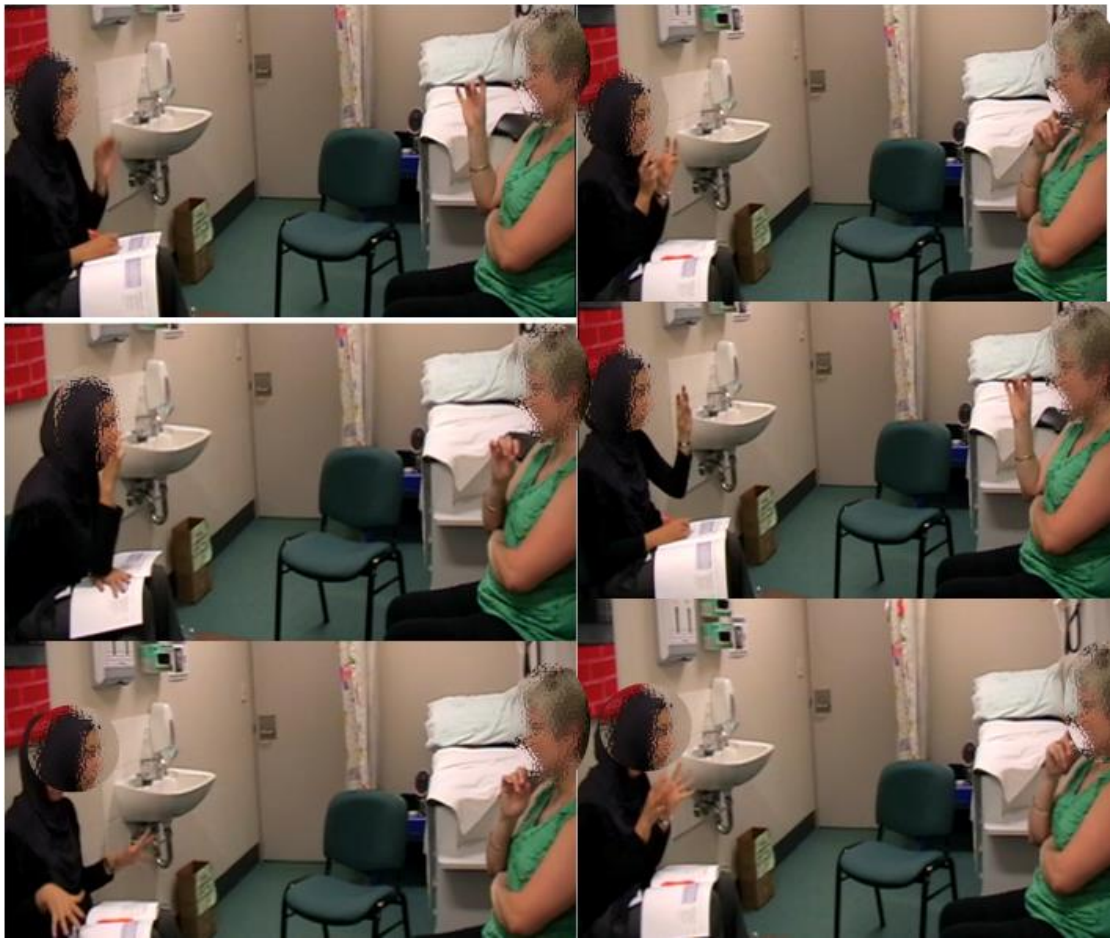
Laura: Yeh, it's like he's looking at his thumb, but he'll put his fingers together.

Psych: Yeh!

Similarly, the interaction conveyed in the Figure 6.10, below, between the psychologist and Leo's mother, Alice, highlights the way that corporeal labour is used by the parent and mimicked by the psychologist so that she can be sure she has understood the parent correctly. Here, Alice is demonstrating a variety of behaviours that Leo exhibits and the psychologist is mirroring these hand gestures to ensure she has interpreted correctly, and then follows up by

Figure 6.9: Video stills of Laura demonstrating her son Patrick's quirky behaviour during the ADI-R

Figure 6.10: Video stills of Alice demonstrating Leo's quirky behaviour and the psychologist mirroring the gestures during the ADI-R



clarifying whether Leo performs other similar gestures (see bottom two images in Figure 6.10). Together, Alice and the psychologist work alongside each other to formulate, translate, and

settle on these ASD symptoms. This collaboration via their gestures and actions "renders" (Myers 2015) the ASD diagnosis visible, tangible and available to be used as evidence.

For Sophie and Stewart, parents of Rupert – an 11 year old who was diagnosed with autism at the age of three and likes to make up rap songs – participating in the ADI-R involved the added challenge of completing the interview in English, their second language. Sophie and Stewart's use of corporeal labour throughout the ADI-R is key to the way they were able to clearly convey their knowledge about Rupert to the psychologist. Through the clarity of their performances they are able to combine language and corporeal labour to successfully translate their knowledge into "evidence" that can be used by the psychologist in the ADI-R format. I will use three forms of data to illustrate how this was achieved when the psychologist asked Sophie and Stewart about whether Rupert had any unusual sensory interests: transcription of the interaction; video stills of Sophie and Stewart's body movements; and an image of the diagnostic tool with the psychologist's notes inscribed. Working alongside each other, both the parents and psychologist are able to collaborate and formulate the diagnosis together.

In the following transcription, the psychologist asks Sophie and Stewart whether Rupert "seems particularly interested in the sight, feel, sound, taste, smell of things or people." Sophie and Stewart answer the question using a combination of language and hand/whole body movements and gestures:

Sophie: I took him back to home and I saw how he…[*demonstrates by raising her hands to her eyes*]

Stewart: [*gesturing towards the blinds in the clinic room*] He saw, like, lines… [*tilts head to the side with arm outstretched, moving head and arm simultaneously as if following an object moving along a straight trajectory*] and goes like that [*whips his head to the side*]

Psych: Ahhh, I know what you mean!

Sophie: [*pointing at the blinds*] This window, now, these lines [*gestures by pointing and drawing a line with her finger in the air*] when he comes, straight away he will: [*tilts her head to the side and then begins rolling head around in circles repetitively whilst looking at the blinds from the corners of her eyes*] look at it this way.

Stewart: He just look and look [*demonstrates by tilting head to the side and looking out of the corners of his eyes*]

Psych: Yeh [*nodding in confirmation*], he's stimming!

Without the transcription of the gestures and bodily movements used by Sophie and Stewart, the reader would have very little insight into what Rupert's "unusual sensory interest" entailed; and likewise if the psychologist was only privy to the words used to describe Rupert's behaviour, she would have little to no understanding either. The video stills reproduced below

(see Figure 6.11), whilst unable to fully capture the in-vivo richness of the video itself, add another layer of insight into the translation of this corporeal knowledge.

Figure 6.11 shows Sophie's use of hand gestures to convey Rupert's focus and attention directed towards the blinds, and the two images at the bottom/middle of Figure 6.11 show the way that Sophie acts out Rupert's head rolling (due to confidentiality, I am required to blur participant's faces so unfortunately the images here are unable to convey the detail in the facial expressions and head movements). Stewart's body and arm movements at the top of Figure 6.11 illustrate his interpretation of Rupert's mannerisms when looking at the light through the blinds.

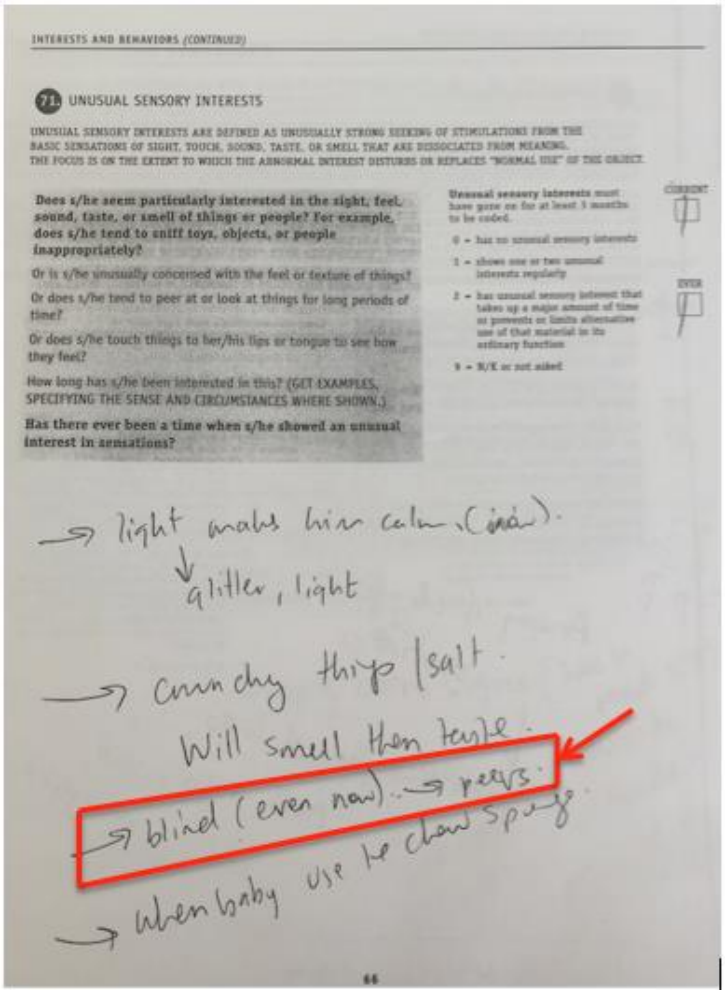
If we return to the transcription of this interaction, we can see that the psychologist displays clear signs that she understands Sophie and Stewart's words and actions. She affirms and acknowledges Stewart's performance: "Ahhh, I know what you mean!" and validates both parent's accounts at the end of their enactment by translating their knowledge into a

Figure 6.11: Video stills of Sophie and Stewart using corporeal labour to explain Rupert's "unusual sensory interest" in light and blinds during the ADI-R

medical/psychological term: "Yeh [*nodding in confirmation*], he's stimming!" By using the term "stimming" the psychologist is referring to a clinical term to describe self-stimulatory behaviour, which involves the repetition of physical movements, sounds, or the repetitive movement of objects. In doing so, she categorises Rupert's behaviours as part of the broader

ASD symptomology. Further, she goes on to record this interaction in the ADI-R booklet (see Figure 6.12), albeit in simplified terms, thus counting this piece of knowledge as "evidence" and a verification of autism.

Figure 6.12: Psychologist's inscriptions in the ADI-R booklet for "Unusual Sensory Interests"



In the video-reflexive interview with the psychologist, I played back various clips from Sophie and Stewart's ADI-R interview, and questioned the psychologist about the difficulties associated with conducting the ADI-R with culturally and linguistically diverse families. In the following excerpt from the video-reflexive interview, the psychologist discusses the strategies that she uses to address this:

Me: How do you deal with, you know, working with families where there is a little bit of a language barrier, or there is a bit of, you know, a lack of understanding – how does that work for you [with] diagnosing and coming to that…

Psych: Usually with families with a language barrier, because they don't understand, umm, often you let them talk first and then you'd ask the same type of question but in a

> different way. Like, for example, it's very clear – there are repetitive behaviours and stimming [*points at computer screen where video has been paused*] – [the parents] don't understand that, they actually don't understand what the concept of autism is. So, just collect the data and then go through [it] with them. So, sometimes I have families like that and I'll say, "Well, actually…we call that sensory stuff, so it just means, you know, impulsivity, and he can't control it, and he enjoys it". And I always give an example, I'll say, "You know how you click a pen [*demonstrates curving fingers around pen and moving thumb up and down rapidly as if clicking the top of a pen*] – it's like that! And he needs to do that". Umm, so with a family like that, I would normally, yeh, break it down. I know the questions are standardised, but, families like that, they don't understand those standardised questions, and they don't even understand - this family specifically – they don't understand what autism is…

Through this response we obtain more insight into Sophie and Stewart's situation, and their limited understanding of and knowledge about ASD. The psychologist emphasises the limitations of language, especially in the form of standardised questions, in this context and the importance of *collecting the data* and *going through it with them*. As the transcribed interaction during the ADI-R, video stills and snapshot of the scored ADI-R booklet show, the data collection process for Sophie and Stewart involves significant collaboration and translation via corporeal labour. The psychologist, in turn, acknowledges and affirms the behaviours during the ADI-R, as well as during the reflexive interview, where she reinforces her translation of the parents' performance of Rupert's behaviours as a display of "repetitive behaviours" or "stimming." She goes on to stress that a part of this collaborative process of "rendering" (Myers 2015) an ASD diagnosis involves reflecting and validating the behaviours described by providing an example and acting this out (in the excerpt above the psychologist demonstrates this by clicking the pen repetitively). Thus, both parents and psychologist have used the same language – performance or corporeal labour – to reach a common understanding in the diagnostic encounter.

Using video as a form of evidence in the ADI-R

The focus of the chapter so far has been on the way that the parents and psychologist use corporeal labour in the negotiated space of the ADI-R diagnostic encounter, and how I have analysed this through my video-reflexive ethnographic work. However, some of the parents that participated in this clinical trial have also engaged in their own video ethnography in their home lives. Recognising that the psychologist will have limited interaction with their child, some parents independently decided to film their children at home when they were displaying some of their puzzling, quirky or difficult-to-explain behaviour.

For example, Sarah, the mother of Gil (a nine year old boy who is quiet and engages in rocking behaviour), brings in a video of Gil rocking (that is, while seated he rocks back and forth) to show the psychologist and help determine if this behaviour is viewed as "repetitive". Similarly, Jenny and Matthew, the parents of Stephen (who is seven years-old and has a diagnosis of Agenesis Corpus Collosum (ACC)), play three separate videos to the psychologist: two demonstrating the intensity of Stephen's tantrums, and the other focusing on his reading ability and a conversation he has with his parents (see Table 6.1 and Figure 6.13). This takes up ten minutes of the nearly three-hour diagnostic session, and prompts some comments, observations and questions from the psychologist that help inform her overall diagnostic opinion of Stephen.

Table 6.1: Transcription of psychologist's comments during video playback during Stephen's ADI-R

Reference in video	**Psychologist comment/question/observation**
Stephen having a meltdown	"You're not even talking to him and he gets quite worked up!"
Stephen having a meltdown	"Did he have a meltdown because he was frustrated?"
Stephen reading	"Can he attend to his work at school?"
Stephen talking about a TV show	"I think he's reciprocating though in that situation. I know it's his own interest, but at least he's able to build on it."
Stephen reading (focus on bodily movements of child)	Psych confirms that the bodily movements are not stereotyped or repetitive according to ADI-R criteria because "they are contained".

When asked about this video in the reflexive interview, the psychologist explained the importance of being able to see a video if she is unable to see the child in the diagnostic encounter:

> Psych: So, I remember I requested [the video]. Yeh, I requested it because I wasn't going to see him, because he had already [done] a WISC assessment. So I wanted to make sure that what they were saying was reliable.

The video, in this case, provides the psychologist with an opportunity to observe Stephen in his home environment engaging in the behaviours that the parents have referenced throughout the ADI-R. Given that the ADI-R is contained within the clinical trial (with strict protocols around which diagnostic tools can be used), the psychologist does not have the opportunity to view Stephen in his everyday environment. The video of Stephen is natural and contextual (Stephen is not aware he is being filmed in the lead up to, and during, a

Figure 6.13: Psychologist, Jenny and Matthew watching videos of Stephen's behaviour

tantrum). The psychologist goes on to clarify the importance of including a naturalised, contextual observation of the child in the diagnostic process:

> Psych: They probably should make video as part of the assessment process. And this is why we use school observations – because you're getting more realistic pictures than what parents report. Like I said, parents could overestimate or underestimate, but when you *see* it...
>
> Psych: Yeh, I think sometimes, I like seeing the child because sometimes I doubt…I don't *doubt* the parents, but like I said, you need more than one source of information. Umm, especially Michael's Mum [Teneale]…she would be one parent – and I had another parent the other day – where I didn't really feel that they understood the ADI-R enough. So, I was really relying on seeing the child. So, when I saw the child – for example, on Monday, I was like, "Oh, he doesn't have autism", and it was just validated…

The video example of Stephen not only highlights some complex behaviours that the parents needed help deciphering, but also demonstrates some strengths Stephen possesses, namely his reading ability and conversational skills. In relation to the video of Stephen's conversation with his parents, the psychologist notes: "I think he's reciprocating though in that situation. I know it's his own interest, but at least he's able to build on it." The psychologist acknowledges the importance of the role video could play in the diagnostic encounter, highlighting that naturalised observations are crucial in a normal clinical diagnosis (as opposed to the diagnosis that takes place in a clinical trial). Given the time and funding constraints of the clinical trial, video could be a valuable addition to ensure some naturalised data is taken into account in the diagnostic encounter.

In the video-reflexive interview, the psychologist reflects on her focus on writing in the scoring booklets during the diagnostic encounter, and feeling like she is missing out on important observational opportunities. She seems disappointed that she was not able to pay more attention to her "clients" and notes the pressure she is under to record the data: "you miss that opportunity" and "it's always about the collation of data." She suggests, in the excerpt below, that perhaps videotaping the diagnostic session (as I have done as part of my research) would be helpful, enabling the clinician to watch and observe more throughout the session itself, instead of focusing on recording the data:

> Psych: [after watching first video] Well! I'm not very tuned-in with some of my clients! I'm just like [*mimes head down and writing – she smiles and laughs while she does this*].
>
> Me: Well, it's interesting because…and that's something as well that struck me, there's obviously a lot of pressure on you…to write all of this and to get it all down…
>
> Psych: …to interpret it…
>
> Me: Yeh! In the ADI-R I find it's not as much of an issue, but in the WISC it's the same thing – you're writing and there's often times where the kids will be doing stuff and…
>
> Psych: You miss that opportunity!
>
> Me: Yeh, yeh, yeh! And that's interesting you've pointed that out yourself. I don't know if you were as aware of that having not seen the video?
>
> Psych: Yeh, you do! It's hard! I try and…with ADOS videos, because you need to watch more, I normally video tape [the diagnostic session], but, we're supposed to write and just do it then. I find it's hard…I do find it hard with some of these families. Like, for example, with Daniel, I knew him – it was easy for me. I was like, "beh beh beh beh beh [*gestures as if robotically writing*], yeh I see that". With the families where I'm not sure, yeh, I try and get more specific examples. But it is hard to write as well. But, in saying that, at the end of the day, it's always about collation of data.

The psychologist's observation demonstrates an implicit value placed upon the qualitative, observational and emotionally nuanced aspects of the diagnosis. The psychologist critiques both the diagnostic tool and her subsequent implementation of it in practice, describing the diagnosis as a *missed opportunity*, and her practice as *not very tuned-in*. Given the pressure to write, observe, analyse, score and demonstrate sensitivity to the parent, videoing the session may allow the psychologist to focus on observing and "tuning-in" during the diagnostic encounter.

"Caring about" and "caring for" (Lappé 2014): the clinical trial as a route to access resources

Early on in my VRE data-gathering and in general observations of, and interactions with the main trial psychologist relates, it became clear how much extra care work, or "off protocol

activities," were carried out between the psychologist and parent(s). This extra care work is a product of the inevitable tension that exists between doing good research and simultaneously delivering patient care within the clinical trial. Chen, Miller and Rosenstein (2003) argue that research and care are in fact very different kinds of activities given that hypothesis-driven research is ostensibly independent of a patient's best interests, whereas care is about treating the individual needs of a patient. Throughout the diagnostic encounter, the psychologist offers each family numerous therapy suggestions, strategies to combat problematic behaviour, and general advice on autism. In addition, there is constant care and advice provided to the child and family with regards to the medication. The family is encouraged to seek extra support and regularly consult with the trial psychologist and paediatrician should they have any concerns about the medication and its effects, even if their concerns relate to their belief that the child is taking the placebo and not coping, and may therefore need to be removed from the trial. An important component of this care work relates to the low socio-economic background of many of the participants in the trial. Consequently, the trial represents not only a means to access medication but also high level of care and resources that may otherwise be unavailable to them.

In order to better understand this notion of care work in the clinical trial I draw on Hochschild's (1983) concept of emotional labour. This involves the cultivation of a deliberate emotional response by (in the case of this thesis) the psychologist in order to interact with patients, as well as repressing unwanted emotions to deliver care. Hochschild (1983) explains that it is the separation of acting or displaying emotion and genuinely feeling emotion – that is, emotive dissonance – that leads to emotional labour. This emotional labour is performed through (Hochschild 1983): (1) Surface acting – shaping how we outwardly appear through body language, facial expressions, posture and sympathetic noises (for example, sighing). In terms of the psychologist and patient, surface acting manifests as expressing empathetic behaviour towards the patient in the absence of consistent emotional and cognitive reactions: the psychologist tries to seem sad, concerned or happy during the diagnostic session. The facial expression/body language/posture and so on are "put on" (23); (2) Deep acting – involves creating "the inner shape of feeling" (22): the psychologist attempts to generate empathy-consistent emotional and cognitive reactions, that is, attempting to actually feel the emotion that they are expected to display. This "conscious mental work" (23) separates the manufactured feeling from their central self; or (3) A combination of both.

The relationship between clinician and patient has long been acknowledged as a vital component of treatment and effective care (see for example, Cassel 1997; Epstein & Hundert 2002; Larson 2003). In this section, I explore the ways that the psychologist performs this emotional labour to cultivate an affective atmosphere within the diagnostic encounter, and

how this in turn produces an affective response in herself, the parents, and the children. I will also explore the strategic motivations behind such an approach which can encourage compliance of participants within the clinical trial.

Jespersen, Bonnelycke and Eriksen's (2013) ethnographic examination of a randomised controlled trial investigating the effects of exercise amongst moderately overweight Danish men raises a key point about the care practices that take place during a clinical trial. They argue that care practices – that is, expert advice, personal and emotional considerations, and encouraging conversations – play a vital role in encouraging and maintaining participation and helping to improve the research process. Jespersen and colleagues (2013), Timmermans (2010) and Mol and colleagues (2010) all emphasise that it is this practical and emotional work that enables the production of the scientific data, and, in fact, that this emotional labour could be considered inherent to clinical trial work. But perhaps most importantly, "these heterogeneous, messy and dirty practices are washed away in the abstractions and purifications that are necessary to produce scientific results." (Jespersen et al 2013: 658).

For Jespersen and colleagues (2013), this care work is often strategic. For instance, they draw on examples from their ethnographic observations of men participating in exercise tasks in which they are encouraged with motivational cheering from the scientific staff. This care, via praise and applause, is seen to not only motivate participants to continue exercising, but also to "secure their compliance" (Jespersen et al 664). Likewise in the WISC-IV sessions with the children, the psychologist often encourages and reinforces through verbal praise, and in one session, even rewards a child's compliant behaviour with an electronic toy provided earlier by the parent.

Lappé (2014) argues that, "research and care become intimately intertwined and mutually constructed during the research process" (304). This *caring for* the child and parents takes the form of "another set of eyes" (Lappé 2014: 311) directed towards the child. Specifically, in this fluoxetine trial, this takes shape through the extra work performed by the psychologist. The following excerpts from the diagnostic interview with Laura and Tom, Patrick's parents, illustrate a common occurrence throughout each diagnostic session that I observed:

> Psych: I'm just going to suggest, to help him – because he's starting a new school, and you want him to start off well – I mean…with kids on the Spectrum, it's all about tweaking stuff. So, for him, you know, you say something, then you give it to him, and so he understands the system. But, what about having it visualised as well. So, you know, going back to basics, you know how they have the "tick chart" or a jar where he gets tokens and he puts them in? But for Patrick, because he can't regulate himself, coming up with goals for him…so for example, if you say, "If this person swears/says a bad word at you, you did …." And

then you have a solution for him, and if he does that, then he gets a tick, then it goes in the jar, and then however many things he gets in the jar, he gets a reward. Just so that way, he's starting to use the stuff he's been taught. Because he's got a lot of tools from what it sounds like.

Laura: He just doesn't know when and how to use them.

Psych: Exactly!

Psych: That's something…I mean, he doesn't have an anxiety specifically, but because he's a very anxious child and very inflexible, there's a program that a lot of psychologists use, it's called "Cool Kids" – it's for kids on the Spectrum (they've made one specifically). So, if you want to have a look into it, it's at Macquarie Uni, and they run it really cheaply. I mean, they'll screen first to see if he is suitable for the program, but I think it might be something to look into.

Psych: So he needs to have like, a manual.

Laura: Yeah, I like that! We're going to do that. I'm going to get him to help me write it – all the pictures and stuff.

Psych: You know what you do: take photos of him, put it in a PowerPoint, and then print them out. Kids love it!

Laura: Yeah, I think it's a great concept! And I'm going to get him to keep it with him all the time.

Psych: Yeah, yeah. Get him to keep it in his bag, call it "What to do when Patrick gets angry".

In the video-reflexive interviews with the psychologist, I asked what motivated her to provide this extra care for families:

Psych: I think families need to know that it's not such a bad thing…like [getting a diagnosis of ASD] is not the be all and end all. There's always ways to help these children and I think the problem is that there are services out there that, I guess, oversell when they shouldn't be, and some of these families just need some basic strategies. And, not only that, they are coming into this trial, they are so desperate [for help] – they're at the point where they need to try medical intervention [medication], and behavioural medications [like Fluoxetine] still *do* work. Yeh, it helps [the family] and I think having the experience, like doing both [diagnosis and treatment] – because some clinicians only do the diagnostic stuff – when you do the assessment *and* the intervention, I think you can connect it a little bit more. So, with the families, when you've got that example [of a strategy the family can use to target a difficult behaviour] there you realise it helps them understand what they can do. Yeh, I do that a lot [in the trial diagnostic sessions] [laughs] – I go off topic!

Throughout each interview, the psychologist consistently offers helpful tips and guidance to families based on her years' of experience working as a therapist for children with autism. She often veers away from the standardised format of the very long (three hour) diagnostic interview to make sure she is able to include information on treatment strategies that the

family has, in most cases, never heard of. For example, in the case of Stephen who has problems with social interactions with his peers during play dates, the psychologist recommends that his parents, Jenny and Matthew, try implementing a schedule or plan before the friend comes over for the play date:

> Psych: Just a little bit off topic, while we're on the subject of friends: when he has friends over, it's a good idea to set the routine up before they come over, so you have a plan. So then you write down a schedule of what he should do. Maybe, "10 o'clock play blocks or Lego…" just so that he knows how to set up the play and maintain that for a decent period of time, because he struggles with that [side of] friendship.
>
> Jenny: That sounds really good.
>
> Matthew: It's weird because he'll sit and play with Lego, but his friend wants to play with the computer game, so he'll play that for 5 to 10 minutes, but then he's like, "Oh, I want to go back and play with the Lego."

Similarly, in the diagnostic interview with David's mother, Abigail, this care work comes in the form of the psychologist expressing concern over the way that David's school is dealing with him in the classroom. During the interview, Abigail provides many examples of problems that David has experienced, and relays her frustrations, anxieties and sense of powerlessness. In response, the psychologist offers advice as well as *action* on her part:

> Psych: With the [diagnostic] report, I'll do it as fast as I can, but I can write down, "he does need more support", and "we saw from our interview that once you establish some routine with him, he's able to respond and learn". And I think *they* need that as well, so if we've signed off on it, they can see that it's not just you, that you've got clinical support that's saying: "this is what this child needs". So hopefully that might help a little bit as well.

In the video-reflexive interview, the psychologist talks about this care work as being part of her "ethical practice" and stresses that ultimately this trial involves the mental health of the patient. She talks about the sensitive and patient-centred work that is important to her practice as a psychologist:

> Psych: That's part of our ethical…I mean, it's common sense! It should be part of your ethical practice, like it should be part of your ethics, or whatever you want to call it! Yeh, it should be part of your practice because psychology is very sensitive – it's about the *patient*. So, I think it's a little bit different to medicine, because [with] medicine we're focusing on that biological component, and I mean, you do your follow-up and that's it! Whereas this [trial], it's mental health, the mental health of the patient…It's more like: there's a problem, and there are strategies to manage these problems – "this is what I need to do". It's the same as medicine – you need stitches to stitch up a wound [mimes stitching with needle and thread]. In psychology, you need to give families strategies to help them manage their [children's] behaviours, their problems, or whatever it is.

This *caring for* the child and family also manifests in the *free* provision of psychological and medical diagnostic and treatment services. Many of the families participating in this trial are from a low socioeconomic background, and have limited access to care and services, particularly given the intensive treatment schedule demanded by autism therapies such as applied behavioural analysis (ABA). Trial staff consistently fielded emails and phone calls from the parents of participants that required help and support that went outside of the trial protocol parameters. These extra consultations may involve asking the psychologist for their advice on therapies, to discuss other medications that may be helpful for the child, or even simply to "vent" to the psychologist about a particularly bad day that the child had at school. Lappé (2014) demonstrates that this *caring for* attitude of autism research is perhaps more common than we might think:

> The relationship built into the conduct of the research do more than just satisfy the methodological needs of the study. In a changing ethical and societal environment, they actively create science as a particular route for assessing resources that may not otherwise be available to families. (312)

In the video-reflexive interview, the psychologist makes an important point about the importance of being a clinician that is involved in working with children with ASD in both a diagnostic and treatment capacity, and using this experience and knowledge within her role as diagnosing clinician in the clinical trial. The psychologist makes an important distinction between "clinicians" (those that practice outside of the clinical trial) and "researchers" (those that work within the research space of the clinical trial):

> Psych: The trial's an opportunity for [the family]. I mean, it's not *supposed* to be, but it's a way to help them. And, I mean, trials are hard because the risk is you'll be on placebo – and that's that ethical dilemma. But, the good thing about the trial is, because we're clinicians on the trial, I think it makes it a bit easier – it's not *easy* – but I think we have more of an understanding of when [the children] have to be pulled out. Whereas – and this is where I find for researchers it's a bit difficult… - if you're not a clinician, I don't think you *get it*. Because, it's not the numbers, it's: "this isn't working for this child, we need to do something else, it's not *practical*, we've got enough data". Whereas a statistician: "No, because you haven't reached the full twenty-two weeks [set out in the guidelines of the Fluoxetine trial], we're not going to have the statistical power that needs to be reached, blah, blah, blah. They can only be withdrawn if X, Y, Z". It's not as concrete as that, it's not black and white! The clinical stuff is *grey*! [laughs]

Thus, for the psychologist, the trial protocol and the clinical trial itself are malleable entities that are able to incorporate affect, caring, and individualised approaches into their apparent "rigid" and "scientific" structure. For the psychologist, duty of care and what is best for the child can override the strict parameters of the clinical trial.

As Jespersen et al (2013) point out, “Interfering elements, such as emotions, actors and practicalities, are not just obstacles that are later removed, but also allies and resources that are drawn upon while engaging in the [trial]” (666). Thus, the emotional labour that the psychologist employs throughout the trial in both the WISC-IV and ADI-R sessions is crucial to the data gathering and overall success of this clinical trial.

Conclusion

This chapter has examined the key ways that the psychologist, parents, and children are involved in the construction and formulation of an ASD diagnosis. In the clinical trial studied for this thesis, it is clear that diagnosis is reached through a complex process of negotiating, shaping, ordering, matching, observing and coding. Techniques used by clinicians to achieve diagnosis include tinkering with standardised tools, corporeal labour, and balancing the tension between quantitative and qualitative approaches to diagnosis. Canguilhem’s (1989) work is used throughout this thesis to demonstrate a tension that exists in this clinical trial between science in theory and science in practice. As I have argued, the ever-looming presence of the scientific ideal of the gold-standard randomised controlled trial – with its foundations in quantitative theory and statistical methods – is always seen as the ultimate goal for this clinical trial. The outputs of the study – the protocols, the publications and reports, and the statistical data generated – will always need to somehow fit this quantitative paradigm, whereby disorder is understood as a quantitative deviation from a statistical norm. However, it is behind the scenes that the *real* labour of the clinical trial occurs. This labour generates data through participants’ value-orientation, their experiences, stories, corporeal labour, translation of knowledge about their child, and their negotiation within the clinical encounter with the psychologist, and the diagnostic tool itself. This work is above all unique and *qualitative*. It is the job of psychologists involved in the diagnostic encounter to filter, translate, categorise, codify and quantify this complex, inter-subjective, experiential knowledge to fit with the clinical trial agenda which views disorder as a quantitative deviation from a statistical norm.

Significantly, the ADI-R diagnostic tool is described as an *assessment* tool, and for many, this denotes traditional medical or clinical hierarchical relationships of the doctor and the patient, or the scientist and the clinical trial participant. However, if we examine the meaning of this term further, the root of the word assessment is from the Latin word *assidere*, which means, “to sit beside” (Stefanakis 2002). The data from my observations and filming of the ADI-R overwhelmingly supports this notion that the ASD diagnostic process is reliant on collaboration between the psychologist and parent, achieved through shared and negotiated corporeal labour.

CONCLUSION

Rethinking autism diagnosis through an "alongsider" approach

The value-laden and qualitative practice of autism diagnosis

This thesis has focused on the quandary facing clinicians and researchers involved in diagnosing and defining autism spectrum disorders in the clinic, the clinical trial and in research more generally. Clinicians must follow strict protocols, guidelines and standardised tools that dictate the questions to ask, how they should be asked, the order in which they should be asked, how they should react to the answers, what information they need to record, and the form in which these answers should be recorded. Or so medicine would have us believe.

It is clear from the video data gathered for this thesis, and the subsequent analysis of this data alongside the clinical trial psychologist, that autism diagnostic practices are far from neat, objective, certain or ordered. Yet, assessment tools used in the autism diagnostic session continue to reduce differences between individuals labelled with autism and those classed as neurotypical ("normal") to a quantitative deviation from a fixed norm (that is, a number, code or score). Throughout this thesis I provide insight into what diagnosing autism as part of a clinical trial looks like in practice: the reframing of autism as a disorder firmly located in the brain; the complexities of the clinician-parent-pharma alliance; the constant clinical struggle of following the assessment tool or deviating from it to obtain useful data; the corporeal labour carried out by both parent and clinician to convey and translate complex behaviours; and the emotional labour and care work carried out by the trial clinician. Using VRE has allowed me to engage with this qualitative, nuanced, messy and complex view of autism and the diagnostic practice that goes with it. Rather than offer solutions or ways to counteract this mess, I seek to show, following Canguilhem (1989), that it is this qualitative diagnostic work that provides a more candid and authentic account of the lived experience of autism and what real diagnostic practices entail.

However, this thesis does not wish to discount or dismiss the contribution of these standardised approaches in diagnosis, and indeed recognises that these tools have a role to play. The clinical trial diagnostic encounter frequently engages with these two, at times, conflicting discourses of (1) the positivist view of health – focusing on objectifying and standardising autism diagnosis; and (2) Canguilhem's (1989) qualitative conception of health – focusing on how a patient feels and what they individually experience as health and illness. As I

have discussed in both Chapters One and Two, clinicians acknowledge that this qualitative approach to autism diagnosis in both the clinic and clinical trial is an inevitable part of their practice given the heterogeneous nature of autism: it is about doing the "doable job" (Lenne and Waldby 2011).

However, evidence, standards, guidelines, tools and "medical treatments" (namely medications such as fluoxetine) are ever-present in the clinical encounter, looming in the background as an undeniable presence and in some way contributing to the formalisation of clinical behaviours and research practices. Importantly, this formalised structure has its foundations in the classificatory drive that emerged in the early twentieth century in Australia and the rest of the world, and has persisted across many significant diagnostic revolutions (such as the introduction of the DSM and subsequent revisions). The much maligned eugenics movement also played a key part in cementing the role of this overarching classificatory and statistically, "science"-focused hierarchy. Today, we can still see the connections between what were and are considered "problem populations" (then, the feebleminded, and today, those individuals diagnosed with autism) and the need for "social control" (then, institutionalisation, and today, medicating using SSRI drugs such as fluoxetine to manage repetitive ("difficult") behaviours). This is not to say that these diagnostic tools and guidelines play a necessarily domineering role in the clinical encounter today, but I do seek to show that they are a factor in diagnostically shaping and driving the moving target of autism. This is characterised by different impairments and strengths of autism reported across particular contexts and participants. My discussion of the classification of deviance in the early twentieth century in Australia highlights that this category, throughout history, experienced many ebbs and flows, and the individuals labelled as "deviant," "feebleminded," "mad," "mentally defective" and so on experienced changing fortunes as these categories shifted and were redefined. Significantly, while diagnostic decisions were perhaps simplified in the early twentieth century in terms of whether an individual was institutionalised or not, as I discuss in Chapter One, the stability of these categories was still highly scrutinised. For example, it was the "higher-functioning" classifications that were the most difficult to assess, which presented problems from the point of view of eugenics, because the "feeble-minded" could slip between the diagnostic cracks and thus avoid the scrutiny and gaze of the state. Classificatory practices have made the surveillance of children a priority, and we can directly trace the current fervour to use assessments, checklists and intelligence tests – not just in relation to children's health, but also in education and social interactions – back to this period when the application of IQ tests within schools was perceived as allowing the success of eugenic reforms.

This thesis argues that current medical protocols and guidelines hold up this positivist, objective view of diagnosis via standardised tools as the gold standard of practice. Yet, when we observe

clinicians *doing* this diagnostic work and talk to them about the diagnostic encounter, we see that there is constant negotiation between the quantitative approach – and the very obvious critique and scepticism that clinicians seem to have about the arbitrariness and flaws built into these standardised documents – and the more nuanced, creative and "gut feel" of the qualitative approach. While this thesis often sets up a dichotomy between the qualitative and quantitative approaches, the VRE data also provides some initial insights into the subtleties and strangeness of these diagnostic tools that warrants further investigation. However, the focus of this conclusion is on the utility and value of qualitative data in the diagnostic session. Later in this chapter, I will argue that when this diagnostic information is used appropriately, it can provide a more holistic and nuanced assessment of the child and their abilities.

The mechanisms involved in diagnosing autism in practice

This notion of what "should be done" according to the rules and protocols of the clinical trial, compared with the practical reality of the diagnostic session, is one of the key themes the clinical trial psychologist returns to in the reflexive interviews conducted for this thesis. In each diagnostic session the psychologist is required to follow the standardised diagnostic tool. However, she is also required to gather detailed information about the child's repetitive behaviours and restricted interests in order to test the medication's efficacy. To do so, she must, at times, creatively move outside of the confines of the tool to gather this data. This is particularly evident in the way that the psychologist draws information from the parents in the ADI-R by using her body to act out behaviours, and encouraging the parents to do so too, allowing them to communicate by way of this common corporeal language. This clinical creativity is quite different to the rigidness of the WIC-IV session with the children, where what the clinician and children say is more tightly controlled, and what counts as evidence is narrower and more prescribed.

It is the constant clinical interplay, negotiation, and compromise between standardised tools, the reality of diagnostic practice, and the relentlessly changing conceptions and definitions of what autism is that drove my reflexive interview sessions with the clinical trial psychologist. Trying to grapple with these seemingly disparate concepts, which each playing a role in directing the autism diagnostic encounter, was a major theme in our discussions. In observing her diagnostic practices during the clinical trial and in our reflexive interviews, the psychologist actively tries to balance and negotiate a diagnostic process that allows all three of these elements to work together.

In Figure 7.1, below, I seek to represent this diagnostic approach through three separate machinery cogs, constantly in motion, working together to drive the autism diagnostic process.

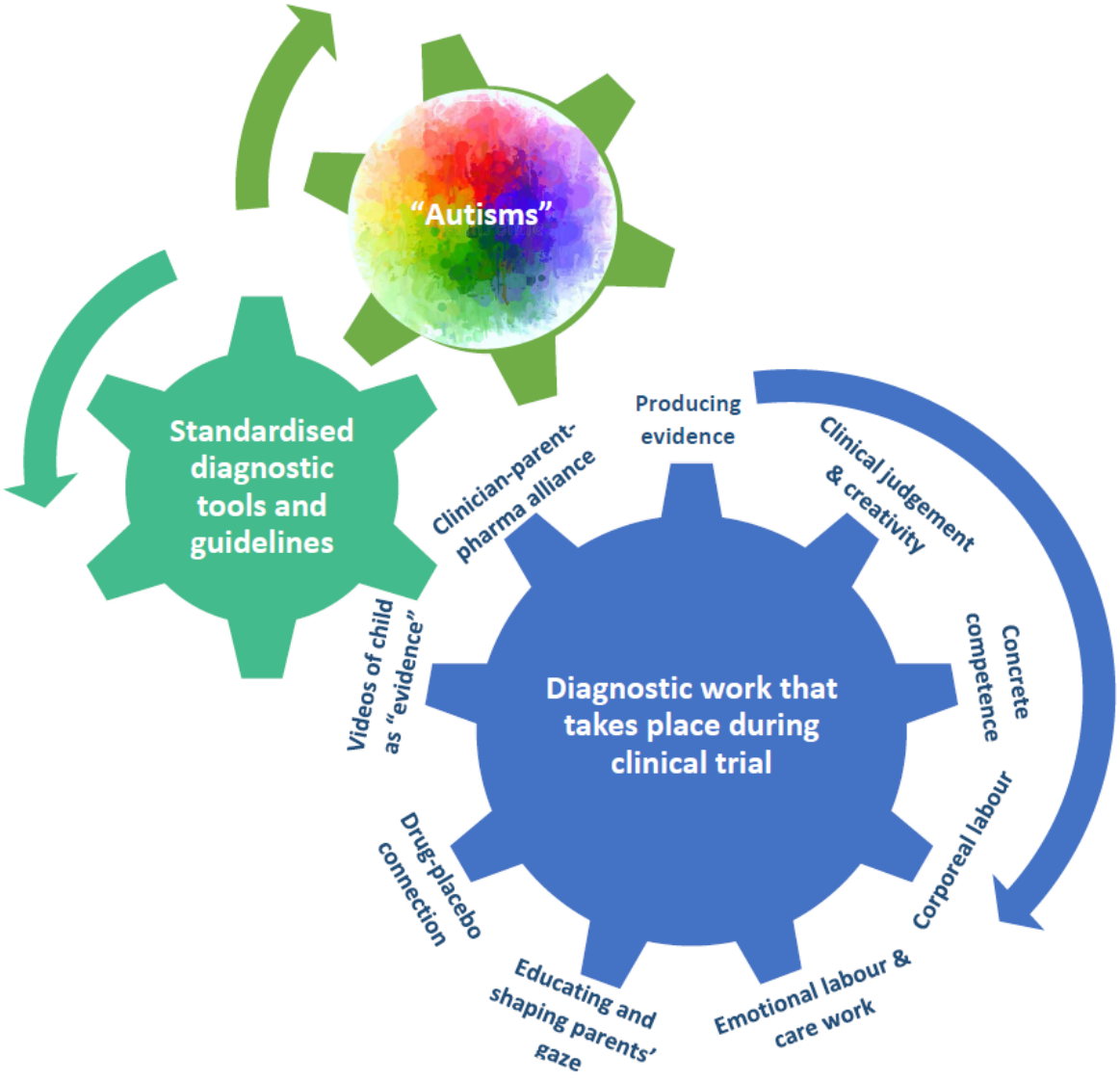
If one cog stops working, the process breaks down. The blue cog represents the qualitative, nuanced and creative diagnostic work that I have documented in Chapters Four, Five and Six. This work acknowledges and embraces the complex and messy aspects of autism diagnosis in the clinical trial. This approach privileges: the emotion and care work involved in autism diagnosis; the need to rethink diagnosis to focus on the strengths and abilities of the child; the ability to convey complex clinical ideas using our bodies; the complex alliances and relationships that evolve in the clinical encounter; and the various ways clinical creativity can be used to produce "evidence".

However, this qualitative diagnostic work does not function in isolation, but interacts with and is driven by the quantitative-based standardised tools (green cog, Figure 7.1[14]) that seem to hem-in the diagnostic process. These documents not only drive the decisions behind what data is collected in the clinical trial, but also (unofficially) shape the way that clinicians engage in these creative diagnostic practices given that they are still required to produce evidence that fits within the accepted clinical trial paradigm. The standardised tools provide a structure and framework to the diagnostic session: clinical tasks and questions that have been researched, tested and validated within the epidemiological paradigm.

Furthermore, these messy and qualitative diagnostic practices that act upon the protocols and tools, and vice versa, also feed into, and act as influencers on, what Singh (2015) terms "multiple autisms" or alternatively, what Hacking (2006) describes as the "moving target" of autism. This final multi-coloured cog (see Figure 7.1) represents the open-ended and uncertain nature of this diagnostic category: what this category has been, and what it will become, remains an open black box. The uncertainty surrounding the category of autism is constantly present during the diagnostic and reflexive sessions filmed for this thesis. Parents were often confused about the changing labels associated with autism, why their child had not been diagnosed sooner, how and why the medication being tested for the clinical trial would help a child with autism, and what the shift from the DSM-IV-TR to the DSM-5 would mean for their child's diagnosis. This in turn meant that the clinician was also grappling with and trying to provide answers to these complex questions during the ADI-R with the parent(s). For example, within the same diagnostic session the psychologist would often use definitive neurological explanations of autism when asked about the medication, framing autism as an "anxious brain" disorder; yet later in the session, she would talk about the heterogeneous nature of autism and how the criteria are constantly changing.

[14] This diagram is intended to be interpreted as a visual conceptualisation of the diverse findings of chapters four through six. I do not wish the diagram to be read as an attempt to impose order on the diagnostic mess that I focus on and reveal throughout this thesis, it simply represents a way of demonstrating the dynamic and constantly moving diagnostic work that goes on in practice according to my VRE data.

Figure 7.1: The dynamic process of diagnostic work in practice during the clinical trial and its impact on standardised diagnostic documents and criteria



In Chapter Four, I consider the differences between autism that is diagnosed in the clinic and the autism that is diagnosed within the clinical trial. Participation in this clinical trial is linked to what Mol (2002) describes as multiple ontologies, "Different enactments of a disease entail different ontologies. They each *do* the body differently" (176). We can see that through the treatment of autism with medications (such as SSRIs, stimulants and antipsychotics) the classification of autism is reframed. Inevitably, this trial promotes a particular enactment of autism (that is, as treatable with the SSRI Fluoxetine), which produces a corresponding ontology (that is, autism is shaped as a disorder of the brain and seen through the lens of anxiety, as

indicated by the child's manifestation of repetitive behaviours). This process of fostering and promoting the image of the "anxious autistic brain" (multi-coloured cog) is exemplified in Figure 7.1, above. A key section of the ADI-R involves questions about repetitive behaviours and stereotyped movements of the body, and therefore this becomes a significant component of this diagnostic session within this clinical trial. Obtaining this data involves gathering complex clinical evidence from the parent through corporeal labour (blue cog, Figure 7.1) and then shaping and translating this data to fit within the ADI-R (green cog, Figure 7.1). In the context of this clinical trial, the focus of the ADI-R is not only to determine whether the child meets the cut-off scores for autism diagnosis, but also, whether and to what extent these repetitive behaviours and stereotyped movements are exhibited by the child. This is crucial given that a decrease in these behaviours is the only measure of the medication's effectiveness.

The VRE approach allowed me to focus on the active and dynamic forms of knowledge production that went on within the clinical trial. New ontologies are linked to the ways in which autism itself is enacted. In the context of the clinical trial, autism is enacted as: a "treatable anxious brain" where autism is reframed and reconceptualised (almost too deliberately) with the drug fluoxetine, repetitive and stereotyped behaviours, and anxiety (Chapter Four); a disorder to be standardised, with the prime aim of delineating what counts as normal and pathological, at the cost of discounting the lived experience of health (Chapter Five); and "corporeal labour" that can be translated into "clinical evidence" (Chapter Six).

The intention here is not to suggest that there is a "correct" or "incorrect" way to diagnose autism. Instead, I would like to highlight to the reader the complex ways that different knowledges and competing priorities must be negotiated and ultimately work alongside each other to reach a diagnostic decision. This is truly a remarkable achievement and demonstrates the immense amount of clinical labour, on the part of both clinicians and the trial participants, that goes into producing this data.

There are three key ideas that I would like to leave with the reader, which seek to build on my exploration of the autism diagnostic encounter in the clinical trial. First, future research in this field needs to consider the vital role that VRE plays in capturing rich, candid and dynamic data that is produced and analysed alongside and in consultation with the patients, families and clinicians involved in the research. Second, I consider the importance of shifting autism diagnostic emphasis to an approach that includes the child's voice in a more meaningful and non-standardised way. By drawing on my review of the historical literature in Chapter One and the contemporary landscape of autism diagnosis and definition as it stands today, I argue that this approach is key to providing a more holistic and meaningful diagnostic experience. The third area for development in this research involves viewing medical and psychological

assessment and diagnosis as an opportunity to embrace an "alongsider" (Carroll 2009) approach. This alongsider approach focuses on clinician, researcher and patient working collaboratively and sharing their expertise to strengthen or improve the clinical encounter. The data collected for this thesis demonstrates the potential to incorporate a qualitative, candid and collaborative approach during the diagnosis of autism. This is evidenced by the trial clinician switching between "assessor" and "alongsider" approaches during the diagnostic sessions and contrasting the different information gathered from the children and parents under these distinct styles.

The clinical trial in action: a dynamic and negotiable space explored through VRE

During my time as an ethnographer observing, filming and participating in the clinical trial, it was clear that this clinical domain was in fact an alive and negotiable space. Importantly, VRE brings forth and makes visible ideas that may otherwise have remained hidden and tacit components of practice if another methodology were used. This thesis demonstrates that the clinical trial and its processes are both influenced by, and influencers on, real clinical practices. This leads to reshaping clinical gazes, diagnostic behaviours, ways that data is collected, and how findings are produced. However, it is only through the methodology of VRE and its emphasis on rapport-building through ethnographic practice, visual recording of data, and engaging clinicians in reflexive viewings of their videoed practice, that these complex and nuanced clinical practices are revealed. In this way, VRE holds value for future explorations of clinical practices relating to diagnosis, treatment and research of autism.

As Chapters One and Two demonstrate, a large body of literature already exists documenting clinicians' attitudes (usually through interviews or surveys) towards EBM and standardised tools and their use in practice. These studies report what clinicians choose to share, and what is most meaningful to them in this clinical setting. VRE offers a richer account of this issue: it allows the researcher to embed themselves in the clinical situation as an outsider and familiarise themselves with this new environment, simultaneously building rapport with the clinicians around them; it provides a visual record that can later be played-back and watched repeatedly for analysis; it reveals tacit, ritualistic, and unspoken practices that may seem mundane or insignificant to those that perform them every day, but may in fact be the key to gaining insight into complex clinical problems; it offers an opportunity to make sense of and analyse the visual data alongside the participants involved in the research in a collaborative reflexive process; and it provides the impetus for practice change to occur because the participants are given the opportunity "to articulate changes to better suit their contexts and purposes" (Iedema 2014: 196).

Given this VRE research was embedded within a clinical trial, and clinical trials are governed by strict protocols and rules regulating their practices, achieving practice change was beyond the scope of this study. However, this is an important element in the VRE methodology (Iedema et al 2013) and warrants discussion as to how it could play a role in future sociological investigations of autism clinical practices. In Chapter Three, I discuss how VRE is used in hospital settings to enact practice change: for example, to strengthen health professionals' infection control and limit hospital-acquired infection and improve quality of care for end of life patients (see Collier & Wyer 2016). By including the practitioner and patient in the research process, and in subsequent self-reflection and collaboration, VRE enables clinicians to identify changes in their practice that can be tailored to their circumstances and needs. VRE is above all a *collaborative approach*: where the researcher, clinician and patient come together to negotiate what issues are important, what data to collect, how to collect this data, and how to use the data (Iedema 2014). The people involved in the research care about its process because "they have been given a stake in it and its outcomes" (Iedema 2014: 197). In the following section I will explore this notion of enacting change through VRE within the context of autism diagnosis.

Including the child's voice in a more meaningful and non-standardised way

This thesis, and other emerging sociological research interested in autism diagnosis and treatment (see Fitzgerald 2014; Hollin 2013) has identified a clinical creativity that exists alongside the standardised approaches upheld by medicine as the "gold standard" in clinical practices. This research shows that clinicians are already well aware of the messiness of the autism diagnostic process and are developing their own informal techniques to work around and on the margins of the clinical diagnostic "gold standard" tools. What needs to be addressed here is the organisational and institutional drive of the fields of medicine and psychology to oversee and regulate autism diagnosis through standardised tools.

As I have outlined in Chapter One of this thesis, the fields of psychology and medicine are inextricably intertwined with standardisation and EBM. Since the early twentieth century in Australia, standardised tools have been used to classify children with developmental delay. Over the past 120 years, this process has become far more formalised, with many more diagnostic labels available to diagnose children that were, back then, simply identified as "mentally deficient." This pursuance of standardised practices has persisted, over time, despite the enduring mystery and messiness surrounding the etiology and causes of autism. In view of this power, and the awareness amongst clinicians of what clinical practice actually entails, it appears that what is needed to effect change in autism diagnostic practices is organisational

and institutional change. It would be open to future researchers and policymakers to encourage a formalised and more widespread adoption of qualitative, candid and socially nuanced approaches within the existing standardised autism diagnostic framework.

As I have already argued in this chapter, this approach does not seek to dismiss or discount standardised approaches. Figure 7.1 clearly illustrates the important role that these tools and guidelines play in allowing the process of autism diagnosis to unfold. Instead, I suggest that based on the VRE data gathered in this thesis, this practice change could take the shape of: incorporating elements of a strength-based assessment for children undergoing an autism diagnosis (as discussed in Chapter Five in relation to "concrete competencies"); including the child's voice in a more meaningful and non-standardised way, especially within the context of clinical trial research (as discussed in Chapter Five); and acknowledging the importance of corporeal and emotional labour in forming an autism diagnosis (as explored in Chapter Six).

Demonstrating the usefulness and value of these qualitative approaches could ideally be achieved using the VRE methodology in further research, clinical trial and clinic settings. For example, in Chapter Five I discuss the way that the psychologist uses the WISC-IV in a highly structured and restrictive way that omits the child's strengths and emphasises the child's cognitive "deficits." I reflect on the way that this tool narrows the clinician's gaze to focus on and look for these deficits, rather than seeing the interaction with the child as an opportunity to gather information on other more complex and nuanced behaviours and abilities. I use numerous examples from the filmed WISC-IV sessions to document these overlooked competencies, and draw on some key statements made by the psychologist in the reflexive interview where these video clips were played back. The psychologist acknowledges in these interchanges that valuable information about the child is lost and concedes that this is a "shame," and yet she must reconcile this with the clinical trial directive of following the strict protocol. Crucially, it was only through the VRE process of embedding myself within the clinical trial and observing many WISC-IV sessions, watching these videos repeatedly to begin the analysis process and selecting clips to play back in the reflexive interview, and then discussing and analysing these video clips alongside the psychologist that this finding was revealed.

The challenge for future researchers, and indeed the institution of medicine, is to extend the diagnostic gaze, and reimagine the diagnostic process to formally acknowledge the value of both qualitative and quantitative conceptions of autism. As Michael McDowell (2017) points out in his recent article in *The Conversation*:

> Rather than striving to secure diagnostic precision in the complexity and imprecision of the real world, a more salient question is how best to help children when diagnostic uncertainty is unavoidable… consider two children almost identical in need. One just gets over the diagnostic

> threshold, the other not. This may be acceptable for academic studies, but it's not acceptable in community practice. An arbitrary diagnostic boundary does not address complexities of need.

The focus of future researchers within this field of autism research needs to take into account the individual, unique and complex needs of each child.

Assessment and diagnosis as an opportunity to embrace an "alongsider" approach

I would like to conclude by considering the symmetry between the VRE approach to research and the more candid and qualitative autism diagnostic approach that I suggest should be formally incorporated into existing diagnostic frameworks. In Chapter Five, I demonstrate that the diagnostic practices of the trial clinician (as framed by the WISC-IV) objectify the social and cognitive functioning of children, and this in turn produces a picture that is at best a filtered down and oversimplified representation of the child's capacity, and at worst completely at odds with the child's actual abilities.

I argue that we need to embrace the same reasoning that is used to support the use of VRE in social research within the clinic to encourage the "alongsider" approach to autism assessment, diagnosis and research. VRE research can be successful in implementing practice change due to the reflexive, collaborative, "alongsider" approach that it embraces (Carroll 2009). Participants are active in the research project: they have a stake in its process and outcomes (Iedema 2014). As Kindon (2003) articulates, VRE moves away from traditional methods of inquiry in which the researcher is required to look "at" participants, and instead focuses on observing and analysing "alongside" those involved in the research. This is not only evident in the way that the data is analysed in collaboration with participants, but also in the way that the researcher's gaze is exposed or made explicit through playing back the video-ethnographic footage (Carroll 2009). Importantly, the researcher is *held accountable* for what they have filmed and how they have interpreted it. In the VRE work I carried out for this thesis, this collaboration and accountability is evident in the way that my gaze (that is, the video material that I have recorded), the way that I have framed the psychologist's work through my selection of video clips played back in the reflexive interview, and my perception and analysis of these clips, can all be questioned, challenged and negotiated throughout the reflexive interview.

In the autism diagnostic process described in this thesis, the clinician scores the child based on "objective criteria" (through the ADI-R parent interview and the WISC-IV with the child), essentially forcing children to fit into these criteria with limited consultation or collaboration with the parent and/or child. While I show that the clinician still engages in some diagnostic

creativity and embraces some qualitative approaches to work around the margins of the standardised diagnostic approach, they are still bound by the limits of the diagnostic tool, the protocol, or the guidelines.

Significantly, the ADI-R diagnostic tool is described as an *assessment* tool, and for many, this denotes traditional medical or clinical hierarchical relationships of the doctor and the patient, or the scientist and the clinical trial participant. This mentality of traditional medical diagnosis and assessment encourages the clinician to look "at" the patient. However, if we examine the meaning of this term further, the root of the word assessment is from the Latin word *assidere*, which means, "to sit beside" (Stefanakis 2002). The data from my observations and filming of the ADI-R and WISC-IV overwhelmingly supports this notion that the autism diagnostic process is reliant on collaboration between the clinician, parent, and child and this is achieved through shared and negotiated knowledge transfer.

This "alongsider" mentality during autism diagnosis should be an overt and well-publicised component of the diagnostic process. While the ADI-R embraces aspects of this "alongsider" mentality through its reliance on the parent's knowledge, narrative, and memory, the tools used in the assessment of children present a different picture. The WISC-IV upholds the traditional clinical hierarchy and separation of clinician-patient, and the rigidity of working within the confines of the criteria. Tellingly, the WISC-IV is also often used in clinical trials involving children with a developmental disorder to get an indication of their cognitive functioning. In Chapter Five, I discuss some glimpses of an "alongsider" approach between clinician and child that emerged during the WISC-IV assessment process. These were rare, but they were powerful, and they demonstrate the potential of this approach in changing the landscape of diagnosis and assessment of children to better reflect their abilities and capacity.

Autism diagnosis and research is messy, imprecise and thus constantly changing. Embracing this heterogeneity and accepting that we will never have a distinctive and clearly defined entity that we call "autism" is the challenge going forward for medicine. I argue that the alongsider approach to diagnosis and assessment of autism is one way of ensuring collaboration and encouraging parents, children and clinicians to have a stake in the diagnostic and research process and its outcomes. To truly achieve and effect practice change, this element of alongsider engagement is crucial.

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