

The London School of Economics and Political Science

*Paediatric bipolar disorder in the United States and England:
Psychosocial processes shaping the emergence of a
contested diagnosis*

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A thesis submitted to the Department of Psychological and
Behavioural Science of the London School of Economics for
the degree of Doctor of Philosophy, London, September,
2016

Declaration

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Jane Roberts

Abstract

This thesis investigates the genesis, knowledge and practice of paediatric bipolar disorder (PBD) in the US and England. Using a social representations framework, the thesis expands the socio-cultural psychology of medicalisation to elucidate how an emergent condition moves across cultures through the interaction, transmission and application of multiple forms of knowledge. The research design was comparative and multi-method, comprising three empirical studies, each studying key actors in the diagnostic process. Study 1 examined the ‘voice’ of the pharmaceutical industry incorporating analysis of de-classified internal industry court documents, marketing plans, and pharmaceutical advertisements. Study 2 drew on eighteen in-depth interviews with clinicians and study 3 was drawn from twenty in-depth interviews with parents, both in the US and England. Results show that the pharmaceutical industry uses unstable representations of PBD, and childhood itself, to expand market possibilities of what mental illness in a child could look like. Clinicians in both contexts struggle with pressures to be certain in the face of something unstable, anchoring representations of PBD in what they already know. For American clinicians, parents are allies shaping PBD as distinct from adult bipolar while the child is in need of early diagnosis and management; English clinicians approach PBD as adult bipolar and place the child in context, keeping the diagnosis rare. Parents in both the US and England feel frustrated and cast aside; American parents channel this into a sense of agency, developing ‘experiential expertise’, while in England, parents position themselves as amateurs ,confronting wider hierarchies within which they feel helpless. Overall, the thesis concludes that diagnostic practices are driven by processes of social representation and social influence: definitions of PBD, and its emergence as a diagnosis, are extrinsic to the condition itself, forged instead at the meeting point in which actors, cultures and multiple systems of knowledge and experience interact.

Acknowledgements

It's hard to believe I've finally reached the point where I'm writing the acknowledgements for my PhD thesis, but here I am, and with many people to thank for making this four-year journey possible.

First and foremost I would like to thank my supervisor, Professor Sandra Jovchelovitch, for taking me on as a student and giving me the confidence to develop intellectually. Her wisdom, guidance, and belief in the research have been an indispensable part of this experience. I have learned so much from our conversations, and those within her lab, which have shaped not only this PhD, but the world outside of academia as well. To my Jovchelovitch lab-mates: Natalia Concha, Maria-Cecilia Dedios Sanguinetti, Sandra Obrodovic and Jacqueline Priego- Hernandez, thank you also for your support and interesting discussion over the years.... From Latin-American mythology to dialogical methods and back again in one conversation! It was an honor to be part of such an engaged group.

I would also like to thank Dr. Alex Gillespie for helping to clarify direction in the early days, and providing initial feedback that was kept on board throughout the research process. To Professor Cathy Campbell for being so enthusiastic and passionate about mental health research, and providing inspiration through the sharing of articles and opportunities that fed into the work presented here. To other LSE department members: Saadi Lahlou for heading up the PhD students for much of my time in the department, and holding us up to a standard. To Steve Bennett, and LSE IT services for having such patience. To Daniel Linehan, Terri-Ann Fairclough, Jacqueline Crane for being so ready and willing to help with issues big and small (and of course extra sandwiches!).

This process has not always been easy, and a massive thank you goes out to my friends both here and across the pond who have made it infinitely easier, with a good laugh, a night out, or a chat to keep things in perspective: To Kim Sullivan, Paula Bronson,

Joanna Stronach, Marianne Westphal Vincent, Jill Van Buren, Sara Archambault, Gavin Hesketh, Maude, Laura Sommerville, Dan Holmes, Julie Bennett, Geetha Reddy, Cathy Nicholson, Sara Belton, Jacob Metz, Helen Green, and to Clare Coultas for being such a star and top-notch desk-mate/co-conspirator/ choir buddy/all around ace friend. To those fellow-PhD students not mentioned here who made the last four years such an adventure-I feel lucky to have been part of such a supportive group.

I want to extend an extra special debt of thanks to the families and clinicians who made this research possible. Their willingness and openness to share their stories and experiences about a difficult topic was the foundation for this project. I learned so much from reflecting on what they have been through. And to Dr. Anthony James who provided help and support in contacting parents in England, I am incredibly grateful and appreciative of all your help.

To Si for being so proud and such an incredible source of support, especially in this final stretch. Your humour, insight, good conversation and love of good, long wanders around London and beyond, kept me going and kept the more difficult moments in perspective.

And finally, to my family who has always been so supportive of whatever it is I've done, and provided such great reasons to come back home as often as possible: Mom, Dad, John, Sherry, Dawn, Liam, Cian, Shannon, Joanne, Uncle Tom and Elizabeth, and a special dedication to brother Tom. Thank you, thank you thank you.

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Acronyms

ADHD	Attention deficit hyperactivity disorder
BD	bipolar disorder
CAMHS	Child and Adolescent Mental Health Service (UK)
DMDD	disruptive mood dysregulation disorder
DSM	Diagnostic and Statistical Manual of Mental Disorders
Dx	abbreviation, ‘diagnosis’
FDA	Food and Drug Administration (US)
ICD	International Classification of Diseases
NHS	National Health Service
OCD	obsessive compulsive disorder
ODD	oppositional defiant disorder
PBD	paediatric bipolar disorder
SI	social influence
SRT	social representations theory

1. Outlining the problem: The birth of a diagnosis

A word contains a means of classifying individuals, as well as implicit theories concerning their constitution, or the reasons for their behaving in one way rather than another; an almost physical image of each individual, which corresponds to such theories. Once this content has diffused, and become accepted, it constitutes an integral part of ourselves, of our intercourse with others, of our ways of judging them and interacting with them...if the word “neurosis” were to disappear and be replaced with “disorder”, such an event would have consequences far beyond its mere significance in a sentence, or in psychiatry. It is our inter-relations, and our collective thought, which are involved and transformed.

(Moscovici and Duveen, 2000, p.26)

1.1 Introduction

My interest in this research emerged from a curiosity borne of my Master’s dissertation, where I became interested in how contested diagnoses catch on in a particular time and place. The Master’s was in the field of medical anthropology, and thus included a number of readings on the idea of culture-bound syndromes, and the myriad ways cultural manifestations of emotional distress were interpreted and acted upon. The question of how modern societies understand and respond to emotional suffering is of concern to many scholars across the social sciences (See Summerfield 2008; Davies 2011) who point out the reworking of suffering and dis-ease from something once seen as a necessary aspect of the human experience, to something now understood at the level of biology and neurochemistry. Societal values shape notions of mental health and illness, an idea at the heart of my thesis, acting as a driver motivating my own examination of one such illness: paediatric bipolar disorder (PBD). A normative and moral component is very much alive in the debates surrounding children’s mental health. Conditions such as attention deficit hyperactivity disorder (ADHD), autism, and PBD develop in concert with, or in reaction to, prevailing moral standards, not just over what it means to be a child, but what it means to be a parent or clinician existing, making decisions and developing knowledge within a context that currently favours biomedical explanations. Such a context has given rise to the rapid emergence of childhood mental disorders and focused attention on seeking out symptoms to fit the diagnosis. While many receiving the diagnosis of PBD are no doubt ill, the brisk

increase in numbers indicates something happening on a deeper societal level. In looking at conceptualisations of PBD among the pharmaceutical industry, clinicians, and parents it is possible to see this process in action, shaping the understandings that lead to establishing wider notions of the child and their behaviour, and how these understandings are developed. The mere fact of PBD, and the many other diagnoses of children's mental illness, into the realm of academic research, clinical trial, and diagnosis has already changed how we think about the child as potentially disordered, lending credence to the idea that very young children might experience illness in ways previously never attributed to them. While advances in diagnosis and treatment have no doubt changed young lives for the better, giving children with mental illness a chance to engage with the world in ways that may have been previously limited, this thesis is concerned with the zone of ambiguity and uncertainty that remains for a child when a diagnosis continues to gain in popularity despite not being grounded in clinical agreement.

PBD does not exist as a diagnostic category in the sense of being reified in either of the two diagnostic manuals used in the US and England. As this thesis will explore over the course of the following chapters, the diagnosis given to children is based on an amalgamation of other subtypes of bipolar disorder, as well as schizophrenia, major depression, and conduct disorders such as oppositional defiant disorder (ODD). However, an essential starting point for this research is to define the subtypes of bipolar disorder as elaborated in both the Diagnostic and Statistical Manual of Mental Disorders (from now on, DSM) published by the American Psychiatric Association, and the International Classification of Diseases (ICD-10) published by the World Health Organization in order to ground initial understanding of PBD. In this section, I will outline the diagnostic criteria for bipolar subtype I (BP I); bipolar subtype II (BP II) and bipolar not-Otherwise-specified (BP-NOS).

BP I: This is more serious of the two types of bipolar due to the presence of manic episodes in the diagnostic criteria. For a BP I diagnosis, criteria must have been met for at least one manic or mixed manic/major depressive episode. A manic episode

is defined in the DSM as a persistent elevated, expansive, or irritable mood lasting at least one week (American Psychiatric Association, 2000).

BP II: The presence of manic episodes is not required, instead the BP II diagnosis looks to the presence of ‘hypomania’, a less severe type of mania in which impairment is not significant enough to cause extensive social distress, psychosis, or the need for hospitalization (American Psychiatric Association, 2000). In order to assign a BP II diagnosis, criteria needs to have been met for at least one Major Depressive episode, one Hypomanic episode, and no history in the patient of manic or mixed-episodes (American Psychiatric Association, 2000).

BP-NOS: Bipolar disorder not otherwise specified is a diagnosis of bipolar disorder which doesn’t align with the other subtypes of BP I and BP II and is characterized by manic, hypomanic, or mixed episodes which are too short in duration to meet the criteria in the DSM (Towbin et al 2013).

The 10th edition of the International Classification of Diseases (ICD-10) published by the World Health Organization does not categorise bipolar disorder as BP I, BP II and BP NOS, instead defining criteria for Bipolar Affective Disorder, Bipolar Affective Disorder with Current Mixed Episode, utilising separate codes for mania with and without psychosis, hypomania, major, mild and moderate depressive episodes (World Health Organization 1992). A main point of differentiation between the two lies in the establishment of the number of episodes needed for a diagnosis to be established, with the DSM stating one, and the ICD stating at least two. Clinicians in the US rely on the DSM, while in England both are used in clinical practice, with the ICD 10 used more frequently among members of child and adolescent mental health service (CAMHS) teams.

This chapter acts as a foundation for the thesis, grounding the theoretical and empirical chapters in what I lay out as the ‘problem’ of PBD; an unstable diagnostic category that remains contested even though it continues to expand, now moving beyond borders and slowly emerging in a cultural context, England, separate from that or its origin, the United States. I begin with a brief outline of the trajectory of the diagnosis, which necessarily incorporates a brief history of adult bipolar disorder. This

leads into a review of clinical literature on the development of PBD, and the position of the diagnostic manuals, the DSM in the US and the ICD-10 in England, as cultural artefacts. The final section of this chapter presents examples of PBD as it has emerged in both the clinical, specialist, and lay public spheres, changing perceptions of how children might fit the diagnosis. This examination of the movement of PBD into the public sphere begins with discussion of the highly influential book *The Bipolar Child* which was aimed at parents as a guide for identifying and living with a ‘dysregulated’ child, and moves into the articles, editorials and commentary in the popular press, where questions began to materialize surrounding the validity and legitimacy of the diagnosis and the pharmaceutical treatments being advocated. The chapter concludes by grounding what is presented here with the wider project as a whole.

1.2 A brief history of paediatric bipolar disorder

The idea that children who manifest extreme moodiness may actually suffer from a psychiatric disorder represents a paradigm shift in a field where this sort of behaviour was once characterised as a normal part of development (Post 2009). The development of the concept of bipolar disorder in children has come as a result of favourable conditions taking shape within a particular moment in history. Healy and LeNoury (2007) note that the diagnosis of bipolar disorder in children has been made with increasing frequency in North America in the last decade “despite a century of psychiatric consensus that manic-depressive illness rarely had its onset before adolescence” (p.209). This development has taken place against a background of “vigorous marketing of bipolar disorder in adults” which has also seen a rise in prevalence rates (ibid). Our modern ideas about bipolar disorders are, as Healy (2008) suggests, in some ways conceptually novel, however defining aspects of what was commonly known as manic-depressive illness are as old as medicine itself (p.xii). Healy writes of mania as a “curious beast, in that the term crops up in antiquity, whereas schizophrenia and depression do not” and it is this long lineage of the disorder that has been so readily drawn upon by academics and pharmaceutical companies seeking to lend weight to contemporary developments around PBD (Healy 2008, xvi). A dramatic shift from external behaviour to internal states took place in the nineteenth century

marking a departure from early Greek practices basing diagnoses on visual manifestation of disorder, and moving towards psychiatrists using words to access internal mental states (Healy 2008, 18). Such trends continue in the realm of children's mental illness, in which diagnosis is often based on third party verbal reports (ibid).

Eisenberg (1986) coined the terms 'brainless psychiatry' and 'mindless psychiatry' in order to describe the swing in thinking from the thought style in which 'brain-based' explanations of mental illness rooted in faltering neurochemistry were not yet at the forefront. Psychoanalysis, family psychiatry and the emergence of the antipsychiatry movement were at their peak, fading into the background as the move was made, in America at least, towards "excessive biological reductionism" in which previous emphasis on 'the mind' is cast aside (Parry and Levin 2012, p. 54). In the US, 1990 represented the beginning of the 'decade of the brain' as declared by President George W. Bush leading to advances in neuroimaging and genetic studies in search of biomarkers for mental illness (Parry and Levin 2012). In questioning whether psychiatry can be reduced to neurochemical mechanisms in the brain, there is the related question of why psychiatric classification is as behaviouristic and operationalized as it is?

Evans (2013) notes that after World War II, British and American psychiatrists diagnosed in entirely different ways for a given patient. The worry was that these judgments lacked any clinical agreement among colleagues. One way of solving this problem was to disconnect the idea of diagnosis from as much aetiological or causal theory as possible and just describe the behaviour being expressed (Evans 2013). The way taxonomy is developed is impacted by social changes. Thus, the increase of epidemiological studies and casting of behavioural characteristics associated with particular diagnoses had a huge impact on the category being defined. Evans (2013) uses the example of autism to illustrate how changing conceptions of mental disorders reflects on new conceptions of what is 'normal' cognitively or behaviourally. Prior to epidemiological studies, autism was described in terms of hallucinations and a loss of contact with reality linked to ideas advanced by Bleuler and Freud (Evans 2013), however the idea transformed into one of autistic children have no fantasy life at all. It has now become a diagnosis characterised by logical thinking. Measures being applied

have changed the meaning of that particular category, reflecting more general perceptions of infant thought and cognition (ibid). As I will illustrate in the following chapters, the change in meaning of bipolar disorder has occurred in the United States, and is still being negotiated in England. Rather than epidemiological studies transforming the nature of how we categorise this new breed of children, I will argue that it is a range of psychosocial processes taking shape in response to institutional and cultural cues which allow for a re-categorization and reconceptualization of a once rare diagnosis found only in adults, into a more common and treatable disorder found in very young children.

The concept of bipolar disorder (BPD) was initially extended in the 1970's with the introduction of the subtype of Bipolar 1, characterised mainly by depressive episodes accompanied by occasional minor episodes of mania. This was not widely accepted outside the United States, however, and thus not featured as a major diagnosis in the 10th edition of the ICD (Moncrieff 2014). The view that mania could exist in children was first suggested in a paper by Carlson et. al. (1983) in which the possibility was presented that mania in preadolescent children could present as irritability and emotional instability, as opposed to the more 'classic' presentation of elevated mood and grandiosity found in adults. Geller et. al. (1995) extended this idea to argue that children with rapid-cycling mania/irritability could actually have bipolar, however researchers hesitated to use irritability as a characterization of BP because it also commonly appears in ADHD (Parens and Johnson 2010).

The birth of the controversy surrounding the current conception of PBD came with its initial unveiling by a group of influential clinicians affiliated with Harvard Medical School. Prior to 1995 there was very little mention or public awareness about the diagnosis, but the publication of a series of papers (Wozniak et. al 1995; Beiderman et. al 1996) brought the conception of the disorder to life. The group had been focused on ADHD in children until it was proposed that those who weren't responding appropriately to Ritalin and other medications for ADHD might have a version of bipolar disorder. This early research utilised a child behaviour checklist to confirm the bipolar diagnosis in children who met the criteria for mania because they were showing

evidence of chronic irritability, and suggested that children with ADHD were also at an increased risk of developing PBD (Beiderman et. al., 1996). Something in the research resonated with the larger audience of psychiatrists and, shortly after, the lay public, as Wozniak's (1995) paper quickly became one of the ten most cited papers ever published in the Journal of the American Academy of Child and Adolescent Psychiatry (Finkel 2012).

Disagreement surrounding how best to characterise PBD is based on differing approaches to diagnostic criteria. Early research (Wozniak et. al 1995, Beiderman et. al 1996) suggested a much more broad spectrum approach to diagnosis of the disorder in children in which the well-accepted classical presentation, or 'narrow phenotype', found in adults with the illness (recurrent episodes of mania, defined as elevated mood and grandiosity, were followed by severe depressive episodes also lasting weeks or months) was readapted and applied to young children, where the criteria now allowed for "rapid cycling", in which young children could have several episodes per day (Washburn, West and Heil, 2011). Episodic changes in mood, and the marked euphoria which previously characterised mania, was replaced by chronic irritability for the presence of mania in children (Carlson and Meyer 2006).

Pavuluri et.al. (2005) produced an early review the literature on PBD finding that the disorder is increasingly recognised by clinicians, however, as mentioned above, differing clinical perspectives on how the disorder manifests in children remains the rule. Pavuluri et.al. (2005) use this as the motivation to push for future research that focuses on "the external validation" of PBD in the form of more longitudinal studies using genetic, neuroimaging and neurochemical methods to increase understanding of PBD's origins (p.867). The high rates of co morbidity with ADHD were suggested as one reason why proper identification of children is difficult. It is this desire to find something to observe, some physical manifestation of a phenomenon that remains a vague collection of competing definitions, that is central to the development of PBD in the US as diagnosis and treatment are steered towards something that can be 'fixed'. Pavuluri et.al. (2005) play down disagreement among clinical colleagues about PBD,

suggesting that there is in fact consensus that PBD exists, but more research is needed to determine whether the 'broad' phenotype actually falls within the bipolar spectrum.

Faedda et al. (2004) note that the differentiation of PBD from other disorders remains challenging due to high comorbidity with other childhood disorders and lack of similarity of the episodic nature of childhood bipolar as is found in adult BPD. Their study examined children meeting DSM IV criteria for bipolar disorder (with the exception of episode duration criteria) analysing clinical records to evaluate age of onset and other factors. Of the 82 young people diagnosed PBD, psychopathology was recognised before age 3 in 74% of the children, presenting as mood and sleep disturbances, hyperactivity, aggression and anxiety (Faedda et. al. 2004). The study concluded that PBD is often mis- or undiagnosed although it often manifests with mood lability and sleep disturbances in young children. Parens and Johnston (2010) seek to distinguish between the small number of children who do fit the criteria for bipolar disorder in the DSM and the much larger group of children who have been given the diagnosis despite not conforming to the criteria. In outlining the controversy, they argue in favour of the development of a new diagnostic category of 'severe mood dysregulation' in order to cut down on the number of children being misdiagnosed, and thus mistreated (Parens and Johnston 2010).

In contrast, Post (2009) supports the idea that PBD is an early manifestation of what is seen in adults, arguing that there is not enough recognition of the disorder in young people, resulting in inadequate treatment. These assertions are drawn from a study examining retrospective assessments among adults with bipolar in which they recollected the age of onset of their symptoms. Post (2009) is a proponent of early diagnosis and treatment (and maintains professional links to the pharmaceutical industry as a paid consultant) singling out analysis revealing that the length of the delay between a child's diagnosis and the first treatment is a predictor of more serious on-going illness into adulthood. Proposing that childhood onset illnesses would have a better outcome with earlier, more appropriate, interventions, Post (2009) concludes that intensive investigations should be undertaken into the more controversial variations of

PBD spectrum, such as BP-NOS or conduct disorder with ADHD, in order to define their optimal treatment strategies, including in very young children (p. 884).

Despite the controversy over this relabelling, rates of PBD have continued to increase. Moreno et al (2007) found a 40-fold increase in the number of outpatient visits reported in the US between 1994 and 2003. The rise of PBD in outpatient settings was also illustrated by Blader and Carlson (2007) who reviewed records from the annual National Hospital Discharge Survey finding that the rates of children given a diagnosis of bipolar increased from 1.3 per 10,000 US children in 1996 to 7.3 per 10,000 in 2004. A diagnosis of bipolar was the least frequent diagnosis recorded for children admitted as in-patients for psychiatric reasons in 1996, however it was the most common in 2004 (Blader and Carlson 2007).

Further shaping debate around PBD is the influence of the pharmaceutical industry, which played a major role in funding the initial research that was meant to provide results which would benefit the company (Harris 2009b). As a result of its contentious introduction, there remain distinct sides of the debate. Those in favour of diagnosis argue against turning childhood mental disorders into polemics. Timimi and Taylor (2004) cite a lack of evidence for social factors as the cause of certain disorders, however others have argued that leaving children untreated leads to greater risk of social problems including incarceration, substance abuse, fractured families (Volkmar et al 2002), and mistreatment with the wrong medications (Wozniak et al 1995; Beiderman et al 1996). Others suggest it is not a new problem at all, but rather follows the lead of other previously overlooked mental illnesses in childhood which can be successfully treated (Pavuluri 2005; Danner et al 2009), thus cutting down on potential neurocognitive deficits as a result of missed diagnosis. Those supporting a diagnosis of PBD say more research into the underlying causes is needed via neuroimaging, as the identification of biomarkers and genetic insight will lead to greater understanding of PBD as a developmental illness (Leibenluft 2008).

While much of the literature on PBD remains in the clinical realm, Parry and Levin (2012) discuss the rise of the diagnosis in terms of wider systemic influences at play. They express concern that trauma, attachment and other psychosocial factors are

not as given as much consideration when making the diagnosis, owing to what they consider and overemphasis on neurochemical and biological explanations. Instead of being viewed as a previously overlooked disorder, Parry and Levin (2012) argue that PBD is reflective of several factors associated with a wider paradigm shift within psychiatry. Diagnosis is a product of an American system that prompts diagnostic ‘upcoding’ as a result of pressure to assign a diagnosis in order to get reimbursement for treatment from insurance companies, potentially leading to increase in diagnosis of PBD and the influence of the pharmaceutical industry (ibid). Corcoran and Stubbins (2015) have also sought to understand broader systemic factors at play in the rise of PBD in the US. They have found that a lack of child psychiatrists to assess children properly, combined with insurance restrictions limiting the amount of time a clinician can spend with a child leads to children being assessed by medical professionals not trained in child psychiatry (Corcoran and Stubbins, 2015). In contending that PBD is a phenomenon confined mostly to the US, Parry and Levin (2012) offer that it is best understood via a “broad, systemic perspective”, which thus warrants moving beyond the clinical academic literature and the focus on mediations and neuroimaging (p. 53). There is a clear need to explore the “broader paradigmatic shifts in psychiatry” (ibid. p 55) to fully grasp what is at play in the genesis of a diagnostic category that counts very young children among its members. This is something this thesis is setting out to explore.

While PBD is still very much aligned with the US, a central question of this thesis is how understandings of what makes the diagnosis are moving and establishing themselves in a different cultural context, and what bearing context has in how such a diagnosis catches on or remains in the background. I suspect it goes beyond the statement of one prominent American psychiatrist who suggested “Europeans are biased against recognizing psychiatric disorders in children... US rates of diagnosis reflect a deeper understanding of the disorder among US psychiatrists” (Parens and Johnson 2010, 5). Literature exploring international comparisons in the understanding of PBD remains rare, while epidemiological international comparisons into prevalence rates are only slightly more common. Soutullo and colleagues (2005) sought to address

scepticism surrounding PBD by gauging international perspectives on the epidemiology and phenomenology of PBD in non-US samples. They noted often overlooked divergent approaches to defining bipolar disorder in the ICD-10 as compared to the DSM IV leading to methodological differences in epidemiological studies which could help explain international prevalence rates. Among their conclusions, it was suggested that different levels of recognition of child and adolescent psychiatry as a true speciality in Europe, combined with clinician bias against bipolar disorder internationally, over-diagnosis in the USA and/or actual higher prevalence of PBD in the USA may explain their results (Soutullo et al. 2005). In a study exploring how British clinicians apply the diagnosis of bipolar disorder to children, Chan et al (2011) found that the diagnosis was rarely made by clinicians working in Southern England, and out of 3586 children in the study, only 35 participants (1.0%) were diagnosed as having bipolar disorder. Of those, only 9 children (0.3%) were under the age of 13 (p. 75). Contrast this with rates of diagnosis in the US where, according to Kaplan (2011), the rise of outpatient office visits for children and adolescents with bipolar disorder increased 40-fold from 20,000 in 1994–95 to 800,000 in 2002–03, with number no doubt having increased since then.

More recently, a study comparing hospital discharge rates for children in the US and England with a diagnosis of PBD suggests that by the age of 5 years old, the rate of discharges of American children have already exceeded that of their English counterparts, where the peak occurs at 19 years of age (James et al. 2014). Also significant is a 114- fold difference in rates found in adolescence with a peak age in the US of 342 per 100,000 at age 16, versus England at 3.0 per 100,000. Does this suggest a US propensity to diagnose adolescents exhibiting adolescent behaviour as ill, or an English reluctance to pay attention to warning signs? Crossley (2006) suggests that the self-image of British psychiatry “emphasises eclecticism and open-mindedness” noting the contribution of a number of professionals, not just psychiatrists, to the care of one individual. Clacey, Goldacre and James (2015) conducted an international comparison of hospital discharge rates for children diagnosed with PBD using national data sets. In the US the discharge rates per 100,000 population for those under the age of 20 were 95.6 as compared to 0.9 in England, noting that the most significant diversions

occurred among those aged 5-9 years old. The authors describe how American authorities maintain that PBD is characterised by non-episodic, chronic, ultra-rapid cycling, mixed irritable states. In the UK, such cases would be conceptualised not as paediatric bipolar disorder but as oppositional defiant disorder, conduct disorder and/or ADHD with emotional dysregulation. (Clacey, Goldacre and James, 2015). This was also proposed by Dubicka et al., (2008) in a study presenting five standardized vignettes illustrating complex scenarios of mania in children in which four represented incidents in which the diagnosis would be controversial, and one ‘classic’ case of mania in an older child in which it was thought there would be easy agreement. The vignettes were shown to child psychiatrists in both the US and UK and provided evidence that PBD is more readily diagnosed in the US.

1.3 The DSM and ICD as cultural artefacts

The entry of PBD into the public domain has not been without controversy. A main point of contention lay in the fact that PBD as a diagnosis doesn’t exist in either the DSM 5, which is used in the US, or the ICD-10 used in Europe, leading to accusations of the misapplication of adult criteria to children. And it is not only borrowing criteria from adults which is at issue, but also the redefinition of criteria in order to make sense of what clinicians might actually see in children, given that many classic bipolar symptoms are rare to non-existent in pre-pubertal young people. Central among these redefinitions is the use of irritability as a way of identifying both mania and depression in children. In the US, where there is already a long-held familiarity in diagnosing children with behavioural disorders, this notion of mania has gained more traction. Not so in England, where there is a desire to stay aligned with more established, conservative definitions, as well as a desire to maintain distance from what is widely seen as an American fondness for over diagnosing and medicating children. This will be explored more in *chapter five* when considering the development of clinical representations of PBD in the US as compared to England.

In discussing disorders of childhood as they relate to cultural psychopathology, Lopez and Guarnaccia (2000) note that it is a “rich field of inquiry for those interested

in culture” (p. 572). The position of the child in a particular context speaks to how those around the child give rise to new understanding about childhood and what constitutes ‘normal’ conduct. Weisz et al. (1997) suggest that child psychopathology requires attention be given to the behaviour of children as well as the view of those adults- particularly parents, teachers, and mental health practitioners- for it is the adults who usually decide whether a problem exists. The fact that others determine whether children’s behaviour is problematic indicates the importance of the social world in defining mental illness and disorders of children and adolescents (cited in Lopez and Guarnaccia 2000, p.584).

The cultural background of a child is present both in how the child’s behaviour is interpreted by others, as well as in how their psychological distress is expressed. For example, Lopez and Guarnaccia (2000) discuss a cultural propensity to foster either internalizing manifestations of distress, such as depression and anxiety, or more external manifestations, such as acting out, or aggressive behaviours. A culture that values self-control and emotional restraint, or one valuing achievement and success, leads to children expressing psychological distress in a way that doesn’t violate cultural norms (p. 584). The question arises, why is there such international variation in discharge rates for paediatric bipolar disorder, even allowing for the overall differences in the total discharge rates between countries, and are they warranted? (Clacey, Goldacre and James, 2015).

Both the DSM and the ICD are cultural artefacts reflective of, and shaped by, current conceptions of what counts as scientific evidence, and what makes up a “real” disorder (Summerfield 2008). New assumptions about what is normal versus what is disordered are incorporated into common sense beliefs about the world and a person’s own relationship to psychological norms (Offman and Kleinplatz 2004), which then contribute to the construction of new diagnostic categories reflective of such societal trends (Summerfield 2008; Jutel 2011). Bipolar Disorder Not Otherwise Specified (BP-NOS), is the most commonly seen subtype in paediatric psychiatric clinics, and is not clearly defined in the DSM IV. The symptoms of mania in a child had to have lasted at least 4 hours within a 24-hour period for at least 4 "cumulative lifetime days” (National

Institute of Mental Health, 2006). In this description, it appears that even children having a severe temper tantrum could fit the diagnosis, an issue leading the British Psychological Society (2012) to voice concern over the validity of diagnostic categories for PBD, noting that “assumption, rather than hard evidence from empirical research are driving development of diagnostic criteria” (p. 3). Clacey, Goldacre and James (2015) suggest that in the United States, PBD is a diagnosis of inclusion of children with symptoms of ADHD, irritability and fluctuating moods, whether or not there is clear evidence of a manic episode, raising the possibility that severe adolescent mood dysregulation is being diagnosed as bipolar.

The most recent edition of the DSM, DSM 5, requires only one such manic episode before a diagnosis of bipolar can be made. To receive the BP-NOS diagnosis, a child does not need to meet the criteria for any of the other subtypes of BPD. For example, a child may have an unstable mood and rapid movement between more manic and depressive symptoms, however those symptoms do not meet the “minimal duration criteria for a Manic or Major Depressive Episode” (Parens and Johnson 2010, 6). Compare this criterion for mania to the classification in the ICD-10 in which more than one manic episode is required (Clacey, Goldacre and James, 2015). Moreover, the UK National Institute for Health and Care Excellence (NICE) clinical practice guideline advocates a more conservative approach to diagnosing bipolar I in children, and urges against bipolar 2 diagnoses for young people (ibid.). According to Healy (2007), the DSM makes it easier to diagnose bipolar disorder in children than does the ICD while Wang (2012) identifies the DSM as something of a road map reflecting rapid revision of scientific views on mental health.

Among British psychiatrists, there is a concern that PBD is a “catch-all category, which will broaden the rates of diagnosis of such conditions...and result in significant side effects due to the unnecessary medication prescribed as a result of false positive diagnoses” (British Psychological Society 2012, p.11). In a 2006 report outlining clinical guidelines in the management of bipolar disorder, NICE stated their position as acknowledging that while children can “present with many features suggestive of a diagnosis of bipolar disorder”, they remained unconvinced that there

was enough clinical evidence available to support the everyday clinical use of the diagnosis” (NICE 2006, p. 526).

1.4 PBD in the public sphere: The Bipolar Child, social knowledge and diagnostic legitimacy

The emergence of PBD in academic literature was followed soon after by the introduction of the diagnosis to the wider public. Perhaps the most significant shift in understanding came with the publication of *The Bipolar Child: The Definitive and Reassuring Guide to Childhood's Most Misunderstood Disorder* (Papolos and Papolos, 2000), a book that led to a swell in the number of parents asking for the diagnosis. The publication of the book was the most salient indicator of a shift in thinking about PBD (Healy and LeNoury 2007) and suggested, among other ideas, that PBD could actually emerge in infancy, or even in-utero (Papolos and Papolos 2000, p. 8). I first heard about this book when conducting my initial review of literature for this research, as it was mentioned in a number of popular articles expanding on the increasing prevalence of PBD in the US. The importance of the book's influence was further cemented once analysis was started on the interviews conducted with American parents for this project. It became apparent that each one had mentioned the book as being an essential resource in their understanding of the diagnosis. An indication of the level to which *The Bipolar Child* caught on can be seen in its sales trajectory, as it was initially published in January 2000, was in its 10th printing by May, and sold 700,000 copies in its first six-months (Healy and LeNoury 2007).

The knowledge about PBD perpetuated in *The Bipolar Child* suggested that the disorder is not new, nor is it uncommon. Rather, the authors suggest that PBD represents a neglected public health problem, citing research that up to one third of American children given the diagnosis of ADHD likely have PBD instead (Papolos and Papolos 2000, p. 4). The book goes on to tell parents that bipolar disorders have “probably been conserved in the human genome because it confers great energy and originality of thought” thus equating having the diagnosis with being intellectually or creatively gifted. Indeed, in speaking to American parents, each one also mentioned the gifted status of their child, suggesting that the label of the diagnosis obscured the true

nature of their child, but perhaps finding comfort in the idea that the fact that the child was exhibiting certain behaviours was to be equated with heightened abilities. Thus, many children with PBD are described as:

...extremely precocious and bright-doing everything early and with gusto. They seem like they are magical children, their creativity can be astounding and the parents speak about them with real respect, sometimes even awe (Papolos and Papolos 2000, p. 8)

In presenting the diagnosis in this light, the authors make the idea of PBD more palatable to parents who may be worried enough about their child to seek professional help, yet sceptical about the label 'bipolar'. The push for increased individuality that is so central to the American mentality has been manifested in how diagnostic categories are introduced to the public who may be responsible for their wider acceptance, in this case parents. A diagnosis, however difficult, marks a child as different or special, and thus attempts are made to locate positive associations of the illness in history, or characteristics of genius, creativity, and gifted intelligence, perhaps as a means to soften the blow for some, or providing a sense of increased comfort with the idea of seeking out the diagnosis for others. The characterisation of the bipolar child presented in the book is also a manual for parents in terms of presenting a new way to shape responses to the child by aligning potentially disturbing behaviours with brain chemistry:

Bipolar children seem to be out of sync. ...they seem to have great difficulty making shifts from one context to another. When the demand to do so is made- and it may only be a request to stop watching television and join the family in the kitchen for dinner- he or she may not be able to brook the transition and the change in the state of mood, attention, or motor response required. The child may become easily frustrated and irritable, and a repeated demand may provoke the child's angry outburst or rage. The limbic system (the emotional brain) seems to be involved with the integration of sensory experience, and we will explore this more closely in chapter 7 (Papolos and Papolos 2000, p. 17)

Of interest is the way the authors immediately follow up the vignette of a rage set off by being asked to come to the dinner table with something beyond the control of any of the actors involved: the limbic system. Thus the context is removed from how behaviour should be interpreted and placed squarely within a disrupted neurochemistry.

The power in the vignette above is given to the child, however the book places power in the hands of the parents by presenting information on such topics as “How to Judge a Doctor’s Ability to Diagnose and Treat Bipolar Disorder in Children”. The authors lay out a series of ten bullet points as to what parents should look for, including the need for an aggressive physician who is not afraid to initiate treating with medications as soon as possible, as “taking too much time to give a diagnosis and initiate treatment hurts the child and the family” (Papolos and Papolos 2000, p. 60). Parents are then advised which questions to ask the physician, and which clinical responses they should take on board:

If the doctor mentions that most children who have bipolar disorder cannot be diagnosed according to current diagnostic criteria, and he or she knows that the duration of cycling is much shorter in children, and *then treats this form of the condition as bipolar anyway*, the parents should breathe a sigh of relief (Papolos and Papolos 2000, p. 69. Emphasis added)

Parents are being actively encouraged to challenge clinicians who don’t subscribe to the more controversial broad-spectrum approach to diagnosis advocated by the authors, instead being told to “breathe a sigh of relief” when they find someone willing to diagnose bipolar in a child despite the fact that the child may not meet traditional diagnostic criteria. Papolos and Papolos (2000) suggest that parents have to abandon the idea of traditional parenting practices involving consistency and authority, as the idea of the parent establishing control in order that the child feels safe, doesn’t stand a chance in the family with a bipolar child. They note that:

Any assertion of authority is viewed by the child as the parent dominating him or her, a domination to be resisted at any cost. Something goes off in the child’s brain and a rage gathers. A simple “no” triggers a nuclear explosion (Papolos and Papolos 2000, p. 253).

Again, it is the child’s brain that is responsible, thus the parent isn’t necessarily reacting to their child’s behaviour as much as they are responding to something separate within the child. The popular dissemination of this idea that parental authority won’t work, and in fact can make a bad situation worse, is an approach that has been implicated in the critique of the expansion of mental illness diagnoses in children. The degree to which *The Bipolar Child* caught on and became a significant, if not unique source of

information for parents seeking answers provides an indication of how in the development of the concept of PBD, representations of acceptable parenting practices are given almost as much weight as representations of the child. This supports Harris' (2005) assertion that telling parents their child has a biologically based mental illness, although difficult, is easier than examining family interactions that provoke such behaviours, something that is sure to cause a certain level of parental guilt. Thus, a new dynamic is created between parent and child, in which the parent sees child as ill and in need of nurturance, and the parent feels relief that the child's conduct is not their fault (Harris 2005, 531). Physicians are also able to gain a positive sense of their own position as a fighter for what's best for the misunderstood child who has labelled as 'bad', but who actually suffers from chemical imbalance that can be treated (ibid.). Books like *The Bipolar Child*, and the many of its ilk which followed over the following decade, not only increased awareness about PBD, but provided some insight into how the "enormity of the problems faced by many children makes the simplicity of a biological explanation incredibly appealing" (ibid).

Parry and Levin (2012) note the dearth of studies in the psychiatric literature being openly critical of PBD, proposing that "contrary views about PBD are seen as opinion based and lacking in data" in a field that holds quantitative research in higher regard than qualitative. Following on from the publication of the book, a series of in-depth media reports, commentaries and editorials presented details about the lives of young people living with a diagnosis of bipolar. The tenor of the articles was more questioning and critical of the diagnosis however, with several highlighting instances of the diagnosis and its treatments gone horribly wrong. Most significant among these is the story of Rebecca Riley, a Boston toddler diagnosed with PBD at age two after her mother became concerned that she seemed hyperactive and wasn't sleeping well. The diagnosis led to the prescription of a cocktail of medications, including the antipsychotic Seroquel, which ultimately led to her death from overdose at the age of four. The story was one of the first to bring PBD into the mainstream, and highlighted the fact that Riley's ten-year old brother and four-year old sister were also being treated for PBD as well, by the same psychiatrist. (60 Minutes, September 28, 2007).

One year later PBS aired a documentary on “The Medicated Child” (PBS Frontline, 2008.) which profiled four-year old DJ Koontz who was given the diagnosis of PBD after his parents noted his temper tantrums became more frequent and uncontrollable, leading to him being prescribed powerful antipsychotic medications. The story quotes DJ’s mother as saying she was concerned about the use of medications but that without it they wouldn’t be able to function as a family. The lack of a link between PBD and the adult manifestation of bipolar was highlighted by Thomas Insel, then the director of the National Institute of Mental Health, noting that there was no indication that adults with the illness started with what is now being called PBD, nor was it certain that these kids would grow into the more classical manic-depressive type illness on which its name is based.

Similarly, a Time Magazine cover story highlights a single mother with three children, two of whom have BPD, a son aged five, and a daughter aged two asking the question of why so many children are being diagnosed with a disorder previously known as manic-depression? The boy at the heart of the article, Ian Palmer, began treatment with stimulants and Prozac, responding inadequately to both, and subsequently put on antipsychotics (Kluger and Song 2002). The article suggests that the most serious symptoms for children may appear just when the academic challenge of grade school starts to be felt, and doctors who recognize BPD and know how to handle it are in critically short supply. As Healy and LeNoury (2007) observe, the Time Magazine piece, and other popular articles, cite surveys suggesting that 20% of young people in the US have some sort of diagnosable mental illness. A more recent Newsweek story written by a well-known child psychiatrist (Kaplan 2011) denounced the “unwarranted enthusiasm” for PBD. The article noted that despite practicing for three decades and seeing faddish illnesses come and go, the momentum behind PBD was unprecedented. No scientific evidence exists to support PBD, instead Kaplan (2011) suggests that PBD is “almost always a case of severe ADHD combined with severe oppositional defiant disorder” (ibid). This is echoed in a New York Times story which sheds light on the fact that psychiatrists often disagree over what is wrong with a child (Carey 2006). A Boston Globe article in which psychiatrists interviewed noted that

the question of whether or not to give a diagnosis of bipolar can be an agonizing decision for clinicians who are at the mercy of both conscious and unconscious pressures to medicate such children. However, the article cites one psychiatrist as stating that central to making progress in understanding PBD is to understand better, as a field, which pre-schoolers warrant increased attention and need to be treated aggressively (Goldberg 2007).

In England there has been much less attention to PBD in popular media outlets; however, that is beginning to change. A CAMHS mental health nurse writing in a blog for the UK-based mental health charity MIND questioned whether small children can get bipolar disorder, noting that her professional colleagues are taking sides in the debates, suggesting what is happening around PBD is similar to the debates that took shape around ADHD years ago. While some argue it is “the new big thing”, others insist it is the American link to the vested interests of Big Pharma at play (Zarathustra 2010). The blog cites the example of a young girl in the CAMHS caseload who had been diagnosed with ADHD in Britain and prescribed a stimulant, methylphenidate, but was promptly diagnosed with PBD (and prescribed antipsychotics) when her parents took her to America. On return to Britain, the child was reassessed by CAMHS and not found to have any of the signs or symptoms of bipolar, and switched back to the treatment with a stimulant (Zarathustra 2010). While most of the popular media attention in England has been focused on ADHD, a 2014 article in *The Sunday Times* entitled ‘Can a Child be Diagnosed with Bipolar Disorder?’ in which readers were introduced to the types of children profiled over the years in US media (Glass 2014). This article in particular featured the perspective of a frustrated parent in England, desperately seeking the diagnosis for their daughter, but meeting resistance within the NHS. The parent is driven to seek advice from American experts (ibid). Such articles, and the comments they receive, act as an indicator for where popular knowledge about PBD lies. One comment to the blog posted on the MIND website in the UK illustrates an issue common among many in England, that there is something of an opposite problem to America’s perceived over-diagnosis taking shape, in which there is a sense that doctors believe one’s brain suddenly changes once a young person turns 18, and

prior to that point any signs of mental illness are not taken seriously enough (Zarathustra 2010).

It has been argued that differing diagnostic practices are responsible for higher rates of PBD in the US as compared to England (Stringaris 2010; Clacey, Goldacre and James, 2015). The question that is central to this thesis is why? What is shaping these practices beyond mixed use of diagnostic manuals and the level of influence of insurance systems and socialized medicine? There is no doubt that such ingrained, systematic differences are central in how diagnostic practice is manifested, however this project is concerned with what lies behind these systems, how these systems are internalized and enacted at the level of interaction between individuals and groups. I argue that one way to understand these differences is to look at psychosocial processes taking shape within the interactions of those most involved in perpetuating the diagnosis: clinicians, parents and the pharmaceutical industry. Current research in the clinical literature necessarily focuses on clinical issues, while acknowledging that more needs to be done to understand conceptual differences and wider political, social and economic factors shaping diagnostic practice around PBD. We are all embedded in social environments in which traditions and practices come equipped with previously constructed meanings, norms and expectations that only carry on to the extent that they are able to orient to new circumstances (Linell 2009). It is within these situations, or in the case of this research, the cultures of diagnosis allowing for knowledge to evolve in a particular way, that the meaning of the child is negotiated among professionals and parents, acting within spheres of influence in which top-down pressures continue to operate in the background.

1.5 Conclusion

In this chapter, I have briefly outlined the early trajectory of PBD, reviewed key literature on the diagnosis, and presented the problem of PBD as it exists in the public sphere in terms of the knowledge presented to the wider public in the form of an influential book, as well as more critical voices coming out of popular media. The controversies remain despite twenty years of development of the concept of PBD. Although there is a fair amount of clinical research on PBD since it was popularized in

1995, and no doubt significantly more on bipolar disorders in history, the present emphasis on investigations into neurochemical explanations leaves a gap for more research pursuing explorations concerned with the psychosocial development of the diagnosis and the role processes of social influence and social representation have on the development of such a category. Much of the current literature on PBD focuses on clinical understanding of the disorder, however less evident are more qualitative explorations of how PBD is conceptualised by those most involved in treating, and caring for those living with the diagnosis. There is a significant amount of literature on the related, often overlapping, diagnosis of ADHD (see for example Singh 2002, 2007, 2011; Timimi 2003; Edwards and Howlett 2013), which this current research builds on, however as an area of study, PBD is unique in that it is a diagnosis that is still seeking to be understood and defined.

Childhood mental disorders such as ADHD and autism spectrum disorders come equipped with all of the controversy, contestation and debate that surrounds PBD, however those illnesses have succeeded in solidifying their place in the realm of, as Fleck (1979) would say, scientific fact, or at least public understanding. The exact position of PBD continues to be negotiated making it a valuable point of departure to understand how and why a controversial diagnosis catches on or gets discarded. How does the interaction between different knowledge systems in two different cultural contexts - in the case of this study professional biomedical knowledge, the experiential knowledge of parents and the political economy of the pharmaceutical industry - come together in the cultural production of a contested diagnosis? How do these different groups conceptualise the diagnosis of bipolar in children, and how does this shape the ways in which the diagnosis is accepted or rejected as a valid diagnostic category? There are a number of ideas presented here, which may be taken as already established givens. For example, as will be discussed in *chapter two*, the medicalisation of children has been well-researched and forms the backbone of my own interest in developing this thesis, as is the notion that these processes of medicalisation are more often found in America. What this thesis aims to contribute, however, is a better understanding of what is at play in these processes of medicalisation, how a diagnosis in children which has

remained controversial for the whole of its existence is understood by those most directly involved in its perpetuation, and how (and why) this might differ in the US as compared to England. The fact that PBD remains so contentious is a testament to the fact that socio-psychological research is warranted. What happens in the US with regards to diagnostic understanding does tend to migrate to England, and as the English healthcare system becomes increasingly fractured, threatened by privatisation, and the consumer-driven ethos potentially takes hold, an understanding of how knowledge around PBD has developed would support clinicians, parents, and young people in a more holistic knowledge of what is being communicated and asked of them.

This thesis focuses on interaction as a means to explore knowledge construction. Healy (2008) talks about disease as being a “social, linguistic and biological entity, now increasingly part of a world of bureaucratic categories and pharmaceutical practice” (p. xi). Given the multiplicity of ways in which to understand mental illness in children, breaking down practices into interactive and representational components allows a fuller picture of something unstable and constantly changing, or at least to capture a particular moment in its trajectory towards becoming a new entity. Language shapes understanding, thus communication between actors central to a phenomenon meaning becomes restrained if reduced to, or overly focused upon, a particular vocabulary of diagnosis (Parry and Levin 2012, 62). To build on this point, Alderson (2013) discusses the ways in which children can be implicitly blamed for things in which the cause actually lies in adult hands (Alderson 2013). In this thesis I argue that while it might not come down to ‘blame’ as such, the construction of PBD is borne of adult assumptions of how children should behave, or the parent child mismatch in which parenting style causes reactive effect in the child, leading the child to be on the receiving end of resulting ramifications. Tied up in this are the institutionalization of cultural norms and assumptions subtly dictating how not only a child should be, but what a clinician should know, how they should practice, how parents should parent and what childhood should be. My research hones in on what it is that has shaped the knowledge of those above. It is a small piece of the whole puzzle, but seeing how this diagnosis has developed, and now catching it as it moves into a

different social context, met with localized resistance, provides a way to shed light on psychosocial processes accompanying PBD diagnosis.

This will be further unpacked in the following chapters. *Chapter two* presents the theoretical framework guiding this thesis in which the development and construction of psychiatric knowledge is approached via a social representations framework emphasizing the anchoring of the unknown in the known, knowledge encounters among and between competing perspectives, and the modalities of social influence and asymmetries on knowledge that make up a dialogical approach to interaction. *Chapter three* illustrates the research design and methodology grounding this project, including the rationale for undertaking research with the particular groups and contexts that were ultimately chosen. *Chapter four* presents the first of the three empirical chapters, focusing on the voice of the pharmaceutical industry, which plays such a central role in the genesis of this diagnosis. An analysis of the organisational perspective of the industry communicating PBD is represented via internal documents, de-classified court documents, marketing, and continuing education materials, while the ‘external voice’ of the industry is explored through pharmaceutical advertisements. *Chapter five* unpacks clinical representations of PBD, comparing what, and who, clinician’s talk about when discussing PBD in the US as compared to England. The position of the clinical ‘Self’ in relation to significant Others, including parents, clinical colleagues, and the child at the centre of the debates, sheds light on how the representations that shape diagnostic understanding and practice are developed. *Chapter six*, the final empirical chapter, turns attention to parents in the US and England in order to see what factors shape the development of their knowledge about PBD. The final chapter, *chapter seven*, presents a discussion tying in theory and context to provide a model for how psychosocial processes shape the emergence and resistance of a contested diagnosis.

As will be discussed in the following chapter, the guiding theoretical framework of this thesis relates to social representations, and the particular concern with the transmission, diffusion and transformation of scientific knowledge, and relationship between scientific and common sense thinking. In the case of this project, an exploration of these processes can be seen in the transmission of knowledge about

PBD through encountering knowledge of often competing knowledge systems, which allow for new associations upon which to crystallize opinion and attitudes about PBD; diffusion through media and pharmaceutical advertising, as well as communication between colleagues, peers, professionals and the lay public; and the transformation of knowledge about PBD, the stage I argue we find ourselves in at the present time. By attempting to catch a diagnosis as it is transforming, this project contributes to debates surrounding children's mental health and the medicalisation of childhood. I propose that incorporating these frameworks alongside social psychological contributions including social representations, social influence and ideas of dialogicality will lead to a social psychology of medicalisation that, in addition to examining practices leading to medicalising childhood, will also look at the knowledge processes behind this increasingly dominant paradigm in the debates around children's mental health.

2. Theoretical framework: the acquisition and transmission of medical knowledge

Controversies are fascinating social processes because they make apparent all of the normally silent and hidden activities that regularly produce our taken-for-granted everyday world- shows us competing voices, fractious voices, contradictory facts and uncertain compromises in the world of knowledge production

(Dumit 2012, 32)

2.1 Introduction

Conrad and Barker (2010) suggest that what gets labelled as disease or qualifies as biological is often socially negotiated. Central to this negotiation is the acquisition and transmission of medical knowledge through which attitudes and beliefs of organizations, professionals and the lay public are shaped and put into practice. It is this notion of paediatric bipolar disorder as being the socially elaborated product of different spheres of knowledge coming together that is the fundamental concept driving this thesis. It is informed by theories related to how illness is constructed. As Barker (2010) explains, illness and disease exist as phenomena shaped by experiences, interaction, and shifting frameworks of knowledge as opposed to fixed realities. When it comes to mental illness in particular, everyday meanings may differ from more scientific and clinically based understanding (Dixit 2005) thus, an exploration of the relationship between how individuals conceptualize a diagnosis such as PBD in a wider social context made up of myriad implicit social knowledges is warranted. This chapter is therefore concerned with the social and psychological genesis of PBD as being made up of both representational and dialogical processes. The chapter begins with by grounding my socio-psychological exploration in selected literature on the social construction of illness, and more specifically the development of psychiatric knowledge and the expansion of diagnostic categories into the realm of the child. The next section explores social representations theory (SRT) as an overarching framework of the thesis, concerned as it is with the movement of knowledge within and between groups and contexts, and the processes involved in anchoring and objectification, rendering the

unfamiliar familiar, ultimately finding a home in a new object, in this case a new diagnosis. The chapter then moves on to discuss the use of a model of knowledge encounters to explore the role of recognition and perspective taking when coming up against the differing, often contentious, knowledge of Others. The final section introduces the idea of dialogicality as it coincides with knowledge encounters, focusing on the interaction between Self, Other, and Object, the tensions present when such interactions are asymmetrical in terms of power positions or knowledge held, and the role modalities of social influence including persuasion, conformity, and minority influence play in shaping such interactions. The chapter concludes with a summary of the chapter and brief discussion of how what is presented here relates to the wider contribution of this thesis.

2.2 The development and construction of psychiatric knowledge

A psychosocial analysis of the construction of scientific, medical, or psychiatric knowledge needs to address questions regarding what is already known about a specific object or phenomenon, and the social factors upon which this knowledge depends (Flick 1998). It is at the point between subjective and socially shared understanding that diagnostic boundaries are contested and reshaped. Categories of disease are contingent on a particular time and cultural context, existing as reflections of wider social attitudes, values and social mores. Psychiatric diagnoses in particular are often seen as vehicles of absorption for social and cultural circumstances, arising not just from the introduction of various diagnostic technologies and new options for treatment, but also wider socio-political ideas at play within a given context, in which what is culturally valued becomes objectified in the form of a diagnosis (Summerfield 2001). Harré (1998) noted that “psychological phenomena do not just happen in response to environmental contingencies, they are brought about” (p.137). The development of medical knowledge, and the construction of illness categories that happens as a result, is a circular process involving multiple actors invested in whatever potential benefit a diagnostic label might provide. Explanatory frameworks designed to understand pathological behaviour have shifted. Where once explanations for the eccentric or the peculiar might have been explored within a religious structure, the language of biomedicine, and a

concurrent “vocabulary of distress” have become the modern source of everyday explanation (Summerfield 2004; see also Davies 2011). Biological explanations leading to diagnosis and pharmacological treatments are now applied to “problematic behaviours” including those related to low achievement and underperformance (Davies 2011), a phenomenon reflective of the increased prevalence of, and trust in, biomedical knowledge. The availability of certain types of knowledge is a central concern of this thesis, and one that is highlighted by the child psychiatrist Leon Eisenberg, the so-called “father of ADHD”, in a paper constructing an argument in favour of the idea of mental illness as a social construction. Eisenberg (1988) includes a quote from Einstein who, reflecting on methods in the development of theoretical physics, suggests:

To the discoverer...the constructions of his imagination appear so necessary and so natural that he is apt to treat them not as the creations of his own thought, but as given realities (p. 2).

What constitutes a given reality, especially with regards to a diagnosis in children for which there is no agreed upon diagnostic criteria? Who decides what is valid to draw on in order to make definitive diagnostic decisions? The influence of social factors on the development of scientific and medical knowledge has been explored across disciplines, most notably in the philosophy of science (Fleck 1934/1979; Kuhn 1962; Hacking 1998, 1999) and sociology (Berger and Luckmann 1966; Abraham 1995, Brown 1995; Conrad 2007, Conrad and Barker 2010; Rose 2004, 2006, 2010). The starting point for this thesis, and its consideration of how a diagnosis is constructed in two separate cultural contexts lies in Fleck’s (1934/1979) exploration of the development of the modern concept of syphilis, in which the objectivity of scientific knowledge is questioned. Fleck (1979) argues that even in the face of ‘hard’ science and medical technologies, illness remains a culturally conditioned object.

The epistemology developed by Fleck didn’t ask what science should be, but what it actually is, and the ways in which “historical processes and social institutions are related to the emergence of scientific facts” (Lowy 1988, 137). Kuhn (1962) advanced Fleck’s perspective, proposing that it is the adjustment of scientific belief and alteration of theory on the part of professionals seeking to “eliminate any apparent conflict with evidence” which provides an illustration of the relativistic nature of scientific “truth”

(cited in Abraham 1995, p. 4). Such “shifts” can be seen in not only in science, but medicine as well in which clinicians change how they see behaviours in order to fit with what is expected within a dominant paradigm. This point will be subsequently supported in this thesis through findings among American clinicians to be discussed further in *chapter five*. In the US and England, societal norms dictating how a child should be inevitably play into how psychiatrists and other practitioners expand their understanding of pathological behaviours. These paradigms fall under what Fleck (1934/1979) termed a ‘thought style’ in which groups form, often unconsciously, into ‘thought collectives’ allowing for the development and survival of a scientific explanation only if it conforms to the prevailing habits of thinking. A central point of Fleck’s thesis that is relevant here as well is the idea that scientific exploits “can prevail only if they have a seminal effect by being performed at a time when the social conditions are right” (Fleck 1979, 45).

The acceptance or rejection of a diagnostic category, and all points in between, need favourable conditions in which to grow and expand, as well as to be discarded. In the case of a diagnosis still in the process of attaining a stable definition, an exploration into what shapes diagnostic practice, parental understanding, and how the child is represented on a broader scale are all central in grasping why here and why now? Would the diagnosis of PBD be able to expand in a culture that was more comfortable with children who lacked a certain level of focus, were perhaps less sociable, and not as achievement oriented? Fleck (1979) suggests that ideas do not arise spontaneously, but rather “are determined by their “ancestors” thus “a field undergoing development should always be investigated from the viewpoint of its past development” (p. 20). The development of PBD is the latest in a long line of diagnoses applied to children, and with each new category comes an increased familiarity with the language of diagnosis, and a reification of representations of the behaviours that shape its manifestation.

As an early proponent of the idea of cognition taking shape not as an individual process, but rather as the product of social activity, Fleck’s case study illustrates the ways in which a stock of scientific or medical knowledge exceeds the range of any one individual (Fleck 1979, p. 38). As expanded upon by Fleck, the individual is hardly ever

conscious of the dominant paradigms guiding their thinking. In the current climate, such thought styles veer towards the biomedical, with neurochemical explanations for a child's behaviour seen as more valid than those emphasizing social or environmental rationales. Key actors central to the development of PBD belong to different thought collectives, with General Practitioners working at the community level in England holding a different set of beliefs from those practicing in specialist research centres. Similarly, parents in the US maintain a perspective that perhaps differs from their English counterparts. Differing spheres of knowledge, yet all are responsible for holding and perpetuating awareness about the same object, often appropriating and advancing knowledge across boundaries, as will be discussed throughout the remaining chapters.

For Brown (1995) the construction of medical knowledge is based on the origin of professional beliefs and diagnosis, described as “ways of knowing that are shaped by the dominant biomedical paradigm, as well as ethical and moral values, the professional and institutional practices of the health care system, and the larger social structures of society” (p. 37). The construction of a new diagnosis is a dynamic process, constantly changing based on what those involved in its construction find necessary or meaningful. This looping effect of knowledge systems as revealed in Fleck's study provides an illustration of popular ‘lay’ knowledge feeding expert knowledge, which then translates back into a generally accepted knowledge simplified for the masses (Lowy 1988, 146). The diffusion of theories of mental illness into popular culture, or via direct communication to the patient by “the authority of the physician” have the ability to shape how symptoms are defined, as well as the wider course of the illness (Eisenberg 1988, 6). However, findings in the present research, which will be illustrated in the coming empirical chapters, and discussed in *chapter seven*, suggest an increasingly circular process in which the vectors of influence move both ways, with “lay” knowledge playing a central role in the development of professional knowledge about mental illness.

A significant insight of Fleck's (1979) thesis is the idea that attention initiates the development of knowledge and ideas, thus he elaborates on the “capacity of

observation acquired through learning process” explaining differences in the perception of medical specialists to the differences inherent to their training (p. 2). They are being educated to “see the right picture” (Lowy 1988, 142). As will be seen later in section 5.3.1, the “seeing is believing” mentality is very much a part of diagnostic practice among clinicians, but why should this seem less valid and more contentious for mental illness? Fleck is arguing that even things that can be “seen” under a microscope are constructed, as what is seen is an interpretation steered by training in a particular thought style which then clouds one’s ability to see the same object from a different perspective (ibid). In the development of knowledge around a particular diagnostic category, the question remains as to why a particular set of behaviours or physical sensation becomes identified as pathology in a particular place at a particular time. Such questions are of concern to Brown (1995) who asks questions relevant to this thesis as well:

Why was action taken or not taken? Who benefits, or at least avoids trouble, by identification and action? How did the divergent perspectives on the phenomenon merge or clash? How does the person's experience of the illness affect the course of the disease, as well as the social outcome of the illness? (p. 37)

A more critical view suggests that all diagnoses, not just those of a more contested nature such as PBD, are social constructions designed as a means of social control, segregating those deemed uncontrollable, and medicalising their deviance (Foucault 1971) or as a myth “providing professional assent to popular rationalization” (Szasz 1974, 262). Diagnostic categories are put forth as the product of lobbying and advocacy (Seale and Pattinson 1994) or social circumstances leading certain behaviours to be labelled problematic, and thus included in a diagnostic framework (Jutel 2011) all of which suggests the validity of Fleck’s early notions of what constitutes a scientific ‘fact’. There is always a process of social elaboration at play in terms of what gets picked up, and what gets discarded. Illness emerges as unique product of unique societal understandings of Self and resultant established norms (see for example Kleinman 1988; Littlewood 2002), a concept taken up by Hacking (1999) in his inquiry surrounding the act of classification as mechanism responsible for reshaping the way

individuals experience themselves. The ‘looping effect’ Hacking describes involves the evolution of an individual’s feelings and behaviours in concert with a ‘Self’ that has been newly classified as somehow disordered. The more knowledge people have about which behaviours constitute a particular diagnosis, the more the classification alone will cause those who fall within its boundaries to behave accordingly. Thus, categories of thought about people actually leads to the existence of those kinds of people, suggesting that there are expectations for what someone classified as having a particular illness will look like, filing away what behaviours are indicative of a specific diagnosis, and “what is believed to be true about behaviour affects the very behaviour which it purports to explain” (Eisenberg 1988, 1).

2.2.1 Expanding diagnostic categories into the realm of the child

Ever changing societal attitudes shape the way individuals define what it means to be healthy or ill, as well as ways in which they seek treatment for what they perceive to be wrong (Summerfield 2004). Sociological perspectives such as those related to the medicalisation of the everyday (Conrad and Leiter 2004; Barker 2010; Conrad and Barker, 2010), the effects representations of health in the media have on our sense of Self (Seale 2003), and the consequences of an increased societal comfort in using psycho pharmaceuticals as a psychic cure-all (Rose 2004, 2006, 2010) shape “how individuals and groups contribute to producing perceived social reality and knowledge” (Conrad and Barker 2010, p. 67). Cultural standards of behaviour, and related notions of what it means to be “normal” continue to assert themselves, most visibly in the current debate surrounding children’s mental health. The medicalisation of distress and emotional unease now being imparted on children leads to the question of unknown consequences. What are the consequences of imposing new social norms and values attributed to the fast-paced, neo-liberal economic climate, giving rise to values related to maximizing profit? Or as will be discussed throughout this thesis, what are the consequences of multiple systems of knowledge interacting with one another in reference to a child unwittingly thrust into the centre of political and moral discourse? Distraction, a less-than-upbeat mood and low productivity have become pathological (Davies 2011), a set of circumstances leading Verhaege (2014) to argue that in the

struggle for identity in a market-based society, new norms are being created, where different contexts push different definitions of what constitutes deviance, leaving children and young people on the receiving end of a new moral model.

It is in light of this wider market-based context that Timimi (2006) advances the idea of how “ childhood often represents a central arena through which we construct our fantasies about the future and a battleground through which we struggle to express competing ideological agendas” (p. 35). In presenting a socio-cultural account of the development of the ADHD diagnosis in children, Timimi (2006) expands on the early post-war construction of childhood as we now know it, seeing it as a springboard for the eventual medicalisation that has become increasingly common for this stage of life. In grounding the development of childhood in the shift in parenting practices after World War II from those emphasizing discipline and authority, to more modern incarnations privileging guidance, compassion and consideration of the rights of the child, Timimi (2006) makes a compelling argument for the origin of medicalisation among young people as stemming from the reshaping of family life, and the accompanying “renegotiation of power” within the family resulting from shifting economic structures, and mothers now able to go off to work (p. 36). Such a familial restructuring led to more professional ‘ownership’ of tasks once relegated to the role of extended family, such as child-rearing and parenting advice (ibid.). For Timimi, this is the point at which a more “child-permissive” culture takes shape, and children become socialized into a wider cultural ideology promoting ‘freedom’ through individualism, competitiveness and the rejection of authority (Timimi 2006, 36). With this socialization comes a blurring of boundaries between childhood and adulthood, between power of the parent versus power of the child; a power that is increasingly given stature via the child’s introduction into a world that seeks to identify them as small adults, drawing on the child as a new consumer, increasing parental anxiety in the meantime and leading to an increased reliance on professionals (Timimi 2006). The construction of this type childhood is then open to forces of medicalisation in which:

...economically and politically powerful groups, such as doctors and the pharmaceutical industry, have enabled Western medicine to push back its frontiers of influence. In the sphere of children’s mental health this has resulted in the creation, not only of new diagnostic categories, but whole

new classes of disorder such as ‘developmental neuropsychiatry’ (Timimi 2006, 38).

The definition of new diagnoses comes as a result of reshaping expectations of children, drawing on ideas which position emerging problematic behaviours in the realm of the biomedical, thus allowing for targeted treatment. The broader cultural context is then “relegated to that of triggers or modifiers of the disease” and it is the market forces that shape psychiatry’s response (Timimi 2006, 40). The construction of psychiatric knowledge and the development of new ‘conditions’ of childhood then become validated as established medical conditions alongside requisite pharmaceutical treatment, via inclusion in official guidelines for practitioners (Timimi and Moncrieff, 2013). Wider conditions surrounding the child that could account for changes in behaviour, such as poverty, abuse, or an unstable upbringing are then cast aside in favour of the immediate and treatable biomedical explanation.

Singh (2006) suggests that there are multiple factors that have supported the development of the ADHD diagnosis, not least of which are the institutional and professional contexts surrounding the child, what is referred to as the child’s “ecological niche” (2011; 2012). Citing schools as a major player, Singh positions their role as “mechanisms to produce and embed socio-cultural knowledge about children’s behaviour and approaches to treatment” as evidence of their integration with a wider medical agenda (p. 451). The need for inclusion of the world around the child is essential in order to better understand the diagnosis as it stands now, and future directions for diagnosis and treatment. The institutionalization not only of practices, but beliefs about what ADHD means and the justification of psycho-stimulants as treatment, illustrates the depths to which socio-cultural and socio-historical context plays a role. It is through acknowledging these contexts that Singh advances the moral dimension of ADHD by seeking to understand the experiences of young people themselves. Through an exploration comparing children in the US and UK, Singh (2014) illustrates the context dependent nature of diagnostic categories, and the differing representations children themselves have of their diagnosis and its meanings.

The representation of ADHD as the product of a child's "ecological niche" is part of a broader picture suggesting that a lack of motivation with regards to schooling and education is a symptom of a culturally ingrained lack of social mobility present in the UK context. While the lack of social mobility may provide the child with an increased sense of community in the form of family and friends close by, it is the ingrained nature of these social patterns that remain difficult to shift (Singh 2006) leading to Singh's finding that for kids in the UK, ADHD becomes a problem of "behaving well" as opposed to their American counterparts for whom ADHD is about achievement and a problem of "doing well" (Singh 2006, 892). Singh proposes that comparisons between the US and the UK point to cultural context emphasizing competing 'ecological niche' related to conduct versus performance. Such an ecological view allows for "more relevant judgments about impact of drug treatment on children's moral capacities, and informed views about those drugs, more informed ethical judgments" (Singh 2014)

If we are to support Murphy's (2006) assertion that "biology produces the impairment and society its manifestation" (p. 274), then we must acknowledge that how we choose to label such manifestations leads to how it is treated and understood by individuals, and represented on a wider social scale. The construction of a particular diagnosis is then the result of factors such as increased professional concern with a particular disorder, which provides a narrative guide on which to base thinking about the condition. With regards to PBD, Parens and Johnson (2010) acknowledge that rates of the diagnosis are much higher in the US than anywhere else in the world, leading to the suggestion that it is the redefinition of what mania looks like in children that is responsible for the recent increase. This redefinition comes as a result of American diagnostic practice, as opposed to just genes or environment, with American clinicians using lower thresholds for identifying symptoms than their European counterparts (Parens and Johnson 2010). Discussing what they term a "zone of ambiguity" between children who clearly do and do not suffer from a mental disorder, Parens and Johnson (2010, 2) elaborate on the complexities involved with identifying and beginning the proper course of treatment.

The expansion of a symptom such as mania, which has a very clear and defined meaning in the realm of adult bipolar makes diagnosis difficult when it becomes aligned with children. A clinician is no longer faced with a clear set of diagnostic boundaries, but is now required to draw on more subjective representations of what a ‘manic’ child should look like, and increasingly, the available explanation is that a manic child looks angry and irritable. Healy (2006) argues that Big Pharma is uniquely responsible for creating bipolar disorder in children through disease-mongering tactics, whereby the push to normalize notions of adult bipolar disorder and its treatment through direct-to-consumer advertising has shifted the possibility for such illness into the domain of children. In an analysis of medical advertisements promoting the use of psychostimulants in children, Singh (2007) traces the pharmaceutical construction of the ‘problem child’, an issue taken up by Healy and Le Noury (2007) in their exploration of the emergence of PBD. Their contention that it is an industry reliance on Other key actors, such as academic experts, parental advocacy groups, diagnostic measurement tools that spreads recognition of the disorder is a concern for this thesis as well. It is important to consider the multiple sources disseminating this particular brand of knowledge, as Healy and Le Noury (2007) have done; however, in order to explore the wider phenomenon of why it has stuck, it is necessary to have the space to consider what drives individual and intergroup meanings surrounding PBD, something a socio-psychological approach is well positioned to explore; moving beyond what is being constructed and how, to get at the why. How are ideas being borrowed and re-appropriated? To what end?

Berger and Luckmann (1966) suggest that it is through the accumulation of different perspectives that an object of thought becomes ever more crystallized. The meeting of multiple perspectives, and their associated knowledge systems, forms the core of my own exploration into the development of PBD in the US as compared to England. The development of a new diagnostic category, and the shifting knowledge surrounding how it should be defined, is a process that is always in a state of flux, especially with regards to mental illness, and particularly mental illness in children where moral and ethical considerations are brought to the fore in a way that allows

perspectives regarding diagnostic criteria and prevalence rates to never remain unchallenged. This chapter has illustrated so far some socio-historical and socio-cultural reasons for the rise in children being deemed mentally ill, but the remaining sections will focus on frameworks for studying psychosocial processes which are this thesis' central contribution.

2.3 Social representations theory (SRT) as a framework to explore the genesis of a new diagnostic category

How does one actually know what one is seeing when witnessing a child acting out with a certain set of behaviours? How can one be so certain that this particular constellation of behaviours are actually 'symptoms' and should equated with a particular diagnosis? How we acquire knowledge happens via direct, lived experience, or that which comes via indirect experience, drawing on ideas we come into contact with and relying on what we trust to be true (Moscovici and Duveen 2001). In studying the emergence of a new diagnosis, it is this indirect social knowledge that is important to explore. What becomes of a new diagnostic category as it moves from the domain of specialists into that of the public, and the adoption, resistance, or reshaping of such a category is a question addressed in this thesis. The clinician and parents making decisions on behalf of the child are not usually basing their assumptions and actions on first-hand experience, so what is it that guides them, and what role does the wider cultural context have on how they come to 'know' the child and potential 'pathological' conduct? Social forces at play, manifested via communication and discourse, contribute to how new phenomena are understood by different groups. This is a central concern of SRT as a social constructionist approach, particularly those phenomena related to the ever present tension between scientific knowledge (or medical and psychiatric knowledge in the case of this thesis) and more common sense knowledge (Kronberger 2015).

Moscovici's (1961) original development and application of SRT considered knowledge in relation to the context in which it is produced, taking into account the impact of scientific knowledge on everyday perception and thinking (in Farr 1998), a central component of the theory that makes it especially relevant to this thesis. Social representations are defined as:

systems of values, ideas and practices with a two-fold function: first to establish an order which will enable individuals to orientate themselves in their material and social world and to master it; and secondly to enable communication to take place among the members of a community by providing them with a code for social exchange and a code for naming and classifying unambiguously the various aspects of their world and their individual and group history. (Moscovici 1973, p. xiii)

As a theory concerned with how meanings are produced and propagated, exploring how knowledge about health and illness moves from the more reified domain of clinical knowledge and expertise into that of the lay public, SRT provides valuable tools for how wider forces, both historical and cultural, impact an individual's understanding and behaviour surrounding health and illness (Joffe 2002). Wagner et al., (1999) suggests how "in contrast to theories of attitudes, beliefs and values, which study phenomena only in terms of evaluations or as cognitions, the approach of social representations allows us to capture macro social phenomena in their historical totality and dynamics" (p.99). Such an approach allows for a more all-encompassing analysis of the multifaceted nature of groups in context, which is necessary given the complex, layered problem such as the emergence of a contested childhood mental disorder. As one aspect of socially shared knowledge, Linell (2009) considers social representations as "potentialities to evoke particular types of discourses, actions, and attitudes" (p. 242). It is those social phenomena arising from such discourse, especially those that tend towards remaining contested and of concern to the wider public, which produce tension and thus incite action through communication (Marková 2003).

Theories of medicalisation have focused on external factors shaping the construction of illness, but the strength of a socio-psychological approach in general, and the use of SRT in particular, lies in opening up the "black box" of medicalisation and paying attention to the role of representations, dialogicality and social influence shaping subjective and social reality. Exploring the tension between individual and societal knowledge, and understanding where the conflicts lie, or ways in which a diagnosis might be beneficial, and why it makes sense to have this particular category of behaviour, can all be better understood by thinking about the way PBD is discussed. Bauer and Gaskell (2008) write that the theory of social representations illustrates the

“process of transformation as ideas move in society” with such movement producing meaning through contact with the ‘Other’ (p. 339). In their contribution to Moscovici’s original theory, Bauer and Gaskell (2008) take as their central question what happens to ideas when they become part of common sense in particular contexts? When a new medical phenomenon emerges, different groups make sense of it in different, sometimes oppositional, ways. Bipolar began as a rare adult affliction that has gradually expanded to include children. Even among those expressing concern about the expansion of diagnostic categories there is often acceptance that this is a ‘new normal’.

According to Duveen (2000), two central functions of social representations are that they serve to both *conventionalize* the objects we encounter, locating them within a specific category allowing a starting point for interpretation, as well as acting as a *prescriptive*, becoming a guideline for thought and action. Such a combination enacts a structure “which is present before we have even begun to think, and of a tradition which decrees what we should think” (p. 23). Such structure is helpful in considering the psychosocial processes shaping how a new diagnostic category comes to pass, and can be seen in findings discussed in later chapters in which clinicians and parents realign what is seen in the behaviour of children they interact with what they feel they should see. How do ideas of what should be seen as representative of a diagnosis of PBD become integrated into wider thinking? Social representations function by “giving form to objects, people and events that one may encounter by locating them within a given category”, thus providing a point of reference with which to communicate with one another (Moscovici 1984, 7). We are then able to draw on representations that are most useful and make the most sense when attempting to account for new phenomena.

There is a tension that exists between prevailing psychiatric descriptions of disorder and a growing critique over the increase and expansion of psychiatric classifications. Looking at how PBD is constructed, produced and objectified by parents, clinicians and the pharmaceutical industry inevitably brings such contradictory representations to the fore. It is during periods of questioning, upheaval and change in which individuals are most motivated to apply meaning to experience in order to understand their increasingly uncertain world. Instead of focusing solely on the social

structures shaping how certain behaviours end up being labelled as pathological, SRT provides a framework to understand why and how this might happen, and additionally, why and how at multiple levels and across different spheres of knowledge. In focusing on how knowledge of PBD is constructed by different groups, SRT moves beyond the surface of the debates to examine the ways in which the diagnosis might be useful (see Cornish and Gillespie 2009) in the context not just of culture, but of daily lived experience. Representations of a powerful few have significant effects on what becomes accepted as fact. This legitimization is a circular process in that mutual influence and negotiation that comes into play with PBD, in which parents and clinicians view themselves, and one another, both as experts and as lacking full knowledge of what the diagnosis of PBD means. In writing of the role of social representations in the construction of social reality, Herzlich (1973) explains the fusion of individual experience with social phenomena that takes place through encounters with numerous values and models within a culture. It is through channelling the resultant knowledge into shared conceptual categories that Herzlich suggests results in the production of “a unique entity within which communication, consensus and social norms become possible” (p. 11). It is this space, this shared entity between three different spheres of knowledge production, that SRT is well positioned to explore in relation to the development, acceptance and resistance of a contested diagnosis such as PBD.

2.3.1 Making the unfamiliar familiar

Societies necessarily contain points of tension and disjunction. In considering the development of social representations within a culture that loathes uncertainty and absence of meaning, Duveen (2000) proposes that it is “around these points of cleavage in the representational system of a culture that new social representations emerge...in these points of cleavage there is a lack of meaning, a point where the unfamiliar appears” thus initiating the representational work to “familiarize the unfamiliar so as to re-establish a sense of stability” (p. 8). Social representations exist as a means to make sense of the unfamiliar. Anchoring and objectification are two social psychological processes central to the formation of new social representations proposed by Moscovici (1961, 1984) in which individuals and groups construct and make sense of new

phenomena by linking up new, potentially threatening knowledge and realigning it with previously understood concepts and understandings, thus, the unknown is now included in an already established category. In his original examination of the concept of psychoanalysis, Moscovici (1961) noted the myriad ways different groups made sense of the idea by suggesting how the social group to which one belongs is central to shaping which aspects of socially embedded knowledge are drawn upon, and provide a map on which to base perceptions, comparisons and in the case of an emerging mental disorder, understandings of what constitutes normal versus pathological behaviour.

While anchoring leads to the creation of the mental map with which to make unfamiliar phenomena familiar, objectification renders the abstract, unknown concept into something concrete, reducing “the mental to the physical and the unknown to the known by means of the creation of a figurative nucleus, words into images, or the transformation of images into elements of reality that can be concretely observed in people and things” (De Rosa 1987, 51). Objectification comes in the form of a physical symbolic object, for example a diagnostic label providing a set of behaviours into something tangible that can be assessed, acted upon and treated, a fact which provides comfort when faced with symptoms or behaviours less easily explained in terms of physical causes. In this sense, objectification of symptoms into diagnosis “saturates the unfamiliar concept with reality, changing it into a building block of reality itself” (Moscovici 1981, 198). Duveen and Lloyd (1990) propose that objectification is impossible unless a representation is already anchored (p. 2), however as I will show in later chapters, one of the theoretical contributions of this study will be to show that it is possible to have both happen simultaneously, in a way reminiscent of ‘build it and they will come’. In the case of a new diagnosis such as PBD, the idea of what it should be, or how it should look is introduced in the form of a diagnostic label, with individuals and groups then use as a point of reference with which to anchor new representations; representations which then make sense in terms of the object. The physicist James Maxwell captures the relevance of these processes noting that:

what seems abstract to one generation becomes concrete to the next- what is unfamiliar and unperceived on one generation becomes familiar and obvious in the next (quoted in Moscovici 1984, p. 37)

Knowledge thus becomes objectified by virtue of the fact that it is passed on, whether among individuals, groups, or as in the excerpt above, generations. As a diagnosis, PBD is itself the direct result of the anchoring process, based as it is on a series of borrowed representations, rather than possessing any clearly defined diagnostic criteria of its own. PBD doesn't exist as a category in the DSM 5 or ICD-10. Instead, its establishment as a diagnosis has happened as a result of drawing on adult criteria for bipolar disorders, realigning the symptoms and presentation with what is seen in children who show up in clinics with behaviours that lack a clear diagnostic home. More established illnesses such as ADHD and schizophrenia are repeatedly used as reference points by academics and clinicians in order to make sense of the children they see, adapting and reshaping adult criteria to try and fit with the new label that has been introduced. It becomes a circular process at that point, in which the anchoring of PBD in more established diagnoses creates the conditions for a new disorder to be reified as fact.

Anchoring extends beyond the realm of diagnostic criteria to include treatment options as well. Healy (2006, 444) writes of how psychotropic medication for treatment of bipolar disorders was “based on analogy with epilepsy, rather than on demonstrations of proven clinical benefits” suggesting that even the choice of what medication to use is based on what has been used with other conditions. As it stands now, the most frequently used pharmacological interventions for PBD have never been the subject of clinical trials with children, but are instead used in smaller doses based on what has been known to work in adults, and as Healy (2006) has pointed out, adults with conditions other than bipolar disorder. Such choices are not made in isolation, however. What is required for anchoring and objectification to take place is a subscription to collective thought through which communication transpires. Whether in the form of newspapers, television, or research journals, turning the unfamiliar familiar necessarily requires interaction and engagement with others in order to establish a point of reference. The importance of a point of reference comes into play in further discussion of social influence in section 2.5.1 below, in which the development of new norms of childhood, and the definition, diagnosis and treatment of pathological conduct is shaped by these processes.

Moscovici (1984) suggests that a consequence of the classification that comes as a result of seeking to generate meaning and understanding about the unfamiliar is that it provides a set of characteristics on which individuals can form interpretations, base opinion and initiate action. These interpretations and opinions can only go so far on their own, as the true development of new knowledge and social objects is necessarily contingent upon interaction. As will be explored in the following sections, interactive processes shaping the social negotiation of what constitutes a new diagnosis in children stems from the clash and alignment of perspectives multiple individuals and groups encountering one another's knowledge, as well as the dialogical interactions between one's self, the other, and the object of PBD. Processes of perspective taking, recognition of the other, social positioning and influence are all involved in shaping the development of new social representations, and thus the acquisition and transmission of new knowledge.

2.4 Encountering the Knowledge of Others

This chapter began by highlighting Fleck's epistemology in which the development of thought collectives stemmed from an examination of the changing concept of syphilis over time. The definition of what we have come to know about syphilis developed through interaction among and between these 'thought styles', through the meeting of ideas both in opposition and cooperation (Fleck 1979, 3). It is this encounter with other knowledge systems that is a central focus of a socio-psychological understanding of the development of a diagnosis. Without consideration of the perspective of the Other, there is nothing to come up against, react to, move on from or make sense of. "Knowledge" as explained by Linell (2009) is "socially generated, socially sustained, socially negotiated, transformed, confirmed and censored, and socially distributed" (p. 241), brought about, reshaped, maintained, often rejected and rendered obsolete by virtue of communication between individuals and groups. For Jovchelovitch (2007) these aspects of knowledge production are necessarily interconnected with, and rooted in, the wider social and cultural context.

In developing a framework to examine issues of communication for different groups, Jovchelovitch (2007) defines a knowledge encounter as "the meeting between

two or more representational systems, expressing different subjective, intersubjective and objective worlds” (p. 129), proposing a social psychology of such exchanges in which different representations, and the knowledge systems they enable, meet and communicate in public spheres. As defined by Jovchelovitch (2007), interactions:

involve meeting points between knowledge of Self and knowledge of Others, between competing representations, practices and views of the world that both recast the communicative dynamics between Self and Other and bring to the fore the nature of the dominant representations Self holds about the knowledge of Other (p. 128)

The use of the knowledge encounter framework is relevant for this thesis as knowledge about new disorders does not come out of nowhere, but rather through interactions between multiple actors, each with their own representational systems, both collective and social, that provide the context in which to develop understanding of a child’s behaviours, push specific agendas, engage in diagnostic practice, and position oneself as clinician or parent in the face of something so poorly understood. The construction of a diagnosis takes place through such interactions, and the variable nature of subjective and social knowledge and representations held within one individual or group, and the ways they can be reshaped through interacting with the perspective on the ‘Other’, makes this a compelling model for exploring the emergence of PBD.

The diagnosis encompasses not only the child who carries the label, but also institutions and industry who have a vested interest, parents who both contribute to, shape and internalize such research, and the mental health professionals who find themselves negotiating all of these spheres, in addition to external pressures from a wider institutional framework in the form of social services, schools or the pharmaceutical industry. Notions surrounding behaviours making up PBD, or concerns related to prevalence, options for treatment, or even whether or not it exists as a biological entity, are acquired, consciously or not, via processes of negotiation. Within groups, there are those who will seek out knowledge in line with a desired outcome, and others who find themselves in receipt of a new set of terminology and behavioural categories that they were previously unaware of. Accepting and recognizing knowledge

held by another as legitimate is shaped directly by a participant's existing knowledge of themselves and others (Jovchelovitch 2007, p. 139) as well as representations they may have regarding the source of information they are receiving, for example an innate mistrust of doctors, or a belief in the veracity of anything proposed in an academic medical journal.

Instances of knowledge encounters can be seen in research related to social representations, such as Marglin's (1990) examination of globalised (logocentric) versus localised (non- logocentric) conceptions of the smallpox vaccine brought from England to India in the 19th century. In highlighting competing meanings of illness both as an enemy to be prevented, controlled, conquered, or destroyed, and as part of a wider holistic system, Marglin (1990) explores attitudes towards vaccination through religious, political and naturalistic discourses. It is the battle between the scientific and the supernatural, in which one form of knowledge is presented as superior.

Studies looking at representations of health and illness have also provided examples of knowledge encounters in action. In focusing on representations of mental illness specifically, Jodelet (1991) cites such explorations as "an ideal vehicle for the study of social thinking and its functioning" given how unstable and up for debate many ideas and assumptions about the nature of many mental health diagnoses continue to be (p. 8). In addition, the health sector more generally provides salient examples of the emergence not just of lay and professional knowledge systems, but the development within those areas for new forms of knowledge to enter the fray, such as that of experiential knowledge (Jodelet 2013). Jodelet's (1991) study of representations held by members of a French community towards mentally ill lodgers living among them investigated ways in which the idea of 'Otherness' is constructed. In this case, representations of madness linked with fear and contagion led to a "belief in the transmission of insanity" which was at the heart of conceptions of madness (p. 21). The concept of feeling threatened and afraid of the Other is also of concern to Foster (2001; 2003) in seeking to understand representations of mental illness constructed and maintained by both the lay public and mental health service-users. Proposing differentiation as a means through which 'healthy' individuals hold up particular

ideological positions and strengthen identity, Foster (2001) suggests the emphasis on 'Otherness' becomes much less straightforward and more complex when examining representations held by the service users themselves. Knowledge encounters between both lay and professional systems emerges in Morant's (1998) comparative study of mental health professionals in the UK and France, suggesting that professional common sense is rooted in constant debate surrounding the many competing types of social and cultural knowledge, as well as institutional agendas (p. 834). Morant (1998, 2006) argues that position of mental health practitioners as intermediaries between professional and non-professional worlds come as a result of their being called upon to translate knowledge between the scientific and lay spheres rendering it "compatible with and integrated into 'common sense' (ibid. 819).

Beliefs about mental health and illness are not the result of a lack of knowledge or misunderstanding, but rather they are actively constructed to make sense of the frequently confusing and often contradictory experiences that people have (Zani 1995). In proposing that strategies developed for confronting illness are shaped by culturally specific health care systems, Zani (1995) suggests that it is the immediate need to assign a meaning to an illness that leads to an incompatibility with "slow, progressive advance of knowledge" producing "a continuum in which different interpretive planes co-exist" (p.145). Such a 'quick-fix' mentality can be seen in American diagnostic practice, where clinicians themselves experience tension between top-down and bottom-up systems of knowledge to create certainty in the face of an unstable, newly emerging diagnostic category, forced by virtue of professional reality to quicken the pace of knowledge advancement in the name of innovation.

While the above review illustrates ways in which encounters between knowledge systems can be at odds, such meetings can also lead to fruitful dialogue between individuals, their wider community and context (Aveling and Jovchelovitch 2013). The idea of knowledge as produced from lived, situated action provides the means towards knowledge encounters developing into partnerships between all stakeholders shaped by institutional and sociocultural contexts (Aveling and Jovchelovitch 2013). Thus, knowledge encounters can be seen as overcoming necessary conflict to arrive at a

moment of joint action leading to positive intervention (ibid). Encountering the knowledge of others involves struggles over both content of representations, as well as identities and group projects that a system of knowledge expresses (ibid., p. 36).

2.4.1 Recognition and perspective taking in knowledge encounters

The knowledge encounter approach draws on interrelated concepts of perspective taking and recognition (Jovchelovitch 2007, 129), with different outcomes produced by Self and Other which depends on whether “interlocutors can communicate and mutually recognize one another as legitimate partners in interaction” (ibid. 132) The emergence of PBD can be seen as an illustration of what Jovchelovitch (2007) refers to as a “hierarchical representation of knowledge” in which imbalances in status and one’s power position link to the perceived worth of different types of knowledge and has a direct influence on the way that knowledge is communicated, received and legitimated. In this sense, the way in which a disorder is first presented to the public, or rather who is responsible for the introduction contributes to a social construction of meaning in which knowledge is often linked to specific interests and agendas, where problems such as those related to legitimation of certain knowledge systems by groups with powerful interests come to the fore (Campbell and Jovchelovitch 2000). The process of acquiring and diffusing knowledge about PBD is not a straightforward, top-down progression. Rather, there is an element of knowledge appropriation taking place in which boundaries between knowledge systems are blurred.

Of particular interest is how individuals and groups use the new knowledge, for it is only in its usefulness that it may cross boundaries between institutions, professionals, parents and young people. The development of a new medical phenomenon is reliant on different groups making sense of it in different, sometimes oppositional, ways. Gillespie (2012) suggests that it is by holding on to one’s own perspective, while simultaneously considering and adapting to those of others, despite the possibility of significant differences in attitude, opinion, or understanding that allows action to take place. The integration of perspectives allows individuals to move between their own perspective and that of the other leading to processes of representing. A central question to address in approaching a socio-psychological

analysis of the construction of knowledge relates to the question of what individuals or groups know about a particular domain or object, in this case diagnostic criteria for PBD, and on which social factors this knowledge depends (Flick 1998, p.45). Diagnostic boundaries are perpetually being reshaped, and with that reshaping comes the need to recalibrate representations. Whether this happens through overt dialogue, or less obvious, more subjective mechanisms, it is an area where looking at different types of knowledge produced via knowledge encounters is useful. Names, symptoms and treatment of specific conditions, are communicated in conversation or through media, shaping representations of what is normal versus disordered, shifting and changing shape as other knowledge systems are encountered. Thus, members of a group or similar social context develop different representations from one another or even within themselves. Conversely, a controversial diagnosis has the power to bring together people from different backgrounds in their collective identification with the struggles that go along with having experience with the disorder, demonstrating “how transformations in the public spheres of communities relates to the transformation of knowledge” (Jovchelovitch 2008, p. 129).

Bauer and Gaskell (1999; 2008) suggest that the knowledge output of groups is not static. Over the course of the development of a disorder what begins as a sphere of knowledge made up only of professionals begins to open up to parental knowledge as well, creating new knowledge, which then may morph over time into a different representation of an object, or perhaps a different object all together. When it comes to a battle of meanings, not all ideas are equal (Castro 2014), and the clash of ideas and knowledge systems taking place in the development, adaptation and resistance of PBD as a diagnostic category can be seen as indicative of this. Of interest is the multidirectional flow of information and social influence, changing as it moves among groups. Perhaps a reference point is established within an organisational knowledge system, framed in terms of making a profit. Moving into the realm of those who mark it as such by virtue of their professional affiliation, it becomes reified as professional ‘expert’ knowledge, finally being made sense of on the practical level of a parent who attempts to put such understanding into action through parenting the child. But often

what is put forth doesn't make sense in a way that aligns with experience, so the lay knowledge is then fed back into the world of the professionals, who perhaps take it on board to reshape how they understand the object, which in turn feeds back to the institution, who looks at these knowledge systems as a means to further customize what they are putting out (fig. 2.1). So the knowledge encounter becomes a feedback loop, in which the encounter is never complete, and the knowledge is in a constant state of being added to.

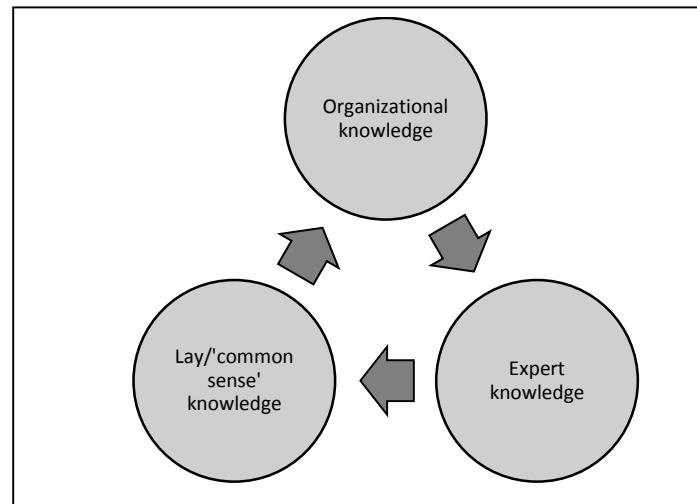


Figure 2.1: Knowledge encounter feedback loop

The following section elaborates on this looping effect to understand the dialogical interrelation between Self-Other-Object. As social representations are understood as socially embedded knowledge stemming from an individual's membership and positioning within social groups, what people know and the way they come to know it is dependent upon the social groups to which they belong (Flick 1998; see also Fleck 1979). Recognising and taking another's perspective necessarily requires interaction, and it is the dialogue that takes place, or is shut down, that forms the point at which a new object in the form of a contentious diagnosis in children takes shape.

2.5 Dialogicality

Social knowledge is made up of multiple voices, which take up fluid subjective positions in relation to actual or perceived others. A dialogical framework seeks to account for

how people relate to and understand the world, acquiring knowledge in divergent ways and proposing a way to understand human beings as not fully autonomous, but rather highly interdependent and reliant on one another's perspective to shape our own (Linell 2009). Thus, the development of knowledge, and resulting social representations, are socially elaborated via debates in which multiple perspectives come together to transform abstract information into more concrete meanings based on their own unique points of view (Clémence 2001). How these new social realities are devised, generated, understood and communicated are of concern to Marková (2003), who argues that such processes are necessarily take up between Self, or Ego, and Other, or Alter. The capacity of the human mind to relate and communicate, acquiring, appropriating and making sense of different forms of knowledge, grounds Marková's explanation of the ontological nature of dialogicality, in which it is through communication that the Ego-Alter "intersubjectively co-constitute one another: one does not exist without the Other" (Marková 2006, 126). The knowledge generated as a result of these interactions is captured as a triangular relationship between Ego-Alter-Object in which the object can exist as both external and internal to the Self (ibid. 128).

In considering the importance of interactions between Ego-Alter, the question of what is actually meant by the Self and the Other is significant. Who exactly is the Self being referred to? And who is the Other? Linell (2009) discusses the possibility for "multiple abstract dialogues" that may take place within oneself such as internal dialogue, dialogue between competing 'I' positions, between ideas, paradigms or even cultural artefacts (p. 6). All represent aspects of what Hermans (2001) refers to as a 'dialogical Self' in which such internal positions contribute to a 'multivoiced Self' (p. 250). This is echoed by Linell (2009) elaborating on the multiple 'Others' a dialogical Self comes into contact with: those who we communicate with directly (concrete Other), and those who might be considered a more 'generalized Other' coming in the form of peripheral third parties who may shape how we think and position ourselves. Such 'third parties' often become aids to, or partners in communication, allowing us to move beyond expressing ourselves "only with regard to the immediate addressee, but also with respect to, and in respect of, absent third parties that:

must be made relevant by the primary participants, in spite of the fact that they may be silent in the interaction, play more peripheral roles than primary participants, and are sometimes even only virtually present (Linell 2009, 100)

These insights regarding multiple voices coming together in an individual Self stem from Bakhtin's notion of 'heteroglossia' which, as Marková (2003) emphasizes:

...saturates all aspects of dialogicality: ambivalence, hidden and open polemics, collisions and quarrelling. All of these are ridden with tension in which different points of view clash and languages overlap exposing them to new interpretations (p. 113).

The tension brought about by interacting with competing perspectives, either internal or external, allows for one's position and intention to be solidified. Of relevance to this thesis is the idea that dialogue does not only take place within interpersonal exchanges between Ego-Alter, but also simultaneously on the level of wider sociocultural practices within communities and institutions, orienting towards the wider "sociocultural and historical belongingness" of the interaction, a level that Linell (2009, p. 54) terms 'double dialogicality'. This dialogue "at two levels" suggests one mechanism at play in the process of anchoring (*cf* 2.2.2), as in the case of imparting information or developing knowledge about a new diagnostic category with an unknown aetiology, paying attention to what is said about behaviours as symptoms is viewed in light of how it makes sense with a) what came previously, and b) acceptable explanations to draw upon to determine origins of illness, such as neurochemical explanatory frameworks that may filter how information about a child is processed.

Dialogicality as a theory of social knowledge takes as its point of departure the "dynamics of social action" which, according to Marková (2003) provides a more robust model than those such as social cognition which tend towards regarding knowledge as somehow stable, not accounting for the dynamics of interaction between Self and Other (p. xii). This approach to dialogicality does not suggest a fusion of Self and Other. Instead, Marková (2003) allows that while communication can bring the position of Ego-Alter closer together, there remains room for independence as

individuals, despite a “dialogical interdependence” highlighting the role of perspective-taking and intersubjectivity as a means to orient oneself in respect to another (p. 155). There is space for a ‘dialogical Self’ to emerge via multiple ‘I’ positions within an individual, and the reflexivity that comes through assessing the relationship between internal feelings and external events (Valsiner and Han 2008). This dialogical Self is thus positioned both personally and culturally, internalizing what takes place externally and becoming subjected to ‘position’ leaps in response to uncertainty and anxiety (Hermans 2001). Shifting contact with multiple Others necessitates a recalibration of one’s ‘I’ position in response to the position of one’s interlocutor. In referencing Bakhtin’s position that the Self does not become one with another over the course of dialogue, rather what is at play is a development of understanding the strangeness that is the perspective of the Other (Marková 2003, 103). Such processes to understand and access ‘the strange’ are what drive communication in the first place. It is the encounter between the Self and the strangeness of Other that leads to the imposition of meaning onto what is not known, as well as the appropriation the Other’s knowledge in a way that facilitates and supports making sense and rendering the unfamiliar familiar (Marková 2003, 104). Bakhtin (1981) expresses the interplay between Self and Other, and the process of taking on board another’s words and with it, it could be argued, aspects of their perspective:

The word in language is half someone else’s. It becomes ‘one’s own’ only when the speaker populates it with his own intention, his own accent, when he appropriates the word, adapting it to his own semantic and expressive intention. Prior to this moment of appropriation, the word does not exist in a neutral and impersonal language...but rather it exists in Other people’s mouths, in Other people’s concrete contexts, serving Other people’s intentions: it is from there that one must take the word, and make it one’s own. (Quoted in Linell 2009, p. 76)

This idea of appropriation is central to the construction of diagnosis. Researchers collaborate, ideas are borrowed and readapted for a different context, clinicians look to both pharmaceutical representatives, colleagues, parents, and their own subjective sense of expertise to shape diagnostic practice, and parents take on board academic and popular research, clinical advice, aligning that knowledge with their own experience as

parents of a “dysregulated” child. In all of these cases, the development and perpetuation of a diagnosis comes as a result of taking what is “half someone else’s” and making it one’s own, a process requiring reflection on how what is taken in makes sense, and is useful, in light of what is outside.

2.5.1 Modalities of social influence

While social influence represents its own core field of study within social psychology, it is included here as a subsection of dialogicality as, for the purposes of this thesis, modalities of social influence are considered as a communicative practice. In building on what has been laid out as the guiding framework for this thesis so far, the construction of diagnosis is seen as social and psychological processes dependent on the nature of the encounter between multiple stakeholders. Dialogical theory enabled an in-depth exploration of the interactions between Self-Other-Object involved in the construction of the diagnosis. These, I will argue here, are all guided and shaped by social influence, specifically the modalities of persuasion, conformity, accommodation, assimilation and resistance through minority influence, which this thesis will show to be key drivers in the development of PBD.

Revisiting Fleck’s work, we are reminded of the trajectory of a new idea, beginning as hazy and lacking necessary proof for validation, but becoming more “precise and substantial” as evidence is culled from multiple points of view (Fleck 1979, p. 23). It is the pressure stemming from public opinion that steers scientific knowledge towards accepting the ‘correct’ hazy ideas and moving away from those that don’t belong (ibid). How an idea is deemed correct however, and why there may be several versions of what ‘correct’ looks like, is bound to how established a system of opinions has become, and how powerful the position of those advocating a particular system continues to be. As a diagnosis given to children, there is a conspicuous moral component built into the establishment of diagnostic criteria and the assignment of behavioural symptoms. The question of what is normal is the natural counter-question to the push for pathology, thus exploring the evolving frames of reference and maintenance of norms giving rise to PBD is necessary starting point for further

understanding of the role of social influence in shaping wider representations, not only of the diagnosis, but the child as well.

Sherif (1936) notes that rather than existing as absolutes, social norms develop over the course of relationships between individuals (p. 17). In this respect, the role of perceived social consensus in the development of knowledge about PBD then becomes central to the establishment of normative frames of reference, as well as its development as a diagnostic category. Moscovici (1976) postulates that consensus has two socio-psychological functions. The first refers to the validation of opinion and judgment. The confirmation that one's social reality corresponds with the wider "socially endorsed" reality is essential in order to remove any doubt when encountering the perspective of another that may contradict one's own. Conflict is a necessary condition of influence, stirring uncertainty and ambiguity and leading to the second function of consensus, Self-affirmation through making one's private reality a public reality (Moscovici 1976, p. 152). In externalizing our private reality, we are asking others to join us in seeing what we see to be true. Consensus is a central consideration of this thesis, as it is a lack of consensus surrounding what bipolar disorder in children should look like that shapes how clinical representations of PBD are formed. The lack of agreement opens up space for a clinician's own subjective doubt, as well as sidelong pressure from colleagues, institutional pressures from above, and parental anxiety from below, all of which create multiple "socially endorsed realities" that the clinician must then make sense of and choose from. Both of the above functions of consensus-validation and endorsement- become part of the influence process. However that which dominates, and therefore shapes interaction, is determined by social norms (Moscovici 1976).

Social norms remain unstable entities, however Sherif (1936) posits that there can be a collective decision among individuals faced with an ambiguous object to perceive order by developing a frame of reference among themselves, thus lending some temporary stability (p. 90). As a practice, psychiatry is built on an individual clinician's subjective appraisal of a situation and set of behaviours, however as a profession positioned within the field of medicine, objective measurements and

empirical evidence are seen as being essential for credibility. Thus, the need for validation that one's opinions are correct and in line with prevailing norms of the group, what Festinger (1954) refers to as 'subjective validity', becomes a driver shaping understandings of PBD. The issue lies in the uncertainty surrounding the diagnosis, both in terms of diagnostic criteria, as well as clinical agreement over how best to define the disorder. The more ambiguous a situation or phenomenon, the more likely one is to depend on social reality, and collective consultation with a reference group, for orientation (Moscovici 1976, 31). The reference groups with which one aligns is significant in this respect, as it is this group that provides the norms and values against which one evaluates and compares one's own opinion (Turner 1991), supporting Festinger's assertion that an opinion is only valid to the extent that it is aligned with a group of people holding similar beliefs, opinions and attitudes (ibid, p. 19).

In examining how such norms are developed, Sammut and Bauer (2011) present a model of the cycle of normativity as a mechanism through which influence is put into practice in the development and maintenance of norms. The cycle presents normalization as resulting from the accommodation and assimilation of new knowledge, perspectives and ideas. The starting and end point of the cycle is the notion of a frame of reference, which provides a structure against which one might measure how well aligned their (or another's) perceptions, judgements, and attitudes actually are (fig. 2.2).

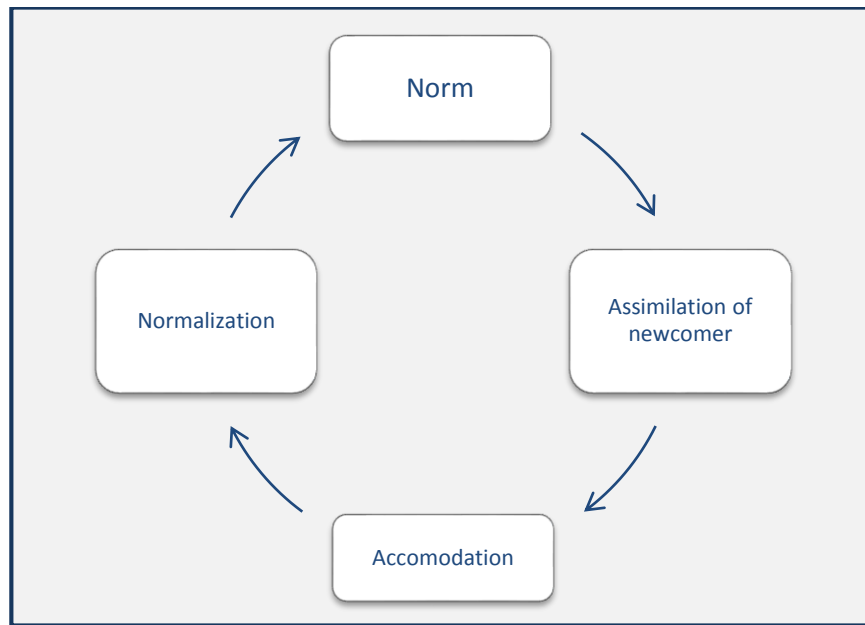


Figure 2.2: The ‘cycle of normativity’ as described by Sammut and Bauer (2011)

Thus, the success of a frame of reference is necessarily dependent upon how members of a group are able to abide by them, and provide a means against which to judge newcomers (Sammut and Bauer 2011). A central modality of influence involved in the development of a frame of reference is that of persuasion. Within social psychology, multiple socio-cognitive models exist to elaborate on how and why people change attitudes as a result of persuasive techniques of communication. The Yale Group, established by Hovland and colleagues researching at Yale University Sought to identify effects of persuasion on attitude change, paying particular attention to power and characteristics of the source of a communicative message, the nature and particular features of the message itself, and a consideration of the audience receiving the message, and how different audiences might be receptive to such changes (Hovland, Janis and Kelley 1953). This was expanded upon by Petty and Cacioppo (1986) in developing the elaboration likelihood model of persuasion (ELM) proposing a more cognitive, dual-process route to persuasion via central processing (slower and more deliberative, however likely to lead to lasting change) and peripheral processing (more immediate, but fleeting). While this thesis emphasizes the multiple directions of influence, the ideas laid out in the ELM model provide an understanding of how, for

example, the position of a clinician as a respected expert might make for a credible source, sought out by pharma as an influential ‘opinion leader’ (*cf* 4.6.1) or trusted by parents who may feel they have no other point of information, as with those living in England (*cf* 6.3.3). Sammut and Bauer (2011) discuss the notion of soft-power tactics as a means to persuasion, seeking to resolve conflict through communication by attempting to convince another that one’s own perspective is right, with the intended outcome that the recipient of persuasive communication ultimately shifts their position to align with that of the source of the communicative act (p. 88).

The accommodation and assimilation of new individuals, ideas and understandings is central to the cycle of common sense laid out by Sammut and Bauer (2011) as well. In this thesis, it is the presence of conformity pressures, minority influence, and the challenging of consensus in shaping the level to which knowledge of the Other is accommodated, or rejected, that is of concern. As will be discussed in later chapters, the assimilation of a new ‘broad spectrum’ idea of PBD is not taking place in England, while in the US it is the challenging of previous consensus in psychiatry stating bipolar cannot exist in young children that is being challenged. Adapting, or conforming, to group norms allows for a sense of group orientation and increased Self-esteem via social validation, as discussed in the previous section. However the presence of one group’s version of reality existing as the version of reality to be held as ‘correct’ leads to shutting down the consideration of alternative options in favour of maintaining some illusory form of consensus (see for example Janis 1972). The strength of a dominant perspective that others may unwittingly conform to thus has the power to change what is morally desirable as well, as in the case with the increasing medicalisation of children’s behaviour. Normative influence exerts powerful force in shaping conformity, as illustrated in classic studies by Asch (1952) showing the degree to which errors in estimation of objective truth can quickly become biased towards an objectively incorrect view held by the majority (Sammut and Bauer 2011) leading to a new frame of reference. Once a system of opinions has been established, it offers on going resistance to anything that may contradict it (Ng 2001) however those who find

themselves in a minority position still have the power to reshape such systems, as long as there is consistency (Moscovici 1976).

Social representations are co-constructions produced by different groups, with “executive producers” changing over time as the representation develops (Breakwell 1993, p.183). These representations held by a powerful few are significant in the way they affect the views of those with less status, legitimacy or recognition who may have less recourse to influence the development of the representation (Breakwell 1993, p. 188) and indeed it is through such patterns of influence processes that specific representations become stabilized (Duveen 2001). However, as will be shown in this thesis, a characteristic of minorities suggesting a desire for recognition and belief in the necessity of influencing the dominant social order to come around to see its own perspective as valid is what drives persistence and innovation (Moscovici 2001). The power of the minority lies in its ability to challenge consensus and resist conformity pressures, as will be illustrated in the discussion of clinicians and parents in chapters *five* and *six*.

The exercise of social influence via normalization acts as a powerful system fostering the accommodation of new ideas, a model of which proves particularly relevant to this thesis as it pertains to modalities of persuasion, soft-power, conformity and minority influence as significant mechanisms at work in shaping norms dictating the development of knowledge and practice around PBD. While I draw on this ‘cycle of normativity’ to explore the role of influence as a communicative practice shaping the development of representations, my own approach moves away from seeing the assimilation of newcomers and accommodation of dissenting views as being based in Piagetian ideas of socio-cognitive development and a schema/environment interaction as proposed by Sammut and Bauer (2011), instead focusing on it in terms of challenging consensus, conformity pressures and validation shaping accommodation of the knowledge of Other, and the establishment of a new norm. The salience of these particular processes as they relate to the development of a diagnostic category will be illustrated in *chapters four, five and six*, and discussed in depth in *chapter seven* when looking empirically at the role of the pharmaceutical industry, clinicians and parents in the US

and England in the development of representations of PBD. The modalities, and interactions themselves, need not only to be considered as mechanisms driving social influence, but also as processes with multiple vectors. The myriad directions of these modalities of influence, whether they are unidirectional, or exist multi-directionally as a feedback loop via interaction with Others, is central to the degree at which an idea may be taken on board or discarded.

In discussing the need for the temporal and cultural context to be open to a new idea or object, it is influence through the power of language and dialogue that emphasizes how a new idea might be useful through both revealing and reflecting the power behind it (Ng 2001, p. 90). Thus, in looking at the way in which the pharmaceutical industry, clinicians and parents in the US and England discuss PBD, paying attention to who's terminology and perspectives are adopted, and the processes guiding this adoption (or rejection as the case may be) sheds light on where the power, and thus influence, lies.

2.6 Conclusion

A diagnostic category such as PBD is more than a mental illness. Rather it is a set of expectations surrounding what constitutes normal behaviour, made up of contrasting representations surrounding the meaning of childhood that collide in local (family), institutional (medicine, education, pharmaceutical industry), and societal knowledge systems, becoming more powerful and reified the more institutionalized they become. Fleck (1979) writes of the necessity of a concept to be “sufficiently intertwined or interwoven within the fabric of contemporary knowledge in order to be considered finally established as an undoubtedly “real fact” (p.6). This project, through closely examining the construction of a new diagnosis by multiple actors in two separate cultural contexts, provides insight into why certain disorders take hold, while others continue to be resisted. The positioning of clinicians (see *chapter five*) negotiating a wider social and institutional hierarchy, in which they may exist as majority or minority players, are faced with top-down political and economic pressures from local medical systems, as well as bottom up psychological pressures which directly influences clinical approaches to diagnosis and treatment. Parents (see *chapter six*) face their own battle for

recognition of their experiential knowledge, wanting not to be blamed for poor parenting, but to be heard, understood and accommodated. Always in the background is the influence, however camouflaged, of the pharmaceutical industry (see *chapter four*) who has relied on persuasion via mechanisms of soft power to influence interaction with those deemed useful in order to shape new representations, and thus norms, of childhood.

Exploring multiple modes and levels of knowledge production is where a socio-psychological approach to the problem of changing definitions of healthy versus ill can provide a more dynamic account of how and why this happens than might be found in other socio-scientific approaches. It is the role of representations as modalities of knowledge in the construction of social, and psychiatric, reality that makes it a useful framework in which to study how such a disorder is constructed and taken up by different groups. Gaskell (2001) advocates a social representations perspective noting that it allows room for the dynamism present in cultural, scientific and technological developments to be considered, as different knowledge bases represent differing realities, each with their own concerns, enthusiasms and agendas. Thus, social representations of PBD may actually play a central role in the development of the wider, continuously developing reality of PBD, pointing to the co-constitutive development of medical knowledge. Jaspers notes that “more than the physicians’ judgment, it is the dominant ideas of the social context, which determine what is called “disease”” (quoted in Canguilhem 1989, p. 121). It is precisely this idea that can be brought forward through an exploration of dialogical processes and representations held by members of the wider social context, and modalities of influence as communicative practice underlying their development.

Central to how this thesis has been approached theoretically is the question of the function and motivation of particular discourses, and in particular the quest for validation and legitimisation of particular knowledges, whether they are institutional, professional or lay knowledge systems. The appropriation of language and ideas related to PBD points to the strategic action of dialogue, as well as the presence of asymmetrical knowledge and power dynamics influencing which understandings of

PBD are taken up. Vaughan (2011) brings to the fore power dynamics that can shape a more ‘strategic’ approach to communication. Strategic action:

...may involve appearing to accommodate the Other’s perspective, but this, importantly, is not for the purpose of developing new knowledge and a mutually derived communicative goal. Rather, the purpose is effective achievement of the speaker’s ‘I’ intention (Vaughan 2011, 51)

One’s subjective opinion within a wider collective determines how one makes sense of and communicates information about a particular object. PBD has developed as a result of interactions between the very powerful, and those who may be perceived by themselves or others to be less powerful, but they have all had a stake in the development of the diagnosis on some level. All have produced knowledge, accommodated the knowledge of the Other and contributed to redefining representations of the child at the centre of the diagnosis. The strategic action of dialogue in order to maintain one’s power position, as elaborated in the excerpt above, allows for a deeper understanding of social processes, such as medicalisation, by highlighting intentions and goals present in communication. The generation of meaning and redefinitions of problematic conduct can be found in an exploration of the function and motivation surrounding what is said. The multiple ‘voices’ playing a part in developing knowledge of what behaviours should be deemed pathological for example, introduces a way of considering why there is an increased comfort with identifying certain aspects of childhood as being worthy of medical study, diagnosis and treatment.

It is this focus on representational processes of anchoring and objectification, combined with knowledge encounters, dialogical processes, the personal positioning of Self and Other within those interactions, and the role of social influence shaping those interactions that form a central contribution of this thesis, one which will be explored in further detail in the remaining chapters. The following chapter, *chapter three*, will present an overview of the methodology involved, followed by analysis of the ‘voices’ of the pharmaceutical industry on a global scale (*chapter four*), clinicians in the US and England (*chapter five*), and parents in the US and England (*chapter six*). A final discussion chapter will bring the empirical analysis together with the theoretical frameworks that

have been presented here in order to advance a socio-psychological understanding of the construction of knowledge around a diagnosis, which remains controversial, contested and uncertain, and what impact cultural context has on the development of this knowledge.

3. Research design and methodology

3.1 Introduction

This thesis is concerned with the diagnosis of PBD and the psychosocial processes at play shaping how a new and emerging condition is constructed in the US as compared to England. The availability of particular assumptions and ideas circulating in the public sphere are very much a product of a unique set of circumstances that make up a cultural ‘present’; one in which notions of health and illness are formed out of established and newly emergent social norms, as well as the wider political economy of groups and organisations with interests in how the wider society understands and acts upon notions of health and illness. The purpose of my research builds on this idea to explore how and why a new mental illness in children, PBD, has taken hold in a particular time and place, and how differing perspectives have contributed to acceptance or contestation of the diagnosis. In order to address this, the current study utilises a grounded-theory (Glaser and Strauss 1967) qualitative approach to analysis in which the voice of the pharmaceutical industry, clinicians and parents in the United States and England is explored, allowing theory to develop from the data. A qualitative comparative research design using document analysis, image analysis and semi structured in-depth interviews was chosen in order to develop an understanding of the multiple perspectives in their particular social contexts, and in relation to this specific disorder (see fig. 3.1 below). PBD remains controversial, as there is still no firmly established, agreed upon set of criteria objectified in any diagnostic manual. The United States and England represent two different ‘cultures of medicalisation’ in which societal values and social norms feed into how emotional distress in a child is interpreted. The diagnostic debates taking place around PBD acts a vehicle to understand how these different systems of knowledge operate in order to develop an understanding around diagnosis and practice. Thus, context is central to understanding PBD, making a qualitative approach useful in exploring the multiple perspectives, knowledges and interactions taking shape in the establishment of the diagnosis.

In what follows, the methodological framework for the thesis is presented, beginning with an outline of the research contexts. I will then present the procedures involved in the three empirical studies that make up this thesis: the ‘voice’ of the pharmaceutical industry as accessed via the analysis of internal documents and pharmaceutical advertising; clinicians in the United States and England; and parents of children with the bipolar diagnosis in the United States and England. The analytic procedures for each study will be described in more detail in the associated empirical chapter. My aim with this chapter is to present the empirical component of the thesis and offer the reader a full methodological account of the research. The overarching question guiding the research has been how is the diagnosis of PBD constructed in the US as compared to England. The three studies were guided by the following sub-questions:

- 1) What are the social representations of PBD held by the pharmaceutical industry, and how has the industry contributed to wider understandings of PBD as a diagnostic fact?
 - 1a) What factors shape such representations within the pharmaceutical industry?
- 2) What are the representations of PBD held by clinicians in the US and England, and what psychosocial processes have shaped those representations?
- 3) What are the representations of PBD held by parents in the US and England, and what psychosocial processes have shaped those representations?
- 4) What do the content and processes of representations of PBD among Pharma, clinicians, and parents suggest about the construction of the diagnosis in the US as compared to England?

An important factor when considering a research project related to a contested mental illness in children, a sensitive topic where strong opinions, moral and value-based assumptions are necessarily brought to the fore, is my own position as a researcher. I bring up the idea of reflexivity here, before detailing the methodological approach taken in the research, as it was my position as investigator, but also as an

outsider in most respects, that was on my mind at every stage of the research process. Robson (2011) asks what responsibility investigators have for the knowledge they have acquired as a result of the research they have conducted (p.199). This was something on my mind constantly, both while conducting the interviews and analysis. While speaking with parents, for example, I was conscious of the fact that I was not a parent myself, so how could I possibly know what it was like to be a parent in the situation my participants were in, and make assumptions about what it is they were really saying or thinking? While I don't doubt that my attention might have been directed differently had I been in a closer position to my participants, I believe my distance from the immediacy of their experience was important for the sake of attempting to maintain objectivity. Qualitative research necessarily involves interaction between the researcher and the data and thus interpretation and presentation of findings always involves some part of the researcher (Cutcliffe 2000). As such, individual researchers act based on the meaning the object of their research has for them as opposed to any outside scholar, determining what is taking place in interaction rather than imposing a subjective set of expectations and assumptions (Blumer 1969). As a researcher, I agree that an awareness of preconceptions, beliefs and any prior knowledge being brought to the study needs to be maintained, however I disagree that it should be cast aside all together, as that would be impossible. Instead, I agree with Stern (1994) in the assertion that it is the creativity in the act which qualitative research allows that "brings the truth of a social situation into being" (Cutcliffe 200, p. 1479). This is not to say that as a qualitative researcher I was giving myself free-reign to pull concepts and theories out of nowhere, rather I sought, through a deep familiarity with the data, to respect what was said and continued attention to the research questions. My awareness of my position hopefully allowed me to approach the interviews and analysis with a sensitivity to the fact that I was on the outside, while at the same time keeping the research questions and theoretical frameworks close.

3.2 Research contexts

This thesis is generally concerned with questions surrounding how a medicalised condition becomes a globalised diagnosis, moving across cultures by virtue of construction, transmission and application of medical knowledge. The United States and England were selected as two cultural contexts representing two ends of the spectrum: expansion versus resistance of a new diagnosis. As discussed in *chapter one*, PBD is still very much rooted in the US context, with literature suggesting differing diagnostic practices as the reason for cross-cultural discrepancies in prevalence rates (see Stringaris 2010; Clacey, Goldacre and James, 2015). As mentioned earlier, the rationale for a comparison with England rests on a number of factors: the broader institutional cultures of medicine in the two contexts (consumer-driven versus socialised), the use of different diagnostic manuals and related reliance on insurance codes, variations in lay- familiarity with the language of diagnosis, arrived at via exposure to self-help manuals and direct-to-consumer marketing of medications and the conditions they treat, and finally the role of health care users in steering clinical practice. An exploration into how those practicing or parenting within these systems provides insight into whether the genesis of PBD is something of a modern-day ‘culture bound’ syndrome, or if there is in fact another way to understand why the diagnosis, how it comes to be conceptualised and enacted, has thrived in the US while remaining rare elsewhere in the world.

Chapter two introduced the conceptual framework guiding this research in which a social representations approach is drawn on as a means to understand the movement of knowledge about PBD, something which is still very much in-progress and affords a unique research opportunity on the emergence of a psychiatric condition. Given the concern of social representations theory with the transmission, diffusion and transformation of medical knowledge, and particularly the way it is held and rendered useful by non-professionals, a comparison not just among individuals, but also across cultural boundaries, allows for a way of understanding diagnostic construction as it continues to take shape. England was seen as an appropriate comparative context in that it has gradually seen an increase related diagnoses, such as ADHD. Additionally,

PBD has been recognised, though not fully accepted, as a diagnosis both clinically (See Dubicka et. al 2008; James et. al 2014, Chan, Stringaris and Ford 2011) and in the most recently updated NICE guidelines (NICE 2014). Thus, comparison between the birthplace of the diagnosis and a place where it continues to be negotiated allows for an exploration of what social psychological processes are at play in the development, acceptance, or rejection of a particularly controversial diagnostic category.

In seeking to understand this condition in particular, the US is an obvious starting point given its position as the birthplace of the diagnosis. The consumer-driven nature of the US healthcare system, and questions surrounding broad systemic and institutional practices leading to increasing medicalisation and treatment on mental health conditions, provides the backdrop out of which PBD emerged and continues to be contested even as the diagnosis continues to become more common. The healthcare context of the US is made up of a combination of government programs such as Medicare and Medicaid and for-profit private insurance programs all of which provide health coverage for approximately 260 million Americans, with about 49 million remaining uninsured (Sillup and Makowska 2013, 6). The majority of Americans are privately insured (195 million) with the majority of that population covered through their employers (ibid.). The importance of access to insurance matters when it comes to discussion of PBD, as the link between insurance and the pharmaceutical industry dictates how the disorder is diagnosed, who is diagnosed, and how it is treated. A related aspect of the US context which will be discussed in *chapter four* of this thesis is the presence of the direct-to-consumer advertising of pharmaceuticals, permeating the public sphere with a familiarity of myriad health conditions, as well as their pharmacological treatments. Such advertising does not exist in England.

England provides an interesting comparison in that there is significant overlap with regards to research, the use diagnostic tools such as the Diagnostic and Statistical Manual of Mental Disorder (DSM), and the acceptance of several formerly contested diagnoses, for example Attention Deficit Hyperactivity Disorder (ADHD). However, ideas about children and mental illness continue to be secondary, where the national health system is less prepared to ‘see’ such illnesses in very young children, and as a

result the diagnosis of PBD remains rare, with an element of resistance to the possibility of existence as defined by broader diagnostic criteria coming out of the US. The differences in the debates surrounding children's mental health in these two cultural contexts provides a fertile ground on which to explore how such a diagnosis comes to be accepted or rejected on multiple levels. Several years ago the diagnosis of ADHD went from being seen in England as virtually non-existent "American problem" to something diagnosed not just in children, but now adults as well. There is a sense that a similar cultural shift is taking place with the diagnosis of PBD, however the degree to which it is recognised by professionals and the general public depends on the extent to which knowledge about the disorder circulates, and is understood, in a wider societal context.

The English healthcare delivery system is the responsibility of the central government (Grosios, Gahan and Burbridge 2010) which designates a healthcare budget generated from tax revenues for the National Health Service (NHS), which is the main employer of medical staff and one of the largest healthcare systems in the world (Sillup and Makowska 2013, 6). Although the NHS represents the fifth largest pharmaceutical market in the European Union, it continues to control the majority of drug prescriptions, signifying that the UK is "the highest user of generic drugs and the lowest user of new drugs in Europe" (ibid., 8).

This research is especially timely given the most recent publication in the US of the latest version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013, a publication recently dismissed by The National Institute of Mental Health (NIMH) in the US, who called into question its legitimacy as a diagnostic tool (Insel 2013). Its publication has reignited debates in the US and beyond surrounding what constitutes mental illness, how best to approach expanding diagnostic categories for children, and the potential medicalisation of childhood behaviours. A comparison with England provides a compelling angle in that the UK, by virtue of the way the NHS is set up, is less bound to the rules and codes of the DSM (using the ICD-10 in conjunction) and the influence of the pharmaceutical industry and its related marketing practices in the US.

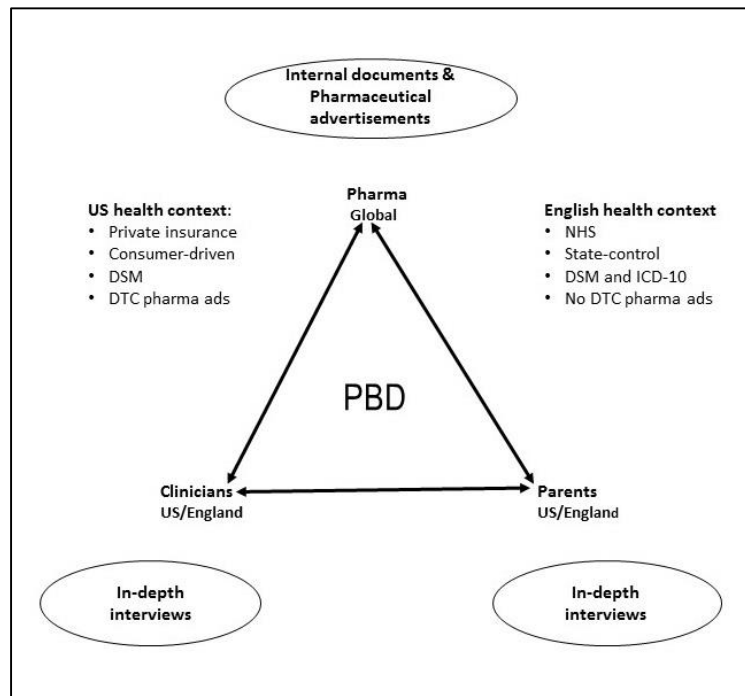


Figure 3.1: Illustration of overall research design

3.3 Study 1-The ‘voice’ of the Pharmaceutical industry

The first study explores the ‘voice’ of the pharmaceutical industry as a key actor in the development of PBD as a diagnostic category on a global scale (see *Chapter Four*). Medical and scientific knowledge is generated through social processes made possible by myriad institutional practices including political decision-making, research funding, collaborations between researchers and institutions (Pickersgill 2010). The pharmaceutical industry sits at the intersection of these practices, where research, marketing and dissemination of medications and the conditions they treat shape wider understandings of what it means to be ill, and what pathology can look like. For this reason, the inclusion of the pharmaceutical industry as one of the three ‘key’ voices was deemed necessary to provide a more complete picture of the genesis of this particular diagnosis.

3.3.1 Internal pharmaceutical industry documents

Documents are a useful source of data as they provide a level of understanding of the social realities and representations taking place within particular institutional contexts (Flick 2006). Internal industry documents are used here for their role as communicative devices that were designed to fulfil a practical purpose, thus illustrating the existing knowledge systems within the industry at the time, reflecting the industry's own agenda in developing a wider understanding of children's mental illness. In total, fifteen documents were chosen for analysis to represent a range of perspectives from within the industry (see table 3.1). The documents were selected based on the most prescribed medications to children for PBD and include Risperdal (Johnson and Johnson), Zyprexa (AstraZeneca) and Seroquel (Eli Lilly). The documents were previously confidential, but are now found in the public domain, and included court transcripts from a former CEO of a pharmaceutical company, a former pharmaceutical sales representative who would make sales calls to clinicians, marketing plans for medications, internal emails, and slide presentations used to educate clinicians and sales representatives.

Table 3.1

Internal pharmaceutical industry documents

	Document Name	Pharmaceutical affiliation	Year
1	Seroquel strategic plan, 1997-2001	AstraZeneca Seroquel	1996
2	Drug evaluation letter from US Food and drug Administration	Johnson & Johnson (Janssen) Risperdal	1997
3	Zyprexa Marketplace Strategy	Eli Lilly Zyprexa	2000
4	Business Plan Summary, Risperdal	Johnson & Johnson (Janssen) Risperdal	2000
5	Minutes of meeting with FDA to discuss pediatric exclusivity and development program for conduct disorder	Johnson & Johnson (Janssen) Risperdal	2000
6	PCP (<i>primary care physician</i>) Discussion Guide	Eli Lilly Zyprexa	2000

7	2001 Integrated Product Plan, Zyprexa product Team	Eli Lilly Zyprexa	2001
8	Zyprexa Global Marketing Plan, 2003-2004	Eli Lilly Zyprexa	2002
9	Zyprexa primary Care Sales Force Resource Guide	Eli Lilly Zyprexa	2002
10	Proposal/Budget: trial 99, 104, 105, 104+105 Abstract preparation and submission, USPMHC 16 th US psychiatric & mental health congress	AstraZeneca Seroquel	2003
11	Zyprexa Retail Resource Guide	Eli Lilly Zyprexa	2003
12	Internal email	AstraZeneca Seroquel	2004
13	Risperdal litigation trial, Bentley vs. Janssen. Transcript of Pharmaceutical sales rep Tony Jones	Johnson & Johnson (Janssen) Risperdal	2012
14	Risperdal litigation. Transcript of videotaped deposition of Alex Gorsky, former CEO Janssen	Johnson & Johnson (Janssen) Risperdal	2012
15	Civil action court document, United States in Complaint Intervention, including sales call notes from pharmaceutical sales reps	Johnson & Johnson (Janssen) Risperdal	2013

Sources: Documents 5, 13-15 from Brill, S. (2015). All Others from University of California San Francisco Drug Industry Document Archive (<https://www.library.ucsf.edu/db/drug-industry-document-archive-dida>)

Documents were drawn from two sources. Eleven came from the University of California San Francisco online drug industry document archive, which is a collection of documents “created by major pharmaceutical companies related to their advertising, manufacturing, marketing, sales and scientific research” (<https://industrydocuments.library.ucsf.edu/drug/>). The search focused on three medications, using childhood/paediatric/bipolar as search terms. The remaining four documents, all related to the drug Risperdal, came from an interactive article published by the Huffington Post (Brill 2015).

3.3.2 Pharmaceutical drug advertisements

The second data source in the study of pharmaceutical representations of PBD was the external manifestation of the industry’s ‘voice’ in the form of drug advertisements. In citing McCluhan, Farr (1995) suggests that advertisements are “part of the folklore of

an industrial culture. It is quite literally, possible to read the signs of the times” (p. 15). In conducting an analysis of pharmaceutical drug advertisements, it is possible to get an illustration of which ideas about mental health are being perpetuated (Foster 2010). Advertisements are designed not only to influence, but also to reflect existing professional ideas and to support professional identity (Foster 2010) thus contributing to wider implications for how treatment is perceived. Thirty-two unique advertisements (there were multiple ads repeated) were drawn from paper copies of the Journal of American Child and Adolescent Psychiatry (N=12) and the British Journal of Psychiatry (N=20) at three points in time: 1997; 2004; and 2011 to reflect any potential growth in familiarity with PBD after it was introduced in 1995 (see table 3.3).

Table 3.2

Medical journals and advertisements accessed January-June at three points in time: Total ads (unique ads)

Journal	Timeline		
	1997	2004	2011
British Journal of Psychiatry	19 (7)	19(11)	9(2)
Journal of the American Academy of Child and Adolescent Psychiatry	5 (1)	14 (6)	14(5)

Advertisements selected excluded those for anti-depressants, instead focusing on medications exclusively indicated for childhood mental disorders (ADHD) or were used off label for PBD (antipsychotics such as Risperdal). An initial scan of the ads was done to get a sense of what stood out visually and in terms of text, size of ads, which journals they were found in before undertaking a semiological and thematic content analysis discussed in section 3.6.2 below

3.4 Study 2-Clinicians in the US and England

The second study focuses on clinical representations of PBD, comparing health professionals practicing in the US and those in England (see *Chapter Five*). Clinicians in the US and England play a significant role in communicating the disorder to parents and recommending treatment options. Clinical professionals, particularly those working

in children's mental health, are working amidst what Galanter and Patel (2005) refer to as the "variability and inaccuracies in diagnosis" (p. 675) in which the risk of a child being misdiagnosed as a result differing clinical perspectives can result in inappropriate or harmful treatment. This diagnostic inconstancy is central to the debates around children's mental illness, thus the inclusion of clinicians allows not only for an understanding of professional opinion and personal struggles regarding the existence of the disorder, but also what drives diagnosis, especially in the realm of third party (parents, teachers) pressures, and their subjective positioning in relation to these. The decision to use semi-structured in depth interviews was one of both practicality and theoretical considerations. Gaskell (2000) writes how "the social world is not an unproblematic given. It is actively constructed by people in their everyday lives, but not under conditions of their own making" (p. 39). Thus, the usefulness of depth interviews lies in their potential to explore how ideas and meanings are developed in the course of a conversation, through shifts in thinking and the choice of how other perspectives are represented. Exploring clinical discourse, or by extension that of the pharmaceutical industry and parents also present in this thesis, is of interest as an approach as it acts as a behaviour in its own right, as well as "the virtually unique window that it opens on what lies behind our actions" (Robson 2011, 280).

3.4.1 Participants

Semi structured interviews were conducted with mental health practitioners in the United States (n=8) and England (n=10). In the US, child and adolescent psychiatrists, and one psychiatric nurse, were sampled from both private and public health services and interviewed in June and July 2013. The sample comes from university clinics and community hospitals four urban areas on the East Coast (n=4) and in the Midwest (n=4). In England, the sample is made up of clinical psychiatrists and psychiatric nurses who were contacted via Child and Adolescent Mental Health Services (CAMHS) and specialist clinics in Greater London (n=7), Gloucestershire (n=2) and Oxfordshire (n=1) and interviewed March-December 2013. All clinicians, including those who were affiliated with research, were practitioners involved in the daily assessment and

treatment of children with behavioural disorders (see table 3.3 below for participant information).

Table 3.3

Clinician participants and codes: England and the US

English participants	Position	US participants	Position
UKC 1	Child and adolescent psychiatrist: practitioner/research	USC 1	Child and adolescent psychiatrist: practitioner/research
UKC 2	Child and adolescent psychiatrist: practitioner/research	USC 2	Child and adolescent psychiatrist: practitioner/research
UKC 3	CAMHS nurse	USC 3	Child and adolescent psychiatric nurse
UKC 4	Child and adolescent psychiatrist: practitioner/research	USC 4	Child and adolescent psychiatrist: practitioner/research
UKC 5	Clinical child psychiatrist	USC 5	Clinical child psychiatrist
UKC 6	Clinical child psychiatrist, CAMHS	USC 6	Child and adolescent psychiatrist: practitioner/research
UKC 7	Clinical child psychiatrist, CAMHS	USC 7	Child and adolescent psychiatrist: practitioner/research
UKC 8	CAMHS mental health nurse	USC 8	Child and adolescent psychiatrist: practitioner/research
UKC 9	Clinical child psychiatrist- CAMHS		
UKC 10	Child and adolescent psychiatrist: practitioner/research		

This project takes a theoretical approach to sampling, which Gobo (2008) describes as constructing a sample, meaningful through building in certain characteristics or criteria, which helps to develop and test the proposed theory and explanation. Gobo (2008) notes that groups are selected on the basis of relevance to research questions, theoretical position and analytical framework, analytical practice and explanation being developed. The sample was constructed in order to access perspectives of those working with children with PBD in order to enable specific questions to be answered related to the development of knowledge around the diagnosis. It provided a set of clinical and parental voices on PBD, allowing for a comparison of how these different groups contribute to the construction of the condition, illustrating socio-psychological mechanisms at play in the construction of diagnosis.

One limitation with this aspect of the study, however, was that the inclusion of more ground-level community psychiatric practitioners in the US would have provided a broader perspective, but as a testament to the shortage of services available, it came as little surprise that they were over-subscribed and unable to speak to me. Clinicians were contacted initially via phone or email and provided a brief description of the project. Information sheets and consent forms were sent via email to those who expressed an interest in learning more. Those who agreed to participate were interviewed in their office where all interviews were audio recorded with permission and lasted from sixteen minutes to one hour and a half for a total of 18 hours of interview data.

3.4.2 Interview protocol

In-depth individual semi-structured interviews were conducted with all participants. The aim of the interviews was to explore clinician's own conceptualizations of bipolar disorder in children, and to discuss the diagnosis in relation to a number of dimensions, which included the children, parents, school and the pharmaceutical industry. The interview explored three levels: (i) description of PBD, (ii) sources of knowledge about the disorder and (iii) personal feelings about diagnostic practice. Questions raised concerned each of these levels. Additionally clinicians were asked about their interactions with parents and children, what their ideas were regarding how best to treat the symptoms, and broader questions related to changes they may have seen in children's mental health over the course of their careers. The questions served as a guide, and interviews were open to move into territory not formally laid out in the topic guide. For the full topic guide of interviews, see Appendix 8.

3.5 Study 3- Parents in the US and England

The final study seeks to understand representations of PBD held by parents in the US and England (see *Chapter Six*). Carugati and Selleri (1998) write that parents “find themselves daily at the crossroads of salient and socially value laden experiences of differences, for which both experts and parents have no ultimate exhaustive explanations” (p. 178). Tied into this are dominant social ideas regarding “normal”

childhood behaviour, and moral judgments over parenting skills. Thus, the perspective of parents, and an awareness of the way PBD is understood and communicated by those living within different cultural and medical cultures, is central to understanding the construction of a diagnosis.

3.5.1 Participants

Participants interviewed included 15 American parents drawn from regions, both rural and urban, across the US, and 5 in England, specifically Greater London, (n=2) Oxfordshire (n=1), Gloucestershire (n=1), and the West Midlands (n=1). As it can be noted, the number of parents interviewed in England was considerably smaller than in the US. Parents selected had children aged 4-16 who had been formally diagnosed with PBD, and there were difficulties in establishing a more symmetrical data set. It was extremely challenging to gain access to parents in the UK. This is itself indicative of the differences between the two contexts, and will be discussed further in *chapter seven*. In the US, diagnostic criteria is often applied to pre-school aged children, while in England, the age is typically young people who have reached adolescence. Thus, the age range was chosen in an effort to capture possible cultural differences in age of diagnosis, allowing for younger children and older adolescents to be represented. Parents are not included if an official diagnosis had not been made.

In the US, parents were recruited via an organization devoted to paediatric bipolar disorder called The Balanced mind Foundation, based in Chicago, Illinois. After making initial contact with Balanced Mind, information sheets about the research were submitted, which they then disseminated to their mailing list of families located all across the US, in both urban and rural areas. Those parents who were interested then contacted the researcher, and a phone or Skype interview was arranged.

English parents proved to be much more difficult to access as participants, as will be discussed at greater length below. I began my search by contacting an online forum that was based out of the US. There were several parents from England on this website, however only one who responded to my request for an interview. In the context of the forum, this parent mentioned they had self-diagnosed with bipolar disorder, and now felt they were seeing the same thing in their eight year old daughter.

Noting that in England it was impossible to get her daughter assessed and treated for bipolar disorder at such a young age, they sought advice from other parents in this forum. I then contacted a number of mental health charities in the UK, including those specifically for children's mental health, and those for bipolar disorder. When asking about the potential for speaking to parents of children with bipolar disorder, I was told on a number of occasions that the diagnosis didn't exist in England, and that I would have better luck focusing on ADHD. Never the less, an advertisement was posted on the Re-Think website, and from this I had a second parent contact me agreeing to participate.

The rarity of the diagnosis in England, combined with the stigma that remains around mental illness, meant that acquiring a snowball sample for this population wasn't materializing. A final attempt to access parents via local CAMHS teams resulted in an involved process applying for ethical approval through the NHS Integrated Research Application System (IRAS), a process which ultimately took close to two years to finalize. An initial application was made to work with a group in one particular council who had agreed to put me in touch with parents. At the last minute, this fell through due to short staffing. A new application was made, and a new sponsor found with a consultant child and adolescent psychiatrist at the Highfield Unit at Warneford Hospital, Oxford. With this psychiatrist's assistance, three more parents were found who were interested in participating. We were unable to access any more than this however, leading to a very small sample size for this population.

3.5.2 Interview protocol

In-depth individual semi-structured interviews were conducted with all participants. The aim of the interviews was to explore parents' own conceptualizations of bipolar disorder in their children, and to discuss the development of their understanding of the diagnosis, from their initial knowledge up to the present. The interview explored three levels: (i) early understandings and sources of knowledge about PBD (ii) navigating the search for support and treatment and (iii) definition of PBD and how parents believe Others think about PBD, including those in England (asked of US parents) and those in the US (asked of English parents). The questions served as a guide, and interviews

were open to move into territory not formally laid out in the topic guide. Most parents seemed eager to share their experiences, and often “began at the beginning”, communicating their trajectory into the world of PBD in a manner suggestive of a personal/familial narrative. Interviews lasted from forty minutes to over two hours in some instances and resulted in 24 hours of recorded data: 15 hours for American parents and 9 hours for those in England. For the full topic guide, see Appendix 7.

3.6 Analysis of data

As stated previously, a qualitative approach to analysis was taken in this study. Analysis of pharmaceutical industry internal documents and interview data with parents and clinicians all involved both thematic (Attride-Stirling 2001) and dialogical (Sullivan 2012; Gillespie and Cornish 2010) analyses, while analysis of advertisements incorporated a semiological analysis (Penn 2001) combined with a qualitative content analysis (Bell 2000) in order to fully explore and appreciate the visual elements so important in shaping how illness is represented in this format. The use of thematic analysis allows for flexibility in organizing and analysing the data, as it is free from any one theoretical or epistemological stance it can be applied using a number of approaches (Braun and Clarke 2006) and allows for the identification of significant themes coming up in discussion. Here it was used as a constructionist method examining how realities, experiences and meanings surrounding the emergence of PBD as a diagnostic category are shaped by multiple, often competing, discourses taking place in the wider cultural contexts of the US and England.

A dialogical approach to analysis was pursued as a second order level of analysis as it allows for a more nuanced exploration of subjectivity (Sullivan 2012). As I will show in the three empirical chapters that follow, these theoretical drivers inform analysis in that a consideration of who is being addressed in an exchange, and the ‘multiple voices’ that are present are central shaping individual perspectives, as it grants a level of understanding of explicit and implicit views and reference points (Gillespie and Cornish 2010). Drawing on notions of the ‘dialogical Self’ as proposed by Herman (2001) the struggle for dominance that multiple subjective I-positions experience at

different times, depending on the context and the relationships being addressed, is of interest methodologically for the purposes of this thesis. Such attention shifts a researcher's attention to the 'personal position' of a speaker, which involves identifying the varying 'positions' that the Self assumes, whether internal or external (Sullivan 2012). The significance of these positions become salient when looking to see which 'Others' coming up in conversations, and how the speaker positions both themselves and the Other, and in what capacity. The steps taken in the analysis of the data sets making up this project are now presented in the following sections.

In approaching the analysis of interviews, attention to what people say, but also what is not being said, helps access representations held without witnessing an actual physical interaction (Flick, Foster and Caillud 2015, 68). As it was not possible to arrange focus groups as part of this research due to clinician schedules, and the far reaching logistics of parent-participants, this approach proved valuable as a tool to explore the function and motivation of participants' discourse as it related to those with whom they are interacting, addressing, echoing, and thus constructing knowledge about PBD.

3.6.1 Internal pharmaceutical industry documents

The steps taken in the analysis of internal pharmaceutical industry documents are listed below. As with the interview data, the documents were analysed at two levels: a first order thematic analysis in order understand what was being said by those voices within the industry, followed by a second order dialogical approach to analysis in order to understand who was being addressed in the documents and how. This analysis helped answer research question numbers 1 and 1a:

- What are the social representations of PBD held by the pharmaceutical industry, and how has the industry contributed to wider understandings of PBD as a diagnostic fact?
- What are the factors shaping such representations within the pharmaceutical industry?

From the beginning it was determined that the documents would be analysed according to notions of Self and Other, thus, these classifications were assigned as global themes,

perhaps beginning at for what is often the end point of a thematic analysis. With this in mind, documents were read in order to familiarize with the data, and coded based on initial descriptive dialogical coding to identify who was being discussed as ‘Other’ and In Vivo coding in which words and phrases from participants own language in the data (Saldana 2013). Coding methods were chosen based on the nature of the research questions, which sought to explore the phenomenon of PBD from the myriad perspectives involved in shaping its construction. Central to the research design was a desire to understand the processes and interactions taking shape within pharmaceutical industry discourse, thus allowing for an exploration of what was being said about PBD, the dynamics of the wider industry culture, who the central players were, and how they were being discussed. Codes were refined and merged before then being grouped into what became ‘basic themes’ (see Attride-Stirling 2001). For example, a number of codes for the internal documents related to profit-motives, economic pressures, and competition from other pharmaceutical companies, and threats to the business marketing model. Codes of this type were grouped into a basic theme 1.1.1: *Pressure to expand indications for medications in the face of competition and economic pressure*. See appendix 9 for coding framework.

These ‘basic themes’ were based on the content of the data, however at this stage a dialogical approach to analysis was introduced in which the themes pulled from the data were analysed and grouped according to who’s ‘voice’ was coming through in the text. On the most basic level, the voice was a question of whether it was the multiple actors making up the pharmaceutical industry speaking as an industry-wide ‘Self’, or whether the content of discourse focused on, echoed, or referred to various ‘Others’, and if so, who those Others might be. These ‘Others’ showing up in pharmaceutical industry discourse were then positioned as ‘organizing themes’ as follows:

- The voice of pharma (‘I’ position)
- Industry competitors
- Clinicians
- The child

While parents are central to this thesis, they were not a significant point of discussion within the documents so were thus left out of the framework. Once it became clear who was being discussed in relation to the development of PBD, these actors were aligned under the appropriate global theme of Self (in the case of the industry talking about its own position) or Other (incorporating competitors, clinicians and the child). Coded excerpts were then revisited and analysed paying more attention to how significant others were being discussed in order to report the basic themes for discussion.

3.6.2 Pharmaceutical drug advertisements

Analysis of pharmaceutical drug advertisements also set out to answer research questions 1 and 1a as above. The idea was to have an internal voice of the industry represented through documents, followed by the analysis described here, representing the external voice of the industry that is presented to clinicians and the consumer public. Ferner and Scott (1994) propose that:

Science requires the unambiguous description and logical analysis of facts. This is not the purpose of advertising, which shares with art the use of oblique visual and verbal images to convey the message it wants us to receive. The advertiser tries to influence our visual and verbal images to convey the message it wants us to receive” (p. 1734).

In the analysis of pharmaceutical advertisements, my concern lay in the intention of the ad. What is the discourse being put forth? What debates does it enter into? A semiological analysis of these images allow for an understanding of how images make meaning and how they work within a broader system of meanings (Rose 2001). Penn (2000) notes that the act of viewing image or reading text is a constructive process, thus an analysis of pharmaceutical advertisements employing a process combining denotative semiological analysis (outlined by Penn 2000) sought to identify what was happening in the image and what level of knowledge was needed to “grasp” the signification at this level. An initial scan of the images to see what stood out at first glance was combined with a qualitative content analysis following Bell (2001) in which

the variables and values present in each advertisement were coded. The final connotative level of the ad was concerned with more dialogical associations such as what knowledge is required to see the image a certain way, and who might the intended audience be? The steps involved in analysis of the advertisements are as follows:

Step 1: An initial scan of the full sample of ads was undertaken to get a sense of what stood out visually and in terms of text, size of ads, which journals they were appearing in, and any difference in prevalence or type of ad over the course of the years.

Step 2: The second step in analysis of the advertisements involved performing what Penn (2000) refers to as a “denotational inventory” (p. 232) in which elements in the image and text were coded to identify what is being said in the text, where text and image is positioned, how it is represented visually. The purpose of this stage was to capture the literal meaning of what was being presented in the advertisements, a systemic approach which Penn (2000) suggests is necessary to ensure that analysis is not “selectively Self-confirming” (ibid). This stage of analysis followed Bell’s (2001) approach to visual content analysis in which codes were assigned by attributing values to variables (such as image type, pictorial elements, gender, role represented and setting). For example pictorial elements might include that the advert was muted and dark, covering two full pages, while the text suggested a “mind in turmoil” presented in blurred text emerging out of the obscured profile of a middle aged-woman in an unknown setting. Coding at this stage also considered what appeals were present in the ad, what normative values were being perpetuated, who the ad was addressing, and how. This added an element of dialogicality in seeking to get beyond the literal image, allowing for a broader understanding of how the ads were being used, and what cultural knowledges were required of the viewer.

Step 3: The final stage built on the denotational inventory to analyse what associations are brought to mind in the image and text, what is absent, how the elements relate to each Other. The wider context of the ad was considered at this stage as well, considering whether it was found in a US or UK based medical journal. See

appendix 10 for a full coding frame and sample of analysis notes for a selected advertisement.

3.6.3 Interviews with clinicians and parents

Analysis of interviews involved a combination of an inductive approach in which interview transcripts were coded openly to see what patterns developed in data, and a more deductive approach in which data and developing themes were viewed with a socio-representational framework in mind. This analysis helped answer research questions 2 and 3:

- What are the representations of PBD held by clinicians in the US and England, and what psychosocial factors have shaped those representations?

- What are the representations of PBD held by parents in the US and England, and what psychosocial factors have shaped those representations?

Applying a socio-representational approach to the data builds on notions surrounding how illness is constructed by moving beyond looking wholly at external social factors shaping diagnosis, and adding the dynamic of constructive processes at play which allow individuals and groups to produce, objectify and make sense of a new disorder. As discussed in section 3.4 above, analysis of interview data was broken down into two levels with a first order thematic analysis following Attride-Stirling (2001) followed by a dialogical analysis (Gillespie and Cornish 2010; Sullivan 2012). The steps taken in analysis are presented below.

Step 1. Becoming familiar with the data

In order to become familiar with the data, I transcribed all interviews, taking informal notes as I did so in order to catch potential areas of interest coming up in discussion. This, along with reading and re-reading the interview transcripts, allowed for a reflection on the data, serving as a sort of preliminary analysis to begin thinking around not just what was being said, but how it was being said. Interview transcripts from clinicians and parents were then uploaded into NVivo 10 in order to begin coding.

Step 2. Generating initial codes

The process of coding began in an exploratory fashion, with an initial coding frame created using open codes generated inductively from all interviews, beginning with clinicians, combining the US and England data sets. Excerpts of the data coded included text segments relating to meanings, assumptions and interpretations of PBD (for example “unstable” or “neurochemically based”) as well as specific actions or practices around the diagnosis (such as the tendency elaborated by clinicians for American parents to “shop around” for a doctor willing to consider PBD as a diagnosis). This initial coding frame was then revised to approach analysis of the groups separately so as to compare themes and dialogical processes coming out in data. Coding was then expanded beyond open coding to a more theoretical ‘axial’ coding (Robson 2011) to interconnect the previous open codes, and approach the data with a renewed approach to relationships and interactions being depicted or discussed in the data.

It was decided that as the focus of my research questions narrowed, and themes emerged from the initial descriptive coding, that the coding framework should be expanded to allow for the uncovering of knowledge encounters and dialogical processes taking shape in the interviews. Thus, the most significant ‘Others’ to come up in discussion with clinicians and parents, including the parent and clinician’s subjective positioning of their ‘reflexive Self’ were taken as the basis for NVivo’s ‘parent- nodes’ (global themes according to Attride-Stirling, 2001) forming the structure of the coding framework. For clinicians this was as follows:

- Position of the clinical Self
- Clinicians on professional colleagues
- Clinicians on parents
- Clinicians on the pharmaceutical industry
- Clinicians on the child
- Clinicians on the US/England

As the clinician data set was the first to be analysed, it acted as a template for how to develop the subsequent coding frames. Once it was decided that the inclusion of a dialogical perspective was going to be central to the analysis, the coding framework for parents began by laying out the global themes of parent as Self, identifying who the significant Others were in their discussion, and then coding and clustering into themes according to what was being said with regards to a specific Other. The framework was refined and reflected these ‘Others’ coming up in conversation:

- Position of the parental Self
- Parents on clinicians
- Parents on schools
- Parents on the pharmaceutical industry
- Parents on peers/colleagues
- Parents on the child

For parents, the first round of descriptive coding resulted in initial themes that were then sorted into whom this content was referring to. For example the code of ‘feeling ignored’ came about in how parents discussed their interactions with clinicians, so was placed as a child node under the global theme ‘Parents on clinicians’. All of the codes coming under this heading were then grouped together to form organizing themes making up what parents were saying about clinicians with regards to PBD, and how they were saying it. Excerpts in which parents or clinicians were talking about these significant others were then isolated and interpreted in order to bring out themes emerging to further explore what message was being communicated and why it was being communicated in a particular way.

Step 3. Identification of themes

Once coding was complete, the text segments were then analysed to pull out salient themes. The themes were grounded in the data, however were based on decisions shaped by the theoretical approach chosen and were clustered together. All of the excerpts falling under the headings outlined above were re-read, sometimes reworked

and moved or deleted as part of an iterative process where the data was revisited, followed by analysis, followed by revisiting the data, and so-on until it was determined that a valid set of themes could be established, and compared within their networks. The coding frameworks for clinicians and parents can be found in appendices 11 through 14.

Step 4: Dialogical analysis of representative quotes

After pulling out themes in the interviews with parents and clinicians, representative quotes were selected for a more in depth dialogical analysis to contribute to the final interpretation and summary outlined in the following section. Quotes that made up the basic themes were carefully read to identify subject position, paying particular attention to what/who was being quoted directly. Questions asked of the data at this stage follow recommendations from Gillespie and Cornish (2010) and include the following:

- What is the context?
- Who is being addressed and how?
- Who is doing the talking and how?
- What are the responses, actual or anticipated?

In approaching selected excerpts this way, I sought to illustrate not just how clinical and parental discussion about significant Other plays into their own understanding of PBD, but also how they positioned themselves in relation to these various Others, and what that might suggest about why they conceptualize PBD the way that they do. An example of dialogical analysis can be found in appendix 15.

Step 5: Interpretation and summarization of themes and dialogical processes taking shape in the data

The final step involved the fine-tuning of the global theme Self and Other into expansive organizing themes of who the Self (e.g. the ‘clinical Self’) and who the others were (e.g. ‘the child’), and finally into basic themes for discussion (how the clinician was discussing the child, for example as ‘a cluster of symptoms’). Throughout analysis, I maintained a focus on the interactive threads present in the data, and how the thematic elements (content) coincided with the dialogical elements (process) when parents and

clinicians were free to elaborate on PBD, from the very practical definitions and symptoms, to more abstract ideas and meanings about perceptions of pressures shaping the development of thinking around PBD, or the crystallization of a perspective on a significant Other.

3.7 Ethical considerations

The ethical review board at the London School of Economics and Political Science approved the study and informed consent was obtained for each interview. In addition, approval for the English parent-participants was obtained from the NHS via the Integrated Research Application System as discussed in section 3.5 above. In considering ethical issues with regards to the research I am engaged in, there is a risk that when parents are asked to reflect on their experiences negotiating their child's diagnosis they may become upset. It was not my aim to ask such personal, probing questions, however if it edged towards this in the course of conversation, I responded asking if the participant wanted to move on to a different topic. This was never taken up, however. I was able to provide web addresses and phone numbers for support groups for parents of children with bipolar as part of my information sheet provided to parents so that there was an awareness of outside support as being available. Additionally there is the issue of confidentiality. In order to ensure confidentiality is maintained, all interview data was anonymised at the point of transcription, with participants given unique codes instead of using names. I was the sole transcriber of this data, and as I transcribed I was also in a position to remove any identifying details such as the location or institutional affiliation of participants. Informed consent sheets were sent out alongside information sheets explaining the research, were discussed and signed prior to beginning the interview. Participants were also offered the opportunity to view the anonymised transcript once it had been transcribed.

4. Pharmaceutical marketing practices and the expansion of a diagnostic category

4.1 Introduction

The aim of this chapter is to understand the role of the pharmaceutical industry in shaping representations of paediatric bipolar disorder (PBD). Medications used to treat the diagnosis feature prominently in the analysis that follows, which leads to the question of why a study focusing on a representation of a particular diagnosis includes analysis of representations of medications. The answer lies in the genesis of PBD as a diagnostic category, and how closely bound its emergence was, and continues to be, with the production of medications in need of something to treat. From its inception as a diagnostic category, PBD has been rooted in controversy as a result of its attachment to a pharmaceutical marketing model, something not as salient in other childhood mental illnesses such as unipolar depression or autism spectrum disorders. This chapter focuses on the organisational ‘voice’ of the pharmaceutical industry as communicated in marketing practices for the medications used to treat bipolar disorder. The decision to have a chapter focusing on medication grounding a wider project concerned with conceptualizations of the diagnosis itself is rooted in the fact that PBD as a diagnosis is directly related to the development of the medications which could act as a treatment. The expansion of disease categories as a means to justify new uses for medications, or revamp the indications for existing drugs is central to the debates surrounding PBD as a diagnostic category and will be shown in my analysis of internal documents related to the marketing and promotion of the medications used to treat PBD (Risperdal, Zyprexa and Seroquel), as well as the advertisements used to market these medications, in the following sections.

The research questions guiding this chapter are as follows:

- What are the social representations of PBD held by the pharmaceutical industry, and how has the industry contributed to wider understandings of PBD as a diagnostic fact?

- What factors shape such representations within the pharmaceutical industry?

The chapter is broken down into three sections. Section one is a background to contextualize the role the pharmaceutical industry has played in the development of the diagnosis so far. This is followed by section two, an analysis of internal industry documents and finally section three, and analysis of advertisements ending with a chapter conclusion.

4.2 The pharmaceutical industry and the genesis of a diagnosis

In their exploration of how the concept of paediatric bipolar emerged out of a once-rare diagnosis of manic-depressive psychosis, Healy and LeNoury (2007) present a narrative history of the diagnosis applied to children as being borne out of the aggressive marketing of bipolar in adults, illustrating how “company strategies in one domain can resonate in another, in this case the paediatric domain” (p. 209). Central to their argument is the idea that the construction and expansion of this diagnostic category can be directly linked to pharmaceutical marketing practices. In seeking to expand the market for the new breed of ‘atypical’ antipsychotic medications, a process takes shape in which “a new and flexible notion of the condition that bears little resemblance to the classical representation of bipolar can then be applied to ordinary variations in temperament” (Moncrieff 2014, 582). This link has become common knowledge as a result of lawsuit in which the pharmaceutical company Johnson & Johnson was forced to pay \$2.2 billion in criminal and civil fines for improperly promoting the antipsychotic Risperdal to children, including those with PBD (Thomas 2013). A relationship between Johnson & Johnson and a leading child psychiatrist at Harvard Medical School, Doctor Joseph Biederman was exposed, as the company had paid Dr. Biederman to act as a “Key Opinion Leader” and provided over \$700,000 to establish a centre for the study of paediatric psychopathology. Doctor Biederman and his group began generating studies suggesting that children suffering from ADHD could actually be suffering from Bipolar Disorder, thus fuelling a 40-fold increase in the

diagnosis, and the expensive, risky antipsychotic Risperdal as its treatment, from 1994-2003 (Harris 2008).

A 2014 report from The Agency for Healthcare Research and Quality (AHRQ) shows that mental health conditions are repeatedly found to be the largest expenditure for children's health (Express Scripts, July 10, 2014) with roughly 41.5% of mental health expenditures coming from prescription medication (Soni 2014). In a recent study comparing hospital discharge rates for paediatric bipolar in the US as compared to England between 2000 and 2010, James et al. (2014) found a 72-fold difference in discharge rates for young people with a diagnosis of PBD (US: 100.9 per 100,000 population versus England: 1.4 per 100,000 population). Overall, hospital stays for bipolar disorder for all children aged 1-17 increased 434% (O'Meara 2013), while from 2005 to 2009, disruptive behaviour disorders were the most common diagnoses in child and adolescent visits resulting in the prescription of antipsychotics, accounting for 63.0% and 33.7%, respectively (ibid.).

The growing use of antipsychotic medications in this age group, coming from both off-label and FDA approved uses, has greatly expanded both the range of mental disorders treated with these medications (Olfson et. al., 2012) as well as the ages of the children receiving the medications, with some being prescribed to preschool children aged 2-6 years despite little understanding of their long term effects (Harrison, Cluxton-Keller and Gross 2012). These statistics demonstrate the reality of how the link between medication and diagnosis comes into play, with antipsychotic medications that once existed solely in the realm of treatment for serious psychotic disorders in adults now being used to quell disruptive behaviour in young children. Parents, providers, and policy makers are "eager for quick, effective, and inexpensive treatment to stop children's disruptive behaviours, as children with emotional and conduct-related disorders are more likely to be expelled from preschool, require special education and healthcare services." (Harrison, Cluxton-Keller and Gross 2012, 139).

Fortune 500 drug companies have emerged as the most dominant influence in the US healthcare system due to the powerful economic sway they hold (Diller 2008). The field of child and adolescent psychiatry is especially open to influence owing to the

uncertainty surrounding children's mental illness, an openness that sees drug company research funding, professional medical education and direct to consumer advertising contributing to wider explanatory frameworks emphasizing neurochemical explanations for behaviour, and pharmaceutical solutions, as opposed to approaches such as education or parenting skills (ibid). The disease model of psychiatry has drastically reshaped how we view behaviours in light of what is considered normal versus pathological, and nowhere is this more apparent than in the field of children's mental health. The pursuit of medical facts "is increasingly dominated by considerations of marketing from start to finish" (Kirmayer and Raikhel 2009, 9).

Medications play a direct role in the process of diagnosis when illness is diagnosed with a specific course of treatment in mind. Norms for behaviour end up being associated with a specific illness organized around medicines available to treat the problem as much as symptoms that may be present (Vuckovic and Nichter 1997), thus, a situation is created in which the process of defining a diagnostic category comes not via objective and agreed upon criteria, but rather the medications which are available to potentially provide treatment (Wedge 2015). Increasing clinical acceptance of antipsychotics for problematic aggression in disruptive behaviour disorders may have increased the number of children and adolescents being prescribed antipsychotics, while the growth in clinical diagnoses of bipolar disorder for children and adolescents may have further increased antipsychotic use in young people. This is especially the case for boys and racial minorities (Olson et. al., 2012) leading some to suggest that pharmaceutical companies are "abusing kids by treating behaviour like a disease" (Azerrad 2016) and blurring the boundaries of where health ends and disease begins, redefining undesirable behaviours as potentially risky symptoms (Tone and Siegel-Watkins 2007).

4.2.1 The US as compared to England

In the United States there exists free market approach to access to medications while in England, a voluntary scheme keeps access to medications affordable while also leaving room for industry profit (Collins 2015). Although EU countries have different healthcare systems, there are European directives concerning pharmaceutical marketing

in member countries that must be obeyed. In the US, however, regulation comes not as a result of federal law, but rather guidelines that the pharmaceutical companies trade association, PhRMA, developed for member companies to follow and avoid government regulation (Sillup and Makowska 2013, 14). The Medicines Act in the UK prohibits the pharmaceutical industry from promoting unlicensed medications, such as those prescribed off-label for children with PBD. As a result, the conflict of interest generated by influence of relationships between doctor and industry is not as salient in England (Rani et al, 2007).

A British Psychological Society report on understanding psychosis and schizophrenia suggests that antipsychotic medications may be useful, but they hold fast to a lack of evidence suggesting such medications correct any “biological abnormality” (Luhmann 2015). The report goes on to emphasize that for any severe mental illness, the risks of taking antipsychotic drugs for years may outweigh the benefits, and more needs to be done to make services available allowing people to discuss their experiences and what it means to them, a radically different approach from that held by most Americans (ibid.) The use of antipsychotics in children is not licensed in the UK, and parental training is often favoured as a first line approach when children are involved (James 2010). In response to the growing literature out of the US on the use of atypical antipsychotics in very young children (under 5 years of age) for the treatment of bipolar disorder, James (2010) suggests that there is limited evidence for the effects these medications have on children, thus the practice of prescribing these medications is not licensed or recommended in England, as the risk then becomes about antipsychotics becoming the go-to first line treatment for PBD as they have done in the US, especially if psychological treatments are not readily available (ibid).

Dumit (2012) makes the assertion that “each kind of knowledge produces more needs, more actions” (p.31), something which can certainly be seen in the connection between an organisational desire for profit and the development of a diagnostic category as a means to satisfy that desire. The controversy surrounding the inclusion of children in this equation illustrates the ways in which controversies are “fascinating social processes” in which “all of the normally silent and hidden activities that regularly

produce our taken-for-granted everyday world show up in competing voices, contradictory facts and uncertain compromises” making up the production of new knowledge (ibid., p. 32). The process of an industry coming to see children as potential patients, and communicating this to clinicians, allows the verification of new identity for the child through marketing practices elaborating new norms for how a child should be.

4.3 The ‘voice’ of pharma: analysis of internal documents

Healy and LeNoury (2007) have highlighted the pharmaceutical industry mechanisms involved in the development of PBD, working around regulations that prevented direct marketing of the illness itself to clinicians and the wider public. In attempting to understand the influence of pharma in the genesis of PBD when the obvious routes to construction are so heavily veiled, this analysis builds on Healy and LeNoury’s (2007) assertions beginning with an analysis of internal industry documents as a means to access the organisational perspective that was shaping representations about children’s behaviour, leading to the development of a new diagnostic category. This section presents the findings from an analysis of the documents in which the focus is on what those inside the industry were saying in the early days just prior to, and just after, the idea of PBD came about. Specific attention was paid to who was speaking in the document, what was being said about PBD, and who was being addressed. Of note was the fact that the presence of parents didn’t feature strongly within industry discussion of the child, suggesting the further isolation of the child as more of a target as opposed to an individual in the process of developing as part of a wider context of family, school and societal expectation. Details of the analysis are outlined in detail in *chapter three (cf 3.4.1)*.

4.4 The organization as ‘Self’ in industry documents

4.4.1 Economic pressure

The subjective ‘voice’ of the pharmaceutical industry is articulated through the words of pharmaceutical representatives, key executives in the industry, and an anonymous, more

generalized voice that is responsible for the development of educational materials and presentations that are then communicated to sales representatives and clinicians. When examining internal industry documents related to the marketing of medications used to treat bipolar disorder in children, one thread that remains consistent is the role external economic pressures and an increase in competition play as a motivator for the development of new diagnoses for old treatments. The process of reshaping perceptions of a child's behaviour as pathological begins here, with the pressure to stay afloat as a business in the face of increasing additions to a very specific market. This is illustrated in the words of a sales representative discussing the move to expand the prescription of the antipsychotic medication Risperdal from adults with schizophrenia into children:

So this over here, when you look at hostility, aggression, agitation, this was a -- I mean, a significant opportunity for growth for Risperdal, because we weren't really winning in this area here; our competitors were. That's in a nutshell what our sales aid would look like; and when we would go in to talk to physicians, we would talk about these symptoms with the focus here; thus, yeah, I have, you know, the younger population has hostility, aggression, those type of symptoms; and thus, they would use Risperdal for those (*Testimony of pharmaceutical sales representative, Document 13, 2012, p. 140*)

The excerpt above illustrates how a voice within the industry is openly acknowledging the persistent presence of competitors as being a force in how they position their own marketing practices. The speaker is presenting the push to recognize hostility and aggression as a matter of necessity in a world where opportunity for growth and a desire to come out on top take precedence over the reality of what the sales representative is proposing when he goes in to make a sales call to the clinicians. The child at the centre of the push for expansion is not present Other than as a representation of a market that remains, at that time, untapped.

The subjective positioning of the pharmaceutical industry in the face of increasing economic pressure illustrates a concern with marking the symptoms of hostility and aggression, mentioned above, as part of a wider legitimate diagnostic category. The need for validation, which is seen here as coming in the form of a blessing form the US Food and Drug Administration (FDA), comes from a larger

discussion surrounding key factors identified in reifying PBD as a diagnosis through acquiring the FDA label that would render Risperdal as an exclusive treatment legitimate in the eyes of the US government. The following quote comes from a deposition of the former CEO of Janssen Pharmaceuticals, a subsidiary of Johnson & Johnson responsible for marketing Risperdal, the medication that gave rise to the diagnosis of PBD initially. In recounting his reading of an early marketing plan for Risperdal, the importance of official validation is conveyed:

A. As it's read, that the first factor was to "establish evidence in support of the diagnosis of BPD," bipolar disorder, "in children, that bipolar disease is a distinguishable and reliably identifiable disorder with a poor prognosis that can be moderated by treatment."

It then goes on to say that "The second would be to have the FDA acknowledge that this would be a treatable diagnostic entity that could result in filing more [sic] clear cost-benefit related to treatment to be established."

(Doc. 14. deposition of former CEO for Janssen Pharmaceuticals, p.80)

The importance of having PBD officially endorsed as an identifiable mental disorder in order to justify prescribing practices acts as a starting point from which a new diagnostic entity is shaped. The speaker above anticipates that without official acknowledgement, they are likely to lose out to the competition. Thus it becomes a race to see who can succeed in establishing evidence in favour of the diagnosis first. The point is made by this CEO later in the deposition that "because parents, patients and clinicians are exposed to a media that frequently questions the validity of childhood disorders, genetic and brain imaging studies are needed to show the validity of these disorders as brain disorders that respond to medication." (Document 14, 2012, 99). The notion of validity as being rooted in something scientific, and thus objective and trustworthy, is perpetuated to counteract the industry's own understanding of a wider public perception surrounding their practices. There is an organisational Self-awareness

at play in which those on the inside responsible for communicating new criteria for a new diagnosis do so strategically, in full consideration and expectation of potential critique.

4.4.2 *Indirect marketing practices to ‘get the word out’ about PBD*

The ‘Self’ awareness of how those on the outside, whether government regulatory agencies, practicing clinicians, or the more general public, are likely to meet with the recommendation for a new diagnosis of PBD, drives early strategic marketing practices in the development of PBD. The need to ‘get the word’ out among potential early-adopter clinicians who would be likely to influence their colleagues is evidenced by how the industry talks about the process of going about this:

84. In 2002, defendants created a new sales force, “the 500 Gold,” to market Risperdal to primary care physicians (PCPs), who do not generally treat schizophrenia or psychotic disorders.

(Doc. 13. Risperdal rep call notes, p. 27)

The above reference to industry practice illustrates the move away from attempts to get psychiatrists on board, manoeuvring instead into the realm of general practice physicians who have little training the diagnosis or treatment of mental illness. By expanding the marketing of the condition and its treatments into a less specialized field of medicine, the industry begins the process of building alliances among those who will be useful in further legitimizing the diagnosis. Of particular importance for steering the building of these alliances is the sales force team responsible for interacting with the clinicians. An internal resource guide for those on the sales force for the medication Zyprexa highlights how the industry builds up the importance of their mission using emotional appeals:

The Primary Care sales force will be a major part of helping to improve these statistics, and behind every statistic is a patient and their family struggling with mental illness. Years from now, as Lilly is launching new revolutions in neuroscience, you can look back and say that ZYPREXA

changed the way bipolar disorder was viewed, diagnosed, and treated by primary care physicians. (*Doc. 9. Zyprexa primary care sales force resource guide, p. 4*)

The motivational tone of the excerpt encourages commitment to the cause, emphasising the positive, life-changing role the sales rep can have on an individual level. The industry recognizes the sales team as being their public face, on whose shoulders the responsibility of convincing a potentially sceptical professional field of the importance of their mission. The incongruity of a young sales representative with no medical training convincing a medical professional how to diagnose and treat an unstable, yet-to-be-legitimated diagnosis is not lost on those at higher levels within the industry. Thus, their interaction with sales representatives, and the way directives to carry out less overt marketing practices in order to ‘get the word out’ about bipolar, are all driven by elevating the representatives’ sense of their own power to ‘help a struggling family’. Included in this is the power of the representative, as proxy for the industry as a whole, to completely reshape representations of bipolar disorder from something once rare and only seen in adults, to something more chronic and treatable, seen in young children. Ultimately such a push comes back to economic pressure and competition leading to justification of the expansion of diagnostic categories through reshaping understandings of what bipolar looks like, and how clinicians think about the medications used to treat them.

4.5 Competitors

4.5.1 Accommodation of a persistent threat

The most significant ‘Others’ to come from analysis of industry documents were pharmaceutical companies all vying for similar markets. The Big Three with regards to PBD include Johnson & Johnson/Janssen (makers of Risperdal), AstraZeneca (makers of Seroquel) and Eli Lilly (makers of Zyprexa). Viewing the industry’s subjective perspective put forth in their own documents, the presence of other companies is keenly felt, and often overtly referred to in terms of how competitive intelligence about

what one another are up to shape which opportunities are pursued, as is evidenced in the following excerpt from one company's strategic plan:

SEROOUEL will face considerable competition at launch given its timing to the market relative to olanzapine and sertindole, as well as the formidable presence of Janssen, Lilly, Abbott, and Pfizer in the psychiatric marketplace... The strategic positioning statement for SEROOUEL at launch is:

"The atypical antipsychotic agent for first line treatment, with proven efficacy against positive and negative symptoms plus no EPS or prolactin liability compared to placebo across the SEROOUEL dose range."

Risperidone's positioning has been "The only first-choice serotonin-dopamine antagonist" ... emphasizing efficacy against both positive and negative symptoms, and "EPS comparable to placebo at doses <10mg/day". This positioning will be weakened by the new entrants, including SEROQUEL. (*Doc. 1. Seroquel Strategic plan, p. 4*)

Here, the positioning of the other is taken on board and willingly accommodated into this company's objective, and this is not unique. While other companies within the industry are viewed as a threat, their presence is also recognised as a necessary, galvanizing force crystallizing a company's own objectives and steering pursuit of a share of the market in a new diagnosis such as PBD:

Competitors will become increasingly creative and look for new opportunities within the current market to steal ZYPREXA share. To remain competitive, ZYPREXA will have to increase marketing spending levels and also recognize that the incremental return per dollar may decrease. Aripiprazole and risperidone depot are the two most significant short-term threats to ZYPREXA. (*Doc. 8. Zyprexa Global Marketing Plan, p.25*)

As illustrated above, competitors function as a presence to position oneself (on an industrial scale) against. Threat is not articulated here as something negative necessarily, rather the tone of the marketing plan suggests this as the reality of the industry, and that the ever present risk of others stealing market share is a positive, providing a catalyst to stake out a unique corner of the market- a process discussed in the next section.

4.5.2 *Need for differentiation from competition*

Dissonant thinking in terms of maintaining inconsistent positions appears commonplace at the organisational level within the pharmaceutical industry. As discussed in the section above, the threat posed by other companies is a significant driving force that is not entirely negative in terms of how it is understood by those within the industry, however at the same time there exists a sensed of forced differentiation, with different companies employing different tactics to perpetuate their definition of PBD. One mode of differentiation which served as an early attempt to shape representations of the new diagnosis was the push from within one company to focus on symptoms instead of a specific diagnosis thus ensuring that a clinician didn't automatically rely on previous understandings of 'schizophrenia' or 'psychosis' when considering how best to treat a patient:

However, in the meantime . . . BRING IT BACK TO THE SYMPTOMS . .
. with ANY disease state we can sell Risperdal instead of any of the
competition using the studies we currently have in our hands.

Bipolar Disorder. BRING IT BACK TO THE SYMPTOMS (Excitability,
Agitation, Aggression, Depression, Delusions)

Pediatrics: BRING IT BACK TO THE SYMPTOMS (Impulsiveness,
Agitation, Aggression, Depression, Anxiety).

(Doc. 15. Janssen sales call notes for Risperdal, P. 28)

A focus on how to steer clinical attributions of behavioural symptoms allows for a readjustment of how clinicians conceptualise PBD by changing what is available and acceptable to draw on when faced with an unstable young patient. By using this focus as a tool, a company sets itself apart from the competition by indicating these behaviours as problematic and warranting their company's specific medication as the recommended treatment. In the excerpt that follows from a young pharmaceutical sales representative, threat and need to stand out and form a unique niche in the face of

competition can be seen as a central motivating factor shaping marketing practices and thus the early shaping of how to understand PBD. Additionally, two vectors of influence are at play: the industry influencing the sales representative, and the sales representative influencing the clinician.

Q. From the national office where you trained on what you were allowed to do in regards to encouraging, if you did encourage, doctors to prescribe Risperdal to children?

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Bentley vs. Janssen - Trial - 9/24/12 - Volume I

A. Yes. We were trained on that, and we would focus on symptoms.

Q. Can you explain that, please?

A. Yes. So basically, there were three, I'd say, three buckets, if you will. We had a, you know, a positive symptom bucket that we would focus on, which primarily were for the adult patients.

Then we would have a negative symptom bucket with social withdraw, flat affect that also was more for adult patients; but then there was a hostility, another bubble where it had hostility, excitement, irritability, agitation and aggression. That would be the third bucket.

And we would show that to the physicians; and they knew exactly what we were talking about, because they would -- as you know, we come in after patients; and many times, the physicians would either have seen those symptoms or think about a patient that has those symptoms.

(Doc. 13. Testimony of pharmaceutical sales representative, p. 138)

Here, education is used as a means of informational influence in which the sales representative was encouraged by the national office to focus on excitement, irritability and aggression when making calls to clinicians who treat children, thus pushing those clinicians to remember children they may have just seen in their office, and align their behaviours with what is being presented by the representative. Such behaviours are presented as normal indications warranting treatment with Risperdal. An emergent norm effect begins to take shape in which, as in the example above, the push to view symptoms as pathology has done more than provide a unique selling point for an

individual company, but has also succeeded in normalizing aggression and irritability as symptomatic of a new definition of bipolar disorder in children. Through differentiating themselves from competitors, the industry has successfully taught key clinicians what to see and how best to interpret what they see.

4.6 Industry alliance with clinicians

4.6.1 Essential to have on board as ‘opinion leaders’ for wider validation of PBD

While the pharmaceutical industry ‘Self’ and the role of competitors as ‘Other’ illustrate the development of marketing practices related to PBD, the clinician plays a central role in terms of putting those practices into action. It is through the clinician that a company communicates and legitimates the understandings it has sought to develop regarding PBD. The clinician becomes responsible for perpetuating the message, influencing colleagues, and reifying the concept of PBD as being defined by certain behaviours, which are best treated through the use of specific medications. The development of a strategic alliance between the industry and clinicians becomes of central importance, resulting in a common industry-wide practice of establishing ‘opinion leaders’ in the field.

The table presented below from a marketing plan illustrates the consideration taken in targeting clinicians, with the notes in the margins highlighting industry views of physician type 1, one who has a demonstrated expertise in treating mental illness, requires certainty about what is being treated before acting, and is uncomfortable with the idea of prescribing medications off-label, beyond their indicated range. This clinician is seen as “panic bound”, yet likely to be influenced by physician type 2, the “high flyer” who is more experimental in their approach to diagnosis and treatment and has a high level of ‘Self-perceived’ expertise. Clinician 2 is labelled as likely to be an opinion leader, suggesting the industry seeks to target clinicians and nurture alliances with those who are giving signals of being open to influence.

Physician Types

Research was also conducted to help identify target physician types who are most likely to prescribe and stay loyal to ZYPREXA. Of the different physician types identified along the left axis of the market map, two to three per country are identified as primary and secondary targets. While physician attitudes were very similar across all researched markets, their resulting behaviors do vary. The following physician types, based on the US segmentation, are provided as an example:

Physician Type 1

- Has a strong familiarity with diagnosing and treating mental illness
- Wants to be certain of diagnosis before moving ahead with treatment
- Is uncomfortable dosing outside a drug's recommended range
- Is a slow adopter of new drugs/new usage areas
- Is heavily influenced by Physician Type 2

Primary
Secondary

Physician Type 2

- Has the highest level of self-perceived expertise in diagnosis and treatment
- Seeks input from a narrower treatment team
- Engages in a high level of experimentation with psychiatric medications
- Likes atypicals but tends not to differentiate among them
- Is more likely to be a key opinion leader

High
Low

Physician Type 3

- Has a lot of experience with severely ill patients but is less likely than Physician Type 2 to remain loyal to one brand for treatment
- Typically works in a community mental health center
- Is very familiar with diagnosing and treating mental illnesses
- Tends to concentrate more on the symptoms than the diagnosis
- Has the highest likelihood of trying drugs in new ways (dosages, indications, off-label)

(Doc. 8. Zyprexa Global Marketing Plan, p. 22)

Once a clinician has been identified as being developed as a key opinion leader, the sales representative may then go about putting a reward system in place, in which the clinician is put in a position of power, authority and expertise, but only in exchange for delivering what is expected from the company:

102. Sales representatives identified local doctors to be trained as speakers based on their potential for writing Risperdal prescriptions. Sales representatives told doctors that if they wanted to speak, they had to increase their Risperdal prescriptions. For example, in an October 7, 2003, e-mail, one sales representative told her district manager that a doctor in her district wanted to be a speaker for Janssen, but only 16 percent of his antipsychotic prescriptions were for Risperdal. The representative discussed plans to tell the doctor that he could qualify to speak the following year if he wrote 50 percent of his prescriptions for Risperdal. The doctor subsequently increased his Risperdal prescriptions and became a paid speaker in 2004.

(Doc. 15. Risperdal sales representative call notes, p. 26)

Here the desire to get the word out is driven by a mutually beneficial arrangement that has little to do with how these medications might be used, and on what populations. Of interest is the fact that it is not only psychiatrists being sought out as opinion leaders in the development of PBD, but the emphasis placed on educating and influencing those primary care physicians who, due to different fields of expertise and training, would not have previously been known to diagnose or treat the mentally ill- let alone be familiar with antipsychotic medications used for treating severe mental illness.

4.6.2 Responsible for knowing how best to diagnose and treat PBD

The reliance on clinicians by the pharmaceutical industry is twofold. On the one hand they are courted or encouraged to lend their position to the act of influencing colleagues and the wider public about the existence and validity of PBD, as well as acceptable ways of treating the disorder. Simultaneously, in developing an affiliation with clinicians on the level of their expertise and opinion, the responsibility also shifts away from the industry (still very much at work behind the scenes) to the public face that the clinician provides. Strategically, this allows the industry to fend off criticism of practices related to perpetuating increased diagnoses of children with mental disorders, and their treatment with antipsychotic medications, by reinforcing the understanding that it is the clinician that is ultimately making the decision, that it is their competence

of judgement that leads to diagnosis and treatment of a child as evidenced in the following excerpts from a former pharmaceutical CEO:

I mean, first of all, there is the issue of how that particular market is defined, and I believe they're defining it as on that particular portion of the market, again, where physicians are attempting to treat a very difficult condition among children and adolescents; where, to the best of my knowledge, none of the antipsychotics were approved and yet there were little to no other options for physicians to use in a particular population; hence, they were making a decision, based upon their knowledge and understanding of the different data, to treat these patients in what they considered to be the best possible way, which is different than promoting the product in a particular area under an indication.

(Doc. 14. Risperdal Litigation, CEO deposition, p.163)

What I can tell you is, at that time it was very important to try to gather information. And frankly, that's where I had to rely on the psychiatrists and the clinicians who were using the DSM-4 to fully understand and characterize its use the right way. That really wasn't my decision.

Q. What I'm asking you is that Risperdal and most of the atypical antipsychotics are indicated for very serious mental disorders. I think you would agree with that, right?

A. I don't know what the specific independent indication is at this point in time. I haven't been directly associated with the drugs for many years.

(Doc. 14. Risperdal Litigation, CEO deposition, p.215)

In the quotes above, the CEO defends the position of the company's practice by shifting the focus onto the experienced clinician, first reiterating the uncertainty surrounding the diagnosis of PBD, and the fact that clinicians were facing not just the unfixed diagnosis, but the fact that none of the most suitable treatments (as defined by the industry) were allowed to be prescribed for children. Clinicians are presented as being bound by restrictions, but solely in control of how they diagnose and prescribe. Here, the industry seeks to remove any residue of perceived influence they may have

held over the clinicians by rooting clinical practice in a reliance on diagnostic manuals such as the DSM to help them do what they thought was best for the patient. The industry here is positioning itself as an outsider, standing by while the clinician does what they will do, thus attempting to distance themselves from the controversy and their role in perpetuating the diagnosis of PBD. For the industry, the function of clinicians is to legitimate and validate the diagnosis for the industry through practices such as signing their names to ghost written papers, presenting at conferences, and influencing their colleagues as knowledge leaders, but also as a scapegoat when controversy arises. The expertise that renders them so valuable in advancing notions of PBD also becomes an asset in separating the industry from any perceived liability that may result.

4.7 The Child

4.7.1 Unmet need and opportunity

The child in pharmaceutical industry documents is presented as an opportunity to move into new territory previously untapped in the prescription of antipsychotics. Most of the documents covering the testimony of those voices from inside the industry (CEO, pharmaceutical rep), as well as the marketing plans and educational materials all refer to children as the next frontier:

If the paediatric indications for schizophrenia and bipolar disorder are approved, the ZYPREXA patent will be extended by six months in the US.
(*Doc.8. Zyprexa global marketing plan, 2002, p. 15*)

There is no attempt to hide the fact that the move into paediatrics would be beneficial in terms of profit, as it would allow for the extension of patent protection giving exclusive license to, in this case Zyprexa, to be prescribed for PBD. Opening up the possibility of bipolar in young children in this context has nothing to do with what is happening within the child, rather it is the process of coming up with a diagnosis to meet the treatment that takes precedence, trumping any further consideration of how a child might be affected by the untested medications, or whether a new diagnosis such as

PBD is warranted. The child is simultaneously at the centre of, and removed from, the cold, hard business of profit margins and staying ahead of the competition.

The representation of children as an opportunity to expand a market provides a basis for widening the more general assumptions about which behaviours may ultimately be deemed pathological:

There are significant unmet needs in these populations and there are significant opportunities for therapies that go beyond symptom control (e.g. improved attention). Bipolar Disorder represents a huge market potential and it is currently in the early stages of development. Treatment for Bipolar Disorder will grow dramatically if a solution to under- and misdiagnosis is created. (*Doc. 8. Zyprexa global marketing plan, 2002, p. 13*)

The idea of “unmet need” perpetuated by the industry suggests that clinicians have been missing something in these children all along, that they have a need that is not being provided for and which the industry is in a position to facilitate the clinician taking action. A problem has been created so that a solution may follow, and what is presented here is a solution not only to the problem of dwindling profits, but to clinical uncertainty as well. Validating the possibility that these disorders can exist in children, and framing it in terms of ever expanding criteria (such as the need now for improved attention) provide clinicians with an explanatory framework that is broad enough to make sense of many of the children who will likely be showing up in their offices, and a new category under which to interpret their behaviours. Clinicians are thus provided a mechanism allowing them to have a sense of fulfilling their obligation to patients as knowledgeable clinicians, while moving the industry into new territory whereby childhood conduct is redefined in order to satisfy a marketing opportunity.

4.7.2 Suffering from a debilitating “constellation of diseases”

The blatant proposition of children as an unmet need is not how the industry presents the development of PBD to the outside world, however. Instead, the external representation is not of children as an opportunity, but rather that they are suffering from a debilitating illness which, if left untreated, can ruin their lives as well as the lives of those around them. It is the notion of the greater good which is communicated when the voice of pharma enters the public sphere:

So, again, I'm not sure if this was -- what I do remember is trying to better understand exactly what the nature of the disease in adolescents and children was versus adults and in better understanding the overall condition.

Q. And better understanding the overall condition would lead to more diagnoses of pediatric bipolar disorder, which would then, in turn, lead to more prescriptions for antipsychotic drugs including Risperdal. Is that right?

MR. MURPHY: Objection to form, lack of foundation. You may answer it.

THE WITNESS: I can't speculate. I think at this time those recognition -- that many of these children were suffering debilitating illness and there was little in the way of literature on the appropriate diagnosis, I believe as this was referred to, and on the appropriate treatment based on the physicians' understanding of the patient and the different options that were available to them as well as the patient.

(Doc. 14, pharmaceutical industry CEO deposition testimony, p. 77)

Q. Right. But besides the actual recognition of the disorder, I think what we're looking for, what they were looking for here was to see if there was just one objective test, one way to figure out whether this mental disorder or this illness existed. Is that right?

MR. MURPHY: Is that his understanding of a goal?

MR. McCORMICK: Yes.

MR. MURPHY: Do you understand the question?

THE WITNESS: That's not my understanding. I think usually these diseases are very difficult and lie along a continuum. I'm not a full expert in the area, but from my exposure it was actually a constellation of diseases that had a lot of different inter-patient variability.

(Doc. 14, pharmaceutical industry CEO deposition testimony, p. 137)

The excerpts above communicate a message of a desire for understanding on the part of the industry, to make sense of the debilitating illness causing the suffering of an increasing number of young people. PBD is presented as existing in uncharted territory, where a clinician was faced with something new, with no template to follow in terms of how best to treat. There is a sense of retrospective urgency as the speaker depicts the child at the centre of the discussion as in distress over a lack of clarity surrounding what

is happening to them, and that a push for objective diagnostic certainty to help these children is what motivates off-label prescribing of antipsychotics, as opposed to callous profiteering. The inclusion of a child's suffering into the discussion of marketing practices has the effect of justifying convention while at the same time giving pause to various others who may attempt to position the industry as caring little for a child's welfare.

4.8 Pharmaceutical advertising as external manifestation of industry behaviour

Physicians often deny the relative importance of commercial sources influencing their prescribing (Avorn et. al., 1982) but studies have shown that drug advertising does influence prescribing patterns (Quinn et. al., 1997, citing Hemminki 1975). Drug advertisements are “an important part of a drug company's persuasive arsenal used to ‘educate’ doctors and the general public and shape attitudes about health and well-being as part of a campaign to create desire for pharmaceutical product” (Singh 2007, 133) and act as useful window into ideas and representations about health and illness that are held, and disseminated, within the health industry (Foster 2010). While some messages are intended, others are less obvious in the perpetuation of views through the choice of images and text used in the ads (ibid, 27).

By using advertisements to market their medications, companies normalise the notion of disorder through presenting the pharmaceutical solution. Goldman and Montagne (1986) note that pharmaceutical advertising campaigns are often based on abstract visual metaphors so as to generate cognitive connections between the meaning of the images and the medications being advertised, encouraging the viewer to “infer connections between multiple meaning systems” (Goldman and Montagne 1986, 1047). In the case of the advertisements in the section that follows, the medications are those prescribed to children with PBD, so there is an interesting contrast present in how the medications are discussed internally, versus how they are represented here and how those representations might be generalised into wider pharmaceutical representations not of the medications, but the conditions they are advertised to treat; conditions which provide the meaning anchors for PBD: ADHD and Schizophrenia.

4.8.1 Analysis of advertisements

Farr (1995) notes the importance of linking up the image with the text when interpreting advertisements, as there is often a relationship between them, which should be considered. Analysis of the images here thus incorporated a semiological analysis following Penn (2000) and qualitative content analysis (Bell 2001) (*cf* 3.4.2) which aimed to interpret the image and text to understand how the visuals were being used to communicate a message about the medication. Analysis was made up of three steps involving an initial scan of the images to see what stood out in terms of text and image, followed by a “denotational inventory” where the elements of the advertisements were coded according to a ‘variables and values’ framework outlined by Bell (2001) in which attributes such as image type, social distance, the type of appeal being used to persuade, and the normative values communicated were coded. Once coded for values and appeals, a dialogical approach was employed which explored the type of knowledge the ads are presupposing, the debate is the ad entering into in terms of wider institutional and cultural frameworks, and who is being addressed in the ads. The findings of the analysis of ads are presented below. For full details of the sample and coding frame see *chapter three* and appendix 10.

4.8.2 ADHD medications

It is interesting to note that in the medical journals surveyed, those in the US were dominated by medications for ADHD as opposed to the antipsychotic medications which were more common in the UK. What this suggests is the level to which norms of childhood are perpetuated and constructed in these ads, making the idea of comorbidity between ADHD and PBD make sense. A clinician’s perspective in thinking about mental illness in children is consistently brought back to how a child ‘should’ behave, thus when confronted with an aggressive child in the office, these representations will never be far off. These are images of what constitutes normal boyhood in a particular cultural context. Engagement, achievement, and social adeptness are highly valued, thus

the one interpretation might be that if they are lacking in your child, this can be seen as pathological.

The advertisements in figure 4.1 below are text heavy and factual, communicating statistics on efficacy, improvement ratios, and performance.



Figure 4.1. Comparison of Adderall advertisement, Journal of Child and Adolescent Psychiatry 2004 and Equasym advertisement, British Journal Psychiatry 2004

Also included in the ad are specifics on how the medications work- extended release tablets, information in the main text on dosage etc. A common theme in ADHD advertisements is the notion of performance, with math tests often cited as evidence of how effective the medication is. The school day constantly referenced as a point of measure (eg, “improves attention and behaviour throughout the school day” or “Equasym, with the school day in mind”). Advertisers and the pharmaceutical industry are not hiding the fact that this is being marketed as a performance-enhancing drug. The representation of this as a mental illness has fallen by the wayside. The ad is addressing clinicians, however the content of the text suggests a sense of asking the clinician to become the parent. The Adderall ad on the left tells the viewer to “reveal his potential” before noting that the medication improves academic performance, citing a trial in which patients completed 26 more math problems correctly as opposed to

those not taking the medication. The Equasym ad plays into the innocence of a child's aspirations, including a "spring school year plan" penned in the child's hand that include "becoming part of the theatre group, making a card for mother's day and making a costume for the Easter parade". Aspirational appeal for a wholesome, 'normal' childhood is made to the clinician presenting an image to contrast with those children they might be seeing in their office.

4.8.3 *Risperdal*

As discussed in the previous section, the desire to expand the market for Risperdal was what gave life to the diagnosis of PBD. As one of the most prescribed medications for children with both ADHD and PBD, it is particularly interesting to see how this medication is marketed externally, after getting a sense in the previous section of how it was discussed internally. The off-label indication for Risperdal means that it cannot be actively marketed for children, so what is presented here provides an indication of how they are being represented. The ad presented in fig. 4.2 below is dramatic in its presentation, presented almost as a work of art. The text at the top of the ad, reading "Amelia, virtually housebound through fear, believes that when she goes out she's followed by a menacing black dog. And that the dog and her coalesce." is presented in a very small font, inviting the viewer in, perhaps suggesting they get close to her delusion—an invitation to share her fear.

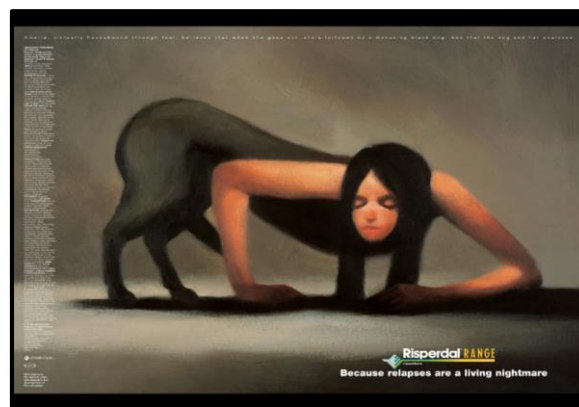


Figure 4.2. Risperdal advertisement, British Journal of Psychiatry, 2004

The premise of this ad is that relapses are a living nightmare, though it's never specified what the relapse refers to. There is an ambiguity felt in the absence of a specific diagnostic indication, allowing space to for the clinician-viewer to consider that the medication can be used for any number of conditions. The overall tenor of the ad is unsettling, going deep into wild delusions of a living nightmare. The woman appears to be young, her expression one of remove, perhaps lost in her delusion, unaware of the world around her, providing a window for clinicians into her mind. The appeal of the image is emotional, while the size and content of the text attempts to bring viewer in to a shared experience.



Figure 4.3. Risperdal advertisement, British Journal of Psychiatry 1997

In contrast to the first Risperdal image, the advertisement above again hits first with an emotional appeal suggested by the image of a woman staring off into the distance with a soft, calm gaze. Her profile emerges out of a red fog of blurred, swirling text symbolizing the turmoil she is experiencing in her head. The face is semi-obsured by this red fog suggesting without the medication, a sense of identity is lost. There is minimal text, instead the peace of the ad is preserved through muted colours, the reddish brown leading into a soft blue indicating hope and healing, while the crystal clear text advises the clinician-viewer that 'peace at last' can be achieved. Risperdal equals power, but a soft power here. The medication has the power to relieve

symptoms, as indicated in the first bullet point, while the slogan reminds viewers that Risperdal is “power you can trust”. Power is the central theme here, with a sense of mastery and control over the diagnosis reminding clinicians that the power to calm the mind in turmoil lies in their hands. Assumed cultural knowledge in the form of norms emphasising turmoil and chaos as negative and treatable, while peace is sought as a desired outcome. Unlike the previous ad, this specifically indicates that Risperdal relieves symptoms of schizophrenia without specifying what those might be. This ad is also from 1997, as opposed to the first, which was from 2004, perhaps suggesting an increasing desire to stay vague on specific indications in keeping with increasing off-label prescription practices. In addition to the overall emotional appeal, the text citing studies alluding to the power and efficacy of treatment suggests factual, scientific appeal.

4.8.4 Seroquel

This ad for Seroquel, another of the atypical antipsychotics indicated for treatment of PBD, presents the medication as an ‘add on’ for the treatment of depression- a much more benign characterisation of the medication given its severity.



Figure 4.4. Seroquel advertisement, British Journal of Psychiatry, 2011

The clinician-viewer does not need to be immediately reminded of the seriousness of, or stigma surrounding the medication they will be prescribing. But what does the viewer see? The muted, mustard yellow tone of the illustration suggests something stale, stagnant, and depressing. On the left, we see a slumped individual who appears to have just come home, or rolled out of bed, perhaps getting ready to go out, gathering bag and computer, but they are stopped in their tracks, unable to continue on. The roll of tissues close at hand illustrates the depth of the sadness in the tears that keep flowing. The position suggests weight, the inability to move from this place. The single/twin bed, half unmade, suggests loneliness. There is a small sense of chaos and searching, as though something has been lost, in the way the belongings are scattered about on the floor, but also behind, the dresser drawers are opened. On another table next to the bed lie boards of some sort, suggesting taking something apart, or an unfinished project. These things also barricade the bed, and the individual from the window, and the light. The window appears to be open, ushering in a breeze, a shift, a wind of change into this stale, dormant environment. A camera lies in disuse, a life and interests left behind. However there is hope to the right of the page, with the warm glow of light that bathes the name of the medication. The association with creativity in the presence of the camera, and also the way the ad itself is illustrated stirs an association about the creative temperament who may also veer towards sadness and madness. The emotional appeal here lies in the loneliness conveyed, the life put on hold.

4.8.5 Fact versus narrative in pharmaceutical advertising

In PBD, the findings presented in this chapter suggest that a disorder of adulthood has been reconfigured as a disorder of childhood, grounded in representations of both the behavioural problems associated with ADHD, and the severity and future risk associated with schizophrenia. Both become ‘meaning anchors’ on which to ground a new interpretation of childhood behaviour as potentially pathological. These advertisements could be seen as visual representations of what the industry communicates internally, seeking to expand the idea of who or what types of individuals can be a candidate for these medications and their related diagnoses. Elements of ADHD incorporated in to diagnosis of PBD include chronicity,

treatability, and value judgements as to how a child ‘should be’, while element of schizophrenia in PBD include the desired link to neurochemical imbalance, risk, urgency, and a need for treatment that can’t be ignored- this despite the fact that in the US, psychosis need not be present as a symptom. The ads for ADHD medications are cantered on the child, reinforcing norms of childhood, while the child is absent antipsychotic ads. The presence of such absence begs the question of deliberate absence or ambiguity utilised as a means to support the expansion of diagnostic categories, thereby leaving space to attribute ever-more symptoms to PBD in children, possibly resulting in more off-label prescribing of antipsychotics.

The common sense understanding of ADHD grounds new notions of how a child might come to be identified with a new diagnosis of PBD. Early marketing practices sought to anchor the new conceptualization of PBD within ADHD by suggesting both a high co-morbidity between the two, as well as the potential misdiagnosis of ADHD instead of PBD due to overlapping symptoms. The antipsychotic medications continue to be grounded in Schizophrenia, where the images presented are much more orientated towards creating an emotional narrative as opposed to grounding the medication, and associated conditions in factual text. The images are darker, murkier and more intense, incorporating elements of the delusions experienced by the isolated individuals depicted. Of interest is that often time a specific diagnostic indication is not made clear in the ad, or if it is, there is the suggestion that what is presented in the images represents ways of being that could be attributed to multiple diagnoses, and thus the medication is a treatment not for one condition only, but for a more generalized representation of a clinician’s sense of what it means to be disordered. The images allow the viewer to get inside the experience of the individual, or the position of a parent in the case of the ADHD advertisements, but also to remain objective knowing what’s wrong and how best to treat. The power and control lies with the clinician viewing the advertisement.

Ferner and Scott (1994) remind us that “science requires the unambiguous description and logical analysis of facts”, a process at odds with the purpose of advertising, which they suggest “shares with art the use of oblique visual and verbal

images to convey the message it wants us to receive” (p. 1734). In the case of marketing medications used in the development of PBD as a diagnostic category, the textual and visual images simultaneously create an explicit sense of social norms on which to draw in diagnostic practice, while at the same time allowing for ambiguity, leaving it up to the viewer how a medication should be used, and for which treatments. Both normative and informational influence are at play within the advertisements, with the use of emotion (in the case of antipsychotics) acting as a tool perpetuating descriptive norms which visualize the current state of mind within sufferers, in need of clinical intervention. Within the advertisements for ADHD, a more factual presentation indicates the level to which injunctive norms are utilised in an attempt to align notions of childhood with what *should be* (as opposed to what *is*) providing a sense of possibility through correct diagnosis and use of a specific treatment.

The persuasive power of a message, visual or otherwise, lies not only in the message itself, but the education designed to align with the content of the message. As this chapter has shown, the education of clinicians by the pharmaceutical industry has been a key aspect in building a particular understanding of PBD. That education ensures aspects of the message are internalised, thus, when coming across an advertisement for a medication which a clinician has recently learned can be used to treat a more broad range of conditions, and may also be sanctioned for the treatment of children, both informational and normative processes are drawn on to absorb the message as a whole. Medications themselves can be seen as representations that:

carry meanings and shape social relations as they evolve in conjunction with individuals and collectivities...and are intertwined to form ‘social facts’ that are highly responsive to culture, history and social context” (Cohen et al 2001, 442).

It is at this level of interaction, between the development of a diagnosis to expand the market of a medication, and how this is communicated via image and text, that contributes to a wider exploration of the role of pharmaceutical advertising as one aspect of the ‘voice’ of the pharmaceutical industry as it relates to shaping understandings of PBD.

4.9 Discussion

This chapter has explored how pharmaceutical industry marketing practices shape representations of PBD in the US and England via the internal and external perpetuation of narratives found in documents and advertisements. Findings are illustrated in figure 4.5 below, and suggest the centrality of economic pressures and fierce competition in the development of PBD as a diagnostic category. Rather than seeing competitors as a threat, their developing understanding of PBD is accommodated and applied towards further development and perpetuation of what the disorder should look like. As a result, children are represented in terms of their market potential, reflecting ‘an unmet need’ who need to be positioned as suffering and at risk in order to campaign for their treatment with severe and untested medications.

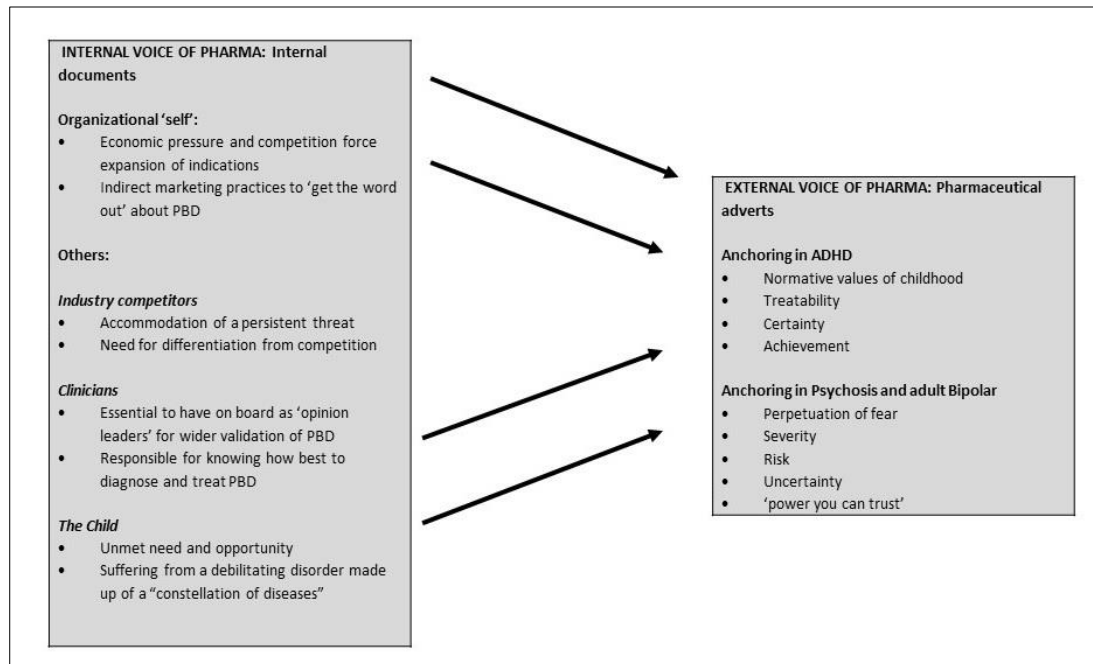


Figure 4.5: Illustration of the internal v. external voice of the pharmaceutical industry

Encounters between industry representatives and clinicians steer processes of anchoring PBD in an already established diagnosis of ADHD, emphasising the chronicity and treatability, while steering away from previous associations with more severe, psychotic presentations such as schizophrenia. Thus the objectification of a

more ‘broad spectrum’ PBD as discussed in *chapter one* begins to take shape. The education of clinicians taking place via office visits from pharmaceutical representatives leads to a variation of bipolar disorder now anchored in rage, excitability and aggression as symptoms. The interpretation of such behaviours as pathological is driven by mechanisms of soft-power via financial incentive, for both the industry itself, as well as the clinician prescribers it seeks to influence. Clinicians are rewarded for their ‘expertise’ in the form of being designated opinion leader, and reminded of the role they hold for their patients as trusted, respectable, and knowledgeable. The overt use of persuasion as a tactic is illustrated in figure 4.6 below, in which a PowerPoint presentation shown to sales representatives reminded them of their role in getting clinicians on board. Central to the industry’s construction of PBD as a valid diagnostic category lies in changing previously, potentially well-entrenched, long-held beliefs about what bipolar means.

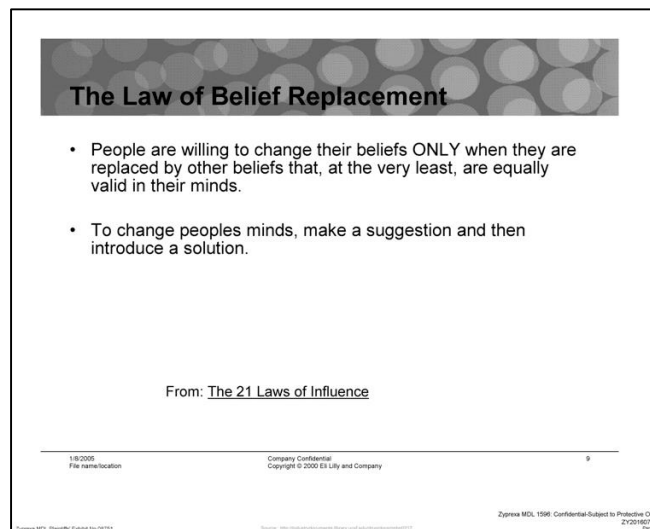


Fig.4.6 Zyprexa marketing strategy presentation to pharmaceutical sales representatives

For the external voice of the industry as manifested in drug advertisements, it is not the diagnosis represented specifically, but rather norms and appeals, both rational and emotional, which are used to elaborate and make sense of this condition. There appears a deliberate ambiguity in what is absent from these ads, allowing clinicians to see these medications as existing for multiple uses, not just what may be indicated by official

regulating bodies- something which is emphasized in the education they receive from industry representatives, as discussed previously. Gervais et al. (1999) suggest that ‘as much theoretical attention needs to be paid to what is not there as to what is there, not least because the former shapes the latter (p. 420). In this case, the idea perpetuated as seen in the internal documents, in which clinicians are encouraged to abandon previous notions of what ‘bipolar’ stands for, adopting a new perspective which suggests rage, irritability and inappropriate conduct can be indicative of disorder is thus born into the way the medications are marketed as a diagnosis comprised of elements from many other diagnoses.

For the pharmaceutical industry, bipolar disorder in children need not solely associated with manic-depressive psychosis anymore. Instead, what we see in the analysis of the pharmaceutical industry ‘voice’ are the industry behaviours acting as mechanisms of influence which drive the move beyond only using these medications for Schizophrenia, as on its own this is not lucrative enough. We see how uncertainty combined with pressure and the promise of prestige is used to reshape how one thinks about this disorder, but more importantly, how knowledge of what makes up this diagnosis is realigned to make sense in children. A previously objectified psychotic disorder becomes re-objectified as behavioural through persuasion and conversion of clinical thinking, the soft power of economic incentives, validation of the diagnosis through alliance with ‘expert’ clinical professionals, and the perpetuation of risk in order to maintain a level of uncertainty and ambiguity in need of frequent re-validation. Both normative and informational influence can be seen in the way ads visualize the tension between how things are versus how things ought to be, a presentation that is enhanced by the steering of clinical perspective through education.

Playing on risk, fear, confusion and comparing this with a future possibility that incorporates achievement and sociability, the pharmaceutical industry engages in persuasive techniques in which the clinician’s position as trusted expert is played into as target-audience. Prescription decisions made by a clinician can be influenced by a number of factors including diagnostic uncertainty (Cohen et al 2001) and have been identified as a “symbol of doctors’ control and power to heal” (Vuckovic and Nichter

1997, 1296) both of which are present in the ads. Medications inform the interpretation of illness “to the extent that explanatory models for illness may be framed in terms of the type, strength and quantity of medication consumed. The severity of the illness is inferred from how powerful the medication is perceived to be” (ibid.). Thus, the alignment of antipsychotics as an acceptable treatment for PBD simultaneously communicates a lack of stigma in the treatability of an increasingly common diagnosis, with the urgency stemming from the association of antipsychotics with severe mental illness. PBD is thus severe enough to warrant these strong medications, yet not so severe that clinicians shouldn’t be seeing more and more cases in their offices. This exemplifies ways in which psychiatric knowledge and diagnostic practice can be shaped by the interests the pharmaceutical industry, as well as broader social and cultural attitudes toward medication (Kirmayer and Raikhel 2009).

Dumit (2012) introduces the concept of “pharmaceutical witnessing” as a type of “biomedical informing” in which “facts are passed on embedded in stories or images in which the viewer is put in the position of having to make sense of the story or ignore the risk it portrays all together” (p. 75). In the context of what has been discussed here, this suggests that clinician-viewers of advertisements, participants in direct interactions between sales representatives and physicians, or indirect actions the result of being on the receiving end of targeted education and marketing campaigns, it is they who become responsible for making a diagnostic or prescriptive choice and thus being responsible for the outcome. This level of informing is illustrated in the marketing mechanisms used by the industry as knowledge is passed from top levels of the industry down to the sales representatives, who then have a tremendous amount of power in shaping what clinicians should be seeing, how they should be defining what they see, and how it should be treated. Stories come in the form of personal profiles of hypothetical patients presented in education seminars or sales calls, or those implied by top level executives to the sales representatives doing the groundwork, that their work is important, they are contributing to the greater good through the reduction of childhood suffering.

The ‘pharmaceutical witnessing’ is present in the narratives suggested in the advertisements, in which instead of a condition being marketed directly, social norms are reinforced and space left open for wider notions of what this particular diagnosis might look like in a child. These are ways the voice of the pharmaceutical industry tells its story and shape representations of PBD as a diagnostic fact.

As will be discussed in the remaining empirical and discussion chapters, the way this discourse has been internalised by clinicians and parents in the US and England will show the pharmaceutical industry as a unidirectional vector of influence, establishing very direct presence within American practice, and even among American parents, while remaining less overt in England. Among English clinicians, the influence of pharma with regards to contested treatments for unstable diagnostic categories serves as a force to collectively resist as much as possible. Central to the differences between the two contexts is the conflict that exists in England, where the field of psychiatry, and families of children living with bipolar disorder, pull between competing representations of the diagnosis; one as illustrated here as stemming from an industry seeking to make a profit, and a more stable, long-term representation of bipolar which remains a highly stigmatized life-long illness aligned with prior representations of bipolar disorder as manic depressive psychosis.

The conceptualisation of PBD taking shape in the US as an uncertain and unstable diagnosis comes as a result of the way the diagnosis came to be; the product of a pharmaceutical company seeking to extend its patent on an antipsychotic medication, seeing children as marketing opportunity, and deliberately expanding and confusing the behaviours that can be seen to be indicative of the diagnosis so that just about any undesirable childhood conduct could be included in the pathology. This conflicts with the representation of PBD in England where the notion of bipolar in young people is still in the process of migrating from the US, a second-hand diagnosis one step removed from its beginnings as a US based marketing strategy. Thus professionals and parents in England still hold on to the idea of PBD as the same as bipolar in adults, usually involving psychosis, and not occurring in very young children. The presence of the pharmaceutical influence in shaping representations in England is placed as

something to either rally against, reaffirming expert knowledge in traditional definitions of bipolar disorder, or else slowly adopting what is perpetuated in the US, seeing an expanded idea of bipolar in children as something useful and worthy of attention.

5. Clinical representations of PBD in the US and England

5.1 Introduction

While the previous chapter (*chapter four*) focused on the role of the pharmaceutical industry, illustrating how processes of anchoring, objectification, and social influence succeeded in reshaping how bipolar disorder in children is defined, the aim of this chapter is to explore how these new representations may have been internalised in the understanding of clinicians, and how a clinician's own knowledge combines with the new 'broad spectrum' conceptualization of PBD. The results suggest that clinicians in the US and England have differing ideas over what counts as 'disordered' behaviour, as well as which other knowledges are being relied upon to generate representations of both the diagnosis, as well as the child at the centre of it. The questions guiding this chapter are as follows:

- What are the representations of PBD held by clinicians in the US and England
- What psychosocial processes shape the development of these representations?

The data presented in the following sections address my research questions by exploring the significant others coming up in conversation about PBD for clinicians in both contexts, beginning with the clinician's positioning as a 'reflexive Self', followed by how clinicians in both the US and England discuss, or take on the 'voice' of the parents they interact with, the pharmaceutical industry influence that in both subtle and not so subtle ways, and finally the child at the centre of it all.

The findings in this chapter connect to the overall thesis as it presents one set of three key actors whose knowledge is involved in the construction of PBD as a diagnostic fact. Clinicians hold a significant and unique place in three knowledge systems explored, as they exist as a point of reference between top-down institutional

processes and bottom up anxieties of parents and pressures making their understanding of the diagnosis central to how it is perpetuated on a wider, more common sense level. In looking at how American and English clinicians differ in whose knowledge they take on board, who they see as allies, and how they discuss the child, it is possible to get a sense of the wider culture of practice in which their knowledge takes shape. The purpose of the analysis presented in the following sections is to provide empirical evidence for how clinicians in the US and England develop an understanding of PBD, and how this knowledge is taken up in clinical and diagnostic practice. Such evidence provides a contribution to understanding the wider mechanisms shaping how the diagnosis has come to be, in particular why it has expanded in one cultural context while remaining rare in another.

5.2 Analytic procedures and findings

The purpose of the analysis discussed in this chapter is to provide an empirical grounding as evidence for the development of clinical representations of PBD. The findings presented here are the result of thematic and dialogical analyses, which is discussed in further detail in section 3.4.3. In conducting separate analyses on US and English clinician data, I sought to develop a coding framework that reflected both the content and processes involved in the development of knowledge of PBD; what was being said about PBD, and how it was being said. After early initial round of coding each set of interviews for the US sample of 8 clinicians and the English sample of 10 clinicians, it was decided that Self and Other would be made global themes. The data was then re-approached with this organizing framework. An initial identification of who the significant others were coming up in conversation acted as organizing themes under the global heading of 'Self-Other'. For American participants, this resulted in organizing themes of the clinical-Self- 'I' position followed in frequency by significant others in the form of colleagues, parents, the pharmaceutical industry and the child. For English clinicians significant others coming up in conversation were the same, but the degree of presence in discussion differed. Discussion of colleagues took precedence, followed by the child, parents and pharma, with talk of their own history or trajectory into working with PBD minimal in discussion. Each group of participants was coded separately so as

to allow for comparison. Coding was an iterative process in which data was read with the positioning of the Self and mention of Others in mind, but allowing space within those broader headings to develop basic themes specific to what was being said in relation to PBD. Basic themes then reflected what was being said about these significant others. Coding frameworks can be found in appendices 11 and 12. . It was in the final interpretive stage of analysis, once the coded segments were in place, that a dialogical approach to selected segments was undertaken. While the coding and resulting thematic framework developed identified the ‘who’ and the ‘what’, the dialogical analysis of those coded segments addressed the ‘how’. For an example of dialogical analysis, see appendix 15.

The most significant others among both American and English participants was the pharmaceutical industry, clinical colleagues, parents and the child. Analysis of the data resulted in often overlapping themes, as discussion about the wider diagnosis often contained issues related to more than one isolated group or theme. Discussion of a child’s behaviour for example, is relevant to how clinicians are discussing the child, but also how parents interpret present that behaviour to the clinician, and how it is then viewed as a symptom to be medicated. Thus, themes and subthemes could be seen as intertwined when discussing this diagnosis. In the final stage of analysis I explored what came out in the basic themes, identifying how clinicians positioned themselves in relation to others, noting who had more of an influence on their thinking and why, what representations were generated as a result of interactions described. This allowed me also to see how clinicians positioned others as well, and how their reflections on the knowledge held by these others was responded to with acceptance, wariness, or flat out rejection. An illustration of the themes that came out of analysis, as well as the positioning of US and English clinicians in relation to significant others coming up in discussion can be seen in *figure 5.1* below. The presentation of these themes are discussed in detail in the remaining sections of the chapter.

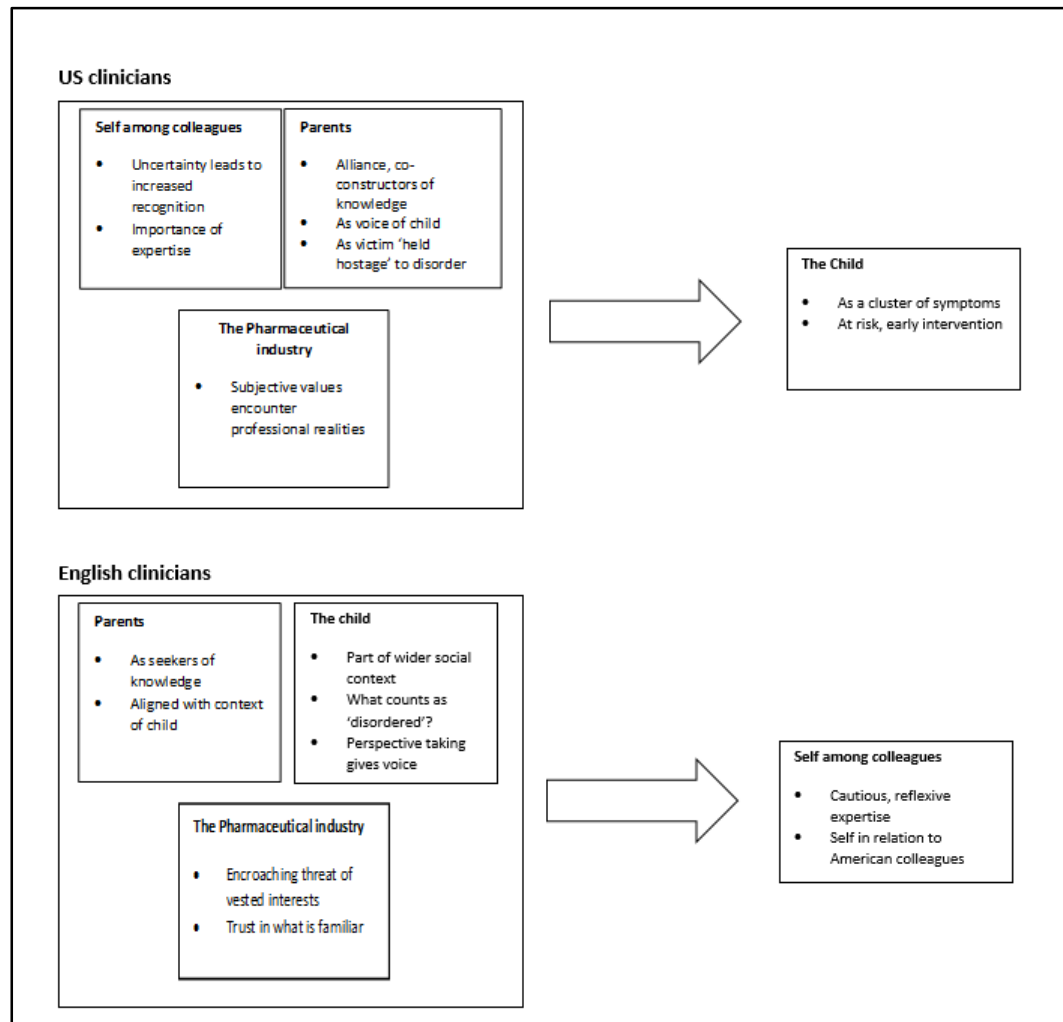


Figure 5.1: Illustration of themes and significant 'Others' among American and English clinicians.

As illustrated in *figure 5.1*, for American clinicians, the role of parents is central to their development of representations of PBD, relying on their experiential knowledge in the early days of the diagnosis to validate their own professional trajectories. Equally, as the diagnosis expanded, clinicians sought to perhaps justify their own approaches to diagnosis and treatment, which they may not have been entirely comfortable with. As a result, a dyad is formed alongside parents in which both are able to legitimate one another's decisions for the child. In this sense, the child remains peripheral, despite

being central to the conversation at hand. The way clinicians position themselves in relation to professional colleagues and the pharmaceutical industry is also central to how PBD is understood, and professional knowledge developed, suggesting the role sidelong and top-down influence can have on the way the clinician ultimately approaches the child. Among American clinicians, PBD is seen as a parent-driven diagnosis, unstable and still in-flux, requiring a high level of expertise to truly understand, and a potential risk for the child, thus warranting early intervention for pharmaceutical treatment.

Among English clinicians, it is their position within a collective field of mental health practitioners that governs the development of representations about PBD. Parents are not as influential as they appear to be in the US, and they are positioned alongside the child in discussion suggesting that parents are seekers, rather than holders of knowledge. There is still a hierarchy in place in which clinicians are seen as holding the expertise, however there is a sense of the responsibility of working with young children that weighs on these practitioners, thus there is a caution present that steers a desire to understand the wider context of the child, of which the parent is a part.

5.3 Reflexive professional Self among colleagues

What is meant by a 'reflexive Self'? In referring to the work of Hermans, Sullivan (2012) suggests that one's Self is actually made up of multiple 'I-positions' which are constantly struggling for dominance, activated or deactivated depending on context and relationship to Others being addressed directly, or more indirectly through presence in conversation (*cf* 2.4). For US clinicians, the dialogical self is situated as 'I' in relation to significant others to illustrate interactions taking shape in the world of the clinician, with an emphasis of incorporating a personal narrative trajectory into current opinion and practice around PBD. Among English clinicians, the subjective clinical 'Self' is discussed less in terms of the clinician as individual practitioner, but rather in conjunction with the wider professional field of psychiatry in the UK. In paying close attention to how professionals were positioning themselves in relation to the diagnosis of PBD, and when the choice was used to refer to 'I' as a practitioner versus 'we' as

clinicians, the wider influence of clinical colleagues became apparent, and the impact that influence had on clinical practice.

American Clinicians

5.3.1 Uncertainty alongside increasing recognition

When asked to define bipolar disorder in children, clinicians responded in terms of visible signs of the disorder, using the way children presented with various symptomatic behaviours as their point of departure for discussing PBD on a broader scale. Symptoms and presentation of children are at the heart of the debate, and drives the controversy surrounding PBD by virtue of the fact that there is so little clinical agreement on what this disorder looks like. Clinicians openly questioned their own application of the diagnosis to something so poorly understood, suggesting an acknowledgement of their own internal conflict when presented with children whose behaviours seemed unclassifiable. There was a very real sense of both internal and external pressure to find them an appropriate ‘diagnostic home’. Analysis of data found that the lack of specific criteria leads clinicians to fend for themselves in terms of how exactly to define the disorder, leading to multiple ways of interpreting behaviours:

So my opinion on this, and this is purely an opinion, is that you had a lot of clinicians looking at the same behaviour and calling it different things, and again, influenced by the literature. I call it evidence-based practice gone awry. (USC2)

In acknowledging the lack of consensus among colleagues, the speaker above suggests diminishing confidence in just what it is they, as a collective field, are seeing. It as if this clinician is accepting as a reality the fact that when dealing with this particular diagnosis, the state of the field in which he practices remains diffuse in its approach to defining PBD. American clinicians find themselves navigating between two beliefs about the nature of PBD:

There’s a lack of consensus on what the criteria’s gonna be. Do we use new broader criteria, or do we use the traditional old timey criteria where they were manic for days in a row, staying awake all day with all this energy, and a euphoric or explosive mood that goes along with decreased need for sleep for signs of psychosis? (USC5)

The clinician above questions the two polarities available to draw from; the ‘broader criteria’ which includes rage, irritability and is at the heart of the controversy, or the more classic approach to PBD prioritizing psychosis, the latter seeming to fall out of favour among US clinicians. There is a sense of resignation, ambivalence and conflict in assessing the context in which they practice, but also an acceptance of responsibility in perpetuating this state of affairs as this clinician aligns with his colleagues in the use of the term ‘we’. When there is no clear, agreed upon set of criteria to look for, and clinicians have different opinions on whether PBD is a stand-alone diagnosis, or something related to adult bipolar, the circumstances are favourable to begin realignment of what should be seen to match what actually is being seen. This can be seen in a clinician interviewed elaborating on the early diffusion of knowledge among clinicians over how to ‘see’ bipolar disorder in children, despite it not have ever been seen before:

So a lot of adult bipolar researchers, and then also child and adolescent psychiatrists mostly started to say ‘well, wait a second. If they’re reporting this, and we’re seeing some behaviour that may be like this, what’s going on? We should see this. So if everybody’s saying these things are starting when I’m a child or early adolescent, why aren’t we seeing it? Why do we have rates of BPD that are extremely low in children?’ (USC1)

The tone of the speaker suggests the urgency with which clinicians in the early days sought to make sense of what they were seeing that was in line with what colleagues were seeing. When reports of this new ‘broad spectrum’ approach to PBD began to trickle down from more prominent members of the field, there was a sense of not wanting to miss out on something potentially important, but also perhaps a desire not to be deemed uninformed or lacking in expertise. This presents an illustration of how the uncertainty surrounding diagnostic criteria began to impact the action and behaviours of the field of psychiatry as PBD was just beginning to emerge as a phenomenon. Awareness and increased recognition of PBD is shaped not by a new set of behaviours emerging out of nowhere, but rather as a result of seeing what is presented in a different way, a view articulated by one clinician involved in the early diffusion of knowledge about the diagnosis:

I will tell you that between the time I was training in 1991 and 1995, there was not a dramatic increase in our clinic. *It was that I saw what was in front of me in a different way.* The same children were right in front of us, but when you started to say, ‘well could this be a diagnosis of mania? Why did I never call it mania before?’ Because I was told that children don’t get mania, so I’d read the same symptoms through a different lens. (USC7, *emphasis added*)

Here the idea of ‘seeing is believing’, where a lack of belief leads to a lack of recognition, allows for a specific set of behaviours to be assigned ‘manic’ when previously they may have been considered within the normal spectrum of childhood experience. This comes not as a result of something changing within the child, but rather a clinical perspective that chooses to see those behaviours as pathological, suggesting the wider representations being established and perpetuated. More common sense beliefs about the rise of ‘new’ disorders such as PBD position them as being modern afflictions-the product of a unique set of environmental or societal stressors impacting directly onto the child, but what comes out of discussion here is that their own role as diagnostician, and thus perpetrators of diagnosis, plays a significant role in its expansion. Seeing “the same symptoms through a different lens” is an example of how such negotiations also involve changing the interpretation of a child’s conduct by clinicians. Reshaping how behaviour is viewed as normal versus pathological is central to the current paradigm shift that is taking place as a battle is fought over whose knowledge matters. The open acknowledgement of clinicians that it was their own shift in thinking, positioned in reaction to others, that brought the diagnosis to the fore as opposed to something innate in the child is of interest, and yet it is this shift in thinking that now drives a deeper search for more children who meet the poorly defined criteria for the diagnosis.

5.3.2 Career development and expertise

The development of expertise, and the related positioning that entails, in one that is earned. The importance of early career trajectories, and the influence of mentors on the evolution of their thinking about PBD, was a point of departure for wider discussion about the diagnosis with US clinicians. As one recalled:

I was like, I don't really totally understand [*the diagnosis of PBD*] and knew that it was a very new area of research, so in many ways kind of ripe for people to come in and make it their specialty and study it. So it seemed like an exciting opportunity that way. (USC1)

The ambiguity proved intriguing and the induction into a new world where more established colleagues will clarify this practitioner's own thinking about what can be seen as symptomatic of PBD. The influence of education and knowledge sharing, in which a medical student or trainee psychiatrist is open to being steered and thus converted to a way of thinking is central in establishing how professionals came to understand PBD. Where a clinician was trained, and whom they trained under determine what type of knowledge is being assimilated. The necessity of developing a career thus becomes central to how open a young clinician may be in shaping their interpretations of behaviours leading to PBD.

The desire to establish a refined and discreet diagnosis and find a diagnostic home for children who no one knew how to label or what to do with is deemed necessary to create certainty in place of the discomfort that comes with ambiguity. A realm of expertise is created, so that the ability to 'see' PBD in a vague mass of symptoms is represented as being an acquired skill, where awareness is equated with experience. Clinicians position themselves against apprehensive and sceptical colleagues who are seen as a barrier to their own advancement and thus discredited in conversation. This drive for advancement, couched in innovation, suggests the level of autonomy clinicians in the US strive for in their practice. Such representations lead to a further identification of the Self as the voice of reason in a sea of criticism, as the following example of a clinician re-enacting interactions with colleagues illustrates:

Other researchers were quite nasty in their responses to me: "I've been working 20 years in this field, I've never seen a case!"... "well you must be looking at this funny, you must be making this up". Accusations. "It can't be true. You can't be competent, because if it existed, I'd be seeing it". (USC7)

Failure to recognize PBD is seen as risky potentially leading to a loss of esteem among colleagues, as well as a sense of one's subjective sense of expertise. In order to facilitate a search for what 'should' be seen, it becomes necessary to establish fields of expertise

and specialized clinics; tangible evidence of a process taking shape, a diagnosis objectified, with a 'build it and they will come' phenomenon contributing to the evolution of exactly what is being sought out to treat. In the excerpt above, the clinician positions themselves as a fighter, giving a sense that their belief in pursuing PBD was for the greater good and came at a great personal cost.

While clinicians working in children's mental health operate as part of a wider collective of specialists, when discussing their own professional position among colleagues, there was a sense of operating independently of one another, maintaining opposing views and proposing contrasting approaches. There was little unity or cohesion evident, instead the way clinicians themselves in relation to their colleagues was oriented towards reiterating their expertise in the face of controversy, as is evident in this recounting of an interaction between two child and adolescent psychiatrists:

I had a child under my care who I had diagnosed with PBD. And I was treating him with medications for PBD, and...was hospitalized at a local psychiatric hospital. The doctor there said "well, this is a boy that's depressed, but I don't see the bipolar" and I said, "well he's not manic now. He's depressed now. He has a history of mania". (Doctor:) "I heard that history and I don't think it sounds like bipolar disorder". And so the doctor told the patient and the mother "I don't believe Rd. USC7 has the correct diagnosis. I think you should take an antidepressant. Here's Prozac." And they discharged him on Prozac. That was February. It's now July. I decreased the Prozac dose because after several months he started to seem more agitated and irritable, and so he went to the emergency room. He wanted help, because he goes nights without sleep, he's very agitated, he's exploding with his mother, he's been making odd sexual comments to her. Well what is that? He's got bipolar disorder. So, they tried to re-hospitalise him, he didn't want to stay, so he left after a day, and the doctor there said "I don't think you have bipolar disorder, I think you have depression" Well how - aren't they hearing these same facts?! (USC7)

The way the speaker presents this scenario above illustrates the multiple systems of knowledge coming up against one another in a quest for validation. The sense of the speaker feeling undermined is offset by positioning themselves as the expert trying in vain to do what's best for the child in the face of a misinformed colleague. The colleague as 'Other' is represented as out of touch, a source of confusion for the parents and oblivious to the 'facts' of PBD. The tone is almost conspiratorial with the listener, inviting us to take a position as well. The interpretation of clinicians of

colleagues as a threat is tied to competition for legitimacy when engaging with an unstable diagnosis.

The notion of expertise is a fundamental aspect in the development of clinical thinking about PBD. In positioning themselves as experts in relation to this very murky, ill-defined diagnosis, professionals are forced to crystallize their ideas about what the diagnosis means, holding their opinions close in order to maintain the sense of mastery in the eyes of their colleagues:

I: How can you be certain that when you do give the diagnosis of PBD that that's what it is?

R: Oh it's a matter of going with your diagnostic skill. Years and years of experience. Scores and thousands of children over the years that have come through our threshold, and so we could tell them from a mile, which spectrum where they are, because that's something that you develop very well over time, but if you're not used to that, it's very hard. (USC4)

The above quotes indicate the beginning of a thought process in which “recognition” of behaviours as being pathological is calibrated with the clinician’s own well-developed proficiency in diagnosing. There is no questioning on the part of the speaker that they would get it wrong, or not know what they were looking at. The certainty present in this quote is indicative of having decided what children with PBD look like, and if that differs from what other experts see, then that must come down to a lack of experience. Diagnoses such as schizophrenia, childhood depression, and ADHD don’t always elicit the same discussion surrounding the need for a well-trained eye to make the call. The overlap and comorbidity of PBD with these other disorders illustrates the ongoing negotiation involved in positioning PBD alongside other mental illnesses.

English Clinicians

5.3.3 Interdependence and cautious, reflective expertise

Among English clinicians, the Self was positioned as cautious, often deferring to what one clinician referred to as “the culture of second opinions” that seems to govern practice in England. There was an overarching sense of wanting to see as complete a

picture of the child's life beyond presenting symptoms, and a hesitancy to stand alone in making a diagnosis:

I think just in thinking about it without really having thought about it, you know to diagnose a child of 3 or 4, we would be very cautious and concerned, I mean, we get a lot of children with ADHD or referred for ADHD at very young ages, and again we're very um...because you can't diagnose, or you're not meant to diagnose before the age of 6 anyway. You know we're very cautious, and we'd want to know what else is going on with the family, so I think we'd be, I'm guessing that we still feel the same if we had a referral that said 'we have a 3 year old and we're concerned about him or her having a bipolar disorder' to a certain extent. (UKC 3)

Diagnostic instability creates a space for influence at multiple levels. Normative pressures illustrate the conflict among clinicians over the interplay of their sense of themselves as independent practitioners, as well as members of a wider collective field of practice. There may be an assumption that a certain level of expertise solidifies positions and shields clinicians from doubt, however as the following excerpt illustrates, when it comes to facing a murky and contentious diagnosis such as PBD, maintaining a set position without regard for the beliefs and approaches of colleagues is difficult to sustain:

The proper manic depression, everybody would recognize that, even the taxi driver can make that diagnosis you see. But for these other cases that are kind of-- we are very inconsistent in our practice, and as I say the diagnosis will be anything from stropky adolescent to something with the parents to proper bipolar, you see. In between you have these other differentials, you see, and I think we are still...I mean, the ADHD and bipolar is a very sensitive area, yeah? And there are people who say they have ADHD and bipolar, and people who say it's ADHD but present with bipolar, and others say it's bipolar and present as ADHD. That is a very controversial. *There are some political elements to these things where you have the kind of view that make you unpopular with peers and things like that. You're judged by peers, and if peers are not tolerant of something like that, you probably will not maintain it.* (UKC6, emphasis added)

Here the inconsistency lies within the collective 'we'. The clinician above doesn't make an attempt to distance himself, rather there is a sense of surrendering to the realities of the profession in which sometimes being part of a wider collective results in one's own subjective perspective being subsumed by the politics of the broader field of practice. Conformity pressures from peers point to a wider trend towards building consensus,

going along with the dominant ideas of psychiatric practice even if it may not align with an individual clinician's perspective. In alluding to the uncertainty over how to label children presenting with ADHD who may be given a diagnosis of bipolar, or vice-versa, prevailing norms among this clinician's peers suggest how a set of behaviours is diagnosed is significantly shaped by how professional colleagues think about and attribute those behaviours. The power of the beliefs of one's peers is internalised, indicating the ongoing tension between remaining separate and going along with dominant practice, and the possible realignment of what clinicians are seeing, with what they may feel they should see. As much as they may practice as individuals, it is the continued association and acceptance by fellow practitioners that take precedence in the face of the uncertainty and controversy surrounding PBD.

5.3.4 Independence as positioning in relation to American colleagues

For English clinicians, American colleagues were central to discussion in a way that suggested the level of influence the US has in the genesis of PBD in England. As such, the conception of an independent clinical Self situated within, and identifying with, a wider collective field was reinforced by a sense of clinicians in England position themselves in relation to the Americans, crystallizing aspects of their own practice as a form of resistance to the potential future impact of US influence. As one clinician noted, philosophical issues are one core difference between the two cultures:

Some of it I think is just that there's a stronger emphasis on theory and tradition here, and in Europe in general, whereas back in the US it's about innovation and moving forward. (UKC2)

While for others, resistance goes beyond deep-rooted notions of tradition versus innovation into a feeling that what is being proposed by American psychiatry is not to be taken seriously:

So there have been some American researchers who have come over, and we've listened and gone "no I don't believe you. I just plainly don't believe you at all" when they've gone on about 5 year olds with Bipolar, and you're going 'this is ridiculous, you're in stupid territory here'. And actually even peddling this stuff is stupid. And there isn't that discourse around. There isn't enough of that discourse within the people feel to kind of challenge to that orthodoxy. (UKC9)

In the quote above, the idea of such young people being given such a severe diagnosis is ludicrous. The clinician is positioning themselves, and the field as a whole, in response to this by noting that the collective ‘we’ has listened to this and dismissed it as out of line with the values held by practitioners in England; values which include the ability and willingness to challenge the orthodoxy. Tied up in this resistance is an awareness of, and perhaps ambivalence about, the very direct influence American psychiatry has had on the genesis of PBD as a diagnostic category in England:

R: I suppose we all heard about it as the diagnostic rates in the States went up, and we collaborated very much with (institution X) and we visited and went along and you know, I spent some time just sitting in clinics there, and picking up some of their thinking about bipolar disorder. ..I remember some American child psychiatrists saying, “oh, this is so old hat, please don’t tell us anymore about the differences, we know, we know, we think we’re on the right track”

I: Did you feel they were trying to convince you their approach was better?

R: No, I think they felt that they had the research to support what they were identifying and diagnosing and um, and as the years have gone by I think that they have always felt that we haven’t been as acutely aware about some of the issues, although the pendulum’s swung back a little in the States as well, hasn’t it? (UKC 1)

The exchange above illustrates the tension present between top down and bottom up influences in dialogue with American colleagues. On the one hand there is the recognition of American colleagues as being influential in steering knowledge and development of PBD, but alongside this is a need to assert professional independence. The inclusion of the clinician’s assumption that US psychiatry believes practitioners in England are somehow naïve with regards to understanding this new diagnosis functions as something UKC1 can rally against. What is suggested in how this clinician is discussing the American psychiatrists is perhaps some level of resentment in assuming England is behind the times with regards to research, which when internalised on the collective whole can act as a motivating factor to act on the thinking that this clinician ‘picked up on’ while visiting colleagues in the US. Another clinician illustrates this

tension through reference to cultural stereotypes as an explanation for why PBD has become much more common in America:

this is totally speculative now, but national stereotypes, what might've happened in America was, you know people are very solution focused, so 'we're going to give it a different name now, we want to treat it now, we want to get it better'. People are less cynical, so they just want to do something about it (UKC4)

Here the speaker is acting on the need to articulate differences beyond diagnostic cultures, instead looking to cultural disposition as a mechanism to distance the collective (more cynical, process oriented) field in which he himself practices from the less considered approach articulated as he takes on the voice of an American counterpart. Tension between admiring American colleagues for doing what they do well, being at the forefront in advancing new theories, treatments and practices, while at the same time providing a reminder of elements that English clinicians proudly distance themselves from, defining their own practice and position as a clinical Self, in relation to how it differs from their American colleagues.

5.4 Parents

Parents figure strongly in discussion with American clinicians, where they are positioned as co-constructors of knowledge about PBD, their experience of living with, and caring for the child central to how they are seen by clinicians as contributing to validation of the diagnosis. Among English clinicians, parents were present in discussion of PBD, but not to the same extent as their colleagues in the US. English clinicians interviewed indicated a desire to understand fears a parent may have on how they are perceived by others, however their experiential knowledge is not automatically taken as truth, instead they are viewed as seekers, rather than holders of knowledge, aligned with their children in that they are seen as part of the wider context of the child that needs to be considered when evaluating disruptive behaviours.

American Clinicians

5.4.1 Alliance with parents as co-constructors of knowledge

American clinicians portrayed parents as collaborative allies, noting a parent's experiential knowledge achieved through living with a 'dysregulated' child as a form of expertise that contributed to the early establishment of American specialist PBD clinics. As one clinician who had previously specialized only adult bipolar disorder described his reasons for moving into working with children:

One factor was, *the* factor was, parents complaining about this. (USC8)

Parents are strongly present in clinical discourse surrounding PBD among clinicians in the US, and are presented as in a dyad with the clinician, while the child often remains peripheral to discussion. American clinicians discussed parents as often, if not more, than their young patients, and frequently described them in a way that suggested how intertwined with their child's diagnosis they were. For clinicians involved in early investigations, seeking parental involvement was necessary as a means to direct their own research in a way that would allow it to be taken up by a targeted population, while at the same time achieving credibility for taking into account parental needs and consideration of their experience. In finding themselves faced with something they are unable to understand, clinicians look to parents to shape their own clinical understanding through defining what they see and what they need. Collaboration and negotiation between these two groups thus proves beneficial, where parents see the legitimation of what they have been seeing in the establishment of a diagnosis that makes sense to them, while clinicians find something to grasp in parental experience, and upon which they justify the establishment of clinics and research groups. Thus, parental need and demand presents an acceptable explanation for clinicians to explain increased diagnostic rates, rather than something suggesting vested interest or career advancement.

In seeking to get parents 'on board', they become something of an ally for academic clinicians who come up against resistance from fellow researchers. By

providing first-hand vignettes of behaviour, and legitimizing clinical claims based on their experience, parents become useful to set the course for acceptance by clinical colleagues who may have otherwise been dismissive:

The research community was very sceptical. Some of the clinicians were too. And the parents were immediately on the bandwagon. “Finally you’re describing my child. This is what I’ve been experiencing. I’ve been trying to tell the doctor for years.” And sometimes parents who had bipolar themselves who were dismissed. “Well, you have bipolar disorder Mrs. Smith, so maybe that’s how you see the world, and why you’re so worried about it”. And in fact you see these moms who either had bipolar themselves or in their families were often the best reporters, because they were knowing what to look for and were able to describe it in ways that I thought were especially articulate and insightful. So parents were immediately big fans, and believers, and relieved. And then I watched researchers get on board. (USC7)

Here the power bestowed on the parent lies in backing up the clinical agenda, in which a parent’s first-hand experiential knowledge of the child as valuable in convincing others that PBD should exist as a diagnosis. The interaction between this clinician’s Self, clinical colleagues and parents come together in a narrative which suggests that it is the clinician following the parents lead. On the one hand this can be useful in influencing colleagues to ‘get on board’ with the idea that PBD exists as a real diagnostic entity, but on the other hand there is a sense that imparting this level of capacity onto the parent removes responsibility from the shoulders of the clinician, allowing them a sense of justification in the face of controversy.

5.4.2 Parent as voice for the child

Parental representations occupy a position as important as a clinician’s own direct observation and interaction with the child. A frequent refrain among American clinicians was the idea that a young child doesn’t have the language to articulate mania and depression, thus necessitating the heightened role of parental involvement.

The depression sometimes is easier, but even the depression you have to take into account the age of the kid. The kid is not going to come at 7 or 8 years old and tell you they’re depressed, and so the parents have to come in. (USC8)

Clinicians are seeking out parent's subjective judgments about their child's behaviour and basing their own clinical notions of PBD on this, as much as what they actually see in front of them when the child visits their office. In this way, ideas about what PBD looks like in a child are co-created by parents and in a circular process of interaction in which parents are encouraged to pay attention to certain behaviours, and as a result are trained to see such behaviours as pathological, which is then fed back to clinicians, reinforcing clinical expectations while legitimating and perpetuating the diagnosis. Parental demand, based on lived experience with their children, initially focused clinical attention on specific behaviours, which clinicians have then adopted into their representation of a disordered child. The behaviours thus become reified as 'symptoms' through the process of negotiation with parents tutored to view certain conduct as symptomatic of this illness. Parents direct clinical attention, which clinicians then direct back at parents and, by proxy, onto the child.

5.4.3 Parents as victims 'held hostage' to PBD

Conflicting clinical representations of parents are evident in the way parents are discussed by professionals as both co-constructors of knowledge about the diagnosis as well as co-patients alongside their child and victims in need of support themselves. Parents at the mercy of such out of control children need their own training to 'manage' the child at home. The idea clinicians have of parents being intertwined with their child's diagnosis leads to a conflicting representation in which, in addition to being victimized by their child, they are also partly responsible for exacerbating the behaviours leading to the child being deemed ill:

Now, back 12 years ago, I think a large part of the evolution of this disorder was from a clinical standpoint we were struggling with 'what do we call it?' but what we heard from parents was that oftentimes they were almost like the victims of an illness that didn't have a name... If the parents are so beaten up and worn down and trounced upon and have no energy to really interface with a highly intense kid, it doesn't matter what you do with the kid. I mean, you can help with their intensity, but their parent still needs some skills. (USC3)

The clinician above admits the possibility that parents and family dynamics are responsible for the child's behaviour, however responsibility is removed by aligning

approaches to parenting with a lack of support, both within their immediate social sphere as well as on a wider societal level, in the face of an uncontrollable child. When it comes to addressing the problems in a therapeutic setting, children are often left out of the picture:

Oftentimes we feel our parents probably get even more benefit [from therapy] than the kids do...parents can start to feel a sense of mastery again over the illness. (USC1)

The representation above depicts a child in need of management, and the parent's need for clinical help to learn how to 'master' the illness, and thus the child. The diagnosis of PBD here is as much about parents as the child actually given the diagnosis and subjected to treatment. The perception is one of parents as victims, at the mercy of their unruly children, and in need of support, and thus becoming patients alongside their child, with one clinician likening the parent experience as being "held hostage" to the disorder- an association that indicates an omission of the child's experience. The child becomes viewed as a threat, capable of beating down their parents and taking control through aggressive behaviour.

By removing the child from the equation and instead focusing on parents and 'the disorder', the child is kept at a distance and left open to the portrayals that make the most sense for clinicians and parents. In questioning why this might be the case, it becomes necessary to consider once again the role of what interests are at stake in favour of advancing the diagnosis. By presenting parents as victims, a powerful mechanism is created in which the potential for further expansion of PBD is grounded in lived experience, albeit not the experience of the child at the centre of the diagnosis. The notion of parent as victim, held hostage to the out of control child is directly related to the push for establishment of the diagnosis. Clinician's positioning of parents in this way allows for the inclusion of something concrete, in the form of a parent's experiential knowledge, to counteract the uncertainty. Additionally, a space is opened up for further encounters between parents and clinicians as a result of working alongside parents to manage their child.

English Clinicians

5.4.4 Parents as knowledge seekers

Interviews with English clinicians stood out for the note of caution expressed regarding over-reliance on parental accounts of a child's behaviour. While they noted that parents were a key part of solving the puzzle, they were not viewed as a central source of information. In describing the level of knowledge about the diagnosis that parents show up with to the initial consultation, one clinician noted that:

Um, the level of knowledge isn't deep, or the level of information that they have, rather, so even if they come to us with a potential diagnosis of BPD, they often don't know what the implications are. When we give them a diagnosis of potential, possible BP, we call it not- otherwise –specified, spectrum or whatever, you can qualify it in a number of ways, then they really need some help with that, so what we do is give them some of our papers that are written for a more general audience, and spend a lot of time explaining to them what it means, and the reason this question is important. (UKC4)

The parent here is seen as being in need of some helpful education, lacking the same level of expertise as the clinician. While there was a theme of alliance with parents for American clinicians, among the English sample, there was distancing from the parent in which the clinician used influence and education to shape parental thinking about the diagnosis and associated behaviours. The relative absence of parental influence on clinicians in England can also be seen in the deliberation involved in ascertaining whether a child meets the criteria for PBD. The experiential knowledge possessed by parents is not enough. The clinician in this case requires more than one source of information about the child:

When there's a discrepancy between what the parent is telling you, and what you see in front of you don't match. So we've had a couple of parents come in and say "he's bipolar, he's restless, he's stomping all over the place, he's rude" and you see a child who's sitting quietly during the assessment for an hour or so, being very polite, and you think this is not- something doesn't match up. Particularly when there's only one source of information, so in CAMHS, we try to get as many multiple sources of information as we can, mainly from schools, parents and the young person themselves (UKC7)

The tone of the excerpt above appears to negate the parental account, suggesting that they are almost not to be believed. The clinician notes the importance of the child's own perspective in trying to get a holistic picture of what is going on. The child is kept at the heart of discussion, and the overall sense is one of collaboration among multiple groups, bringing together myriad perspectives, to ensure that once a diagnosis is made it has the backing of several professional frames of reference. Here there is the impression of caution that goes along with the idea of England as being a "culture of second opinions" as one clinician allowed. In contrast with the US, clinicians in England, as the above examples suggest, acknowledge the position of parents in clinical discourse as being one of many sources of knowledge about the child as opposed to the key holder of information.

Understanding parents is central to attempts by English clinicians to interpret what is going on in the mind, and wider context, of a child presenting with behavioural issues:

One of the things that's really hard for parents is when you come to services like CAMHS, the worry in the back of your head is that the fingers are going to be pointed at you as a parent. In some ways that's where diagnosis can seem like an effective option because you sort of go from being a failed parent to a heroic parent struggling with a disabled child. But, in my experience worry and that sense of guilt doesn't disappear when they get a diagnosis. Different sorts of guilt start to appear... and if you don't have those conversations they sit there in the background and they continue to worry what you think about them. (UKC5)

The parent in the above quote is integrated into the experience of the child, where the parent is no longer able to think of adolescence in ordinary terms. For the speaker, the parent's inability to see beyond the particular illness framework is problematic, however there is a sense of understanding the role diagnosis can play for an anxious parent, acknowledging feelings of guilt and inadequacy and the lure of being recast as a struggling, heroic parent. The clinicians' own complicity in shaping parental representations of 'normal' childhood behaviour is evident in the admission that it becomes difficult to think of them as anything other than disordered after having been encouraged to view them this way. The position of parents and the family as seekers of

information elicits sympathy in the form of a clinician's desire to understand parental experience:

Somewhere in the back of their head they're going 'is this normal adolescence, or are we dealing with something qualitatively quite different from that?' And that obviously has not only a kind of rather personal overlay, but also has a cultural one. So, what people expect in different cultures is hugely different of their kind of kids. (UKC9)

Taking on the voice of a parent here, the clinical insight opens up to wider cultural factors influencing perceptions of behaviour, suggesting a level of understanding that no two parents will see behaviour in the same way. In demonstrating an openness to parental perspectives, the clinician is taking on board more than just the child being brought in for consultation, but also the wider context from which the child comes, allowing for a fuller picture, and perhaps more considered, reflective path to diagnosis.

5.4.5 Alignment of parents in dyad with child separate from clinician

In discussion with English clinicians, the same sense of separation between the parent and child isn't present in discussion as it is with American clinicians. Instead, parents are aligned with the child, positioned as a piece of the broader contextual puzzle in which a 'mood-dysregulated' child exists. The sharing of familial context is a key component to a clinician's perspective that the two exist parallel to one another:

With PBD, you have to do a lot of work with parents. There's no point just working with the young person, because they live in their families, they are part of their families, and the families are crucial in identifying if things are breaking down again, and are crucial in supporting their recovery, so if the parents don't really understand what's going on then nothing's gonna work, really. (UKC8)

Families are crucial, valued as a source of support and structure for the child. Parents are also seen as unified with the experience of their child in terms of motivation for seeking a diagnosis of PBD is discussed. The previous section discussed the clinical perspective outlining parents as seekers of information, thus for English clinicians faced with parents showing up assuming knowledge of PBD, there is often inherent suspicion related to ulterior motives for seeking the diagnosis:

Another example of somebody I had where the child didn't have PBD, he had, for example conduct disorder, and he was getting into all sorts of fights and criminal activity and shoplifting and so on, and being aggressive at school, but both mom and the young person were invested in having a medical explanation of their difficulties. So they would read on the Internet and read what BP is, and then come and tell you, almost word for word, "Oh he has elated grandiose mood, or he's..." and I'm like, these aren't even your own words. These are coded words, because there's an investment in having that diagnosis because it sort of takes the responsibility of his and mom's actions (UKC7)

Here, parent and child are seen as one, evident via references to the "mom and young person" and "their" difficulties. Allusions to the parent and child as an interrelated micro-collective suggests a level of clinical distancing, allowing for the incorporation of parental dynamics to be viewed by the clinician seeking to make a diagnosis in direct line with the young person's 'symptoms'. There is a wariness in approaching those who seem over-invested in a diagnosis:

I don't want to be too damning and judgmental, but it tends to be the personality disordered families who are like that, so they've got a very, very troubled teenager in the family, but the whole family is troubled, and they've had- they're the ones who when they come to us they've got three CAMHS files already, and it's like...they're desperate for you to say "this is this, and have this medicine and make it all go away and make it all be better" And it's always that they're the ones who aren't anything like manic depressive. (UKC8)

Motivation is a key factor considered by clinicians in England, often approached with a degree of apprehension and an attribution of interrelated behaviours among both parents and their children. Parents are seen not as separate entities, but rather very much at the centre of what clinicians consider when considering whether a diagnosis of PBD is warranted for the young person or not.

5.5 The pharmaceutical industry

Despite the overt influence of the pharmaceutical industry in the US, both in terms of the early development of PBD, as well as continued presence in diagnostic practice, the presence of pharma in clinicians talk was stronger among clinicians in England, perhaps suggesting the power present in a less obvious influence. Among American clinicians interviewed, the dominant theme related to a sense of feeling stuck, pulled between

subjective values coming up against professional realities, which involve the use of medications on oftentimes very young children. In England, the role of pharma remains tied with debates surrounding medication practices not only on a practical level, but also in the perception of trust, which underscores discussion about how to approach medicating children. Several English clinicians noted that medication is not thought of as a first-line treatment, and articulated reluctance in going along with US led research that has been financed, and thus influenced, by the pharmaceutical industry, suggesting a subjective conflict surrounding putting the research into practice via approaches to medicating.

American Clinicians

5.5.1 Subjective values encounter professional reality

The presence of pharmaceutical industry influence is tied up with debates surrounding medication practices and shapes clinical understandings of the diagnosis. There is reluctance in having to go along with research that has been financed by pharma resulting in inner conflict that comes with top-down pressure to put the research into practice via approaches to medicating. Many who work in the field have been on the receiving end of criticism for perpetuating a diagnosis many believe was created in order to sell certain medications:

Pharma has had a big role in getting some of the early science up off the ground that's how in America, well I don't know what it's like in the UK, but to get studies up off the ground, it's very difficult without pilot data which requires money, so back in the day there was no way to get things up and going without some relationship with pharma, so I see how the criticism [of PBD] could be put into play. (USC3)

Here there is an acknowledgement of the necessity the industry plays in early research on PBD, while also maintaining an awareness of how this is perceived by those who are critical of the diagnosis. In the course of conversation clinicians revealed ways in which they reconciled their conflicted feelings regarding having so little control over how children given a diagnosis of PBD were supposed to be treated. Several professionals positioned themselves as caught in the middle, uncomfortable with prevalence of

medication and their place in perpetuating the diagnosis, and expressing discomfort with how they have been knowingly complicit in the expansion of PBD:

How do you justify giving an unstudied medication to children and teenagers? Well, you do it by saying they've got bipolar disorder, and so if they've got PBD, I've got a drug that treats PBD. And those are the second- generation antipsychotics. So, that I believe is the reason why we have such an expansion of BPD in this population, because it justifies our treatment for them. (USC5)

Clinicians are forced to reconcile their positions within the wider social and cultural hierarchy in which they practice with their personal values in any way they can by finding ways to make sense of how they practice. As discussed in *chapter three*, this excerpt presents an illustration of how ingrained the tension that exist between existing normative pressures and injunctive norms suggesting how a clinician should practice. Here we see a desire to rally against the system, but the reality is that this clinician will conform to prevailing standards while recognizing their own role in the perpetuation of the diagnosis. In presenting more personal and value laden accounts, US clinicians imply that while the culture in which they practice emphasizes the use of medication as being a necessary component of treating this disorder, no matter what the age of the child, they are not always entirely comfortable with the idea:

The sad piece, in my opinion, people often have too blind a trust in our medical system. Again, I feel that the majority of people the medical system...are doing what they think is right, but that doesn't mean that it is right. I just think our system, for whatever reason, maybe it's the influence of pharmaceutical companies, but we have such a drug centred health care system. Everything is about 'what medication, how can we treat you? (USC1)

As the above quote reveals, internal conflict and pressure to be responsible and fulfil professional duty in the face of uncertainty encounters an external pressure to prescribe. The trajectory of the conversation with the speaker above kept coming back to the role of pharma and the emphasis on medications, suggesting this was a source of inner strife. As with several professionals interviewed, there was talk of feeling trapped in a system:

Why do I put a kid in the hospital? Well, if I'm going to justify it to an insurance company, I get, it's easy to get the insurance to cover Bipolar

disorder. It's easy to get treatment authorized for BPD....sometimes it puts me in ethical dilemmas where a government agency is requiring me to do one treatment like a stimulant, which I feel is going to be worse for the patient, and I'll lose sleep over that. Should I fight the system? Fight the bureaucracy to do what's right, or just go along with it, and it puts me in a difficult position. (USC5)

A lack of control and feeling trapped in the middle drive an agentic shift away from the clinician themselves, and towards the broader context in which the presence of Pharma, and its influence on the process of insurance reimbursement, were responsible for why younger and younger children were being treated with such strong medications lacking clear clinical evidence for efficacy. The speaker above faces a more direct dilemma in confronting very real top-down pressures from higher-ups who have significant influence over diagnostic practice, despite the fact that knowledge drawn from this clinician's daily experience directly contradicts the pharmaceutical suggestions being made.

The fatalism present in conversations with American clinicians suggests the pharmaceutical influence is seen as something unavoidable, controversial and necessary for research funding, and thus a force to be worked around. The top down influence extends beyond clinical trials shapes policies of government agencies responsible for dictating prescription practices of doctors on a more localised level. The process of reconciling beliefs with actual circumstances is not always successful, however, and often clinicians live in a constant state of limbo that never gets fully resolved. A sense of resignation and justification reigned as clinicians sought to align personal values with the realities and pressures of their profession, practicing in a healthcare system where insurance practices are closely linked with pharmaceutical influence.

English Clinicians

5.5.2 Encroaching threat of vested interest

One repeated theme to come out of discussion with English clinicians was a desire to maintain a level of scepticism and resistance, instead of blindly accepting the treatment approaches to PBD normalised in the US:

So people are quite worried. When research is being sponsored by a pharmaceutical company, people have a knee-jerk response, particularly in this country. It implies in some way, not that they're necessarily in cahoots or anything, or being paid to lie, but that they're somehow biased...that has played a role in the resistance here I think. And the other one is perhaps latent anti-Americanism (laughs), so I shouldn't say anti-Americanism, but saying 'oh well, it comes from America, let's be very sceptical about it'. It's a very interesting- it's a funny attitude because in other matters its 'oh its American, it's got to be good' do you know what I mean? But in these matters, people are very sceptical. (UKC4)

The above excerpt illustrates the core of resistance to the expansion of PBD in the form of distrust of US led research. The American influence is simultaneously reviled and appropriated in that the US leads the way for English clinicians ('it must be good') while also representing what they as a group don't necessarily want to become (at the mercy of vested interest). Here, a desire for recognition comes up against an inherent distrust. The ingrained scepticism in the tone above stems from widespread understanding that the promotion of PBD in the US has been the result of a very small, extremely influential group in receipt of enormous pharmaceutical funding:

So there was a very successful influence coming down from a few people who became very key individuals in promoting this concept [of PBD], and basically increasing the sale of antipsychotic, or atypical antipsychotic medication to young people. (UKC5)

The link between understanding a diagnosis and medication as an initial response is a multi-tiered process in England. Thus, the idea of a condition predicated on the existence of a pharmaceutical treatment is one that leaves many practitioners in England wary. Perhaps there is a sense that the field of psychiatry in England may become increasingly influenced by practices taking shape in America, as some have suggested it already has with the arrival of ADHD going from rare to common in a matter of a few short years. By staying alert to pharma led research emerging from the US, alongside prescribing trends of antipsychotics to children, clinicians in England are able to maintain a level of questioning remove in an attempt to keep the diagnosis of PBD from becoming reconfigured as something assumed to be much more common than they believe that it is.

5.5.3 *Trusting the familiar, resisting the unfamiliar*

The tension present between English clinicians and how they view the potential for pharmaceutical influence to shape the knowledge about PBD disseminated by their American colleagues leads to a desire to try and focus on home-grown research and practice as much as possible. This allows for the reinforcement of their own positioning, forcing a redefinition of what they as individual practitioners within the wider field value in terms of professional autonomy. As will be discussed further in *chapter seven*, it is the point at which a gap in knowledge takes shape that allows for a level of trust to fill in. In this sense, a lack of trust, or wariness, of American-led research becomes objectified as something against which to position oneself and resist. In the case of a psychiatric nurse within a CAMHS team quoted below, these values extend to where professional attention is paid:

I mean we don't really have much contact with the reps, the drug reps, so I suppose we don't, we're not that, we don't really get influenced by it all. We are really only working on the criteria because that's the criteria if you see what I mean. We're not thinking well, and our first line isn't medication, so we wouldn't be thinking we've got to look at this in terms of whether we've got to medicate or not, we're looking at it as whether they meet the criteria. (UKC3)

Medicating is not seen as the first option, and the specific reference to pharmaceutical representatives and the influence they wield indicate the fact that they are a force to be contended with, despite this nurse saying they are actively not influenced, preferring to focus exclusively on the behaviour they see, and what that means for treatment, as opposed to the other way around. Resistance to increasingly strong influence of the pharmaceutical industry is presented as the result of lively debate, and again, as something coming from the outside that clinicians in England can position themselves against:

There has been a very lively debate in this country about the influence of the Pharma industry, and much more vigorous attempts by the medical community in this country to get to grips with the pernicious influence of the pharma industry, so there is that, a much bigger community of people within the medical profession who are trying to do something about it. But their influence [pharma] is strong. Very strong. (UKC5)

Here the clinician indicates a collective refusal to go along with the increasingly pernicious attempts of the pharmaceutical industry to sway practice in this country, actively resisting a perceived imposed consensus coming from the US. While there may be a sense of a critical perspective here, the speaker is at one with the wider field, expressing a sense of pride in the culture of questioning and debate, as opposed to just accepting recommendations at face value. It is an active resistance that stems from distrust of US research and practices, where several clinicians interviewed stated a greater level of trust in 'home-grown' knowledge, as it is perceived as being less heavily pressured by vested interest.

Having the presence of pharma to come up against leads strength to identification with one's own colleagues, a perspective expressed in several instances by way of the introduction of cultural stereotypes into conversation:

I think there is a cultural split between the UK and US. There is a view that a lot of American psychiatry...well, you become stereotypes...and the American stereotype is that its drug company led, and over reliance on medication rather than psychotherapies. (UKC10)

It is not just the mention of stereotypes, but the idea that when faced with a contested diagnosis, with controversial beginnings such as PBD, one becomes the stereotype. American psychiatry on the whole becomes a metaphor for a focus on solutions, quick-fix treatments and an emphasis on conquering the illness and getting better. Such perspectives allow for a greater sense of what clinicians in England are up against when learning more about PBD, navigating the terrain of a rapidly shifting diagnostic category.

Clinicians interviewed in England proved to be more outspoken in their thoughts about the level of influence maintained by the industry, and the implications it may have on the future of how they practice. A common feeling among clinicians was that of Pharma as an encroaching threat to their understanding of PBD. As one clinician stated:

'The developmental stream in the States for bipolar? Money' (UKC9)

An awareness of the origins of this particular diagnosis as rooted in American controversy led those interviewed in England to reiterate this as central to their resistance to the idea of expanding the diagnosis into younger and younger children.

5.6 The child

It is the child who ultimately bares the weight of diagnosis, thus clinical representations of PBD shaping diagnostic practice largely come down to the position of the child in discussion, a position that is shaped by interactions with the three significant others highlighted in this section so far: clinical colleagues, parents and the wider influence of the pharmaceutical industry. Interviews with American clinicians revealed the child on the periphery of discussion, which tended to focus most heavily on the clinical Self, colleagues and parents. The child figures more prominently among English clinicians for whom a more holistic approach to diagnosis and treatment is favoured, with the child often consulted for their own feedback. Clinicians in the US may desire this as part of their own professional practice as well, but it remains uncommon due to a lack of space within the wider diagnostic culture to explore these options. How a child's behaviours are assigned the category of PBD, and deemed pathological or not, is central to the way in which the 'voice' of the child was accessed in interviews.

American Clinicians

5.6.1 The child as a cluster of symptoms

The child is largely absent from conversations with US clinicians, who tend to be more parent-centric in discussions surrounding PBD. When the child is present, they are largely portrayed as a collection of symptoms and behaviours in need of management:

It's very important to think about the symptoms of the children, and the domains that are affected, and I think it's the functioning that I care about, and children, it's a little bit like a sculpture as they're growing up, and it's very fluid, and we need to shape this carefully, and there are many problems sometimes, and they overlap, because just like a circuitry dysfunction, with multiple circuits being entangled, if one is affected, three or four that are attached to it might be affected, so you need to think carefully. (USC4)

The quote above positions the speaker in a place of remove, evoking in the listener a mechanistic impression of children with PBD as malleable and in need of shaping by the clinician. Such statements are indicative of the elevated importance the clinician places on their role, and the child as ‘Other’ becomes something distant and somehow objectified. Perhaps in thinking about children this way, emphasizing how much they suffer as a result of living with PBD, is a way for clinicians to distance themselves from potential moral concerns associated with such a contested diagnosis. Focusing on children as a collection of symptoms renders the emotional clinical, and removes the clinician from direct engagement with the actual individual at the heart of the symptoms they seek to treat. A framework is then created in which the child is lost to the behaviours that come to define him or her, as is evident in discussion of several of the co-occurring diagnoses that come with PBD:

I'll have the parents track mood changes. If it's something where you don't see a lot of mood lability per se except in an instrumental way, where Johnny starts screaming and shouting because he knows that's going to get mom to change behaviour, and that I can actually manipulate that, I can actually modify his mood lability through consequences, well, then I'm probably going to move away from that and probably just look at ODD [oppositional Defiant Disorder] so those are the things that I start to look at. Is there mood lability that is unrelated to a child getting what they want? (USC2)

The child is described not as part of a wider social context, but rather as a collection of potential diagnoses. Nowhere in the above quote is there a suggestion that the child may not actually need to be diagnosed with anything. The clinician is so trained to see sets of behaviours as representative of disorder that there is no way to see otherwise, thus, a child who cries in response to not getting what he wants is given the diagnosis of ODD. And once again, the perception is mediated by the parent who is asked to pay attention to, and track, mood changes. While parents may have been instrumental in getting the disorder off the ground, clinicians are now training parents to see their child as they do, with just about any behaviour suggesting something pathological. Multiple factors have come to shape clinical thinking of children with PBD to the degree that it becomes so entrenched that they must see something that any behaviour becomes a symptom.

5.6.2 At risk and in need of early intervention and treatment

A common theme among American clinicians was a conceptualisation of the child as a potential risk to be recognised early on before any questionable behaviours had even emerged (“prodromal diagnosis”). Every American clinician interviewed was in favour of prodromal diagnosis with many suggesting that such ‘problem behaviours’ can be seen in children as young as three years old. Clinicians in favour of early intervention repeatedly point out that PBD is a serious diagnosis not only to give, but also not to give, suggesting the cumulative disadvantages bestowed on a child with PBD, everything from doing poorly in school, to a later life of criminality and social deviance, warrants treatment as early as possible:

The reason to treat is that in the here and now, it’s causing tremendous disruption in everyone’s life- the child’s life, first and foremost... And then [the symptoms of PBD] leads kids to do reckless things, leads them to take a different path in life, to find different peers, they get arrested, they get involved in drugs and alcohol, there’s a lot of terrible outcomes from PBD, so if you can help detour somebody from that terrible course, and give them some relief in the here and now. (USC7)

For the speaker above, PBD represents a present disruption, and a future risk not only for the child, but those around them. By framing the diagnosis this way, clinicians’ justification for prodromal diagnosis is driven by their perceived need to ‘catch’ something before it can do any real damage, whether neurobiological or social. But who ultimately benefits from this practice? The assertion that clinical concern lies with the symptoms, not the diagnosis, is in direct contrast to prodromal diagnosis in which you’re not treating actual symptoms, rather the future risk of getting the disorder. This ties into a need for clinical mastery, again suggesting the role of professional interest in the expansion of PBD. Discussion with American clinicians also highlighted the very prominent position the medicating of children held within the practice of prodromal diagnosis:

In the old days, ten years ago, if a kid was out of control, but the parent was like “I don’t want to do medicine” I was like, “ok that’s fine. If you can handle it and you can deal with them, we’ll try without medicine.” But now, if you wait, you’re just letting their brain deteriorate and become more severe, so in those cases I would try to get them to agree to medication... So PBD and Schizophrenia we’ve had studies in the last few years showing

you can have significant nerve deterioration and atrophy if the brain if its untreated, so that kinds of changed my perspective on how soon I give medicine. (USC5)

Here, the clinician's idea of PBD has shifted based on discourse surrounding early diagnosis and treatment. New knowledge has taken shape in practice which emphasises the neurochemical explanation for behaviours, validating the use of medication, and instilling the importance of catching and treating PBD early as essential to the future of the child. The clinician above uses early intervention as a tool in order to get parents to come around to the idea of medicating, this from the same clinician who had earlier expressed discomfort with the pressures to medicate in a certain way that left him losing sleep at night. Again, in the quote above, we can see the anchoring of PBD in schizophrenia, despite the fact that in the US much of PBD is seen as rooted in rage and irritability, rather than the concrete psychosis of schizophrenia. However when it offers an explanation that makes sense and backs up clinical intentions, this clinician puts into practice in order to position the child at risk and push the idea for early diagnosis and treatment. The position of the child in clinician's discussion about PBD is a reflection of the wider system in which they practice. In the case of those in the US where the dominant social representation is that of a collection of problematic behaviours, they are working within a culture that has normalised the medicalisation of children, and the emphasis is on prevention alongside the push for innovation.

English Clinicians

5.6.3 The child as part of a wider social context

The wider social context of the child was of great importance in discussion with English clinicians. There is a greater resistance among this cohort to label too soon before grasping the wider systemic understandings of the behaviours they're seeing. The child is represented as being a product of their environment in which wider contextual factors such as family dynamics are considered alongside parental accounts, teacher accounts and the clinician's own observations. A notable finding to come from analysis

of the data was the fact that every clinician interviewed in the English sample referenced the conditions making up the wider world of the child as necessary to understand in conjunction with whatever their presenting behaviours:

You'll have the psychiatric diagnosis there, but it will always include the whole child in terms of the child's cognitive functioning, medical, physiological functioning, and finally the context. So, for instance, if you see that a child's disturbed because the parents have just got divorced 3 months ago, or there's a new baby sister, or they've all been in some huge house fire, you don't ignore that context. That's terribly important to be included any sort of formulation. (UKC1)

Common among English professionals was a sense of caution and a need to know what else is going on with the family before landing on any type of diagnosis for the child:

The African girl I saw for example, I will not stop her father from drinking alcohol. I am going to make a diagnosis of the child and a factor precipitating the behaviour is the fact that her father's not available, and he has a 24 year old as a girlfriend. That's when things are not clean. That's when people like myself or others will say look, we need to sort out the social adversity before we start working with a diagnosis. I think it's a chicken and egg, you see. (UKC6)

Acknowledging the challenge of diagnosing a condition when 'things are not clean' is indicative of the unstable nature of PBD. Here, a number of social factors are listed as being reasons why a girl might show up with disordered behaviours. What the clinician suggests through this example is a sense of how much one should draw conclusions from dominant ideas circulating in the public sphere. In this instance, there is an understanding and acceptance that a clinician will get behind what is presented at face value to access underlying causes for unfamiliar or threatening actions on the part of the child, as well as an understanding of the tenuous nature of the diagnostic process as being very circular in ideas about cause and effect; a fact which shapes how behaviours may or may not be defined as pathological in the first place.

5.6.4 PBD not distinct from adult bipolar

Defining the diagnosis and deciphering what a child with PBD looks like was a significant point of contrast with colleagues in the US. Where in the US context, the child was discussed as a collection of symptoms, English clinicians have more space

built in to their practice to explore multiple contextual causes for problematic behaviour. There was a wariness of slipping into characterizing PBD as rage and irritability. Instead, there was a tendency to discuss the diagnosis, and symptoms, as something extremely rare, as well as in line with a manic-depressive, psychotic episode requiring in-patient treatment:

So with PBD it would be something that looked much more similar to a kind of chronic relapsing psychotic picture, so something that you would see in a diagnosis of schizophrenia. (UKC9)

According to this clinician, a diagnosis of PBD is not one to be given lightly. The alignment with schizophrenia suggests the child with PBD is in fact very ill in a way that can't be contested as easily as a child characterised by rage and irritability. Despite the representation of children with PBD as psychotic, however, discomfort and uncertainty remain, with several clinicians acknowledging the act of giving the label of PBD as making them nervous. The severity of the diagnosis is central to this clinician's interpretation of how a child is presenting. Their reluctance to give the label of PBD, the fact that it makes them nervous, reveals a concern for the child that moves beyond the immediate treatment into future implications for what this particular diagnostic label would mean.

5.6.5 Giving the young person a voice

English clinicians attempt to take on the perspective on the young person with PBD, as made evident when providing specific examples in discussion of young people in their care. Clinicians sought to take on the voice of the child, unpacking what the diagnosis, and the requisite treatments, means to them. There was a sense of wanting to move beyond the diagnosis itself with the child in order to start to work on the core problems rather than the controlling symptoms:

Get them to think about what's going on at school, what's going on at home, what they'd like to achieve, what activities are they doing, helping them recast their image of themselves away from being sort of disabled towards what are their strengths, what are things that they're interested in, and so on and so forth, (UKC5)

This speaker sees their position as one who can help the child reshape their identity in line with how they see themselves, as opposed to allowing the diagnosis, or other individuals, to define it for them. The notion of a feedback loop in which those given a particular diagnosis of mental illness can learn to reshape their sense of themselves in response to external expectation, is especially salient for young people still in the process of finding out who they are. Clinical consideration of these processes is helpful in allowing the child to make attempts at healing in whatever way possible. The challenges for adherence to medication is highlighted by another clinician, but again there is compassion in understanding just what that might mean for a young person:

One of the main difficulties with psychiatry in general I think, and particularly BP is that when you're high, you are feeling amazing, you're feeling invincible, you feel that you are witty and clever and funny and so on, and the medication brings you back down, which is very boring for people with BP to be on a stable level on an even keel, that's very boring, so one of the main problems I think in general is non-compliance with medication. (UKC7)

In England, the youngest PBD patients clinicians are likely to see are aged 13 and 14:

So here people wouldn't even dream of calling, or many wouldn't, a child below the age of 16 as having BP. (UKC4)

Developmentally they are at a stage where they are trying to manage a number of different changes, from school and exams, to hormones and changing relationships. Thrown into this adolescent sea change is the uncertainty of what is happening on a behavioural level, and in the responses those around the young person may be having to their new behaviours. Negative responses can cause the young person to feel that their already fragmented world is becoming less stable, and as clinicians with a more psychoanalytic grounding to their practice, clinicians in England illustrated these issues as shaping how they view the child:

So a lot of these kids will say 'well I'm not taking meds'...alright. And I'm not there to- I can tell them about the risk factors that show this, that and the Other, but at the end of the day, part of the subtlety is not exactly- and I don't think it's about persuading, it is something about laying out the lay of the land, and to then slightly unpick what their narrative is in the midst of all of this. So is it about not being controlled, because mom and dad do enough of that. Is that because their mates at school are going to go 'well you're a spaz aren't you', because you can't, for whatever reason. Is it

because of the side effects of the medicine, they feel sick on it and what have you, which is a big reason why people stop taking meds. So there's all kinds of little bits you need to kind of pull out in this. (UKC9)

The excerpt above shows an attempt to access the child's own narrative. The clinician here even looks to the power of the young person's peer group, and the impact that has on how the child views themselves. They recognize their unique position in the life of the child- one that is not teacher, or parent, or Other figure of traditional authority; rather the clinician here, in discussion how the child is perceiving the world around them, illustrates a desire to move beyond symptoms and help the child retain a sense of their own identity in the midst of diagnostic uncertainty.

5.7 Discussion

This chapter has focused on clinicians in the US and England, and how their interactions with significant others shape the development of their representations of the diagnosis. The questions guiding this chapter asked about the representations of PBD held by clinicians in the US and England, as well as the psychosocial processes at play in shaping the development of these representations.

For American clinicians interviewed, representations of PBD are anchored in associations with ADHD, and represented as something murky and unstable, clouded by uncertainty and ambiguity, yet continuing to expand, encompassing more and more children with disparate sets of 'symptoms'. PBD is thus objectified and enacted as a diagnosis, which is more common in the young than previously thought. The analysis of data from interviews with American clinicians has shown how PBD exists as an unstable diagnosis based ever-changing criteria, which has been borne out of the influence of parents and clinical colleagues, as well as external pressure from the pharmaceutical industry, all of which shape representations of the child at the heart of the diagnosis. Representations of the child held by American clinicians tend towards seeing the child as being at risk, thus initiating the need for prodromal diagnosis and treatment. Professional perspectives outweigh any more personal considerations in seeing the child as a cluster of symptoms in need of management suggesting the need to

separate a more holistic feeling about the child and their behaviour with more clinical distancing that allows the clinician to practice in delicate and controversial territory.

Dialogical processes shaping American clinical representations of PBD point to a sense of uncertainty combined with the development of expertise, which leads to an increased “recognition” of behaviours indicative of PBD. Among colleagues, clinicians seek to stand alone. Unlike their colleagues in England, there is no sense in discussion with American participants that the dominant view of the wider field of practice in the US is influencing their thinking. Instead, there is an acknowledgement of how fractured the discipline is, with each clinician subscribing to a different school of thought with regards to PBD. As there is no central force to react against, American clinicians practice as “islands” in a sense, developing knowledge of PBD within a context that valorises autonomy and the push for innovation as the norm. Innovation here comes in the consideration of PBD as risky to overlook, thus in need of a definitive explanation and course of early treatment. While on the one hand there is a normalization of independent practice, there is at the same time a desire to build consensus as a field, yet the differences appear too deeply ingrained, the multiple schools of thought within American psychiatry too divergent, for any real consensus around how best to approach PBD to be achieved.

Parents play a pivotal role in the development of clinical understanding of what they are seeing, acting as co-producers of expertise and thereby exerting minority influence, which is accommodated by clinicians in that it functions to validate an uncertain and unstable diagnosis. Parental demand, based on lived experience with their children, initially focused clinical attention on specific behaviours, which are then adopted into their representation of a disordered child. Rage and irritability thus become reified as ‘symptoms’ through the process of negotiation with parents to log certain aspect of a child’s conduct as symptomatic of this illness. Parents are the voice for the child, and among American clinicians there is a sense of the parents as victims of the disorder. An alliance between clinician and parent paves the way for the perpetuation of new knowledge and understanding of PBD, however the child becomes

almost peripheral. Thus, this chapter has shown how parents directed clinical attention, which clinicians then direct back at parents and, by proxy, onto the child.

The presence of pharma forces an examination of subjective values in the face of professional realities, leading American clinicians to negotiate a wider social and institutional hierarchy, in which top-down political and economic pressures from the local medical and pharmaceutical systems encounter bottom up psychological pressures, such as from anxious parents, directly influences clinical approaches to diagnosis and treatment, by incentivizing early and rapid diagnosis. In summary, the interaction between clinical knowledge, and their presentation of the knowledge of others, namely colleagues, parents and the pharmaceutical industry, lead to a representation of the child as defined by the symptoms they exhibit, and thus a risk in need of early intervention.

In England, PBD is represented as a rare diagnosis, anchored in more classical bipolar presentations not seen in very young children, and often involving marked periods of mania and psychotic behaviour, often associated with schizophrenia, and in need of multiple sources of information and perspectives to arrive at a proper diagnosis. The objectification of PBD as a separate entity from adult bipolar is rejected, thus traditional understandings of bipolar are adhered to, keeping the diagnosis rare in young people. The child is central to clinical discussion and is seen as part of the wider social context of family, school and peer groups. Interpretation of the data suggest desire to understand PBD from the perspective of the child.

Dialogical processes shaping English clinical representations of PBD include the redefinition of the clinical Self in reference to various Others and positioned within a wider collective field. This can be seen as an illustration of greater interdependence among colleagues, however such interdependence, while positive in that it suggests a level of unity, indicates conformity pressures to local system of knowledge (e.g. UK practice) leading to social validation from colleagues of how what is seen clinically should be interpreted. In contrast to their American counterparts, the unspoken pressure to conform steers the accommodation of knowledge from one's clinical colleagues over parents. For English clinicians, parents are seen as aligned with the child, a distancing which favours a view of parents less as co-constructors of

knowledge, or victims, and instead as seekers of information which the clinician is in a position to provide. Parents are part of the wider social context of the child, an understanding of which is a key part of the diagnostic process in England, with clinicians hesitant to give such a severe diagnosis young people without a full picture of familial context backed up by concurrent perspectives of Others in the life of the child, such as teachers or care workers.

Minority influence comes into play when considering the positioning of English clinicians against the imposing, yet often indirect, dominance of American colleagues. English participants interviewed expressed conflicted feelings about accepting some aspects of US-led research and innovative perspectives on children's mental health, while at the same time wishing to maintain professional distance in response to a feeling that American psychiatric practice tends towards the over-diagnosis and over-medication of children. Alongside this is the interaction with the pharmaceutical industry, depicted as an encroaching threat, warranting scepticism and generating a propensity to place increased trust in more 'home-grown' research perceived to be less influenced by vested interest. In representing a unified field of practice consistent in their resistance to external American influence, there is a sense that further development of the 'broad spectrum' approach to PBD in England will remain rare. Much depends on the degree to which a few influential clinicians in England push the idea in the future, however. Also potentially challenging their strength as a minority and influencing future clinical thinking and practice around keeping PBD rare will be the degree to which parents adopt 'broad spectrum' thinking. This, in conjunction with a healthcare system in which many who are able decide to pursue private care, thus increasing patient power as a consumer.

The particular vectors of influence for American and English clinicians also drive the development of representations of PBD. In America there are multiple vectors, with the pharmaceutical industry and parents chief among them. In England, however, regulatory practices unique to the UK ensure more limited, disrupted, vectors of influence, in which the pharmaceutical industry and parents are less salient. The indirect pressure from America as a 'generalized Other', however, combined with the

desire to maintain unity with the wider collective field of practice in the UK, means that modalities of influence are present in clinical thinking, however on a different level than that of their American counterparts.

The chapter has shown how social representations of PBD held by clinicians in the US and England encompass not just the diagnosis itself, but also representations of the child in relation to frames of reference suggesting a cultural standard. Knowledge is constructed via encounters between multiple systems of knowledge which shape these representations, as well as through modalities of social influence including conformity pressures, minority influence, subjective and peer validation and the accommodation or resistance to developing notions of PBD. A more in-depth discussion of the findings can be found in *chapter seven*, where the role of cultural context will be expanded upon to understand what role this plays on similarities or differences shaping the development and maintenance of knowledge about PBD, how it is communicated, diagnosed and treated. The following chapter, *chapter six*, is the final empirical chapter and presents the analysis of parents in the US and England.

6. Parental representations of PBD in the US and England

6.1 Introduction

The previous chapter, *chapter five*, focused on the development of clinical knowledge shaping representations of PBD coming as a result of interactions between themselves as individuals operating as part of a wider professional collective, the influence of the pharmaceutical industry, and their positioning of parents as either central (US) or peripheral (England) framing their view of the child and diagnosis. The aim of this chapter is to explore how parents in the US and England develop understandings of PBD, and who else is involved in shaping these representations. The results suggest that parents in the US have many more sources of influence in their thinking, particularly parental peers and the school who don't figure as prominently among parents in England. American parents have found a sense of purpose and advocacy as a result of their struggles with their children, allowing for a sense of expertise to develop. In England, parents continue to feel cast aside and in the dark regarding what the diagnosis of bipolar disorder means for both their child and their family, maintaining a position of themselves as amateurs, unsure where exactly to turn for information and support. The questions guiding this chapter are as follows:

- What are the representations of PBD held by parents in the US and England?
- What psychosocial processes shape the development of these representations?

The data presented in the following sections address my research questions by illustrating that for parents, interaction with key actors involved in the life-world of the child is central to shaping how parents view their own child's behaviour in light of the diagnosis, as is the process of reflecting on their own position in relation to these others. For American parents, the development of their own sense of expertise is necessary in order to feel a sense of mastery over their child's behaviour, and the world of professional interaction that they enter into as part of the trajectory of their child's

diagnosis, while the child is seen as being at the mercy of the diagnosis, not in control of their emotions or actions. Other parents and the school are also significant others for American participants, while among English participants representations of the diagnosis stem from feeling like they have no control or agency themselves, that they are in the position of amateur, reliant upon clinical expertise to provide guidance that, more often than not, proves unreliable. Parents are at the mercy of a wider systemic hierarchy in which they are cast aside as their child is taken into the system without their blessing. The analysis also shows how the influence of multiple third parties contributes to how parents define and respond to a diagnosis that is still in the process of becoming.

The findings in this chapter connect to the overall thesis as the knowledge of parents is central to the wider construction, perpetuation and dissemination of knowledge about PBD on multiple levels. The comparison between how understanding of the diagnosis, and the new identity of their child is developed and communicated by parents in the US as compared to England provides a picture of how what is happening on the top-level of the pharmaceutical industry, and the mid-level of clinical professionals intersects with the knowledge and experience of those living with, and often giving voice to the child. The perspective of parents in these cultural contexts offers a sense of how knowledge about PBD has come to be defined and used by those closest to the child, and the level to which top-down knowledge is appropriated or not.

6.2 Analytic procedures and findings

The purpose of the analysis discussed in this chapter is to provide an empirical grounding as evidence for the development of parental representations of PBD. The findings presented here are the result of thematic and dialogical analyses, which is discussed in further detail in section 3.4.3. In conducting separate analyses on US and English parent data, I sought to develop a coding framework that reflected both the content and processes involved in the development of knowledge of PBD, so what was being said about PBD, and how it was being said. Interactions taking place within parent's talk are central to the construction of their thinking about PBD, thus the data was coded with an eye towards such interactions. An initial identification of who the

significant others were coming up in conversation acted as the organizing themes under the global heading of Self-Other. For American participants, this resulted in organizing themes of the parental-Self- 'I' position followed in frequency by significant others coming up: the child, clinicians, the school, and parental peers. For English parents, In addition to the parental-Self- I-position, only two Other's came up with any frequency, resulting in the basic themes of clinicians and the child (See figures 6.1 and 6.2 below). Separate coding was undertaken for the US sample of 15 parents, and the English sample of 5 parents for a total of 20 interviews. Excerpts of text were coded based on who was being addressed, and within that what was being said about PBD. It was in the final interpretive stage of analysis, once the coded segments were in place, that a dialogical approach to selected segments was undertaken. While the coding and resulting thematic framework developed identified the 'who' and the 'what', the dialogical analysis of those coded segments addressed the 'how'.

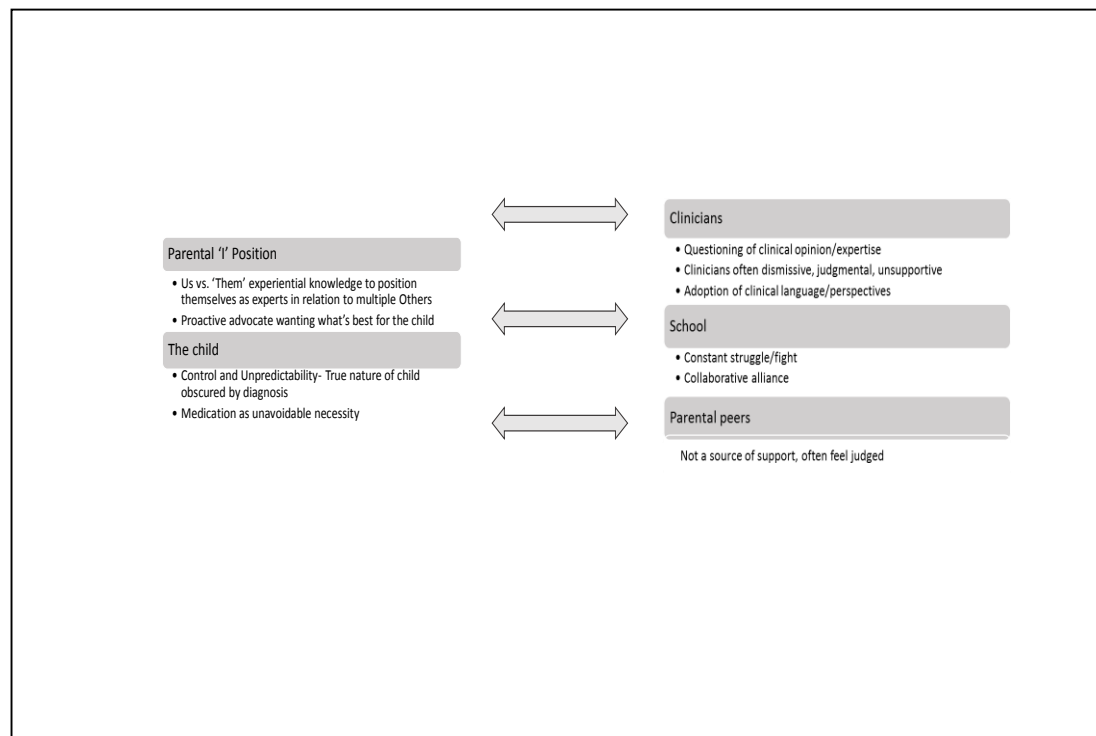


Figure 6.1. Themes from analysis of American parents, and position in relation to significant others

There was often an overlapping between themes, for example as with medication and parental advocacy, which came up in reference to multiple others suggesting how intertwined these ideas are with wider parental representation of PBD. For parents in the US, the validation and development of their own experiential knowledge in the face of multiple other professional knowledges is a key driver in how they arrive at their representations of PBD. Among American parents, PBD is seen as something they experience alongside their child as a helpful, though not always welcome, diagnosis in which medication is viewed as a necessary evil, as does pro-active advocacy.

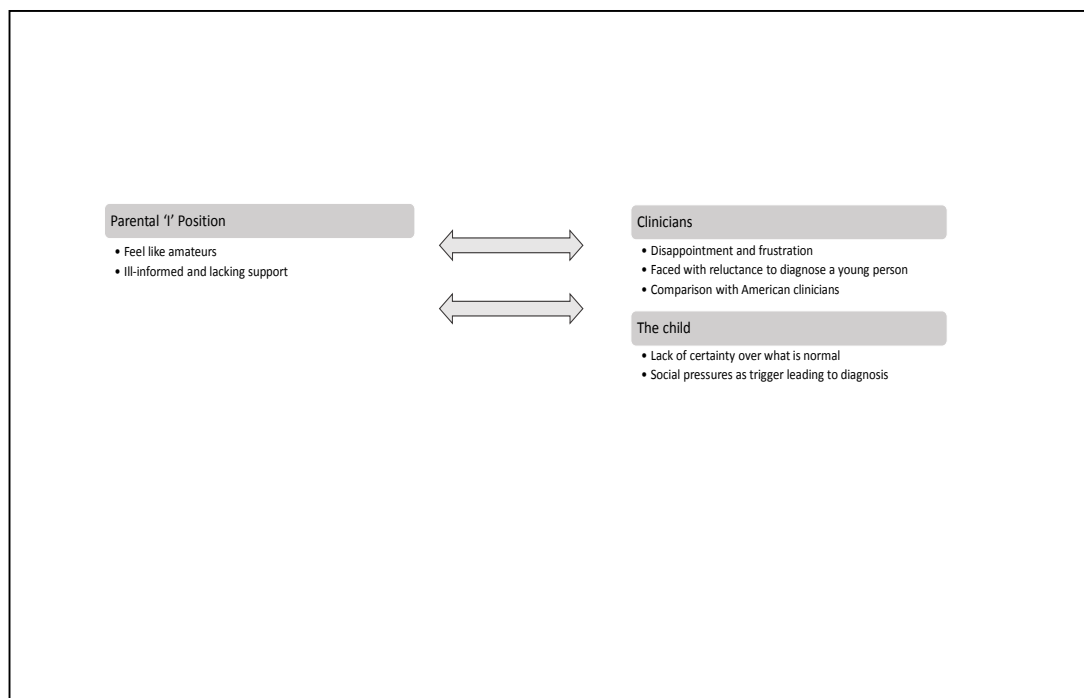


Figure 6.2. Themes from analysis of English parents, and position in relation to significant others

English parents discussed the diagnosis in a way that they were still in the process of making sense of it. The focus tended towards personal narratives that incorporated the parent's own subjective experience and their interpretations of what they were facing with regards to their child's behaviour. Interactions with clinicians took up a significant amount of space in the interviews, as parents in England, perhaps having less access to the cultural openness regarding mental health and mental illness in young people so

prevalent in the US, were much more inclined to articulate their own sense of confusion and lack of understanding the bipolar could exist in young people. As with American parents, those in England discussed feeling cast aside and ignored by clinicians, however the hierarchical nature of the health care system in England shown through in the lack of control or options parents felt they had. Perhaps stemming from a lack of cultural comfort maintaining awareness of mental health issues, English parents discussed the child with a sense of confusion, frustration and guilt over their own inability to see anything was wrong. An overriding sense of seeing the child's increasingly concerning behaviour was often passed off as normal adolescence, something many English parents spent quite a bit of time reflecting on in the interviews. The school was not a significant topic of conversation, with only a few mentions, nor was there much discussion of parental peers. For English parents, the overall tone within the data suggested a sense that they were very much alone in their journey, relying on their own upended sense of subjective norms to try and make sense of their child's behaviour, and what the diagnosis of PBD meant for them.

6.3 Position of Parental Self

As in the explanation of the 'reflexive Self' described in *chapter five* (cf 5.3) the notion of a parental Self here refers to the dominant 'I' position coming up in conversation with parents- whether through their own overt articulation of how and where they saw themselves in the process of coming to understand PBD, or what was interpreted through analysis of their talk.

American parents

6.3.1 Us v. Them: valuing experiential knowledge as expertise

One of the most salient themes to come from discussion with American parents was the idea of parents feeling that they were constantly coming up against various others in their quest to understand what was going on with their child. A sense of 'Us versus Them', in which the parent positions themselves in alignment with the child and counter to others such as clinicians, peers and the school, was present across

interactions, likening such attempts at communication as ‘a battle’ or ‘a constant fight’. Reinforcing this position was a process of providing an account of their expertise arrived at through experience. Often times, parents were keen to integrate their own background with that of their child, for example beginning a discussion by talking about their own experiences living with bipolar disorder if they had been previously diagnosed as well.

Well, when we first started going through this, we went to all the little psychiatrist doctors up there who were treating her for depression, and I was telling them all the other symptoms she was having and they would completely ignore it. And I’m like, well this is what I think is going on with her. This is what’s happening. I see myself in what’s happening, and I know what that feels like, so I know that this is what’s happening with her, and nobody wanted to listen to me...because as a parent - these people see your kid a couple of days, saying ‘ok this is what’s wrong with them’. You see your kid 24 hours a day every day, and you know that it’s much, much worse than they say. (USP7)

By locating themselves as a central character in the master narrative of their child’s trajectory navigating PBD, American parents find a way to sculpt the uncertainty and anxiety they feel into something proactive and meaningful in the face of those who doubt their assertions. In the case above, this is illustrated in questioning the assessment of a clinician who the parent believes is not capable of seeing, and thus understanding, the whole picture. There is a process being made visible of repeated denial and perceived indifference from clinicians leading American parents to position themselves as experiential experts not only against clinical expertise, but also when considering their role as a guiding light to others who may just be at the beginning stages of their own journeys with their children. This drive for recognition of their own expertise comes out in the way in which parents describe interacting with other parents, illuminating the anchoring of their own knowledge of PBD in that of clinicians. There is a need among parents not only to share their experiences of raising a child with PBD, but also a desire to educate:

You get to be an expert- well, you see it in other people that may not realize that they have it, and obviously you can’t go up to them and go “you know I think your kid might be bipolar” (laughs) you know, it’s not really do-able. But there have been people where I have kind of shared my story a

little bit and hopefully they would kind of look at it and think “huh. I wonder” (USP13)

PBD here has provided an object onto which parents can lay claim to their experience as expertise. The parent above positions herself as someone who can see evidence of it in other people’s children, suggesting another way in which the diagnosis is perpetuated and new frameworks developed through which to view a child’s behaviour: peer influence from other parents. There are a number of things at play in the desire to impart this knowledge, the first being that the speaker is able to see beyond the surface of things. There is a goal underlying the sharing of her experience with unsuspecting parents, hoping they will come around. Perhaps if they do, the speaker’s experience can be validated in some capacity, and the struggle endured thus far now serves a greater purpose-to ‘educate’ others. Feeling needed or appreciated in the face of uncertainty, confusion, and dismissal from psychiatrists can prove to be a powerful driving force for parents to communicate their subjective expertise:

I mean there have been a lot of people who have come to me and said, you know, I’m seeing XY and Z in my child, what do you think? And I’ve been able to talk them through, well do you see this or this. Yes? OK, you may want to consider that it could be this. You don’t see that? OK chances are it’s not. The way that, and maybe this is the most helpful, I mean people always ask “how do you know if your kid has it?” and I say, from what I’ve seen (USP5)

Here the parent positions themselves as a clinician-by-proxy, a first point of contact for Other anxious parents, perhaps representing a figure she would have felt relieved to have in the early stages of trying to figure out her child’s behaviour, and finding solace in the notion that her opinion here will be valued. Her child’s diagnosis has provided a purpose, a means to connect with others, and a way to demonstrate competence. It is not only parents seeking to pass on their knowledge unsolicited, but they are also eager to acknowledge that their experience and the awareness that comes with it, is valued by some (other anxious parents), even if it is negated by others (psychiatrists). They are proud of being sought out to share what they have seen, and what others might be seeing. These excerpts illustrate the diffusion of parental representations of PBD in action. The parent positions themselves as expert, and it is this self-imposed label that

acts as a driver to educate others and attempt to steer representations of the child in a way as to align with the speaker's own way of thinking. Perhaps such attempts can be read as an attempt to create a solid base of support in anticipation of future struggles to validate the diagnosis.

6.3.2 Proactive advocate wanting what's best for the child

For American parents, the demonstration of their experiential expertise comes in the form of efforts to advance their understanding of PBD into other spheres of knowledge where they may not always feel they are taken seriously:

I think too often that doctors are looked at as being omniscient and always right, and they're not. They make mistakes. And as a parent you've gotta be an advocate, that's the only way things will change too, (USP10)

Referring to oneself in line with a more general sense of 'being a parent' suggests multiple co-existing value judgments which one must explore in order to fully live within that title. Being a parent for the individual above, as opposed to being a doctor, means constantly questioning information designed to over-ride a parent's own coming from top-down knowledge systems removed from the experience of the child. In suggesting nothing will change unless parents themselves take action, this speaker reiterates a theme that came up among several parents that it is a constant battle to prove their own position as knowing what is best for their children. One way advocacy becomes a beneficial aspect of the child's diagnosis with PBD is the sense of purpose and control it gives to parents who, in the uncertain period prior to a child being diagnosed, may have felt overlooked:

I was ashamed of myself. And being ashamed made it worse. It makes it easier now that I know what's going on and I can talk about it, and people are more respectful when I say these things about PBD now, and they listen more. (USP7)

Here the power of knowledge held and communicated is evident in how it reshapes the parent's own subjective understanding of their relation to others. With respect comes the removal of shame, thus the parent now feels they have something to contribute to the debate. The fact of their position as parent to a child with PBD renders them

worthy of being heard, building up a specific identity with which to share experience, influence others and feel a sense of control that comes with being proactive.

English parents

6.3.3 Feeling like ‘amateurs’

In discussing PBD both as a diagnosis and a process undergone by the family, parents in England positioned themselves as amateurs, lacking the sentiment of experiential expertise expressed by their American counterparts. For the parents interviewed in England, there was a sense of being somewhat lost and trying to make sense of the new world that opened up as a result of their child’s ill health. As one parent stated: “I’m not an expert, I just have this ill child and am trying to understand” (UKP 3). With the exception of one parent, if the expertise earned as a result of living with a child with PBD came up at all, it was later in the narrative, as though discussing their child’s trajectory into diagnosis allowed space to incorporate their own, leading to deeper reflection of their own place within the wider system. The positioning of themselves as novices in the world of mental illness, making sense of behaviours that presented in the child before receiving the diagnosis, however, was murky and confusing:

We always had this concern that with the family background that she could well be bipolar, but she wasn’t exhibiting any of the, what I call “classic” traits of bipolar, nor was-- but if you read all the books, we’re really amateurs obviously, about how it sort of translates what the symptoms are in young people. She didn’t even necessarily have those, but looking back on it now, I think we can see there were signs there, but it was just that we needed to look a little bit below the surface to see where and actually say “well hang on a second, what about that behaviour trait” and so-on. (UKP 2)

What is salient in this excerpt though is the flat out admission of being amateurs in terms of how they as parents are meant to understand what their child’s behaviour means through tapping into a wider system of knowledge available. The parent discusses the role of books as an entry into the acquisition of knowledge about PBD, and it is evident that this knowledge has become internalized in the way the parent describes as “classic’ traits of bipolar”. This echo of clinical discourse has been adopted by the parent as their own in order gain control over how to approach concern over

their child. By stating that they are able to retrospectively see the signs of bipolar in their child, immediately after elaborating on what's been learned from "reading the books", the parent signals how influential the information presented in the literature proved to be, and the function this knowledge held for the parent. Behaviours are reframed as symptoms and signs as the parent-as-amateur seeks a level of expertise with which to take action and move forward.

With the exception of one, English parents interviewed were unaware that bipolar disorder could exist in young people prior to their child's experience. This can be seen as a reflection of both the differing levels of knowledge held by parents in England as compared to their counterparts in the US, as well as the wider professional standard in England in which young people below the age of 16 are rarely diagnosed with severe mental illness:

I: Did you know it [bipolar] could exist in children before you went through this?

R: No, no. I just realised that I could trace it back in me and I began looking it up. I have about ten books on it, and I look it up on the internet all the time, I contact experts, none in this country! (UKP 1)

I: Did you feel bipolar could exist in young children?

R: No. I don't know how they would diagnose it, I think it could be quite difficult, I mean we're all born with different personalities, and sometimes its maybe more to do with personality, but when I read through the BPD information leaflet, to me it seems like sometimes people have ups and downs, to me sometimes I feel questioning about whether my daughter really is matching with bipolar. Because to me, yes, she does have some lows, but her low mood is not very clear. (UKP 3)

In the excerpts above, this lack of knowledge had two different manifestations. For the first parent, it is an alignment of the child's experience with the parent's own, having self-diagnosed as an adult with bipolar (and having been subsequently professionally diagnosed bipolar) which led to a drive to obtain the diagnosis for the child. The development of understanding, and validation of this parent's own suspicion of PBD in her daughter comes from books, internet resources, and experts contacted in the US

more amenable to recognising bipolar in children. For the second parent, there remains a level of denial at play, holding on to an understanding of young people as necessarily having mood swings as part of normal development. There is no discussion of seeking out more information to support a growing sense of seeing PBD as a possibility, instead the information leaflet is positioned as almost an intrusion into a mind set in which perhaps the parent doesn't want to consider that the child really is ill, or that the potential is there for their child to have bipolar. In this sense, the parent's reflexive Self might wish to remain an amateur, suggesting as it does a situation that is not yet fully formed, and where the outcome, in this case diagnosis, is able to remain distant.

6.3.4 Ill-informed and cast aside

The lack of support and information about what was happening to their child was a major theme to come from the way in which parents discussed their own position in the development of their understanding of PBD. A perceived lack of control and agency resulted, with parents each discussing examples of being ignored, cast aside or "removed from the equation" once the psychiatric system of care was put into place. As a result, parents felt a lack of clarity in terms of understanding the process and prognosis once their child received the diagnosis. As the following parent describes:

she was put onto a paediatric ward, not a psychiatric ward at all, because it's not a psychiatric hospital, and there was a psychiatrist there, but it was kind of a junior one, and of course they didn't really know what to do with her at all, Other than that she needed to be kept in the hospital for her own safety. And at this point, as parents we were really taken out of the equation. At that point onwards we were told what was going to happen, not consulted. Or asked. And although at the time when it looked as if we were maybe being sort of consulted, looking back on it in the cold light of day, no, we weren't. At that point I'd say the system took over, and effectively took it out of our hands, so we became really passengers in the whole process. I have to say, it was the most-- it was unbelievable traumatic. (UKP2)

The experience articulated above suggests the power dynamics at play between parents and professionals, in which the parent's perspective suggests little regard for any insight they may have as a result of living with the child experiencing difficulties. Instead, there is an expectation that they accept what they are told and allow the wider medical system

to function as it should. The experience of not being given appointments, not being provided relevant information, and not being taken seriously despite the escalation of extreme behaviours, such as self-harm, push parents to seek out information from non-professional sources, in order to at least feel they are gaining some sort of grasp over what they are seeing in their child. A feeling of not being ‘allowed’ to have a say was alluded to as well, as illustrated in the following excerpt from the data:

I: What sorts of things are you telling them [clinicians] when you see them?

R: Well, I’ve bombarded them with my expertise! (laughs). Probably not the best way, because I think if I hadn’t done that, it’s possible some enlightened person would say “hmm, I wonder if it’s this”, but I think because I’ve gone in there and said “I know it’s this”, the tendency is to say “no it isn’t”. I don’t know if it’s because I’m not allowed to be an expert, I don’t know. You can’t get more of an expert than someone who believes they had it as a child and it interferes with everything in life, and I’m not going to let my daughter go through that. It’s not going to happen. (UKP 1)

This parent stood out against the others for being the only one to feel a sense of experiential expertise (as discussed in the previous section), which when enacted through confrontation with a clinician has sabotaged her chance of obtaining the diagnosis of PBD for her daughter. In suggesting that if she had played down her understanding a bit, some “enlightened person” would come and give the diagnosis, she is highlighting the lack of recognition she feels; a lack of recognition that ultimately leads this parent to seek the opinion of experts in the US. For this parent, discussion is filled with anticipation of how she is being perceived by the clinicians, however her tone is more of defiance as opposed to being beaten down in not being taken seriously. The subjective position here is one of a clash of expertise, in which the perception is one of professional dismissal, determined to see this parent as nothing more than a layperson with outlandish beliefs not in line with their own, or that of wider clinical practice in the UK. The more this parent comes up against this attitude, however, the more conviction is gained to ensure that she gets what she feels she needs for her daughter so that her daughter need not go through what the parent herself went through. This positioning of the Self encountering undermining professionals as a springboard to action was rare in the few interviews conducted with English parents,

however in this instance, the drive was significant and led to a search for a knowledge of PBD that was more compatible with the parent's own.

6.4 The Child

The position of the child was prominent among both American and English parents, however the way they were discussed differed. In the US, the focus was on the true, 'gifted' nature of the child being obscured by the diagnosis, leading discussion to take shape around the child not being in control emotionally or behaviourally, and the parent then feeling torn about the need for medications. Among parents in England, there was more a sense of parents taking on the 'voice' of the child through recounting examples of interactions they'd had in which parents tried retrospectively to figure out of the behaviours seen in their children that were missed as being pathological, but that the child themselves were attempting to communicate a sense of something being wrong. Understanding the triggers of destructive behaviours was also central. Of interest is the gender breakdown between the cultural contexts. The children discussed by American parents were boys who had been diagnosed at a younger age while parents in England spoke of daughters diagnosed at early adolescence.

American parents

6.4.1 True nature of child obscured by diagnosis

Each and every American parent interviewed made reference to their child as 'gifted' in some respect; that while they may be outwardly angry and out of control, they had a heart of gold. Among American parents there was frustration over the power the diagnosis held in shaping perceptions not only of their parenting, but also how the child was viewed by Others. In discussing their children, there was a sense of needing to play into wider expectations and:

You don't really get to say the great things, you love your child and you want to say how smart he is in this area, and how compassionate he is, but that doesn't get you the services that you need, so you have to put these labels, and you have to talk about the worst of the worst part, and you hate to

say all of that because you're proud of your child, but don't say that you're afraid to really go there, you're not going to get the help you need. (USP13)

Ultimately a central aspect of being given this diagnosis is what is opened up to the family in terms of available services and accommodations for the child. The speaker above elaborates at the power dynamics at play, in which the parent and child need to perform the illness in a sense, matching what is seen to what is expected- a theme running through this thesis on many levels. The realignment of expectation on all sides in order to make the diagnosis useful has the dual function of making the child conform to wider assumptions, while at the same time eclipsing their parents, and their own, sense of who they themselves are. This illustrates a point discussed in chapter two (*cf* 2.2) related to the social elaboration of a medical fact in the process of becoming. Here we see an illustration of the classification of a child being needed in order to access services, but the implication of what is at play once a parent starts to view their child through the framework of expectation it the child, in a sense starting to 'become' their diagnosis.

6.4.2 Unpredictability and control

In exploring interactions with the child through discussion with parents, notions of unpredictability and control, both in the sense of a child not being able to control their brain, and thus their behaviour, but also in terms of agency, were significant in terms of how parents were thinking of what PBD meant to them and for their children. Parents positioned themselves as almost being at the mercy of their child's illness, something echoed by American clinicians as well (*cf* 5.4.3) with one parent noting that it is "the person with the diagnosis who is driving the bus " (USP11), and another suggesting:

It's hard to think that what's happening to them is beyond their control, and the behaviours that they're exhibiting aren't just them being unruly, or just being mean, or just being a bad kid, these are, they're doing things that they really can't control themselves (USP7)

Assuming that PBD is responsible for unwanted behaviours removes responsibility from both the child and the parent. The removal of responsibility plays in to how manifestations of the diagnosis are interpreted. This idea of PBD causing instability,

unpredictability and an inability to control one's own behaviour often lends weight to a parent's decision to medicate the child, suggesting that as a parent, they need to help their obviously suffering child- an idea that also plays into the wider discourse surrounding what the diagnosis looks like. Reframing the representation of PBD by removing responsibility of the parent and the child, putting it squarely in the child's out of control brain make the uncontrollable and unpredictable controllable and predictable.

6.4.3 Medication as an unavoidable necessity

In *chapter five*, the pharmaceutical industry was highlighted as a key player shaping American clinical representations of PBD. Among parents in the US, frank discussion of the industry was less salient, however each and every parent devoted a significant portion of the interview discussing the child in relation to the medication they were on. The idea of medicating a wide spectrum of behaviours was one that parents were not all necessarily on board with initially, but came to see as something of a necessary evil that the child needed to survive:

Every once in a while I would think "hmmm, maybe he is over medicated, maybe he is ok" because you start to not know what's going on anymore, I mean, kids are so medicated, you start to wonder what's under there...it's kind of a reality check when you realise no, he actually can't go un-medicated. He's a sick kid. (USP12)

The parent above is questioning the logic of putting her son on such heavy duty medications, lamenting the fact that she no longer knows who he is, and berating herself and her skills as a mother in the process. It becomes a vicious cycle of trial and error, where it is no longer clear what is being medicated, but without it, the child falls apart. The reality that this parent draws on is one of a sick child who can't go un-medicated. Though it pains her to do it, she feels it is the only option, one that she succumbs to out of desperation as opposed to any outward motivation related to mitigating future risk, or feeling an overt push for present achievement. For this parent, medication comes as a result of having a child who is suffering. Underlying what she says is an understanding that her job as a parent is to do what she can to ease that

suffering. While some saw the use of medication as immediately necessary, others required the intervention of a clinician to persuade them to come around to the idea. Ultimately all of the American parents interviewed were able to rationalize the use of medications as it was deemed a necessary evil that is an unfortunate aspect of this diagnosis. Non-pharmaceutical options are not commonly seen as being effective.

The most important thing is that he gets an education, so if can't physically sit in that seat, he can't be educated, so the medicine to me, although I don't love that I have to do it either, but it's a choice you have to make. Not on medication means not sleeping, not functioning, not doing well in school, not being able to deal with his peers, so it's a choice you have to make, and *I feel like you are hurting your child if you don't give them the advantage of being able to learn, and there is no learning in a chaotic brain.* There's no ability to learn, so then you end up with a child who's a mess, who is also academically behind. *If there was no school, and he didn't need to be educated and we're just running around in the woods, you know, with animals, ok great. Be as chaotic as you want. Climb that tree. Jump off of it. Chase this, chase that, but that's not reality. Reality is, as hard as it is, they have to learn to adapt. You do have to learn how to behave in class, and if you need extra help, and that extra help has to come from medicine, then that's what you have to do.* (USP13, emphasis added)

The reality for this parent, unlike the previous quote, suggests that it is not only her and her son's subjective reality, but rather the reality of the diagnosis in the wider context of social norms, which in the US steers towards academic achievement and sociability with peers. Social norms are a player in how this parent sees her son's behaviour, and the medication is necessary here not because she is failing as a parent, as the tone of the first parent suggested, but rather the fact that society is what it is, and this parent's son needs to carve out his existence in it and "adapt". He needs to succeed, and whatever is necessary to make that happen is what she, as a proactive parent, must seek out. The overlapping influence of the clinician's voice is present in how parents are shaping their own thinking about their children's behaviour warranting medication:

I said "I don't want to put him on Lithium, he's so young, what's the disadvantage?" and he said "well the problem is, if it blows up, it could ruin his life. We don't know what it would look like. It could be legal trouble, it could be physical trouble, it could be suicide, homi- it could be any range of things", but he said "this is what I'm trying to prevent". (USP6)

As I will discuss in section 6.5 below, this echoing of clinical perspectives embraced and incorporated into a parents own thinking, as with the quote above, serves to justify and

rationalize what for this parent is a difficult decision; putting their child on Lithium. In repeating the words that were said to her, reiterating the risk involved in not treating the young person, the parent is able to come around to feeling that it is the responsible thing to do, recommended by the professional, and not a negative reflection of her decisions made as a parent.

English parents

6.4.4 Lack of certainty over what is normal

Parents in England expressed more bewilderment and continued confusion when discussing the child. For three participants, the news of the diagnosis was relatively recent, suggesting that there was perhaps less remove the child's identity pre- and post-diagnosis. Parents discussed their children in a manner that suggested they were still in the process of trying to work out what it all meant, retracing events and symptoms such as Self-harm, psychotic hallucinations and suicide attempts, struggling to understand how it was possible that they didn't see this coming. It was in discussing the child that it became clear how much of the way parents in England come to understand PBD stems from an overwhelming uncertainty over what constitutes normal adolescent behaviour, and what indicates something more problematic. Parents discussed feeling something wasn't quite right, but thinking perhaps this was just 'normal' adolescent acting out. This was often followed by frustration with the clinician once the young person was found to be ill, that they themselves were unable to recognize the problems leading up to diagnosis. Missing out on what turned out to be 'symptoms' led some to turn the frustration and guilt from clinicians back onto themselves as parents:

I: You thought it was just normal teenage angst?

R: Yeah. I didn't deal with it very well. I don't think I handled it very well at all. I don't think I gave her enough support. As a Chinese parent I would think, it's like "I give her all this and she has to obey", but she grew up here, and she always said to me "you don't respect me at all" and I was like "what? Why should I respect you? You should respect me because I'm your mother" But looking back, I think she was right. I didn't respect her I should've always listened to her and given her the opportunity to refer to herself which I haven't. (UKP 3)

For the parent quoted above, not having a sense of what is normal was tied up in wider cultural values in which she felt she dismissed her daughters concern, which the diagnosis of PBD has now rendered legitimate. The speaker recreates the interaction with her daughter in which the notion of respect and obedience echo the wider social norms she equates with being Chinese, and through which the daughter's behaviour was viewed by the parent as deviant as opposed to disordered. Here, the parent's words suggest a retrospective blaming of themselves for holding on to ideas of how she initially felt her daughter should behave before there was any idea that the girl was in fact psychotic and suicidal. The uncertainty with encountering not just unfamiliar behaviour in her child, but also an awareness of wider cultural understandings that are at odds with her own parenting and interpretation of her daughter's behaviour, lead to an increased anxiety and confusion over how to understand what is normal versus pathological conduct.

A lack of clarity over what the conduct they were witnessing in their children meant led some parents to feel blindsided and ill prepared when a diagnosis of PBD was suggested:

...all of a sudden this consultant who we'd met for 20 minutes, that A. had met for an hour, we sat in a room and they said 'we would give her a diagnosis of bipolar'. I felt like I'd been hit across the head with a brick. And A. looked at me- she had been saying for about a week 'oh I think I've got bipolar' and we just couldn't- cos also we were very aware that she- that young people- could be very influenced by Other young people when they're in that sort of setting. Um, and you know, and A. did have a girlfriend, and she was probably looking at her symptoms, and I wonder if she was looking at her or trying to match her symptoms up with Others, so we just sort of played it down I suppose. (UKP 4)

There are several interactions taking place in the excerpt above. The parent is caught off guard by the seeming abruptness of the diagnosis made by the clinician after such a short meeting, however again, as with the parent quoted just previously, there is a sense that the daughter was attempting to communicate something she knew to be true about herself that the parents weren't fully hearing, also indicating that she had more knowledge of bipolar than did her parents. Parental knowledge of the diagnosis led to the assumption that it must be peer influence taking hold, rather than some inborn

pathology. This same parent goes on to discuss the daughter's attitude towards the diagnosis as one of relief:

She said she felt total relief, that she was able to put a name to it, she was able to explain to people, and particularly her peers. She immediately came home, and within a couple days wanted me to explain to people what's wrong with her, because I think up until that point, she found it really hard to explain what was going on, and I think that it was important for her to get that diagnosis, and for her to explain to her... because for her, she's also trying to maintain a relationship with her friends as well. So that was really good for A. I'm still struggling with the diagnosis though...(UKP4)

The importance of having the diagnosis of PBD is central to the daughter's ability to realign her identity and move forward, however for the parent, this begs the question of how the diagnosis impacts their own identity as a parent of a child who is now suffering officially with a mental illness. The inability to see the diagnosis coming, of being locked into beliefs, or hopes, that the behaviour being exhibited could have been normal, leaves the parent blindsided and struggling, unsure of how to move forward with her new identity, one which no doubt raises questions of if and how anything could have been done differently had there been an awareness or understanding that something was wrong and not just adolescent acting out. Unlike their American counterpart, discussion of the child among English parent was tied up with their own sense of defeat, feeling problematic behaviours had been overlooked as a result of not knowing what could be defined as normal adolescent conduct, and what should have been approached as something pathological. The context of diagnostic practice in England suggests a culture of second opinions, a desire to 'wait and see'. Perhaps such a mentality trickles down to the world of the parent interacting with their child, providing a culturally accepted model for how to approach questionable behaviour.

6.4.5 Social pressures as triggers

The notion of achievement, which is so prevalent among US parents in conjunction with wider cultural pressures favouring enhancement, does not go without mention among English parents discussing their children. A difference exists in the way it is discussed however. The data from the English sample suggests that achievement is

actually seen as a key stressor triggering PBD and the associated behavioural and emotional changes that can occur:

She was very popular when she first went to the senior school she had lots of friends, and then from year 8 she began losing these friends and she moved friend group and then these problems all started to escalate while she was in year 9. She would come back and report on problems with her friends or teachers- a lot of complaints, a lot of negativity. So, I didn't think there was anything related to my daughter having mental health issues...(UKP 3)

The parent above attributes the stress that came with the changes in friend groups that marks many adolescent experiences as a precursor for what eventually led to PBD. Again, this is wrapped up in questions surrounding what can be perceived as normal behaviour. In hindsight, the strain of adolescence appears to provide a viable explanation for the parent as to why her daughter may have tipped towards illness. Another parent discusses the changes seen in their daughter after she had achieved her goal of becoming 'head girl' at her school and began navigating new dynamics within her friendship circle:

She's always been really bright, really intelligent, that's sort of her identity, she's been very much known in the family, and extended family "A. she's the bright one", you know, she's always gobbled up everything in life, she's always wanted to go on to college and university and do this and do that, and she's always been very mature I suppose. But then we started to see some very unusual behaviours in that she was starting to be quite rude to us, not wanting to come out of her room very often, but the thing we noticed most was that she didn't seem to have much interest in school anymore, she wasn't doing any revisions, reading any books, she just didn't seem to care, so whenever I would bring this up to her she would say "oh I know what I'm doing. You don't trust me" so was there was a sense of well she does know what she's doing, and she's very driven, but it just wasn't sitting right with us. (UKP 4)

The confusion is apparent in this parent's account, where the level to which the parent can trust their instincts is shaped in part by aligning new behaviours with the daughter's identity as the 'good daughter'- bright, intelligent and eager to move on to university- is challenged. There is a sense that this parent wanted to believe that her daughter knew best what was going on within herself, having always been accomplished, driven and successful, however it becomes clear as the parent continues speaking that this identity

held by others of the young person was masking underlying pathology. What emerges in the interactions recounted here is the degree to which others in the world of this young woman relied on her living up to her familiar identity within the family, and relying on her to communicate that she is okay even as aspects of her personality began to change. The context of the family thus becomes the place where emerging behaviours either fit with what is expected, or they don't. In this case, the severity of the girl's psychosis (as revealed elsewhere in conversation) is overlooked for a time due to the daughter's competence and 'togetherness', perhaps combined with a growing denial of unsettling behaviours being observed by the parent.

6.5 Clinicians

Clinicians maintain a significant presence in the development of parental knowledge about PBD, perhaps more so in the US, however English parents used clinical interactions as a point of reference in describing their experiences (often negative) in making sense of what is happening with their child. The degree to which clinical expertise is trusted shapes the development of representations of PBD, with both American and English parents expressing dissatisfaction, frustration and in the case of American parents, an often flat-out questioning of their expertise.

American parents

6.5.1 Feeling ignored, patronised and dismissed

The level of dismissiveness perceived by American parents either face-to-face, or in the form of unreturned phone calls, was cause for incredible frustration, helplessness and anger, and very much shaped attitudes towards the clinicians responsible for the care of their child:

They just kind of poo poo you away: "oh no, you don't know what you're talking about" or "you're just hysterical", you know, whatever. And it's hard. It's really hard. It was easier after we got her diagnosed, but it was really, really hard prior to that. It was banging your head into a brick wall. I'm trying- why aren't you people listening to me? Why won't you people help me? Why won't you people stop looking at each other like "oh, poor her". They just want to pat you on the head and have you go away. "Poo poo, bye-bye..." It's enraging. It's enraging. (USP6)

This was a common tone taken among American parents when discussing their trajectory into the world of professionals. No one is interested in listening to them. They remain ignored at a time when they feel they are the most desperate. Earlier the theme of parents as advocates was discussed, and in examining how parents discussed their interactions with clinicians, it became clear that often that advocacy was often the result of having to go-it-alone-and not receiving appropriate support from clinicians. Parental discussion gives the impression of a type of ‘forced’ advocacy, not in that they are being pushed against their own volition to act on what’s best for their child, but rather that clinical disengagement leads to a sense of being compelled to develop their own expertise. In addition to feeling that they were being dismissed, parents also talked of feeling that they were being judged harshly by professionals whom they thought should have been more supportive:

So I went back to (psychiatrist) after my son had been diagnosed PBD by another doctor, after he’s been through that, and I had gone back to her because I needed to talk to somebody because I was falling apart. She actually threw her head back and laughed and said “please don’t tell me that he got diagnosed Bipolar” laughing at me, and gave me a huge packet on ADHD, and I walked out the door and just fell apart. (USP2)

Such interactions suggest that a growing animosity among parents towards clinicians is borne out of not being taken seriously, either on the level of a parent, or on the level of an individual. Dismissiveness on the part of clinicians then reinforces the parent’s position that they are in a position of ‘us versus them’ with professionals, in which their helplessness is channelled into rage and finally a sense of needing to be proactive to make sure that their child is actually accounted for and doesn’t suffer the same neglect they perceive.

6.5.2 Questioning clinical expertise

A compelling aspect to the way American parents discussed the professionals they interacted with in the care of their children was just how much frustration was apparent. Emerging out of a sense of feeling patronised and ignored was a widespread questioning of clinical expertise, often veering between disdain and disbelief over a perceived lack of awareness and professionalism on the part of the clinician. Parents felt

entitled to question and criticise clinical judgment illustrating a clash of expertise at play between what they were being told about the child and what they were experiencing first hand:

I know what a manic episode looks like because I've had 'em. So I knew that she was either high, or she was totally in a manic episode. And they tested her for drugs and her system was perfectly clean. There was no drugs in her system, there was no alcohol in her system. Nothing. So then the psychiatrist on duty at the time in the ER and I were discussing what was happening with her, and he was the one who finally agreed with me, he was like "ok yes, this seems to be, I mean like she is exhibiting signs of having bipolar". (USP7)

As in the excerpt above, several parents inserted their own knowledge and experience into recollections of interactions with professionals. Here the parent is the one driving the diagnosis, suggesting a level of understanding that surpasses the clinician's limited knowledge, as the parent here has first-hand experience of a manic episode, thus is able to bring the clinician around to acknowledging what she already knows. There is a sense of the parent having the higher ground, while the clinicians were not always seen as knowing how to best handle the situation:

The minute he [son] was diagnosed, I forced education, and I never allowed the diagnosis to define him, nor I would I allow anyone else around him to speak in a way that it would allow the diagnosis to define him. We had doctors who would say "shh, he's sitting right here". I know he's sitting right here, and you're going to talk with him sitting right here. You are talking about him. Do not talk about him in third person. You have to involve the person who is most personally affected. He will help us understand how his brain works if you can help him understand how his brain works. (USP11)

The parent above speaks to the imagined Other in the form of the clinician, asserting her authority and laying claim to her expertise, while at the same time protecting her child from what she feels is a secondary, patronizing interaction. In this version of events, the parent is left with the last word, commanding authority and respect in the retelling, from both herself as an actor, as well as to the listener. The parent is asserting power and control, elevating her son and illustrating the ways in which he is more than what the diagnosis suggests he should be. Excerpts such as this highlight the motivation involved in shaping a narrative that supports parental representations of the child, in

this case an adolescent who is given the position of dominance by his mother. This representation of the clinician as somehow lacking the necessary expertise is echoed by others as well:

We told her what was going on and what we saw, and then we went to her office, you know, we sat down with her and she said, “right off the bat, I need to tell you, I would never medicate a child under the age of six”. I said, “Ok, I hear you” I said “I would rather have a glass of water and a nap, than take a Tylenol when I have a headache, I hear you. I’m all for the least invasive approach first, but my question for you is this, if that doesn’t work, how do we survive until he reaches this magical age of six? Right now as a family we cannot function”....and she goes “well, I’d really like to start with fish oil” and I said “ok, well, by the way, what’s your experience with children with paediatric bipolar disorder?” and she goes “oh, well, I’ve read a few articles”. (USP5)

In recounting this exchange, again, the anger and sarcasm is palpable as the parent communicates to the listener how inept and out of touch the clinician seemed when faced with the specific problem that was this parent’s child. At the same time, there is desperation present in the voice of the parent. ‘How will we survive?’ living with this aggression and uncertainty? Here there is an expectation that is not being met and because the clinician is not able to immediately meet that expectation, their knowledge is dismissed. The question of when, how, and why knowledge is taken on board and internalized or accommodated is central to this thesis overall, but seems especially salient here in the examination of an American parent’s subjective recounting of an interaction with clinical knowledge. The fact that the information presented doesn’t align with a parent’s expectations, isn’t useful in any capacity, causes a reactive questioning of that clinician’s true level of expertise. Of interest is the question of when clinical knowledge, despite being questioned and challenged, is taken on board by parents in their own way. This is to be discussed in the following section.

6.5.3 Internalisation of clinical expertise

The level to which professional discourse had been internalised by American parents was of particular interest. The adoption of certain terminology and perspectives surrounding PBD, despite the sense of distance and neglect that dominated the overall negative assessment of their relationship to clinicians, led parents to often refer to their

children ‘presenting’ with ‘symptom patterns and clusters’, describing their children as manic or hypomanic’, and viewing behaviours through the lens suggestive of professional influence:

It worries me sometimes because she’s not as insightful. When she is high she just says she’s happy, and ‘I just feel good’, you know, she’ll go to a concert and it’s like ‘oh that was the best concert ever’. She likes to go to Disneyland, she has a pass and she’s always like “I had the best night of my life!” you know, she’s always kind of over the top and doesn’t realize it. Or a lot of the Internet texting and, you know, posting a lot of pictures. You know it’s a different generation, but you know... I want her to be more insightful, you know “do you think you’re a little high?” you know? And she doesn’t like that word. She’ll say elevated, but she doesn’t like to say “high” you know? (USP9)

In the quote above, the line between what might be construed as normal behaviour has the potential to be pathologised, and the parent’s suggestion to her daughter that her elated moods might be equivocal with a manic episode illustrates the influence of available explanations being drawn on, and wanting her daughter to acknowledge this as well by being ‘more insightful’. In appropriating an exploratory framework that moves beyond a parent describing their child into something reinforcing the idea of a manic episode, the indirect influence of the professional can be seen. The adoption of such language and thought processes likely provides a semblance of mastery over the diagnosis, further reinforcing a sense of their own parental knowledge so often ignored by psychiatrists as being useful and relevant. The influence of clinicians in parental discourse also extends into the way parents talk about the need and justification for early intervention, adopting the view perpetuating fear and risk for a child’s future so often cited by professionals as part of their own dialogue, even as they voice frustration at trying to get clinicians to consider PBD as a possibility for their children. The justification for early, prodromal diagnosis coming from the parent indicates that a certain line of thinking has been absorbed and used in a way that makes sense for the parent making sense of their child. What is happening in this parental appropriation of clinical discourse refers back to Bakhtin’s (1981) elaboration on the interplay between Self-Other which was discussed in section 2.5. Here, it is the parents own experience

and intention which has allowed clinical knowledge to be adapted and shaped into an idea of what a child with PBD looks like. In this way, clinical influence on parents is manifested dialogically.

English parents

6.5.4 Disappointment and frustration

As with their American counterparts, clinicians came up as a significant other in interviews with English parents with the dominant theme threading through conversation one of feeling defeated and dissatisfied with these interactions. As mentioned in the previous section, one reason for this was an absence of information being communicated, however a lack of accessibility, professionalism, or ability to understand fundamentally what could be wrong with the child were central to how parents regarded these communications.

So to be honest, I noticed a change, and I thought at the time my daughter has a mental health problem. So I...approached the GP, and the GP had no idea how to assess her, and even though the GP did offer me an apology, and in England, the GP knows nothing about mental health (UKP 3)

This GP as gatekeeper for specialist services is called out for being somewhat inept in the parent's view. Despite concern over the mental wellbeing of the young person, the parent is met with a barrier in the form of professional lacking any awareness over how to properly assess the child, leaving the responsibility with the parent, and offering not much more than apology. This feeling of frustration with the lack of knowledge among professionals is echoed by another parent who notes:

I picked up a book and got more out of the first five pages than I did with CAMHS. (UKP 1)

The parents speaking in the quotes above exhibit a resignation to the idea that they aren't going to be receiving any guidance, or gaining any information, from the clinicians they have interacted with. The parent in the first quote further indicates the perceived incompetence of the clinician in describing how the clinician offered an

apology after having no idea how to assess the child with a suspected mental illness. The second parent appears further along in the process of dismissing clinical knowledge, or lack thereof, having already sought information from outside resources. In considering how parents in England acquire and construct knowledge around PBD, these feelings around clinical encounters are significant.

Disappointment and frustration related to a lack of competence or efficiency led parents to feel lost and desiring more information. Parents seeking to gain knowledge that makes sense to them often met with clinical understandings not in line with their experience. As an example, a parent who is met with a psycho-dynamic understanding of the child's illness:

She was still seeing and hearing the voices in hospital, she was still scratching herself a lot, and then CAMHS came in, the doctor, and they said, and this is often said, but they said that she needed to go home, they thought that this was an emotional response that she couldn't tolerate her emotions, and that I needed to have much firmer boundaries around her emotions, and they described it as a toddler having a tantrum...They were saying it was about boundaries, and it was behaviour, and it was about her not being able to tolerate her emotions (UKP 4).

Here the parent comes up against an explanation that places some of the responsibility for her child's behaviour on herself, and her supposed inability to impose boundaries on the child. Despite the fact that the parent specifically mentions the child's psychotic hallucinations and delusions, they are still encountering the knowledge held by the clinician, rooted as it is in less neurochemical explanations that would possibly make sense to the parent, but instead something much more psychoanalytic. In recounting this interaction, the tone of the parent was one of irritation, as the idea that her psychotic daughter was in need of firmer boundaries to sort out her behaviour was a ludicrous suggestion not to be taken seriously, and causing her to question not only the clinician communicating this, but the wider system as well.

6.5.5 Faced with professional reluctance to diagnose

In seeking to arrive at an understanding of what was happening to their child, English parents described coming up against clinicians who were hesitant to assign a diagnostic

label, even in the case of one parent who was convinced that their child was suffering specifically from PBD:

I: So you said you'd already been to CAMHS?

R: We see them, they just won't believe that it's PBD. I can say it until I'm blue in the face and they just won't entertain it. In this country I'm normally ignored. I don't get a response at all. Or you get fobbed off, you know, "wait until she's 18". Well no. I'm not going to wait until she's 18. (UKP 1)

This parent had spoken in the interview about the level of knowledge about PBD acquired as a result of searching for answers, which led her to contact consultants in the US and parents in online forums. Armed with her understanding of the broader spectrum of symptoms favoured in the US, she sought the validation from the CAMHS team. As she notes above, she is met with professionals who won't consider the possibility of a child having bipolar. Again, competing knowledges clash in an attempt to make sense of a child's unfamiliar behaviour, with one parent claiming knowledge in need of validation, and those in the position to validate her understanding of her daughter's experience refusing to align their way of thinking. The parent here positions themselves as frustrated and helpless in the face of clinicians who just won't listen, amidst a system that is not primed to see illness in a young person until they turn 18. This 'refusal to see' was echoed by another parent:

I: What sorts of things were you being told by these various professionals? Was there an immediate diagnosis of PBD?

R: No. I'd been asking and they said they didn't want to give the diagnosis to someone 14 and under. It's not best practice. I said to doctor, "I understand maybe your practice is to not to give the young people any diagnosis because the diagnosis can affect them in the long run", maybe that's why they hesitate, but I said "I'm open, and but I would like to know what I'm dealing with" That's why he told me it was clear to him that my daughter has BPD. (UKP 3)

Here, the parent speaking is a nurse who perhaps feels able to push to get her child diagnosed based on her own position as a health professional. In communicating to the

clinicians that she is open to the idea of the diagnosis, she is granting permission to the clinician, removing some of their fear of being responsible for the implications of the diagnosis. For the parent, the need for certainty, and an understanding of what is being dealt is the central concern, but from the parent's perspective, that is not something forthcoming unless one knows what to ask for. The way it is presented by the parent above, it was clear to the clinicians that their child had PBD, however they weren't going to come out and say it without some sort of tacit understanding with the parent. This particular knowledge encounter is coloured by clinical hesitation, leaving the parent in limbo. The suspicion of PBD is present in the clinician, however parental permission is implicitly sought out, leading to the question of whether or not action would have been withheld had the parent not pushed a bit. As one parent expressed over the course of the conversation, sometimes getting out of one's comfort zone and playing the part of the "pushy middle-class parent" is what was required to move forward.

This reluctance takes shape both in the flat out refusal to 'see' PBD, as well as an approach to diagnosing that favours 'wait and see'. In the case of one parent, this came in the form of a clinician aligning with the more broad-spectrum approach to bipolar that is becoming more common in England, but is not yet as widely adopted as in the US:

The psychiatrist she was under then was very keen to emphasize that the symptoms if BP in your people are very different to the more "traditional signs" as it were that adults share, with the depressive instances and the manic cycles. The psychiatrist studied it for a long, long time just by observation from a period of 2-3 months, and at a certain point he was convinced that my daughter E. did not have PBD, so he effectively sort of put that to bed, and so naturally we accepted it, but her problems continued and although she was discharged from hospital after 5 months there was, we felt, really all that had happened was that she'd been stabilized- they hadn't really gotten to the fundamental route of the problem, whatever that fundamental was. (UKP 2)

The quote above illustrates the dynamics at play between a parent with little sense of what is happening, and a clinician who is looking for a different set of symptoms from what the young person is presenting with. Despite the parent suspecting an illness, the clinician remains unconvinced, or unwilling to say anything definitive, thus the parent

“naturally” accepts what they are told, as it is the clinician with the expertise in the position of authority. The parent is rendered passive despite feeling like the real problem has not yet been addressed, while the clinician is perceived to be maintaining an aversion to developing an understanding of a child that has been ill enough in the parent’s eyes to be in hospital for five months. The final words of the excerpt above point to the idea that after all was said and done, no one was any closer to understanding what was wrong with their daughter, much to the consternation of the parent.

6.5.6 Perception of American practitioners as more knowledgeable

A final theme to come from discussion of clinicians among parents in England was the sense that parents weren’t only interacting with the clinician as individuals, but that they were communicating with a wider system that the clinician was often in a position to have to answer to, and parents were secondary to this. This came out in discussion as a comparison of health systems, and in particular the US as compared to England, with parents feeling that clinicians in the US were part of a system that takes parental concerns more seriously:

I went to every expert in the US that I could think of and it was amazing. Every single one of them replied. Janet Wozniak? (*author of original paper on PBD*) She replied. Dimitri what’s his face? (*Popolos, author of best-selling book The Bipolar Child*) He replied. Every single one who I contacted contacted me back. In the UK, very few did. And if they did, it was to say “go to CAMHS, they can help you” (UKP 1)

The parent quoted above was at wits end attempting to deal with clinicians in England. Having suspected bipolar disorder in her child, but unable to get anything validated officially, experts in the US were sought out as this parent believed them to be more knowledgeable. Perhaps most importantly for this parent, she felt her concerns were taken seriously, and significant players in the development of PBD research and the dissemination of information in the US were open to communication with her. The way in which this is contrasted with the treatment with clinician in England reinforces this parents sense that what she is forced to deal with in terms of local expertise and CAMHS teams clashes with her own beliefs- beliefs which are backed up in the US, yet

she is at the mercy of the system in England, which she associates with a lack of knowledge, understanding and competence. While this was the only parent to directly seek advice and expertise from those in the US, Other parents echoed the sentiment, comparing how they felt they were treated in England with how they perceived the situation to be in America:

We have no doubt that the way the US looks at and deals with mental health is just streets ahead of the way the UK does it. (UKP2)

So I think the general belief is that the US system is the envy of the world (UKP5)

Despite the fact that parents in the US also discussed a feeling of not being heard and of being cast off to the side, parents in England held the impression that had they and their children been having their experiences in that context, the complex trajectory trying to navigate a new mental health diagnosis would have been much more straightforward. The professional psychiatric climate in the US was discussed as one that was open to understanding pathology in children on a number of levels, while in England there was a sense of clinicians not knowing how to interact with, or understand, young people potentially suffering from mental illness. As an extension of comparison between the two contexts, one English parent noted that young patients were treated more like offenders as opposed to adolescents with mental illness in the English system.

They would say to us “E. needs to take responsibility for her behaviour” and we’re thinking, “She’s ill!” You know, and they would say “she needs to know the consequences of her actions” and they had this horrible term they would talk about “we need to punctuate E’s behaviour” in the way that they would punctuate involvement by the police. So it was like an admission of self-defeat that they were unable themselves to handle the young people, so whenever things got tricky, they would call the police. (UKP 2)

Criminalisation takes precedence over understanding as this parent recounts interactions with the staff at the hospital where their child has been an inpatient. Again, for the parent, there is an assumption that clinicians involved that the daughter should

be held responsible for her actions, that a lesson should be learned. A removal of clinical responsibility takes shape in clinicians faced with not knowing what they are dealing with in the young person. Frustration, disbelief and a sense of helplessness come up in the tone of the speaker, with a sense, as discussed previously, that a wider system has taken over, and the parent is removed from the equation. This was counteracted by discussing perceptions of America, where among parents there was thought to be a more understanding approach to young people who are mentally ill.

6.6 Other parents

For American parents, the perceived attitudes from other parents came up quite a bit in discussion, however this was not at all the case among English participants. Other parents acted as something of a mirror for parents interviewed, reflecting back their own imagined worst fears about how their children's behaviour and subsequent diagnosis would be tied up with their parenting. For parents, negation of their ongoing struggle, not being heard, and being blamed for their child's temperament came to a head in their interactions with other parents, either family members, friends, or those acquaintances in the wider community. That this was only a significant other among the Americans suggests the more open, interwoven projection and enactment of norms and expectations, and perhaps more openness in expressing opinion.

6.6.1 Judgment, conflict, and a lack of support

The topic of how other parents perceived them was often a sore point for the parents interviewed. While I had entered into these conversations thinking that parents would find support and solace in learning of other parents' experiences, often it was the opposite, with parents avoiding what support groups were available, noting that there was too much complaining involved, and parents felt like the tone was one set to inadvertently keep parents in 'victim' mode. Stigma and a lack of social support were central themes coming up in discussion of how interactions felt with peers about their child's PBD, as was the difficulty eliciting understanding when the child's diagnosis suggests an 'invisible' illness as opposed to something such as physical disability or cancer:

I couldn't really go to my church and say "oh, could ya'll bring by some food? My daughter's in the psychiatric hospital because she wanted to kill herself" (USP6)

In the hypothetical interaction quoted above, the parent here echoes a sentiment expressed by many other parents; that for a stigmatizing mental illness with less obvious cues than a physical illness, people are less inclined to offer support. The tone of the speaker illustrates the bitter edge this can have, especially when loaded on top of perceived neglect from clinicians as well. This feeds into a parent's sense of having to go it alone in isolation in the face of an illness that they know not everyone agrees exists. PBD is seen as both an obstacle to support, but perhaps also a motivational force pushing the parent to further solidify their position as advocate for their child, and for themselves as parents.

You know, I think people are so willing to assume and judge. There's a big tendency to suspect the parents. I don't doubt that there are children who are misdiagnosed, that for someone's convenience they get slapped with a label or whatever, and handed a handful of pills, but my experience has been, and other parent that I know who have suffered through this is, none of us have us have gone into this lightly, like 'oh good its bipolar. Throw a pill at him'. It's been painful and excruciating, and very deliberate ok what do we do? How do we handle this? How do we manage? How do we help our child to live? It bothers me when I think people are so quick to say this isn't real...really? It's not real? Because my son has been like this since birth. Don't tell me that this is manufactured. See what my life was like for the first four years, when he had nothing but love and healthy food and exercise. No. I'm sorry. This did not come from nothing. (USP5)

There always remains an undercurrent of being judged by others, and a need to prove that as a parent you're aware of how others might perceive you and your child:

You know inside they're thinking "she's crappy as a mother, she's not able to handle her kid, he's just a little crying brat" you know, you know it. You see the condescending looks at you, like "hmmf. OK". (USP13)

The eyes of others, and the impressions they are forming, are internalised by parents across situations. Here the speaker assumes they know that others are deciding she's a bad mother- an attitude that is no doubt perpetuated on a wider cultural level in the debates surrounding children's mental illness. Parents are not immune to what is said in the public sphere, and in recognizing that her son's behaviour on the ball field is out of

line with what would be considered ‘normal’, this parent is drawn to pre-empt what she fears others are thinking by acknowledging an awareness that they see her son’s behaviour as problematic. Perhaps parents feel their experiential insight into their child’s condition is devalued in the face of wider assumptions about parents of difficult children that circulate. In response, there is a drive to position themselves as experts among peers, utilising the difficulties they have faced after being introduced, voluntarily or not, into the world of a controversial diagnosis to render those experiences subjectively valuable and useful in some capacity.

6.7 The School

Perhaps due to the small sample size of English parents who participated, the position of the school as significant other was not as present in conversation as it was for American parents, for whom the relevance of schools, teachers, and access to individual education plans (IEP’s) was intertwined with how they understood and made meaning of PBD in their child. It was in the discussion of the school that the prevailing politics of diagnosis could be interpreted, as well as how top-down influence in this sense came to shape the development of parental representations not just of PBD, but wider cultural norms of how a child should behave.

6.7.1 Collaborative alliance...

While American clinicians felt the top-down influence originating from the pharmaceutical industry, for American parents, the top-down influence stemmed from the power of schools in determining to a large extent how far parents should go in order to pursue a diagnosis, or once a diagnosis was obtained, special accommodations for their child. It is in the realm of education where the politics of PBD as a diagnosis become most salient. Several parents noted with agitation that special attention and support from schools is tied to specific diagnoses, with ADHD and Autism receiving priority. Thus, in seeking to obtain an IEP, the negative aspects of the child’s behaviour were brought to the fore in order for the child to get the help they need. In this sense, the IEP is a driver for diagnosis, as it is this document that requires parents to pinpoint certain behaviours and get a label in order for services to be generated.

I think it's more from a school standpoint, now they know they can put a label on it, and I think that helps them, although they don't always like to do that, it depends on who you're dealing with, and it does all turn back in terms of the services he gets, but it didn't change anything except give me a little bit of peace of mind that I wasn't the one with the problem. (USP 12)

In the quote above the parent suggests that the push for diagnosis comes from the school, illustrating the conflicting ways in which these two spheres interact. On the one hand schools have the upper hand, determining who gets which special accommodation and steering certain children towards evaluation for specific diagnoses. On the other hand, it is the parent who pushes to make sure that they can get every last bit of help they are entitled to as the parent of a special needs child- a position often putting them at odds with themselves having to emphasize the more stereotypically 'bad' aspects of their child's behaviour. But as the parent quoted above illustrates, there is validation in a school's assessment, reinforcing as it does the subjective sense that it is not her parenting to blame for her child's diagnosis. Positive communication with schools were often aligned with how much special accommodation the child gets, and teachers described as 'good' were those who were most receptive and willing to provide specialized treatment:

My school was just out of this world, awesome. Once they got that understanding, the teachers had understanding, the principal had understanding, they all listened to me, they let me talk, they let me educate, it was just- I can't even say how good it was. (USP 3)

Here it is the fact that a parent feels heard, that the school has listened to her, let her educate them about PBD, and put her in control which has led to a favourable interaction, something that was echoed by the few parents who expressed positive experiences with schools response to children with PBD. The collaborative alliance at play is thus a reflection of the ways in which the parents can help shape the consequences of a diagnosis if PBD in their favour through a mutually beneficial relationship with the ever-powerful forces that be within the school setting.

6.7.2 ...but also a constant struggle

Schools also represent the symbolic fight against a wider system of norms, in which what gets played out and manifested through interactions between parents, teachers and school officials is indicative of the processes involved in shaping how a child's behaviours should be interpreted and objectified. Among parents, interactions with schools were described as fraught- a battle of wills and clashing expertise in which each sought to define problematic behaviour. This desire to demonstrate righteousness and persistence comes out in a parent's desire to use education as a means to influence the mechanisms taking shape around the child as well:

A lot of it for me was educating the teachers. And I was on a mission for many years, and every year at the beginning of the school year- I knew I was asking a lot of these teachers who were in a group of kids, but I would make up a binder, and I would have all these educational materials about 'what is bipolar' and I'd have an introductory letter and I would have a picture of P. so I think that's another important rule for parents, that yes, you can try to advocate for your kids and get them the services, but you need to educate the teachers, because it is a scary term, and often the only context they know it in is in reading about a kid who murdered his parents, but of course who wouldn't be a little bit afraid of that. So I tried to humanize it a little bit more and break it down, and of course this was very helpful for me as well. (USP10)

The diagnosis represents a reason for parents to make sure that teachers direct their attention towards their child, something the speaker above values for the added benefit of reducing fear and stigma that teachers may have upon learning they have a student with PBD. Again, the diagnosis represents "a mission" for the parents, not comfortable with the idea that the child might alleviate stigma through their own interactions with teachers, but rather seeing it as their own prerogative to pave the way, to ease the child's transition into a new setting. As this parent also indicates, humanizing the child in the teacher's eyes is helpful to her as well, as in this sense she can build a potential ally. In recounting her 'mission', the parent above lapses into addressing other parents in her talk, using her own experience as an example they might follow thereby illustrating a full circle in which the uncertainty surrounding the child's diagnosis with PBD became a mission undertaken by the parent to gain knowledge, validate their experiential expertise and educate others, both parents and teachers. For

this parent, the struggle has culminated in a level of confidence and agency shaping a developing awareness of their own power as a voice for their child living with PBD.

6.8 Discussion

This chapter has taken findings from interviews with American and English parents of children with PBD to examine interactions with significant others coming up in discussion about the diagnosis. These interactions determine how parental knowledge about the condition is constructed, indicating that knowledge encounters with professionals and peers shift parental conceptualizations of PBD, and of their child. The influence of these others, and the accommodation of this knowledge into the parents' own thinking, suggests the role representational and dialogical processes play in the development and transmission of understandings around PBD.

American parents view themselves as a central character in the master narrative of their child's trajectory navigating PBD, providing a way to validate the decisions they have made as they have gone along. Participants spoke of having had previous awareness that bipolar could exist in children, and once it became part of their own reality, the diagnosis was represented as a phenomenon rendering the parents victim to a set of unstable and unpredictable behaviours for which there is no clinical agreement on what should be done. Thus, a key finding of this thesis lies in how PBD is represented as something requiring first-hand experience to truly understand. American parents place a high value on their experiential knowledge, rendering themselves as experts- a position that becomes problematic when encountering professional knowledge systems where on the one hand the clinician is needed, trusted and relied upon, by the parent who then also views these interactions as a source of endless frustration, alongside a sense they are not being heard. Encounters (or lack thereof) with clinicians become a springboard for parents to develop both a sense of their own knowledge built out of a shared experience with their child, and a clarity of purpose with regards to advocacy. An overarching sense of 'us against them' takes shape in dialogue, further distancing the parental Self from wider professional and institutional frameworks to, in a sense, go it alone with the child.

Among American participants, PBD is understood by to be a problem of their child's physical self, a disordered neurochemistry indicating a risk in need of early pharmaceutical treatment to prevent the worst future outcomes. While many articulate a discomfort with the push for medication that accompanies the diagnosis, an acceptance takes shape as parent's appropriate clinical perspectives into their own internal dialogue in order to why it is necessary. As a "physical brain disorder", alignment with physical illness allows for justification of pharmaceutical treatments that parents may have been initially resistant to, and removes of some element of shame and stigma. This explanatory framework through which American parents consider PBD is the result of processes of normalisation, in which clinical knowledge, as well expectations of other parents and the school is accommodated. As was discussed in *chapter three*, the accommodation and assimilation of, and conformity to, other perspectives is central to the development of parental thinking about PBD as a whole, but also the wider normative framework into which they send their child to make their way. No frame of reference regarding what is 'normal' leaves parents open to influence. The more they research on their own, speak to and come into conflict with others, the more they begin to rely on their own expertise; an amalgamation of all they have come into contact with that makes the most sense for their unique circumstance. Strength and control via knowledge and mastery over diagnosis is driven out of a sense of duty to be a good parent, and very much based on acknowledging the right of their child to a "normal" childhood.

The data informing this chapter has shown that the key issues framing understanding of PBD among English parents involves a lack of information, uncertainty, and a reinforcement, both subjectively and based on interactions with professionals, of their position as amateurs who are often cast to the side. In discussion with English parents, three significant others stood out as being central: the parental 'Self', clinicians, and the child. Discussion of the child and PBD is much more rooted in extreme behavioural presentations among English parents, where the boundaries of diagnostic criteria hold true to the 'classical' bipolar model involving week and month long periods of mania, often combined with paranoid delusions and psychotic episodes,

episodes four of the five parents interviewed acknowledged as what finally gave them cause for action.

Achievement figured prominently in the talk of English parents, however it was almost in a way as to suggest this as a trigger for the psychosis and related behaviours. Unlike their American counterparts, there was no sense that PBD could exist in children prior to being ushered into their new reality. With the exception of one parent, they discussed still not understanding, or wanting to accept, the diagnosis, and that their interactions with professionals in charge with their child's care did little to provide comfort or alleviate confusion. A lack of trust in clinical judgement led English parents to compare how their circumstances would have played out had they been in the US as opposed to England, feeling that the hierarchy in place within the UK system left little room for the development of their own understanding, instead fostering a sense of helplessness, being side-lined by their position as parents, and at the mercy of a wider system. This sense of disconnect between English parents, clinicians, and the wider healthcare system stands in stark contrast to the consumer driven system in the US which allows parents to feel that they may be capable of having an influence, thus using their experiences as a springboard to advocacy, communicating their knowledge about PBD to other parents, and clinicians for that matter, ensuring that the diagnosis and how it is represented among this group, is perpetuated.

Further in depth discussion of American and English parents' representations of PBD, and the dialogical processes shaping these representations, will take place in the next and final chapter. A summary and wider discussion of the comparison between parents and the significant others referenced, as well as the role the cultural context of the US and England play in the development of these representations, will tie this empirical chapter in with the two that have come previously, and will also incorporate the theoretical framework outlined in *chapter two* in order to advance a model of how representational and dialogical processes, as well as modalities of social influence, contribute to the construction of diagnosis.

7. Discussion and implications

It's the disinhibition or impulsivity of ADHD. It's the irritability of a depressed state, it's the psychosocial stressor of being unable to sit still in the middle of a classroom. Whatever it was, once you start to view it in a different way, you could then make the appropriate diagnosis. (American clinician on learning to 'see' PBD)

7.1 Introduction

This study has used a social representations approach illustrating processes of anchoring, objectification, knowledge encounters and dialogical processes as mechanisms involved in shaping the diagnosis of PBD in the US and England. In the previous chapters, I have mapped out the representations of different stakeholders in the life of the child with PBD, and in this final chapter, these findings will be integrated in order to construct a model for how the development of a diagnosis is generated out of the sometimes competing, sometimes intersecting perspectives of the pharmaceutical industry, clinicians and parents in the US and England. Discussion here will support the main finding of this thesis that construction of PBD is extrinsic to the condition itself, and instead forged at the interactive meeting points between the three stakeholders. To reiterate, the overarching question being asked of this thesis is that of how knowledge about PBD is constructed in the US as compared to England. The individual research questions are as follows:

- 1) What are the social representations of PBD held by the pharmaceutical Industry, and how has the industry contributed to wider understandings of PBD as a diagnostic fact?
 - 1a) What factors shape such representations within the pharmaceutical industry?
- 2) What are the representations of PBD held by clinicians in the US and England, and what psychosocial processes have shaped those representations?
- 3) What are the representations of PBD held by parents in the US and England, and what psychosocial processes have shaped those representations?

- 4) What do the content and processes of representations of PBD among Pharma, clinicians, and parents suggest about the construction of the diagnosis in the US as compared to England?

What this thesis has shown is that ultimately PBD is made of a patchwork of representations about the condition, the child, and the role of different actors. Driving these representations are 1) the interaction between the actors, how they understand and influence one another, and 2) the pragmatics of cultural background and the feelings and interests being accommodated as multiple actors negotiate PBD. This will be discussed more in depth in the following sections, beginning with discussion of the US and England as distinct cultural contexts and followed by discussion of the child at the heart of the debates. Following on from this will be a summary of representations held by pharma, clinicians and parents, illustrating the organisational and lay knowledge at play in shaping the diagnosis. The psychosocial processes shaping these representations will then be expanded upon in a final section that will bring together knowledge encounters, and dialogical processes of Self-Other interaction and modalities of social influence. The chapter concludes with discussion of implications, limitations and future directions for research.

7.2 Comparison of cultural context: The US and England

When it comes to developing a line of thinking around children's mental illness, what shapes how a society interprets and categorises emotional, behavioural or cognitive aspects of childhood experience? How is individual experience perceived, both subjectively and objectively, on a wider cultural level? Davies (2011) discusses the sense-making struggle that comes not only with the generation of a new phenomenon, but also the consequences of how a particular phenomenon, such as a new diagnosis, is "defined, socially understood, and ultimately managed" (p. 190). In the preceding chapters, I have sought to illustrate this dynamic of constructive processes at play that allow individuals and groups to produce, objectify and make sense of a still-emerging disorder.

Unspoken cultural assumptions shape behaviours in unique ways, as it is through the context in which something is said that shapes interpretation (Jovchelovitch 2007). In the case of a contested diagnosis such as PBD, in which biological behaviours may be present, understanding of these as symptomatic is socially and culturally based. Van Bavel and Gaskell (2004) have suggested that societies draw on sets of cultural symbols in order to develop explanations for phenomena and events. Such symbols instil a believability which allows explanations to make sense, thereby increasing acceptance (ibid). To this point, the diagnosis of PBD itself has become a cultural symbol, imbued with all of the values, morals and assumptions that lead to its enactment as a diagnostic category in the US, while remaining rare in England. Jovchelovitch (2007) suggests that the “concrete social conditions within which knowledge develops are intrinsic to the process of knowledge formation and shape the internal structure of knowledge” (p.167). Thus, in looking to summarise and discuss how the pharmaceutical industry, parents and clinicians develop representations of PBD, cultural context encompassing diagnostic and parenting understanding and practice exists as an actor in its own right. This section will aim to unpack the role of cultural context as it pertains to the construction of PBD in order to ground the more fine-grained analysis of the processes at work in such construction that has been presented in chapters *four*, *five* and *six*.

As discussed in *chapter one*, the American healthcare system remains one of the most highly regarded in the world, prized for the efficiency and level of care afforded to those who have access. Alongside this exists a pressure to stay innovative; an unspoken demand driven through being a consumer-driven, for-profit model of healthcare delivery, reliant upon third party payers in the form of insurance companies, and the ever present influence of the pharmaceutical industry steering research funding. The much studied and debated increase in the medicalisation of once ‘normal’ aspects of human behaviour represents the less-favourable flipside of innovation. This culture of medicalisation in the US is reflected in the widening scope of American clinical and parental notions of what behaviours can be included in a definition of PBD. Bipolar disorder was at one time a more clearly delineated in patients who manifested the

dramatic highs and lows, accompanied by psychosis. This conceptualisation has been redefined, indicating wider cultural schemas objectified through practice, taking shape as an increasing number of individuals and groups who decide that explanations such as rage and irritability, for example, make sense.

Resilience, moving forward, innovation, and efficiency are often associated as American cultural norms; factors that are exemplified in the creation of PBD as a separate dialogical entity from established classifications of Bipolar I, II and ‘not otherwise specified’ that are used when diagnosing adults. Now, the psychosis and extended mood swings that had been defining features of bipolar disorder have been adjusted to reduce the duration of mood swings for children, allowing for recognition of the broader symptoms of irritability mentioned, as well as ‘rapid cycling’ of a child’s temper in one day.

Added to this definition of PBD developed in the US context is the importance that the concept of risk holds in terms of the rationalization and justification of the diagnosis in children; a popular understanding is developing suggesting that mental illness in younger children looks different than it does in adults or even older children. The outcome of the development of the idea of a child as ‘at risk’ is the increased push for prodromal diagnosis, in which a diagnosis is made, and treatment started, before any symptoms appear. According to the National Institute of Mental Health (NIMH 2009) changes in a young person’s body leading to mental illness may start very early, before any symptoms present. Thus, the idea has been established that the ability of clinicians to help parents and their young children manage difficulties early in life may prevent such disorders from developing. Parents and clinicians both adopt the idea of risk involved in leaving a child untreated, tapping into both the neurochemical risk of brain atrophy that can supposedly result, as well as the social and economic risk in which undiagnosed PBD leads to potential criminality and sours any chances at future achievement. Despite the fact that “much more research is needed to determine the effects and benefits of medications in children of all ages” clinicians and parents are asked to “keep in mind that serious untreated mental disorders themselves can harm brain development” (NIMH 2009). It is this aim at preventing the development of

disorders that remains controversial given that there is no certainty surrounding these assertions. A delay in seeking help, it is claimed, will be detrimental to the child's future mental health. Thus, PBD as an emerging diagnosis is presented as an urgent matter to be dealt with as soon as possible, reinforcing the 'quick fix' mentality perpetuated by the US healthcare system.

This cultural pressure pushing innovation leaves little incentive to take time to explore what lies behind a set of behaviours recast as 'symptoms'. In England where the reluctance to act to quickly can be seen as the result of a 'culture of second opinions' there is less pressure from above to derive a quick fix. The present research suggests that it is a wider cultural comfort with ambiguity as opposed to an American need for certitude that drives this difference. One plausible reason lies in a comparison between cultural moralities in which the American mind-set, pushing innovation and moving forward despite the potential costs being discussed here, come up against an English perspective keen to maintain theory and valuing tradition as part of diagnostic and treatment practices. The conceptual differences between the US and England were illustrated by an American clinician discussing an interaction with the English publishers of a textbook that the clinician was writing for:

We used the phrase 'paediatric bipolar disorder. They don't like that because it implies that PBD might be different from adult BP. I didn't mean to be, you know, a 'paediatric specific phenotype', I was trying to not have to say 'children with bipolar disorder' sixty times in a chapter, I just transferred it to say a word, but they were very concerned about, "well this gives the impression that you're implying that there's a different type of bipolar disorder, or a different standard for kids. (USC6)

This excerpt illustrates the concern of English psychiatry to hold tight to specifics and not imply something is present which remains unproven. This is indicative of the level of resistance to the broad-spectrum approach to bipolar disorder in children held by Americans. For the English, bipolar disorder is bipolar disorder, made up of an established set of diagnostic criteria that need rarely be deviated from. The uncertainty of the diagnosis' validity is deemed too risky to apply in a population for whom so much is at stake in a potentially stigmatizing label and treatment with heavy medications. In discussing the importance of semantics as present in the language of

suffering, Brinkmann (2014) notes that specific terminology and vocabulary used to articulate an experience frames how that experienced is acted upon. Specific vocabularies make possible specific actions, so whether one is reliant on a biomedical, religious, existential or political means of explanation impacts how a specific set of behaviours is viewed. Ideas and diagnoses cannot be separated from “the institutional and material bases from which such ideas arise and influence our understandings; both are aspects of social practices, and the linguistic articulations of practices necessarily operate within a complex field of social practices with symbolic and embodied aspects” (Brinkmann 2014, 634). There is, however, a growing sense that it is only a matter of time before PBD becomes a more acceptable diagnosis in England. This ties in with Fleck’s (1935/1979) assertion that part of the process of establishing a medical fact is a period of debate and questioning, writing that a fact

...begins with a tentative signal of resistance by the collective, which acts as the predisposition for an emergent fact. Through collective interaction, this tenuous indication gradually becomes stylised, undergoes consolidation, and emerges as accepted fact (Fleck 1979, 157)

Indeed, this consolidation has potentially started to take shape with the publication of updated NICE guidelines for bipolar disorder diagnosis and treatment released in September 2014. The mere mention of a new condition in any sort of official guideline can act as enough of a spring board just by virtue of planting the idea that the condition exists enough as an entity somewhere to warrant mention in a localised guidance or protocol. It is the presence of such guidelines which Moncrieff and Timimi (2013) suggest can be misleading via the management of contradictory data to support, and not jeopardise, the dominant medical discourse suggesting the validity of contentious medical conditions, such as ADHD or depression, and the requisite pharmacological treatments. Such clinical guidelines are central to the construction of psychiatric knowledge, thus, if more ‘official’ mention is made of something like PBD, the more familiar the idea becomes, the more it becomes picked up by clinicians and ultimately becomes a part of common sense thinking.

The US and England hold on to different vocabularies, whether in textbooks, research, clinical or parental discourse. How these cultural vocabularies are echoed by

individuals, becoming part of how they understand something like PBD, are of particular interest in the transmission of knowledge about PBD. These cultural differences in what language is adopted, what behaviours are sought out and labelled, whether to seek treatment, and practices around diagnosis provide insight into the cultural comfort each context has with the notion of a ‘disordered child’. Representations diffused by larger, powerful industries like that of Big Pharma are internalised by the wider professional and lay public, echoing a wider discourse and illustrating the internalisation of this discourse made evident in practice. The fact that the diagnosis was born in the US makes sense of the trend that sees increasing numbers of parents and clinicians no longer uncomfortable with the idea of childhood diagnosis. Attention paid to ADHD and autism spectrum disorders have brought discussion of children’s mental illness to the fore, often with the element of political advocacy shaping them as causes related to a child’s rights, whether to proper schooling or beyond that, a proper childhood. Such attention, while not necessarily advocating an increase in these diagnoses, nonetheless serves to normalize the idea of them. What constitutes a proper childhood, and how a child should be, are necessarily at the core of the development and perpetuation of social representations about PBD and will be discussed in the following section.

7.3 The child at the heart of the debates

In comparing the knowledge of PBD held by the pharmaceutical industry, clinicians and parents in the US and England, a central finding of this thesis was how the diagnosis was made up of representations not only of the condition, but also the child at the centre of the discussion. In looking at how a diagnosis encompassing very young children is represented, it is necessary to consider not just the diagnostic label, but how the existence of such disorders ties in to larger presumptions of childhood in general. An interesting point that I noticed while conducting interviews with parents in the US as compared to England was the seemingly gendered differences inherent in which children had the diagnosis. In the US, all but two of the parents I spoke to had younger sons with the diagnosis, while the limited number of parents I spoke to in England had adolescent daughters. This observation supports other research pointing to gendered

notions of ‘deviance’ (see for example Singh 2007) and could work towards explaining differing cultural norms in what is acceptable behaviour.

D’Alessio (1990) explains how adults “maintain and construct the idea of a normal child” establishing norms in the process that are then used to make judgments and moral assumptions (p. 71). Childhood is presented as an object that is at once familiar and distant, making it difficult to distinguish between what is just the child acting of their own volition, and what is behaviour that depends on the presence of an adult (D’Alessio 1990). As adults seek to familiarise themselves with childhood through communicating about, classifying, and representing childhood development, D’Alessio (1990) reminds us that children play in active role in shaping the resulting adult representations, by being “active participants whose activity provides a source of feedback on the adults ideas” (p. 73). It’s a circular process that has children being labelled as a result of deviating from a set of normal behaviours, and adults learning to see their behaviour in light of those norms. It is striking to note that even after a child has been undiagnosed with PBD, the parent often has difficulty not seeing their child as still being ill, despite assurances that perhaps their behaviour is developmentally normal, but what is developmentally appropriate has been lost in the murkiness of an ever-changing diagnosis.

This coincides with Duveen and Lloyd’s (1993) assertion that one characteristic of communities made up of adults is that part of the culture will be inclusive of expectations for how a child should behave, how they should have developed by a certain age, what they should understand, and how competent they should be with regards to communication (p. 98). Such assumptions shape representations of the child, which then feed into wider understandings about what is normal versus what could be seen as on the spectrum of pathology. When societal thinking about such expectations is always in flux, it makes seeking certainty through medical explanation a viable option for parents to make sense of their child’s behaviour. Adults are the ones who position children within a society and whose own representations provide the scaffolding which allows the young person to internalise the identity imparted through adult representation (Duveen and Lloyd 1993, 92), but the question remains to what extent

children and young people accept such representations without resistance. In discussion with parents of children with PBD, many talked of their older adolescent's refusal to accept the diagnosis after having lived with it for many years, preferring instead to accept as their own brand of normal those aspects of themselves deemed 'ill' at a wider societal level. Conversely, younger children often tried to communicate to their parents that they didn't feel right, that they thought something was wrong with them and they wanted to be more like other kids. How much of these children's perceptions of themselves is the result of adapting to representations held by adults in their world? PBD is more than a set of words, or a diagnosis. The label comprises a set of expectations of what constitutes 'normal' behaviour. Behaviours running contrary to that established social norm leads to the possibility of seeing such conduct disordered and dis-regulated. It also acts as a flashpoint, highlighting contrasting ideas over what childhood should mean and subsequently raising issues surrounding the increasing medicalisation of childhood.

This thesis uncovered the systems involved in this process as a new diagnostic category takes shape. Organisational, medical, educational, parental spheres of knowledge- all contain reference points determining what 'normal' should look like. Of particular concern is the question of how such definitions and points of reference change through the introduction of new information. Representations become powerful through institutionalisation. Knowledge encounters among and between often competing systems of knowledge lead to the adoption of ways of seeing the child that are useful in some capacity, either as a means to the development of a business goal, or an explanation that makes sense and provides a sense of certainty and action to be taken. The more aligned what is seen becomes with what an individual or group feels should be seen is the result of changing representations of the child and the incorporation of these representations into wider practices and common sense assumptions about how a child should be. A child's identity is constructed out of socially shaped resources (Campbell and Burgess 2012) leading to the question of what function certain representations play in wider social relations. For example, the representation of the suffering child used by the pharmaceutical industry as discussed in

chapter four allows for the establishment of the child as an ‘unmet need’, which then acts as a useful point from which to base marketing campaigns around the definition of what this ‘need’ looks like, as well as the treatment available to mollify it. Thus, all of the representations and processes discussed below necessarily begin with the child who, while unfortunately not a source of data for this thesis, maintains the central position at the core of how the key actors around them develop and apply their knowledge about PBD.

7.4 Organisational, professional and ‘lay’ knowledge: pharma, clinicians, parents and the representations of a new diagnostic category

This section presents the key findings from each chapter for the purpose of comparing themes across actors and contexts. The construction of PBD takes place at the meeting point between these three stakeholders, in which the representations developed of the diagnosis extend into representations of the child as well. The content of these representations is presented in table 7.1 below and forms the basis of the summaries presented in sections 7.4.1- 7.4.5.

Table 7.1

The making of a diagnosis 1: Social representations of PBD (content)

	Pharma	Clinicians		Parents	
	Global	US	England	US	England
The Condition: PBD	Adult disorder reconfigured for childhood	Anchored in ADHD	Anchored in manic-depressive psychosis, schizophrenia	Requires first-hand experience to understand	Requires professional expertise to understand
	Anchored in ADHD and schizophrenia	Diagnosis ‘in flux’ - uncertainty	‘bipolar is bipolar’ - rare	Knowledge of its existence in young children	Unaware it could exist in children
	Characterised by rage, irritability. Psychosis need not be present.	Broad spectrum’ approach more	‘classical presentation’ more accepted	Genetic, neurochemical explanatory framework	Social pressures as trigger

		accepted			
	Treatable. Urgent.	PBD more common than originally thought	Uncommon in young people, virtually unheard of in children		
The Child	Unmet need/market opportunity	'at risk' : prodromal treatment	Part of wider social context	True nature of child obscured by diagnosis	Uncertain over what is 'normal' behaviour.
	Suffering from 'constellation of diseases'	Peripheral in discourse	Central position in discourse	Rage, irritability, crying fits main symptoms	Psychosis, Self-harm, suicidality main symptoms
		Cluster of symptoms in need of management	'voice' of child incorporated into diagnostic practice	Lack of control or responsibility for behaviour	

While the above table provides an illustration of the content of the representations held, a central aspect of this thesis has been to illuminate the role of interactions in shaping such representations. Table 7.2 below brings together these interactions by focusing on the positioning of the 'Self' in relation to significant others. A more in-depth discussion of these knowledge encounters, and the processes of influence which allow representations of PBD to form in extension, will be elaborated upon in section 7. 5 below.

Table 7.2

The making of a diagnosis 2: Self-Other interactions shaping development of representations of PBD (dialogical process)

	Pharma	Clinicians		Parents	
	Global	US	England	US	England
Self: The reflexive 'I' position	Pressured for diagnostic expansion	Independent	Interdependent	Expert	Amateur
	Driven by competitive economic forces	Uncertainty amidst pressures for recognition	Positioned in relation to American colleagues- prominent in discourse	Pro-active advocate wanting what's best for the child	Ill - informed and cast aside
		Role of career development; expertise	Cautious, reflective expertise		
The voice of significant 'Others'	Competitors Differentiation via accommodation of knowledge	Parents Experiential experts- co-producers of early knowledge about PBD; as voice for the child; as victims.	Parents Novice- seekers of knowledge; alignment with child, separate from clinician	Clinicians Questioning clinical expertise; feel ignored and patronized; Direct and indirect adoption of clinical perspectives	Clinicians Disappointment and frustration; faced with reluctance to diagnose; perception of US clinicians as more knowledgeable
	Clinicians Industry alliance: shaping opinion leaders, sharing responsibility	Pharma. Subjective values compete with professional reality	Pharma Encroaching American threat- vested interest. Leads to trust in 'home-grown' research.	Parental Peers Judgement; lack of support; Desire to impart expertise	Parental peers No mention
	Parents Notably absent from industry discourse			The School Collaborative alliance while also a constant struggle	The school Minimal mention

The tables above present the main points of discussion to be expanded upon in the remaining chapter, tying empirical findings in with the theoretical framework in order to advance a model of social representations and dialogical processes at play in the construction of diagnosis. The discussion begins with a summary of representations held by the pharmaceutical industry.

7.4.1 The global influence of the pharmaceutical industry

Chapter *four* presented the ‘internal’ and ‘external’ voices of the pharmaceutical industry through the analysis of internal industry documents and advertisements. Representations of PBD were dependent upon the voice that was enacted, as the internal voice sought to establish the objectification of a set of symptoms indicative of a new type of child into a new diagnosis, while the external voice sought to reify this objectification through the suggestion of norms so central to pharmaceutical advertisements. Advertisements for the antipsychotics used to treat PBD on the one hand incite fear, tapping in to the notion of future-risk affiliated with PBD, as well as deep-rooted anxiety and the disintegration of self that comes with mental illness. The internal voice of the industry represents the child as an ‘unmet need’ suffering unnecessarily, thus existing as a marketing opportunity for future profit. Those advertisements for ADHD, the most salient anchor for the diagnosis of PBD in the US, promise a highly regulated child who will succeed socially and academically. The analysis of representations held by the pharmaceutical industry acted as grounding for the remaining empirical chapters, as the representations of PBD developed by Other key actors could be said to stem directly from how this industry reshaped representations of the child.

For the pharmaceutical industry seeking to treat an as-yet-unnamed disorder, PBD began through a process of anchoring the new condition in more well-known, previously established conditions, namely ADHD in the US and illnesses such as more established notions of manic-depressive psychosis and schizophrenia in England (Figure 7.1). New symptoms to single out as pathological in children were taken from older categorical symptoms of schizophrenia (representing severity and urgency of

treatment) and ADHD (representing chronicity and treatability) in order to initiate off-label prescribing. This, combined with the inclusion of broader spectrum criteria such as rage and irritability, perpetuated an idea of the child via the new possibility of treatments available.

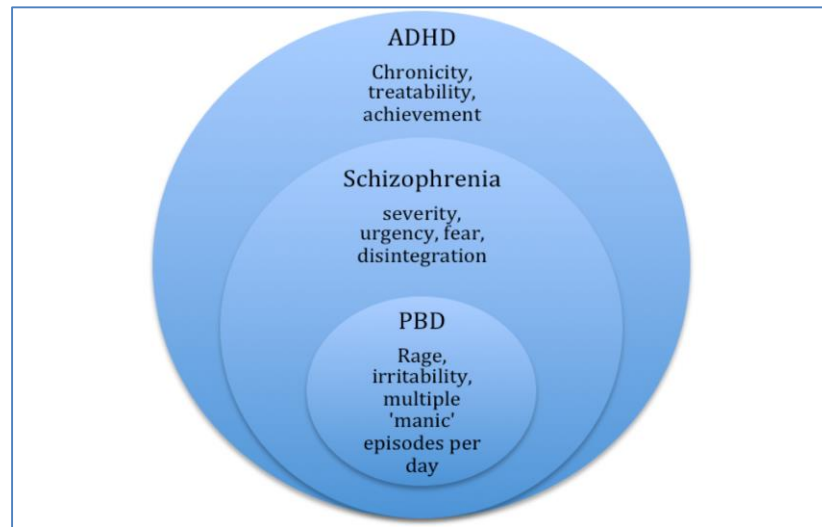


Figure 7.1 Pharmaceutical anchoring of PBD

The concept of PBD as developed by the pharmaceutical industry remained vague enough to be encompassing of more and more children. Marketing strategies, professional education, and the push for sales representatives, and thus prescribing clinicians, to anchor PBD in something more ‘treatable’ such as ADHD established a new set of criteria on which to draw on, however the development of what behaviours are indicative of PBD being developed in concert with sales and marketing model is concerning. Clinicians were brought on board, nurtured as ‘opinion leaders, and retained for their level of influence both on clinical colleagues, and the parents of their young patients. Conveniently, the position of clinician as reliable expert liaison between industry and public, also allowed for the industry to shrug off controversy, reassigning responsibility when the criticism got too close.

Dialogical processes shaping the development of pharmaceutical representations indicated the unidirectional, top-down nature of Self-Other interactions. The industry

‘Self’ was positioned in response to economic pressures from competitors in the field, in which pushing to expand diagnostic categories, and the symptoms they encompass, is about survival. It was this need for survival in a competitive market that drove the accommodation of external threat and need for differentiation in terms of what was being offered as new treatment for novel conditions. Industry influence in the form of persuasion played on the ego and esteem of practicing clinicians, reifying their expertise in the promise of paid speaking engagements and positions as opinion leaders. Also being played into was a clinical sense of ‘moral entrepreneurship’ (Becker 1963) in which clinicians’ act as ‘rule enforcers’ to the industry’s position as ‘rule creator’ via an organisational understanding of clinical perspectives validating the clinician’s role as something of a saviour to their patients. The building of trust through the provision of answers in the face of uncertainty allows clinicians to succeed in interactions with their patients. This will be unpacked further in relation to the wider theoretical issues in section 7.5 below.

7.4.2 Representations of PBD among American clinicians

PBD represented an initial career opportunity for many of the American clinicians interviewed, supporting Fleck’s (1979) assignment to the importance of the role of education and indoctrination into an already established thought collective. Among those interviewed, there was very much a sense of autonomy of practice, and independence from the wider field of practice in the US, in which there is no agreed upon understanding of what PBD actually is. For American clinicians, the closest point of reference on which many agree is that PBD is anchored in the existing diagnosis of ADHD. The overlap in the two diagnoses often leads to initial mistreatment with medications that can end up making things worse, or as some clinicians contend, create the problem by initiating a manic episode where none would have occurred organically. It is seen as a very different entity to adult bipolar, carrying with it its own unique sets of behaviours that do not make up the diagnostic criteria in adults. Characterised by rage, irritability and restlessness, American clinicians interviewed note that PBD can be present in children as young as three years old. As a diagnosis, PBD is thought to be more common than originally thought, due to more adept diagnosis, but yet remains a

diagnosis in flux. Despite this, PBD is objectified through its enactment as a diagnostic category, and if suspected, the first-line treatment is with antipsychotic medications.

For American clinicians, parents are collaborative allies shaping PBD as distinct from adult bipolar disorder. Based on their lived experience with their children, it is parents who were often described as initially focusing clinical attention on specific behaviours, which clinicians have then adopted into their representation of a disordered child. The behaviours thus become reified as ‘symptoms’ through the process of negotiation with parents to log them as symptomatic of this illness. Parents directed clinical attention, which clinicians then steered back to parents and, by proxy, onto the child. Clinicians, as the Self, engage in this circular process with multiple Others, with the child seeming to exist on the periphery. These interactions are taking place as clinicians negotiate their position within a social hierarchy that finds them between top-down pressures from the pharmaceutical industry, and bottom up pressures in the form of subjective anxiety based on their own conflicts between values and practice, and external anxiety in the form of parental pressure for explanation of their child’s behaviour. As discussed in section 7.2, representations of the condition include representations of the child, whom American clinicians conceptualize as at risk; a cluster of potentially damaging symptoms in need of management.

Dialogically, there is a tension present between the clinicians’ subjective ‘I’ position and professional reality, something which is manifested in the positioning of the clinicians as an expert among experts practicing in a healthcare system that leaves little space for deliberation, rather emphasizing the immediacy of a quicker fix. Also present in this tension is the position of clinical colleagues as a potential threat, and the distancing of the child in conversation, perhaps to keep the interactions clinical and devoid of emotion, alongside the concurrent alliance with the parent. In attempting to build consensus around the development of a more ‘fixed’ set of criteria for PBD, the accommodation of parental experience becomes a source of validation of clinical perspectives. The privatized, consumer-driven culture of practice in the US places a level of power in the patient, in this case the parent, to get a level of care deemed worthy of what is being paid for it. Thus, in the development of PBD, the position of

clinician as a mid-point between the wider healthcare system and the parent, in which top down influence meet bottom up pressures, contributes to the establishment of understanding the symptoms and behaviours that make up PBD.

7.4.3 Representations of PBD among English clinicians

In contrast to their American counterparts, for English clinicians interviewed PBD is still considered very rare, is not normally seen in younger children, and is not seen as distinctive from bipolar in adults. As a diagnosis, it remains anchored in schizophrenia and manic-depressive psychosis, in which young people diagnosed are often in the midst of psychotic delusions or other severe behaviours warranting in-patient treatment. The objectification of the diagnosis then comes in the resistance to use of the category, instead focusing on more traditional notions of bipolar disorder. There was awareness among English clinicians of the broader spectrum approach favoured in the US, however the context of the child was central to discussion, and it was the more holistic approach to diagnostic practice that was a central finding setting English practitioners apart from their American counterparts. English clinicians interviewed pointed out that it is rare to see very young children with severe mental health issues, and unless stabilization is required, psychopharmacological treatment would not be seen as a first line treatment.

The culture of socialised medicine, as exists in England, has embedded within it an established hierarchy among clinicians and patients. English clinicians positioned themselves interdependently, as part of wider collective field of practice. Such identification with a group of practitioners allows for an alliance with clinical colleagues, but also serves to open up the space for influence, in which each practitioner, as a member of the group, feels a subjective obligation to maintain consistency of practice, illustrating what one clinician referred to as a “culture of second opinions”. Parents are seen as seekers, rather than holders of knowledge, thus, parents are positioned alongside their child in a dyad. The established hierarchy present within the English medical system shapes this distancing between themselves and the parent, in which it is the clinician who holds the necessary proficiency to impart sound and uncontested

judgment. With regards to the child, however, intersubjectivity and a desire to understand the experience of PBD from the young person's perspective marked clinical practice. While English clinicians identify as being part of a wider network of practitioners, it is America, and their American colleagues, which represent a globalized Other against which to express opposition. For the English clinicians interviewed, this comes in the form of referencing and addressing American clinical colleagues in discussion, expressing a conflicted thinking around acceptance and rejection of information shared via research and professional settings. On the one hand, there is a sense of America as leading with innovation, remaining at the forefront of research and practice surrounding children's mental health. However this is tempered by a lack of trust and due to an assumption of American clinicians practicing in a culture of vested interests, whether professional, therapeutic, personal or scientific.

7.4.4 Representations of PBD among American parents

Parental representations of PBD in the US are very much bound up with how parents position themselves in relation to other key significant actors in the life of the child, namely clinicians, teachers, and other parents. When referencing interactions with these groups, parents position themselves, across the boards, as experts, no matter the position in the professional hierarchy their interlocutor holds. A dynamic of 'Us versus Them' is a common thread in discussion, in which the child's diagnosis sets parents up for battle with schools and clinicians. PBD is seen as something that requires experience to understand, experience which provides them with a level of knowledge unlike that of clinicians, but which should be seen as valid. This sense of experiential knowledge allows American parents to take an active role in their child's illness trajectory, a role perhaps driven by an understanding of PBD as obscuring the true nature of the child, one that needs fighting to preserve. For parents interviewed in the US, this contributes to an external locus of control in which a biological or neurochemical explanation for behaviour means that associated behaviours are beyond their, or their child's control.

Dialogical processes incorporating outward resistance to, and internal accommodation of, clinical knowledge helps foster a sense of mastery of the diagnosis,

as well as interactions with clinicians who are generally found to be dismissive and unsupportive. Interactions with schools and parental peers present an opportunity to exercise, and feel appreciated for, experiential expertise allowing for the communication, perpetuation and dissemination of understanding PBD that may often times rival clinical knowledge for those still unfamiliar with the diagnosis. Of interest is an apparent mismatch between clinicians and parents, which will be discussed in a final section exploring the directionality of influences. While clinicians take on board parental experience and remain open to their influence, particularly in the early days of PBD, parents don't recognize this themselves, instead feeling shut out, unheard and cast aside. American parents simultaneously challenge clinical expertise, while at the same time internalizing clinical perspectives (often indirectly, as through online fora and books such as *The Bipolar Child*) in order to advance their own knowledge of PBD through advocacy and sharing with Other parents.

7.4.5 Representations of PBD among English parents

For the modest sample of parents interviewed in England, discussion of PBD was presented in much more of an uninterrupted narrative, suggesting a pent up desire to communicate concerns and be heard. This was consistent with the representations of PBD interpreted from analysis pointing to a sense of confusion around the diagnosis, and an almost complete lack of awareness that it could exist in young people. English parents were caught off guard by their child's diagnosis, with behaviours misattributed to what was thought to be 'normal adolescence'. Social triggers were suggested as a cause, in which high achievement indicated as leading to a level of stress causing breakdown. A diagnosis of PBD came only after suicide attempts, psychotic breaks and extreme Self-harm.

The most significant others to come out of conversation with English parents were clinicians, who were referenced with disappointment and frustration. Caught up in this talk were comparisons of American clinicians, with English parents imagining less reluctance getting a diagnosis for their child if they were going through the same process in the U.S. With the exception of one, English parents positioned themselves as amateurs, perhaps at the mercy of the previously mentioned medical hierarchy in which

parents accept what they are told, feeling little sense that they could change anything. Both an internal and external locus of control emerges in dialogue, in which internally parents feel responsible for having “missed” signs by thinking it was normal adolescent at play. This can be seen to tie in with wider cultural explanatory frameworks available to parents, in which the context of the U.S. has a more readily available medicalized explanation for behaviour, ‘normalizing’ disorder in a sense encouraging parents to pay close attentions. English parents raise their children in a setting with a different set of cultural, and thus explanatory, norms. Mental illness is not as in the foreground as it is with American parents, leaving English parents to feel ill-informed, cast aside by a system within which they have little control, and left feeling that there might have been more they could do to prevent the suffering that their child now endures. The fact that mental illness is not as much of the conversation in England as it is in the U.S. can be seen as a contributing factor to the difficulty in accessing parents to speak to. Not only is PBD a much rarer diagnosis, but the willingness to openly acknowledge and share the experience is one which is still gaining traction.

7.5 Social representations, dialogical processes and modalities of influence shape the emergence of PBD

This thesis has explored the making of a diagnosis, and its development in two cultural contexts, and what has been shown is that such diagnostic construction is a social and psychological process. I have shown this process to exist in the interrelation of three key actors involved in this condition, while child at the heart of it all is present in their voices. The main finding of this project points to how the construction of PBD in the US and England is driven by factors extrinsic to the actual condition, or something innate in the child, but is rather the result of social representation, dialogical processes and modalities of social influence taking place at the meeting point between these three groups, and their associated spheres of knowledge production.

An illustration of what Moscovici (1994) would refer to as the social sharing of meaning, the emergence of PBD has been the result of developing criteria based on well-established, popularly accepted disorders such as ADHD, schizophrenia and adult bipolar disorder, applying them to children who don’t necessarily have the exact

symptoms of those illnesses. Rage, aggression and irritability have become three defining hallmarks of bipolar disorder in children, despite not having any connection to these disorders from which PBD is drawn, illustrating the processes of anchoring at work. Actors are thus enabled to construct a condition that can be viewed as less contested, less unstable, and more useful. The concepts of anchoring and objectification (Moscovici 1961, 1984) are especially important in relation to the way PBD has been constructed as a diagnosis because of this power that they have as 'meaning-making structures' (Schmitz et al 2003). As a diagnosis, PBD is itself an objectification, the result of the anchoring process, based as it is on a series of borrowed representations, rather than possessing any clearly defined diagnostic criteria of its own. Clinicians are then in a position to realign what *is* being seen what they feel *should* be seen, creating the conditions for a new disorder to be reified as fact.

The content of these representations are shaped by cultural context, in which the salience of pharmaceutical influence, professional hierarchy within differing medical systems, and access to parental knowledge contribute to how knowledge about PBD is constructed. In the US, PBD is further along in the process of becoming objectified as a medical 'fact', as Pharma, clinicians and parents have moved closer to what Fleck (1979) refers to as a "structurally complete and closed system of opinions consisting of many details and relations" which, once established "offers enduring resistance to anything that contradicts it" (p.27). English clinicians continue to be both open to new research coming from the US, while at the same time priding themselves on a healthy scepticism that allows a sense maintaining clinical autonomy in the face of an at times overwhelming American influence. Whether there will be a complete recognition on the part of English practitioners of the knowledge of PBD coming from America remains to be seen, as in order for such knowledge to be observed, "new paradigms, patterns or frameworks of thinking have to be recognised and accepted, and theories have to change" (Alderson 2013, 5), a process which is still very much underway.

The psychosocial processes central to development of PBD will be elaborated below, beginning with representations of the new idea of PBD as resulting from anchoring and objectification, followed by the role of knowledge encounters, Self-

Other interactions, and culminating in an extension to Sammut and Bauer's (2011) cycle of normalisation, here presented with PBD as a new frame of reference driven by the steering psychiatric knowledge via persuasion, accommodating that knowledge in ways that are useful, and finally confirming new knowledge and representations via wider social validation.

7.5.1 Anchoring the unfamiliar; objectification via enactment

In coming to terms with the phenomenon of a new diagnostic category, the act of attaching a label and set of characteristics is essential in order to allow it to be discussed and communicated more broadly (Wagner et. al., 1999). Biomedical explanations provide a tempting certitude given the complex problems faced by many children with behavioural difficulties, and the fear among their parents of being somehow labelled as "bad" (Harris 2006; Singh 2011). With Americans, and increasingly English, publics becoming well versed in the language of childhood mental disorder as a result of the emergence of Other illnesses such as ADHD, situating conceptions of a child's threatening behaviour within a label of PBD is in fact attaching unfamiliar conduct to something that has been rendered familiar; a diagnostic label and a promise of treatment.

The anchoring of PBD in more established diagnoses is what leads to realignment of what should be seen based on what is being seen, thus one is more likely to see and label a child's conduct pathological if primed by information circulating in public sphere. The anchoring of the new is done with much more reluctance in England, a culture in which medical practice gives more weight to theory and traditions than their American counterparts, perhaps suggesting one explanation for resistance of the diagnosis. Findings suggest that the process of anchoring the unfamiliar in the familiar is significant both in the development of knowledge around a diagnosis, as well as how that knowledge is applied. It illustrates the transformation of expert knowledge as being circular in nature, and where there is room for different forms of expertise, both professional and experiential. At the dialogical level, the empirical data presented here has shown the transmission of knowledge in action, illustrating mechanisms to explore how, when, and by whom knowledge is appropriated, accommodated, or

resisted via multiple modalities of social influence. In *chapter two*, Duveen and Lloyd (1990) were singled out for proposing that a representation to be anchored before the process of objectification takes place. I would argue that PBD as a case study in the construction of a diagnosis is an illustration of both processes happening simultaneously. In the US, objectification through enactment and application of the diagnosis is happening before the diagnostic category has been firmly established, or even fully understood. In England, there is a sense of waiting for some certainty from the US before accepting the possibility of PBD, thus objectification has yet to take place on a wider scale.

7.5.2 Encountering multiple system of knowledge

The model of knowledge encounters (Jovchelovitch 2007) has been employed in this thesis as a means to explore the production of knowledge around a contested diagnosis, and the development of new norms, that comes as the result of interaction among and between competing knowledge systems. The findings show how expert, experiential and market-driven knowledge builds discourse and classification systems on the basis of intensely social processes. Thus attempts to stabilise a diagnostic category and establish validated criteria are related to a number of psychosocial processes in relation to significant others.

Encounters between diverse representations, such as experts and laypeople, or the questioning of one's own subjective interpretations of behaviour when confronted with another type of expert knowledge (America v. England; pharma v. clinician; clinician v. parent; parent v. parent; clinician v. colleague) are significant in their contribution to the establishment of PBD as an object to be considered and acted upon. The direct and indirect interactions between the pharmaceutical industry and American clinicians for example, initiated a pushing of boundaries, stretching the definition of a category to accommodate the confluence of 'new' symptoms, both old and new. Or to use another example, a major finding of this thesis, the role of parents especially, and their centrality to the expansion of the diagnosis in America, provides an illustration for knowledge encounters in action.

Healy (2007, 218) notes that clinicians are making diagnoses “not based on publicly visible signs in the patients in front of them, or publicly demonstrable public tests, but rather on the basis of what third parties, such as parents or teachers say” (p. 218). On what are these third parties basing their knowledge, and how are different meanings asserted and contested? According to Brown (1995) “patients and other lay people can be active collaborators in their own medicalisation, although sympathetic professionals are usually needed for successful claims-making” (cited in Conrad and Potter 2000, p.560). A lack of standardised diagnostic criteria could lead to third parties being more influential in shaping clinical decisions of what is best for the child, leading to a conflict between, as Markova (2008) writes, “‘epistemological priorities’ in which on the one hand there exists a knowledge based on common sense versus that which is professional knowledge acquired through training” (p.461). Thus the ways clinicians produce and objectify PBD is determined by their own positioning in the cultural context, and how well they are able to fuse common sense and expert knowledge.

Parents have taken part in influencing clinicians’ social representations of PBD by shaping how clinicians view their children, and their own experiences as victims held hostage to the diagnosis, blamed and not taken seriously by peers and other psychiatrists. Clinicians are complicit in this however, sourcing parental experience as a means to ground their own theories in something real, refining what PBD means to them in the process. The extent to which parents are aware of their level of influence in the development of the diagnosis that has now become their child’s reality is not known, however parental accounts of interactions with clinicians, both in the US and England suggest that they feel their experience is ignored. Whatever validation they have unknowingly provided clinicians has left parents feeling lost and frustrated, with American parents taking it upon themselves to turn to action and advocacy, while those in England struggle to make sense of the system they have now been entered into, one in which, as parents, they often feel as though they are somehow in the way. In the same way clinicians have used parental experience, parents have taken from clinicians the language and interpretive frameworks and made it their own, so the influence may be unidirectional with regards to what one group is getting specifically from the Other,

however both are taking on board new knowledge, and making it their own, as a result of their interactions.

7.5.3 Self-Other-object interaction

Interaction is at the core of a second framework drawn on in this research, that of dialogicality. This idea of encountering, and then appropriating, the knowledge of others illustrates processes of poly-vocality and intertextuality (Bakhtin 1984; Linell 2006) at work. New meaning is created from those that are more established, and are adapted and reshaped to make sense among a new set of actors in a different contexts. Elements of dialogue are taken from other sources and internalised, accommodated into one's own thinking via the recognition, or lack thereof, of the perspective of the Other. With the emergence of PBD, we can see a shift in the discourses Foucault termed 'discursive orders', those patterned ways of thinking that shift between domination and subordination within a cultural context or community over time (Linell 2006). As discussed in *chapter three*, asymmetrical knowledge among actors, and the hidden or more open polemics taking place in their actual or implied interaction between Self-Other-Object, alter what becomes the dominant way of thinking. In discussing the dialogical nature of interaction, and the resulting asymmetries in power, authority and knowledge, Marková (2014) introduces the importance of epistemic trust, noting that it is where knowledge ends that trust or distrust necessarily comes into play. Social representations can be either knowledge-based or belief based and dependent on cultural definitions of what constitutes 'truth' (Marková 2014). Those representations that are belief (and trust) based develop out of the strength of the relationship between Self - Other. I argue here that the dialogical basis for the development of social representations of PBD are belief based, as at this point, there is no set 'truth' present in any aspect of PBD, with the exception perhaps of the representations of condition and child perpetuated by the pharmaceutical industry, who have constructed their own truth. For the other key actors though, there remains a lack of certainty. Thus, trust between Self-Other presents more certainty in the face of an unstable object, while a lack of trust leads to resistance, and alignment on the belief and opinions of others in order to determine a point of reference that makes sense.

This has been illustrated in findings from English clinicians who position themselves as a collective in response to American representations of PBD. As discussed in section 5.5.3, there is an underlying distrust of America and what it represents in terms of vested interest. Among English parents, however, PBD as conceptualized in the US represented more of an ‘imagined’ Other, imparting a trust in the American system to provide a quick and accurate diagnosis for their child, increasing a sense of certainty in what parents were dealing with, and an opportunity to take action (*cf.* 6.5.6). The level to which trust in the knowledge of the Other is incorporated into one’s own understanding about PBD is based on modalities of social influence in which systems of knowledge compete for dominance in the establishment of PBD as a social object, and thus a new normative frame of reference.

7.5.4 Modalities of social influence

Social influence was approached here as an extension of the dialogical framework, pointing to the role of influence as being borne out of the negotiation and positioning that takes place in relation to Self-Other-object. Sammut and Bauer’s (2011) cycle of normativity (*cf.* 2.5.1) was drawn upon as a means to explore how new social norms are established, and new reference points made salient. This thesis has found that normative frames of reference for PBD remain in flux and contested. Despite two decades of clashing over the existence of PBD, it remains in a sort of limbo, at which point it may become more established as a diagnosis on its own, or be subsumed into other diagnostic categories. The recently established diagnosis of disruptive mood dysregulation disorder (DMDD), is one such example, developed to find a ‘diagnostic home’ for children who are deemed in need of help, but don’t fit common understandings of bipolar disorder. The debates continue, however, and driving the degree to which PBD remains a valid diagnostic entity are modalities of persuasion (in the assimilation or challenging of institutional, clinical or parental knowledge), accommodation of the perspective of the Other (dictated by conformity pressures and minority influence), and finally the social validation sought to achieve recognition and verification of one’s own level of knowledge about PBD in reference to others.

Figure 7.1 below illustrates my variation of the cycle of normativity as it relates to the modalities found to be most salient in this study. As discussed in *chapter two*, such processes can lead to a collective decision among individuals to establish a frame of reference that makes sense, so as to have a sense of stability in the face of inherently unstable social norms (Sherif 1936). Such a collective decision has not yet taken place more broadly, with a lack of consensus among clinicians still dominating in the US, and an adherence to the narrower, more classical presentation of bipolar disorder maintained in England.

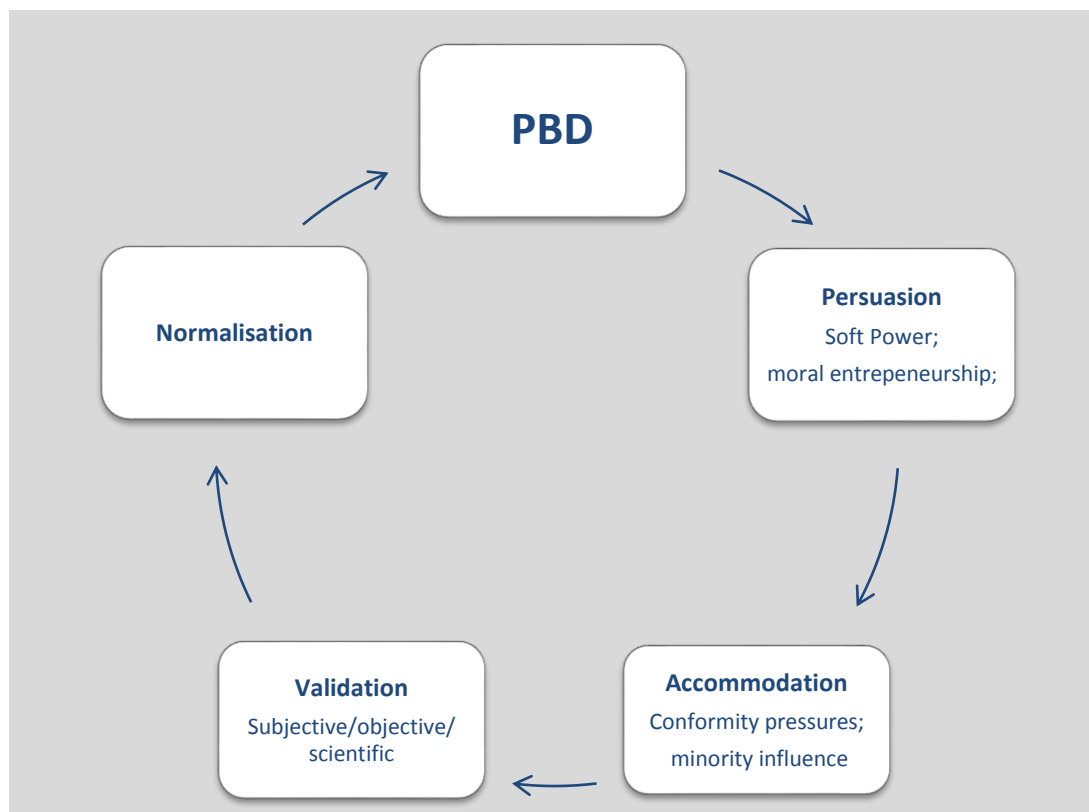


Figure 7.2 modalities of influence central to the development of PBD as a normative frame of reference

What has taken shape via these forms of social influence discussed below is the development, however un-fixed, of a wider representation of PBD on which to position

oneself and accept as a possible diagnostic fact, or discard as clinically unsound. What is established regardless of position, is an entity, however transient, that allows for action.

Norms and frames of reference

The establishment of social norms is especially important with regards to children's mental illness, where the alignment of 'badness' with pathology has been in place for decades. Suggestions of norms for how children should conduct themselves have led to points of reference against which the medicalisation of children takes shape, requiring medication for anything that falls outside of normative boundaries. In discussing the power of uncertainty to open up spaces for influence, Moscovici (1976) notes that the more ambiguous a "non-social stimulus situation", the more dependent one is on the social reality created through "consultation and agreement among group members on the basis of different observations they could make to support their opinions" and thus orient themselves (p. 31). Social consensus is central to the development of PBD as a diagnostic category, or as is the case in England, rejecting an encroaching idea which advances the existence of PBD as a distinct diagnosis to that of adult bipolar. Consensus building, either in support of or in response to a new phenomenon, comes as a result of 'processes of normalisation'. As discussed in *chapter four*, the pharmaceutical industry has sought to establish behaviours of rage, irritability and restlessness as a reference point for PBD, normalizing the idea of the diagnosis, and its recommended treatment, through identification of the disorder in children as more common than previously thought, and treatable. Playing upon wider social norms of childhood that favour achievement, sociability and staying out of trouble, the industry is then able to diffuse this knowledge into the wider sphere of prescribing clinicians. In establishing the idea of PBD as a new point of reference, new norms regarding what is morally desirable are established through respectable channels: that of the expert professional.

In *Chapter five*, findings showed how American clinicians interviewed changed their own understanding and knowledge about bipolar disorder to fit with these evolving norms set out by pharma. What resulted involved American clinicians seeing what was in front of them in a different way; the child presenting in their office was

now viewed through a framework in which what was being seen was altered to fit with what *should* be seen. For English clinicians the frame of reference remains bipolar disorder as found in adults. The wider collective field of practice in the UK unites in not adopting PBD as a legitimate category. While positive in that this encourages a more deliberative approach to treating young people with mental health issues, one critique might be that while no one would advocate moving towards over-diagnosis and treatment, there is a fear that in maintaining norms of rarity of mental illness in children, legitimate concerns and alternative options may not be considered in favor of maintaining consensus with colleagues.

For American parents discussed in *chapter six*, normative frames of reference are murky, and do not necessarily stem from their interactions with professionals. Instead, a finding of this thesis points to the fact that these parents don't seek out the influence of clinicians to the same degree that clinicians sought out parental influence to validate the diagnosis in its early days. While American parents echoed clinical perspectives and terminology in their own discourse, indicating the presence of clinical influence, the accommodation of this thinking was outwardly resisted, despite being internalised. Instead, parents placed trust in their own knowledge developed through research, and significantly, the book *The Bipolar Child* which provided parents with a set of norms on which to base their own interpretation of their child's behaviour. While the knowledge disseminated by the book was often similar to that held by many clinicians, the position of the book as a reference point suggests the degree to which parents in the US often lacked trust in clinical knowledge they came into contact with directly. Thus the book, combined with peer influence, allowed for an alternative source of initial knowledge about PBD.

English parents, in comparison, lack any solid frames of references or sense of what is normal. This "lack" is illustrated in the way English parents often referred to themselves as amateurs, of unsure what bipolar meant for their child, and acknowledging ignorance that a) the diagnosis could exist in young people, or b) that the behaviors they were seeing in their child was anything Other than normal adolescent behavior. This despite the fact that for the English parents interviewed,

those behaviors were much more severe than their American counterparts, often involving paranoia, psychosis, and attempted suicide. For English parents, there was no mention, or knowledge of, *The Bipolar Child*. There was no network of peers openly comparing notes about their own children's difficulties. Instead, English parents exist in a continuous state of trying to get answers from a system where they feel consistently set aside and left in the dark. The following sections will explore the modalities of social influence that shape the development and salience of the normative frames of reference for PBD in the US and England, and will show persuasion, accommodation, and validation all, to varying degrees in the groups studied here, lead to the acceptance or challenging of PBD as a diagnostic fact.

Steering psychiatric knowledge via persuasion

In the cycle of normalization leading to the development of PBD as a diagnosis, persuasion plays a central role in how knowledge takes shape. It is central to the idea of social influence as a communicative process as well, in that it relies upon engagement with the perspective of the Other in relation to reshaping understandings of the social object. Findings from *chapter four* illustrate the degree to which the pharmaceutical industry relies upon persuasion as a modality of influence in order to change previously held representations of bipolar disorder to emphasize the new criteria the industry is pushing for to sell medication. Nowhere are these persuasive tactics more present than in the interactions with American clinicians. Mechanisms of soft power and financial incentive are used to develop an alliance with clinicians targeted by the industry, identifying those willing to come on board to be fostered as opinion leaders, who will seek to persuade colleagues. Such alliance with clinicians has the benefit of validating the position of the pharmaceutical industry while at the same time removing a level of responsibility that then becomes shared with the clinician.

As found in *chapter five*, American clinicians on the receiving end of persuasion in form of 'soft power' from the pharmaceutical industry did in fact reshape their representations of a 'disordered child' in line with what was being suggested via

targeted education campaigns. Early financial incentives and offers to be an opinion leader among colleagues also played into a desire to be held in high esteem by patients and colleagues. Thus, persuasion as a modality of influence extends into seeking to persuade colleagues by using parental experience and accounts to back them up, and parents through the emphasis on future risk.

Persuasion here ties in with the idea of ‘moral entrepreneurship’ (Becker 1963) mentioned previously, and it is here that it figures in to a wider argument about the role of persuasion in the shaping of clinical thinking about PBD. Becker’s (1963) idea positions individuals or groups into two camps; those who have a moral imperative to create a new set of rules (or norms) (‘creators’) and those who have little stake in the ‘content’ of the rules (‘enforcers’) and as a result develop their own personal assessment of what ideas are worthy of being perpetuated and acted upon accordingly. Both the creators and enforcers of norms influence one another, with the creation of new notions of what makes up PBD stemming directly from how new sets of norms are enforced, with rejection also serving as a form of enforcement. If this idea is taken into the realm of diagnostic practice, in which the pharmaceutical industry represents the institutionalisation of rule creation, the rules here become the rules of a diagnostic category. They become synonymous with symptoms to be actively sought out and re-categorised. Clinicians incorporate their own understanding of these norms from what has been handed down from the pharmaceutical industry, modified through interaction with parents and clinical colleagues, and acted upon accordingly.

The extent to which the rules/norms differ in the US versus England is thus shaped by the level of openness to persuasion, which ultimately stems from the degree to which there exists cultural comfort with uncertainty and caution in approaching diagnosis. For English clinicians, there is a refusal to assimilate the ‘broad spectrum’ idea of PBD, resisting persuasion by remaining actively sceptical that such a diagnosis can be present in very young children, and instead maintaining the more established and traditional conceptualisation of bipolar disorder as manic-depressive psychosis.

Integrating the knowledge of ‘Other’ through accommodation

The degree to which unfamiliar meanings are accommodated and incorporated into the establishment of new norms is reliant upon influences becoming internalized. In *chapter four* it was shown how the pharmaceutical industry used information from competitors, accommodating that knowledge to their own ends instead of seeing the competition as a threat. This allowed for the crystallisation of a new way to understand how behaviours could be recast as a new diagnostic entity and was thus used as a basis to diffuse this understanding to prescribing clinicians. In *chapter five*, these processes of accommodating pharmaceutical knowledge, and the persuasive influence discussed above, was illustrated in clinician interviews regarding the new symptoms of bipolar in children, echoing what was put forth in education campaigns from pharmaceutical representatives. For American clinicians, new ideas of how the diagnosis might present also came as a result of taking on board parental knowledge. Parents here represent the minority coming into contact with a seemingly more powerful ‘expert’ Other, but in the development of clinical representations of PBD in concert with parental influence, making concessions to what parent’s saw as a need which has shaped the development of a new clinical frame of reference (*cf* 5.4.3).

In contrast, the accommodation of knowledge for English clinicians came not from parents, but from clinical colleagues, suggesting the value placed on different systems of knowledge plays into a wider cultural hierarchy emphasizing the importance of an alliance among clinical colleagues, and perhaps not trusting parental experience and understanding of their child as enough to steer clinical thinking. Among American parents, understandings of PBD came not only directly from interactions with professionals (*cf* 6.5.3), but also through channels such as *The Bipolar Child*, as well as knowledge and recommendations from peers and schools. This ties in with discussion in section 7.5.3 in relation to parental development of representations as a function of trust and the strength of relation between Self and Other. For American parents interviewed, there was an active lack of trust in clinical guidance, thus clinical knowledge, while not discarded, is instead accommodated via more trusted sources. English parents’ representations of PBD remain largely unformed due to the efforts of

the wider clinical sphere to keep the notion of such a diagnosis in young people rare. As a result, English parents hold a murkier understanding than their American counterparts, as well as a less established network to draw on. That's not to say there is no influence on their thinking from external sources, however it remains less specific, where English parental knowledge is accommodated from a more generalised 'Other' in the form of American perspectives on PBD gleaned anecdotally, or in the case of one parent interviewed (UKP 1), actively seeking out information online and via direct contact with American clinicians in order to validate what this parent believed they were seeing in their daughter (*cf.* 6.5.6).

What determines whether accommodation of the knowledge of another takes place? Findings from this thesis, and particularly those from English clinicians and American parents, suggest that unspoken pressures to conform play a key role in the degree to which other perspectives are taken on board. For English clinicians, conforming to the wider field of practice is understood as a means to maintain consensus. Thus, unspoken pressure from colleagues, as discussed in section 5.3.3 for example, determines which normative frame of reference will be drawn on- that of the American 'broad spectrum' approach, or the more established manic-depressive psychosis representation held in England, which also play into wider ideas about mental illness in children. For American parents, such conformity pressures come from interactions with parental peers, schools, wider societal norms closely tied to their parenting practices. Lacking in discussion with English parents was any mention of school or peer influence that was so present in conversation with American parents. Conformity pressures were not as salient among American clinicians, however this may be due to the fact that it remains hidden. One clinician interviewed clearly struggled in having to cater to the realities of answering to wider institutional systems (*cf.* 5.5.1), conforming to their wishes, however this was rarely made explicit.

A second determinant shaping whether knowledge of another is internalised, and one which stands in contrast to conformity pressures, is the degree to which the majority accommodates minority understandings of PBD. A key issue in social influence is the psychology of minorities, as minorities have the capacity to bring about

innovation through the power of ideas (Moscovici 2001) in which the power of minority influence lies in its inherent challenge to consensus as a means to innovation (Moscovici 1976). Central to this is how useful such knowledge is deemed to be. Minority influence serves as a challenge to consensus, leading to innovation. As discussed in *chapter five*, the perceived alliance with parents on the part of American clinicians allows for the wider diffusion of PBD as a new diagnostic entity, using their status as minority as a tool to validate the need for increased attention to this particular problem as highlighted by parents. As such, those clinicians who were early proponents of PBD, and perhaps in the minority themselves, are able to position themselves as innovators at the forefront of a new field of research into children's mental illness.

For American parents, it is their position as minorities driving the desire for recognition of experience living with their child. A culture of advocacy in which parents find comfort, power, and perhaps a decrease in stigma in the support of others lead to their increased presence in clinical understanding of PBD. The more American parents engage in research, and interact with others, the more they become experts of their own, challenging the judgment and opinion of professionals in the field. Strength and control via knowledge and mastery over diagnosis stems from a sense of duty to be a good parent, awhile acknowledging the right of their child to a normal childhood, whatever that may mean for them. Once parents take ownership of professional knowledge, the murkiness expressed by clinicians is replaced by a certainty expressed by the parents suggesting again that how much a diagnosis proves to be useful shapes its staying power. Parents positioning themselves as the real expert leads to a forging of their own way when dismissed by clinicians who they feel do not truly value their knowledge. Thus, finding solidarity and purpose in advocacy groups, American parents are able to take steps to end their 'silent suffering' through the education of peers and teachers, moving the diagnosis further towards fact.

It is this persistence that allows a minority to be successful, allowing its own perspective to become more familiar to the majority. The last group in this study where this can be seen is among English clinicians. While not a minority within the context of the UK, in the development of PBD as a diagnostic category, it is the American

ideology that has remained dominant. Thus, in challenging consensus through resisting the imposition of American understandings of PBD (as discussed in section 5.3.4), which English clinicians interviewed link to the vested interest of pharma, English clinicians may not necessarily succeed in getting Americans to take on board their minority perspective, nonetheless have upheld a culturally situated discourse that maintains distance, and remains firm against assimilation to a more dominant representation of PBD.

Confirmation through validation

As discussed in *chapter two*, the social dependence on Others for validation, and a resulting informational dependence leading to influence (Turner 1991, 19) is especially salient as a final process in the development of PBD as a normative object. Among parents in both the US and England, the world of professional expertise remains inaccessible in many capacities, with a lack of resources in both contexts leading to shortages of child psychiatrists, putting them at the mercy of whatever information is available. For American parents, this results in taking it upon themselves to develop the expertise they deem necessary to make informed decisions about their child, often relying on peers in support networks to validate what they are seeing. This validation is then used to impart knowledge on less informed parents going through a similar experience with the child, serving as a means to uphold their own sense of mastery and control in the face of uncertainty. In contrast, for English parents interviewed, professional validation took precedence over that of peers, suggesting again a lack of knowing who else to turn to or where to begin in order to interpret or confirm what they were seeing in their child as anything other than normal adolescent behaviour.

Both American and English clinicians represent the meeting between lay and institutional spheres of knowledge in which their own subjective values and personal judgment can't be objectively validated, something which may be problematic in a field that is based on empirical evidence, but which relies on subjective appraisal of a situation. For clinicians in England, as has been discussed in relation to accommodation

and conformity pressures, this validation of the view of ‘bipolar as bipolar’ disconnected from any separate diagnosis specific to children, came through confirmation from clinical colleagues, supporting discussion above related to the nature of diagnostic practice in England specifically, and within a socialized medical framework more generally. Among American clinicians it was subjective validation, which confirmed their own perspective was correct, utilising parents’ experiential knowledge in as much as it held significance and utility in backing up an existing clinical agenda. American clinicians discussing PBD as an uncertain, ambiguous entity allows them to create a space in which they might carve out their own niche, demonstrating mastery in the face of something so poorly understood, strengthening their individual position in the process.

Finally, the pharmaceutical industry, despite its dominance in shaping representations of a broader spectrum bipolar disorder in children, was not immune to validation. As was illustrated in analysis of industry documents, there was a definite concern around these new behaviours being legitimated, most notably in the eyes of the FDA. Thus, validation came via seeking alliance with clinicians, as well as scientific validation established through anchoring PBD as a neurochemical problem.

Vectors of social influence

The mechanisms of social influence discussed here all exist in different degrees among groups and between cultural contexts. Equally as important to the actual mechanisms of influence involved in the cycle of normalisation shaping construction of PBD is the directionality of these forms of influence. For example, these so-called “vectors of influence” (Sammut and Bauer 2011) are manifold and multidirectional in the US, where channels of influence are quite open between pharma, clinicians and parents. In England, however, they are much more restricted. English clinicians, for example, rely on conformity and consensus within the group, and their position within the wiser hierarchy of practice, as a means to resist multiple sources of influence. Pressures for innovation and staying ahead which are so prevalent in the US, and a regulatory

framework encouraging this, allows for an increased openness to influence from one another, and other sources as well.

In contemplating why this might be the case, we need to consider who is taking part in the knowledge encounters that render such influence possible. As an example, in the US the parents are self-declared experts, whereas in England they define themselves as amateurs. As an amateur, the degree of influence you are likely to have on a clinician, whether subtle or overt, is likely to be nil. American parents take the pieces of knowledge that make sense to them from clinicians, other parents, and their own developing expertise to generate their own assumptions of what makes PBD. Such belief -based representations are open to change, as the drive towards the truth in something unseen is in a state of constant flux. Steering this evolution of representation through dialogue and knowledge encounter is the directionality of professional versus lay influence. American clinicians cite parents as influential in the development of their own early knowledge about PBD, however this is not reciprocated by American parents, for whom clinicians are a source of frustration and a lack of trust. The consumer-driven nature of the US healthcare system impacts on the doctor patient relationship in that the increase in the power of the consumer has caused patients to question professional authority, while at the same time allowing clinicians to shed some responsibility onto the parent (Lupton 2003).

In elaborating on the idea of experiential knowledge, Jodelet (2013) asks how, within a specific context, are “representations created that incorporate the subjects’ history, social belonging and practices while being, at the same time, influenced by larger social systems?” (Jodelet 2013, 9.4). It is in the health sector that the development of the idea of experiential knowledge has developed the most, where patient experience, or in this case parental experience as proxy for that of their child, is given a privileged place for how illness and treatment is dealt with (Jodelet 2013, 9.15). There is no consensus among clinicians in either the US or England, with children being given the diagnosis of PBD presenting very differently from one another. English clinicians use their lack of trust, or wariness of the American influence to govern their own practices and development of thinking around the diagnosis, while English parents

feel they have no choice but to put their faith in the clinicians treating their child, as there are few other options, and the system is one they find hostile and closed to their input.

American clinicians see themselves as innovators, and attempts have been made to influence colleagues in England, but this has largely been resisted due to English clinicians as interdependent consensus builders aligned with the wider profession, and engaged in collective resistance to American influence. The degree to which this holds in the future is up for debate however, as those few clinicians interviewed who do subscribe to aspects of US thinking on PBD are in a position of power and influence in their own right. With regards to the pharmaceutical industry, the degree of influence in England is thwarted due to regulatory frameworks in place, whereas the connection is much more direct in the US. This research has shown that the pharmaceutical industry is a major vector of social influence through the adoption of a number of behaviours that influence clinicians and parents. Uncertainty combined with pressure and the promise of prestige is used to reshape how clinicians think about this disorder, but more importantly, how knowledge of what makes up this diagnosis is realigned to make sense in children. A psychotic disorder becomes behavioural through persuasion, soft power of economic incentives, and the perpetuation of risk, exemplifying the power of the industry shape psychiatric knowledge, steering broader social and cultural attitudes toward medication (Kirmayer and Raikhel 2009). Overall, the vectors of influence between Pharma, clinicians and parents is uninterrupted in the US while in England they are more disjointed.

One of the key issues discussed by Moscovici (1976) was the idea that contrary to more traditional views of social influence as a top-down approach, it actually exists as a much more multi-directional phenomena. This idea is supported by the findings of this thesis, which illustrate the circular nature of influence, supporting Moscovici's assertion that information begins within fields of established expertise before diffusing into more wide spread common sense assumptions about bipolar disorder specifically and mental illness in children more generally. This view of influence ties in with how this thesis presents an added dynamic to early conceptualisation of medicalisation that

focused almost exclusively on a clinician's interaction with a patient. Exploring the multiple vectors of influence points to the idea that medicalisation does not just happen uni-directionally, nor does it necessarily involve direct interaction with the patient. Rather such reshaping of problems can happen with patients-by- proxy, as with parents of young children, or even within an individual clinician, the subjective self in negotiation with a professional self for example, or the institutional influences shaping less direct, but no less salient interactions.

Social influence has been incorporated here as a communicative practice. At the heart of this discussion is the construction and negotiation of a new medical fact via the development of a new normative frame of reference, culminating in a new diagnostic category. In referring back to the overarching theoretical framework of social representations informing this thesis, what has been reiterated is the importance of the social group to which one belongs as central to shaping which aspects of socially embedded knowledge are drawn upon, providing a map on which to base various interpretations and comparisons of what constitutes normal versus pathological behaviour (Moscovici 1961). Different forms of knowledge can co-exist, undergoing what Jovchelovitch (2007) refers to as “productive transformations” in which knowledge is “cross fertilized” based on dialogical encounters (Jovchelovitch 2007, 6). It is this culmination of encounters which I have attempted to illustrate below in figure 7.3, bringing together the multiple frameworks discussed in this chapter into a model illustrating PBD as a diagnosis constructed via psychosocial processes.

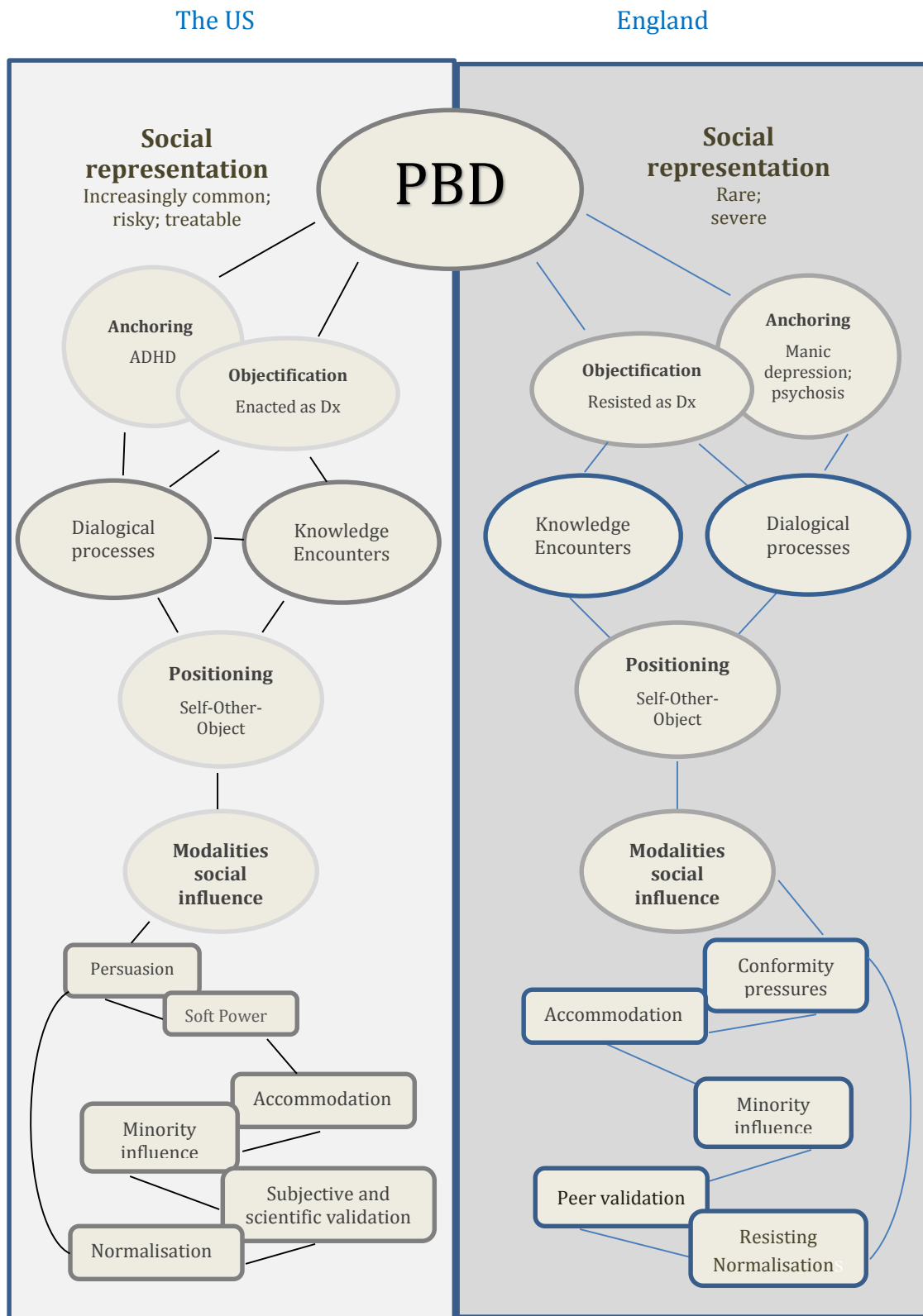


Figure 7.3 psychosocial model of diagnostic construction in the US and England

7.6 Implications, limitations and future directions

Exploring the genesis of a new diagnostic category in children from a socio-psychological approach is meaningful and significant because, as Davies suggests, “how we are marked shapes how we feel” (2011, p.190). When children are being ‘marked’ at younger and younger ages, they end up somehow removed from determining how they feel. Instead, their identity is developed in concert with one that has been imposed on them. Social psychology sheds light on those practices allowing for the appropriation of knowledge or specific terminology that has found a home in everyday discourse and common sense thinking, and understand the impact this might have on the child. There is the idea of a ‘looping effect’ that takes shape (Hacking 1995; Brinkman 2014) in which behaviours are interpreted, reassigned and acted upon in a way suggesting that individuals become their illness, and thus perform as expected. The diagnosis and treatment of young children with a mental illness that has no stable base is of great concern, and a phenomenon that seems too multifaceted and grounded in social processes to be solely left to statistics. This thesis has shown that transformations in the representations of PBD are also in fact transformations in representations of childhood. In one we see the other. To be considered here are the implications for assigning younger and younger children a diagnostic label which carries with it so many associations.

Through the integration of socio-psychological frameworks including social representations, knowledge encounters, dialogicality, and modalities of social influence, the findings presented offer one explanation of diagnostic construction, and expands the socio-cultural psychology of medicalisation. The focus of this study on the interaction, transmission and application of organisational, clinical, and parental knowledge as related to PBD contributes to the wider scholarship on medicalisation and the debates around children’s mental health in that such an exploration goes deeper into the processes and social forces determining which aspects of childhood behaviour might be deemed pathological, and why.

An important point for discussion to come from the findings presented lies in potential implications stemming from the meeting of lay and professional systems of knowledge. Is it always advisable to enable forms of nonmedical knowledge to push the development of medical behaviour and understanding? The importance of local and experiential knowledge has been advocated for decades, where the achievements linked to empowering patients via the incorporation of lay experience and understanding into policy and practice has resulted in positive steps forward, especially with regards to awareness and destigmatisation campaigns around mental illness, such as the international Hearing Voices Network, and the inclusion of user experience into mental health intervention models. It is not my intention here to negate the experience of those living with or alongside mental illness, or to suggest it is somehow wrong to include such knowledge into policy and practice. What is being suggested instead is space to consider, and be attentive to, any unintended consequences of these multiple pressures and anxieties coming together in a focus on the child.

Oftentimes medicalisation appears as the ultimate remedy for issues that should be solved elsewhere, but the confluence of these knowledge encounters is enabling multiple medical understandings from both industry and lay spheres, driven by dimensions and interests extrinsic to the actual understandings that constitute a mental condition. The findings from this thesis indicate diverse anchors for the understanding of PBD. The objectification of the diagnosis has taken place quickly in the US, despite it only existing as a theoretical assumption. In England, it remains resisted, however this could change as those clinicians in a position of power find separating paediatric bipolar out as a distinct diagnostic entity to adult bipolar disorder makes sense. Such a shift has taken place with ADHD, which, while much more common now, was rare in England twenty years ago and was also conceptualised as an American problem.

Van Bavel and Gaskell (2004) suggest that when it comes to the supposed “knowledge deficit” held by the wider public about specialist domains of knowledge, what is not understood tends to be resisted. While this might be true in some domains, when it comes to navigating unsettled behaviour in children, this thesis has shown this to be culturally variant. While a degree of resistance has taken hold in England, in the

US, that which is not understood has led to a drive to develop understanding in concert with multiple sources of information. The drive to understand has led to an expansion of behaviours that could be included in diagnostic criteria, as well as parental advocacy, which has been a source of clinical knowledge as well.

The implications for the merging of multiple knowledges lead to broader questions relating to appropriateness of care and systems of clinical practice in which shortages of resources are a source of the issues being discussed here. The current systems in both the US and England allow for diagnosis and treatment of children by medical professionals not formally qualified in psychiatry, treating outside their realm of expertise. As such, the reliance on knowledge, and openness to influence from various others, could be proposed by many as necessary in the face of diagnostic uncertainty. At risk is closing the space within clinical practice to consider of a child's developing identity. Contentious diagnoses in children's mental health are unlikely to disappear anytime soon, however a considered approach incorporating the child's position, focusing on a child's strengths rather than letting the diagnosis define them, would be a step away from seeing child as more broadly 'disordered'. Social knowledge is very much tied to the social and cultural background against which it is produced (Jovchelovitch 2001) and while it is true that we are continuously constructing social knowledge, we do so "in relation to a reality which permanently escapes from our making" (ibid, p. 180). That is, what we know about a diagnosis such as PBD is evolving, existing as it does alongside a set of circumstances unique to a particular place and time. Thus, what is understood and presented here will no doubt change. However it is the attempt to capture a snapshot of how unstable diagnoses flourish or disappear that can be useful in understanding the historical cycle related to the development of diagnostic categories.

7.7 Study limitations and areas of further investigation

This project contributes a small piece of a very large pie. While it would have been ideal to be able to study the construction of PBD on a much larger scale, the limitations imposed by access restrictions, the time and funding scale of a PhD, and the emergence

of possible new angles of study late in the research process all mean that there are many areas which I feel would benefit from research attention in the future. Perhaps the most significant omission from this thesis is that of the direct voice of the child at the heart of the debate. Alderson (2013) emphasizes the necessity for the inclusion of the child's voice in research, criticizing earlier traditions across the social sciences that have omitted the child from national statistics and economic policies. Highlighting the recognition children should receive as "social agents shaping their own lives and influencing the world around them" Alderson (2013) suggests that children should not be dismissed as "pre-social and pre-moral entities, or as the mainly passive object of adult socialization" but rather as respected potential research participants in their own right (p. 34). This was also addressed in Singh's (2012) work on the ADHD Voices study (Voices of Identity, Childhood, Ethics and Stimulants) illustrating the importance of having the perspective of young people when discussing issues around their diagnosis and treatment that are directly pertinent to them. Alderson and Singh's inclusion of the child is something I would like to have seen for this project, and indeed to me this thesis represents the beginning of what I hope will be a much more extensive research, one which will seek to include children living with a diagnosis of PBD as participants. While inclusion of the child here would be ideal, the child as captured in the voices of those interviewed provided a sense of their position in relation to the diagnosis constructed around them. A next step would be to speak to young people, accessing their understandings and attitudes towards their diagnosis, and how it differs between those diagnosed young, with the broad-spectrum diagnosis, and those diagnosed as older adolescence.

A second limitation to my research involves the small sample size of parents from England. As discussed previously, the process of accessing these parents was a challenge that ultimately resulted in only five interviews. While a frustrating aspect of the research process, I think this difficulty, as compared with the relative ease of accessing parent-participants in the US, points to wider mechanisms at play in this diagnosis. This 'lack' can be viewed as a form of data in its own right, with the absence serving as a tool with which to refocus attention to what is significant. In the future, a

more engaged study incorporating attitudes and experiences of parents in England would provide a more in depth account of the similarities and differences between the two contexts, as well as providing an interesting longitudinal case-study in the event that PBD begins to expand as a diagnosis in the UK over the coming years.

A final aspect of the present study that could be developed for future research is that of seeking out a larger and more varied sample of mental health practitioners, particularly non-prescribers, in the US and England. Clinical social workers, psychologists, more CAMHS nurses and members of mental health teams who are perhaps more often placed on the periphery would provide an interesting and nuanced perspective on understanding the development of PBD at many more levels than have been accessed here, allowing for a more representative view of how ‘professionals’ conceptualize this particular diagnosis.

Methodologically, the scope of this project was concerned with the development of knowledge around a particular diagnosis, and for this the use of semi-structured interviews was useful. Given that this project is so closely bound up with the idea of interaction and dialogical processes, however, future research might incorporate evidence of ‘interaction in action’ via focus groups, an approach that was not a feasible option for this project given the constraints of very tight clinician schedules, and the scattered locations of parent- participants. The use of surveys to glean much more wide-scale assumptions and attitudes towards PBD as compared to other diagnoses would provide interesting insight as well, allowing perhaps for a much more wide-scale comparative study across multiple contexts.

As mentioned in *chapter one*, clinical literature suggests that diagnostic practice, as opposed to epidemiological prevalence rates that is central to the increase in PBD in the US as compared to England. The reports and studies suggesting this were not in a position to delve into greater detail to processes shaping diagnostic practice, however, as the emphasis was (necessarily) on the hard data. It is in this respect, getting ‘behind’ the data that a social psychological approach can contribute to the clinical literature, as well as wider research on medicalisation of children. The hard data is of obvious

importance, but qualitative studies lend valuable and necessary insight into the why and the how questions at the heart of social phenomena, as has hopefully been shown here.

Reshaping how something is seen is ingrained within the diagnostic process, however with a condition as unstable as PBD, calling attention to wider cultural processes that shape thinking, whether they be the roles of gendered norms, breakthroughs in the ever-present quest to find a biomarker for mental illness, or even the politics of globalisation leading to lifestyle changes such as job loss, and poverty, provide a more nuanced way to understand the development and representation of the child. The treatment of a child is reflective of larger societal forces, in a sense, the child acts as a mirror, absorbing the wider anxieties and cultural concerns at play around them. Thus, a focus on who is present in the life of a child, and who they are interacting with, allows for deeper consideration of processes shaping how a diagnosis emerges, is defined, and thus accepted or challenged as valid. In contexts where PBD remains something of a peripheral notion, there is an opportunity present through which we can learn what drivers are in play influencing how certain sets of behaviours become synonymous with disorder. Such understanding might enable greater scrutiny of broader cultural systems and socio-psychological mechanisms shaping conceptions of the child, and childhood more generally, before advocating diagnosis and treatment of something that remains poorly understood.

Appendices

Appendix 1: NHS ethical approval



NRES Committee East Midlands - Derby

Research Ethics Office
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839436

09 August 2013

Ms. Jane Roberts
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE

Dear Ms. Roberts

Study title: Paediatric Bipolar Disorder in the US vs.UK: The Emergence and Resistance of a Contested Diagnosis
REC reference: 13/EM/0313
Protocol number: N/A
IRAS project ID: 134148

Thank you for your letter of 09th August 2013, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Tracy Leavesley, NRESCommittee.EastMidlands-Derby@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

"Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Evidence of insurance or indemnity	Zurich Municipal	01 July 2012
Interview Schedules/Topic Guides	2	23 July 2013
Investigator CV	Jane Roberts	23 July 2013
Participant Consent Form	3	08 August 2013
Participant Information Sheet: Information Sheet	2	23 July 2013
Protocol	2	23 July 2013
REC application	134148/466000/1/115	21 June 2013
Response to Request for Further Information		09 August 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/EM/0313

Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Mr Peter Korczak (Chair)
Chair

Email: NRESCommittee.EastMidlands-Derby@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mr. David Coombe

Appendix 2: Participant information sheet- parents, England



Science

London school of Economics and Political

Department of Social Psychology
St. Clements Building
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London WC2A 2AE
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7712
Fax: 020 7955 7565

Information about the Research for Potential Participants

Paediatric Bipolar Disorder in the US vs. UK (REC Ref No: 13/EM/0313)

As a parent of a young person living with the diagnosis of bipolar disorder, I would like to invite you to take part in a research study. Before you decide I would like you to understand why the research is being done and what it would involve for you. I would ask you to go through this information sheet and should you have any questions contact me and I will answer them as thoroughly as possible. Please talk to others about the study if you wish in order to help you decide.

Purpose of the study:

Over the course of the last ten years in North America, the diagnosis of bipolar disorder in children has been made more and more frequently. This has happened against a backdrop in which many mental health professionals did not think such disorders could exist in younger children and adolescents. In contrast, there seems to be more reluctance among psychiatrists in the UK towards making the diagnosis, with some arguing that while children may have symptoms that suggest bipolar disorder, they are not convinced that there is enough evidence from research to support its wider use as a common diagnostic category. Part of this reluctance stems from a fear of misdiagnosis, and possible over- medication of children; issues that are very much a part of the conversation in the US.

This leads to the purpose of my research, undertaken as part of my PhD in social psychology at the London School of Economics, which is to explore why paediatric bipolar disorder (PBD) has become much more common in the US while remaining less so in the UK. As part of the research, I have already spoken to 20 American parents. In order to explore similarities and differences in the two cultural contexts, I'm hoping to speak to 15-20 parents in England as well. My interest lies in investigating this apparent difference in prevalence, and I want to understand your (parental) perspective on your own initial sources of knowledge about pediatric bipolar, experiences negotiating the period before they had an official diagnosis (such as interactions with various professionals), issues related to accessing support (both professional and social) and treatment post-diagnosis, and perceptions of stigma. I hope to get a sense of how PBD is understood and communicated by different groups.

Why you have been invited to participate:

You have been invited to participate as the parent of a child up to the age of 18 who has been given the diagnosis of bipolar disorder. It is completely up to you to decide to join the study. If you do agree to

take part, I will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason and this would not in any way affect the care you or your child receives.

Details of your involvement:

This project is based on interviews with participants. If you decide to participate, we would go through any further questions you may have about the research in general, or my project in particular, and then discuss the informed consent sheet that has been provided. We would then decide if you were able to meet in person, or if a telephone interview would be preferable. Pending your consent, the interview will be recorded and last from 45 minutes to one hour. There would be no expectation to answer all of the questions, and you would be free to stop the interview at any time.

Questions asked would be related to how you first heard about the PBD, what kind of treatments have been made available and how you feel about them, how much you knew about PBD before your family's own experience, and your experiences accessing support from Other parents, schools and mental health professionals. At the close of the interview, you will be invited to receive a copy of both the final report, as well as the written transcription of our conversation to see if there is anything you would want to be further anonymised, or omitted altogether.

There would be no expectation of a follow up, however I am happy to stay in touch and provide updates on the research, or answer further questions. If the decision was made to withdraw before any formal write up or publication, the transcription of your interview would be destroyed and any included quotations omitted. If you decide to withdraw after a piece has been submitted for publication, data collected prior to withdrawal will need to be included, though quotes will be removed and data destroyed prior to any future inclusion.

Risks and benefits to participation:

As this can be a difficult and private topic, there is a risk that when asked to reflect on your experiences about your child's diagnosis you may feel upset. It is my aim to be sensitive to this and not ask too personal, probing questions. If this should happen in the course of conversation, you should feel free to stop answering at any time. I will of course move on to a different topic. I am also happy to provide a list of resources available offering parental support.

The benefit would be contributing your experience to the debate surrounding PBD. In addition, though sharing your story you can raise awareness, offer hope and decrease stigma with others parents who may be just starting this journey.

What if there is a problem:

If you have a concern about any aspect of this study, you can contact me directly at 07954 210294 and I will do my best to answer your questions. If you remain unhappy and wish to complain formally, there are several options.

First, you may contact my academic supervisor, Professor Sandra Jovchelovitch: 020 7955 6863

If you wish to make a complaint to my university, you may contact the director of the LSE research division, David Coombe: 020 7955 7114

Finally, if you wish to complain to the NHS about an aspect of this research, you may contact the complaints manager for the Oxford Health patient liaison officer via email: PAALS@oxfordhealth.nhs.uk or by phone at 0800 328 7971.

Confidentiality:

All information that is collected about you during the course of the research will be kept strictly confidential, and any information about you that leaves the CAMHS site will have your name and address removed so that you cannot be recognised. I will be the sole individual responsible for collecting, recording and transcribing the interviews that make up the data for this project. Participants will be anonymised at the point of transcription, and identifying details of the individual or the location will likewise not be included. Instead of using names, participants will be referred to by a unique number code.

Immediately following the interview, the recording will be uploaded to the secure LSE server that only I have access to via remote desktop where the data will be kept secure. Anonymous transcripts of our interview will only be accessible to myself and my academic supervisor for purposes of monitoring the progress of the research. Additionally, if you allow it, anonymous quotes from our interview may be used in future publications or presentations.

The interview transcripts will be retained for a period of five years to allow for the completion of the PhD and related publications. While I intend to finish within the suggested three-year time frame, the publication and dissemination of findings to take place after the period of analysis means the data will need to be stored for a period of longer than three years. Following Medical Research Council guidelines, the data will be held for five years after which time I will be responsible for destroying it.

What will happen to the results of the research study?

The results will be written up as part of my PhD thesis. In addition, results may be included in academic journal articles and conference presentations.

Who has reviewed this study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by Derby Research Ethics Committee. In addition, the research ethics committee in the Institute of Social Psychology, London School of Economics and Political Science has approved the project.

Further Information and Contact Details:

General information about research:

Oxford Health Patient Advice Liaison Service (PALS): 0800 328 7971 or PALS@oxfordhealth.nhs.uk

Specific information about this research project:

Jane Roberts (researcher): +44 (0)7954 210294

j.roberts7@lse.ac.uk

As a participant in this research, you will be given a copy of this form to keep, along with a signed copy of the attached informed consent.

Thank you for your consideration.

Jane Roberts, MSc
PhD Candidate
Department of Social Psychology

Appendix 3: Recruitment letters to Young Minds- English Parents



THE LONDON SCHOOL
OF ECONOMICS AND
POLITICAL SCIENCE ■

YoungMinds

Suite 11, Baden Place

Crosby Row,

London, SE1 1YM

1st March, 2013

To Whom It May Concern,

I recently contacted YoungMinds regarding my research looking at the diagnosis of bipolar disorder in children in the US as compared to the UK. As part of the project I am looking to interview parents (as well as child psychiatrists) about their experiences. I understand that this is a sensitive topic, and I understand the importance of confidentiality, so I suggested that I might put together a pamphlet about the project with my contact information in the event that anyone was interested. The Parent's Helpline Advisor who responded mentioned I might send you the pamphlets to be included with information to be sent out to parents requesting information. I have enclosed some of these and wonder if this might be possible?

Please don't hesitate to contact me with any questions.

Yours Sincerely,

Jane Roberts

MPhil/PhD Candidate

Institute of Social Psychology
London School of Economics and Political Science
Houghton Street
London
WC2A 2AE
J.Roberts7@lse.ac.uk



Paediatric bipolar research

Hello,

I am currently a PhD candidate in the Institute of Social Psychology at the LSE where I'm in the initial stages of research looking at the diagnosis of bipolar disorder in children in the US as compared to the UK. In the last twenty years, the diagnosis has become increasingly common in the US, while here in the UK there seems to be a resistance to the diagnosis, at least on a clinical level, despite an increase in parents seeking treatment for their children who are suffering with what they feel is more than just depression or anxiety. I'm interested in exploring why there is such a big difference between these two countries. As part of my research I will be looking to interview both parents and child psychiatrists in the US and UK about individual experiences, and to get a sense of various factors at play in

knowledge surrounding bipolar in children generally, as well as attitudes surrounding available treatment options.

As someone who has contacted the YoungMinds parent helpline, I wanted to pass this pamphlet on to you in the event that you might consider participating. Even if your child hasn't been formally diagnosed, I would be interested in hearing what your experience has been so far.

This project has been approved by the ethics committee at the Institute of Social Psychology at LSE and, in accordance with those standards, all contact will be confidential and any record of conversation anonymised. If interested, I would be looking to conduct an interview lasting about 45 minutes, either in person (if in the vicinity of London) or over the telephone.

Please feel free to contact me with any questions or for more information via email at: J.roberts7@lse.ac.uk

Yours Sincerely,

Jane Roberts

Appendix 4: Recruitment letter to MD Junction- English parents

Submitted via online form

April 23, 2013

To Whom it may Concern:

I was recently in touch with one of the bipolar forum group leaders who suggested I contact you directly. I am currently a doctoral candidate in Social Psychology at The London School of Economics where my research is looking at comparisons in the diagnosis of childhood bipolar disorder between the US and UK. For my research, I have been interviewing psychiatrists in both contexts, but I think it is important to get the perspective of parents as well, as they are the ones living with the unfamiliar behaviour and are responsible for negotiating health care systems in search of appropriate information and treatment for their children. It is my understanding that the experience of parents in these two cultural contexts is quite different, with parents in the UK encountering a higher level of clinical resistance to the idea of the diagnosis, making it difficult to begin treatment in children under 18. In speaking to parents, I would seek to understand similarities or differences in accessing care and types of treatment, as well as understanding cultural differences related to levels of social support and acceptance for their child's diagnosis.

I am writing to request permission to make one- time posts on both the UK BP forum page, as well as the more general BP forum. It is not my intention to contact users directly, rather I am seeking permission to post a description of the project along with my contact information and leave it to the parents to decide if they want to make contact with me. The project has full ethical approval of the governing body at The Institute of Social Psychology at LSE, and in accordance with this, all information from those interviewed will be confidential and anonymous.

Thank you for your consideration, and I look forward to hearing from you.

With Best Wishes,

Jane

Jane Roberts, MSc

Appendix 5: Participant Information sheet- parents, United States

The London School of Economics and Political Science



Institute of Social Psychology
St. Clements Building
Houghton Street
London WC2A 2AE
Tel: 020 7955 7712
Fax: 020 7955 7565

18 June 2013

To Potential Participants:

I'm currently a first-year PhD candidate in the Institute of Social Psychology at The London School of Economics and Political Science (LSE) where my research is looking at the diagnosis of pediatric bipolar disorder in the US as compared to the UK. Central to my research are questions surrounding why it has expanded so rapidly in the context of the US, while there seems to be a level of resistance, at least on a clinical level, here in the UK, this despite increasing frustration on the part of parents unable to get the disorder recognised in their children. In trying to understand factors contributing to such a disparity, I hope to get a sense of how the disorder is understood and communicated by different groups in these contexts and, and that conversations with those who are directly involved with PBD, whether as family, clinicians, or researchers may shed some light on the phenomenon and the personal experiences behind the debates.

As part of the research I'm hoping to speak to parents in the US and UK about their own initial sources of knowledge about pediatric bipolar, as well as experiences negotiating the period before they had an official diagnosis (such as interactions with various professionals), and issues related to accessing support and treatment post-diagnosis. Interviews would be conducted over the phone or in person if you were willing. Pending your consent at the start of the interview, the interview will be recorded and last around 45 minutes. There would be no expectation to answer all of the questions, and you would be free to terminate the interview at any time. Anonymity and maintaining confidentiality are of the utmost importance. For this reason any identifying details such as names, locations, schools etc. will be anonymized when transcribing the interview, and participants will be referred to by code, for example the first parent I speak to in the US would be USP01, and so on. The recordings are destroyed after being transcribed, and the remaining anonymous data is to be stored on the secure servers at LSE which is password protected, and only I have access to. Similarly, consent forms will be stored in a locked cabinet in a locked office at LSE, which again, only I have access to.

I will be in the US from Tuesday June 25th through Friday August 9th. While there, I can be reached by phone at 773-396-8318.

I will be in the UK after the 9th of August and can be reached by phone at 011+44+ (0) 7954210294. I can be reached via email at all times: j.roberts7@lse.ac.uk.

I invite any you to contact me with any questions you may have prior to deciding whether or not to participate. The project has received ethical approval from the committee within the Institute of Social Psychology at LSE.

Thank you for your consideration, and Best Wishes,

Jane

Jane Roberts, MSc

Appendix 6: Informed consent

The London School of Economics and Political Science



Department of Social Psychology
St. Clements Building
Houghton Street
London WC2A 2AE
Tel: 020 7955 7712
Fax: 020 7955 7565

Participant Identification code:
5th November 2014: Version 4
REC Ref No: 13/EM/0313

CONSENT FORM

Title of Project: Paediatric Bipolar Disorder in the US vs. UK

Name of Researcher: Jane Roberts (j.roberts7@lse.ac.uk)

Academic Supervisor: Professor Sandra Jovchelovitch (s.jovchelovitch@lse.ac.uk)

Please initial box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without mine or my child's medical care or legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the London School of Economics where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data. ☐
4. I agree to allow the researcher to audio record the interview and allow use of anonymised quotes in presentations and publications. ☐
5. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Researcher

Date

Signature

When completed, 1 for participant; 1 for researcher site file

Please provide contact information below if you would like to receive a copy of the transcription or final report:

Appendix 7: Interview schedule- parents

Project Title: Paediatric Bipolar Disorder in the US vs. UK

Interview Schedule

Introduction and developing rapport:

I want to thank you again for agreeing to participate and share your experiences.
Just in terms of a time frame, I anticipate this interview lasting for about 45 minutes.
Will this work for you today?

I know you've had a look at the information sheet and consent form already, but I thought I would begin by just telling you a bit more about the research, what I've done so far, and why I'm glad I can talk to you today (discussion)

Do you have any questions for me at all before we begin?

Body:

I'd like to ask you some questions about your experiences related to the time leading up to your child's diagnosis, as well as how things have been since that time. Maybe I could begin by asking how old your son/daughter was when they were first diagnosed with bipolar.

Can you describe what it was like for you and your family before your child received the diagnosis?

Did you have a sense of what was wrong?
What sorts of things were you being told?

Had you heard of Paediatric bipolar disorder prior to your family's own experience with it?

If not, how was it described to you?
If so, where had you heard about it?

Can you talk about how you felt on learning of the diagnosis?

How would you say things changed after they were diagnosed?

Transition

Can you tell me a bit about your experiences seeking help and accessing services for your child?

GP/psychiatrists
Teachers
Other mental health professionals

Can you describe the treatments that have been made available to your child and how effective you find them?

Psychosocial interventions- focus on the child or heavy family involvement?
Feelings about medication?

Do you feel you've had access to positive social support?
If so, where have you found it? (e.g. peer support groups, online, family)

Do you feel your child (if old enough) has the support he/she needs?
If not, what would you like to see?

What are your thoughts generally on stigma surrounding children's mental health in the US/UK, and PBD in particular?

If you were to hazard a guess, how do you imagine things are different for parents in the US/UK (*country Other than where participant is from*)?

Transition

I know this is a bit broad, but if you were to try and describe childhood bipolar to someone who had never heard of it before, what would you say? (you can be as specific or abstract as you wish)

What tips might you have for parents encountering this for the first time?

Conclusion:

I don't have any more questions, but I'm wondering if there is anything I may not have touched on that you would like to add?

I want to thank you again for being so generous with your time. I'll be in touch soon with a copy of this transcription (if requested) which you can review. That way if you come across anything that you would like further anonymised you can let me know. Otherwise, feel free to be in touch generally with any questions.

Appendix 8: Interview schedule- clinicians

Introduction and developing rapport:

I want to thank you again for agreeing to participate and share your experiences.
Just in terms of a time frame, I anticipate this interview lasting for about 45 minutes.
Will this work for you today?

I know you've had a look at the information sheet and consent form already, but I thought I would begin by just telling you a bit more about the research, what I've done so far, and why I'm glad I can talk to you today (discussion)

Do you have any questions for me at all before we begin?

Body:

I'd like to ask you some questions about your experiences related to the ...Maybe I could begin by asking you just to tell me a bit of what you do here at xxx?

In your practice do you see kids w/ PBD?

- General ages?

What sorts of changes have you noticed regarding mental health in children over the course of your career?

When/ how did you first start hearing about PBD?

What do you think causes PBD?

How do your young patients arrive in your office?

- Parent/teacher/GP concern?

Are you often the source of initial knowledge about the disorder, or do the parents have some understanding already?

- Where do you think their knowledge come from?

Are you able to tell me how parents, or children if they're old enough, react to the diagnosis?

What are some of your approaches to treatment?

- Attitudes towards medication?

Brief discussion of verbal vignette presented in which a child's behavior (taken from parental account of child with bipolar) is described and clinician asked to reflect on how they would respond to such a child in their office.

In your opinion, why is it so contested a diagnosis?

What do you think it is that drives this difference of opinion?

Do you have any ideas about why it might be more recognised in US but not UK?

Any sense of how your professional colleagues in the US/UK think about PBD?

Conclusion:

I don't have any more questions, but I'm wondering if there is anything I may not have touched on that you would like to add?

I want to thank you again for being so generous with your time. I'll be in touch soon with a copy of this transcription (if requested) which you can review. That way if you come across anything that you would like further anonymised you can let me know. Otherwise, feel free to be in touch generally with any questions.

Appendix 9: Coding frame- pharmaceutical industry internal documents

CODES	BASIC THEMES	ORGANISIN G THEMES	GLOBAL THEMES
High cost of hospitalization	1.1.1 Pressure to expand indications for medications in face of competition and economic pressure	1.1 The voice of Pharma ('I' position)	1. SELF
mental illness a drain on resources			
stagnant mkt for antipsychotics			
medication's benefit to society			
context of US marketplace			
European market			
Medicaid -Medicare			
external economic pressure			
FDA as a potential threat			
goal of expanding market to children			
Increase awareness to increase prescription rates off label prescribing-defense of	1.1.2 Need for use of indirect marketing practices to 'get the word out' about PBD as a diagnostic category		
off-label promotion denial of			
off-label promotion pushing			
strategic collaboration with clinicians			
Advocacy groups to influence			
education of primary care phys.and psychiatrists			
influence and persuasion of sales reps			
influence and persuasion from reps to clinicians			
development of opinion/knowledge leaders			
education of pharma reps			
sell symptoms not disease states			
publications and presentations to validate and influence			
advisory committees to educate and influenced			
focus on symptoms not diagnosis			
incentives to promote PBD in children			
aggressive treatment warranted to reduce future risk			
expansion of approved indication			
threat-Seroquel/Astra Zeneca			
threat- Risperdal / Johnson & Johnson			

	<i>medications a constant threat</i>		2. OTHERS
threat-Zyprexa /Lilly			
industry-wide competition			
perceptions on industry			
perceptions of medications			
Maintain credibility through message of dependable medication			
Expand approved indications of medications	2.1.2 <i>Need for differentiation from competition</i>		
incentives to promote PBD in children			
focus on symptoms not diagnosis			
strategic collaboration	2.2.1 <i>Essential to have on board as 'opinion leaders' for wider validation of diagnosis of PBD</i>	2.2 Clinicians	
potential as paid speaker as incentive to prescribe			
education about symptoms			
instil confidence in idea of diagnosing and prescribing			
reassurance they are doing what's best for patient			
development of diagnostic fact			
defining PBD			
parents need validity to accept diagnosis			
Increase awareness to increase Rx			
Manipulation of trial data	2.2.2 <i>Relied on for knowing how best to diagnose and treat PBD</i>		
justification and defence of off label practices			
PBD as a "difficult condition"			
focus on symptoms not diagnosis			
promote notion of reassurance from Rd. to patient			
bipolar in kids easy to miss	2.3.1 <i>Unmet need and opportunity</i>	2.3 The child	
business and marketing trumps science and research			
expansion of sales			
bipolar behaviours increasing occurrence in physicians offices			
Increase awareness to increase prescription			
Manipulation of trial data			
paediatrics as 'fastest growing market'			
ADHD anchors PBD	2.3.2 <i>suffering from debilitating disorder made up of "constellation of diseases"</i>		
Conduct disorder anchors PBD			
rage, irritability, aggression as			

main symptoms in kids			
psychosis need not be present			
focus on symptoms not diagnosis			
misdiagnosis and uncertainty			
No previous history of depression needed			

Appendix 10: Coding frame and sample analysis, pharmaceutical advertisement

Variable	Value
1. Image type	1.1 photo 1.2 illustration (drawing) 1.3 cartoon
2. Social distance	2.1 intimate 2.2 close personal 2.3 far personal 2.4 close social 2.5 far social 2.6 public
3. Pictorial elements	3.1 bright 3.2 muted 3.3 dark 3.4 size
4. Age	4.1 child 4.2 adult 4.3 elderly
5. Gender	5.1 male 5.2 female
6. Role represented	6.1 parent 6.2 teacher 6.3 student 6.4 son/daughter 6.5 patient 6.6 Unknown sufferer
7. Individual manner	7.1 physical poses 7.2 expression
8. Setting	8.1 home 8.2 school 8.3 unknown/not indicated
9. Text	9.1 content/tone 9.2 position 9.3 size 9.4 prominence
10. Appeals	10.1 emotional 10.2 factual/ scientific 10.3 aspirational
11. Normative values	11. 1 achievement 11.2 social belonging 11.3 control (Self or clinical) 11.4 active 11.5 obedient

(Template as presented by Bell 2001)



Variable	Value
1. Image type	1.2 illustration (drawing)- artistic, dark
2. Social distance	2.2 close, personal
3. Pictorial elements	3.2 muted 3.3 dark 3.4 size- double page spread
4. Age	Not clear- young adult??
5. Gender	5.2 female
6. Role represented	Self as delusion - half woman-half dog
7. Individual manner	7.1 physical poses- woman morphing into a dog, crouching low to the ground. 7.2 expression- eyes closed, unaware, out of it, removed.
8. Setting	8.3 unknown/not indicated
9. Text	9.1 content/tone- blurb about the character, Amelia, and her delusions- a window for clinicians into Amelia's mind. The blurb serves to reinforce the slogan at the bottom, about relapses being a living nightmare. 9.2 position- tiny font at top so you really have to get up close to read about Amelia's delusions. Prescribing info off to the side and easy to ignore. 9.3 size/ prominence- unobtrusive

10. Appeals	10.1 emotional- very much in the image. Fear, depth of pain that delusions must bring. Text attempts to bring viewer in to a shared experience. Aimed at prescribing clinician viewer- get inside the experience 10.2 factual/ scientific- none
11. Normative values	Losing control; antisocial behavior driven by fear;

This is a very dramatic ad, presented almost as a work of art. The text at the top of the ad: “Amelia, virtually housebound through fear, believes that when she goes out she’s followed by a menacing black dog. And that the dog and her coalesce.” Is presented in a very small font, inviting the viewer in close, perhaps suggesting they get close to her delusion. An invitation to share her fear. The premise of this ad is that relapses are a living nightmare, though it’s never specified what the relapse refers to- schizophrenia? Something else? The overall tenor of the ad is unsettling, fear, going deep into wild delusions, a living nightmare. The woman appears to be young, her expression one of remove, perhaps lost in her delusion, unaware of the world around her. The ad is edgy and alternative and relies on the image and cryptic text to make its case with very few other indicators. Dark, foreboding. This time the light in the image appears to be a hazy glow coming from below. Mythology- shapeshifting- confinement and restraint- metamorphosis- horror.

- Associations: extreme otherness; uneasiness;
- Addressivity: clinician/ viewer. Vague
- Cultural knowledges required? Equating otherness/ delusion with fear. This is not a culturally universal approach, therefore this ad plays on the assumption that this image, and connotations will have effect of wanting to ‘fix’ the delusion.

Appendix 11: Coding frame, US clinicians

CODES	BASIC THEMES	ORGANISING THEMES	GLOBAL THEMES
<p>early career influences and opportunities</p> <p>fear of missing something</p> <p>better at diagnosing; previously under-recognised</p> <p>cautious and reasonable in approach to diagnosis</p> <p>acknowledging the controversy</p> <p>same symptoms, different diagnoses by Other clinicians</p> <p>what do we call this?'</p>	<p>1.1.1</p> <p><i>Uncertainty surrounding diagnostic criteria leads to increased recognition</i></p>	<p>1.1 'I' position-US clinical Self</p>	<p>1. SELF</p>
<p>clinician duty of care</p> <p>helpful to the parent, teaching parenting skills etc.</p> <p>understanding of what is being seen</p> <p>risk if left untreated</p> <p>Disengagement with the controversy</p> <p>Justification for medication</p>	<p>1.1.2</p> <p><i>The importance of expertise</i></p>		
<p>Working in conjunction with parent</p> <p>parental diaries/logs relied on</p> <p>Parents asking about diagnosis</p> <p>what parents see as a need</p>	<p>2.1.1</p> <p><i>Parents as co-constructors of knowledge</i></p>	<p>2.1 On parents</p>	<p>2. OTHERS</p>
<p>BP parent not wanting same thing for the child</p> <p>accounts of behaviour at home</p> <p>Relief at diagnosis</p> <p>explanation for child's behaviour</p> <p>child lacks appropriate vocabulary</p>	<p>2.1.2</p> <p><i>Parents as voice for the child</i></p>		
<p>Parent-child mismatch</p> <p>beaten down</p> <p>repercussions of illness without a name</p> <p>At the mercy of child's behaviour</p> <p>confused, misinformed</p> <p>judged by Others</p>	<p>2.1.3</p> <p><i>Parents as victims 'held hostage' to diagnosis</i></p>		
<p>rage, irritability</p> <p>emotionally and behaviourally dysregulated.</p>			

clinical distance symptom overlap with ADHD Parental accounts of behaviour sadness/depression Same behaviours seen in a different way	2.2.1 <i>child as a cluster of symptoms</i>	2.2 On the child	
social risks cognitive risks ‘emotional lability’ in best interest of the child to treat early Role of parent significant management of early symptoms behaviours as symptoms	2.2.2 <i>at risk and in need of early intervention</i>		
As a threat Defensive doing disservice to child clinical mastery what's at stake disagreement over symptoms and presentation forced to justify own position	2.3.1 <i>lack of consensus, unity of field</i>	2.3 on clinical colleagues	
pharma as a necessary evil hands are tied Caught in middle Clinical distancing strong influence needed for funding rationalization through suffering child justification for medications	2.4.1 <i>subjective values up against professional reality</i>	2.4 on Pharma	

Appendix 12: Coding frame, English clinicians

CODES	BASIC THEMES	ORGANISING THEMES	GLOBAL THEMES
nervous about making the diagnosis stigma through labelling second opinion risk reflection on practice position as educator clinical mastery wider community of practice caution with regards to labelling a young person Judgement of colleagues	<i>1.1.1 Interdependence and caution</i>	1.1 Reflexive clinical 'Self' among colleagues	1. SELF
perception of US feeling UK is behind US as source of knowledge about PBD awareness/recognition of PBD differing prevalence prevalence rates broad spectrum v. classical presentation Stereotypes US is drug company led over reliant on medication English scepticism conflicted attitudes towards US	<i>1.1.2 Positioned against American colleagues</i>		
sceptical of parents seeking the diagnosis seeking reassurance/removal of blame level of knowledge about PBD not deep	<i>2.1.1 Parents as seekers of knowledge</i>	2.1 On parents	2. OTHERS
parental investment in medical explanation parent seeing child as ill psychoeducation for both parent and young person parent/child interaction a factor in behaviour	<i>2.1.2 clinician distanced from parent-child dyad</i>		
pharma a 'pernicious' influence fatalism and inevitability	<i>2.2.1 Encroaching threat, vested interest</i>		

active resistance link w/ American colleagues		2.2 On the pharmaceutical industry	
dominance of US led research UK: space for non-pharma treatment drug company financed research openly sceptical pharmacotherapy in children very recent phenomenon	2.2.2 <i>Trusting the familiar, resisting the unfamiliar</i>		
social adversity multiple factors shaping a child's behaviour desire to understand "the whole child" hidden factors contributing to behaviour	2.3.1 <i>Child as part of a wider social context</i>	2.3 On the child	
age of child uncertainty manic-depressive psychosis Self-harm/ suicide attempts severity classic presentation	2.3.2 <i>PBD not distinct from adult BP</i>		
psychosocial approach before medication hopes and fears feelings about medications experiences with friends move beyond control of symptoms recast Self-image unpacking narrative, meaning	2.3.3 <i>Giving child a voice</i>		

Appendix 13: Coding frame, US parents

CODES	BASIC THEMES	ORGANISING THEMES	GLOBAL THEMES	
knowledge as leverage	1.1.1 <i>'Us v. them': Valuing experiential knowledge and expertise</i>	1.1 Position of the American parental 'Self'	1. SELF	
shared experience with child				
integration of subjective experience into child's illness trajectory				
parents know best				
development of knowledge essential				
need for mastery, control				
need to be taken seriously				
power struggles with professionals				
need to be a pushy parent				
education of others	1.1.2 <i>Proactive advocate</i>			
what's best for child				
sense of purpose				
need for a solution				
gradual acceptance after initial discomfort				
validation of decisions made on behalf of child				
"gifted" child				2.1.1 <i>True nature of child obscured by diagnosis</i>
angry child with a heart of gold caring and affectionate underneath it all				
have to perform illness				
diagnosis to access assistance				
never know what you're going to get	2.1.2 <i>Unpredictability and control</i>			
fear				
child in control				
no sense of what is normal	2.1.3 <i>Medication as an unavoidable necessity</i>			
removal of responsibility				
medication is a choice you have to make				
wish it wasn't needed but its reality				
not in control of their brain				

<p>help child who is suffering treat now to prevent future risk fall apart when off medication ashamed "at a loss"</p>		
<p>multiple clinicians consulted to find right 'fit'</p> <p>lacking support unreturned phone calls dismissive attitude feel judged by professional disdain on our own' enraged nobody would help us</p>	<p>2.2.1 <i>Feeling ignored, patronized, dismissed</i></p>	<p>2.2 Clinicians</p>
<p>professionals nothing more than prescription fillers lack of professionalism clash of expertise desperate for answers lack of recognition of child's behaviour as problematic/illness lack appropriate awareness/knowledge</p>	<p>2.2.2 <i>Questioning clinical expertise</i></p>	
<p>use of professional terminology need/justification for early intervention establishment of workshops to educate Others increased certainty</p>	<p>2.2.3 <i>Internalization of clinical expertise</i></p>	
<p>blamed for bad parenting parents of non-BP kids can't understand- naïve parents of BP kids in support groups too 'victim' oriented Need for education of other parents perpetuation of stigma stemming from fear feeling isolated from other parents, family Difference of opinion with father of child</p>	<p>2.3.1 <i>Judgement, conflict and a lack of support</i></p>	<p>2.3 Other parents (peers)</p>
<p>good teacher is a receptive teacher reliance on school/teacher to monitor child</p>	<p>2.4.1 <i>Collaborative alliance</i></p>	

need to educate teachers accommodation- Indiv. education plans		2.4 The school	
scholastic attention tied to specific diagnoses need to pushy to get child the help they need constitutional right to education' school shirking duties BP child is 'tarnishing' school's reputation emphasis on negative to access services don't take responsibility no appropriate structures in place to deal with BP kids	2.4.2 <i>Constant struggle</i>		

Appendix 14: Coding frame, English parents

CODES	BASIC THEMES	ORGANISING THEMES	GLOBAL THEMES
eager to hear Other's experiences guilt Self-blame overlooked early symptoms not an expert trying to understand every decision is the wrong decision not allowed to be an expert	1.1.1 <i>Feeling like amateurs</i>	1.1 <i>The voice of English Parents ('I') position</i>	1. SELF
desire for certainty little understanding of mental illness not enough done to inform parents Need to act like 'pushy middle class parent' BP the same as Schizophrenia? no prior knowledge of BP in kids	1.1.2 <i>Ill- informed and lacking support</i>		
GP unsure how to assess GP assured everything was fine not allowed to be an expert forced to go private to get adequate support lack of information lack of appropriate resources professionals unsure how to handle child GP not supportive nobody would listen Parents have no control lack of consultation with parents-'system' took over GP didn't delve deep enough symptoms not thought of as being BP pos. interactions equate w/being heard refusal to validate what parent is seeing power dynamics CAMHS wouldn't consider BP	2.1.1 <i>Disappointment and frustration</i> 2.1.2 <i>Faced with a reluctance to diagnose</i>	2.1 <i>Interacting with clinicians</i>	2. OTHERS

Appendix 15: Sample excerpt, dialogical analysis

I had a child under my care who I had diagnosed with BPD. Teenager. And I was treating him with medications for BPD, and he had a relapse and overdosed on one of his medicines, went to the hospital, was hospitalized at a local psychiatric hospital, and the doctor there said “well, this is a boy that’s depressed, but I don’t see the bipolar” and I said, “well he’s not manic now. He’s depressed now. He has a history of mania”. (Doctor:)”I heard that history and I don’t think it sounds like bipolar disorder”. And so the doctor told the patient and the mother “I don’t believe Dr. (Interviewee) has the correct diagnosis. I think you should take an antidepressant. Here’s Prozac.” And they discharged him on Prozac. That was February. It’s now July. I decreased the Prozac dose because after several months he started to seem more agitated and irritable, and last week, and now he’s smoking marijuana every day, so his drug use has picked up, and so he went to the emergency room. He wanted help, because he goes nights without sleep, he’s very agitated, he’s exploding with his mother, he’s been making odd sexual comments to her. Well what is that? He’s got bipolar disorder. So, they tried to rehospitalize him, he didn’t want to stay, so he left after a day, and the doctor there said “I don’t think you have BP disorder, I think you have depression” Well how - aren’t they hearing these same facts?! (USC7)

Representational processes at work

- Knowledge encounters
- Self-other positioning
- Other dr. anchoring in depression
- USC 7 objectifying PBD in ‘fact’
- Negotiation
- Validation of position with listener; validation through illustration of child suffering from lack of appropriate treatment

Self-Other positions

- USC 7- Clinical Self- as voice of reason; expert; intermediary caught in middle
- Other- child as suffering the result of clinical disagreement
- Other- doctor as stubborn, not fully informed, jeopardizing health of young person; causing confusion; positioned as threat

Who is being addressed?

- Researcher/interviewer
- Clinician-Self
- Doctor-Other

- Child and parent indirectly

Functions

- Speaker undermined, seeking alliance of listener; conspiratorial; invitation to take sides
- legitimisation
- validation

Appendix 16 Excerpt from interview transcript

USP5

July 2nd, 2013

Duration: 54:31

Can you describe what it was like for you and your family before your child received the diagnosis. I know you said in your email that he's 14 now, but that he was diagnosed when he was three, is that correct?

Just before his 4th birthday, yeah. Well for us, we've got a really strong family history on both sides. My father has BPD and my father in law had it as well, so we knew genetically speaking our deck was pretty well stacked, so we knew that we needed to keep an eye out for that, but neither my husband nor I have ever been diagnosed with BP or any of those correlated illnesses, I guess you could say. Um, so when, A. is our first, and I don't know if you have kids, but when it's your first, you don't know anything! You don't know if this normal, if it's not normal, are they going to grow out of this, are they not. In retrospect, there were a lot of things that were very clearly not normal. Even when he was in the womb, he was very, like you could watch him get agitated, like he would fling himself from one side of my stomach to the other, we were like wow! OK, how 'bout that! When he was born he had a very normal childbirth, nothing out of the ordinary, no trauma or anything else, and then I think he was probably about 7 months old before he slept through the night at all. Hang on just a sec

(conversation interrupted by child asking to buy a video game online).

Sorry, that's the youngest of five. So he didn't sleep through the night at all until he was 7 months old, so we were like "oh you know, it's your first, it's how babies are" really, really sensitive to noise. When we moved to Illinois from Utah when he was a baby, as I was packing boxes I would do the tape gun, you know just stretch out the packing tape and whatever, and he would howl like someone was stabbing him. We would be sitting around the table and one of us would burst out laughing, and he'd cry, really sensitive to noise. And then when he got more into toddler phase, when everybody else's kids were kind of growing out of the biting thing, his was getting worse, we were like "ok, this isn't so great". When he was two, I think one of our first, in retrospect, clearest indicators when he was just barely two, he had to have steroids for croup, and they made him hallucinate. He was seeing, like, spiders in the air, and, like, big bugs- he was trying to catch them and stomp them, and they weren't there! Something tells you

something when you have a hallucinating 2 year old. Again, in retrospect, I know steroids are contraindicated for a lot of people with BPD because it can make them hyper-manic. Which, for him, it also made him hallucinate So as he got older and we had other children, just the behaviour we were seeing- I mean he would just rage times four, ten times a day, 30 minutes at a crack, he would try to rip my hair out of the scalp, he would try to gouge my eyes out, and we're a very non-violent house. I mean the most violent input he was getting was Sesame Street, so it's not like he was watching WWF and acting something out. It was all very, very internal. I remember when he was three I had cut up a credit card and had put it in the trash, you know, throwing it away. He went and found the sharpest piece he could find and hidden it, and then the next time he went into a rage he went and got that piece of credit card and was slashing at me with it.

Oh my gosh.

Yeah, it was, it was something. So after three, three and a half years of that, we finally said 'you know what, nothing that we're doing is helping' You know, of course we're hearing all the parents saying "he needs more discipline, he needs less discipline, he needs a good spanking, if he bites you, bite him back", you know, all of these things, but nothing worked. And we just said, we knew our deck was pretty heavily stacked, if it looks like a zebra, and smells like a zebra and eats the same things a zebra eats, maybe we need to be concerned that we have a zebra. There's something going on, so that was what led us to seek out professional help.

So you had actually considered that this could be the case given your family history when you sought out help. Did you tell them that you thought this might be bipolar?

Absolutely, absolutely.

And can you tell me about the reaction of the psychiatrist- was it a psychiatrist that you went to initially?

It was. The very first one we went to, and again, you're very much tied by who's in network with your insurance, who's accepting new patients, who's accepting patients as young as your kid, so we went to the first doctor that we could find who fit all of those criteria, it was still a good 50 minute drive from us, which, you know, whatever, we needed to go somewhere. We told her what was going on and what we saw, and then we went to her office, you know, we sat down with her and she said, "right off the bat, I need to tell you, I would never medicate a child under the age of six". I said, "Ok, I

hear you” I said “I would rather have a glass of water and a nap, than take a Tylenol when I have a headache, I hear you. I’m all for the least invasive approach first, but my question for you is this, if that doesn’t work, how do we survive until he reaches this magical age of six? Right now as a family we cannot function”. And, you know, he was raging, so he couldn’t even take swim lessons. You know he would just sit and glower and scowl, he couldn’t even do a lot of the most basic things because he was so incapacitated, and she goes “well, I’d really like to start with fish oil” and I said “ok, well, by the way, what’s your experience with children with paediatric bipolar disorder?” and she goes “oh, well, I’ve read a few articles”. Ok, but remember this was 10 or 11 years ago, PBD wasn’t being as readily diagnosed back then. I think back then it was running about 50/50. 50% of psychiatrists said yeah this is a legitimate occurrence, the other half said this is something else, children cannot have BPD, which is maybe what you’re seeing in the UK, I don’t know. So she said “well I’d like to do fish oil”. Ok, fine. So she had recommended this kind, and after the fact I found out that in general with fish oil there’d been- and I don’t know if you know much about fish oil...

I hadn’t heard about it for this particular diagnosis.

Sure, um. In fish oil there are two main components, EPA and DHA and I found out later that for BPD, I think the ratio that you want for EPA to DHA is like 7:2 or 7:3 or something like that. The one that she had recommended to us was flipped and it was a lot higher in DHA than EPA, so we put A. on it and he went hyper manic. I mean, much more raging, much more violent, whatever else. I’m going crazy, I’m sobbing, I’m trying to call this doctor to get her to call me back, she’s not returning my phone calls. I’m now totally in crisis. I called the insurance company in tears saying ‘I need a different doctor, this one’s not calling me back, she prescribed the wrong thing’ And at this time I have a child that’s one, so it’s not like it’s just him that I’m dealing with. So the insurance company then recommended us to a different doctor who, from everything I could research at the time, that was his thing. He was really working with depression and bipolar disorder, specifically in children and adolescents, so we had videotaped A. in one of his rages, because that was another thing, he’s gonna white knuckle it if he’s in an environment where he doesn’t feel secure, and he’s going to be calm, and he’s going to be, you know, perfect, and wonderful and presentable, so we had videotaped one of his rages for multiple reasons, one so we could show the doctor, and two, if any neighbours heard yelling, things being thrown and whatever else, and reported it, we could show he video and say, ok this is what’s going on, this is what it looks like, we’re not beating him, we’re not, we’re not throwing furniture, that would be him. So we went to this second doctor, we took him the video, we showed him what it looked like, we told him what we’d been through, and this is what we think it is and he

said “I agree”. He then made the actual diagnosis, you know “yes, I would consider this to be paediatric bipolar disorder” and then started him on meds.

In terms of these rages, would he have them at school or pre-school, or was it exclusively in the home?

He started pre- school a month or two after he was diagnosed, ‘cause he was three, he had just turned four, but he had turned four like, he’s a September birthday, so he had turned four after the start of the school year, so he was fully the oldest kid in his class, because if he had been born six days earlier, he would’ve started school a year earlier. It was really- I mean it is, and has been, a really long road, and we were with that psychiatrist, if memory serves, I think we were that psychiatrist for two years, maybe three, and he was clinically good, but his bedside manner was horrible. His last name was xxx, but behind his back and to each other we called him grumpyxxx. He was, you know, I would call him in crisis and he would just be very curt, and very dry and very direct, which, that’s ok but we all felt that we needed a more holistic approach than “here’s the pill, goodbye”

So after that we sought out another doctor, and he was almost the opposite, you know he was very kind and patient, bedside manner was fantastic, but we felt that he was throwing darts. You know, when things would fire up and it was clear that whatever meds we were using weren’t balanced or weren’t the right ones, we felt like he would throw a dart and go ‘OK, let’s try “plink”... this one!”. One time he had prescribed, I think it was Prozac, and I was like, you don’t give antidepressants to people who are clearly bipolar, you boost their mania through the roof when you do that! So at that point we were frustrated. I think A. was probably 8 or 9 and we said, you know, however far we have to drive, we need to go to an expert. We need to go somewhere where they’re on the cutting edge of this, where they know what they’re doing, they know that they know what they’re doing, and they can really give us a clear cut path, because we were just so tired of the “well let’s try this. Oh that didn’t work? Well let’s try this! Let’s try that, well how about this!”

So we ended up going to xxx with Rd. P so that was a long drive, but that was really worth it. I mean, we went down there 5 or 6 times, and she, he had been on Depakote ever since that first diagnosis, and then they kind of played around with a couple other things like Pylectol and a couple other things here and there. She took him off the Depakote and said ‘this isn’t working, obviously he’s not working. We’re taking him off completely and we’re gonna put him on Risperdal” and we were like, well we’ve already tried Risperdal, and I don’t remember if that was the one that didn’t seem to have an

effect at all, or if it was one of the ones that made him lethargic, and she said “you know, I can’t promise you anything, but if I could, I will come as close to promising you as I can that this is going to make a difference” and she said “we’ve got the research to back it, we’ve got the data to back it, this is going to make a difference” and it did. Ever since then, he has been what I would call medically stable, I’d say 95% of the time. I mean, he still has his issues, you know, he’s never going to function as normal. He has a lot of Asperger’s type social issues that can’t be medicated out, that they’re just part of how his brain functions, but you know, the violence, the rages, the massive ups, the depression, they’ve pretty much levelled. I mean he’s very, like I said he’s got Asperger’s like social issues, he’s still sensitive to noise a little bit here and there, but by and large he can function as a human being.

When he was first diagnosed was there ever any attempt to bring you as the parent in to do more psychosocial interventions.

You know, every time we would talk, the doctor would ask, well “what do you do about this, and what do you about that, and how do you handle this and how do you handle that”. Every single one across the board said, “Wow, I don’t really have anything to tell you, you’re doing it already”. We never really got the impression that we should be doing this, or we should be doing that, and, you know, I read a lot. So I’ve read *The Explosive Child* and the book *The Bipolar Child*, and you know, reading as much as I could and trying as many things as I could, just trying to do whatever we could to address what he had going on. But I was never- nobody thought that that was ever part of the problem.

In terms of social support for either you or for your son, have you found it easy to access support?

No.

No? Can you tell me a bit about that?

There aren’t, especially 10 years ago, there was this doubt as to whether or not children could have PBD, so there was a lot of “well maybe its ADHD, maybe it’s this, maybe it’s that”, so I didn’t find that there were a lot of things out there where people were saying ‘this is what they need’. I think- I think bipolar disorder kind of became the diagnosis du jour after ADHD, and I think now BP is kind of fading out a bit, and now its Asperger’s that’s kind of coming in to everybody’s common language, and “oh it’s

on the Dateline special”, you know, and there’s a lot more awareness and misdiagnosis I would say as well, there just wasn’t much of anything. The only place I found that would help sometimes was I was on the board at, it’s called Balanced Mind now, but whatever it was before, CABF (child and adolescent BP foundation) which is where we heard about your study, there were groups there, but unfortunately what it seemed to be a lot of the time was a lot of people getting together and going “oh my gosh, it’s so terrible what do we do, oh my gosh it’s so terrible” and, when you’re in crisis, you don’t want to hear this, that everybody else is having a terrible time too, you want to hear that there’s hope, and I think back then the diagnosis was still fairly new, there weren’t a lot of people who could say yeah my child was diagnosed with this 15 years ago and now he’s a successful college student or whatever, it was just a bunch of us in crisis going “boy, this is terrible”.

Have you found yourself having to defend his diagnosis in conversation with people or met anybody who’s openly challenged that?

Oh sure. The biggest issue we had, I would say was the school. He, let me thinking, he went to pre -school. He was diagnosed right before he started pre-school, and we decided not to say anything. We thought, this is a new diagnosis we kind of suspected this, but we don’t want there to be a stigma if there doesn’t have to be. We’re just going to keep our mouth shut and do it on a need-to-know basis. Well, he punched his teacher in the eye on the first day. It was like ‘ok, I guess that need to know basis is right about now’. So we talked with her about it and she was all ‘oh, I really wish you had told me and this, that and the other’ um, he went there for a year. He finished one full year and had started the second year when the director pulled me aside and said ‘we’re very sorry, but he’s not allowed to attend here anymore’. It was a mixed age classroom and so the second year he was obviously now the oldest of two ages of kids. It was a two year program, but they mix the ages of the kids, and he was very OCD at the time. He would get obsessed by odd things like paperclips, or insects, and that would be the only thing he would think about, the only thing he would want to do. So between that and his outbursts and whatnot, they didn’t feel that it was a safe environment for the other kids. At that time we were moving to a different school district anyway, and they said, you know ‘we’ll give you all the recommendations you need, have him evaluated for special ed. Obviously we’ve seen him now for over a year, we will heartily say that he needs services’ whatever.

So when we moved to the different district he did half a year at their pre-K program, and then in Kindergarten he went to the regular classroom in the morning and then the special-ed kindergarten I the afternoon and continues that through first, second third

and fourth grade. But I found that the school was very...it wasn't that they challenged that he had bipolar disorder verbally or outright, but the way that they treated the problems that he had really demonstrated that there wasn't a lot of understanding. When he was in first grade, he would hide under the teacher's desk because it was quiet over there and nobody would bother him, but they would send him to the office for it. So after, I think this was in first grade, again, he was getting sent to the office all the time, his teacher was one year away from retirement, very old school, very "my way or the highway" and I remember being called into the principal's office and her saying "well, you know, he's very manipulative. He gets himself sent to the office on purpose" and I said, "you know, I'm not disagreeing with you, I agree it's probably on purpose, but did you ask yourself the next question, the next question is why? Why would he get himself sent to the office? Why would he do that? Because it's quiet? Nobody bothers him? He's not distracted? And if he wants to lay his head down and rest for a few minutes? He can do that".

(interruption in conversation).

So I said, yeah, he's doing it on purpose behind it. He has a need and it's not being met. He's smart enough to try and get himself the kind of environment that he needs. So there was just a lot of, I mean he was getting suspended him all the time. I mean, some kid would jostle him in line, and with his very hypersensitive fear of harm kind of thing, you know 'I'm being threatened' he would hit the kid and because there's zero tolerance, you're suspended. Ok, but why?! Why did that happen and what could you have structure to prevent it? If you'd structured it so he could walk inside from recess two minutes earlier than everyone else. So they would suspend him all the way up to the legal limit where they would have to re-evaluate his educational placement, and then the clock would reset every January and it would be the same thing, they would suspend him, suspend him, suspend him, and then the assistant principal, one of the other times he was suspended, she's sitting there, and of course she's glowering and whatever and she says "young man I want you to come in tomorrow with a totally different attitude!" and it was all I could do not to say to her "I would like you to come in tomorrow fifty pounds lighter!...because you obviously have a problem. Fix it! Isn't that what you're telling him?"

So, I really, really, really struggled with the school. I still remember there was this one day with the social worker, she called me up, she was in tears she said (name), I finally understand. And I said 'what do you mean?' and she had been wrestling him to the ground and this that and the other, and I told her, if you have to do that then do that, but ask yourself how he's going to feel when you're done? He's going to feel horrible.

‘cause she’s like ‘I’m just going to let him hit me. I’m just going to let him do it’. I said ‘you can choose that if you want, but if you do that, he’s going to feel that kind of remorse and feel horrible that he did it. You might want to consider avoiding that some other way, or addressing that some other way’. And she called me up and she goes “I get it now. You’re right” She goes ‘I finally told him fine you wanna hit me, hit me” He did it, and then he felt the next hour crying because he felt so bad. And I said “thank you” and from then on, she was my ally, because she had finally seen for herself that this was not a kid that was trying to be horrible. This was a kid who literally couldn’t help it. He literally could not help it. And no amount of carrot or stick was going to make that change.

If I’m being generous I would say they did the best they could. We don’t live in a high income area. We’re not low income, you know, we’re pretty solidly upper middle class, but we have a lot of poor areas within our school district, we have a lot of second language learners, we have a lot of kids who are reading at maybe the 10th to 25th percentile, they have a lot on their plate, and I get that. There’s a lot of policy that they don’t necessarily get to decide themselves, like ‘zero tolerance’. To me that’s a community based reaction to things. They want to know ‘it’s zero tolerance if a kid does this’. I get that, but I really think in a lot of ways they have their hands full. And what do you do with a kid that’s violent? You have to protect the other kids. I get that. I would never say that they shouldn’t, but U felt that they were really lacking in compassion. They really wanted somebody to blame, and unfortunately that’s not really helpful. He always had- I think from second, maybe third grade on, he always had the special ed classroom for things like math. He processed things slower academically, where he could handle the thinking part of it, but just the processing, or just the mechanics of writing were a lot slower, so he would go to a special ed classroom for that. He had a one to one aid, I think from 3rd grade on, maybe 2nd grade, I can’t remember for sure. So he had a one to on aid, and I really feel like they felt, there’s nothing more we can do, and maybe there wasn’t. I don’t think school was meant to be the end all, be all fix every problem a parent has with a child, but like I said, I think really what was lacking was compassion. I don’t think having a lot of problems should be mutually exclusive to also having compassion.

If you were to try and describe PBD to someone who had never heard of it before, or someone in the UK who was seeing threatening behaviours in their child, what would you tell them?

Grip the wheel and hold on tight, ‘cause it’s going to be a long bumpy ride! I wouldn’t even know what to say, I mean there have been a lot of people who have come to me

and said, you know, I'm seeing XY and Z in my child, what do you think? And I've been able to talk them through, well do you see this or this. Yes? OK, you may want to consider that it could be this. You don't see that? OK chances are it's not. The way that, and maybe this is the most helpful, I mean people always ask "how do you know if your kid has it?" and I say, from what I've seen, not just in A. but in my other kids, I would describe full on BP disorder as say 10 switches, and maybe those switches are rage, being easily irritated, being sensitive to noise, hyper sexuality, whatever, an whole panorama of what BP can be. Picture those each being their own switch. Full on BP is 10 switches being all turned on. Now A. at certain times in his life I would say he was 9 or 10 switches all turned on, now with medication, with growing older, with time, maybe he's only got 7 switches turned on. I have a daughter that when she was 6, I'd say she also had about 5 switches turned on. Never was on meds, never had to go to a psychiatrist or anything else. As she grew into herself and becoming the person she is, I think she maybe got one switch flipped on. I wouldn't even think she has BPD, because it's only 1 dimension of her life. And one that she's able to manage without anything else, so at what point do you say 'yes this is BPD' or 'no it isn't', I don't know.

And the thing that I think gets complex is, there are a lot of factors, and maybe this is part of why it's different in the UK, I don't know, but over here, there's a lot of talk about ingredients in foods and vaccines and things like that, so a lot of people I see on some of these boards are like 'oh my god, I took red dye out my kid's diet and he's been wonderful'. I don't doubt that there are kids who have BP type symptoms in response to food additives or sensitivities, or a vaccine reaction, or something. I don't discredit what they've experienced with their own children, but I also don't think that that is the cause for every person that has those symptoms, and I think that's where you get those people saying "oh you should never medicate a child!" I get that. There are some kids that their cause is something else, but that to me does a discredit to the people who say, you know what we've tried everything and its still happening. Don't assume that they are doing something wrong, or they're not doing enough, because their experience is different from yours. There's a big tendency of suspect the parents. The parents what the meds, or the parents what this, or the parents want the meds, or the parents are disciplining incorrectly, or the parents aren't providing healthy enough food. Whatever it is, know what? Sometimes the crappy universe answer is, yeah, this stinks, and he's got a disorder. It just is, like anything else, sometimes it just is.

References

- Abraham, J. (1995). *Science, politics and the pharmaceutical industry*. London: UCL Press.
- Alderson, P. (2013). *Childhood real and imagined, volume 1: An introduction to critical realism and childhood studies*. Oxford and New York: Routledge.
- American Psychiatric Association (2000) *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.) Washington, DC: Author.
- Asch, S.E. (1952/1987). *Social Psychology*. Oxford: Oxford University Press.
- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research* 1 (3), 385-405.
- Aveling, E.L and Jovchelovitch, S. (2013). Partnerships as knowledge encounters: a psychosocial theory of partnerships for health and community development. *Journal of Health Psychology*, 19 (1), 34-45.
- Avorn, J. Chen, M., and Hartley, R. (1982). Scientific versus commercial sources of influence on the prescribing behavior of physicians. *The American Journal of Medicine*, 73, 4-8.
- Azerrad, J. (2016, February 16) Behind the childhood bipolar boom. *Metro West Daily News*. Retrieved from <http://www.metrowestdailynews.com/article/20160227/OPINION/160226556>
- Bakhtin, M.M. (1981). *The dialogic imagination*. Austin and London: University of Texas Press.
- Barker, K. (2008). Electronic Support Groups, Patient-Consumers, and Medicalisation: The Case of Contested Illness. *Journal of Health and Social Behavior*, 49, 20-36.
- Barker, K. (2010). The social construction of illness: Medicalisation and contested illness. In Bird, C. Conrad, P. Fremont, A. and Timmermans, S.(eds) *Handbook of medical sociology, sixth edition* (pp.147-162). Nashville, Tennessee: Vanderbilt University Press.
- Bauer, M. (2000). 'Classical Content Analysis' in Bauer, M. and Gaskell, G. (eds) *Qualitative researching with text, image and sound: A practical handbook*.(pp. 131-151). London: Sage Publications.
- Bauer, M. and Gaskell, G. (1999). Towards a paradigm for research on social representations. *Journal for the Theory of Social Behavior*, 29 (2), 163-186.

- Bauer, M. and Gaskell, G. (2008). Social representations theory: a progressive research programme for social psychology. *Journal for the Theory of Social Behavior*, 38 (4), 335-353.
- Becker, H. (1963). *Outsiders: Studies in the sociology of deviance*. New York: The Free Press.
- Beiderman, J., Faraone, S., Mick, E., Wozniak, J. Chen, L., Oulette, C., Marrs, A., Moore, P., Garcia, J., Mennin, D. and Lelon, E. (1996). Attention-Deficit Hyperactivity Disorder and Juvenile Mania: An Overlooked Comorbidity? *Journal of the American Academy of Child and Adolescent Psychiatry*, 35 (8), 997-1008.
- Bell, P. (2001). Content analysis of visual images. In Van Leeuwen, T. and Jewitt, C. (eds) *The handbook of visual analysis* (pp. 10-34) London and New Delhi, Sage
- Berger, P. and Luckmann, T. (1966). *The social construction of reality: A treatise in the Sociology of knowledge*. London, Penguin Books.
- Bhugra D. and Mastrogianni, G. (2004). Globalisation and mental disorders: Overview with relation to depression. *British Journal of Psychiatry*, 184, 10-20.
- Blader, J.C. and Carlson, G.A. (2007). Increased rates of bipolar disorder diagnoses among U.S. child, adolescent, and adult inpatients, 1996-2004. *Biological Psychiatry*, 62 (2), 107-114.
- Blum, L. (2015). *Raising generation Rx: mothering kids with invisible disabilities in an age of inequality*. New York, NY: NYU Press.
- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Berkeley: University of California Press.
- Breakwell, G. (1993) 'Integrating Paradigms and Methodological Implications,' in Breakwell, G.M and Canter, D.V (eds) *Empirical approaches to social representations* (pp 180-201). Oxford: Clarendon Press.
- Brill, S. (2015). America's most admired lawbreaker. *The Huffington Post*. Retrieved from: <http://highline.huffingtonpost.com/miracleindustry/americas-most-admired-lawbreaker/>
- Brinkmann, S. (2014). Languages of suffering. *Theory and Psychology*, 24 (5), 630-648.
- British National Institute of Health and Clinical Excellence (2006). *National clinical practice guidelines number 38: Bipolar disorder: the management of bipolar disorder in adults, children and adolescents in primary and secondary care*. London: National Collaborating Centre for Mental Health.

- British Psychological Society (2012). DSM-5: The future of psychiatric diagnosis. British psychological society response to the American psychiatric association.
- Brown, P. (1995). The social construction of diagnosis and illness. *Journal of Health and Social Behavior*, 35, 35-42.
- Bury, M. and Gabe, J. (2004). *The Sociology of health and illness: A reader*, London and New York: Routledge.
- Campbell, C. (11 June, 2012) PS950 research seminar, department of social psychology, London.
- Campbell, C. (26 November, 2013). Revisiting the “new social studies of childhood”: conceptualising the agency of children in extreme settings. Psychology@lse Research Seminar, London.
- Campbell, C. and Jovchelovitch, S. (2000). Health, community and development: towards a social psychology of participation. *Journal of Community and Applied Social Psychology*, 10, 255-270.
- Campbell, C. and Burgess, R. (2012). The role of communities in advancing the goals of the Movement for Global Mental Health. *Transcultural Psychiatry*, 49 (4): 379-395.
- Canguilhem, G. (1989). *The normal and the pathological*. New York: Zone Books.
- Carey, B (2006, November 11). What’s wrong with a child? Psychiatrists often disagree. *New York Times*. Retrieved from <http://www.nytimes.com/2006/11/11/health/psychology/11kids.html>
- Carpenter-Song, E. (2009). Caught in the psychiatric safety net: meanings and experience of ADHD, pediatric bipolar disorder and mental health treatment among a diverse group of families in the United States. *Culture, Medicine and Psychiatry*, 33, 61-85.
- Carugati, F. and Selleri, P. (1998). Social representations and development: experts and parents’ discourses about a puzzling issue. In Flick, U. (ed). *The Psychology of the social* (pp. 170-185) Cambridge: Cambridge University Press.
- Chan, J., Stringaris, A. and Ford, T. (2011). Bipolar disorder in children and adolescents recognised in the UK: a clinic-based study. *Child and Adolescent Mental Health*, 16 (2), 71-78.
- Clacy, J., Goldacre, M., and James, A. (2015). Pediatric bipolar disorder: international comparisons of hospital discharge rates 2000-2010. *British Journal of Psychiatry Open*, 1 (2), 166-171; DOI: 10.1192/bjpo.bp.115.001933

- Clemence, A. (2001). Social positioning and social representation. In Deux, K. and Philogene, G. (eds). *Representations of the social: Bridging theoretical traditions* (pp. 83-95). Oxford and Malden, MA, Blackwell Publishers.
- Cohen, D., McCubbin, M., Collin, J., and Perodeau, G. (2001). Medications as social phenomena. *Health*, 5 (4): 441-469.
- Collins, T. (2015, September 25th). Big pharma, profits, and the value of a human life.[Blog post]. Retrieved from <http://www.tomcollinsscribbler.com/big-pharma-profits-and-the-value-of-a-human-life/>
- Conrad, P. (2007). *The medicalisation of society*. Baltimore: Johns Hopkins University Press.
- Conrad, P. and Barker, K. (2010). The Social construction of illness: key insights and policy implications. *Journal of Health and Social Behavior*, 51, S67-S79.
- Conrad, P. and Bergey, M. (2014). The impending globalization of ADHD: notes on the expansion and growth of a medicalized disorder. *Social Science and Medicine*, 122, 31-43.
- Conrad, P. and Leiter, V. (2004). Medicalisation, markets and consumers. *Journal of Health and Social Behavior*, 45, 158-176.
- Conrad, P. and Potter, D. (2000). From hyperactive children to ADHD adults: observations on the expansion of medical categories. *Social Problems*, 47 (4), 559-582.
- Cornish, F. and Gillespie, A. (2009). A pragmatist approach to knowledge in health Psychology. *Journal of Health Psychology* 14,6: 800-809.
- Couric, K. (September 28, 2007). *60 minutes: What killed Rebecca Riley?* New York, NY, Central Broadcasting Service.
- Crossley, N. (2006). *Contesting psychiatry: social movements in mental health*. London and New York: Routledge.
- Cutcliffe, JR. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31 (6), 1476-1484.
- D'Alessio, M. (1990). Social representations of childhood: an implicit theory of Development. In Duveen, G. and Lloyd, B.(eds) *Social representations and the development of knowledge*. (pp 70-90). Cambridge: Cambridge University Press.

- Danner, S., Fristad, M., Arnold, L., Youngstrom, E., Birmaher, B., Horwitz, S., Demeter, C., Findling, R., Kowatch, R. (2009). Early-onset bipolar spectrum disorder-diagnostic issues. *Clinical Child and Family Psychology Review*, 12 (3), 271-293.
- Davies, J. (2011). Positive and negative models of suffering: an anthropology of our shifting cultural consciousness of emotional discontent. *Anthropology of Consciousness*, 22 (2), 188-208.
- De Rosa, A.S. (1987). The Social representations of mental illness in children and adults. In Doise, W. and Moscovici, S. (eds) *Current issues in European social psychology*, vol. 2. (pp 47-138). Cambridge: Cambridge University Press.
- Deutsch, M. and Gerrard, H.B. (1955). A study of normative and informational social influences upon individual judgement. *Journal of Abnormal and Social Psychology*, 51, 629-636.
- Diller, L. (2008, July 13th). Are our leading pediatricians drug industry shells? *San Francisco Chronicle*. Retrieved from <http://www.sfgate.com/opinion/article/ARE-OUR-LEADING-PEDIATRICIANS-DRUG-INDUSTRY-3204431.php>
- Dixit, S. (2005). Meaning and explanation of mental illness: a social representations approach. *Psychology and Developing Societies* 17 (1), 1-18.
- Dubicka B, Carlson GA, Vail A, Harrington R. (2008). Prepubertal mania: diagnostic differences between US and UK clinicians. *European Child and Adolescent Psychiatry*, 17, 153-61.
- Dumit, J. (2012). *Drugs for life: how pharmaceutical companies define our health*. Durham and London: Duke University Press.
- Duveen, G. (2001). Introduction: the power of ideas. In Moscovici, S. *Social representations: explorations in social psychology* (pp.1-17). New York, NY: New York University Press.
- Duveen, G. and Lloyd, B. (eds) (1990) *Social representations and the development of knowledge*. Cambridge: Cambridge University Press.
- Duveen, G. and Lloyd, B. (1993) An ethnographic approach to social representations. In Breakwell, G.M and Canter, D.V (eds) *Empirical approaches to social representations* (pp. 90-109). Oxford, Clarendon Press.
- Edwards, C., and Howlett, E. (2013). Putting knowledge to trial: 'ADHD' parents' and the evaluation of alternative therapeutic regimes. *Social Science and Medicine*, 81, 34- 41.

- Eisenberg, L. (1988) The social construction of mental illness. *Psychological Medicine*, (18) 1, 1-9.
- Evans, B. (2013, May 7th). Philosophy of mental illness public lecture: forum for European philosophy consilience panel discussion, London School of Economics.
- Express Scripts (2014, July 10). Children using psychotropics account for 16% of Medicaid drug costs. Retrieved from <http://lab.expressscripts.com/lab/insights/government-programs/children-using-psychotropics-account-for-16-of-medicaid-drug-costs>
- Farr, R.M. (1993). Theory and method in the study of social representations, in Breakwell, G.M and Canter, D.V (eds) *Empirical approaches to social representations*. (pp. 15-38). Oxford: Clarendon Press.
- Farr, R.M. (1995). Representations of health, illness and handicap in the mass media of communication: a theoretical overview. In Markova, I. and Farr, R. (eds) *Representations of health, illness and handicap* (pp. 3-30). Australia: Harwood Academic Publishers.
- Farr, R.M. (1998) *The roots of modern social psychology: 1872-1954*. Oxford: Blackwell Publishers.
- Ferner, R.E. and Scott, D.K. (1994). Whatalotwegot: the messages in drug advertisements. *British Medical Journal*, 309, 1734-1736.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations*, 7: 117-140.
- Finkel, A. (2012). Pediatric Bipolar: how'd we get here? [Blog post]. Retrieved from <http://candidaabrahamson.wordpress.com/2012/04/28/pediatric-bipolar-howd-we-get-here/>.
- Fleck, L. ([1935] 1979). *Genesis and development of a scientific fact*. Chicago and London: University of Chicago Press.
- Flick, U. (1998). *The psychology of the social*. Cambridge: Cambridge University Press.
- Flick, U. (2000). Qualitative inquiries into social representations of health. *Journal of Health Psychology*, 5(3), 315-324.
- Flick, U. Foster, J. and Caillud, S. (2015). Researching social representations. In Sammut, G., Andreouli, E., Gaskell, G., and Valsiner, J. (eds) *The Cambridge handbook of social representations*. (pp. 64-80). Cambridge: Cambridge University Press.

- Forgas, J.P., Williams, K.D. eds. (2001). *Social influence: direct and indirect processes*. Pennsylvania and E. Sussex: Psychology Press, Taylor and Francis Group.
- Foster, J.L.H (2001). Unification and differentiation: a study of the social representation of mental illness. *Papers on Social Representations*, 10, 3.1-3.8.
- Foster, J.L.H (2003). Beyond Otherness: controllability and location in mental health service clients' representations of mental health problems. *Journal of health Psychology*, 8, 632-644.
- Foster J.L.H (2010). Perpetuating stigma? Differences between advertisements for psychiatric and non-psychiatric medication in two professional journals. *Journal of mental Health*, 19 (1), 26-33.
- Foucault, M. (1971) *Madness and civilization: a history of insanity in the age of reason*, London: Routledge.
- Galanter, C. A. and Patel, V.L. (2005). Medical decision making: a selective review for child psychiatrists and psychologists. *Journal of Child Psychology and Psychiatry* 46 (7), 675–689.
- Gaskell, G. (2000). Individual and group interviews. In Bauer, M. and Gaskell, G. (eds) *Qualitative researching with text, image and sound: A practical handbook*. (pp. 38-74), London: Sage.
- Gaskell, G. (2001). Attitudes, social representations and beyond. In Deux, K. and Philogene, G. (eds) *Representations of the social: Bridging theoretical tradition*. (pp. 228-241). Oxford, Blackwell Publishers.
- Gaviria, M. (Producer, Director and Writer) (2008). The medicated child. [Television series episode]. In Mangini, T. (director) *Frontline*. Arlington, VA: PBS. Available from <http://www.pbs.org/wgbh/pages/frontline/medicatedchild/>
- Gervais, M.C., Morant, N. and Penn, G. (1999). Making sense of absence: towards a typology of absence in social representations theory and research. *Journal for the Theory of Social Behaviour*. 29 (4), 419-444.
- Giddens, A. (2002). *Runaway world: How globalisation is reshaping our lives*. London: Profile Books.
- Gillespie, A. (2008) Social representations, alternative representations and semantic barriers. *Journal for the Theory of Social Behaviour*, 38 (4), 375-391.

- Gillespie, A. (2012) *Position exchange: the social development of agency*. *New ideas in psychology* 30 (1), 32-46.
- Gillespie, A. and Cornish, F. (2010). Intersubjectivity: towards a dialogical analysis. *Journal for the Theory of Social Behaviour*, 40 (1), 19-46.
- Glaser, B. and Strauss, A. (1967). *The discovery of grounded theory: strategies for qualitative research*. New Brunswick and London: Aldine Transaction.
- Glass, K. (2014, February 9). Can a child be diagnosed with bipolar disorder? *The Sunday Times*. Retrieved from <http://www.thesundaytimes.co.uk/sto/Magazine/article1371135.ece>
- Gobo, G. (2008). 'Reconceptualizing generalization in qualitative research' in Alasuutari, P., Bickman, L., and Brannen, J. (eds.) *The SAGE handbook of social research methods* (pp. 193-213) London: Sage.
- Goldberg, C. (2007, February 15). Bipolar labels for children stir concern. *The Boston Globe*. Retrieved from: http://archive.boston.com/yourlife/health/children/articles/2007/02/15/bipolar_labels_for_children_stir_concern/?page=1
- Goldman, L.S. et al (1998). Diagnosis and treatment of attention-deficit/hyperactivity disorder in children and adolescents. *Journal of the American Medical Association*. 279 (14), 1100-1107.
- Goldman, R. and Montagne, M. (1986). Marketing 'mind mechanics': decoding antidepressant drug advertisements. *Social Science and Medicine*, 22 (10), 1047-1058.
- Grosios, K., Gahan, P.B., and Burbridge J. (2010). Overview of healthcare in the UK. *Journal of the European Association for Predictive, Preventive and Personalised Medicine*, 1 (4), 529-534.
- Hacking, I. (1995). The looping effects of human kinds. *Causal Cognition*, 12, 351-383.
- Hacking, I. (1998). *Mad travelers: reflections on the reality of transient mental illnesses*. Cambridge: Harvard University Press.
- Hacking, I. (1999). *The social construction of what?* Cambridge: Harvard University Press.
- Harre, R (1998). The epistemology of social representations. In Flick, U (ed.) *The psychology of the social* (pp. 129-137). Cambridge: Cambridge University Press.

Harris, G. (2008, November 24). Research center tied to drug company. *The New York Times*, A22. Retrieved October 22, 2014, from http://www.nytimes.com/2008/11/25/health/25psych.html?_r=0

Harris, G. (2009, March 20). Drug maker told studies would aid it. *The New York Times*, A16. Retrieved October 22, 2014, from <http://www.nytimes.com/2009/03/20/us/20psych.html>

Harris, G. (2009b, September 2). Pfizer pays \$2.3 billion to settle marketing case. *The New York Times*. Retrieved from http://www.nytimes.com/2009/09/03/business/03health.html?_r=0

Harris, J. (2005) Child & adolescent psychiatry: the increased diagnosis of “juvenile bipolar disorder”: what are we treating? *Psychiatric Services*, 56, 529 – 531.

Harrison, J.N., Cluxton-Keller, F., and Gross, D. (2012). Antipsychotic medication prescribing trends in children and adolescents. *Journal of Pediatric Healthcare*, 26 (2), 139-145.

Hamilton, J. (2004). Evidence-based thinking and the alliance with parents. *Journal of the American Academy of Child and Adolescent Psychiatry*. 43(1), 105-108

Healy, D. (2006). The latest mania: Selling bipolar disorder. *PLoS Medicine*. Retrieved from <http://dx.doi.org/10.1371/journal.pmed.0030185>. November 11, 2012.

Healy, D. (2007). Folie to folly: The modern mania for bipolar disorders and mood stabilizers” in Tone, A. and Siegel Watkins, E. (eds) *Medicating modern America: Prescription drugs in history*, (pp 42-62). New York, NY: New York University Press.

Healy, D. (2008). *Mania: A short history of bipolar disorder*. Baltimore: The Johns Hopkins University Press.

Healy, D. and LeNoury, J. (2007). Paediatric bipolar disorder: An object of study in the creation of an illness. *International Journal of Risk and Safety in Medicine*, 19, 209-221.

Hermans, H.J.M. (2001). The dialogical Self: toward a theory of personal and cultural positioning. *Culture & Psychology*, 7, 243-281.

Herzlich, C. (1973) *Health and illness: A social psychological analysis*. London: Academic Press for the European Association of Experimental Social psychology.

- Hovland, C.I., Janis, I.L. and Kelley, H.H. (1953). *Communication and Persuasion: Psychological Studies of Opinion Change*. New Haven: Yale University Press.
- Illich, I. (1976). *Medical nemesis: The expropriation of health*. New York, NY: Pantheon Books.
- Insel, T. (2013, April 29). Director's blog: transforming diagnosis [Weblog]. Retrieved from <http://www.nimh.nih.gov/about/director/2013/transforming-diagnosis.shtml>
- James, A. (2010). Prescribing antipsychotics for children and adolescents. *Advances in Psychiatric Treatment*, 16, 63-75.
- James, A. Hoang, U., Seagroatt, V., Clacy, J. Goldacre, M., and Leibenluft, E. (2014). A comparison of American and English hospital discharge rates for pediatric bipolar disorder, 2000-2010. *Journal of the American Academy of Child and Adolescent Psychiatry*, 53 (6), 614-624.
- Janis, I.L. (1972). *Victims of Groupthink: A Psychological Study of Foreign Policy Decisions and Fiascoes*. Boston, MA: Houghton Mifflin.
- Jaspers, K. (1963). *General psychopathology*. Chicago, IL: University of Chicago Press.
- Jodelet, D. (1991) *Madness and social representations*. Hertfordshire: Hemel Hempstead, Harvester Wheatsheaf.
- Jodelet, D. (2013). Encounters between forms of knowledge. *Papers on Social Representations*, 22, 9.1-9.20.
- Joffe, H. (2002). Social representations and health psychology. *Social Science Information*, 41 (4), 559-580.
- Joffe, H. (2003). Risk: From perception to social representation. *British Journal of Social Psychology*, 42, 55-73.
- Jovchelovitch, S. (2001). Social representations, public life and social construction. In Deux, K. and Philogene, G. (eds) *Representations of the social: Bridging theoretical tradition*. (pp. 165-182). Oxford, Blackwell Publishers.
- Jovchelovitch, S. (2002). Re-thinking the diversity of knowledge : cognitive polyphasia, belief and representation [online]. London: LSE Research Online. Available at: <http://eprints.lse.ac.uk/2628>. Available in LSE Research Online: August 2007.
- Jovchelovitch, S. (2007). *Knowledge in Context: Representations, community and Culture*. London and New York: Routledge Press.

- Jovchelovitch, S. (2008). Rehabilitation of common sense: social representations, science and polyphasia. *Journal for the Theory of Social Behaviour* 38 (4), 431-449.
- Jovchelovitch, S. and Gervais, M. (1998). *The health beliefs of the Chinese community in England: A qualitative research study*. London: Health Education Authority.
- Jutel, A.G. (2011). *Putting a name to it: Diagnosis in contemporary society*. Baltimore: Johns Hopkins University Press.
- Kaplan, S.L. (2011). U.S children misdiagnosed with bipolar disorder. *Newsweek Magazine*. 157 (26). Retrieved from <http://europe.newsweek.com/us-children-misdiagnosed-bipolar-disorder-67871?rm=eu>
- Kaplan, S. (2012, January 27). The world series of child bipolar disorder. *Psychology Today*. Retrieved from <https://www.psychologytoday.com/blog/your-child-does-not-have-bipolar-disorder/201201/the-world-series-child-bipolar-disorder>
- Kirmayer, L.J. and Minas, H. (2000). The future of cultural psychiatry: An international perspective. *Canadian Journal of Psychiatry*, 45, 438-446.
- Kirmayer, L.J. and Raikhel, E. (2009). From Amrita to substance D: psychopharmacology, political economy, and technologies of the Self. *Transcultural Psychiatry*, 46 (1), 5-15.
- Kluger, J. and Song, S. (2002, August 19). Young and bipolar. *Time Magazine*. Retrieved from <http://content.time.com/time/magazine/article/0,9171,1003048,00.html>
- Kronberger, N. (2014). Of worlds and objects: scientific knowledge and its publics. In Sammut, G., Andreouli, E., Gaskell, G. and Valsiner, J. (eds) *The Cambridge Handbook of Social Representations* (pp. 358-368). Cambridge: Cambridge University Press.
- Kuhn, T. S. (1962). *The structure of scientific revolutions*. Chicago: University of Chicago Press.
- Kuhn, T.S. (1979). Forward. In Fleck, L. ([1935] 1979). *Genesis and development of a scientific fact*, (pp. vii-xi). Chicago and London: The University of Chicago Press.
- Lagache, D. (2001) 'Forward' to S. Moscovici, *Social Representations: Explorations in Social Psychology*. Edited by G. Duveen. New York: New York University Press.
- Leibenluft, E. (2008). Pediatric bipolar disorder comes of age. *Archives of General Psychiatry*, 65 (10), 1122-1124.

Linell, P. (2006). Essentials of dialogism: aspects and elements of a dialogical approach to language, communication and cognition.
<<http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.203.831&rep=rep1&type=pdf>>

Linell, P. (2009). *Rethinking language, mind and world dialogically: interactional and contextual theories of human sense making*. Charlotte, NC: Information Age Publishing,

Linell, P. and Markova, I. (2014). Epilogue: trust seen as embodiment, culture, language and morality' in (Linell and Markova, eds.) *Dialogical approaches to trust in communication*. Charlotte, NC: Information Age Publishing.

Littlewood, R. (2002). *Pathologies of the west: An anthropology of mental illness in Europe and America*. Ithaca, New York: Cornell University Press.

Lopez, S.R. and Guarnaccia, P.J. (2000). Cultural psychopathology: uncovering the social world of mental illness. *Annual Review of Psychology*, 51, 571-598.

Lowy, I. (1988). Ludwik Fleck on the social construction of medical knowledge. *Sociology of Health and Illness*, 10 (2), 133-155.

Luhrmann, T. (2015, Jan. 17). Redefining mental illness. *The New York Times*. Retrieved from <http://www.nytimes.com/2015/01/18/opinion/sunday/t-m-luhrmann-redefining-mental-illness.html>

Lupton, D. (2003). *Medicine as culture: Illness, disease and the body in western societies* (2nd edn). London: Sage Publications Ltd.

Marglin, F. (1990). Smallpox in two systems of knowledge. In Marglin, F.A. and Marglin, S.A. *Dominating knowledge: Development, culture and resistance* (pp.102-144). Oxford: Oxford University Press.

Marková, I. (2003). *Dialogicality and social representations: The dynamics of mind*. Cambridge: Cambridge University Press.

Marková, I. (2006). On 'the inner alter' in dialogue. *International Journal for Dialogical Science*, 1 (1), 125-147.

Marková, I. (2008). The Epistemological Significance of the Theory of Social Representations, *Journal for the Theory of Social Behavior*, 38, 4: 461-487.

Marková, I. (2014). Social representations, dialogicality and trust. *PS410 lecture, Department of social psychology*, February 6, 2014, London School of Economics

Moncrieff, J. (2008). *The myth of the chemical cure: A critique of psychiatric drug*

treatment. Hampshire: Palgrave Macmillan.

Moncrieff, J. (2014). 'The medicalisation of 'ups and downs': the marketing of the new bipolar disorder. *Transcultural Psychiatry*, 0 (0), 1-18: DOI: 10.1177/1363461514530024

Moncrieff, J. and Timimi, S. (2013) The social and cultural construction of psychiatric knowledge: an analysis of NICE guidelines on depression and ADHD, *Anthropology & Medicine*, 20 (1), 59-71. DOI: 10.1080/13648470.2012.747591

Morant, N. (1998). The social representation of mental ill-health in communities of mental health practitioners in the UK and France. *Social Sciences Information*, 45, 663-685.

Morant, N. (2006). Social representations and professional knowledge: The representation of mental illness among mental health practitioners. *British Journal of Social Psychology*, 45, 817-838.

Moreno, C., Laje, G., Blanco, C., Jiang, H., Schmidt, A., and Olfson, M. (2007). National trends in out patient diagnosis and treatment of bipolar disorder in youth. *Archives of General Psychiatry*, 64 (9), 1032-1039.

Moscovici, S. ([1961] 2008). *Psychoanalysis: its image and its public*. Cambridge: Polity Press.

Moscovici, S. (1976). *Social influence and social change*. London, Academic Press (European Monographs in Social Psychology).

Moscovici, S. (1984). The phenomenon of social representations. In Farr, R. and Moscovici, S. (eds) *Social representations*. (pp. 3-69). Cambridge: Cambridge University Press.

Moscovici, S. (2001). Why a theory of social representations? In Deux, K. and Philogene, G. (eds) *Representations of the social: Bridging theoretical tradition*. (pp. 8-36). Oxford, Blackwell Publishers.

Moscovici, S. and Duveen, G. (2000). *Social representations: Explorations in social psychology*. New York: New York University Press.

Murphy, D. (2006). *Psychiatry in the scientific Image*. Cambridge and London: MIT Press.

National Institute of Mental Health (2006). 'Largest Study to Date on Pediatric Bipolar Disorder Describes Disease Characteristics And Short-Term Outcomes'. Available online at <http://www.nimh.nih.gov/science-news/2006/largest-study-to-date-on-pediatric-bipolar-disorder-describes-disease-characteristics-and-short-term-outcomes.shtml>. Retrieved 10/11/2012.

Neill, J.R. (1989). A social history of psychotropic drug advertisements. *Social Science and Medicine*, 28(4), 333–338.

Ng, S. H. (2001) Influencing through the power of language. In Forgas, J.P., Williams, K.D. (eds) *Social influence: direct and indirect processes* (pp. 185-198). Pennsylvania and E. Sussex: Psychology Press, Taylor and Francis Group

Olfson, M., Blanco, C., Liu, S.M., Wang, S., and Correll, C.U. (2012). National trends in the office-based treatment of children, adolescents, and adults with antipsychotics. *Archives of General Psychiatry*, 69 (12), 1247-1256.

O'Meara, K.P. (2013, March 25). Pharma funding & shrinks for sale—the creation of pre-school age bipolar epidemic [Weblog]. Retrieved from <http://www.cchrnt.org/2013/03/25/pharma-funding-and-shrinks-for-sale-the-creation-of-pre-school-age-bipolar-epidemic/>

Papolos, D. and Papolos, J. (2000). *The bipolar child: The definitive and reassuring guide to childhood's most misunderstood disorder*. New York, NY: Broadway Books.

Parens, E. And Johnston, J. (2010). Controversies concerning the diagnosis and treatment of bipolar disorder in children. *Child and Adolescent Psychiatry and Mental Health*, 4 (9), 1-14.

Parry, P. and Levin, E. (2012). Pediatric bipolar disorder in an era of “mindless psychiatry”. *Journal of Trauma and Dissociation*, 13, 51-68.

Pavuluri, M. Birmaher, B. and Naylor, M. (2005). Pediatric bipolar disorder: a review of the past 10 years. *Journal of the American Academy of Child and Adolescent Psychiatry*, 44 (9), 846-871.

Penn, G. (2000). Semiotic analysis of still images. In bauer, M. and Gaskell, G. (eds) *Qualitative researching with text, image and sound: a practical handbook*. London, Thousand Oaks, New Delhi: Sage Publications.

Petty, R.E. and Cacioppo, J.T. (1986). The elaboration likelihood model of persuasion. *Advances in Experimental Social psychology*, 19, 123-162.

Piaget, J. (1929). *The Child's conception of the world*. Trowbridge & London: Redwood Press Limited.

Pickersgill, M. (2010). Psyche, soma and science studies: new directions in the sociology of mental health and illness. *Journal of Mental Health*, 19(4), 382-392.

Post, R.M. (2009). Childhood onset bipolar disorder: the perfect storm. *Psychiatric Annals*, 39 (10), 879- 886.

- Quinn J, Nangle M, Casey P.R. (1997). Analysis of psychotropic drug advertising. *Psychiatric Bulletin*, 21, 597-9.
- Rani, F., Murray, M. P., Byrne, P., and Wong, I. (2008). Epidemiologic features of antipsychotic prescribing to children and adolescents in primary care in the United Kingdom. *Pediatrics*, 121 (5), 1002-1009.
- Robson, C. (2011). *Real world research: A resource for social scientists and practitioner-researchers*. Oxford: Blackwell Publishers.
- Rose, D. (2001). *Users' Voices: The perspective of mental health service users on community and hospital care*. London: Sainsbury Centre for Mental Health.
- Rose, G. (2001). *Visual methodologies: An introduction to the interpretation of visual materials*. London: Sage.
- Rose, N. (1996). *Inventing ourselves: Psychology, power and personhood*. Cambridge: Cambridge University Press.
- Rose, N. (2004). Becoming neurochemical selves' in Nico Stehr (ed) *Biotechnology, commerce and civil society*. (pp.89-128) Somerset : Transaction Press.
- Rose, N. (2006). Disorders Without Borders? The Expanding Scope of Psychiatric Practice. *BioSocieties*, 1, 465-484.
- Rose, N. (2007). Psycho pharmaceuticals in Europe. In Knapp, M., McDaid, D., Mossialos, E., and Thornicroft, G. (eds) *Mental health policy and practice across Europe: The future direction of mental health care*. (pp. 147-183.) Berkshire England: Open University Press, McGraw Hill.
- Rose, N. (2010). Normality and pathology in a biomedical age. *The Sociological Review* 57, s2, 66-83.
- Rosenberg, C.E. (2006). Contested boundaries: Psychiatry, disease and diagnosis. *Perspectives in Biology and Medicine*, 49 (3), 407-424.
- Saldana, J. (2013). *The Coding manual for qualitative researchers*. London: Sage.
- Sammut, G. and Bauer, M. (2011). Social influence: modes and modalities. In Hook, D., Franks, B. and Bauer, M. (eds) *The Social psychology of communication*. (pp. 87-106). London: Palgrave Macmillan.

- Schmitz, M.F., Filippone, P. and Edelman, E.M. (2003) Social representations of attention deficit hyperactivity disorder, 1988-1997. *Culture and Psychology* 9 (4), 383-406.
- Seale, C. (2003). Health and Media: An Overview. *Sociology of Health and Illness*. 25, 6: 513-531.
- Seale, C. and Pattinson, S. (eds) (1994). *Medical knowledge: Doubt and certainty*. Buckingham: Open University Press.
- Sillup, G. and Makowska, M. (2013, September 6). Different healthcare systems influence marketing practices by pharmaceutical companies [Weblog]. Retrieved <http://www.pharmaphorum.com/articles/different-healthcare-systems-influence-marketing-practices-by-pharmaceutical-companies>
- Singh, I. (2002). Biology in context: social and cultural perspectives on ADHD. *Children and Society*, 16, 360-367.
- Singh, I. (2006). A framework for understanding trends in ADHD diagnoses and stimulant drug treatment: schools and schooling as a case study. *BioSocieties*, 1, 439-452.
- Singh, I. (2007). Not just naughty: 50 years of stimulant drug advertising. In Tone, A. and Siegel Watkins, E. (eds) *Medicating modern America: prescription drugs in history*. (pp. 131-155.). New York and London: New York University Press.
- Singh, I. (2011). A disorder of anger and aggression: children's perspectives on attention deficit hyperactivity disorder in the UK. *Social Science and Medicine*, 73, 889-896.
- Singh, I. (2011a). Listening to children with ADHD. In E. Parens and J. Johnston, "Troubled children: Diagnosing, treating, and attending to context," special report. [Hastings Center Report](#), 41 (2).
- Singh, I. (2012). Not robots: children's perspectives on authenticity, moral agency and stimulant drug treatments. *Journal of Medical Ethics*, 359-366. doi:10.1136/medethics-2011-100224
- Singh, I. (2014, September). ADHD: cultural differences between the US and the UK. Paper presented at the UK Adult ADHD Network (UKAAN) Congress, ADHD: mind, brain and Body. London, UK. Retrieved from: www.ukaan.org/getfile.php?type=site_documents&id=2014%20Iina%20Singh
- Soni, A. (2014). The five most costly children's conditions, 2011: estimates for U.S. civilian non-institutionalized children, ages 0-17, *Medical Expenditure Panel Survey, Statistical Brief* 434.
- Soutullo, C.A., Chang, K.D., Diez-Suarez, A., Figueiroa-Quintana, A., Escamilla-

- Canales, I., Rapado-Castro, M., Ortuno, F., (2005). Bipolar disorder in children and adolescents: international perspective on epidemiology and phenomenology. *Bipolar Disorders*, 7, 497-506.
- Stebbins, M., and Corcoran, J. (2016). Pediatric bipolar disorder: the child psychiatrist perspective. *Child and Adolescent Social Work Journal*, 33, 115-122.
- Steinman, M., Bero, L., Chren, M.M., and Landefeld, S. (2006). Narrative review: the promotion of gabapentin: an analysis of internal industry documents. *Annals of Internal Medicine*: 145(4), 284-293.doi:10.7326/0003-4819-145-4-200608150-00008
- Stringaris, A. (2011). Irritability in children and adolescents: a challenge for DSM-5. *European Child and Adolescent Psychiatry*, 20, 61-66.
- Sullivan, P. (2012). *Qualitative data analysis using a dialogical approach*. London: Sage.
- Summerfield, D. (2001). The invention of post-traumatic stress disorder and the social usefulness of a psychiatric category. *British Medical Journal*, 33 (322), 95-98.
- Summerfield, D. (2004). 'Cross cultural perspectives on the medicalisation of human suffering' in Rosen, G. (ed.) *Post traumatic stress disorder: Issues and controversies*. (pp. 233-246) East Sussex: John Wiley and Sons.
- Summerfield, D. (2008). How scientifically valid is the knowledge base of global mental health? *British Medical Journal*, 3 (336), 992-994.
- Szasz, T. (1974). *The myth of mental illness*. New York, NY: Harper and Row.
- Thomas, K. (2013, November 4). J&J to Pay \$2.2 Billion in Risperdal Settlement. *New York Times*, B1. Retrieved from <http://www.nytimes.com/2013/11/05/business/johnson-johnson-to-settle-risperdal-improper-marketing-case.html>
- Timimi, S. (2003) Developing nontoxic approaches to helping children who could be diagnosed with ADHD and their families: reflections of a United Kingdom clinician. *Ethical Human Psychology and Psychiatry*, 6, 41-52.
- Timimi, S. (2004). Rethinking childhood depression. *British Medical Journal*, 329 (7479), 1394-1396.
- Timimi, S. (2006). Children's mental health: the role of culture, markets and prescribed drugs. *Public Policy Research*, 13 (1), 35-42.
- Timimi, S. and Taylor, E. (2004). In debate: ADHD is best understood as a cultural

Construct. *British Journal of Psychiatry*, 184, 8-9.

Todd, S. and Jones, S. (2003). 'Mum's the word!': maternal accounts of dealings with the professional world. *Journal of Applied Research in Intellectual Disabilities*, 16: 229-244.

Tone, A. and Siegel Watkins, E. (2007). *Medicating modern America: prescription drugs in history*. New York and London: New York University Press, 1-14.

Towbin, K., Axelson, D., Leibenluft, E. and Birmaher, B. (2013). Differentiating bipolar disorder—not Otherwise specified and severe mood dysregulation. *Journal of the American Academy of Child and Adolescent Psychiatry*, 52, 5: 466-481.

Turner, J. (1991). *Social influence*. Milton Keynes, Open University Press.

Van Bevel, R. and Gaskell, G. (2004). Narrative and systematic models of economic thinking. *Culture & Psychology*. 10, 4: 417-439.

Vaughan, C. (2011). 'Dialogue, critical consciousness and praxis. (In Hook, D. Franks, B. and Bauer, M. eds) *The Social Psychology of Communication*. (pp. 46-66) Palgrave Macmillan.

Valsiner, J. and Han, G. (2008). Where is culture within the dialogical perspectives of the Self? *International Journal for Dialogical Science*, 3 (1), 1-8.

Verhaege, P. (2014). *What about me? The struggle for identity in a market-based society*. Melbourne, London: Scribe.

Volkmar, F.R. (2002). Changing perspectives on mood disorders in children. *American Journal of Psychiatry*, 159 (6), 893-894.

Vuckovic, N. and Nichter, M. (1997). Changing patterns of pharmaceutical practice in the United States. *Social Science and Medicine*, 44, 9: 1285-1302.

Wagner, W., Duveen, G., Farr, R., Jovchelovitch, S., Lorenzi-Gioldi, F., Markova, I., and Rose, D. (1999). Theory and methods of social representations. *Asian Journal of Social Psychology*, 2 (1), 95-125.

Wang, S. (2012, October 16). The long battle to rethink mental illness in children. *The Wall Street Journal*. Retrieved:
<http://www.wsj.com/articles/SB10000872396390444273704577633412579112188>

Wedge, M. (2015, April 23) . The ADHD fallacy: its time to stop treating childhood as a disease. *Time magazine*. Retrieved from
<http://time.com/3822755/adhd-disease-called-childhood/>

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

Wozniak, J., Beiderman, J., Kiely, K., Ablon, J.S., Faraone, S.V., Mundy, E., and Mennin, D. (1995) Mania-like symptoms suggestive of childhood-onset bipolar disorder in clinically referred children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34 (7), 867-876.

Zani, B. (1993). Social representations of mental illness: lay and professional Perspectives. In Breakwell, G.M. and Canter, D.V (eds) *Empirical approaches to social representations*. (315-329) Oxford: Clarendon Press.

Zani, B. (1995). The mentally ill person and Others: social representations and interactive strategies. In Markova, I. and Farr, R. (eds) *Representations of health, illness and handicap*. (pp. 145-162). Switzerland: Harwood Academic Publishers.

Zarathustra (2010, March 19) Can small children get bipolar disorder? [Weblog] Retrieved from mind.org.uk.