

Remembering Turbulent Times:
Accounting for Adult ADHD through the
reconstruction of childhood

Claude Jusselin

Department of Anthropology, Goldsmiths, University of London

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GOLDSMITHS, UNIVERSITY OF LONDON

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I, Claude Jusselin, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Abstract

This thesis explores the diagnosis of ADHD among adults in the UK. The condition has only recently been defined as a lifelong disorder and extended from childhood to adulthood. Through ethnographic research in a specialist psychiatric clinic and with a patient organisation, this thesis traces the diagnostic process as it takes place in both sites and also between them. It highlights the role of memory practices in the many versions of ADHD that circulate.

I outline clinical and lay practices of identifying ADHD. Individuals in the support groups identified with the diagnosis through recognising themselves in other people, as if in a mirror, which I describe as 'moments of recognition'. In the clinic, the elicitation of medical histories brought contrasting memory practices to the fore, as patients sought evidence from their childhood necessary to a formal diagnosis. Although these memory practices appear distinct, they are combined in practice.

This fieldwork led me to concentrate less on the potentially negative medicalisation of human experiences, the main topic of social science research in the field, than the ways in which memory practices were mobilised. These practices were key to the production of evidence-based diagnosis in the clinic and to collective archives in the support groups. Moreover, both types of memory practices informed wider relations. Thus, I explore unexpected ways of making kin such as the manner in which children, more commonly diagnosed with ADHD than adults, 'made' their parents in the light of a shared condition. Furthermore, concepts of neurobiology led some research participants to recognise strangers as 'family', linked by a common factor and celebrated as neurodiversity.

This thesis attends not only to the emerging and mostly unexamined lived experiences of adults with ADHD, but it also contributes to an anthropological exploration of social and caring practices more broadly.

Table of Contents

Acknowledgements.....	3
Abstract.....	5
Table of Contents.....	6
List of Abbreviations and Acronyms.....	9
Chapter One: Introduction.....	10
ADHD in adults	14
Medical and lay descriptions	14
Demography.....	17
Multiple already.....	18
Is it real?.....	19
Forces of medicalisation	19
Materials and practices that shape realities.....	20
The diagnostic process.....	22
A social process rather than clinical moment.....	22
The role of remembering and of family resemblance	23
Methods and orientation.....	26
Field sites	26
Clinical site	27
Patient Organisations and Support Groups sites.....	29
Words, voice and anonymity	32
Thesis outline and chapter summaries.....	36
Chapter Two: ADHD from childhood to adulthood: how children stopped ‘growing out of it’... 39	
Pushing back the history of ADHD	41
Working memory rather than textbook memory.....	44
A foot in each camp	46
‘Repairing a plane while keeping it flying’	50
Taking a ‘crosswalk’ to harmonisation.....	55

Remembering forgetfulness	59
Being a good historian	64
Conclusion.....	68
Chapter Three The scaffolding of memory: the support structures for remembering	70
Introduction	70
“Memories are about what happened then, but they are also about who we are now.”	73
“Sharing is like taking medicine through the ears”.....	80
Pre-frontal cortex device	88
Conclusion.....	92
Chapter Four Techniques and strategies: absorbing inattention into everyday life	93
Living with untreated symptoms	93
The casual straightjacket	98
Strengthening the muscle	100
Keeping myself in check.....	105
Burdened with potential.....	109
Conclusion.....	115
Chapter Five Moments of Recognition: identifying ADHD inside and outside of the clinic	117
Newcomers	117
That’s me! Recognising oneself as if in a mirror.....	121
Beyond recognition.....	125
Questions, scores and algorithms.....	130
To recollect the old, to produce the new: that is the task of Anamnesis.....	134
Chapter Six Family resemblance: how children make adults	143
New kinship imaginary.....	143
The child is father of the man	146
The future in the mirror	149
The parent of a child with ADHD	153
The paradox of kinship.....	155
Running wild in the family	161
Chapter Seven Extended kinship: diversity in the support groups.....	168
“My butterfly brain is a curse and a blessing”	168

The side effects of medicalisation	174
‘Diversity is not disease; the anomalous is not the pathological.’	179
The gift of neurodiversity.....	184
Autism is the second cousin of ADHD.....	189
Conclusion.....	193
Chapter Eight Ordinary problems: living with ADHD	196
Specialist training for an ordinary disorder	196
People with ADHD are extra-normal because being normal is too ordinary	200
Pills don’t build skills.....	206
What’s in a word	211
« Les gens vulnérables n’ont rien d’exceptionnel ».....	218
Chapter Nine An open window	224
A window of time.....	224
Influential methodologies and concepts	226
Collaboration.....	229
Widening the diagnostic process	232
‘Remembering is the discovery of kinship connections’	235
Vulnerability as a shared condition	239
What next?.....	243
Bibliography	247

List of Abbreviations and Acronyms

AADD-UK – Adult Attention Deficit Disorder UK

ADDISS – Attention Deficit Disorder Information and Support Service

ADHD – Attention Deficit Hyperactivity Disorder

CAADDID – Conners' Adult ADHD Diagnostic Interview for DSM-IV™

DIVA – Diagnostic Interview for ADHD in adults

DNA – Did Not Attend

DSM – The Diagnostic and Statistical Manual of Mental Disorders

GP – General Practitioner

ICD – International Classification of Diseases

MSE – Mental State Examination

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

SpR – Specialist Registrar

UKAAN – UK Adult ADHD Network

Chapter One Introduction

In September 2012, I was sitting with members of a support group for adults with Attention Deficit Hyperactivity Disorder (ADHD) that, unlike others in the UK, was run in a public place, a well-known coffeehouse chain. During that evening, it became clear that one of the people sitting amongst us was not there to discuss ADHD but to enjoy the coffee. He asked the small group of three that included myself, if this was some kind of ‘meet-up’. The response from one of my companions was hesitant, “yes kind of, it is for people with ADHD”. The customer looked back at us with surprise and said: “I thought only children had ADHD.” The two men who were sitting with me explained how they always had problems as children, one with inattention and the other with hyperactivity, but they had not been diagnosed then, which had caused them endless problems and crises as they grew older. The customer showed interest and in a friendly manner said that he couldn’t see anything wrong with them and asked what they did in the meet-up, what kind of activities. The answer was quick to come – “we drink coffee and talk of what ADHD is about, how it affects our life, how to get diagnosed and how treatment may be helpful”. One of the men described how being able to meet with people who had the same problems was really helpful; it made him feel that he was not alone. Coming to this group that night had made him feel that he was with like-minded people, that he could be himself and people understood exactly how he felt. The customer nodded and wished us all good luck before making his exit.

I begin with this brief story because the dialogue it contains exemplifies both the public perception of ADHD as solely a childhood disorder and the necessity for adults with ADHD to explain their difficulties and find a supportive environment to share their experience. This entry scene also highlights the importance of support groups as field sites in my research and the methodological choice to extend my fieldwork beyond clinical sites in order to capture the lived experiences and representations of ADHD in adults. My visit to this support group happened at the beginning of my fieldwork and the questions raised by the customer led me to a series of interrogations of my own. How does a childhood disorder, arguably still contested, become re-imagined in adulthood? Do

symptoms remain the same from child to adult? How differently are they experienced? I wondered what changes had taken place to explain that children were no longer growing out of ADHD.

ADHD was first used as a diagnostic category in the revised third version of the American Diagnostic and Statistical Manual (DSM) in 1987 (American Psychiatric Association, 1987) and was the most recent acronym for the clustering of symptoms that combine Inattention, Hyperactivity and Impulsivity. Since the second part of the 20th century it has had other nomenclatures; ADD (Attention and Deficit Disorder with or without Hyperactivity) (American Psychiatric Association, 1987; 1980), Hyperkinetic reaction in childhood (APA, 1968) or MBD (Minimal Brain Dysfunction), (Clements, 1966)¹. What these classifications have in common is that they are all applied to disorders in childhood only, and symptoms are said to reduce and wane through adolescence, becoming absent in adulthood.

It was not until the 1990s that ADHD became a diagnosis applicable to adults, formally identified in DSM VI (APA, 1994) and further reaffirmed through studies that followed children diagnosed with ADD/ADHD into adulthood (Barkley et al., 1990; Mannuzza et al., 1993; Weiss and Hechtman, 1993). Whilst psychiatric classifications made it possible to diagnose children and adults with ADHD from the mid-1990s onwards, their uptake in clinical practice in the UK remained rare for children until the early 2000s (Jick et al., 2004) and was adopted later still for adults (McCarthy et al., 2012). It follows that adults in the UK who are currently over the age of 30 years old could not have been diagnosed with ADHD in their childhood: consequently, if they faced difficulties related to inattention, hyperactivity and impulsivity, they could not have had access to treatment until the late 2000s when diagnosing adults with ADHD became more commonly supported by the guidance published by the National Institute for Health and Care Excellence (NICE, 2009). My research is concerned with this unique moment in time, in which a large cohort of adults living in the UK² can only now be considered for diagnosis and treatment for ADHD. We can imagine that the detection of

¹ For further details on these and earlier diagnostic nomenclatures see: (Barkley, 2006; Conners, 2000; Lange et al., 2010; Taylor, 2011).

² A conservative figure of the prevalence of ADHD in adults in the UK suggests that 2.5% of the adult population may have ADHD, (UKAAN, 2013).

ADHD during adulthood will eventually reduce as children continue to be diagnosed and treated at an ever growing rate (McCarthy et al., 2012). It is this particular congruence of time, place and condition that this study aims to address by asking – what are the practices in place that make the diagnosis of ADHD in adults possible now? Furthermore, this window of time provides us with a particular opportunity to examine how the process of diagnosis can lead to a reconceptualisation of the lifecourse.

In order to explore this question, I situated my research in the juncture between a specialist clinic *for* adults with ADHD and support groups run *by* adults with ADHD. My movement between one and the other allowed me to observe the interplay between the clinic and support groups and to see how they contributed in both divergent and convergent ways towards the making of ADHD.

As my fieldwork advanced in both sets of sites, I was struck by the heterogeneity of the people I met. The stories they offered to clinicians and each other seemed varied, presenting very different life trajectories within diverse social backgrounds and they reflected an almost equal gender distribution. The two men mentioned above were in their late thirties, as were the majority of the people I met in the support groups, and had only recently been diagnosed and treated. This thesis asks the following questions: what are the implications for living with undiagnosed and untreated symptoms for decades? What other means do people develop to counteract the difficulties that ADHD may be causing them and those around them? How are relationships within the family and beyond affected by this condition? Attending support groups and being with like-minded people was described as helpful, but what was it that took place in the group setting that made it so beneficial? The reference to crisis made by one of the two men was echoed many times by others in different support groups and I wondered about the fragility of day-to-day life which is put at risk through inattention or hyperactivity. Faced with the multiple ways that ADHD is enacted and presented, what were the practices in support groups and the clinic that made it possible for this diversity to converge and be bundled into one diagnosis? What do clinicians, patients, support group members, relatives and partners do in order for ADHD in adults to stabilise as a diagnosis at the beginning of the 21st century in the UK?

This introductory chapter aims to map the context of these questions in four parts to set the background for the arguments which this thesis will advance. I will begin by providing medical and lay descriptions of ADHD, including criteria and demographic data for the cohort involved and will further explore the different ways that ADHD is presented. The second part of this introduction will engage with a question that was persistently asked throughout my fieldwork when meeting people outside the main sites of my research: is ADHD real or not? Social scientists have been particularly interested by this question and this section explores their role in the making of one kind of ADHD. In contrast to this approach which considers ADHD as ‘socially constructed’ within a controversial field led by Big Pharma and medical hubris, this thesis aims to extend the interest to the practices that make ADHD in other spheres too. The support groups I attended provided a pragmatic arena where the issues faced by their members were mobilised, not so as to understand what ADHD is in the abstract, but to develop first-hand knowledge about living with ADHD. How did people live with the symptoms, the impairments, as well as with the controversies and the problems they caused? The medical description of ADHD includes multiple sub-types of hyperactivity, inattention and mood dysfunction, as well as a multifactorial aetiology. Thus in this context, I found that multiplicity was already an accepted part of the vocabulary of ADHD in the clinic. The fact that there are multiple realities of ADHD, rather than different ways to theorise it, will become more evident as I follow and elaborate on the practices of clinicians in the making of ADHD.

The ensuing chapters will show how paying attention to the description of everyday experiences of ADHD in support groups presents yet more versions of the condition, relating not only to forgetfulness and memory problems, but also to the concept of ADHD as a gift, an asset and an alternative form of life. Extending my attention to this less visible arena will reveal the diversity and roles of unexpected actors and actants (Latour, 2005) in the making of ADHD, ranging from stimulant medication to old school reports. This thesis will argue that the multiple realities of ADHD are the results of practices in the clinic and support groups and of the interactions between them. It will describe how those practices, based on ideas about memory, kinship and ordinary life, that at times fuel controversies, are also showing ADHD to be fundamentally a social experience that happens

between people and in their relation with the world. Ultimately I am suggesting that the care which people give to each other when faced with the fragility of everyday life constitutes a certain way of being in the world. What seems a theoretical move towards ontology and a concern for reality is, for the purpose of this thesis, also a methodological choice, what Annemarie Mol (2003) described as a 'praxiography'.

Tracing the practices associated with the diagnostic process will help navigate the different sites and highlight connections between them. Thus the third and fourth parts of this introduction will describe the methods and orientation of my study and provide a rationale for choosing to follow and trace the diagnostic process.

ADHD in adults

Medical and lay descriptions

In the last fifteen to twenty years, ADHD has been re-considered and applied to adult populations in the UK. International psychiatric classifications have adapted their descriptions of symptoms to the context of adult life, shifting the emphasis from the school environment to the work place and noting that the central feature of this developmental disorder is that 'symptoms that caused impairment were present before the age of 7 years' (DSM, 2000)³. According to this definition, adults do not develop ADHD within their adult lives but suffer from symptoms that have remained undiagnosed since their childhood. Thus it follows that adults need to demonstrate evidence of retrospective and persistent symptoms which have existed since childhood in order to gain a diagnosis and receive treatments.

According to the criteria for ADHD given in the Diagnostic and Statistical Manual of Mental Disorders (2000), the most common symptoms of ADHD fall into three categories which are

³ DSM-5 was published nine months into my fieldwork in May 2013. The main changes made to the criteria were the age of onset from 7 to 12 years old, and the numbers of symptoms required fell from 6 to 5. Whilst clinicians and support group members were aware of these changes, they did not figure much in my conversations with them. DSM-5 was not applied in the clinic for a few months, nor was reference to criteria in support groups changed during my attendance. For that reason I have decided to use the criteria contemporaneous to my fieldwork unless otherwise stated.

inattention, hyperactivity, and impulsivity. An individual is diagnosed to have ADHD with the presence of either:

‘1) Having six or more symptoms of inattention, or 2) having six or more symptoms of hyperactivity-impulsivity.

Symptoms for either condition must have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level.

The symptoms and impairments of either condition must be present in two or more settings (school, work, home etc.) and must have been present before the age of seven years old.’

(APA, 2000)

This last feature is particularly distinctive of the diagnosis of adult ADHD. Most psychiatric disorders in the DSM require that a medical history is taken for their identification, which may typically record when symptoms first appear. Thus Personality Disorder’s first onset is situated in teenage years, and Schizophrenia typically manifests itself in early adulthood. In the case of adult ADHD, symptoms must have been noted prior to seven years of age.

In addition there must be clear evidence that the symptoms cause significant impairment in social, school, or work functioning and must evidence that they are not experienced as part of a psychotic disorder (schizophrenia) or better accounted for by another disorder (Mood Disorder, Anxiety Disorder, Dissociative Disorder, or a Personality Disorder).

Based on these criteria, three types of ADHD are identified:

IA. ADHD, *Combined Type*: if both criteria IB and IC are met for the past six months

IB. ADHD, *Predominantly Inattentive Type*: if criterion IB is met but criterion IC is not met for the past six months

IC. ADHD, *Predominantly Hyperactive-Impulsive Type*: if Criterion IC is met but Criterion IB is not met for the past six months

There are many sources that describe and identify symptoms for adult ADHD including the DSM, various rating scales used by diagnosticians, NICE guidance, and also support groups' websites, and research publications (Weiss and Murray, 2003). Given the variety of diagnostic sub-types described above, individual experiences are likely to be varied and to combine a range of themes with various consequences such as;

- Difficulties in organising daily activities; forgetfulness; difficulties in time management and procrastination that may be experienced through inability to sustain employment, to meet deadlines, to pay bills
- Physical and mental over-activity; having too many projects going on simultaneously; intolerance of boredom which may lead to feeling of restlessness, of being unfocused and may cause insomnia and a feeling of exhaustion.
- Impulsivity and impatience with a low tolerance for frustration are often experienced through argumentative behaviour in public spaces, speeding while driving, overspending when shopping.
- Mood swings with faster and less pronounced cycles than in bipolar disorder, often experienced as being over anxious, or depressed with low motivation, contrasted with periods of elated moods and being 'the life and soul of the party'.

There are differences in the way ADHD may be experienced by adults in comparison to children simply due to their different lifestyles and positions in life. For example, adults may develop coping strategies which can cause problems in their own right, such as the use of alcohol or other substances. They have the ability to refuse treatment that may have unpleasant side effects and it may be difficult to get collateral evidence from employers and other sources. Adults may themselves be carers of children with ADHD and so need to control their own symptoms not only at work during the day, but also at home in the evening.

As I will describe, the re-conception of ADHD as a lifelong disorder also posits the idea that there is no such thing as a cure for its symptoms: treatments alleviate symptoms rather than removing them. The way that some support group members put this was to say that ADHD was their normal state of being, which medication could only alter for as long as the drug was active. The issue of living with ADHD as a normal state will be developed in the thesis as I describe how support groups devised practices to supplement what the clinic provided.

The emergence of Adult ADHD in the UK is not taking place in an isolated environment. The situation in the USA, where Adult ADHD has been widely diagnosed, treated and recognised as a legitimate disability over the last two decades, can provide a premise for postulating a similar development in the UK. Yet the universal applicability of this kind of classification continues to be challenged and cross-national studies have highlighted both variations in prevalence and a treatment gap between the USA and the rest of the world (Demyttenaere, 2004; Fayad, 2007). It is beyond the remit of this study to attempt a comparative analysis between the USA and the UK, but the American experience does not go unnoticed by clinicians and support group members, albeit greeted with some ambivalence.

Demography

This short section is concerned with the data produced by scientific research which complements the demographic data relating to the people I met in the clinic and in the support groups presented in the methodology section of this introduction. How common is the diagnosis of ADHD in the UK?

Prevalence studies have attempted to respond to this question but have shown considerable variation in their results, from 0.5% to 26% of schoolchildren in the UK (Singh, 2008), a range due mainly to the different methods and classifications used. A commonly accepted rate within the medical and scientific community is that 3.6% of children in the UK are affected by ADHD with a high proportion, between half and two thirds depending on the studies, experiencing symptoms through adolescence and adulthood (Buitelaar, Kan, and Asherson, 2011); it is estimated that 2.5% of adults in the UK are affected by ADHD (UKAAN, 2013). Research is recording a growing rate of

pharmacologically treated ADHD, doubling in children between 2003 and 2008 alongside a fourfold increase for adults, suggesting an increase in the uptake of the diagnosis by clinicians (McCarthy et al., 2012). The gender ratio of people diagnosed with ADHD is reported to be close to 1:1 (Matheson et al., 2013) with variations between the subtypes of the diagnostic criteria (Willcutt, 2012) and slightly more men than women are affected overall. Few studies have attempted to analyse the socio-economic status of adults diagnosed with ADHD (de Graaf et al., 2008) and I do not know of any such studies in the UK. Studies in other parts of Europe, America, and Australia showed differing results, suggesting that further research should take place in order to associate socio-economic status with rates of diagnosis in adults. The same is true of studies that have researched the links between ethnicity and diagnosis (Dwivedi and Banhatti, 2005). Follow-up studies which have shown the persistence of ADHD into adulthood in the 1990s (Barkley et al., 1990; Mannuzza et al., 1993; Weiss and Hechtman, 1993), have more recently described the negative outcomes associated with having ADHD in all domains of life. Sufferers fare worse than control groups in areas such as education, employment, crime, relationships and show an increased propensity to develop other psychiatric disorders such as depression (Barkley et al., 2006; Biederman et al., 2006; Brassett-Grundy and Butler, 2004; Hodgkins et al., 2011; Jerome et al., 2006; Young et al., 2009).

Multiple already

The heterogeneity of the population affected by ADHD was consistently acknowledged by clinicians and people in support groups alike. To the diversity of age, gender and economic status, can be added the varied combination of criteria and subtypes described above: inattention, hyperactivity, and impulsivity and their different nomenclatures. In this way ADHD was already multiple, it was more than one thing, and through the work, actions, and efforts of all those involved, it was less than many (Mol, 2003; Strathern, 2004) in that only one diagnosis is recognised by medical and other institutions in the UK. Let me give a brief example: clinicians conceive ADHD in different ways depending on what they do. They may think of it as a psychiatric disorder if they diagnose within a mental health setting via the DSM; however they may think of it as a learning disability if they diagnose within an education setting, like a university. These two concepts do not exclude one another but depend on

different clinical practices such as psychometric tests or assessment tools which highlight particular contextual concerns. I argue that there are not several distinct kinds of ADHD that compete with each other, but that they are connected and contained within one another.

The patients and support group members I met were also involved in the making of different versions of ADHD. As I will explore in subsequent chapters, they described ADHD in their lives sometimes as a curse, sometimes as a gift, and they did not see these valuations as mutually exclusive. As Mol succinctly put it, ‘Not two different people or one person divided in two. But partially connected’ (2003:82). In other words, it was not necessarily a matter for individuals to choose a particular version of ADHD, the gift over the curse, or the learning disability over the psychiatric disorder, as if these stood next to each other on a shelf. Instead all the different versions were connected, sometimes co-occurring and often implicit. To be clear, clinicians, patients and support group members, rather than explicitly discussing the multiplicity of ADHD with me during my fieldwork, would instead point to the contradictions and ambivalent feelings that they had to reconcile. In other words, they needed to work and live with the different realities of ADHD. So far I have mentioned how ADHD and its clusters of symptoms can be assembled and enacted differently depending on the practices of clinicians, patients, support group members and their families, and next I want to widen the net of actors in the making of ADHD to include social scientists and media actors.

Is it real?

Forces of medicalisation

Social scientists have long been interested in ADHD, and to some extent, the histories of ADHD and social science are intertwined. The increased use of the diagnosis, albeit in its previous nomenclature of Hyperkinesis from 1968 to 1980, was paralleled by the rise of the ‘medicalisation critique’.

Medicalisation, the process of viewing and explaining human problems and behaviours through medical means, is an accepted if somewhat tired concept in the 21st century. The representation of doctors and medical institutions as ‘a major threat to health’ (Illich, 1977) expending their control

over our everyday lives (Zola, 1972; Szasz, 2007), was formulated in the 1960s and 1970s within a context ripe for such critique. On the one hand, medicine and its patients were reaping the benefits of decades of investment; new medicines, such as antibiotics, and other technologies were rendering doctors more visible, business-like and powerful. On the other hand, the zeitgeist of these two decades ensured that state institutions, such as medicine, would be criticised or even demonised for their attempt at governing human bodies. Such a critique was forcefully applied against the power of psychiatry at the time of its classificatory expansion through the DSM, leading Szasz to define medicalisation as ‘psychiatric propaganda’ (2007: xxiv). The most frequently cited article on Hyperkinesis written by a sociologist dates from this period: published by Conrad in 1975, it focused on the use of medicine to control deviant behaviours. It argued that the emergence of new medical technologies, mainly psychotropic drugs, and their promotion by ‘moral entrepreneurs’ (1975: 16) altered the way that children’s behaviours were perceived. From a situation in which ‘disruptive, disobedient, rebellious, anti-social, or deviant behaviours’ (ibid.) were managed by families and schools, children came to fall under the jurisdiction of medicine and were managed with Ritalin. The implication is that Hyperkinesis did not exist before the pharmaceutical companies found a way to use the ‘paradoxical effect’ of stimulants on children; the condition was fabricated, ‘socially constructed’. Similar arguments were made in subsequent decades; these exposed the impact of modern life first on children and then on adults and they denounced the intrusion of medicine in resolving the problems. Thus ‘rapid-fire culture’, constant stimulation in daily life and the inclusion of food colouring in the diet, were suggested as the causes of hyperactivity (DeGrandpre, 2000; Smith, 2011).

Materials and practices that shape realities

My intention is not to refute the warnings that sociologists and other critics give about the role of medicine in our lives, but to suggest that it forms only one part of the reality of ADHD, one in which the economic aggression of pharmaceutical companies, as well the passivity of medicine’s recipients, are emphasised. Denouncing the role of outside forces and the engines of medicalisation (Conrad, 2007) has limited positive impact on patients themselves, and can in some circumstances exert a

stigmatising and disempowering effect (Nathan and Stengers, 2004). This thesis will focus on how the reality of ADHD is made in the UK at the beginning of the 21st century and it will acknowledge the materiality of ADHD including the practices of those actors and actants involved in this process. As Bruno Latour defined the terms, ‘an actor is a semiotic definition – an actant –, that is, something that acts or to which activity is granted by others. An actant can literally be anything provided it is granted to be the source of an action’ (1996: 376). In addition to investigating the role of clinicians, patients and others, this thesis pays attention to objects or concepts that act on the making of ADHD, for example classifications, psychometric scales, as well as school reports through which new meanings are made out of old and transformed relationships. Similarly, I will examine the effect that stimulant medications have on people’s lives, beyond their chemical properties, for example, how the medication itself can be adapted for everyday activities, such as work or holidays. I sought epistemological inspiration from Mol’s influential book *The Body Multiple* (2003), in which she offers a programme for praxiography, ‘a story about practices’ that allows for differences, complexities and co-existence to open up and become visible. Mol traced various practices associated with different kinds of atherosclerosis, for example, during clinical assessment under the microscope, or at home. The multiple bodies thus formed required considerable coordination work, involving negotiations between different actors and medical note-writing in order to ‘hang together’ within a single patient. Mol’s method that ‘no longer follows a gaze that tries to see objects but instead follows objects while they are being enacted in practice’ (2003: 152) highlights the spatial movements involved in diagnostic procedures, from GP to surgeon and sometimes, unfortunately, to pathologists.

To acknowledge the multiplicities and complexities of practice is also to acknowledge the existence of different possibilities of becoming. Mol has described this as ontological politics, ‘the process of shaping’ reality through practices (1999). Tracing the practices for diagnosing adult ADHD across the clinic and support groups will bring to the fore a kind of ontological politics, one that is concerned with pragmatic knowledge production. In the clinic, I observed the way that clinicians used the experiential knowledge they had built over the years, sometimes privileging this over the formal criteria when diagnosing. In the support groups, I saw how people developed pragmatic knowledge

for living with ADHD. Such actions were directed not only at participating in, but also at interfering with psychiatric knowledge (Rabeharisoa et.al, 2014). Overall, by following the diagnostic process to arenas outside the clinic, this thesis highlights how the combined practices of clinic and support groups collectively work to keep together, and to coordinate and uphold the multiple realities of ADHD within one diagnosis.

The diagnostic process

A social process rather than clinical moment

The work of clinicians, patients, support group members and their relatives suggested that one element at least kept the different versions of ADHD cohesive. All were involved through different practices in the diagnostic process. The term ‘diagnosis’ can be used to describe categories of diseases, as well as what clinicians do to identify and apply such categories; both usages are of course intertwined as the naming of a disease depends on the availability of classifications (Blaxter, 1978). Yet it is worth keeping both applications of the word separate in order to examine what takes place in either case. The making of classifications and diagnoses calls upon a wide range of actors and institutions which in turn exert a particular societal impact (Bowker and Star, 1999). The work that is required to diagnose has traditionally been laid in the hands of doctors and clinicians. It is sometimes described as ‘the art of medicine’ and more recently, since the 20th century, as a ‘science’ (Rosenberg, 2002). The tension between art and science in the work of diagnosing is particularly visible in psychiatric clinical events that rely heavily on conversations, narratives and speech events (Gumperz and Hymes, 1972). Thus, distinguishing between different categories and associated treatments calls upon the ability to interact with someone who is often in distress, whilst keeping in mind the various classifications and criteria. The combination of naming and labelling by one person (the clinician) during one moment (the clinical encounter) has come to represent, for most people, the work of diagnosis as the clinically defining moment of the disease.

I will argue that diagnosing adults with ADHD poses direct challenges to this bounded temporal, spatial and hierarchical conception of the diagnostic moment on two counts. First, the health services' institutional structures extend the diagnosis across time by requiring different actors to contribute to the process; GPs, specialist psychiatrists, psychologists and health commissioners. I found that the process could take up to 18 months for most people diagnosed through the NHS (Matheson et al., 2013). Secondly, during the 'waiting period', patients-to-be engage in exploratory work about their conditions of their own volition as well as in response to clinical questionnaires and, during the process, reach out to relatives and support groups for insights. Therefore this study will show how the clinical moment of diagnosis becomes elongated into a social process stretching across time and space. In considering actors outside the clinic, this study recognises the role and expertise of those experiencing ill health in producing knowledge for diagnosing and living with their conditions (Das, 2014; Pols, 2013; Rabeharisoa et al., 2014). As I come to discuss in Chapter Five, the process of identifying what might be wrong in oneself can be described as self-diagnosis. By exploring similarities in the practices of support groups and clinic, this thesis attempts to counteract negative connotations which may be imputed to the self-diagnosis process when it is viewed within medical milieux (Goyder et al., 2009; Jutel, 2010). It is worth noting that such an extended process of diagnosis can increase the sense of uncertainty that is inherent to concerns about ill health (Chilibeck, Lock, and Sehdev, 2011; Jutel and McBain, 2012; Swoboda, 2008) and, for some people I met, particular elements in the process intensified this uncertainty and triggered a sense of vulnerability.

The role of remembering and of family resemblance

As with most psychiatric disorders, there are no biological tests for diagnosing adult ADHD, neither blood nor genetic tests, and whilst some neuroscientific tools are being developed, they had not been deemed reliable at the time of my fieldwork⁴. Instead the emphasis is on face to face assessments where patients can report their ailments via a structured interview and a mental state examination which includes a medical history. As I described earlier, a core element of the criteria for adult ADHD

⁴ I participated in a scientific conference on 21/09/13 run by the International Multicentre Persistent ADHD CollaboraTion (IMPACT), entitled 'From the Workbench to Clinical Impact' which explored this specific topic.

is that symptoms and impairments must have appeared before the age of seven and clinicians must identify retrospective and persistent symptoms which have been present since childhood. There is an important caveat noted in a diagnostic handbook : ‘Adults may have only a poor recall of their symptoms and behaviours as children’ (UKAAN, 2013: 45). From this conundrum, in which memory is at the same time a resource and a want, practices are developed in the clinic and in the support groups that place memory at the core of the diagnostic process. Put another way, remembering, as well as being a human capacity, is also a utility whereby memories are made into objects of evidence (Engelke, 2008; Lambek, 2007).

Following Antze and Lambek (1996), we can view how the role of the institutional practices described above encouraged and condoned a particular function for memories during the making of identity. For the people I met, memories of childhood that were required for the clinical diagnosis were not easily recalled, were often disjointed and needed re-interpretation in the light of persistent difficulties. Thus, part of the diagnostic process required of the patient the exact skills for which they sought support and treatment; focus, attention and memory. The irony of the situation did not escape them and for most this was part of their description of the struggle for recognition. Through observations undertaken in the clinic and support groups, this study shows the work and scaffolding that was necessary for people to remember childhood events, either through structures offered by institutions or through school records and family genealogies, or through practices that they developed themselves. The claims associated with memory work, involving the reconstruction of childhood, were thus aimed beyond the legitimising of people’s condition towards an attempt at confirming a biographical continuity. Recurrently throughout my fieldwork, people described how they knew something was wrong, that they had always had been this way yet did not know what the problem actually was, and that finding clues in the past helped them understand themselves. The need to engage with activities in order to remember past events suggests that ‘remembering happens in the present tense’ (Ferryhough, 2012: 8). This is not to say that memories that are thus constructed in the present are made up and false; instead it highlights how memories may be fluid records whose retrieval offers the possibility for change.

The making of memory and the practices of remembering are an integral part of the relationships that we form, individually and within familial situations (Carsten, 2007). In the case of the people I met in support groups, the childhood memories that were retrieved through the diagnostic process inevitably also implicated personal relationships that were taking place at the time, or at least what was recalled of them. The process of turning to the past for possible answers to present problems is a common practice in medicine, aimed at tracing the triggers and progression of diseases. More broadly, we turn to our past in times of existential crisis when our identity is in question (Antze and Lambek, 1996). The possibility that a lifetime of problems could be re-imagined and exposed as a treatable psychiatric disorder was experienced in ‘moments of recognition’ by some members of the support group. Some described recognising themselves in chance meetings with strangers who had ADHD, whilst others explained how self-recognition was experienced through a child or within other filial relations. ADHD is noted in scientific textbooks as highly heritable, with a 70% to 80% heritability factor (Franke et al., 2012), and with a high familial risk (UKAAN, 2013: 2). It is often said to be ‘running in the family’, and identification sometimes took unexpected forms when undiagnosed parents described a sense of vertigo at the genealogical displacement that occurred as they recognised themselves in the traits of their diagnosed child.

Ideas about family resemblance also included siblings, cousins and grandparents⁵ and, significantly, strangers who shared common traits and difficulties. I found across my field sites that such cases of recognition were based on overlapping similarities rather than on any one common feature. Rather than one symptom being common to all people with ADHD, there are a variety of traits and features present in different people, which give the effect of making them resemble one another. Thus, clinicians developed a typology for diagnosing ADHD, adding to the scales and algorithms, and group members formed bonds on the basis of a neurobiological resemblance. Discussions in support groups often referred to the sense of belonging they experienced when attending the group, of being with like-minded people and of feeling normal amongst kindred. My observations and participation in the

⁵ The diagnosis of older adults, those that might be grandparents of more than one generation of people diagnosed with ADHD, is even rarer than the diagnosis of adults of working age (Brod et al., 2012; Wetzel and Burke, 2008). Some participants described their aged parents as having traits of ADHD, but none of them were diagnosed.

support groups will show that some members set up reciprocal obligations and ‘risk[ed] trusting others because they want[ed] to change their lives’ (Stack, 1975:39). Sharing their vulnerability, as I will show, brought people closer to each other, opening the possibility of receiving and giving support. The practices for diagnosing ADHD therefore catalyse effects beyond the legitimacy that they may bring to a contested diagnosis. The outcome of the process of being diagnosed is of course very important for clinicians, patients and many others, but attending to all that is involved in the process of diagnosis, including practices of memory and of kinship, can reveal the myriad ways that people have devised to live and work with ADHD.

Methods and orientation

Field sites

In order to track and observe the broadened diagnostic process described above, I chose to situate my fieldwork across clinical and non-clinical sites in England during a twelve-month period. Moving from one site to another allowed me to evaluate how sites might relate and to see how their practices either diverged or linked up. The clinical site had formal statutory duties and obligations as part of the NHS, which also gave its practices legitimacy; without the clinical diagnosis, treatments could not be accessed, and recognition of disability/impairments would be withdrawn. Support groups belong to a different sphere of reference; they could be described as informal, often having charity status, and would have difficulty functioning without the co-presence of a clinical space for ADHD. Through this lens the imbalance of power seems obvious, but as the chapters proceed, these two sets of sites will be shown to contribute together to the making of the diagnosis of ADHD in adults. The connections in their practice that I will come to discuss, partial as they were, produced a common advocacy towards the recognition of ADHD in adults as a legitimate disorder. I am suggesting that neither set of sites could achieve such advocacy and legitimisation on their own, and that by occupying a common space of ‘activism’, they contributed to the stabilisation of the diagnosis, however temporary this may prove to be. My aim will not be to compare in a binary fashion clinical and non-clinical practice; instead

throughout this thesis I will explore the network of relations between individuals, patients, clinicians, group members, parents and relatives, to show how these actors made and unmade the diagnostic process of ADHD. The next two sections present the context to my fieldwork and include a detailed account of the make-up of the clinic and support groups.

Clinical site

In my preparation for research at the clinical site, I spent twelve months establishing a role and reason for my presence, securing approval from the local NHS Trust, meeting with the team and the lead clinician, whilst concurrently seeking ethical approval from the National Research Ethics Service (NRES)⁶. The clinic is situated in the outpatient department of a large psychiatric hospital in London. It shares consultation rooms with other specialist services covering eating disorders, autism, addictions and psychotherapy. This is a specialist clinic for adult ADHD and is well known for contributing towards research nationally and internationally as it has accumulated long-term data on adult diagnosis and treatments. Thus it is often visited by clinicians who wish to improve their clinical knowledge and it provides a substantial number of sessions for training Specialist Registrar trainee psychiatrists. Sharing clinical knowledge developed over the years as widely as possible is an important part of the daily practices of the clinic. Clinicians who work in this specialist clinic could be described as ‘clinician-scientists’ in that they all engage with research, often internationally, and they publish widely, whilst continuing to assess and treat patients. In view of the increasing specialism and technological advances in medicine, clinician-scientists ‘are seen as the essential conduit between the bench and the bedside’ (Wilson-Kovacs and Hauskeller, 2012: 499). These professionals bring expertise of new and emergent fields into the clinic, shaping practice around new technologies whilst retaining face to face encounters with patients (Featherstone and Atkinson, 2014).

⁶ The application process for ethical approval in researching in the NHS is often portrayed as cumbersome and lengthy and the drawbacks of this process, such as the standardisation of ethical concerns onto linear forms of paperwork, are debated in the research community (Stewart 2008; Chenhall, Senior, and Belton, 2011; Guillemin and Gillam, 2004). Nevertheless, I found that the prolonged process was also useful in promoting an evolving formulation of the issues that I might encounter in my fieldwork and led me to seek advice and build relationships with partners who were supporting my research proposal.

I joined the clinical team for four days a week over ten months and conducted administrative work, organising the teaching and visiting sessions for local and international doctors. During that time I was based in the clinical office with nurses and psychologists, liaising with other administrators and psychiatrists and attending business, clinical and research meetings. As agreed with the lead clinician and after seeking consent from patients, I observed assessments, mostly towards the second half of my fieldwork. I observed sixteen different assessments spread over a total of 48 hours and interviewed 8 clinicians. Assessments were conducted in two parts, a structured interview called Conners' Adult ADHD Diagnostic Interview for DSM-IV™ (CAADID) and the Mental State Examination (MSE) which is the standard psychiatric interview. These assessments were performed by specialist nurses, Specialist Registrars (trainee psychiatrists, SpR) and consultant psychiatrists. The team consisted of six nurses, one psychologist, one psychologist assistant, one SpR on rotation and six consultant psychiatrists who also worked across other services, such as the autism clinic, and were involved in research with a partner academic organisation. In addition there was a team of administrators and a team leader who also worked across other services.

The main activity of the clinic was to perform assessments on adults who were mainly over 30 years old and with a gender ratio of 52% male, 48% female. The clinic received referrals from across the UK and saw approximately 1,000 patients a year of which around 400 were for new assessments. The other patients attended follow-up appointments where their treatment was monitored and adjusted. The treatment of ADHD in adults remains a contested practice in the UK, and, more often than not, General Practitioners are unwilling to prescribe and monitor the pharmaceutical treatment, namely stimulants, which are classified Class A drugs. The clinic often fulfilled this role for the initial prescribing and titrating of medication until the GPs eventually took over. The clinic also offered psychological treatment in the forms of Cognitive Behaviour Therapy (CBT) for individuals or Psycho-educational programmes for small groups. I could not observe any CBT or Psychoeducational groups as it was felt by psychologists that my presence would interfere with the therapeutic relationship.

The specialist adult ADHD clinic was part of the mixed economy of health services that has been implemented in England and Wales over the last two decades. As a specialist service it had to generate income and did that on the whole through the commissioning branch of the NHS, the Primary Care Trusts⁷. The arrangements were complicated, time consuming, and involved numerous communications between agencies which sometimes led to funding being refused for particular parts of the service offered by the clinic. Thus some patients might be funded for assessments only but not for treatments, or for pharmaceutical treatment but not for psychological therapy. Furthermore, in an era of declared economic austerity, concerns for the financial viability of the clinic became a worry for the clinical team and formed the basis of many informal conversations.

In addition to attending the clinic on a daily basis, I was also given access to a number of events and conferences that were organised within the NHS trust and by a partner organisation, UK Adult ADHD Network (UKAAN). UKAAN is a network of clinicians and scientists whose aim is 'to support clinicians in the development of clinical services for adults with ADHD' (UKAAN 2013). The main activity of UKAAN is the delivery of training accredited by the Royal College of Psychiatry, the dissemination of research findings and organisation of national and international conferences. I attended the three-day specialist training programme for psychiatrists in November 2012 and attended four international and two national conferences between 2010 and 2013. Many of the clinicians that I met in the clinic played a crucial role in setting up UKAAN in 2009 and in subsequent years, the patient organisation AADD-UK also contributed and joined the network.

Patient Organisations and Support Groups sites

Identifying the support groups for my fieldwork sites was a process that spanned five years. From 2009-2010 I conducted a short piece of ethnography as part of an MA degree which involved contact with support groups for adults with ADHD. My focus at the time was on health movements (Brown and Zavestoski, 2005; Epstein, 2008) and I found that there were two national Patient Organisations

⁷ Primary Care Trusts were replaced by Clinical Commissioning Groups towards the end of my fieldwork on 1.04.13.

for ADHD in the UK. Attention Deficit Disorder Information and Support Service (ADDISS) was set up formally in 1998 by parents of children with ADHD and they subsequently developed groups for adults; AADD-UK was more recently set up in 2009 with the explicit intention of representing only adults with ADHD. I kept in touch with the founder of AADD-UK which led me to enter into a collaborative agreement with the organisation when developing my PhD research proposal. Both AADD-UK and ADDISS supported my attendance at support groups and consequently I attended two groups from each organisation. Support groups were loosely affiliated to a national Patient Organisation and I found that each of the groups had unique features which distinguished them from one another, regardless of their affiliations. As part of the collaboration mentioned above, I conducted a survey of adult ADHD support groups in the UK in the summer of 2013, partly to update AADD-UK's data and to better understand their activities⁸. At that time, 23 support groups responded; these were distributed across the UK around the main urban centres, and met mostly monthly with an average of fifteen people attending each group. Most groups (74%, 17/23) were facilitated by individuals who identified themselves as having ADHD, and their activities always included a place to discuss and share, sometimes called 'sharing circles' (Borkman, 1999). They provided advocacy (48%, 11/23), sometimes offering structured courses (26%, 6/23), formal counselling (21%, 5/23) as well as yoga and mindfulness. Most groups had been founded since 2009 (60%, 14/23), the year of the publication of the NICE guidance for ADHD.

The heterogeneity of the cohort I described earlier was replicated in the support groups who were as different from each other as they were from the clinic. Due to the local and historical context, their organisational structures differed and so did their style and approach which I attribute mostly to the personalities of the facilitators. They were all adults who were diagnosed with ADHD and their own struggle for recognition and treatment galvanised them to start local groups. Some groups and their members were more interested in the science of ADHD than others, and some groups offered more recreational or therapeutic activities than others. They all had in common a 'sharing' space in their meetings which consisted of members discussing issues of concern to them and receiving advice and

⁸ Published online on <http://aadduk.org/> on 18/2/14.

acknowledgement. Yet each group ran those 'sharing' moments differently; group size and greater or lesser levels of organisation lent different qualities to the conversations taking place. Nevertheless, they had in common an external orientation towards advocacy and activism which brought a coherence that I observed as I moved from one group to another. As far as I was aware, none of the support groups received funding from pharmaceutical companies, but two received grants from their local authorities as well as charity funding.

The four groups I attended were some of the longest established and were founded between 2001 and 2007; Groups C and D were based in London, Group A in the west, and Group B in the north of England. They met monthly, fortnightly and even, for one group, weekly. I attended 31 support groups' sessions across the four sites, totalling 72 hours, and conducted ten semi-structured interviews of members of those support groups. In between the sessions I had regular contact with some members through emails and internet forums. The gender ratio of those attending was similar to the average I mentioned earlier and one group had a younger cohort than the others. In regard to ethnicity and class, I did not find that I had sufficient data to come to any meaningful conclusion. Furthermore, as Rapp (1999) suggests, definitions of such categories are static, and for the support group members I met, their experiences seemed more fluid. Some people, who described themselves as unemployed, were educated to university level, while others who were working described their inability to build careers due to their symptoms. Some were successful doctors but their personal lives were in chaos; others still were just out of prison and entering rehabilitation centres. Similarly, the boundaries between groups and the clinic were fluid: some people attended more than one group, and some members of a group might also be patients in the clinic I worked in. Doctors could be found both working in the clinic and attending as members of support groups, or a group member could be a main speaker at a scientific conference.

The ethnic origins of members were not discussed in groups, or at least not when I was present; at most, origins were hinted at in conversations when discussing treatments that may or may not have been available in other parts of the world. Research at population level remains inconclusive as to the effect that ethnicity may have on the diagnosis of ADHD (Dwivedi and Banhatti, 2005) and it tends to

amalgamate notions of ethnicity with culture (Brewis, Schmidt, and Meyer, 2000; Caldararo, 2002). Furthermore, most research published on this issue is in relation to children, using data collated from proxies, mostly parents and teachers, which renders the translation to adults problematic. During the five-year period that I had known two out of the four groups I attended, their membership changed entirely, except for the facilitators and I. This longitudinal perspective highlighted how support groups changed over time with implications as to what activities and conversations took place.

Despite the heterogeneity across sites and people described above, I found over the period of my fieldwork that the patients I met in the clinic showed more severe symptoms of ADHD and more often than not their lives were in serious turmoil, involving the police and social services. This difference could be explained in part by the fact that patients who were referred to a national specialist clinic were often referred by other medical institutions in the wake of a crisis. It also seemed to me that some patients had had little access to support, either from families and relatives or support groups. In contrast, members of the support groups were actively seeking help and advice, even if in some cases their lives were in turmoil and crisis too.

Words, voice and anonymity

Some of the vocabulary used in this thesis circulates in debates and controversies within the field of ADHD, in academia and in clinical practice too. The choice of some words over others, such as impairments and symptoms or disability and diversity, quickly positions the writer or speaker on one side of an argument or another. My intention is not to ignore the debates, nor is it to try to resolve them; instead my intent has been to consider the texts and speeches as ‘localized events, with their own matter and their own practice’ (Latour, 1993). The role of discourse in medicine is central to its activity and especially so within psychiatry (Wilce, 2009). The majority of the practices I encountered in the clinic, but also extending into the support groups, are discursive – sometimes in the form of textbooks, psychometric scales, wall displays of pictures and hand written posters, or at other times in

speeches, advice and stories. Paying attention to the use of language in these circumstances can point towards its rhetorical force, the intention behind the words to persuade and convince (Carrithers, 2005). Most of the time the will to persuade was conspicuous as there was much at stake for all parties; receiving or giving a diagnosis and treatment was of great concern to the people I met. Nevertheless, the discursive practices I observed and sometimes participated in were doing things in their own right, rather than being the façade for hidden intentions.

On many occasions the auditory quality of the conversations seemed to be representative of the way the people I met experienced ADHD and its symptoms. The stories that were told by patients and group members in chunks and half sentences, with constant digression, jumping from one topic to another represented what it must be like to experience impulsivity or lack of focus. At times it made for very lengthy interviews and disjointed conversations with stories that were not neat, tidy or predictable and I have tried to retain some of that flavour in the transcripts.

Some terms were used in all sites of my fieldwork with such emphasis and repetition that they became reference points, like beacons, in my fieldnotes. Words such as ‘strategy’, ‘recognition’, ‘ordinary’ and ‘forgetting’, have multiple theoretical backbones and, inspired by Wittgenstein’s morphological method⁹, I have explored some of them in this thesis. In brief, rather than defining these words precisely, describing their essence, I explore how their use created different variations as a ‘pole of a description, not the ground floor of a theory’ (Wittgenstein, 1988 : § 633). Wittgenstein explained that his intention in applying this method to philosophical problems was to open the possibilities for rethinking concepts in their complexities and ‘suggest possibilities of which you had not previously thought...and you are able to look around the field of the use of the expression and to describe the different kind of uses of it.’ (Wittgenstein in Baker and Hacker, 2008: 321). My intention is to bring forth connections between the uses of a word and encourage a broader understanding (Wittgenstein

⁹ The morphological method is part of a broader methodological concept of ‘*übersichtliche Darstellung*’ applied by Wittgenstein, sometimes translated in English as ‘perspicuous representation’ or ‘surveyable representation’ which he considered central to his later work. The genealogy of the method can be traced amongst others to Goethe’s morphological study of nature, and to Spengler’s use of the method in the historical context (Baker and Hacker, 2008).

1972). Crucially the use of the words will remain situated in the context in which they were exchanged in my fieldwork (Chauvier, 2014).

Similarly the rhetorical choices I have made in this thesis will indicate how I have decided to represent the events that took place in my fieldwork and beyond. Ethnographies are never the direct, unmediated, representation of fieldwork (Van Maanen, 2011), and I have used certain writing techniques which require some explanation. Below I provide a kind of lexicon that supports the description that follows in the subsequent chapters.

- Patients, names and anonymity

‘Patient’ is a term shadowed by the politics of words in the mental health field. For some it has been synonymous with the idea of a passive actor in a dependent relationship with a powerful professional. In the last decades other terms, like ‘customers’ or ‘clients’, have been suggested to endow this subject with some agency. Such terminology coincides with an increasingly business-led and market-like approach within healthcare (Mol, 2008). ‘Patient’ was used in my fieldwork in the clinic as well as in scientific conferences to describe adults who were assessed and treated for ADHD. It is included in this thesis in that context. Overall, clinicians referred to their patients by their surnames. Patients addressed clinicians as ‘Doctor’ and I replicate these conventions in the thesis when describing clinical interactions. Similarly the people I met in support groups presented themselves and addressed each other by their first names and I have retained this mode of address too. Nevertheless all names, first and family names, used in this thesis are fictional in order to secure anonymity. For some individuals and groups with international and national renown or those whose activities were unique, preserving anonymity proved to be more problematic. I elected to keep the names of the national institutions due to their involvement in the public domain, but have withheld the names and locations of local organisations.

In some situations, when the details of individuals were such that they could be identifiable, or when clinical and administrative records of attendance could lead to individuals being traced, I have decided to present their situations through composite stories. On two occasions I bring together accounts of a

number of people discussing the same topic, grouped by gender, age, and sites, and from this material I have created a new and composite story that is representative of the experiences of people I met. These stories are not fictional but are based on fieldnotes taken in the clinic or the support groups. Most of my fieldnotes were written after the support group sessions or the clinical assessments as I felt that writing in those contexts would be inappropriate and disrespectful. Some of the conversations I report in this thesis are based on these fieldnotes, whereas others, when indicated, are taken verbatim from interview transcripts. Informed consent was obtained for all interviews conducted with clinicians and support group members as well as for clinical observations of patient assessments. Verbal consent was also obtained from support groups at each session I attended as I routinely re-introduced myself, something for which I was teased as the months went by.

- Support group, self-help groups, mutual aid

The terms used to describe the activities of groups of people that gather together around a particular health problem are varied and change in time (Epstein, 2008). From the 20th century onwards, the terms ‘patient groups’, ‘self-help’ and ‘mutual aid’ have often been used interchangeably in the English speaking world and the increase of the phenomenon in the 1970s led some social scientists to define the terms more precisely. Katz and Bender described self-help thus; ‘Self-help groups are voluntary, small group structures for mutual aid and the accomplishment of a special purpose’ (1976 in Katz, 1981: 135). Others have made a distinction between self-help and mutual aid, one emphasising actions by an individual to help herself and the other as ‘individuals joining together to assist one another either emotionally, socially, or materially’ (Borkman, 1999: 4). The terms ‘support groups’ and ‘patient groups’ have sometimes been used synonymously to describe the involvement of professionals in running the groups (ibid.). It is worth noting that these are definitions pinned by sociologists onto others and that self-descriptions used by those attending the groups are even more varied.

The groups I attended called themselves ‘support groups’ rather than self-help groups, and therefore this is the term I will use in this thesis. I refer to the people attending the support groups as

‘members’, as some facilitators did, but the arrangements they had did not include formal memberships. One had a register of attendance but the others did not; another asked for a small financial contribution for the coffee and tea, but the others did not. All agreements made in regard to attending the support groups were made informally, verbally, and were renewed each time as attendance varied from one session to another.

Thesis outline and Chapter summaries

In order to address the main interest of the thesis, that is the process for diagnosing adult ADHD, its structure follows a reversed chronology that commences from the point at which the formal diagnosis is given in the clinic and moves backwards in time to describe the actions, inventions and interactions necessary to reach that point. Proceeding in this way has two important consequences for the overall argument of the thesis. First, it suggests that the diagnosis is not a determined and inevitable ‘end-product’, as I show that the process relies on a number of actions and actants within local and historical contexts that may alter the outcome. Secondly, the reversed chronology of the chapters emulates the journey of patients who needed to explore their past in order to make sense of their present and it thus aims to understand each stage in view of the preceding ones. Importantly, this reversed presentation ends when Chapter Eight returns to where the thesis started and describes how living with the diagnosis is an on-going process rather than an ending.

To begin, Chapters Two to Seven unpick what it takes to diagnose and be diagnosed with adult ADHD. Chapter Two is concerned with the way the medical diagnosis is enacted in the clinic, and by examining the practices involved globally and locally, it shows the central role of memory and recollection in that process. The theme of remembering is explored further in Chapters Three and Four, but this time in the support groups where members engage in their own explorations for identifying ADHD before attending a clinic. In the support groups the practices of memory were enacted through mnemonics and technological aids as well as being embodied into remedial strategies.

From Chapter Five, I focus on the interplay between clinic and support groups, highlighting similarities and contrasts in their practices and demonstrating their partial connections (Strathern, 2004).

Chapter Five moves further back in time in the diagnostic process and examines how people describe their very first encounter with ADHD as potentially relevant in their lives. The role of recognition in lay and medical practices of identifying ADHD is highlighted and the chapter suggests that a similar classificatory model is applied between the set of sites – a phenomenon best described by Wittgenstein as ‘family resemblance’. Chapter Five connects two main themes involved in the making of the diagnosis of ADHD in adults, namely memory and kinship. The chapter shows recognition to be one element of memory in the way that recognising entails a recollection process, as well as being part of relational practices, when recognising someone is already to acknowledge them.

The following two chapters are therefore concerned with the role that kinship plays in the diagnostic process, through filial relations in Chapter Six and then through relationships with strangers in Chapter Seven. One particular moment of recognition is examined in Chapter Six, in which parents unexpectedly recognised themselves and their own difficulties in their diagnosed children and embarked on a reconstruction of their own childhood. The chapter’s main contribution to the overall argument of this thesis is to show how the recognition of a parent in her child, in itself a common occurrence, becomes an important extension of the diagnostic process for ADHD in adults. Thus parents are ‘made’ by children; firstly through the medical criteria that stipulate that ADHD in the child must precede ADHD in adults, and secondly through an upstream flow of knowledge from a child diagnosed with ADHD to an undiagnosed parent.

Chapter Seven examines how relations made on the basis of sharing common difficulties also apply outside the family circle extending into the support groups. The process of constructing such relations acquires a political dimension through the common search for recognition and resources. The chapter shows that, rather than using the discourse of ‘neurodiversity’ that describes a positive variation on

neurobiological norms, the bonds formed between members are discussed through the language of kinship, that is, caring, sharing and reciprocity.

At this point, the process involved in giving and receiving a diagnosis of adult ADHD has been described and, in Chapter Eight, I return to the beginning to explore what people have to do to live with the diagnosis. Receiving a diagnosis makes treatments available and I describe how, in the context of ADHD where no cure is provided, stimulant medications have to be adapted to the specificity of each individual's life and in that process medications participate in the making and maintaining of relationships. Overall, this chapter suggests that living with ADHD requires endurance, which falters at times when events become overwhelming and at other times is revived and strengthened. I illustrate how the fragility and vulnerability of ordinary life described by the people I met can also be understood as life-affirming and creative through the form of pragmatic knowledge production.

I end the thesis by revisiting its main ethnographic and methodological themes, putting them in the context of other academic work to argue that the diagnostic process for adult ADHD, as it exists in the UK at the beginning of the 21st century, can only be accomplished through the combination of lay and medical practices, which together, are working to stabilise the classification of ADHD, even if only provisionally.

Chapter Two: ADHD from childhood to adulthood: how children stopped 'growing out of it'

'The concept of ADHD is steadily permeating into adult psychiatry, but there is still resistance. Some of that resistance can be traced to history. The attempts of medicine to limit the use of drugs of dependence (including stimulants) made their value for ADHD hard to accept. The drive to avoid medicine becoming an agent of social control created alarm that exuberance might become medicalised. The attempts of classifications to make clear demarcations between normality and disorder, were threatened by the possibility that ADHD is but the extreme of a normal range of variation. It may therefore be helpful for adult psychiatrists to remember how significant they have been in the long history of ADHD. From Crichton's descriptions in the eighteenth century, to Wender's influence on the DSM-III definition, there have been mutual influences between child and adult formulations.' (Taylor, 2011).

During my fieldwork, I attended and participated in a number of conferences, some organised by and for scientists, and others by a Patient Organisation¹⁰. There were many common features between these events, shown notably by speakers who presented a 'state of the field' to the audience. Their narrative began by describing the 'prehistory' (Taylor, 2011) of the concept of ADHD and was followed by an account of the main stages of scientific development which have led up to the present classification. Such presentations seemed to respond to a question commonly posed by people I met who were not familiar with ADHD: 'don't children grow out of it?' The above quote from a prominent contributor to the science of ADHD in the UK at one of those conferences, presents some of the obstacles that might have contributed firstly to the low acceptance of the notion of ADHD in adulthood, and secondly to the idea that history might be helpful for increasing the up-take of the concept by clinicians. The questions I am asking in this chapter are related yet reversed; how did a childhood disorder become conceivable for adults? Whereas Professor Taylor's emphasis was to

¹⁰ I attended four international and two national conferences organised by UKAAN (UK Adult ADHD Network) between 2010 and 2013. I attended two national conferences organised by ADDISS (Attention Deficit Disorder Information and Support Service) in 2012 and 2013.

elucidate the reasons why the notion of adult ADHD was struggling to establish itself, I wish to keep the category of ADHD open and ask — what kind of world makes the translation of ADHD from childhood to adulthood possible?

Therefore the first section of this chapter will plot the history of ADHD, as a category and classification. My account is inspired by the context of the clinic I spent time in, so as to highlight the entanglements between events at a macro and micro level. I will draw on an interview with a clinician to explore how bureaucratic and scientific practices of bridging and harmonisation at local and global level made it possible for adults to be diagnosed with ADHD. Thus I will trace movements between sub-fields of psychiatry, namely neuropsychiatry and developmental psychiatry, as well as between different classification systems such as the Diagnostic and Statistical Manual (DSM) and the International Classification of Diseases (ICD). The fluidity and changeability of the notions I describe suggests, perhaps unpredictably, that the present conception of ADHD is not the result of a ‘linear development of continuous and cumulative knowledge or a sequence of sudden turning-points, discoveries, inventions and revolutions plunging a suddenly outmoded past instantly into oblivion...’ (Serres, 1995:). Instead ADHD emerges out of clinical and bureaucratic practices that are tentative and changeable, that rely on the relations between people, classifications and institutions, and on the translations necessary between them. This is not to say that ADHD (or its history) is fabricated, or that it does not have a purchase in reality. On the contrary, it is precisely the action, involvement and entanglement of the people I met with classifications and other bureaucracies which make ADHD what it is in the UK.

The second part of the chapter will focus on the practices that I observed in the clinic and in asking – how do we know what ADHD is in the clinic? – it shows the central role that remembering and forgetting plays in the diagnostic process. More specifically I examine the administrative measures that have been put in place in order to compensate for the forgetfulness of patients and the resultant high ratio of non-attendance to appointments. Exploring how a clinic adapts, or not, its administrative practices to the specificity of the patient, leads me to ask a similar question of the clinical procedures, and examine what it takes to be a good historian, a crucial skill in the diagnostic evidential tool box.

The administrative and clinical procedures I describe highlight the paradoxical practices involved in diagnosing ADHD in adults: on the one hand, patients are recognised as facing difficulties with recall, yet, on the other, recollection is central to the diagnostic process. These contradictions, mixed messages and double binds (Bateson, 1972; 1956) have to be held together through pragmatic solutions.

Pushing back the history of ADHD

The historical presentations given in conferences varied in their level of detail, but on all occasions they contained an example of the ‘prehistory’ of ADHD which started with the story from ‘Struwwelpeter’ (Slovenly Peter), a children’s book written by Heinrich Hoffman in 1845 (Hoffmann et al., 1999). This book of morality tales written for children has one character amongst others, Fidgety Phil, who has now acquired the status of eponym for ADHD (Budrys, 2005). The nursery rhymes describe Phil, who cannot stay still at the table;

‘He wriggles and giggles and then I declare, swung backward and forward, and tilts up his chair just like any rocking horse.’ (Hoffmann et al., 1999).

He eventually falls down, bringing the table cloth and everything with it crashing to the floor. One hundred and fifty years on, the anecdote resonates with the experience of people with ADHD. The fact that the author had a medical background, a physician who became a psychiatrist, also seems to support the view that ‘Struwwelpeter can be considered the first description of ADHD symptoms by a psychiatrist and, thus represents an important document of medical history’ (Thome and Jacobs, 2004: 306)¹¹.

Within the contested field that is ADHD, where the concept is disputed as being a modern phenomenon and a recent social construction, it is important for people living and working with

¹¹ For ADHD history through other arts, such as painting and poetry see (Bonazza et al., 2011; Kast and Altschuler, 2008)

ADHD to establish an official history which demonstrates how people experienced forgetfulness and hyperactivity in their past. The concept of history as the site for truth was never made more evident than in an article published in 2009 by one of the foremost clinician working with ADHD: ‘History of ADHD pushed back to 1798! [H]istorians can now assert that the initial medical description of ADHD began in 1798 – a remarkable 210 years ago’ (R. Barkley, 2009: 2)¹². The article suggests that the description of patients’ symptoms by Alexander Crichton, a Scottish physician corresponds closely to the contemporary criteria for ADHD. What is often held as the most ‘scientific’ reference of this kind is the work of Sir George Still at the turn of the 20th century, who described case studies of children that showed ‘defects of moral control as a morbid manifestation, without general impairment of intellect and without physical disease’ (Still, 1902: 1079). Often referred to as the ‘founding father of Paediatrics’, he is also credited, in the context of ADHD, with a biological explanation of behaviours – yet the language of his explanation is anchored in moral judgement. He defined defects of moral control as ‘the immediate gratification of self without regard either to the good of others or to the larger and more remote good of self (Still, 1902: 1009). Through his observations, he described children as undisciplined, over emotional, not able to sustain attention, nor to learn from the consequences of their actions.

So far these historical examples have been concerned with the retrospective interpretation of symptoms in children. What of adults? Mostly when examining adult ADHD, it is the history of the disorder in children that is discussed but the relations between the behaviours observed in children in the 19th and early 20th centuries, and their relevance for adults of the same period, goes unexplained. Furthermore, the examples of ADHD in adults during past eras are drawn solely from the literary and cultural world, not from medicine. Thus Lord Byron’s restlessness and creative mind or Mozart’s peculiar and eccentric behaviour have been compared to ADHD-like behaviours (Ashoori and Jankovic, 2007; Fitzgerald, 2001). Such an approach to historical analysis has been critiqued. Historians of medicine have pointed out the difficulties of trans-historical comparison of prototypes from different eras; for example, symptomatic behaviours are only coherent within the cultural

¹² The date has been pushed back again to 1775 see Barkley and Peters (2012).

context in which they are proposed (Berrios, 1999; Smith, 2012). Such use of historical and retrospective diagnosis is better considered to represent the ideological battle that is taking place in the present (Smith, 2010). Nonetheless this historical narrative is now, by sheer repetition if nothing else, accepted, and its linear description of progressive understanding can be found in numerous manuals and articles relating to ADHD (Barkley, Murphy, and Fischer, 2008; Doyle, 2004; Hodgkins et al., 2011; Lange et al., 2010; Taylor, 2007). Little reference is made to the idea that ADHD was a disorder of childhood that would resolve itself during maturation. How was it that children were no longer growing out of it? Seeking historical evidence of ADHD in the distant past, as if a static object of analysis, does not answer this question.

There are other historical inquiries into ADHD, some trace the role of psychotropic medicine and in particular stimulant medication (Rasmussen, 2008), while others have highlighted how ‘the brain race’ of the cold war period contributed to the making of ADHD by changing schooling expectations. Yet others point to the effect of additives used in the food industry in the 1970s (Smith, 2011, 2012)¹³. In the clinic, conversations were pragmatically orientated towards histories of clinical and administrative practices. From the start of my fieldwork, I found myself intrigued by the unfamiliar description of ADHD as a ‘neurodevelopmental disorder’ and I subsequently realised that this term was omnipresent; the clinic itself was part of a Neurodevelopmental Disorder Service; the clinicians I worked with published in a medical journal called Neurodevelopmental Disorders; scientific conferences were regularly entitled as such. As my conversations with clinicians showed, this is a recent concept in psychiatry¹⁴, and new ideas and hopes are being attached to the prefix ‘neuro’¹⁵, claiming diversity (neurodiversity) and complexity (neuroplasticity) rather than linearity and convergence¹⁶.

¹³ For other social inquiries into the history of ADHD see (Lakoff, 2000; Rafalovich, 2001; Singh, 2002).

¹⁴ A search in PubMed showed that the first publication with the term anywhere in the text was in 1968. (Keith, 1968).

¹⁵ See (Rose, 2013) for an in-depth and critical look into other uses of the prefix ‘neuro’.

¹⁶ The following descriptions of neurodevelopmental disorders, executive functions and working memory are based on information I gathered in the clinic through informal conversations, training and conferences.

One crucial element in the reconceptualisation of ADHD as a lifespan condition, is that of a neurodevelopmental disorder which affects individuals from birth onwards, even if its presence is not evident all of the time (Buitelaar, 2011). ADHD is only one of a number of conditions that are classified thus; there are also learning or intellectual disabilities, autism spectrum disorder and motor disorders¹⁷. Common to all these conditions is that impairments, often related to social functioning become apparent early in the development of the child. The age of onset becomes in itself a diagnostic clue for differentiating between conditions as symptoms that may appear similar may point to different diagnoses if observed in different years of childhood. Thus symptoms of impulsivity may be attributed to a Personality Disorder if they start in the teenage years, whereas the same symptoms would be linked to ADHD if they occurred before the age of seven. Similarly, difficulties in social interactions may be linked to autism if they are observed before the age of three years old, but considered part of ADHD if they emerge later on. The neurodevelopmental concept implies that there is an organic basis for disorders within the brain of the individual throughout her life.

Working memory rather than textbook memory

Of particular importance within neurodevelopmental theories is a focus on the impact of executive functions on cognitive abilities including working memory (Bishop and Rutter, 2008; Brown, 2002). Executive functions are described in terms of neurological activities that take place within the front lobes of the brain and which are related to sustaining attention, forward planning, self-monitoring, organisation and generally controlling and monitoring the processing of information. The common analogy used in self-help literature is one of the ‘chief executive’ of an organisation or the ‘conductor of an orchestra’ who ensures that all runs well and stays in tune. The scientific terminology varies between different authors and disciplines (Barkley, 2012; Brown, 2013) but all agree that working

¹⁷ The WHO defines neurodevelopmental disorders as ‘disabilities in the functioning of the brain that affect a child’s behaviour, memory or ability to learn.’ <http://tinyurl.com/p8de5bl> Accessed on 16/12/2013.

memory plays a crucial role in ADHD impairments. Baddeley, who played an important role in developing working memory theory, described working memory as:

‘a system for holding and manipulating information during the performance of complex cognitive activities such as reasoning and active learning. As such, it can be regarded as the temporary memory system that underpins coherent thought.’ (Baddeley in Alloway and Gathercole, 2006: xii).

In other words working memory is related to the ability to keep information available while at the same time performing a task; it is the ability to retain the beginning of sentence when someone speaks in order to understand the point made at the end. A clinician with personal experience of ADHD offered me this metaphor in explanation:

Dr Karl: “Working memory can be thought of in terms of a computer’s RAM, that is how many programs you can have open at the same time. The bigger your RAM, the more different things you can do simultaneously with ease. Working memory helps you hold several concepts in your head at the same time... It’s not quite the same as multi-tasking, because the process comes effortlessly to non-ADHDers. They don’t even realise that they are doing it, it just comes automatically. So the ADHDer exhausts himself trying to do the same amount in a much smaller space.”

In this context, forgetfulness is not about forgetting knowledge of the past, or at least not of the distant past, but of forgetting the ‘just-past’ and not being able to hold information within a kind of elongated present. By describing this short term memory as working memory, Baddeley (1999) added a sense that it was not a passive activity: even if we are not aware of retrieval and storing activities, memory is working constantly. People I met explained how they knew something was wrong, even if they did not know what, because of persistent absent-mindedness. The examples of forgetting that my participants shared with me, of not completing tasks or losing items, all related to everyday and ordinary actions. When they are performed without difficulty, these are practices repeated through habit, literally without thinking, or learnt by rote and embodied. Bloch suggested that the working memory theory can help account for our ability to ‘access our knowledge extraordinarily fast and

fluently...The actor does not necessarily know that she knows nor what she knows, nor how she has acquired her knowledge' (2012: 193). Driving exemplifies a process of learning that takes place through repetition up to the point when it becomes 'second nature' and various sequences of actions can be repeated without thinking consciously about what is taking place¹⁸. Whilst I agree with Bloch that a large part of our knowledge is accessed without our being conscious of it, I also found Lave's caution, that psychological explanations of learning and retaining mechanisms can locate ability and disability solely in the individual, to be equally important (1996). Therefore this thesis will pay attention to the way working-memory may be discussed by clinicians and patients as well as to the practices, mainly collective, that attempt to remediate and support a better functioning; in other words the thesis aims to situate memory in its live working context rather than presenting it as an inert textbook.

A foot in each camp

Dr Goodman is a consultant psychiatrist with decades of experience in the UK and abroad and an extensive historical knowledge of the field of mental health and learning disabilities. Like other clinicians I met at the clinic, he was one of the few specialists concerned with adult ADHD in the UK. At the time he worked within a neurodevelopmental disorder service, sharing his time between sessions at the adult ADHD clinic, and acting as the lead clinician for an inpatient unit. I observed his assessments in both settings and had a number of informal conversations in between appointments – our discussions were often jovial and light in tone. As with other participants in the clinic and support groups, I found that formal interview techniques introduced a serious and sober mode of communication despite my best efforts to conduct them in a conversational style¹⁹. I asked Dr

¹⁸ Some participants have described difficulties with driving such as keeping focus and judging distance. Some research has shown a greater propensity by adults with ADHD for road incidents and traffic penalties (Jerome et al., 2006).

¹⁹ I conducted formal interviews towards the end of my fieldwork when all participants had known me for 9 to 12 months. The issues raised here hint at the performative aspects of interviews, and my interviewees all had very strong views and reasons for ensuring that their message was convincing and that their participation would help towards the legitimisation of a contested disorder (Denzin, 2001; Holstein and Gubrium, 2004).

Goodman a question about the name of his service, the neurodevelopmental disorder service, and how this term came to be used in psychiatry.

Dr Goodman: “Developmental psychiatry was a kind of another name for child psychiatry in the old days, the branch of psychiatry that deals with conditions that arise in the developmental stages. So, nowadays, with I think, a growing interest in neuropsychiatry, better imaging techniques, other kind of investigations, an organic basis can be shown in almost every condition. Personality Disorder is now supposed to have an organic basis, so it's kind of, the boundaries have become more and more blurred.”

His reference to new technology provides a timescale for the conceptual move towards attributing an organic and biological basis to psychiatric conditions. Imaging technologies have been used in research rather than clinical assessments since the 1980s but as Dr Goodman is also pointing out, the technology in the last decade has improved. It is now used to explore the neuro-anatomy of disorders like ADHD by studying static maps of the brain (structural imaging) and dynamic maps of neural activity (functional imaging). To this picture of scientific progress, Dr Goodman adds that disciplinary boundaries between developmental and neuropsychiatry are no longer so pronounced. It suggests a progressive change, rather than a complete replacement which, as he explains more specifically about ADHD, leaves space for different concepts to co-exist:

Dr Goodman: “ADHD was always kind of stuck between neuropsychiatry and developmental psychiatry. I think nowadays people start to talk about developmental neuropsychiatry which is I think a bridge between the two. So, neuropsychiatry is a branch of psychiatry that deals with mental disorders that have an organic basis and brain kind of basis; whereas developmental psychiatry deals with conditions that arise from childhood and then persist into adulthood, like mental disabilities, autism and ADHD. For conditions like ADHD, which has a presumed organic basis, therefore within neuropsychiatry, but also is a childhood condition that arises in the developmental period and persists into adulthood, then I think it has a foot in each camp.”

In describing different branches of psychiatry bridged by this new model of neurodevelopment, Dr Goodman is pointing out how disciplinary models and concepts persist in time and continue to be situated in different camps. Whilst there may be new scientific technology for understanding psychiatric disorders, like imaging tools, the way psychiatry is done remains grounded in institutional structures whereby psychiatrists specialise in working with children or adults, with brains or behaviours. On the one hand, Dr Goodman described a new neurodevelopmental concept, which provides new explanations and a new narrative bringing together different stages of life, and conceiving the individual as a whole. On the other hand, Dr Goodman situates this meta-narrative within a fragmented and moving field of practice between child and adult psychiatry. More than that, there are practitioners and clinicians behind the disciplinary sub-types of neuro and developmental psychiatry who actually do the bridging, as he continues to describe in reference to his training days:

Dr Goodman: “I remember talking to my consultant about [the organic basis of disorders], we were seeing a patient together and we saw somebody with a delusional system and hallucination and I would say – what we need to do is to distinguish whether this is schizophrenia or a brain disorder. He said – “schizophrenia is a brain disorder” [laughter].”

Claude: “There is a neurodevelopmental theory of schizophrenia?”

Dr Goodman: “Yes absolutely, yes it was Murray who did some work about two decades ago. Although it kind of manifests itself around typically late teens, childhood onset schizophrenia is very rare. This hypothesis says that schizophrenia is actually there when you are born, it just manifests itself later on, so it is a neurodevelopmental disorder, and I think that's generally accepted. Now, of course it's not the only explanation [laughter].”

This comment on schizophrenia as a brain disorder, with an organic basis rather than a psychological, remained with Dr Goodman for a couple of decades. The bridging took time, it took a lot of research and building, but it seems that a neurodevelopmental concept of schizophrenia developed by Murray around the time of that conversation in the 1980s is now well accepted (Murray and Lewis, 1987;

Rapoport et al., 2005). The role of individuals and interactions between colleagues in establishing concepts was made even clearer when Dr Goodman discussed the clinic we were in:

Dr Goodman: “The history of the ADHD clinic, kind of reflects that [ADHD has a foot in both camps], because the ADHD clinic before Professor Jones and myself were involved, started within the neuropsychiatry section. That was because one of the neuropsychiatrists had a special interest in ADHD, so he started a clinic which was essentially devoting one half day of his week to see patients specifically with ADHD. Then when he retired and there was no interest from other neuropsychiatrists to take that on under the roof of neuropsychiatry, the neurodevelopmental section so to speak, showed an interest, and we kind of took it under our wing.”²⁰

Beyond this disciplinary positioning, individual clinicians pursue and develop their interests and expertise through meeting colleagues and patients. Institutional and bureaucratic boundaries can be negotiated when it comes to new and emergent concepts such as adult ADHD. Where it should be based was left to pragmatic and practical circumstances, if not to humanitarian considerations through the medical principle of reducing suffering. Indeed some of the actions taken by clinicians towards delivering services can be seen in the light of a tradition that combines medicine and social activism (Bassuk and Carman, 1996; Loomis, 2015) where, as Paul Farmer advocated, ‘science is always already part of an “activist” agenda’ (2008). A number of clinicians shared the thought that they considered their role to be of advocacy when services were denied to patients despite national policies and guidance, such as when GPs refused to prescribe stimulant treatments recommended by NICE. The restructuring of the clinic, from Neuropsychiatry to Neurodevelopment, could be explained through a discourse of scientific progress in locating ADHD within developmental concerns, or even managerial interests in costs and resources. But Dr Goodman points out that this departmental shift was about handing over care, the care of existing patients, whereby the clinic and its patients were taken under the wing of clinicians.

²⁰ See (Young and Toone, 2000) for a description of the first NHS adult ADHD clinic.

‘Repairing a plane while keeping it flying’ (Bernstein, 2011)²¹

The imminent publication of the DSM-5 during my fieldwork provoked me to ask about the inclusion of the neurodevelopmental concept in the new version of the diagnostic manual. The DSM-5 task force, after years of consultation, published its manual on 31/5/13 with a revised structure emphasising a lifespan approach, organising the texts in an almost biographical manner. The disorders that are diagnosed mostly in childhood are placed at the beginning of the book and the disorders associated with old age towards the end. The task force makes its intention very clear in the introduction:

‘To improve clinical utility, DSM-5 is organised on developmental and lifespan considerations... This organizational structure facilitates the comprehensive use of lifespan information as a way to assist in diagnostic decision making (APA, 2013: 13).

The manual gives a prominent position to the neurodevelopmental concept through its internal structure and names its first chapter after it. In this chapter, neurodevelopmental disorders are briefly introduced as ‘a group of conditions with onset in the developmental period [which] produce impairments of personal, social, academic, or occupational functioning’ (ibid.: 31). The introduction also highlights that co-morbidity between disorders is frequent and clinical presentation will likely ‘include[s] symptoms of excess as well as deficits and delays in achieving expected milestones’ (Ibid.). In the space of thirteen lines the DSM lines up the complexity and difficulty of identifying specific ailments by listing all eventualities in an inventory; clinicians have to look for too much or not enough of particular symptoms, they also have to consider that these may be layered on one another and may be relevant to different categories, in the context of age norms. Much criticism is made of the DSM, its validity and impact, including the very project of categorising human behaviours as if they represented ‘the nature or reality of the varieties of mental illness’ (Hacking,

²¹ Commenting on the DSM revision process, Bernstein asked how the improvement of the classification could take place without disrupting clinical practice.

2013: 6)²². However the explicit inclusion of the age context and life stage in diagnosis provokes also a more holistic consideration of individuals. In particular it considers temporal factors to have a crucial impact on life trajectories of individuals, and suggests that impairments may be experienced differently at different moments in life with a potentially cumulative effect over time. I asked Dr Goodman what he thought of the addition into the DSM-5²³:

Dr Goodman: “There is a tendency to talk about lifespan conditions, you don’t have childhood schizophrenia and adult schizophrenia or childhood ADHD and adult ADHD. You have ADHD that manifests in similar ways perhaps with differences in different age groups.”

According to this view, the idea that childhood could have distinctive disorders no longer holds. Instead ADHD may be expressed and experienced differently due to different life circumstances prevailing in childhood, adolescence and adulthood, but organically, it is the same thing.

Just as Dr Goodman suggested, scrutiny of previous editions of the DSM show that the concept of neurodevelopmental disorders was established through small changes over time. The previous version, DSM-IV, mentioned no neurodevelopmental disorder. Instead it had a distinct childhood section with a first sentence at pains to diminish the theoretical basis for such organisation:

‘The provision of a separate section for disorders that are usually first diagnosed in infancy , childhood, or adolescence is for convenience only, and is not meant to suggest that there is any clear distinction between childhood and adult disorders’(APA: 1995: 39).

Written 19 years before the recent version of the DSM-5, this caveat seems to be paving the way, albeit quite slowly, for the removal of a specific childhood section. It seems that it was just a matter of time before a distinction between child and adult disorders would be erased, and this implication is

²² Hacking’s main point here is that DSM is used by clinicians for bureaucratic reasons rather than clinical ones; they use the prototypes that they become familiar with. My data will concur and provide some nuance to this view as, even in the UK, the DSM is explicitly referred to by clinicians in their daily practice; see Chapter Five.

²³ The change of numeral use for the DSM from Roman (DSM-IV) to Arabic (DSM-5) has not been formally explained, and may be the result of a pragmatic decision to make forthcoming revisions easier to enumerate.

also evident in the previous edition, albeit more subtly²⁴. Is this indicative of a broader change in the conception of childhood or even of its disappearance (Aries, 1962; Postman, 2011; Sommerville, 1982)? The official history and the neurodevelopmental paradigm present a continuous person, yet they retain the marks of breaks and of transitions between a state of childhood and one of adulthood. As much as childhood is a concept understood differently within specific cultures, its biological context remains within a life course that includes adulthood (Stephens, 1995). I would suggest that the categories of ‘child’ and ‘adult’ are not stable precisely because ‘the contour of each comes to be formed in relation to the other’ (Das, 2014: 60). Thus rethinking ADHD in terms of a lifespan may affirm the concept of the child as a potential adult, and also blur the boundaries between the two states, so that ways of being that were thought of as specific to children are now considered relevant for the ‘whole’ person.

Of further significance in the transition between DSM-IV and DSM-5 was the removal of the behavioural emphasis that had been established since 1968 when the DSM-III was produced. The DSM-5 replaces the concept of behavioural disorder by a shift of focus towards the brain, a focus which is then coupled to the notion of development. This change represents a kind of double reductionism where brain and developmental change are set as norms that naturalise, biologise and quantify ways of being. It is after all in the zeitgeist of the 2000s to describe psychiatric illnesses through the medium of the brain and neurology, as aptly mapped by Rose (2013)²⁵. But the addition of ‘development’ to the concept is also part of a positivist idea of science and progress and a cultural representation of lifecourse specific to the western world (LeVine, 2007).

In the context I have discussed so far, ‘development’ refers directly to the individual’s cognitive changes across a lifetime; just as it is also a meta-narrative applied to biology as it is to environment,

²⁴ This gradual change of perception is arguably part of a broader shift in our conception of disease progression through the development of genetic sciences. The period between the 1990s and 2013 coincides with very visible scientific advances, such as the mapping of the genome, which have forced a reconceptualisation of ‘life itself’. For an overview see Lock and Nguyen (2010), Rose (2007).

²⁵ The decade of the brain, launched in the 1990s by President Bush, has now been revived by President Obama, in the hope of doing for the brain what was done for the genome, that is to build a map of its activity. See New York Times 17/02/13 <http://tinyurl.com/nrzkrdy> Accessed 8/05/2014.

economics and politics. It is a discourse that assumes a move forward, or more to the point, upward, from lower to higher in an implicit hierarchy whereby children, people or countries require developing to reach normative levels of functioning. This logic of development produces ‘a feeling of inevitability’ (Hacking, 2002: 22) and implies that if individuals or nations fail to progress and develop to their expected potential, then they are seen to be lacking, behind and backwards (Armstrong, 2011; Timimi et al., 2011). Furthermore, developmental notions such as turning points and milestones confirm the sense that the course of a life moves forward step-by-step, within normative frames. Such notions have implications for the way people perceive and discuss their lives – an idea which forms an important part of this thesis. Sophie Day (2007) showed how the description of a life course as undisrupted, planned and predictable may favour a particular kind of narrative best constructed by the well-educated; it lays the responsibility of failure and success with the individual. Day’s work with sex workers foregrounds how an inability or unwillingness to follow such a pre-mapped biography can have unhealthy consequences:

‘Health problems can follow from rather than cause biographical disruption. They are a consequence of the refusal to live out a story of progress, to embody the integration and reintegration mandated by the state, and to tie a peculiarly complicated series of publics and privates into a coherent whole’ (ibid: 229-230).

Trying to fit within the normative expectations of an already delineated life course, yet wanting to retain what made it one’s unique and personal story was part of the ambivalence presented by people in the clinic and support groups. The narrative of the neurodevelopmental concept is doubly powerful and convincing as it moves responsibility from individuals onto the brain, and posits development as normative progress. Developmental norms are often translated in educational techniques that are rigidly applied to meet particular milestones. Amongst the people I met, these pre-figured norms were often experienced as obstacles which highlighted their weaknesses and obscured their strengths.

In a small pamphlet, Michel Serres (2006) pays homage to bridges, some from of his childhood, some ancient, some modern, He subtitled this work ‘*Homo Pontifex*’ in order to position architecture at the

core of human experience. Of particular relevance is his discussion of bridges as symbols of relations, using 'bridge' as a verb rather than a noun, to bridge and bring together: 'we bridge everything that comes into our hands' (ibid.: 42 *my translation*). In his hands, bridging becomes a method of translation, of change and transformation and of reaching towards the other side. He points out that just as bridges have tolls giving authorisation to cross over, relations require mediators²⁶, contracts and agreements. In other words there must be some exchange in order to form new relations. Dr Goodman talked of the emergence of the neurodevelopment model as a bridge between different branches of psychiatry and as the combination of different concepts to make a new one. In his view it was not a theoretical replacement, a revolution, a break or a paradigm change (Kuhn, 2012). If there is a cost to bridging, as Serres suggested, then it may be that the double reductionism I described is an after-effect of the new concept of neurodevelopment. This should not overshadow the opportunities created by an act of reaching out, and just as bridges make it possible to reach new landscapes, re-conceiving difficulties, such as forgetfulness and impulsivity, in neurodevelopmental terms may also bring about new modes of existence.

The addition in the DSM-5 of a chapter on neurodevelopmental disorders is significant, if only because it legitimises the use of the term. It is not contentious to state that psychiatric concepts have a tendency to seep into everyday vernacular, and the acceptance of a new term in that field is but the first step in the process of making certain concepts ubiquitous.

Tracing the changes of names, terms and concepts also highlights how this process occurred tentatively over decades; nothing tells us that the present configuration is the necessary end point of years of research and clinical practice. In fact what we know now as ADHD is as controversial and unsettled, if not more so, as the symptoms described in 1968. The scientific practices that have influenced the current nomenclature were not foreseen 45 years ago; nor are we now able to see all the different steps, including the stumbles and trips that led nowhere, that were necessary to get to this point. Such is the forgetting that most classifications go through in their lifetime, and this of course

²⁶ In an earlier book, Serres uses the term 'parasite' which could be defined as an operator that interrupts an exchange, or more simply as a middle man. I use 'mediator' for better intelligibility in English and in reference to Latour (2005).

gives a sense of finitude to the last version published (Bowker and Star, 1999). For everything that is included in a classification, many other things are disregarded or removed, yet their traces endure nonetheless.

Taking a 'crosswalk' to harmonisation

Dr Goodman, describing the hand-over of the clinic between disciplines, is one such trace and other traces can be found in the making of classifications. The DSM is one of a number of mental disorder classifications²⁷, and it is often linked with the World Health Organisation's International Classification of Diseases (ICD). These systems have run in parallel for decades with notable differences and, for each revision (the ICD is on its 10th version), task force groups are established to attempt to bridge the gaps, as Dr Goodman explained when I asked him what impact the changes in DSM-5 will have on the ICD classifications:

Dr Goodman: "Just judging by the history, the ICD-9 and DSM-III had very little in common; the DSM-IV and ICD-10 were much more similar, in terms of the conditions that they included, still some differences. The phraseology that was used, before the ICD-8 And DSM-II, were not so close, so there is a tendency for these two classification systems to kind of converge, I suspect that the ICD-11 will follow suit."

Claude: "But it has a long way to go, it is still much stricter in its criteria than the DSM-IV"

Dr Goodman: "I don't know, I haven't heard anything specific about the ICD-11 widening the diagnostic criterion, but I suspect this is the tendency, that's the way it would probably go. Changes like the age of onset between seven and twelve, the number of symptoms, the types of ADHD, maybe even the name. It would be interesting, because the ICD hasn't got ADHD, it still calls it Hyperkinetic disorder, but as I was saying there is increasingly more overlap

²⁷ There are other classifications system developed and used in China or France for example.

between the two. I wouldn't be surprised if there is a common name between ICD-11 and the DSM-5.”

Dr Goodman's intuition is based on his historical knowledge and, if one checks the online ICD-11 revisions, his guess is validated²⁸. It should not be a surprise since the World Health Organisation and its members participate and exist in the same world, with similar concerns as those involved in the revision of the DSM. Neuroimaging technologies and developmental notions are not restricted to the American Psychiatric Association.

In conversations with clinicians during a training session²⁹, there was a sense that the two systems were considered to be different and clinicians were surprised at the use of the DSM rather than the ICD criteria for diagnosing ADHD. They felt this was quite significant, as the official classification of mental disorders for the use of mental health professionals in the National Health Service in the UK is the ICD-10³⁰. If the ICD-10 is used as normal practice why should ADHD be different? More specifically they wondered how a diagnosis done through the DSM criteria would then be coded and recorded, as all NHS institutions use the ICD coding system for statistical purposes. How do you diagnose with one classification system and record the outcome with another? This accounting role of medical classification systems has fuelled controversies for many decades, and is sometimes described as 'diagnosing for dollars' (Wylie, 1995), to emphasise the links with health insurance reimbursement. Mapping the different classificatory versions and moving between them may be disorientating; nevertheless I think it is worth exploring some historical details that have led to this situation.

Bowker and Starr (1999) showed how medical classification systems, like the ICD and DSM, were formulated in an attempt to categorise and account for mortality in order to improve the state's interventions in public health. By combining the identification of disorders with a codification

²⁸ A neurodevelopmental disorders category including Attention Deficit Disorder has been proposed to replace the present Hyperkinetic disorder. See online ICD revision: <http://tinyurl.com/on7cmpg> Accessed 20/05/2014.

²⁹ In November 2012 I attended training sessions over three days delivered by UKAAN, a course accredited for Continuous Professional Development for psychiatrists.

³⁰ See Royal College of Psychiatry press release. <http://tinyurl.com/qjklk2> Accessed 20/05/2014.

process, the DSM and the ICD attempted to standardise interventions in the hope of stimulating good practice as well as identifying the resources needed to support such interventions. To categorise illnesses and disorders provides the means to quantify their prevalence, and to plan for the resources required and the associated cost of treatments. In the DSM, that combination of clinical and economical concern was made explicit in the third version, albeit in a reluctant and cautionary manner:

‘The use of this manual for nonclinical purposes, such as determination of legal responsibility, competency or insanity, or justification for third-party payment, must be critically examined in each instance within the appropriate institutional context’ (APA 1980: 12).

Statistics in the DSM, up to 1980, referred to the collating of medical information to further knowledge and scientific understanding, a process described in the DSM-II as the ‘statistical coding of psychiatric case records’ (APA 1968: ix). But, as is made clear in the ensuing version, the manual was also used for non-medical purposes, including assessing reimbursement for treatment, which became a major use for the codes by the time DSM-IV was published (Dumit, 2006; Wylie, 1995).³¹

As Bowker and Star (1999) showed, the process of developing this classification was achieved through continuous and often problematic interactions with numerous and varied bureaucratic agencies, amongst which health insurance companies featured prominently. Thus the coding for reimbursement and resource allocation for health costs in the USA became the remit of the ICD, including the costs for mental health disorders, which are diagnosed through the use of the DSM.

How do you diagnose with one classification system and record the outcome with another? In the USA, as in the UK, only ICD codes are accepted by the health insurance companies that process reimbursement claims. As this has been the practice in the USA for over 3 decades, institutions have had to produce reliable and consistent translations from one system to another in order for payments

³¹ The connection between DSM and health insurances remains a major source of controversy as it is seen to be providing pharmaceutical companies with a vast market for their products. Furthermore a recent publication showed that 56% of the DSM panel members had one or more affiliations with a pharmaceutical company, suggesting a substantial opportunity for influence and lobby. (Cosgrove and Krinsky, 2012; Cosgrove et al., 2006). For more on the links between the pharmaceutical industry and DSM see (Frances, 2013; Kutchins and Kirk, 1997)

and reimbursement to be processed. This translation process was formulated through a table of conversion (DSM on the left and ICD on the right) which was named ‘crosswalk’, a process that has now become so complex that it requires an automated translation software engine³². Of course some codes have the potential to get lost in translation, thus the Hyperkinetic syndrome of childhood, coded 314, or any syndrome making reference to Hyperkinesis in the ICD has no direct equivalent in the DSM. Stranger still, the ADHD sub-type hyperactive/impulsive has no code in the DSM, despite being named, nor does it have any equivalent name or code in the ICD. It is difficult to know if these are glitches but it is likely that the published versions of the ICD and the DSM make the translation unstable in time as the delay in adapting new names and codes leaves the ‘crosswalk’ out of date. In this version, tens of diagnoses are without any correspondences at all or are out of date (Thompson and Pincus, 1989). And the continuous process of revising the ‘crosswalk’ twice yearly, whilst showing signs of rapprochement, is never ending and lags on average a decade behind. The APA has already announced that the ICD-11 coding due to be published in 2015 will not be used in the USA for a decade or more³³.

When Dr Goodman described the standardisation of these classifications from a historical perspective, the mismatched, ill-fitting work I have just described disappeared; instead he offered a vision of convergence between the two classifications which, in time, will come to be harmonised and ‘sing from the same hymn sheet’³⁴. Fleck (1979) used this musical analogy to great effect in describing a process of tuning between different parties in order to be comprehensible to each other and to enable new concepts to be gradually accepted. As I have shown, it is a tentative process, one that is never totally achieved and, in the case of the classification systems described above, there are still dissonant notes or codes that can be heard and noticed. Fleck also pointed out how the sense of harmony that is found once controversies or ill-fitting correspondences are resolved, also obscures the process of

³² The American Psychological Association Practice organisation: <http://tinyurl.com/7y58rqw> Accessed 20/05/2014.

³³ ICD Codes for Some DSM-5 Diagnoses Updated. Psychiatric News October 2013: <http://tinyurl.com/lvytm55> Accessed 20/05/2014.

³⁴ This metanarrative of harmonisation is found in the names of DSM revision working groups (DSM-ICD Harmonization Coordination Group) and repeatedly in articles published on the subject (First, 2009; Jablensky, 2009).

attunement. He called this ‘the harmony of illusion’, not to deny the reality of the new fact agreed upon, but to highlight firstly that this reality depends on the work necessary to access it and secondly that it is not as an objective fact discovered, already complete. In other words, as Young succinctly puts it, ‘there is no representing without intervening’ (Young, 1997: 10).

The revisions of the DSM and ICD, with all their meetings, field trial reports, conferences, consultations, as well as the translation and alignment work required, are steps and practices towards producing knowledge. What I have shown is that this process has a trajectory that twists and turns, speeds up and slows down, depending on the trials and errors of many people and institutions; in other words the traces I have followed suggest a labyrinthine model of knowledge production rather than a straight line (Stengers 2010: 187).

Remembering forgetfulness

In the first part of this chapter I asked how a classification which was specifically allocated to children was translated to fit adults. I have shown how the emergence of a new concept, neurodevelopmental disorders, gradually changed the perception of ADHD away from a behavioural model towards a lifespan vision that combines brain and progress. I examined classificatory texts as actants in the making of ADHD with the same ‘activity, the same materiality, the same complicity, the same historicity, as any other event’ (Serres and Latour, 1995: 130). I have proposed that the neurodevelopmental turn in psychiatry has implications for the ways that people conceive and discuss continuity in their lives, a crucial element in the psychiatric diagnostic process and therefore of importance to this thesis. In the second part of this chapter I want to continue exploring what ADHD might be like from a medical point of view and I focus on forgetfulness as an actant within local administrative and clinical practices of the clinic.

The issue of DNA (Did Not Attend) is particularly high on the agenda for NHS managers since it impacts on costs generally and on waiting times specifically. A range of tools are used to analyse the

rate of non-attendance and the factors involved. Advice from the NHS institute suggested to managers that they should consider organisational factors as well as specific services parameters that could contribute to individuals not attending their appointments. Patient factors, as they are known, include age, childcare, prohibitive transport costs and also categories such as ‘too unwell to travel’ or ‘the nature of illness’³⁵. Thus services adjust their expected rate of DNA to their specific patient group. In the case of the adult ADHD clinic this meant taking into consideration the fact that the propensity to forget appointments may be part of the reason for the referral in the first place. It is worth noting that the overall rates of not attending psychiatric appointments were estimated to be 19% in 2003, ranging between 15% to 28% depending on sites and specialisation, in contrast to an average of 11% in the NHS as a whole (Mitchell and Selmes, 2007). Outpatient referral statistics in England in the last quarter of 2014 were recording 8% DNA³⁶. The figures collated in 2012 by the clinic I was based in ranged from 0% to 4% with an average of 1%. At first glance those figures are surprising; what could be the reason for such difference between the local and national rate of non-attendance? Studies on this issue across all NHS services, including by the National Audit Office, list the main reason for non-attendance as ‘forgetting’ followed by ‘too unwell’ (Dockery et al., 2001; Hamilton et al., 2002; Mitchell and Selmes, 2007; Pal, Taberner et al., 1998). It is therefore rather paradoxical that a clinic specialising towards individuals whose main symptoms are related to forgetfulness had such a low rate of non-attendance.

There are many ways for managers to ensure that targets for DNAs are set and met. The specific definition of DNAs, differentiating between first appointment and follow-up appointments, or even the quality of data collection, could explain the disparity in the figures shown above. But my observations in the clinic suggested that there were other kinds of actions too that could suggest why the figure of DNA was so low. To explain this I want to explore the practices of the administrative and clinical team prior to and during the appointment day, starting with the referral which indicates the beginning of the clinic’s involvement with the care of individuals. The description arises from my

³⁵ For further details on the list of factors see NHS institute website for the document *Reducing Did Not Attend* see <http://tinyurl.com/3opjwnf> Accessed 20/05/2014.

³⁶ See (NHS England 30/5/14) <http://tinyurl.com/q6yvgdl> Accessed 20/05/2014.

participation in administrative tasks in the clinic, for which I received training through verbal and written instructions provided by senior administrators.

When a referral was first received a number of administrative tasks were required; it needed to be dated, stamped and scanned into an electronic register in order to track its progress. Then followed a triage process: what kind of intervention was requested? Was it a new assessment, a follow up assessment, a second opinion, or a medication titration? The referral was then entered into the electronic patient record, or a new record created if appropriate and then added to the waiting list. The funding from referrers needed to be confirmed, a process which could take up to 8 weeks³⁷. When funding was confirmed, the patient was allocated to a clinician, then a paper file was created to include the referral letter and other information, such as previous assessments. At that point, a 'bookable letter' was sent in order to confirm that the referral had been accepted and to request that the patient contact the clinic to make an appointment. The bookable letter was accompanied by one questionnaire for the patient and another one for relatives. If the patient had not made any contact by the time they had reached the top of the waiting list, a phone call was made to book a date. This was followed by a letter of confirmation of the date with basic information about the clinic and further questionnaires, this time much longer pre-assessment scales running to 26 pages. Behind the explicit administrative role of these communications, lay an implicit reminding role for the patient that was acknowledged by the team. One administrator described it as 'keeping the patient on track' during the months of waiting, because as she said "they are really bad at remembering appointments". Finally two or three days before the appointment a 'courtesy call' was made by the administrator to remind the patient of the scheduled time and the necessity to bring the pre-assessment rating scales with them to the clinic³⁸. On the day of the appointment, communication with the patient became the role of the clinical team, mostly nurses but sometimes also trainee psychiatrists. If a patient had not presented at the reception desk at the time set, the clinician would attempt to contact them by phone. If they were successful, they rescheduled the appointment there and then, as patients would usually still be at home

³⁷ This clinic is a national specialist clinic and receives referral from the whole of England and Wales; the cost of assessments and treatment is expected to be funded by the local NHS commissioners.

³⁸ By the end of my fieldwork this was done by automated texts.

or at work having forgotten the appointment. Patients were rescheduled sometimes three or four times and became well known to the team, even before attending the clinic. When patients were seen at the clinic they often forgot to bring the pre-assessment rating scales with them, and so were asked to fill them in during the break between the two assessments.

For the team, the patient's forgetfulness created work; administrative tasks, phone calls, accessing electronic patient records, contacting reception to book rooms, accessing doctors' calendars. But it also created time, as nurses and doctors often found themselves with a spare 90 minutes; in fact this occurred so frequently that nurses completed other administrative tasks such as assessment report writing, as a matter of routine as if it were scheduled within their working day. DNAs were the source of contradictory feelings in the clinic; on one hand a DNA could be a relief on a busy day, it gave a chance to do reports, emails etc. But it also meant that you could not perform your main task of carrying out assessments. Staff knew that DNAs meant no income for the clinic. This is rather complex because, as NHS staff, their employment was strictly speaking not reliant on the income made by the clinic: like all other NHS staff they were public sector employees. Yet, the overall organisation that hosts the clinic, the NHS trust, could have decided that low activity and therefore low income meant that the clinic would no longer be viable and therefore liable to closure.

The administrative practices I have described exemplify the routinisation of forgetfulness as an actant within the clinic. Taking the advice of the NHS institute seriously, the clinic explicitly adapted its administrative procedures to address the needs of its patients, specifically those symptoms that would inherently create obstacles to being assessed and treated. In this way, forgetfulness orients the work that is done or not done in a specific way; attention is given to the likelihood, greater than for most people according to diagnostic criteria, that the appointment might be forgotten. This is then operationalised through the use of technical mediators; the letters and phone calls, the electronic calendars, do the remembering and reminding. Embedding concerns to palliate the effect of forgetfulness into the daily administrative practices of the clinic also has the effect of stabilising a particular version of ADHD, one in which forgetfulness and consequently disorganisation is central. Law's description of this entanglement between practice, instruments and reality is helpful here:

‘[] it is not possible to separate out (a) the making of particular *realities*, (b) the making of particular *statements* about those realities, and (c) the creation of *instrumental, technical and human reconfigurations and practices*, the inscription devices that produce these realities and statements. Instead, *all are produced together*’ (Law, 2004: 31 Italics in original).

The implication that realities may be made in this way is political, because whilst some paths towards a reality are taken, others are precluded. The practice of organising appointments by taking forgetfulness into consideration produces a particular kind of ADHD. The persistence, attention and care given to supporting patients in attending their assessment are not to be taken for granted, they depend on being practiced. And whilst Law goes on to declare that ‘[r]eality is no longer destiny’ (ibid.: 40), as he was well aware, it may be for better or for worse.

Towards the end of my presence in the clinic, concerns from commissioners of services led managers to decide that patients’ appointments could only be rescheduled once in order to reduce the waiting list. Thus the ‘nature of illness’, namely forgetfulness as a factor to consider when dealing with DNAs, was given less weight than the need for increased productivity and a shorter waiting time. A decision of this kind can be explained in economic terms, and the discourse of austerity and financial difficulties was part and parcel of everyday talk in the office. But it is also likely to be a typical dilemma faced by many organisations, including the NHS, to respond to the specific needs of its patients whilst at the same time managing the complexity of balancing competing demands. If managing the complex range of needs across a large organisation becomes too unwieldy to achieve day by day, it will be simplified and reduced (Callon, 2002). Most support group members would support the aim of reducing the waiting list as they often experienced very long waiting times, often up to 18 months. Some people would benefit from such change, if they were able to set up their own reminders with the help of relatives, friends or technology. Yet such change would mean that others, who may or may not have a network of support and whose forgetfulness is pervasive, are not seen, assessed or diagnosed as they repeatedly Did Not Attend. By changing administrative practices, the clinic transferred the responsibility for the memory-work it used to perform onto the patient. Such an

expectation might be beyond what some people could achieve, making it less likely that they would be assessed, diagnosed and treated.

The administrative practices I have described in the clinic along with caring practices aimed at alleviating the problem of forgetfulness together facilitated the externalisation of the process of remembering. The capacity for remembering was aided by embedding actions into the daily tasks of the clinic as a matter of routine, just as we may habituate ourselves to keeping our keys in strategic places in order to find them without hesitation. In this section I have shown how the clinic attempted to reconcile the differing temporalities of the lived experience of ADHD (shifting focus, ambivalence and poor working memory) with the temporalities of a scientific diagnostic process (organised, focused and good memory). It is memory's capacity to 'mark a movement between insides and outsides' (Bowker, 2008: 226) in the way that we use it to describe ourselves that I want to continue exploring through clinical practices.

Being a good historian

The assessment at the clinic was made up of two parts: first a very structured and scripted list of questions aimed to elicit examples from the patient showing how different symptoms manifested in their everyday life, in childhood and adulthood. The second part was like a semi-structured interview that included medical-history taking, with a main line of inquiry, and flowed like a conversation in order to explore the wider context of the patient and his mental health state. Thus, the stories of past events that a patient could recount were at the core of the overall assessment. There are no observational, behavioural or biological tests for diagnosing ADHD, a fact that forms part of the argument contesting the validity of the diagnosis of adult ADHD (Timimi and Taylor, 2004). From the point of view of clinicians, and of the diagnostic tools, there was plenty that they observed in the assessments that could aid towards diagnosing, but which was not considered reliable. It was pointed out in training sessions for psychiatrists that an assessment was not a 'natural' environment within which the behaviours displayed could be trusted to provide evidence for the presence or absence of

ADHD. According to this view, people who did not display signs of disorganisation might be actually highly disorganised, but advance booking meant they would have had plenty of time to prepare for the appointment, or they might not appear hyperactive as the anticipation of attending the assessment might increase their level of adrenaline, which would in turn have a calming effect if they had ADHD.

Crucially these examples from the training session were accompanied by an important caveat; the absence of observable symptoms during assessment does not rule out their presence at other times, and therefore does not rule out the diagnosis of ADHD. This was explained to me by a clinician who described ADHD symptoms as being context-dependent. He said that individuals with ADHD adapt their behaviours to different situations, or avoid those situations altogether. He continued by pointing out how patients can learn to mask some of their symptoms and that the clinic also tends to have that effect on people as they are nervous and keen to do well³⁹. It follows that if observations of behaviours do not reflect the persistent nature of symptoms, as they can be masked voluntarily or involuntarily, then other means of evidence must be gathered. It is worth quoting the diagnostic manual at length as it explains how this should be approached:

‘The reason for [behaviours not being reflected in clinical interviews] is the sensitivity of the symptoms to stimulating and salient situations, which can normalize behaviours for short periods of time. The evaluation of current symptoms should therefore be based on accounts of behaviours and reports of ADHD symptoms during a typical day in the life of the patient.’ (UKAAN, 2013:45)

The aim of the assessment is therefore to collate different accounts of events that are representative of the symptoms associated with ADHD; accounts from the patient, from relatives and institutions such as schools or employers. I want to stress that the accounts are of *past* events, that remembering is required from either patients or their recourse to documents, in order to give a fuller picture of the present. In an exploration of ‘the memory practices in the science’, Bowker (2008) discusses how the past is reconstructed for its use in the present through technologies and efforts that may vary

³⁹ We could think of this as an instance of ‘negative knowing’ defined by Van Der Geest (2013) as ‘the paradox of noticing things and people more in their absence than in their presence.’ The absence of visible symptoms therefore alerts clinicians and makes them perceptive to the strategy in place.

depending on the era. He points out how memory practices play a central role when collectives and institutions are trying to make sense of information. In particular he suggests, in reference to the work of cybernetics, that ‘if we completely know a system in the present, and we know its rule of change...then we don’t need to bring to mind anything of the past. Memory...is a metaphor needed by a “handicapped” observer who cannot see a complete system’ (ibid: 8). Clinicians were describing their own inability to observe the person as a whole during assessments. Hence, the need to call upon records of past events, verbally or through documents, in order to get a more complete picture. The implication for patients was that it was not what they did but what they said that would be recorded as evidence in assessment interviews.

From my observations of assessments and interviews with clinicians, it became clear that some patients were better at giving those accounts than others; they were what clinicians sometimes refer to as either ‘good’ or ‘poor historians’. When I asked a clinician what it takes for a patient to be a good historian, I was told quite straightforwardly that it meant that a person was able to provide a range of examples of events in their past everyday life that related to symptoms of ADHD. This is not so easy a task as it first appears. In the structured interview there were 48 questions for individuals to answer, requiring examples of being forgetful, disorganised, and restless amongst other symptoms. Patients’ responses to this set of questions were often complemented by written documents like school reports and relatives’ testimonies. Furthermore, as with clinical assessments in other parts of medicine, the clinician diagnosing adult ADHD came to expect a particular kind of story in content and form (Garro and Mattingly, 1994). The narratives needed to present some coherence, not necessarily structural but within logic internal to the ADHD concept. It might be that a patient would jump between stories relating to different age spans, or that different symptoms were amalgamated in the recall of one event. If these events were related to particular criteria, then even with gaps or with little elaboration, the clinician could then write the medical history. Even if very few events were recalled by the patient, additional material provided by schools or relatives usually produced enough evidence for clinicians to write a medical history.

The characterisation of a patient as an historian, sometimes poor, sometimes good, was a narrative trope in the clinic which was formulated with a twist peculiar to the diagnosing of ADHD in adults. In addition to the working-memory problems I described above, scientists also suggested that adults with ADHD ‘may have only a poor recall of their symptoms and behaviours as children’ (UKAAN, 2013: 45). It is hard to tell if this problem of recall is related to difficulties of retrieving specific childhood memories in the general population or if it relates to adults with ADHD (Mannuzza et al, 2002). Furthermore, some research indicates that whilst adults who had been diagnosed as children had good recall of symptoms (78% accuracy), adults who had not been diagnosed until later in life did not have such good recall (27%) (ibid.: 1886). The people I met in support groups and the clinic were included in the latter category. Some could recall memories of events that were not especially worthy of notice, such as days spent at school, or regular visits to relatives, giving details that were not necessarily accurate (Neisser, 1988). The point that Neisser makes in discussing what ordinary memories may be made of, is that:

‘it is relatively easy to remember events in a way that is accurate with respect to some overall characteristic of the situation; such as recollection always has some degree of validity even if it suggests nested details that are by no means accurate themselves. The episode-as-remembered ...will be truthful in some respects and yet very far from historically accurate’ (1988: 365).

The diagnostic manuals have a pragmatic approach, maintaining the central role of retrospective diagnosis but diversifying the evidential sources, a kind of triangulation of recall. Thus the DSM-5 states: ‘adult recall in childhood symptoms tends to be unreliable, and it is beneficial to obtain ancillary information’ (2013: 61). The role of informants who may be able to recall childhood behaviours is therefore crucial to confirm or even affirm the diagnosis of ADHD in adults. The clinic provided questionnaires to relatives and encouraged them to attend assessments with the patient. If this tactic did not succeed in gathering enough retrospective data, clinicians would seek permission to ring parents or relatives, often as far afield as New Zealand or Canada, in order to gain what was described to me as ‘contemporaneous data’.

Considering what makes a good historian also begs the question as to who the historian actually is – the patient or the clinician? The clinicians I met were placing the history making firmly within the realm of the patient. Yet the medical history is taken by clinicians and entered into reports and files. Without the work of questioning, clarifying and bringing forth the relevant recollections, the history thus collected would have no use within the clinic. So there are skills and practices that can facilitate this process which were an important part of clinical training for trainee psychiatrists. The interaction between patient and clinician was of great importance, but the work of remembering, central to the diagnostic process, was not facilitated by one (the clinician) and done by the other (the patient). Instead the good historian, as described in the clinic, was a patient who could provide a range of examples through a dialogue with a clinician, not only from their own recollection as this would be unreliable evidence, but also augmented by other sources.

Conclusion

This chapter has been concerned with exploring what ADHD might be like in the context of the clinic. My interest in practices led me to describe a range of actions taken by clinicians, administrators, scientists and patients so as to show the crucial role that remembering and forgetting played in the making of ADHD. I aimed to show the complexity and open-endedness of the process involved in the classificatory work at a global level, and the routine, habitual yet intuitive actions of clinicians and administrators of the clinic. Different kinds of ADHD have been introduced through versions of diagnostic manuals over time as well as through the clinic's variable emphasis on forgetfulness within its appointment procedures. Of note for the remainder of this thesis is that the recent conception of ADHD within a neurodevelopmental paradigm, which promotes notions of progress and normative achievements, is combined with a diagnostic assessment technique based on recollection. This thesis will pay attention to the kind of stories that are shared in the clinic and support groups in the light of a retrospectively obtained diagnosis that may impose a particular structure or obfuscate alternative

storylines. The next chapter moves my inquiry into support groups to ask how ADHD appears and examine the practices which contribute to the diagnostic process.

Chapter Three The scaffolding of memory: the support structures for remembering

Introduction

This chapter tracks the process of diagnosing ADHD into the support groups I attended and asks how we might know what ADHD is in that setting. The last chapter showed that a crucial element for identifying ADHD in adults in the clinic was related to practices of remembering, which we could think of in terms of institutional practices of memory. Similarly, for the members of the support groups that I met, remembering and not forgetting played an important role in their practices, discursive and otherwise. As will become apparent, support group members spent a lot of time engaged in activities aimed at achieving a better understanding of how they could manage their forgetfulness: how not to forget appointments persistently or over-run deadlines due to absent-mindedness. Similar amounts of time were spent by the groups' members recounting to each other past events and their experiences of living with ADHD, which for one group, became a formal activity that classified and recorded a version of ADHD. In this chapter I am interested in exploring the tools that supported and sustained peoples' ability to not forget as well as to remember; I detail the practices that group members used to provide effective scaffolding to memory.

Some clarification of the term 'scaffolding' is necessary before I present my ethnographic examples. I came across it in relation to ADHD at an expert workshop examining the transition of adolescents with ADHD into adulthood. A few months prior to my fieldwork, I had been invited by Professor Jones, a lead psychiatrist in the clinic, to attend this pre-conference workshop as part of my preparation for fieldwork. In attendance were child psychiatrists, paediatricians, adult psychiatrists, psychologists and educationalists and a representative of a patient organisation. This group of 25 or so experts aimed to produce guidance and recommendations for setting up transitional services in order to tackle the perceived difficulties for adolescents needing to access adults' services. Early on in the workshop I noted the high frequency with which the word 'scaffolding' was used, possibly because I was not too familiar with the metaphor, but soon enough the participants themselves

remarked on it too. A brief conversation followed about the value of this idiom. Some attendees were opposed to it, others less so, until the conversation moved on. The term scaffolding was used to describe a support system for children and adolescents put in place in order to improve their social and educational functioning, often through ‘a very supportive family and an organised regime at school’ (Grant 2014:14). As described by participants of the workshop, the transition period from adolescence to adulthood was typically a time when the scaffolding was removed as young people left home. At that point problems of inattention and hyperactivity often came to the fore as the props and support systems were no longer there. In other words, the scaffolding masked the problems so that these were invisible until the support was removed. Subsequently, I found that the scaffolding metaphor is very common in educational milieux as well as in neuroscience and computer science (Park and Reuter-Lorenz, 2009). Just as in the workshop I attended, there are mixed views concerning its usefulness (Maggioli, 2013; Stone, 1998). Engaging with these debates is beyond the scope of this chapter but as I came across the term at other conferences, mostly used by clinicians but also by patients’ organisations, I found that the metaphor of scaffolding for describing support systems was helpful to think with.

Through my observations and conversations in support groups, I observed how adults constructed support for themselves, structuring an array of tools in order to facilitate the process of remembering. It is in that sense that I discuss the scaffolding of memory, a process of mediation between a technological structure and individuals, singly or in groups, that facilitated remembering and kept forgetfulness at bay. Rather than the image of a structure that hides a building, I envisage a structure that facilitates access to areas of a building that would otherwise be out of reach.

My discussion of memory, remembering and forgetting in this chapter and in the thesis as a whole, has a social science orientation, in that it explores memory figured as social activities which evolve within and rely upon a specific cultural context (Bloch, 1998; Fivush, 2011; Halbwachs, 1997; Neisser and Fivush, 1994). That is to say that the process of remembering is mediated through collective experience of intersubjective relations and of human-to-objects relations (Bowker, 2008; Carsten, 2007; Middleton and Brown, 2005).

Antze and Lambek (1996) provide a broad map with which to view issues related to memory, identities and the cultural practices put in place by institutions. They suggest that when individuals or collectives are questioning or being questioned about their identity, it is to their past and the practice of memory that they turn. Antze and Lambek argue for an approach to memory through practices, including the kind of discursive practices which I encountered in my fieldwork, something that Bowker summarises by asking: 'What is memory, that a person may practice one?' (Bowker, 2008; 8). The implication is that remembering depends on a societal context that facilitates and encourages it which, I argue, applies in the case of the diagnostic process of ADHD in adults. I base my exploration of these themes on the empirical data which I collated in my fieldwork. The scientific debates on the reliability and stability of memories (Fernyhough, 2012) that have yet to be resolved, however interesting, are beyond the remit of this chapter; instead I explore the things that participants shared with me and each other about memory and the way they talked about remembering and forgetting.

In this chapter I suggest that those practices and tools for remembering and not forgetting which are used in the support groups are central for living with and understanding the symptoms of hyperactivity and inattention. In response to the difficulties with both short and long term memory as recognised by clinicians (Tripp and Wickens, 2009; UKAAN, 2013) and support group members, the people I met had to work at producing the kind of remembering required for the diagnostic process.

In the first part of this chapter, I discuss how patients and support group members made use of old documents such as school reports in order to demonstrate that the problems of hyperactivity and inattention were already present in their childhood. Rather than taking for granted the strategic and evidential role of such documents, I take note of the materiality of the documents (Hull, 2012; Riles, 2006) and question what the school reports may be evidence of (Csordas, 2004). I will suggest that school reports acted as mediators to memories, in that the language used in them triggered detailed recollections, which in turn were seen as evidence of biographical continuity (Lambek, 1996). In other words, and extending Lambek's statement, remembering may be a human capacity as well as a utility whereby memories are made into objects of evidence (Engelke, 2008; Lambek, 2007).

I follow this section by examining the work that support group members carried out with each other to enumerate and list various experiences of living with ADHD. I suggest that the process I observed equates to the making of an archive, a repository of lived experiences which attempt to give an authoritative versions of ADHD. I show how this archive sometimes accords with the formal and medical diagnosis, and sometimes it does not.

The last section of this chapter is concerned with the kind of support members of the groups put in place for themselves in order to contain their forgetfulness. Whereas the support described in the previous sections was aimed towards early life events and autobiographical memory, the technology discussed in this section is concerned with short term memory and alleviating forgetfulness of the near-past. It was during conversations about phones and computers that support group members often discussed such techniques as ‘strategies’, a topic which I explore in more depth in Chapter Four.

“Memories are about what happened then, but they are also about who we are now.⁴⁰”

Documents handed over by XX on .././...⁴¹

See scanned copies of relevant documents only in correspondence tab

- *Birth certificate*
- *Psychological report from court diversion team*
- *School (college) report , including exclusion reports (torn and seller taped)*
- *DVLA traffic violation records*
- *Parking tickets*
- *Utah self-rating scale*
- *GP referral letter*
- *Letter from Natwest Bank*

PG on behalf of Dr Y dated .././...

Many patients came to their assessments with folders and bags full of papers which they shared with clinicians; this practice was explicitly encouraged in the letter of appointment sent by the clinic. The

⁴⁰ (Fernyhough, 2012: 283).

⁴¹ Anonymised from patient notes.

list above, more extensive than most, was shown to me by a specialist nurse and entered in the electronic notes of a patient as a record of the documents he had brought with him in a plastic bag. With the exception of the Wender Utah Self-rating scale (Ward, 1993), all other documents were reports from institutions commenting on particular aspects of this patient's life, a mix of health reports and records of transgressions. The recording, listing, scanning and storing of such forms is an important part of the administrative procedure involved in the diagnostic process. What was handed over to the clinician in a plastic bag is rendered into a prescribed logic during the ensuing diagnosis. As the note suggested, not all documents in the bag were selected and scanned suggesting that the clinic followed different criteria for what to include in the file.⁴² The medical file is just one example of the materiality of the diagnostic process. Rating scales and psychological tests are others, but the file as a governance record is particularly well suited to bringing forth evidence of the 'social life of things' (Appadurai 1986) as it is invested with agency by a number of contributing actors (Hull, 2003). In the case of ADHD, the social life of the file starts well before it becomes embedded into medical documentation as individuals gather records of life events for evidential and, arguably, existential purposes as they reclaim their past for uses in the present.

Support group members and patients in the clinic spent months tracing documents, negotiating letters and reports from a wide range of administrative agencies and discussing in support groups what would be useful. This process involved interpreting and imagining how certain behavioural symptoms could be materialised into acceptable evidence, derived from documents initially issued for entirely different purposes; in other words creating new usages from old paperwork. As Latour explained, there is no fixed and determined role for these documents, rather, they are in themselves 'participants in the action [that] authorize, allow, afford, encourage, permit, suggest, influence, block, render possible, forbid and so on' (Latour 2005: 72). Hull's discussion of the materiality of documents and bureaucracy (2012) demonstrates further how elements such as the aesthetic of the document, its circulatory role and the emotions attached to it are often all combined within the

⁴² As I did not have access to the electronic clinical notes of this patient, I did not find out exactly which documents were not selected.

substrate of one piece of paper. Symptoms of inattention are thus enacted through traffic offence records or driving license suspensions, speeding tickets, and accidents. These records are then copied, circulated and shared with hospitals and other institutions for varied purposes.⁴³

The documents that were discussed the most by all my participants inside and outside the clinic were school reports from primary and secondary schools. As I described earlier, the psychiatric diagnostic criteria for ADHD in adults are based on the concept that ADHD is a lifelong disorder. The questions asked during assessments are related equally to present adult experiences and to childhood life events. For example, in relation to Criterion A(e) of the DSM-IV (2000), clinicians ask:

- Do you often fail to pay close attention to detail and make careless mistakes?
- When you were a child, did you often fail to pay close attention to detail and make careless mistakes?

(Conners et al., 2001: 21)

The patient is then expected to provide specific examples of events that would either confirm or disprove these difficulties. Depending on the examples provided, the following boxes would be ticked by clinicians:

- Careless mistakes in school work
- Missed items/problems knew how to do
- Didn't go back over work to check answers
- Rushed through work without thinking through

(ibid.)

From my observations in the clinic, patients relied heavily on their old school reports to provide responses to these detailed questions. This reliance should not be a surprise given that school reports have been singled out in the DSM and other diagnostic tools as 'beneficial ancillary evidence', capable of counteracting the unreliable recall of childhood symptoms in adults with ADHD (Mannuzza et al., 2002; Miller et al., 2009). One clinician explained how he considered reports from

⁴³ This is now done electronically; documents are scanned into electronic copies or created directly on computers and stored in databases. At face value this could be considered a process of de-materialisation, the making of virtual records. Hull suggests that files and records have not dematerialised but their 'thingness' is changed from paper to silicon, and that 'electronic technologies have increased rather than decreased the proliferation of paper documents' (Hull, 2012: 260). In the clinic, I observed electronic forms being printed then scanned to be re-entered in the electronic file.

institutions such as schools or the Driver and Vehicle Licensing Agency (DVLA) more reliable than self-reports, as they brought some objectivity to the accounts. Thus, new support group members who had yet to be diagnosed were advised to start locating school reports for the crucial role these would play. As Paul described, this process could be quite difficult:

Paul: "I found some old school reports from public school, we are talking around O-levels and they are very very telling. I got them put away somewhere, because these [ADHD] assessments, they are understandably aimed at young people who are either at school or left school not long ago. When they ask you - "do you have any school reports, or would your parents have them?" You say - well - your parents are geriatric or pre-senile and your school reports are forty to fifty years old [laughter], you probably haven't got them. But actually I did find some mid-seventies school reports."

During one assessment I observed, a patient was asked about his symptoms of inattention and he proceeded to take out his school reports from an envelope. His collection included four years of reports that consistently described him as being distracted and distracting to the rest of the class, of having the potential to get better grades if he applied himself more, and they mentioned his being restless and fidgety. Whilst the clinician seemed satisfied, the patient went on to explain how he could still see the detention room where he spent so much time bored and frustrated. For several minutes, he described intensely his 'friends in boredom', the tricks they had planned, the teachers who had caught them until he was eventually interrupted by the clinician..

The school reports that I saw, in the clinic and in the support groups used a similar template. They were usually of A4 size, browned with age, with lines and boxes in which information was entered by teachers and administrative staff; the name, age and form of the student, the term and the year of the report and boxes in which teachers from different disciplines wrote a line or two to describe the student's achievement or lack of it. Usually there were columns in which examinations marks were entered and sometimes the ranking of the child in relation to others pupils. The bottom of the report was left for the head teacher to summarise the overall performance of the child, including her

behaviour. Finally the signatures of the head teacher and, importantly of the parents, sealed the document. The style of writing was succinct and formulaic, with such predictable lines as ‘could do better’ being recognisable to most.

Here, I am interested in asking what the school reports do in themselves rather than in examining their explicit and implicit intentional uses⁴⁴. I look at them as powerful objects that are rediscovered in attics or such places of storage. Why are they kept for decades? From the numerous conversations about school reports that I witnessed in support groups, the vast majority of members who went looking for their reports succeeded in finding them, even when it required some detective work. Yet school reports are rarely used past secondary school: it is as if they lose their bureaucratic value and usefulness as soon as school days are over. In comparison, birth certificates are regularly requested throughout one’s life for various administrative reasons. Similarly childhood immunisation records can be requested into adulthood for some employment purposes and international travelling.⁴⁵ Despite being redundant to their primary purpose, whether that be communicative or disciplinary, school reports are commonly kept and stored.

In her examination of the documents produced in an Neonatal Intensive Care Unit (NICU), and their use by families, Heimer suggests that ‘the bureaucratic uses of documents often assume that someone outside the organisation will have a rather different relation to the subjects of the documents’ (Heimer, 2006 :21). Forms and documents are designed so as to limit the possibility of addition and improvisation, yet they are also sent into the world to be used, adapted, reinterpreted and reinvented. Just as the documents created in the NICU are often the first descriptions of the new born child’s physical life (Heimer, 2006), the school reports are the first records of the social life of the child outside the family environment and are kept as mementos. They contribute to the biographical records collected by parents, kept along with ultrasound prints and curls of hair, to mark another stage in the life of the child. Documents participate in the stories that are told by parents to their children,

⁴⁴ School reports can also be seen in in terms of disciplinary power; see Foucault in O’Farrell (2005:102).

⁴⁵ During my fieldwork, I was made aware of an inquest into the death of a patient, which examined school reports as part of an investigation into the validity of the ADHD diagnosis and treatment that had been given.

they trigger questions by children and as such ‘must be understood as elements of a conversation’ (Heimer, 2006: 103).

Just as school reports travel back and forth between school and home, the narratives embedded in them circulate between parties. Beyond recording the academic life of the child, school reports are records of the relations between the child, the parent and the school institution, noting whether or not the child contributes to the life of the school. The comments found in the school reports that support group members shared with me often referred to disruptive behaviour which affected other pupils or the smooth running of the school. Equally frequent were comments recording traits of absent-mindedness and not contributing enough or paying attention. In this context the teachers’ comments can be seen as descriptions of the relation between themselves and the child, who is presented as sometimes absent, sometimes overwhelming. The reports I saw were from primary and secondary schools in the 1970s and unsurprisingly none included any mention of ADHD or even formalised words such as impulsive, inattentive or hyperactive⁴⁶. Instead, the reports focused on the relations between the child and the institution, itemising frictions and discords using language that still resonates for adults today. ‘Makes careless mistakes’, ‘Appears not to be listening’, ‘Dreamy or preoccupied’, ‘Frequently arriving late’, ‘Difficulty in sitting still’, ‘Talks during activities when this is not needed’, ‘Difficultly awaiting your turn in the classroom’, are a few examples that could be found interchangeably between old school reports and new diagnostic tools⁴⁷.

As I saw in many assessments, the linguistic and descriptive bridge between the school reports and the assessment questions elicited detailed memories of childhood events. Often the recollection of school days was expressed with humour and a sense of confirmation of a coherent biography. Once they had read their school reports, support group members would commonly comment how the report showed that they had not changed since childhood, that they had always been the same forgetful or restless

⁴⁶ See Chapter One where I note that some of the history of the diagnosis of ADHD showing when the diagnosis became available to clinicians in the DSM-III(1980) and in practice in the UK in the late 1990s.

⁴⁷ These examples are all from the Diagnostic Interview for ADHD in Adults (DIVA) (Kooij and Francken, 2007), one of the diagnostic tools used in Europe, and since 2013 in the UK. In the assessment interviews the examples above are formulated into questions, whereas in the school reports they are used as statements of observations.

person. In other words the reports confirmed a sense that if something was wrong, it had always been there⁴⁸.

Sometimes recollection was tinged with ambivalence, as Simon described when we discussed how he felt about having his recent diagnosis:

Simon: “So, there's the organisation stuff, that's really showing in my school reports, always late that kind of thing. But there is the reports versus reality: when you are at school at eleven, twelve years old, the day to day feeling is so different to the end result. If I tried to think hard enough about the day to day I'll probably think of unhappy kind of things because the homework issues were so stressful, thinking back to then it's probably giving a negative spin to things.”

Claude: “What do you mean negative spin?”

Simon: “It might be bad [having the diagnosis] because it causes me to think more negatively about these things. Although it does not affect me now, it affects my interpretations of the memory, next time I look at that memory. So that's why it's, it's difficult. I am not bothered by it, but it makes it... it brings up the negative more strongly. But it doesn't mean it should not be necessary to go back in time if it is needed for the diagnosis.”

What was striking in the way Simon discussed the act of remembering through school reports was his reluctance and resistance to the intrusion this caused into his memories. The school reports as mediators of memories were distorting what he recalled about his time at school, yet reflecting on them was considered a necessary step to take. Simon's comments denoted an uncomfortable tension between the contents of the reports and his own memories.

⁴⁸ There is an extensive literature critiquing or augmenting the concept of biographical disruption (Bury, 1982) with those of biographical continuity and biographical reinforcement (Williams, 2000). In brief, this literature suggests that chronic illness does not always create a biographical disruption; in some circumstances, becoming ill reinforced an identity (Carricaburu and Pierret, 1995). In others it was the disruptions in people's lives that caused illness (Day, 2007; Skultans, 1999). Here I am suggesting that for the people I met, school reports were confirming a sense that the problems they were facing in adulthood had always been present. As I will describe, finding out that ADHD might be relevant in their lives may have caused some disquiet, and for most participants, the school reports helped make sense of their current difficulties as a continuity in their lives.

We can think of school reports as mediators ‘that transform, translate, distort and modify the meaning or elements they are supposed to carry’ (Latour, 2005:39). In order to respond to clinicians’ queries about childhood life events, patients were calling upon old documents to scaffold and prop up their practices of remembering and, in that process, turned reports into evidence of biographical continuity. Thus the old documents that were discussed and shared in support groups became directly involved in the diagnostic process in the clinic.

In the next section I want to explore how one support group and its members constructed a memory bank, an archive of lived experience which both described and produced a version of ADHD. In addition to using old documents to support their remembrance of past events, I will show how group members also engaged in a collective process of recollection and recording which served as a point of reference and classification.

“Sharing is like taking medicine through the ears”

The four groups I attended were far from homogeneous in their practices, their membership, or their views on ADHD and its treatment. Nevertheless members in the four groups shared an orientation to support each other collectively, developing practices in particular ways, such as a system of accountability in order to improve their organisational skills⁴⁹. In Group B, specific circumstances led members to develop a system of recording members’ experiences of ADHD in order to learn from each other and to find ways to alleviate their difficulties. I liken the recording process they used to the making of an archive where memories of events are deposited and retrieved when needed, which Bowker defined as ‘practices that allow (to some extent) useful/interesting descriptions of the past to be carried forward into the future’ (2008: 7). I am interested in the implications of making collective records in this way for members themselves but also, more broadly, for the concept of ADHD that is thus being enacted. The etymology of the word ‘archive’ as described by Derrida (1996) has prompted me to explore its dual role in assigning origins and in affirming authority. My intention is

⁴⁹ See Chapter Eight.

not to apply a critique of these practices through a Freudian and psychoanalytical lens, as Derrida did, where archiving is a sickness, a feverish search for origins. Instead I aim for a different undertaking in noting how the practices of memory involved in the making of an archive also create a collective endeavour that provides a means for members to live better and to improve their lives.

When I first attended the support group in the north of England, I was struck by the busyness of the room. There were eighteen to twenty people, mingling and chatting in a large space that could have accommodated twice that number. People moved around, made tea, went in and out through the open back doors to smoke cigarettes. Some sat on armchairs and settees arranged in a circle in one half of the room, chatting or using their smart phones. The other half of the room was occupied by tables and chairs also arranged in a circle, and a couple of members were sitting there writing. The volume of speech was quite loud, and to my non-English ears, the accent was also very noticeable, sometimes sounding as singing would, with rising and falling tones where I did not expect them. All this activity gave a sense of excitement that was palpable, and heightened by the visual stimuli too. Three of the four walls were covered with posters of one sort or another and the fourth wall was made of large windows and a glass door, which provided natural light during the daytime. One wall had pictures, some of famous sportsmen and actors with their signatures and dedications, as well as coloured prints, posters and drawings.

The other two walls were covered with handwritten posters, written on flip charts using black markers and displayed in two lines one above the other, with each poster close to the next. There were over thirty posters, each with a different title written in larger script and underlined; some headings were the familiar descriptions of ADHD found in criteria and classification, for example impulsivity or inattention. Others were descriptions of emotions such as anger or depression, and still others were headed by categories such as relationships or addiction. Below each of the headlines numerous bullet points followed listing descriptions of situations related to the title. For the posters dedicated to impulsivity, descriptions included ‘making the wrong decision when at work’, ‘not thinking before talking gets me into trouble and fights’, ‘I got into debts because of it’. The comments were sometimes written in the first person and at other times seemed more general. The posters also

contained responses to the difficulties described such as ‘recognise the triggers and move away from the situation’, ‘avoid doing shopping online’ or ‘put items in online basket and not purchase on the same day’.

After a few weeks of attending, I noted that the display looked neglected, with a couple of gaps in the rows, and more posters threatening to fall off as the blue tack lost its adhesive property. I remember feeling some sadness at the sight of the display, disused and uncared for. Retrospectively I can see that the display had become part of my experience of attending the group, just as it was for the other members, as it was often referred to and called upon during discussion. People would point to a particular poster to back up a point they were making, or a facilitator would suggest that newcomers read them whilst having a cup of tea. It was not like wallpaper lining the room, but an integral part of the group rather like having another member in the room, a kind of lived and live database, an ADHD archive. I asked Caroline, one of the facilitators, about the falling posters and she started to explain how busy they had been. As they were about to start a new course, all the posters would be replaced anyway. As she continued to give me details of this training course, it also became clear why I had not witnessed the making of the posters, as they were made and accumulated over a discrete period of time during the year as part of a module. As a new course was about to start, the process would begin again and the display would be renewed.

Caroline explained that she and the other founder of the group, Tessa, had been doing a lot of networking over the years with various institutions in their cities in order to raise awareness of ADHD in adults. They had made contact with a well-known university in the area which was offering support to students who might have ADHD. Caroline and Tessa had contact with the local probation services and criminal justice workers and with employment agencies too. They offered to deliver basic awareness training on adult ADHD to frontline workers so that they could signpost individuals to the support groups if they felt this might be helpful. They were clearly successful, as I met a number of individuals in this group who started attending as a result of the initiative. As Caroline continued, she told me that they were encouraged by this success and took up the offer of help given by a member of the group who had business and marketing experience. They registered as a social enterprise and

developed a training course for young unemployed adults with ADHD. They then protected the course they had devised under copyright legislation. Subsequently they were commissioned by the local employment agency to deliver this course to twelve young adults in order to facilitate their access to work by explicitly addressing difficulties associated with ADHD⁵⁰, including accessing medical diagnosis when appropriate.

The course as it was described to me⁵¹, was fifteen weeks long, delivered over three days per week and attended by twelve men and women. In this particular cohort members ranged between twenty and 40 years old. They met to explore ADHD, to work out how to alleviate and build awareness of symptoms in an attempt to diminish the impacts in their own lives and in the lives of those close to them. The last five of the fifteen weeks, were dedicated to seeking employment, working on application forms and practicing interview skills. The main part of the course focused on personal experiences of ADHD and its associated symptoms, inattention, hyperactivity, impulsivity, as well as such topics as addictions and relationships. Each of the ten weeks was devoted to a specific topic. From each group discussion, notes were taken and one person wrote these onto a poster that was then placed on the wall of the room for display. The notes recorded experiences which were specific to individuals, yet recognisable and familiar to most members. Some described ways to approach certain social situations better and so avoid unwanted consequences. Responses also highlighted ways to 'harness' behaviours and turn them in to positive assets. Thus one poster noted, 'hyperactivity when channelled can provide endless creative energy'. Each poster included testimonies of events, often disastrous and tragic, with responses that were set out in no particular order. Thus the effect produced when reading the posters, was of a list of variations on a theme, which were not separated into bad and good categories. The categorising functioned on a broader level, so that, taken as a whole, the 30 or so posters formed a description of ADHD as lived and experienced by those in the group. It

⁵⁰ The course that was about to start towards the end of my fieldwork was the third of its kind to be commissioned.

⁵¹ My attempts to get the facilitators to agree to my attendance on the course were not successful. Caroline and Tessa felt that individuals shared very personal issues and that it would affect the dynamic of the group if I were observing. Instead they agreed and facilitated conversations with some of the people who were attending the course. I met with three out of the twelve registered. My description is therefore based on their reports as well as on those of the facilitators.

included elements of the formal diagnostic criteria as well as recording impacts on participants' lives. For example, the posters headed 'addictions' were wide ranging, noting the use of alcohol or cannabis to treat sleeplessness, or the urge to search for thrilling but dangerous situations.

The course took place in the same room as support group sessions but on different days. As the course progressed, posters were added to the display which could also be seen by the support group⁵². The posters were regularly used in this setting, even though they were not written by the support group attendees. On one occasion, an individual was describing their persistent difficulties in staying out of trouble. He described how he often found himself in situations where he could not control his impulsivity and got into fights with total strangers when he could have walked on. He was visibly upset, and other people in the group were showing and expressing their support. At this point Caroline pointed to one of the posters and read out loud – 'by focusing on my thoughts and emotions I can become more aware of my impulses and can try to control them'. She explained that this thought had been shared by someone who also had arguments all the time, and who had found himself without any lasting relationships. Caroline continued to explain how calming activity, like yoga or mindfulness, could be really helpful but that the most important thing was to share your feelings with others and to listen to what other people have to share. Pointing towards the wall full of posters she said; "sharing is like taking medicine through the ears", something that Caroline repeated at least once during every session I attended. I asked her about this motto and she explained that it encapsulated the work of the group. Sharing, in her sense, meant both contributing and listening in the group. Not only would sharing your problems, memories or experiences be beneficial to you, but it would also benefit the others who were listening.

The metaphor of medicine within the motto, suggests not only that ADHD needs to be treated, but that sharing one's experience and listening to others is a worthy alternative to pharmaceutical treatment.

Another reading implies that sharing, like medicine, has to be performed regularly for lasting effect.

Regular attendance was frequently encouraged by the facilitators, just as clinicians reminded patients

⁵² Four members of the course also attended the support group. I had conversations with two of those and a third member of the course came to speak with me at the suggestion of the facilitator.

to comply with their treatment programmes. The motto seemed to capture the ambivalent relation that this group had with medical explanations for ADHD. As the months passed, I became aware of an assertion that behavioural theories had been damaging to people with ADHD, as mothers were often blamed for bringing up their children badly. Neuroscientific explanations had been helpful in dispelling this idea. Nevertheless there was a certain mistrust of a medical approach to explaining and treating ADHD, or at least not a total acceptance. Thus discussion of pharmaceutical treatments took up very little of the sharing time. The topic was often accompanied with the caveat that it should be an individual decision, implying that the group did not have a role to play. As the conversation resumed with the irony that was so prevalent in these sessions, Amy, sitting next to me, added that it was really important to only speak one at a time, so as not to overdose on the medicine.

As people shared their stories, they might point to a poster, and read out a line that they felt expressed their situation. Some responded by highlighting that they felt could be helpful to the person who was telling their story. In effect, the display of posters performed the role of a repository for the description of experience which could then be accessed by others, just as a live database can be shared. As I observed the use of this archive, the retrieval of information was used as both reference and predictor - the experience that you have had and recognise here does not have to be the end of the story. In other words, the past can be made useful for the present.

At face value, the lifespan of this archive was limited; on one of my visits to the support group I found that one of the two walls dedicated to display this archive had been cleared of any posters, and the other had some newly written ones. As the meeting started, and I had time to look at the new display, I noticed one poster that stood out amongst the neat new lines. This poster was on paper yellowed with age, broken along some edges, and not hung as neatly as the others. Later that day I asked Caroline about it, and she explained that as a new course had started, they put away the old lists in the cupboard, and made space for the new, except for that one, as the person who wrote it had asked that it should remain on display. The old poster had a number of notes and bullet points that were written as records of this person's school life and early work experience. These described experiences of bullying and stigmatisation, and the writer wanted to preserve the display as a reminder to the group,

for themselves and for others. The archive was therefore an accumulation of records of different ways that people experience, live, struggle with and adapt to ADHD. The recording, the displaying, and then the storage was a process that made a repository of ‘collective memories’.

Derrida’s examination of *The Concept Of The Archive*, as he first entitled his lecture (1996), helps foreground some of the implications that attached to memory practices within the support group. Taking us back to the Greek etymology of the word, *Arkhe*, Derrida identifies two principles combined in one: that which is the origin, where things begin, and which by that virtue provided authority and power. The materiality is crucial in that an archive is a place, a space, where records are kept and where power may be exercised by allowing or denying access, for example. In the case of the support group, the archive was the room where people met, and the facilitators were its archivers. It seemed that access to this archive was not limited for those who attended the course, but was in fact positively encouraged for all that entered that room. Of course one could argue that the archive was only made available by the presence of the facilitators, and that the records, the raw material as it were, required interpretations by the archiver. But that is not exactly what my observations revealed, as references were made frequently without the mediation of the facilitators. The sharing practice associated with the making and the using of this archive had, in my view, a more powerful impact. Returning to Derrida’s definition, the French words also deployed in the English translation to describe how origins and authority may be intertwined, are revealing: ‘Arkhe we recall, names at once the commencement and the commandment’ (ibid.: 9). The beginning and the order. Authority is thus gained through the work of recording, listing and classifying that asserts where things have started. In this way the group was collating and locating the varied experiences of its members in past events, sometimes in childhood, sometimes not, that might explain how their difficulties had begun. By listing and categorising the experiences of many members, the archive also made forgetting possible, if only temporarily; one does not have to remember and keep in mind all of the ways that ADHD can be experienced and treated if this knowledge is recorded and made retrievable. For members of the groups whose forgetfulness and memory was problematic, this constituted an important benefit.

When one entered the room, one simultaneously entered the archive itself and became immersed in the lists and displays. In this way one was reminded of the snares of impulsivity or inattention and of ways of living better with them. The latter of the two principles found in Arkhe, the order, can reveal both the classifying role of the archive and the authority that emanates from it. An archive contains records that have been selected and preserved, it is never an exhaustive list. Certain things may have been destroyed, others excluded and therefore rendered invisible to future inquiries (Bowker and Star, 1999). The archive and its content define what is remembered. The way it is organised, how its elements are grouped, named, how it is displayed is also a creative act. The categorising and listing that took place was an attempt to produce an authoritative record and a point of reference for its members. In its details, this archive was made of individual stories rooted in specific circumstances; in its totality, it was an ideal, an abstracted version of ADHD and it was precisely the combination of these elements that gave it authority.

This version of ADHD sometimes coincided with formal classifications, but sometimes it did not. It was the experiential knowledge that it contained which was valued. The power of this listing was therefore found in the accumulation and sharing of experiential evidence for ADHD, which is classically associated with self-help groups (Borkman, 1999). In this case, the representation of these experiences in an archive, as an object and a space, asserted a broader authority and legitimacy. Bowker suggests that archives can be classified into two categories: a formal kind that emphasises control and chronology and makes a ‘presentation of the past as rational reconstruction from the present’ (2010:213). In contrast, the other kind of archive evolves without an explicit plan, and is made of the things we leave in our wake, through our habits and customs. The archive that Group B was making strikes me as a combination of both: the recollections being recorded were somehow controlled, classified and ordered through the facilitators of the group while the archive itself evolved in an unpredictable way and was dependant on physical traces left in a particular place⁵³. The support group’s version of ADHD was an assemblage of ways of being, with contradictions and uncertainties,

⁵³ The process of reviewing the DSM-IV as described in Chapter Two is similar.

which was left open ended, for others to continue. Through time the recollections of living with ADHD within the support group also changed and reflected the group's changing membership.

I consider that the work of producing this archive also contributed to the diagnostic process that took place in the clinic, as it helped individuals to identify, classify and categorise events in their lives which could be used as evidence. Furthermore, the records augmented the framework and support already in place to remember past events: as an alternative to the structure offered by school reports and other documents, support Group B constructed their own scaffolding of memory.

The supportive practices in place for remembering were at times targeted towards 'not forgetting' in the present. To conclude this chapter, I want to briefly describe the role that technology, namely phones, played in 'not forgetting'. The practices associated with these devices were not related to archiving and creating a memory bank of past events (Dib, 2013). Instead participants used their phones to support the flow of actions and time. Reminders on a phone could help avoid procrastination taking hold, or missing an important appointment, or they could establish habitual practices through prompts. As participants said, they purposefully and strategically used their phones in ways that would compensate for the difficulties they experienced. As I show further in Chapter Four, the strategies were transformative in that they altered behaviours as much as they altered selves.

Pre-frontal cortex device

The metaphor of the computer RAM as a way to explain the mechanics of working-memory is apt in considering some of the strategic tools that I observed when attending support groups. One of the members of support Group B suggested that her smart phone was her pre-frontal cortex; it was her working memory and it allowed her to keep in mind all the things she needed to do. As she spoke, she was handling a well-used smart phone, her forefinger swiping and tapping alternately, obviously opening apps or other software which the rest of us in the group could not see. We could all imagine what she meant, even those who did not own a smart phone (as I did not at the time). We were all

familiar with the calendars, the alarms and other means for keeping track of events and tasks⁵⁴. Her comment was part of a conversation about the problems and solutions associated with being disorganised and forgetful.

Mobile devices were literally held and displayed constantly during these conversations, not only to demonstrate their capacity, but also to actively do some remembering: what was that last blog that talked of ADHD at work? Apps were used not only to provide information that had been stored, but also to trigger conversations on individual preferences and practical uses for these. In conversations about pharmaceutical treatments for ADHD, it was very common to see people search for that elusive information by consulting their phone: is that new drug slow release? What is the chemical base for it, Dexamphetamine or Atomoxetine? Smart phones were used in this way as referees, called upon to confirm one point of view over another. As well as retrieving data, they were used to record new information such as addresses, pictures and more. Individuals were still forgetful, but the burden of remembering was transferred to these electronic objects, and provided a technical solution.

The strategic position given to mobile devices by group members was also visible on the most popular website forum in the UK for adults with ADHD. The AADD-UK website was well known to all the people I met in my fieldwork, clinicians and support group members alike, for its comprehensive electronic library, its information about local services⁵⁵ and for its forum. In line with the slogan of the forum ‘This is a peer-to-peer support forum! Here we are learning to support and advocate for ourselves and others with ADHD’, many of the forum contributions were from adults diagnosed, or in the process of being diagnosed, with ADHD. A number of boards were available to engage in conversations; one board named ‘symptoms, diagnosis and treatment’ had themes such as medication, coaching, and ‘non-medical treatment, aids and strategies’. In this last theme, one thread of conversation was dedicated to ‘useful apps’ where individuals were sharing their knowledge of

⁵⁴ Since my fieldwork, Microsoft has launched an ‘intelligent personal assistant’ on mobile phones which combines all these features and more as it retains information about the use of the phone to support and predict future requests in order to ‘be the most productive version of yourself’ <http://tinyurl.com/qek3kn7> Accessed on 10/11/2014.

⁵⁵ I conducted a survey of support groups in the UK on behalf of AADD-UK which they published on their website. (See Jousselin, 2013). The website is still very active at the time of writing. See <http://aadduk.org/> Accessed 10/11/2014.

particular apps and software that could help alleviate ADHD-related symptoms. One kind of app that was particularly popular and marketed under different names, turned a to-do list into a game, even a quest, so that for every task completed points were awarded. As one contributor explained:

‘It’s soooooo cool!! You get an achievement when you’ve done something, it motivates you to get more points. It’s a good reminder list. So washing up is set to appear daily and I have assigned it 50 points in the “stamina” category. If I have a stressy email to read and respond to, it’s 100 points in the “spirit” category. You can look back at everything you’ve achieved so far. I love it!’

It would be easy to consider these devices only as memory tools, as the metaphor of the pre-frontal cortex suggests, and to think of them as external support to remedy a deficit, or to extend memory keeping. But I suggest that a dialogical relation between the tool and the individual occurs. By highlighting the mediating role of devices, I am suggesting that neither the tool nor its user is quite the same once they have met. The communication device has become an organiser and a reminder, and the user is not defined by his forgetfulness any longer. It takes the interactions between user and tool for these specific new modes to come into being. Both tool and user produce each other through the possibilities they offer one another. The outcome of that exchange is mostly stable and predictable, as we know what to anticipate when we use a calendar. Nevertheless, as I show below, the interactions with electronic devices and the support they offered were sometimes unpredictable and not always welcome.

During meetings, conversations were often punctuated by moments when cohesion became fragmented and discussions between two or three people would start, soon followed by others forming parallel groups and debates. Inevitably smart phones were involved, either as triggers for bringing in new topics or through searching for pre-recorded information. This would lead to ten minutes, sometimes more, of a disjointed period, of in-between time. As the volume of speech increased, so did the sense of excitement, until the facilitators – when they extricated themselves from their phones –

would try to re-assemble the group into a cohesive whole. As I was a participant without a smart phone, these unexpected breaks in the rhythm of the group always left me reeling, as if experiencing aquaplaning whilst driving; an unexpected and uncontrollable loss of direction. One moment the group would be discussing one topic, in conversations that everyone would follow, and the next moment brouhaha and confusion would take over. By attending groups regularly, I eventually became accustomed to these sliding moments, and was less surprised, and became aware of when they would begin.

I mentioned my sense of displacement to another member who did not have a smartphone, and would often use this chaotic pause to stand up, walk around and sometimes make a cup of tea. We both remarked on our common phoneless status, me saying that I was slowly moving towards acquiring one, possibly, and him explaining that he was actively avoiding them as they were too distracting. He described how he had a really poor attention span so he was easily distracted and could not really watch TV any longer because he could not concentrate and focus his attention. He had used smart phones in the past to help with planning and organising and he thought that that was quite useful, but he had ended up spending too much time on the internet. It became unbearable as he would be using two, sometimes three screens or devices at the same time; watching TV whilst searching on his iPad and tweeting on his mobile. He described how this would give him a real buzz, like brainstorming all the time, and having lots of ideas but in the end it was exhausting and caused insomnia. He knew, he told me, that the benefits of the electronic reminders and notebooks were in the end not worth the problems they caused; he could not cope with all the emails and other flag-ups that he had set, and ended up not responding. So now, he said, he stayed away from mobile devices, but he still used computers at home and work. Instead he was practicing mindfulness meditation which was helping him to focus and be less forgetful. As he showed me, he still used little tricks like having his keys around his neck and making lists daily, but he thought that meditation was what really helped him to keep in mind the things he needed to do. For this person, the benefits that could be gained from using mobile devices did not counterbalance the unexpected and negative effect that they had on his life: in this way they were comparable to the unwanted side-effects of medication.

Conclusion

By exploring what ADHD is like in the support groups, and what such groups contribute to the diagnostic process, I have highlighted the central role of memory practices. In the clinic, remembering was aided through institutional and bureaucratic procedures, whereas in support groups it was the interpersonal practices of memory that I foregrounded. In both settings, remembering and not forgetting took much effort and work. Going beyond the scientific recognition that patients with ADHD will experience more difficulties than most people with long and short term memory problems, I explored the support groups' scaffolding for remembering which they put in place in order to compensate for their difficulties. In some cases, the people I met accessed existing structures such as school reports and other documents in order to aid their memory of childhood events. In one case, support group members produced an archive-like record of past events, collectively supporting each other to remember. In turn, these memories became evidence towards demonstrating that their present problems had been persistent since their early years. In other cases, the props used by support group members were related to improving their lives in the present by not forgetting to complete tasks, which they discussed in terms of strategies. I have argued that the technologies used, namely school reports, the archive and mobile devices all acted as mediators. As individuals gained greater understanding of their difficulties in the context of their lifespan, school reports were re-imagined as evidence of difficult relationships in childhood. Similarly, as individuals reduced their tendency to procrastinate, the phones themselves became 'smart' and turned into personal assistants. The next chapter extends my examination of support groups' strategies which are put in place to improve peoples' lives in the hope that their ADHD related difficulties would be alleviated and absorbed into daily life.

Chapter Four Techniques and strategies: absorbing inattention into everyday life

Living with untreated symptoms

Clinical assessments for ADHD in adults, as I described earlier, are lengthy, consisting of two tasks which together last for 3 hours. Typically, the two parts would be conducted by different clinicians. First, a specialist nurse conducts a structured interview, then the patient has a break and a consultant psychiatrist performs the Mental State Examination. This division of labour allowed for the consideration of different opinions and made the process more manageable as three hour sessions were considered to be too demanding for one person to perform alone.

The assessment I observed earlier in my fieldwork gave me a sense of the demands on patients' attention and resilience. A patient, a woman in her late thirties, came into the consultation room accompanied by a friend and was from the start visibly restless and unable to control her body movements. She removed her shoes and climbed on the chair, she sat with her feet underneath her, yet was unable to keep them still, and as the assessment went on, she would at times get up to pace up and down the room. As she was asked to provide examples of impulsive behaviours in her everyday life, she started to describe how she often behaved without thinking and how she was unable to control or stop herself from acting impulsively⁵⁶.

Pam: "Like the time when I was about ten years old and I jumped in the big pool without knowing how to swim; even later I have jumped out of cars while they're moving. I just felt like it. When you get that monster, the skin will burst. I'm like a dog in a cage, scratching and barking."

Pam said this whilst clasping her upper chest and throat as though she was unable to breathe from the tension. She then grabbed something from her bag, an elastic band, and started to pull and stretch it.

⁵⁶ This is a transcript based on hand written notes during the assessment and augmented with fieldnotes written after the assessment.

She continued to play with it whilst talking in sentences that came out in bursts, not quite finishing one before starting another.

Pam: “Sometimes I play music so loud, and that helps, because I can’t think or hear anything, and then I can feel a bit more relaxed. You know, it feels like I need to lock myself away, so that I don’t do the wrong thing in front of my children, and to do that all the time is tiring, I’m exhausted. I don’t really know what’s wrong. What do you reckon, what should I do?”

At that point the elastic band she was stretching snapped, and she let out a cry of pain; “Ouch”. She immediately took out a bag full of elastic bands and explained:

Pam: “I’ve got them with me all the time, so that when I need to be a bit quiet, like now or in the bus, then I can use them. That was my son’s doctor who suggested it, and it kinds of keeps me under control.”

At the end of the assessment, as I accompanied Pam and her friend back to the entrance of the building, she explained how the mental health services that she had consulted before were, in her view, useless, only interested in giving her medication and with no time to see her. She said how the assessment she just had was the opposite, but probably too long, as she was now exhausted and worried about having to drive right through London and beyond. I agreed with her that it was really tiring to be assessed for three hours, as I was myself feeling the strain and I wished her good luck as she walked away.

This small excerpt from an assessment highlights how individuals who attend the clinic try to make sense of what they are experiencing prior to receiving a diagnosis and treatment. Pam explained that she did not know what was wrong yet she knew that there were some things she could do to help herself in her everyday life such as the elastic band pulling or the loud music. I came across similar stories over and over again as people described many years of developing their own solution to problems that otherwise remained unresolved. Most of the people I met in the support groups described these efforts for living with disabling symptoms as ‘strategies’, a term that was used repeatedly and often with great emphasis. The term ‘strategy’ represented a hopeful move to me, an

orientation towards the future as much as an attempt to gain or re-gain control over events every day, and reduce the negative impact of symptoms.

The three support group members I present in this chapter described very different attempts and strategies which were orientated towards a better future but most importantly aimed to make everyday life in the present easier. Sometimes what they put in place worked, but only insofar as it was repeated, re-enacted and thus habituated with the help of technologies. I will show how the work to establish regimes of behaviours becomes burdensome and how uncertain and changeable the balance is between hope and despair, optimism and anguish. I will suggest that support group members consider medical treatment itself as a strategy when they are faced with making unsustainable efforts to lessen the impact of symptoms: they see treatment as something they *do*, rather than as something they *take*.

In previous chapters, I discussed the practices used in the clinic and support groups in order to arrive at a diagnosis of adult ADHD. I have argued that practices of memory, both institutional and interpersonal, play a crucial role in the diagnostic process, over time and in different settings. I described the work and structures which are accessed and put in place by clinicians and support group members not only to help with remembrance of childhood events, but also to assist with being more awake in the present and not forgetting tasks.

In this chapter, I reach further back along the timeline of the diagnostic process and explore how people describe living with symptoms in the absence of a formal diagnosis or treatment. The people I met were on the whole over 40 years old and, as a result, had been living with the accumulating impact of inattention, hyperactivity and impulsivity for decades. The implication is that people lived their everyday life in childhood, adolescence and then adulthood with a range of difficulties which were caused by being forgetful, having difficulties in keeping their attention on the tasks at hand, or being unable to rest and sleep. As one-off events, these problems are annoying but in their persistence through consecutive life stages, they are actually disabling. They demand endurance and adaptation from the individual and/or her direct social environment. Whilst Pam said that she did not know what

was wrong, the accumulation of problems and difficulties over time alerted her to the fact that this condition was not something that everyone experienced. This kind of suffering, ordinary and cumulative rather than exceptional and discrete, is easily missed or ignored by observers.

Often people described how they had found ways to alleviate the impairments they faced as a matter of survival after too many disasters or crises that left them with no money, no relationships or sense of worth. These strategies were attempts to absorb problems into their ordinary lives, so that their impact was reduced. One support group member explained how such strategies provided means to move forward to a better life and not become ‘stuck in a repeated disaster zone’. In her exploration of health, disease and poverty in India, Veena Das (2014) discusses how suffering can be absorbed into everyday life, so that it *almost* disappears behind the business of carrying on, of living and surviving. Almost, because if one pays attention to the details of daily practices and conversations, Das argues, it will become clearer that this absorption ‘scars [life] with a sense of things not being quite right, even a sense of suffocation and foreboding’ (ibid.: 1).

Das’s work on suffering has been concerned with describing how violence, often extreme, can be integrated into ordinary life, not through transcendence or an escape from reality, but instead by ‘a descent into the ordinary’(2007). The notion of absorbing suffering into everyday life activities is particularly helpful in describing how the people I met discussed their own attempt to live with the consequences of being forgetful and hyperactive. In contrast to the extreme violence that was experienced by Das’ participants, Pam and members of the support groups described how they lived with persistent, continuous and cumulative everyday difficulties by adapting as best they could.

The techniques and strategies that were described in support groups, social media and the clinic as ways of living with distressing symptoms reminded me of the transformative practices that Foucault famously named ‘technologies of the self’ (1988)⁵⁷. In his later work, Foucault described how his

⁵⁷ I have used Foucault’s concept here but I also found De Certeau’s (1984) contrast between strategy and tactics helpful to think with in regard to issues of temporality and power. It is worth noting the contemporaneity of the two authors as *The practice of everyday life* (1984) was published the year of Foucault’s death in 1984. It has been argued that Foucault, when examining everyday practices, had focused on the analysis of power and its loci in institutions, to which De Certeau reacted by concentrating on the everyday practices as the loci of resistance. My discussion in this chapter will be based on the terms and actions used by support group members,

interest moved from the examination of domination and power shown in his previous work (1972, 1975) to an exploration of ‘the modality of relations to the self’ (1984:338). He explored ancient Greek practices of knowledge production and proposed that the notion of caring for oneself, ‘*epimeleia heautou*’ was representative of a particular attitude towards one’s self, towards others and towards the world which was embedded in practices and techniques. In other words, the transformative practices deployed to look after oneself were also the basis for knowing about oneself.⁵⁸ In this chapter I am concerned with exploring how caring for oneself was part of a process of self-knowledge and of becoming adults with ADHD. I am not suggesting that such practices were means of receiving a diagnosis of adult ADHD, but instead, that by looking after themselves people enacted particular versions of ADHD. As I describe in detail, it was through the strategies they put in place, to use their terminology, that they began to understand what might be wrong with the way they experienced the world. It seems to me that these practices and techniques were important in bringing immediate relief, and in time, for enabling their understanding and recognition of what might be wrong.

For the remainder of this chapter I use ethnographic examples to explore the techniques that people deployed, some more strategic than others. The first part introduces Paul and Clara who highlight how some strategies act directly on the body initially but also improve interactions with the world. In the second part I examine how Garry conceived playing chess as a means to become both more awake to the world and to paying attention to others. Finally I conclude this chapter by returning to Clara, who described the potential cost of living by strategies in an attempt to absorb her difficulties into everyday life. Her account shows how hope and despair become co-existent.

which highlighted their ambivalent relations with medical institutions and models, neither rejecting them wholly nor accepting them fully.

⁵⁸ Foucault argued that the ancient Greek notion of caring for oneself was suppressed when it was supplanted by the more recent Christian concept of knowing yourself ‘*gnothi seauton*’. The mot d’ordre ‘know thyself’ was, according to Foucault, based on a renunciation of the self and assumed that knowledge can be acquired without an impact on the self, without a transformation of the self (Foucault, 2005).

The casual straightjacket

Early on in my fieldwork as I attended Support Group B, I met a number of people who were keen to participate in my research. Some I saw regularly, others I communicated with through emails. I interviewed Paul after a few months of correspondences; In his fifties, he held a professional post and arranged to see me in his office, where, apart from a couple of interruptions, we were left to converse in private. When I first met Paul, I found him very articulate and well spoken, with a calm demeanour that was somewhat in contrast to the prevailing mood in the room. As we started chatting in his office, I noticed once again the gentleness in Paul's personality. He discussed local history and I responded to his curiosity about my French background. Paul had clearly given some thought towards our meeting as he explained that we could have an interview lasting 45 minutes and then have lunch with his partner, Wendy. During the interview he described at length his lifelong problems with forgetfulness; he gave very detailed examples from his childhood and early adulthood including how he had first heard of ADHD through a friend who had been diagnosed with the condition. At the time his partner (now ex) was convinced that Paul had ADHD, whilst Paul completely rejected the idea. A decade and a divorce later, as his new partner made similar suggestions, Paul started the process which led to his diagnosis a year before we met. We continued our conversation in a local sandwich bar where we met his partner as planned. Our conversation moved from topic to topic but mostly returned to stories of Paul's forgetfulness. Wendy explained:

“ If you want to know what ADHD is like, all you have to do is to live with Paul for a couple of days; constantly losing things gets very distressing – keys, wallets. On one occasion he lost the keys to the apartment we were renting on holiday and once we got home he'd lost his wallet”.⁵⁹

As we were standing up to leave, Paul put on his jacket, and at that point opened it to show me. His jacket, a regular casual but smart jacket from the outside had a number of pockets with zips fitted on the inside. ‘Wendy did this for me’, he said. He had a pocket for his keys, one for his wallet, one for

⁵⁹ Fieldnotes transcript.

his watch and one for his mobile. He explained that they were not interchangeable; the pockets were specifically sized for the objects destined to occupy them. He had learned to place each object in the right pocket without thinking, but more importantly he had also learned to be aware of an object's absence when a pocket was empty. He would then look for the missing keys or wallet, and locate them fairly easily as they were often in the immediate vicinity. His trust in this system was built through the experience of becoming very sensitive to whether the pockets were empty or not and of being made aware of important objects through their absence. The irony in having developed this technique did not escape him: he called the coat his 'straight jacket'. But along with his partner, he was very pleased that the disruptions caused by forgetfulness were kept at bay.

With the help of Wendy, Paul had found a way to stop his forgetfulness impacting negatively on their lives recurrently⁶⁰. He did this by calling upon a personal technology, the jacket, and training himself and his senses to become alert to changes in the garment. In other words, what his memory couldn't keep track of, his body with the help of the jacket could. As Foucault wrote, the Greek word "epimeleia heautou", which means taking care of one's self ... describes a sort of work, an activity; it implies attention, knowledge, technique.' (1984:359). In Paul's case, the work of looking after himself was achieved through Wendy's adaptation of the jacket, and the training he put himself through so that the technology of the jacket functioned habitually, without requiring conscious thought. Following Foucault, we can think in terms of a physical regimen that aims to regulate an activity that is important for healthy living (1985). Whilst the jacket was not restricting Paul's movement, as the term 'straightjacket' suggests, it was restricting his tendency to forget objects that played an important part in his everyday life; bank cards, phone, keys. The jacket forced Paul to pay attention to the presence or absence of these objects; in other words it focused Paul's attention onto the materiality of life around him, which, if ignored, got him and his partner into trouble. In Paul's

⁶⁰ Throughout my fieldwork I had the opportunity to meet patients and support group members accompanied by their partners, relatives, people who cared for and helped them. My meeting with Paul and Wendy highlighted how much partners contributed to the stories, providing me with an understanding of the impact of symptoms on relations with others. Crucially, it also made visible the caring that takes place in daily lives which I would not have been party to otherwise.

words, the use of strategies such as the jacket meant that he felt ‘in control of life rather than buffeted by it’.

Foucault used the notion of regimen in an earlier text (1975) to describe power relations more overtly, using the political connotation of the word which bears notions of truth (1997). Here I am interested in the notion of regimen which Foucault developed in his later work, as a ‘whole manner of forming oneself as a subject who had the proper, necessary, and sufficient concern for his body... It defined a circumstantial strategy involving the body and the elements that surrounded it; and finally, it proposed to equip the individual himself for a rational mode of behaviour’ (1985: 108)⁶¹. In the next section I explore further how strategies towards living a better life are applied through concerns associated with managing the body, a topic that another participant, Clara, discussed at length.

Strengthening the muscle

I met Clara in the same support group as Paul; we arranged to meet in a local café for an interview and did so approximately a month later. A woman in her mid-thirties, Clara was visibly energetic, and at first impression seemed healthy, something that became a topic early in our conversation as she ordered a fruit smoothie. She had yet to be formally diagnosed and had only recently started to attend the support group. I asked her to describe the kind of difficulties she experienced. Clara explained that she always felt she had difficulties and problems with completing her work at school, that she did not do so well in college and so did not go to University. Instead she had been working with children for a decade, an occupation in which she found that her high level of energy was enjoyable and

⁶¹ It is worth noting as a preamble to the next section, that the French word used by Foucault, ‘régime’, encompasses the meanings of both diet and regimen in English: it refers to a system of government as well as to dietetic practices. Thus the model used for describing practices and procedures that can be found in organising state institutions can also be applied to individuals. It could be argued that the intellectual move Foucault made and described towards the end of his life had a basis in the word ‘régime’:

‘Perhaps I’ve insisted too much on the technology of domination and power. I am more and more interested in the interaction between oneself and others and in the technologies of individual domination, the history of how an individual acts upon himself, in the technology of self.’ (Foucault, 1988: 18)

acceptable⁶². However, she described severe problems with disorganisation and inattention that, in her view, were holding her back from achieving what she wanted. She had recently gone back to studying whilst working in a healthcare environment where she was diagnosed with dyslexia and had been strongly advised to attend an ADHD assessment. Whilst she was waiting for the referral to be processed, she was given advice on what might help her:

Clara: “This person, she said - Oh you need to make sure you have exercise every day, that you drink lots of water, have regular snacks. And I am like... you need to ask me who I am before you tell me what to do! You just described errrm. If you were to ask somebody – who does these things? – they tell you – Clara ! Because that's what I do, that's what I've always done.”

Clara was already following the healthy living habit of taking water, regular snacks and exercise even before ADHD had been mentioned to her. Indeed she had struck me as very healthy and sporty, as she was to confirm by describing how she walked everywhere and practiced martial art. Yet the techniques for looking after her health in general, soon became related to her newly suspected diagnosis as she went on to explain:

Clara: “I look after myself, I always carry water with me, I don't drink tea or coffee. I have done it recently with this job, because when you visit people they offer you tea or coffee, but I know it's not really helpful to me, it's not a matter of not being able to go to sleep at night... but I've just gone off topic...”

Claude: “That's ok.”

Clara: “But it's more that I get so tired, and you know, I live on like, oat cakes, nuts, and chocolate, and I am just constantly eating all the time, to keep myself going and to keep myself up. Because there is this theory with ADHD that it's not that you are more energised,

⁶² Clara did not explicitly describe her work with children as a strategy, but it could be understood as an act that transformed her and made her feel better. In the sense that ethics is concerned with the way we behave (Stengers and Zournazi, 2002), this strategy was also an ethical act, aimed at making her behaviour compatible with her environment.

but you have more of a sleepy brain that needs to be woken up, so when I am working, I am exhausted trying to concentrate on something. I can go to kick boxing and do an hour of punching and everyone gets tired and I can keep going for ever, but when I need to concentrate on writing or something at work, I am exhausted.”

Clara continued speaking without any prompting from me and the energy she described was also very audible as she spoke fast with hardly any pauses.

Clara: “Like I walk everywhere, I get my energy up, I eat a lot of fish, maybe not tuna, because of the mercury thing, but I am super healthy, I hardly drink, don’t take drugs. The only thing I do is chocolate. I don’t really do coffee only like if I have to do something really boring, I have like an espresso, it’s a bit like a trick... So I do all I can do, but maybe I don’t do all of them all of the time, but it’s got to be a crazy life if you have to do that, you got to be pretty OCD to do that. Even though a lot of them are my natural ways, my natural impulse and I get depressed if I don’t walk or get dancing or something like that... So you know strategies do help”.

Paying close attention to food and exercise was common among the people I met, and one of the support groups, Group B, organised sessions specifically aimed at promoting their physical well-being. In particular, they had negotiated with their local councils to receive yoga sessions and relaxing massages from a teacher based in the adult education department. The group facilitator explained that yoga was particularly effective at enabling people to slow down and relax, something that many in the group found difficult. She pointed out that how yoga used the body to bring a sense of peace and quiet⁶³. Foucault showed how the notion of physical regimen in ancient Greece, including diet and exercise, was thought to be the best way to discover and understand one’s self. To take care of one’s self in such a way, would not only bring therapeutic benefits but could ensure that one could make the right decision in one’s life: ‘A concern that permeated everyday life, making the major or common activities of existence a matter both of health and of ethics’ (1985: 118).

⁶³ For more details on the therapeutic use of yoga for ADHD see: (Balasubramaniam et al., 2012; Kraft, 2010)

Foucault points out more specifically how, for Ancient Greeks, following a specific diet ‘was a strategic art in the sense that it ought to permit one to respond to circumstances in a reasonable, hence useful, manner’ (ibid.:106). Using this concept, we can start to understand what Clara meant when she described her intuitive dietary and physical regimen. The techniques and tricks were immediate actions she took to remedy her attention problems, described as her natural impulse, which she explained, she had followed independently of her more recent concerns with ADHD. Over time, Clara learned how some of those techniques were effective in reducing the difficulties she associated with being inattentive and hyperactive. It was only recently, when she heard of ADHD and thought it might be relevant to her, that she started to think of her natural ways in terms of strategies. As I asked Clara how she imagined her life in ten years’ time, she responded:

Clara: “Most people learn as they go along through life, about what helps them, what is not so helpful, you know. We learn from our mistakes, and I know what things are helpful to me as I go along, I hope I will only get better at the things I need to do. I don’t even know all of the little tricks and tactics that keep me sort of alright. I think [silence] it is so easy to kind of slip and get in a mess. The natural me is kind of chaotic, and that chaos is always round the corner and maybe that’s not how it is for everybody. That’s not something that I would change, so imagining 10 years down the line probably I might be more aware of what things work for me and have strengthened that muscle more so I am kind of doing things that are helpful. Or just accept the mess that comes with not doing the things I need to do, but being comfortable with who I am and what is going on for me.”

As time has passed, Clara was learning about herself, her body and her mind. She had hopes that she would still be learning new techniques, training herself and ‘strengthening the muscle’ in order to improve the way she functioned in the world. During this part of our conversation, it occurred to me that she had not envisaged or imagined her future in terms of being diagnosed and receiving treatment. I asked:

Claude: “Do you think getting a diagnosis of ADHD would change things?”

Clara: “I am a bit ambivalent about having this diagnosis anyway; it’s bit like a kind of a stamp on your birth certificate or whatever. For me it’s just a way of understanding myself; I do these things and other people also do these things. It’s nice to know you are not the only one; somewhere over there, there are some of my kind, which is helpful when you behave a bit differently from the norm and you might get negativity and problems because of that. That’s what the diagnosis means to me.”

Clara’s ambivalence about the diagnosis was widely shared between members of support groups and yet she suggests that it is possible for the labelling and categorising to be part of the process of understanding one’s self. The diagnostic process and its practices such as attending support groups and being labelled, are for Clara transformative practices. Foucault’s most famous definition clearly describes the relation between, practice, knowledge and the making of a self as:

‘technologies of the self, which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality’ (1988: 17).

Clara described how finding out about the diagnosis of ADHD had brought her better knowledge about herself, an understanding and some clarity as to what might be going wrong. As I have shown through Clara and Paul’s stories, they achieved this by taking care of themselves by putting in place strategies that could alleviate the forgetfulness or the excess of energy. In the sense that a diagnosis is a process of identification and a differentiation between what is wrong and what is not (Jutel, 2011), the strategies put in place by Paul and Clara contribute to the production of that knowledge. The years of experience in trying to alleviate difficulties provided the people I met with ample time to build strategies which often left them with more of an understanding about the phenomenology of ADHD than many General Practitioners possessed⁶⁴.

⁶⁴ Many members of support groups complained to me of that very point, that they knew more about ADHD than their doctor, from their own bodily experience. See Matheson et al., 2013 and McCarthy et al., 2013 for

Clara also pointed out that in the process of understanding herself better, she became aware that she was not alone in experiencing these difficulties. She suggested that this knowledge of others is also a relief, and hinted that it could be a source of support if contending with stigma. Being with people who have similar ways of experiencing the world is as much a reason for Clara to attend support groups as sharing and learning techniques and strategies from others. I will return to Clara, but first, in the next section, I want to focus on this element and introduce Garry's story to explore how the strategy he developed depended on being with and paying attention to others.

Keeping myself in check

I met Garry in Support Group B which ran sessions that were long enough to offer social activities. Once a week the room that housed the group was open from 10 am and often did not close until 3 pm. I described in Chapter Three the sharing sessions that took place which were considered to be the main part of the group's activity. As the group was open for at least five hours, there was time for informal chats, long lunch breaks and less structured activities such as drawing or playing board games.

Garry was a keen chess player and would inevitably set up his chess board to have a game or two with other people in the group. In an unexpected way, these chess games were social events as they attracted other people who would sit, watch and chat, or sometimes just come in and tease a person who was in obvious difficulty – never Garry. As I found out, the social aspect of the game meant that it was less of a competitive activity than a chance to banter and chat, a feature which made concentration on the moves of the pieces rather difficult. But Garry was adept at talking and playing simultaneously and, in one of the games I played with him, he explained that he was relying on set moves that he knew well because he played in a regional chess club. His chess fluency was evident in the games I played with him, which developed a pattern of my being on the back foot and in the

some accounts of the unbalanced and often unsatisfactory encounter between GPs and patients in relation to ADHD.

defensive position, to the great pleasure of those watching. Caroline, one of the facilitators, had mentioned how Garry started a chess club for the group, and would teach whoever was interested and so I asked him how that was going. He explained that some people were attending, that it was slow to start with, but if there was one thing that chess had taught him, it was not to give up. As we continued to chat, losing my queen and a castle in a matter of minutes, I came to see that chess played an important role in his life. He had learned to play at school and had continued playing throughout his education, thinking it had been helpful when he was taking his GCSEs and later during other exams.

Garry was 39, and had been diagnosed with ADHD as an adult two years previously in 2011 yet he had not been prescribed the usual pharmaceutical treatment. Instead he was given anti-depressants which he felt were helping with his low mood. I asked him how he felt about “not being treated for ADHD”⁶⁵, and he explained that, most of the time he could control some of his symptoms, and that he had been working at it for a long time and that chess had been really helpful.

Through the years, chess had built his confidence - “even when you lost a game, there’s always another one coming”, he said. It had also taught him persistence, not to give up and keep going till the end - “til I drop dead”. He had been playing in a local chess league club in division five for a number of years and had lost his last eight games, but felt confident that he would soon win again. Through playing chess, he was learning to counteract the difficulties that are part of ADHD such as inattention, distraction and restlessness: the strategies on the board became a strategy for everyday life.

Desjarlais (2011) in a recent book on his passion for chess made a similar point in describing the effect of the game on players:

⁶⁵ Although Garry did not say specifically that he found the anti-depressant helpful, I realised that he was reacting to my top down view of what his treatment was, and from other informal conversations I sensed that he was happy with his treatment. He made me realise that I was putting myself in the shoes of a doctor when I did not mean to do that. On reflection, my assumption that the anti-depressants were not treating ADHD can be seen as the result of my habituation to clinical practice through the time I spent in the clinic. At that point in time I had spent six months in the clinic and had completed the diagnostic training provided to psychiatrists. My fieldnotes describe how, when outside the clinic, I would apply a clinical framework to the descriptions provided to me by support group members as a matter of course, and how I needed to ensure this would not obfuscate other understandings.

‘Chess can provide a modest sense of mastery in the world, even if it’s only for moments in time...Chess players can find that they are acting in the world, initiating lines of thought and action, rather than simply responding to whatever life throws at them (2011:42).’

Desjarlais is keen to describe chess in terms of ‘interrelatedness’ and ‘fields of force’ on the board. He considers it interactive and multi-dimensional; it spills out on to the world rather than being contained as just a mental activity.

‘By altering focus, homing in on the task at hand, and gaining a fresh perspective – daydreaming, thinking outside the pre-set frames, stepping into a realm of play – a lifeworld can be altered. Through the sleights of consciousness, people rework the experiential grounds of their lives so that their world becomes different, at least for a spell’ (ibid.: 43).

Echoing this view, Garry explained during one of our imbalanced chess encounters how focusing and planning really did not come to him naturally. It was always the part that went wrong in his life. He had lost work because of it and had been unemployed for two years when I met him; he was in serious debt as he spent impulsively and had been called lazy at school and home. As he explained, playing chess was helpful in dealing with these problems: it taught him to be calm and present in the moment, it pushed him to focus on one task at a time and not be distracted by other things. He demonstrated by swiftly putting me in check whilst other members were joking and chatting around us.

Desjarlais suggested that any change that chess could bring in the lifeworld of its players was only temporary, hence the need to keep playing. Garry kept playing chess, knowing there was always another game round the corner, and thus he felt that chess had a lasting effect on him. Learning to control the board also helped him to control himself or, as he put it, carrying on the chess metaphors, helped in keeping himself in check. He described this as the best strategy he had found to help him to become self-aware, to develop the ability to not get lost in the world and he hoped that this strategy could be helpful to other people with ADHD. The process of mastering oneself through playing chess is described by Desjarlais as a form of ‘cognitive magic... a sort of ritualization [that brings] containment, ordering, making things right’ (ibid.:44).

There are obvious rituals associated with playing chess, setting up the board, using chance to choose which colour to play, and other small habits that each player develops. Beyond these small rituals, Garry made chess a habit in his life, something that he engaged with purposefully on a regular basis in the club and in the support group, because it was helpful to him, and he hoped, to others too. In his own words, Garry felt that chess ‘wised him up’, made him a better person who could achieve better things. Desjarlais in his conversations with chess players came across the same kind of claim for the acquisition of wisdom through chess playing.

‘Chess can serve a corrective function. It can help us counter a too-purposive and linear view of life and make our outlook more holistic and more ethically sound. It can help us to wise up.’(ibid.: 39).

In the context of the conversations I have had with Garry, the expression ‘to wise up’ has acquired a sense of discovery, of becoming aware, of waking up to something. Garry had discussed how chess provided him with the discipline to keep focusing on one task at a time and to avoid becoming distracted by other things. Desjarlais suggested that playing chess provided a structure geared towards expanding and broadening the player’s perception and interaction with the world; in the case of Garry, chess provided a structure with a different kind of impact. It helped Garry to be more discerning in his interactions with the world and not become overwhelmed by an elusive blur of passing events; chess woke him to the present moment and helped to rein in and filter down the world. In other words, Garry was not seeking to escape his difficulties by playing games. Instead chess helped him to increase his focus on his everyday life; it helped him to make decisions, ethical decisions, that would improve his life, or at least avoid those choices that might be detrimental to his well-being (Das, 2014).

As I understood it, rather than closing and reducing his world, chess helped Garry towards being more *selective* in his interactions with the world, something that was apparent in his choice to play chess in social contexts. As is well known, it takes two to play a game of chess, but Garry was also choosing to play chess as a social event which involved many more peripheral players. Observing him in the support group, I never had the impression that he was seeking an audience; instead he seemed to

encourage people to engage with the game as an event, and to make comments on the positions of the pieces which usually led to some banter about which of the players was winning. I saw Garry lose once in the group, to the great delight not only of his opponent but also the four or five other people who were involved. Garry, in his own calm way, was also participating in the celebration and encouraging those who had previously been fearful of challenging him at chess to do so at another session.

The connections between chess and well-being existed long before Garry had heard of or been diagnosed with ADHD. As with Clara, he had intuitively felt the benefit of playing chess regularly; it calmed him and it also kept him alert to the world. There was a sense of hope in Garry's commitment: hope for himself that after losing eight games he would win again, and hope that by using similar perseverance his life would also improve. Hope for others too as he came every week to teach and play chess with the members of the support group and hope that they could win, that they could benefit from chess and make changes to their lives. Importantly, as described by Garry, it was playing regularly and setting a routine of play that produced a change in him that brought more focus and calmness, rather than the magic of one special game. In the next section I want to explore how the various strategies I have described – which can be thought of as hopeful moves, ways to project oneself into a better future, and of being more present in everyday life – may also be coupled with an opposite and darker side.

Burdened with potential

In an interview, Michael Taussig (2002) described the sense of hope as a mix of pessimism and optimism and explained: 'it's like going to the theatre where you suspend disbelief and you become full of hope, but there is another part of you which says it can't last forever. So that seems to me what human beings are about – that level of complexity, the ability to hold opposite ideas at once – and I think that is where hope and the lack of hope are organised in a sort of dynamic mix.' (ibid.:47).

I want to explore Taussig's proposition that hope is not experienced without its opposite, so that it is intertwined with a sense of discouragement or despair. Returning to my conversation with Clara, the theme of hope figured extensively in her story, and as I found in other parts of my fieldwork and further afield, Clara talked of hope in terms of potentiality. There are many publications that urge adults with ADHD to reach, unblock or harness their potential and generally to focus not on the limits that ADHD imposes but on its positive aspects. In simple terms, the argument put forward is that ADHD forms part of a natural diversity that contains hidden strengths, and that some adaptations by the individual and/or environment can help people achieve their potential. Long and Moore recently noted how 'the "language of achievement", in fact, has become one of the defining features of the contemporary moment' (2013: 2), thus highlighting how in the light of the austere economic environment, achievement provides a hopeful, yet rarely obtained, solution. Of particular interest is their notion that achieving takes place within social contexts and interactions, hence the difficulty in defining achievement precisely. In the same volume, Solomon explored the range of narrative genres related to achievement and autism and highlighted how achieving in this context is the result of 'collective, relational, interactional and imaginary work' (2013:134). The strategies that Clara and others described to me can be seen in that light as adaptations and as optimistic actions and relations which bring the hope of achieving a better life.

In gaining understanding of what had been helpful for her, and re-conceiving this in terms of strategies to keep chaos at bay, Clara hoped that she could find still more tricks to keep on top of things. But as she carried on our conversation, it became clear that being 'sort of alright' was not quite enough and she hoped to achieve more and to reach her potential.

Clara: "Half of it is that I found it really hard to think through what I am trying to say, and half of it, I really feel that I have got a lot to say. And I know that whenever I am in a learning environment I get it before anyone else and I am bored. So for me not being able to show that and get my mark, it's so frustrating, so frustrating. When you know you are capable, and you are not achieving what you feel you are able to do, and if for some reason I was not able to finish my dissertation – I know I can do this stuff, I can see that I am a lot faster than other

people, so I should be able to achieve a lot – so if for some reason I was not able to, then that would be a sign that this is a kind of debilitating thing, you know. But I know I am an intelligent person, I know that I should be able to do these things, and if there is something that stops me because I don't seem to be able to concentrate to complete a task, well that's..., it feels like an extreme thing you know. I just want the legs so that I can run.”

At that point of our conversation her frustration was almost palpable as she was moving forward in her chair, slapping the table-top that was between us and asking herself what it was that stopped her reaching her potential.

We can try to understand the combination of aspirations and limitations in relation to potentiality in Clara's experience by recalling Taussig's concept of hope as dynamic and entangled with its opposite, pessimism. On the one hand the possibilities for the future provide a direction to aim for and they bring hope for improvement, for learning new tactics to remediate difficulties. On the other hand such optimism forces a confrontation with the very obstacles that are getting in the way of reaching that potential. Potentiality represents both the limitation of a given, (for Clara, her consistent inability to get organised and keep focused), and the realisation of what is possible for her (that she will get the mark she deserves).

A recent publication (Taussig et al., 2013) explored the concept of potentiality and its relevance in the realm of biomedicine. This work suggested that three meanings were intertwined.

‘The first denotes a hidden force determined to manifest itself – something that with or without intervention has its future built into it. The second refers to genuine plasticity – the capacity to transmute into something completely different. The third suggests a latent possibility imagined as open to choice, a quality perceived as available to human modification and direction through which people can work to propel an object or subject to become something other than it is’ (ibid.: 2013).

From its Latin origin the word ‘potential’ combines the notion of possibility with that of power and force. The word therefore implicitly contains the notions of change and transformation that are

imagined as an intrinsic ability to become something or somebody better. Because potential is hopeful, it is optimistic and positive, it is ‘the flip side of risk’ (ibid.: S4) which would suggest a negative future, one to avoid. Potentiality involves projecting forward an aspiration, something to aim at, a goal to reach; it is already present but needs to be activated so as to be realised. Clara described this dynamic when she explained how she was doing all she could to control her chaos and increase her attention in order to achieve what she knew she was capable of. She called upon strategies in order to enable her potential to become reality.

As part of our conversation, I asked her if she had prepared for her psychiatric appointment, something that is often discussed in support groups, where tips were exchanged such as accessing evidence of past symptoms in school reports. As I described in Chapter Three, locating old documents required efforts often involving conversations with parents and so it was with Clara who explained:

Clara: “I am going to sort out the attic [of my parents], so there is probably a load of school reports in there. I mean, I remember, ‘lots of potential’, that’s what they always said. My whole life has been mired by this bloody word, potential, you know, you just feel like, there is so much more you can achieve and something is stopping me achieving it, you know what I mean?”

With the hope of finding her school reports, Clara was expecting the documents to describe all of her potential for achievement which had remained unfulfilled. Clearly, their content had stayed with her, casting a shadow over her life. What started as an optimistic vision by educators, one that was meant to create possibilities and set high expectations, turned into a burden for Clara. In thinking about the future and how she imagined what it might be like to live with ADHD in the next few years, she continued:

Clara: “The big thing, I guess, this thing that has hung over me since I was a kid, is this idea of potential, and for me it is a very big thing, and it’s probably part of the anxiety of actually managing to get anything written and finish my dissertation. Part of that is a lot of anxiety because I struggled so much at school, there is a lot built up kind of errrrm, an expectation

that I will be up all night, suffering, trying to finish a report, there is a lot of residual memory, so that gets in the way.”

Instead of inspiring and facilitating success, the idea of her potential and the repeated expectations of family and others became restricting, limiting and anxiety provoking. This necessity to perform and succeed, what (Kaufman, 2013) calls ‘the tyranny of potential’, shows how potentialities are formed not only intrasubjectively but also through social relations. What is recognised as potential is part of a process of fitting within social expectations and must be reinforced through relations with others. The potential an individual carries is formed within a wider cultural context, at home with family, at school or work, and it sets the parameters for success and failure, and to some extent can elevate this concept into a duty to others.⁶⁶

Throughout this conversation and at other times when I met Clara, she talked regularly of all the things she does to be healthy, of not choosing the easy medication for headaches or such things, and attempting more natural ways to treat herself. Yet she also seemed to have reached a stage where she wanted to try something different at the same time as recognising the social burden on her:

“I learnt to be more socially acceptable over time, yeah, other people learn to do this in their teens, but I didn't and I still do things that really embarrass myself and you get to a place you kind of accept yourself. I guess that's where treatment comes in, and I am not a magical pill taker, but sometimes you can feel that it's not working or something. I do worry that everything takes me so long, and is such a killer, and if I am doing everything else, I am just like: isn't there something else I can do? I would like to know that there is one more thing I can do which would just, you know. So yes I'd want treatment.”

In acknowledging the limits of her tactics and strategies, Clara is also keeping alive the hope that there is still something else that could make the difference between being all right and achieving more. This is the potentiality that resides within biomedical treatment which promises something

⁶⁶ In that context one's age is likely to make a difference. Clara was in her mid-thirties, having worked and now training for a professional qualification; had she been in her sixties, it may be that her expectations and thoughts on potential would be different.

more than mere tricks⁶⁷. Even though neurodevelopmental psychiatry does not claim to bring a cure through treatment, the treatments do propose to alleviate symptoms and to improve the quality of life of patients. To that extent, the biomedical potentiality for ADHD is about care rather than cure. It seems to me, that if we think of strategies as ways to care for oneself, then medical treatment for Clara in the form of medication or psychological interventions offers another strategy to help her live with disabling symptoms. Despite her ambivalence towards being labelled and about the effect of stimulant medication, she was hoping for an assessment which might provide her with treatment. It seems to me that, even with caution, Clara thought of treatment, including medication, as a strategy and therefore as something she would do actively, rather than something she would take passively.

That taking medicines can be conceived as a social act saturated with meanings and metaphoric powers has been highlighted in the anthropology of health (Whyte, Geest, and Hardon, 2002). In this way we can think of taking medication as an active strategy⁶⁸, something that requires planning and repetition in order for the effect to last. But is taking medicine the same as wearing a modified jacket as Paul did, or as the physical and dietary regime put in place by Clara? We may denote a hierarchy in Clara's consideration of medical treatment as a last resort, after all else fails. But I would suggest that as medication for ADHD can only be accessed legally⁶⁹ through a specialist diagnosis, it also legitimates the problems of inattention and hyperactivity in ways that other strategies cannot. Furthermore, medication in its materiality, simplifies the process of remediating symptoms and extracts it from the relational work involved in other strategies; put succinctly 'healing is objectified' (Geest and Whyte, 1989).

⁶⁷There are other hopes and promises emerging in biomedicine from new technologies that are also accompanied with a darker side. DeVecchio Good (2007) described this in the following way: 'The biotechnical embrace creates a popular culture enamored with the biology of hope, attracting venture capital that continues even in the face of contemporary constraints to generate new treatment modalities' (ibid.: 407).

⁶⁸ I will return to the idea of treatment as an active strategy in Chapter Eight where I explore one way that support group members developed and produced knowledge in relation to the main form of treatment for adult ADHD and how they adapted their treatment to their lives.

⁶⁹ I do not discuss the illegal purchase or use of stimulant medication in this thesis as my fieldwork did not put me into contexts where such activity was disclosed and discussed by participants. The use and abuse of prescribed medication is a topic well researched and written about, in particular in relation to universities in the USA (Bright, 2008; DeSantis and Hane, 2010; DeSantis, Webb and Noar, 2008).

Whilst Clara thought that a diagnosis would provide a way of understanding herself, our conversation did not extend to exploring the kind of knowledge that Clara might gain through using this strategy/treatment. What I felt strongly in our conversation was her sense of frustration and of tiredness. On the one hand, Clara described her energy and determination and on the other, the exhausting process of calling upon tactics and strategies. In describing some of the strategies she had in place to remediate her disorganisation and chaos, she was also pointing out that they did not always work, which was a worry to her in regard to the exams she was working towards. Her desperation about these limits was also expressed when discussing the fragility of her situation and her fear that she could slip back into chaos, a situation which might have dire consequences for her future. Her efforts in seeking ways to remedy her difficulties and her hope to succeed at her tasks may yet come to nothing, leaving her having to keep struggling on. The dynamic mix of hope and despair that Taussig described (2002) is precisely that balancing act of being aware of reality, of the limitations that one may experience due to illness or difficulties whilst striving to improve one's life and not giving up (Mattingly, 2010).

As Clara described, it took a lot of effort to maintain a balance where hope was still present; it took great commitment to practice the physical and organisational regimen she had put in place, every day, day after day and to try not to slip. Yet, that same practice simultaneously reminded her of her vulnerability and of the fragility of her situation.

Clara attended the group intermittently, and I last saw her towards the end of my fieldwork. I did not find out if she had located her school reports in her parents' attic but she told me that she was still on a waiting list for an assessment.

Conclusion

This chapter has explored the way that the people I met in the support groups and the clinic discussed living with disabling symptoms without necessarily knowing what might be wrong. Throughout my

fieldwork and further afield the term 'strategy' was used to describe the purposeful actions that people took in order to alleviate their problems. Chapter Three described elements of ADHD which were enacted in support groups through mnemonics and technological aids. The encounters I shared in this chapter focused on corporeal strategies that involve training and regulating the body in order to counteract the impact of hyperactivity and inattention. I have shown that the practices described by Garry, Clara and Paul for taking care of themselves were congruent with Foucault's concept of 'Techniques of the Self' (1988). The strategies that group members put in place were transformative not only regarding their behaviours but also regarding their selves, as the process brought them new self-knowledge and understanding. Following Foucault, I am suggesting that the acts of self-caring which are put in place through everyday practices and habits are ethical actions directed towards achieving a better life. I concluded the chapter by showing how, for Clara, the hope that was enacted in strategies was also accompanied by despair and exhaustion; the fact that one comes accompanied by the other clearly highlights a sense of fragility and vulnerability. I have shown how strategies are always provisional, needing to be repeated and situated in specific contexts. When situations change, strategies have to be adapted, re-invented. Thus putting in place strategies and keeping them effective in remediating symptoms is always a balancing act between hope and despair that requires constant care and attention. The next chapter moves further back into the diagnostic process; it explores how people described their first encounter with ADHD and its symptoms and how they identified with it. Their descriptions focus on moments of self-knowledge that brought insight and offered explanations as to what might be going wrong for them.

Chapter Five **Moments of Recognition: identifying ADHD inside and outside of the clinic**

Newcomers

Support Group C met in a suburb of London in a newly built centre that accommodated a number of projects related to autism and ADHD in children. A charity, it was established in the mid-1990s to provide a number of services for parents, their children and more recently for adult sufferers, with some paid staff and volunteers running groups and activities. The group for adults with ADHD was run by two women, Anna, parent of an adult with ADHD and Yvonne, diagnosed with ADHD; both had been running this group for many years and were very experienced in supporting individuals emotionally as well as through advocacy work. On that particular night I arrived early and was helping to set up the room for the meeting; chairs were arranged in a circle. In one corner of the room a table was laid out with a kettle for making coffee and tea. There was a row of shelves on the opposite wall full of books. As people arrived and sat down, Anna started by giving some dates of forthcoming events and asked me to introduce myself for those who did not know me. I did this as succinctly as possible so as not to take up too much of the session as sometimes my presence generated questions. The group was well attended, 21 people were sitting in a circle, with slightly more women than men on that evening including one new person.

This group had grown in membership in the last year or two, and in some sessions it became difficult to uphold the principle they described as ‘giving a sharing space’ to all attendees. The sharing space, as I saw it, was a time given to individuals to tell of their circumstances from one session to another and to elicit conversation and comments from other members. Eventually the opportunity for everyone to share became too time consuming, so the facilitators came up with a suggestion that was adopted by those present on the night; a priority list would be drawn at the start of each session. Members would be invited to rank how urgent their contributions were – high, medium or low – with the stipulation that newcomers would always have a protected sharing space. In the ten meetings I attended, there were one to two newcomers per session, sometimes more, and the process of

prioritising was done very quickly, seemingly without problems. It was of course a triage of sorts, a self-triage as it were, which could be interpreted in terms of power relations and inequalities within the group (Nguyen, 2010). But that is not how this came across to me, and the pragmatic solution of ordering contributions which I observed, with newcomers coming first in the ranking, tells another story.

A newcomer's story made the sharing in the group most obviously visible; some group members became at that moment both role models to others and vulnerable members seeking help. Such stories played a foundational role in that they established a common relationship between the newcomer and the group, facilitating entry to the group. In common with the 'coming out' stories described by Weston (2013), adults were revealing something about themselves that had always been there, despite its not being recognised and diagnosed. Whilst their disclosure was often expressed with the hope of being understood and accepted by like-minded people, it was unclear to me if gaining acceptance from their biological families was as crucial an issue as it was for Weston's participants⁷⁰. In this group the time given to newcomers to tell their stories was also a space for regular members to reflect on what they had learned about ADHD, and what effective strategies they might adopt to live with their difficulties. The 'newcomer's time' kept the struggle of living with ADHD in the consciousness of group members as something that was not to be forgotten and still to be worked on. There were few exceptions; on one occasion a couple asked to observe and not contribute, explaining that they needed to understand more about ADHD. Despite the stories being very similar to one another, I always perceived a sense of anticipation, even of rejuvenation, at the moment when a new member started their narrative.

After attending the four support groups and the clinic for a few months, I found myself noticing similarities in the discussions between members of the support groups, as well as with the way the diagnosis process was discussed by clinicians. If the obvious differences of age, class, educational

⁷⁰ This may be due to the age group that I mostly interacted with, who often had children of their own and whose parents were usually over 70 years old. Group A openly referred to 'coming out' stories, describing that, just like gays, they did not choose to have ADHD. More often than not the 'coming out' stories were related to acceptance at work rather than at home.

background and geography between the groups were given less emphasis, certain common themes became apparent. The contributions that seemed to resemble each other the most in support groups, often shared by newcomers, were the descriptions that people gave of their first encounter with ADHD and its relevance to them. In the clinic, I heard clinicians describe their process of diagnosing beyond the textbook approach, in terms of ‘recognition’ through signs and behaviours in their first, and often only, encounter with a patient. It seemed that common to both the clinic and support groups was a process of knowing ADHD that was tentative, cumulative and at times uncertain.

On reflection, my initial awareness of common patterns in the describing of ADHD was an important moment in my fieldwork, but as will become apparent, it was tempered over time by the persistence of other stories that did not share the same narrative structure. My point is that, rather than describing and analysing the way my participants told about their experience of ADHD in terms of a common narrative structure (Favret-Saada, 2009), I want to keep the diversity of personal accounts in the frame and examine how they are linked. This is particularly important if I am to include narratives which at first glance seem incommensurable; the stories of support group members of different genders, classes and from different locations as well as the accounts given by psychiatrists. What connections could there be between the tales of ADHD told from such different perspectives? Could patients’ and group members’ testimonies and stories of their experience of inattention and/or hyperactivity be comparable to the clinicians’ discussions of criteria and the diagnostic process?

In this respect, I found Strathern’s exploration of the difficulties of conducting ethnography in Britain particularly helpful (2004). In highlighting the impossible task of comparing a village in Essex with an urban suburb in Manchester due to the differences in scales and demography, Strathern points out that there are nonetheless connections between their inhabitants. They share ideas and concepts, even if ‘those similar ideas disguise themselves as ideas *about* dissimilarity: they are ideas about how different everyone is from one another, how different places are’ (ibid.: 25 *original emphasis*). Beyond the dichotomy between patient’s and doctors’ perspectives on ADHD, or the differences between support groups in different parts of the country, beyond the gaps, there are connections which link these actors and places. Crucially, the connection is partial in that the ideas, whilst similar, ‘are used

for different effect' (ibid.). In examining the way my participants tell their stories in relation to ADHD, I hope to retain not only the multiplicity and diversity of their stories and how they might be connected but also to explore what they do as narratives.

In the reversed chronology of this thesis, this chapter explores how support group members and clinicians described the process of first knowing ADHD in terms of 'recognition'. As people attending groups, interviews and clinical observations told me their stories of how they recognised themselves in others, in self-help books, or in diagnostic criteria, I came to think of them as moments of recognition. Sometimes these moments were experienced in a flash, often recalled as life-changing and turning points, yet for others the epiphany never came and instead it was friends and relatives who recognised the characteristics of ADHD. Inspired by Ricoeur's study of recognition (2005), I will examine the morphology of the word 'recognition' and unpack the layers of meaning that may be attached to the term.

As noted by Ricoeur (2005), the word suggests notions of truth and identity, whereby recognising something can mean at one and the same time, identifying it and accepting its validity. Secondly, the association between recognising and identifying, as in the process of distinguishing between different objects, becomes useful to think with in relation to the clinical practice for diagnosing ADHD – a topic I explore in the second part of this chapter which documents medical-history taking. Finally the concept of recognition is problematised as my observations in the clinic suggested that prototypes played an important part in the diagnostic process of clinicians, something more akin to Wittgenstein's concept of family resemblance. By asking how clinicians recognise ADHD when it has so many presentations, I explore the tensions arising between the application of precise criteria with algorithmic thresholds and the process of clustering symptoms that are different from one another and yet related. I conclude that the process of recognition inside and outside the clinic is similar and both may be conceived under the common term of 'diagnosis process'.

That's me! Recognising oneself as if in a mirror

Maria had made contact with me after details of my research were posted on the website of Group A and we agreed to meet for coffee. Maria was in her early fifties and described herself as a well-educated struggling theatre actor with a grown-up son. As we chatted she explained that she had been aware of ADHD for many years, as one of her son's friends had been diagnosed with the disorder in childhood and was prescribed Ritalin. At the time she thought how reluctant she would be to give this kind of medication to her son and had never thought this diagnosis would apply to her. I asked Maria how ADHD became relevant to her, and she recalled how a couple of decades later, things had changed. She said:

“Oh well this is funny [laughter] I am not sure how long ago that was, let's say [silence] more than five but less than ten years ago, and my sister was being terribly scatty, and menapausal probably, and she told me some of her problems, and I thought – well I am like that all the time. And she said, - you know, I think I have Attention Deficit Disorder - and I thought really, she thinks she's got it? So I found myself in a bookshop one time, and I saw this book on Attention Deficit Disorder generally, and I had a look and wondered if she had it, thinking about her, not me. And then there was a list of characteristics, and I thought – I tick every single thing – you know, not being good at settling down, having lots of different jobs, always forgetting things, you know I can recognise myself in that. I constantly forget things... very hard to keep hold of umbrellas, scarves, gloves and things like that. I can email you that list – and there was about nine or ten different things, general things, and I thought – I've got it! I thought that's interesting! And I felt quite excited actually, because I thought, - Oh maybe there is an explanation for why I have had such a cock up of a life.”

Throughout this part of my interview with her, Maria was smiling and laughing at some points, clearly finding it funny if not ironic that, in the end, she was the one diagnosed with ADHD, not her sister.

In a similar way in support Group C, Jack recalled the moment he had found out about ADHD and its relevance in his life. Within the sharing circle, it was his turn to speak and as this was his first visit he started ‘at the beginning of his story’ when he was listening to the radio whilst driving home one day. Rory Bremner, the famous comedian, had produced a programme in 2011 entitled *ADHD and me*, recounting how he had lived with forgetfulness and disorganisation and that, following one of his relatives being diagnosed with ADHD, he had wanted to know more⁷¹. The programme was a combination of interviews with children and adults diagnosed with ADHD, with specialist psychiatrists and Rory Bremner’s own reflections on his childhood. Jack told the group that he had not heard of ADHD before this programme, but that when he heard some of the interviewees describe their lives and the difficulties they faced, he exclaimed, “arggh yeah that’s me, that’s me, that’s absolutely me! And I got a lot of identification from it”. As he was telling his story, the rest of the group, were listening, nodding and making little remarks – “I heard of that programme” or “that’s right, the penny dropped”.

As was often the case, the conversation moved towards someone else’s story, but was rapidly redirected as Anna explained gently but firmly that new members needed the space and time to tell their stories. Jack continued, describing how after the programme, he read books on the subject and then found out about this support group on the internet. Jack’s experience of ‘identifications’, to use his term, was strikingly describing a direct connection with the people in the programme, not just their stories but that they were actually the same. Members in other support groups too clearly described this same sensation of seeing themselves as if their own image was being reflected back to them by a mirror.

When I asked Nick to describe his own face-to-face encounter with ADHD, he talked of having been aware of ADHD because of his work but, as with Maria, had not made the connection straight away with his own situation. It was only after a dramatic and tragic event that led him to lose his job, threatening his professional career and leaving him in an emotional crisis, that he started thinking

⁷¹ *ADHD and me* was first broadcast on BBC radio 4 on 21/5/2011 and can still be heard on <http://www.bbc.co.uk/programmes/b011c0nn>. Accessed on 10/03/2014. I return to this programme in Chapter Seven.

about the difficulties he experienced with his own disorganisation. After watching a TV programme on medication that included stimulant treatments for inattention, he started to put two and two together. He told me:

“And the first thing I did, was, in my living room, in my clutter in London, was to go on a website, looking for adult ADHD, and one of the websites had a description of the stuff. And it was one of those moments, one of those moments like; I don't know if you have ever experienced this moment, this moment is so profound. I was like reading, reading a text, [silence] on a website of a description of something and I felt I was looking in a mirror, like pure recognition, looking at myself in a mirror. It's just like one of those mind-boggling moments. Immediately I thought I might have it, I probably got it, but how do I... it's one of those things. Even if you think you've got it, that's the beginning of the journey; that is literally the beginning of the journey when you think you have it.”

By describing this moment of finding out about adult ADHD in terms of an image, his image being reflected back at him, Nick is also describing his difficulty in grasping what this means as if taken by surprise. He is asking himself if he is seeing right, is this him? The descriptions he found on the website, just like the ones Maria saw in a book were most likely based on lists of impairments and symptoms that form part of the diagnostic criteria found in the DSM. Whilst individuals retrospectively discussed their excitement at finding out about ADHD and thinking that it might be relevant in their lives, the revelation was often tinged with ambivalence and some anxieties. As Nick put it, finding out about ADHD is like the beginning of a journey. The average waiting time for being diagnosed with adult ADHD in the UK is eighteen months and the wait is usually followed by difficulties in receiving treatment (Matheson et al., 2013). The journey towards an unknown outcome can of course be the cause of apprehension, anxieties that are turned towards the future. But the ambivalence in recognising oneself can also be about the present as Clara described:

“I remember I was in this field, and I saw this guy that was flying a stunt kite, and I wanted to ask him about it, and it turned out that I knew him from somewhere. I sat down and it was

quite an interesting conversation because, I noticed that he was talking to me but he did not seem interested because he wasn't really looking at me. He was looking around all the time, like not paying attention, but he kept errrm, when he responded it was relevant so he actually was paying attention but did not look like he was. I had not seen this before. And something was kind of dawning on me [laughter] sort of, maybe I started to realise that I kind of do that, you know, and I never really saw that before. And [silence] in during the course of the conversation, he said – “has anyone ever told you about ADHD?” – and I'm like – no – “because I've got this diagnosis and I was like” – oh ok . And he said – “you seem really similar to me” – , and I was thinking yeah, you seem really similar to me [laughter], like really a lot, like he seemed more similar to me than my own twin. I have a twin, and he has the same name as my twin and similar age, and I was kind of joking in my head, like maybe he got swapped or something. And I remember I bumped in to him in the supermarket about a week later, and the way we reacted was like a mirror. It was the strangest thing, we saw each other, and recognised each other, we both kind of... sort of chaotic and really over... I don't know the way we reacted was like, oh oh oh , we kind of... the way we laughed. I can't really explain, but I just really recognised myself in him, even though I didn't know I behaved like that, to see him do that I thought, that's what I do. Oh my god it's really strange, I never realised I was so weird in that respect , until I saw it in someone else, and thought – how weird it is , I think that's me . Same thing happened in the group we met last week”

C: “Really?”

“Yeah! So this guy said this thing to me , I thought right this is weird, and then I was in the library, I go at my lunch break, and there is a book on the side there, that was called - *I am not lazy, crazy or stupid* - and I thought Wow! It was brightly coloured, so I picked it up and the first page that I read was just like – CLANG – [said loudly with a hard slap on the table], you know like through your whole body, it just resonates, everything it said it just described me, in a way I've never... I would never have read a book like that. I could have laughed when I was reading it, but I felt really emotional as well, I mean it's so depressing. OH MY GOD,

they're describing someone who's just quite chaotic potentially, life is a bit messy you know. But it was funny, the way they put it, but kind of distressing as well, upsetting, not distressing, oh my god, you think, life does not have to be like that. So that was for me I guess, meeting this guy, reading this book, and then there was other books on the shelf, and one had a test at the back so I did it very quickly and I scored, like, stupidly high.”

The resemblance that Clara found in this stranger could not have been more personal: she felt even more affinity than with her own twin, sharing the same name and seemingly behaving just like herself. The experience had a great impact on her, and as she described, she was not entirely sure that she should trust her senses; had her twin been swapped for this stranger? As she found out more about what she and the stranger had in common, the sense of recognition became almost physical. It sent out waves and ripples as if it was the aftermath of an impact – CLANG – followed by a turmoil of emotions. The initial surprise, while it initially seemed funny but also uncanny⁷², turned into a stronger sense of disquiet and upset. Clara recognised and identified herself in the descriptions and saw her own chaotic and messy life, but she quickly turned to a different mode of understanding, suggesting the beginning of something else to come; she realised life did not have to be like that.

Beyond recognition

Before I introduce moments of recognition in the clinic, I want to explore the different layers that the word ‘recognition’ carries which have been implicit so far. Recognition is used in many ways and it is likely that the various connotations overlap and influence one another. Here I return to Ricoeur’s (2005) investigation of those layers, which are surprisingly numerous⁷³, embracing over twenty different nuances. Ricoeur summarises them in three main categories:

⁷² Described by Freud (1971) as something strange tinged with fear.

⁷³ Ricoeur used two French dictionaries to expose the different layers of meanings given to the word, yet they translate well in English in that they have similar usage in everyday parlance, except for one element: the

1. To grasp (an object) with the mind, through thought, in joining together images, perceptions having to do with it; to distinguish or identify the judgement or action, know it by memory.
2. To accept, take to be true (or take as such).
3. To bear witness through gratitude that one is indebted to someone for something (an act).

(2005: 12).

The first definition highlights the process of identification, which may involve making connections between different things and noticing the resemblance or difference through comparison. As Ricoeur notes, this is not so different from the notions of cognition and the process of knowing. The second layer emphasises recognition as accepting claims or the validity of documents. The third use of the word involves relations with others, with implications that recognising status may be at play between the parties. The path of inquiry that Ricoeur built from these dictionary definitions could be simplified as moving from cognition, to self-recognition and finally to mutual recognition. Ricoeur's trajectory of recognition, that shifts from the world outside to the shared world via the inner world, is founded on another move, a grammatical one; from the active use of the verb 'to recognise' to the passive use of the verb, 'to be recognised'. The active voice of recognition makes a claim and statement, recognising things, oneself and others. Whereas at the other end of the trajectory, the passive voice of recognition makes a demand, has an expectation of being recognised 'which can be satisfied only by mutual recognition, where this mutual recognition either remains an unfulfilled dream or requires procedures and institutions that elevate recognition to the political plane'(2005: 19).⁷⁴

Ricoeur's analysis is helpful in that it proposes a dynamic vision for the word 'recognition', made up of layers of signification that are in relation and filiation to each other, and suggests the possibility that shades of one connotation are found within another. Thus traces from 'recognising' into 'being recognised' and back again will resonate throughout this thesis' exploration of ADHD as a contested

connotation of gratitude is to be found much more strongly in the French use of 'reconnaissance' than in the English recognition.

⁷⁴ For other explanation of the use of 'recognition', see (Honneth, 1996; Povinelli, 2002; Rapp and Ginsburg, 2011; Taylor, 1994; Ticktin, 2010).

illness (Dumit, 2006). For my purpose, Ricoeur's exposition of the word 'recognition' with all its derivations, is a reminder of the enmeshed meanings of the word rather than a map that might take the reader on an already preordained journey (Latour, 2005) from one state of recognising to another of being recognised. Recognising, and being recognised, were terms that were used in my fieldwork in different situations and by different people. Sometimes using the word expressed notions of truth, yet its meaning emerged in different ways when it was used in the clinic than when it was uttered in the support groups and other contexts. In the situations quoted above, Clara and others described recognising themselves as an epiphanal moment, a revelation of truth about themselves, a certainty and veracity about their identity, which retrospectively seemed a turning point in their lives, sending them on a different path and seeking change.

People made their own inquiries through books, internet websites and support groups; some, like Nick, made contact with their GPs or other medical professionals. For most the moment of recognition seemed to provide a platform from which to rethink their identity and ask as Clara did – 'do I really look this chaotic?' In the stories I heard, the moment of recognition opened the possibility for seeing oneself in a different way. If, after the initial moment, the recognition was repeated through attending support groups or reading books, that glimpsed vision was validated and it acquired a pivotal role as a turning point in the stories that were told and retold in the groups' conversations.

Described as 'the subjective road marks along the lifecourse' (Hareven and Masaoka, 1988), turning points are not isolated events; instead they need to be considered as part of a process that requires certain strategies and choices (Crosnoe and Elder, 2002; Day, 2007; Hareven, 1999; Wheaton and Gotlib, 1997). In other words, agency plays a crucial role and the same event met by different strategies will lead to different trajectories which may be affected by the timing of this event either in youth or later on in life. The adults I met in the support groups were mostly over 40, and recognising themselves in the descriptions of ADHD symptoms was often difficult. Recognising themselves did not necessarily mean that they recognised the validity of ADHD or even only part of it. In my continuing conversation with Maria, she explained that her uneasiness about the use of Ritalin in children had not subsided and that when she was diagnosed she refused to take stimulants as

treatment. Instead she sought alternatives which she considered more natural, such as Omega 3 oils, chamomile tea and evening primrose oil. For other people it took years and a number of incidents or crises to get to the point where they would take the next step to seek help and support. Sometimes this was done with reluctance and required persuasion from another person, often a partner, who was affected by their difficulties, as Paul described in Chapter Four. And as Hareven and Masaoka (1988) warn, turning points are only identified retrospectively and may be considered normative transitional moments by some. In fact, the moment of recognition may not always be experienced as a turning point or it may lose its role as a focal moment in a narrative as time goes by.

I met Ray in Group A and in a long interview he explained to me how he had experienced a number of events that were potentially life changing. He explained that he was university educated, had been attending the support group for about a year by the time I started coming along and, according to him, was financially successful due to his entrepreneurial skills. He was a vocal person in the group, discussing pharmacological information with confidence, and recounting his experience to others and offering advice. He was also quick witted, often making jokes as well as being visibly very active, using his smart phone constantly and moving on his chair incessantly. He had been diagnosed with ADHD four years before we met after a serious physical health problem had led him to receive some psychological support. In that support process ADHD was also diagnosed; this led him to think of himself differently and eventually to seek further support and treatment. But Ray did not position the moment he had found out about ADHD as a turning point, or to be more precise, as a lasting turning point. Our conversations at the group and during this interview were lengthy as his sentences were often full of detours or remained unfinished. As I met with him regularly, I came to think of his digressions as giving ADHD a voice, what ADHD might sound like. He was aware of not finishing his sentences and jumping from one subject to another and thought of them as 'who he was'. I commonly observed such speaking modes in all the groups, as well as in the clinic. In both contexts these verbal modes were seen as a diagnostic criterion (Casas et al., 2013; UKAAN, 2013). Sometimes people were embarrassed or even ashamed, as if caught doing something wrong, yet at other times it was the subject of laughter and fun. In support groups in particular, I found that

conversations were difficult to follow, something that some members felt was a great disadvantage when at work or in ‘non-ADHD friendly’ environments. In these cases we might think that having such a ‘voice of ADHD’ is an impairment and the very opposite of empowering (Das 2007), but as I will explore further on in this thesis, it may be that to digress, interrupt, jump from topic to topic, actually represents the complexities through which this form of life is expressed.

I asked Ray to describe how he came to be diagnosed with ADHD and what that meant to him. After providing a lengthy response he arrived at the following point, saying:

“To answer your question, a diagnosis is only useful if it actually provides me, it makes my life somehow – by life I mean obviously work is secondary – so, not so much in my work success, but in my, my ability to achieve a balance, to interact with my wife and children in a more meaningful way. Now there are elements in ADHD that can make this difficult, isolating yourself and problems in keeping friends. So I am interested in having a diagnosis in terms of what it can do to improve my experience of existence and those around me. As soon as the diagnosis uses its utility, as ability to self-reflect and learn, it's not a useful identity for me. I inhabited the identity of an adopted person for a long time and my roots were – it was almost an existential crisis, and I did inhabit not so much the persona but the identity of an adopted person, for a couple of years, once I had actually addressed the issues and became comfortable with who I was and where I came from. That identity of an adopted person is there, it's part of me, but I don't spend much time thinking about it now, it's not important. I would think that if I can develop the skills and behaviours which are beneficial to – not the pills actually, I have a drawer full of pills but I don't find them helpful at all, they make my heart jump out of my chest and sense of anxiety, you can almost feel your heart up here. That's unhelpful, my blood pressure goes up – oops I've done it again, gone off topic – so to go back to your point, as I don't have to worry about keeping a job I would rather learn the skills to live with ADHD.”

Ray expected that as time passed and he learned to live better with his difficulties, the moment he found out about ADHD would become part of the background of his life. He had gone through different stages with regard to finding out about being adopted, including tracing both his birth mother and biological father through DNA testing, and he had come to feel that the existential questions were no longer so urgent or present. Similarly he expected that the diagnosis of ADHD would have a function that was limited in time for him, as he was already becoming aware that the medication had harmful effect on him. In contrast to the other support group members I have discussed so far, Ray used the word ‘diagnosis’ to describe the moment clinicians described the difficulties he was experiencing as symptoms of ADHD. Similarly, Ron described during his assessment in the clinic how he had found out about ADHD from other people who had recognised symptoms in themselves.

Questions, scores and algorithms

Ron, in his mid-thirties, attended the clinic with his partner, and was visibly nervous or anxious as he twisted and rolled a small piece of paper in his fingers throughout the assessments. Once the administrative tasks were done, including giving consent to my presence in the assessment, a specialist nurse and I accompanied Ron and his partner to a consultation room where the first part of the assessment, lasting approximately 90 minutes, would take place. Based on a scripted questionnaire, the interview consisted of questions exploring the diagnostic criteria found in the DSM (2013): criteria Aa and Ab (inattention and hyperactive/ impulsive symptoms), B (age of onset), C (pervasiveness), D (impairment) and E (symptoms not accounted for by another disorder). There were eighteen questions for each criteria A, nine for the adult context followed by the same nine questions this time in childhood context; two questions for both criteria B and C and four questions for criteria D in adulthood and repeated in the childhood context: a total of 52 questions. The questions were meant to elicit instances of behaviours for each criterion: for example, ‘do you often fail to pay close

attention to detail or make careless mistakes?’⁷⁵ Ron explained that he was always in trouble because of this as he did not thoroughly read information given to him – “like when I write a cheque, I put the wrong name or the wrong amount and I never know how much is in my account.” The same question was then asked, requiring examples from Ron’s childhood which he found more difficult, but with the help of his partner, he recalled having difficulty with homework; his mother had to sit with him through it all until late in his schooling. Both had talked to Ron’s mother before coming to the appointment so that he could repeat certain stories and talk of his school reports. The specialist nurse conducting the assessment kept taking notes of the examples, writing on a form, ticking yes or no to register the presence or absence of particular symptoms. Other questions were: ‘Do you often seem not to be listening when spoken to directly?’ or ‘do you find it difficult to organise tasks or activities?’ and so on. Forty minutes later, the nurse explained that the first part of the assessment was finished and that Ron could have a break whilst he spoke to the psychiatrist.

During this break, the nurse summarised his findings so that they could be handed over to the psychiatrist who conducted the second part of the assessment. Mainly the summary consisted of applying an algorithm⁷⁶ which produced a number that was compared to a threshold determined by the DSM. According to these criteria, Ron must have six symptoms out of a list of nine in relation to Inattention and again six symptoms out of nine in relation to Hyperactivity/Impulsivity; in addition the age of onset and the degree and domain of impairment were also marked. Finally all of the scores gathered from ten pre-assessment questionnaires⁷⁷ that had been handed in by Ron’s partner were then added to the same report to produce a final score. Clinicians explained that the algorithm helped to pin point where the patient was situated in the continuum from normal to abnormal; was forgetfulness or being over active experienced beyond a norm? As with numerous other ailments, it is the accumulation of symptoms and their severity that may tip the individual over the threshold for a particular diagnosis. The scaling and quantifying process was presented by clinicians as an objective

⁷⁵ Questions used here are from a diagnostic tool called CAADIDD: Conners Adult ADHD Diagnostic Interview for DSM-IV (Conners et al., 2001)

⁷⁶ ‘A process to be followed in calculations or problem-solving operations’ Oxford Dictionaries online <http://tinyurl.com/o59q2rk> Accessed on 10/03/2014.

⁷⁷ Close to a 100 questions.

measure that, when triangulated by a mental state examination and by third party information, provided enough evidence to justify giving a diagnosis. It was a decision-making tool aimed at bringing precision and at counterbalancing the effect of intuition in the assessor. To my mind, it raised a lot of questions as it seemed like an attempt to reduce many symptoms described in life events into one score that could be compared to a threshold of normality. Further, the application of the algorithm, doing the calculations, with pen and paper, brought some complications as I found out when I followed the process myself.

On three separate occasions, I paralleled nurses in noting examples during assessments and then marking afterwards, and I then compared my scores with theirs. On each occasion my scores differed from those produced by the nurses, not in the marking but in the calculating element, sometimes but not always due to my mistakes. Overall I found the whole process awkward and fiddly, as scores for Hyperactivity and Inattention were found on alternate lines of the form and the scores above the threshold were found on the extreme right of it. In order to facilitate the calculations, a nurse had devised a masking page that was applied to reveal the scores to be added and hid everything else; it must have worked efficiently until the form's appearance and its font and size changed so that the masking page did not quite fit, yet it was still in use in a rather awkward way. From informal conversations as well as attending research meetings, I was aware that senior consultants in the clinic were mindful of the shortcomings of such systems and they had initiated an inter-rater reliability study within the clinic in order to test and improve the process.⁷⁸

Ron and his partner were called back so that the assessment process could resume. Commonly, once the psychiatrist had explained what the interview would entail, the first question was 'what brought you here?' Thus an opportunity was given for the patient to describe their journey towards this point in time. Some started with their childhood, but more often than not they related those difficulties encountered in adulthood which had peaked to crisis point. Ron described how he'd had a really bad argument last summer with a friend, an event which made him want to seek help. It was, he

⁷⁸ Assessors scored-blind each other's assessments from audio recordings, a process that was envisaged as forming the basis of a training package.

continued, as if he had “a disembodied experience, seeing myself losing it, flipping, and not being able to stop it.” That incident led him to be referred to his local mental health team, who after initially diagnosing him with bipolar disorder, decided to refer him to the ADHD clinic. The assessment continued and with the help of his partner he recounted many stories that described his attention span problems, such as the time when he started stripping all of the wood in their home but never finished the process. During a short break in the assessment I asked him when he had first heard of ADHD and he explained that he had been in ‘special schools’ as a child where other children were on Ritalin so he knew what it was, but had not associated it with himself. At that point, his partner explained how her parents were both mental health professionals, and they had noticed some of the signs and behaviours at home and had recently mentioned it to him. Other patients also recounted how their problems had been noticed by others, either relatives or friends close to them who had knowledge of ADHD, or professionals dealing with crisis in their lives, such as criminal justice staff or social workers, who queried the nature of their problems.

Overall, I observed more assessments where patients did not know much about ADHD and they recounted how they had been directed to the clinic by others⁷⁹. When a patient described a moment of recognition and became convinced that ADHD applied to them, it sometimes made for difficult clinical encounters. Dr Goodman explained how he had seen patients who were convinced that ADHD explained their difficulties, and with whom he disagreed. He had felt in these situations that other explanations were better suited. Some were medical explanations since ADHD symptoms overlap with other classifications (Bipolar, Personality Disorder), but also social explanations as the context of symptoms will impact on the way inattention or impulsivity is construed. He then asked a rhetorical question: “Do you undo their convictions? It may undo their inner world and explanatory models, and surely this would be counter-therapeutic.” As in other conversations with Dr Goodman, I was struck by the pragmatic approach to his work, that strong sense that medicine aimed to relieve pain and that it was expected and required to act when faced with suffering. But beyond the humanistic reflection that this conversation triggered, Dr Goodman also pointed out that self-

⁷⁹ Of course this may be due to the clinical context and it is possible that the relation between psychiatrist and patient, as enacted in a hospital environment, is not conducive to self-disclosure of this kind.

recognition, from the point of view of the clinician may actually be self-misrecognition, that the resemblance between certain traits can be mistaken or confused for something else.

To recollect the old, to produce the new: that is the task of Anamnesis⁸⁰

Ricoeur's discussion on misrecognition⁸¹ is helpful in pointing out first of all that the work of recognition may be at its most powerful when it conquers the doubt of mis-identification. His main point is that, in contrast to objects that are recognised generically, people are recognised through their individual traits, and that consequently time, or the passage of time, plays a crucial part in this process. Dr Goodman and other clinicians could not agree more with this as they attached a lot of importance to the past life-events of their patients including the age of onset of their difficulties. In an attempt to avoid mis-recognising, and therefore mis-diagnosing, clinicians try to ascertain if the behaviours presented have occurred before, and if so with what frequency and severity. They do this by collating a medical-history of the patient and the two parts of the assessment which I have described are complementary ways to do this. A medical-history records a series of events in their sequential occurrence in order to identify difficulties and impairment that could be associated with the ADHD diagnostic criteria. It is typically done by initially using open and broad questions 'what brought you here?' that gradually hone onto specific events of ill health. Although out of regular use, this process of provoking recollection is called anamnesis and is defined as follows:

'Anamnesis is the recalling to mind of things past and is used in two specific medical senses: firstly to mean a patient's recollection of his symptoms and illnesses as recounted in the history he gives; Secondly, to mean immunological memory, exemplified by the rapid reappearance of an "antibody" in response to an "antigen" to which an immune response as occurred on a previous occasion (see immunology).' Oxford Companion of Medicine (Lock et al., 2001).

⁸⁰ Taken from a publishing company called "re-press": <http://re-press.org/category/series/anamnesis/> Accessed on 10/03/2014.

⁸¹ The French 'meconnaissable' that Ricoeur uses is translated as 'unrecognisable'; I prefer to emphasise in the French word the sense of what could be mis-identified rather than what could not be recognised.

From its ancient Greek origin, anamnesis has the meaning of remembrance and calling to mind; it is the praxis of recollection. Anamnesis describes the work directed towards remembering, of bringing back to the present something that was forgotten, making present a memory that was latent, undefined and vague and in this way it is closely related to the process of recognition. The recognition moments that were described earlier were not quite déjà vu, but memories that required active recollection. Anamnesis and recognition are engaged in a dynamic process of un-concealing, recalling and identifying that feed on each other. The immunological image is helpful here, if we consider the booster jab that re-activates the effectiveness of an antibody present from previous immunisation, we can similarly imagine how the recalling of memories brings the reality of past events back to life. The moment of recognition involves this double orientation of anamnesis, seeking in the past for something that was forgotten, and making it present for future use.

In another of our conversations, Dr Goodman and I were speculating on the reasons why ADHD was not yet on the radar of general adult psychiatrists in the UK. Generally adult psychiatrists did not have much awareness or training on ADHD. He volunteered the following opinions:

“It may be that you are kind of shying away from things that you are not familiar with, but also generally, you cannot recognise something unless you are familiar with it, if you don't know what you're looking for, then you can't recognise it.”

This excerpt is from a recorded interview, but because of the numerous conversations I had with Dr Goodman, it felt more like a continuation of themes that we often discussed. Dr Goodman always left me with a lot to think about and many research articles to explore, so on this occasion I had not noticed that, whether intentionally or not, and I was never to find out, he seemed to make a direct reference to the Socratic dialogue with Meno on virtues, knowledge and recollection. This is the section which is relevant:

‘Meno: How will you look for it, Socrates, when you don't have the slightest idea what it is? How can you go around looking for something when you don't know what you are looking for? Even if it's

right in front of your nose, how will you know *that's* the thing you didn't know?' (Holbo and Waring, 2010 original emphasis).

Michel Serres (1995, 2014) offers a reading of this text that brings nuances to the representation of anamnesis particularly relevant to my exploration of diagnostic practices in the clinic. In his exploration of the origins of geometry in ancient Greece, Serres describes through the example of Meno a shift in scientific concepts from procedural to deductive, from concrete to abstract. According to Serres, Socrates's argument is that learning is really the recollection of things already there, anamnesis, but in order to parry memory's fallibility, abstract reasoning is required, that is the art of deduction. Socrates goes on to test this by asking the slave Meno to solve a geometrical problem, which he can only attempt by remembering his time tables rather than thinking deductively. Thus Serres argues that this dialogue shows a play of power by the philosopher over the slave Meno in order to establish the modern science of demonstration. The struggle between two concepts of geometry, an older version based on pragmatic tools and the other on abstract calculation presented by Serres is, I suggest, good to think with for my description of the clinical diagnostic process conducted in two parts. The first part of the assessment, described in the previous section, was conducted through scales and calculation, a kind of abstraction in an effort to bring objectivity. The second part of the assessment conducted through an unstructured interview, includes the medical-history taking and as well as recognising familiar symptoms and patterns. What Serres helps me to highlight is that the tension he described between two different learning modes in science, is also found in the clinical practice I came across in my fieldwork⁸².

Yet I wonder what Dr Goodman was doing by bringing this paradox in our discussion. It seems that he was using it as an example of clinicians not being able to recognise ADHD because they had not seen it before. The notion of familiarity was mentioned again later in that same conversation when discussing the possible increase of ADHD diagnosis: the more familiar we are with ADHD, the more likely we are to recognise it for what it is, or as he put it "ADHD is what is called ADHD". This last

⁸² Serres (2014) suggests that a reversal is currently taking place as memory through computers may regain the upper-hand over abstract and ideal thinking.

statement left me puzzled. Was he affirming a positivist view that ADHD is already there to be identified? Or was he suggesting that ADHD depends on the act of naming it? Other clinicians talked of familiarity by describing how through time they would build a repertoire, catalogue, or ‘typology’ as Warren described it, to which they could refer when conducting an assessment. Warren was a specialist psychiatric nurse, with more experience of diagnosing adult ADHD than most of the psychiatrists who were working in that clinic. He had been working in the clinic the longest of the team and was involved early on with the founder of the clinic in participating in research and publishing. Having over ten years’ experience, other team members including doctors would often refer to him in difficult cases, and in a poised manner, he would consider the case in question. He could nevertheless get quite despondent about the continuous changes he had seen in this clinic and generally in the NHS, as he would describe the re-organisations and other management strategies which he felt negatively affected his clinical practice. When in between assessments or meetings, we would find ourselves in the office, typing notes or emails. Often for long periods, silence was only broken by the noise of the keyboards, printer or the phone ringing. And then conversations would start, sometimes triggered by an annoying email someone received or something heard on the radio that morning, just like in most offices of this kind in the UK. After a number of months in this office, the rhythm of work/chats that was initially unreadable became second nature to me and I was able to initiate conversations that did not seem to interrupt people’s work. Often too, the office was empty except for me, doing my administrative work, responding to emails, booking training or observation sessions.

On one such occasion, Dr Fring from a neighbouring clinic came in with his colleague, Dr Shrader, in search of computers, their office being very busy and unable to accommodate them. They had obviously been engaged in conversation and continued as they sat down, commenting on the current round of re-organisation and efficiency measures. The tone was rather light with good-humour banter and, as I had met them before, I joined the conversations responding to their questions on my interest in the diagnostic process. Dr Shrader started to explain that the more assessments she was doing the shorter the time she needed to diagnose. She said that often there were signs, visual signs that were

easier and quicker to observe than relying on verbal communication and that less than twenty minutes could sometimes be sufficient. Those signs were subtle, of hand or head movements, of gait and other such body language, and recognisable with experience. At that point, Dr Fring suggested that Dr Shrader should really try harder and attempt a 'two minutes diagnosis', which would save the NHS lots of money. Beyond the obvious irony of the comment, the idea of 'speed recognition' and reliance on non-verbal signs was something that I had heard previously. When I interviewed Warren towards the end of my fieldwork, I asked him questions on the way he perceived the evidence that was required for diagnosing. Were there some pieces of evidence that were more important than others, some that would trump others in a hierarchical order? His response was:

Warren: "I guess it is very much about putting together the jigsaw puzzles perhaps, rather than to seek some gold standard if you like and then working your way down."

Claude: "More a matter of accumulation?"

Warren: "yes or I guess that's how I think of it [silence] and I guess a lot of the time [silence] I am hesitant to use the phrase but you almost go on a sort of gut feeling as well, it's difficult to pin down what it is. But it's something about what the person's telling you, how they are telling you, getting a fuller picture, their expressions, or you know, little gestures when you ask questions, that can often tell you more than the answer does. And that works when you have informants, when you ask a question, it's like – oh yeah it's him in a nutshell – and it's hard to actually always pin that down, and it's hard even to get the person to exactly pin that down and provide good examples. But there is something very powerful in the initial reaction a lot of the time. Especially when you have got two or three people in the same room and they have little smiles at each other or giggles when you ask questions, that's quite a powerful thing to observe."

Claude: "I found myself few times being suspicious about why some people were here [at the clinic], feeling sceptical and not seeing impairments or disabling symptoms. And every time it happened, the clinician [doing the assessment] had no doubt that the patient had ADHD. And

I would tell them I was not convinced and they would describe things that they had picked up that maybe I hadn't. So the more you do those assessments, errrm do you get better at finding what you are trained to look for in a way?"

W: 'Yeah I think you get more accustomed to, you know, you're almost thinking – yeah I have seen this type of patient before – or it's that twenty something man whose mum does everything for him, or it's that self-employed businessman, and you've seen that before, whose wife does all the paperwork. And you quite quickly, possibly too quickly put people into those sorts of pigeonholes if you like.'

Warren described how through his years of experience in diagnosing, he had built a typology of the way ADHD might be displayed in adults and he found those signs reliable in a 'gut-feeling' kind of way. Warren spent a lot of his time doing the first part of the assessment and even more in applying the algorithm and scores into his reports. Nevertheless, his ability to recognise some signs which might not fit a particular criterion remained at the heart of his diagnostic practice. In her ethnography of psychiatric practice, Luhrmann described the processes of building clinical experience as a move 'from memorising criteria to recognising prototypes' (2000:41). Warren described this clearly too, yet in what I observed it seemed to me that his typology was an additional mode of diagnosing which was kept in tension with the algorithm, even if sometimes reluctantly.⁸³ By paying attention to the whole picture presented by the patient, such as self-employed business man, as well as the smiles and glances shared, Warren can cluster together elements that were not clearly defined yet which contributed to the diagnosis of ADHD. The similarity between what he observed and the definition of ADHD in the DSM, did not rely on all criteria being met, nor did it rely on all patients sharing the same characteristics. In other words, when Warren relies on his "gut feeling", he is suggesting that the vagueness provided by capturing the whole picture of a person, is more helpful to identify ADHD

⁸³ Prototypical theories of classification when applied to psychiatry each claim a different genealogy such as Karl Jaspers and Max Weber's ideal type (Schwartz and Wiggins, 1987), or Wittgenstein's family resemblance (Mackinejad and Sharifi, 2006). Such theories highlight that characteristics and personality are not clearly defined and bounded but situated on a continuum (Schwartz and Wiggins, 1987; Westen and Bradley, 2005). Such means to categorise have been part of on-going debates in psychiatry since the DSM-III claimed to bring precision to psychiatric diagnostic practices by providing rules for the decision making process; for example the algorithm I described in the first part of the assessment . (Mirowsky and Ross, 1989, 2002; Wakefield, 2012; Westen et al., 2010; Zerubavel, 1996).

than to reduce it to a precise check list. Wittgenstein described the kind of connection as: ‘a complicated network of similarities overlapping and criss-crossing: sometimes overall similarities, sometimes similarities of detail’ (Wittgenstein, 1972 § 66).

In his investigation on language as an activity Wittgenstein famously proposed the concept of family resemblance to describe the diversity of multiple yet related forms that language might assume. Here I am interested in Wittgenstein’s proposition that in order to understand a complex concept as a whole, one should seek to see the connections between parts, how they are related rather than seeking a common element between all parts. In other words, and to paraphrase Wittgenstein (ibid.: § 65), I am saying that the signs, smiles and symptoms observed by Warren have no one thing in common which makes him diagnose ADHD, but that these observations are *related* to one another in many different ways. And it is through the absence or presence of these relationships that Warren identifies ADHD. Warren described his practice of diagnosing as akin to putting together a puzzle, working out how the parts relate to the whole when none of the pieces have one shape in common. Wittgenstein’s exploration of family resemblance led to him to ask questions regarding recognition and he pointed out that recognition was in many cases not achieved through the recollection of a picture already stored in the memory: ‘as if recognising always consisted in comparing two impressions with one another... But it is not so much as if I was comparing the object with a picture set beside, but as if the object coincided with the picture. So I see only one thing, not two.’(ibid.: § 604, 605). I found this description helpful when considering how recognition takes place and it made me wonder what Clara and others recognised. The kind of recognition they described was in regard to themselves and to strangers, for whom they did not hold any pictures in their mind. Did they recognise features they could apply to them? According to Clara, she was not aware that she behaved in a chaotic and inattentive way, until she saw those features in a stranger: she did not carry a picture in her mind that she compared with the person in front of her, instead she recognised herself instantly in the overall demeanour of the stranger. In juxtaposing Clara’s account of recognition with Warren’s, I am suggesting that the processes of identifying ADHD when first encountered inside and outside the

clinic are similar, because whilst their practices are not the same, both set of sites aim to apprehend a full picture, rather than capture a precise definition and essence for ADHD.

Conclusion

This chapter has examined how the people I met in my fieldwork spoke about their first encounter with ADHD in their lives and at work. Support group members described moments of recognition which activated instantaneous identification with strangers they met, or they spoke of the descriptions they found in books and radio programmes which brought the concept of ADHD into their lives. For others it took much longer to get to that point and was a process triggered by others, sometimes medics. Examining the details of the two-part assessment process in the clinic showed how the seemingly incompatible approach of the two parts – categorising through specific thresholds and building a whole picture – were complementary and held together in the daily practice of the clinic. In the clinic, the two parts of the assessment brought together deductive and experiential modes of learning with the aim of avoiding mis-recognition. The practices I witnessed in the clinic and support groups suggest that, overall, the essence of ADHD was conceived not through a singular element, but through multiple and overlapping similarities. My suggestion that the processes of recognising and identifying ADHD were part of the same family of practice, that is a practice of diagnosing, must be seen in view of debates on self-diagnosis. The process of diagnosing oneself, arguably ubiquitous across a wide range of illnesses, is often portrayed in medicine as a challenge to medical authority, sometimes described as being driven by pharmaceutical companies and, when it is acceptable, is usually found in circumstances where other alternatives are not available (Goyder et al., 2009; Jutel, 2010). Wittgenstein's concept of family resemblance allows for rethinking the structural dichotomy between clinical and lay practices. It also highlights the importance of relations, connections, influences and links in the making of a group, cluster or family. Whereas this chapter has shown how people recognising similarities led them to see and make relations and connections, sometimes through recollecting, the next chapter will explore how this process can take place the other way

round. I will describe how, within kinship and familial relationships, people recognise unexpected similarities; in other words resemblances between members of the same family. In drawing on examples of this recognition process, I will trace how kinship is related to recognition.

Chapter Six Family resemblance: how children make adults

New kinship imaginaries

In their examination of the diagnostic process of ADHD in adults, the previous chapters have highlighted the central role played by memory practices of clinicians and members of support groups. In Chapter Five I showed that the work of remembering entailed elements of recognition; recognising similarities and resemblances between people helped identify symptoms as belonging to the defined cluster named ADHD. Thus relations between similar parts were brought to the fore in the diagnostic process and, as such, it was the assembling of familiar elements that facilitated the identification of ADHD. What I want to take forward in this chapter is the idea that the memory practices involved in the diagnostic process are inseparable from the relationships people engage in. In this way Chapter Five and the memory/recognition practices it described acted as a connector with the kinship/recognition mode that will form the basis of the next two chapters. The connections between memory and kinship have been noted in their many forms, suggesting that remembering is always embroiled in a network of relations, with one's self, others and institutions (Carsten, 2007; Radstone and Hodgkin, 2003). Following Strathern (2014) who showed that the concept of 'relation' implies the notion of 'recognition', as in 'acknowledgement', I want to explore how kinship is enacted in the diagnostic process as one element of recognition and, more specifically, to ask what kind of kinship is put into play.

In their article *Reverberations: Disability and the new Kinship imaginary*, Rapp and Ginsburg (2011a) suggested that families of children with disabilities, in their case Learning Disabilities like autism and dyslexia, have to re-imagine their daily lives and interactions with the world, in order to organise the care and support required for their child to thrive. They demonstrated that in this process a new narrative of family life emerged which questioned the kinship relations that could no longer be taken for granted. The unexpected recognition of ADHD in a child by his parent, that I will come to describe in the next section, epitomises Rapp and Ginsburg's insight that 'kinship imaginaries require

continual reinvention' (ibid.: 10), whereby adults reformulate their identity and knowledge of themselves from information about their child. Furthermore, Rapp and Ginsburg go on to show that this new kinship imaginary extends beyond the family, as individuals find themselves meeting other adults in similar predicaments, seeking support and in that process becoming 'accidental activists' (Panitch, 2008). In a similar way, the people I met in the support groups were also engaged in seeking public recognition and making claims for resources. Yet in the support groups I attended, parenthood was not the only bonding element between members as many, often the majority, were not parents. Instead the kinship that was being re-imagined outside of the family and in the support groups was based on sharing a way of being in the world through the lens of ADHD.

It is this notion of relating to others through ADHD, of the making of kin, within a family and with strangers as part of the broad diagnostic process, that I want to explore in the next two chapters. In Chapter Seven, I will explore how kinship relations extend outside home and are made between strangers on the basis of a shared neurology (neurodiverse) that distinguishes them from others (neurotypical). In this chapter, Wittgenstein's concept of family resemblance (1972), which I introduced earlier in regard to modes of categorisation, will be explored to support my investigation of how similarities between family members within existing kinship relations can lead to unexpected outcomes. As with other disorders (Lock et al., 2006), the notion that ADHD may run in the family seemed to be accepted as a matter of course within my field sites. Widely available lay information regarding ADHD, in self-help books and website forums, emphasised this familial connection by referring directly to the scientific discourse of heritability. ADHD is often described in this scientific context as one of the most, if not the most, heritable psychiatric disorder, with a 70% to 80% heritability factor (Franke et al., 2012). What that means exactly to support group members is not always clear, as I found their interest in genetics or molecular biology to be limited. Nevertheless these scientific concepts run along a more general notion of family resemblance, whereby certain traits and characteristics are passed on within a family, as one manual explained: 'because of the high familial risk of ADHD, [practitioners] are also aware of the high proportion of parents of children with ADHD who present with similar problems' (UKAAN, 2013: 2). Support group members related

to this instinctively as they saw how their parents, siblings or cousins also got into difficulties due to their lack of attention or an inability to control impulsive behaviours.

The main question I ask in the last section of this chapter is: what kinds of kinship relations are encouraged through these practices? In the context of the expansion of ADHD into adulthood, as a lifelong disorder, my query is how this change may affect kinship relations. Making reference to some recent anthropological debates I ask: is this kinship founded on the basis of sharing blood or sharing genes? Alternatively, could kinship consist in the sharing of medicines between generations, possibly the sharing of biological traits that are not genealogical? If kinship exists in the realm of caring for those who are close to us, I want to ask how this is achieved in the context of cross-generational ADHD. What are the implications when support groups advocate for treatment of the whole family? Is kinship in this case a resource towards a claim for recognition and, by extension, the basis for an activism and politics of difference? The specific relations implicated in the making of ADHD as I describe it do not suggest a fundamental move from the idea of kinship as it is known and experienced in the UK, but rather the description of a particular and unexpected way that knowledge about kinship is put to work and re-imagined.⁸⁴ The reformulation and re-imagining of the biological explanations for ADHD, which often lead to the making of new relations, suggest that the social and biological notions of kinship require work in order to be held together. As I will come to show, there are contradictions and ambivalence arising from feeling connected with kin on the basis of an affliction. For example, the sense of genealogical responsibility that parents might feel towards their diagnosed child might be marred with guilt; or the sense of vertigo that a parent may experience when made aware of ADHD as potentially relevant to their lives through the diagnosis of their child, bringing relief, turmoil and confusion all at once. The paradox of kinship in the lives that people described to me is that it highlights problems and difficulties that have been and continue to be endured, whilst also providing creative opportunities for the making of new relationships.

⁸⁴ In this chapter, I focus on a particular kind of kinship relations, namely the parent-child bond, as it featured prominently in the support group members' discussion on recognition and diagnosis. As it will become apparent, other members, who were not parents, also experienced a sense of identification with others, which leads me, in Chapter Seven, to extend notions of kinship to include the sharing of neurological differences.

This chapter also contributes to the anthropological proposition that kinship systems may not all be based on biological links and reproduction as proposed in the western popular mode (Bloch, 2001; Sahlins, 2013; Schneider, 1984). Rather than putting forward a radical proposition departing from the accepted British folkbiology, my fieldwork encounters indicate an additional direction in the expected descending links and influences passing from parent to child⁸⁵. Thus I suggest that adults with ADHD are made by children on two accounts: first, according to diagnostic criteria, ADHD in the child must precede ADHD in the adult. Wordsworth's famous line 'the Child is Father of the Man', is often used in medical and scientific publications, to describe this continuity of personhood during a lifetime: how adulthood is dependent on, and follows from, that person's childhood. It is a popular image that took hold at the beginning of the 20th century in public health debates, when states were concerned with building strong nations, and the correlation between child development and adult health was made (Harris, 2001). But my interest here, and my second point, is that the specific moment in time we are in, when adults could not be diagnosed until recently, has put a cross-generational twist onto Wordsworth's line. Thus the transmissions of characteristics can take place not within one individual but across age groups and, more specifically, upstream from children to adults. What is asked in the next section is: how can a child beget a parent?

The child is father of the man

Keith⁸⁶ was in his mid-forties when he first came to the support group. The facilitator gave him, as was customary, the chance to speak and explain why he was attending. The group was quite large with over twenty participants, with the majority of people being regular members, including myself.

⁸⁵ I am suggesting a co-existing ascendant and descendant transmission, the former being implicit in the practices I have described yet counter-intuitive to western concepts of kinship and reproduction.

⁸⁶ Due to reasons of anonymity I described in the introductory chapter, I have decided to combine a number of stories told by support group members, representative of the common experience that I came across in order to make new ones. Thus in the case of Keith and Bridget in this chapter, their stories have not been experienced nor told by just one person, but by a number of people with similar experiences. I hope that the composite stories I present will help to illuminate the practices of kinship that are common to my participants.

We were sitting in a circle as usual and most had made a cup of tea or coffee before settling down. When it came to Keith's turn to speak, he explained that it had taken him quite a while to decide to come along to the group and that he still wasn't sure that he had ADHD. He was not diagnosed and he did not have an appointment to see a doctor yet. He was hoping to get more information from the group. Anna, one of the facilitators, asked him how he came to think that he might have ADHD. Keith then told the following story:

“I've got a son called Billy and he is twelve years old. He had been given an appointment at the Child and Adolescent Mental Health centre, because he'd been in trouble at school. He was constantly getting detentions for disrupting the class, or not finishing his work, that kind of thing. He had always been like that, at home as well, always on the go, never staying still. Not stupid though, he still managed to get good grades. Anyway, on that day we were running late, I am always late for things, you know, and so we went in and there was a psychiatrist there who asked us if we had done the forms. We had been sent forms to fill in with lots of questions, like maybe 50 questions, and we'd done most of them, so I gave them to her. She explained that there were quite a few school reports which suggested that Billy was restless in the classroom, and that was why we were there. She then started doing the assessment, which was like more questions, mostly for my son to answer, but also for me, about his sleeping pattern, about him forgetting things, or feeling anxious. This was taking quite a long time, like an hour or so, and I could tell it was really hard for Billy to be there. The psychiatrist then asked Billy if he had heard of ADHD, and we both said yes, because the school had mentioned it *already*. She thought it was ADHD that caused him his problems, like stopping him sleeping properly and not being able to relax. And then she said to him but pointing at me: ‘you see your dad sitting here, how he is twisting his fingers and moving his legs all the time, well I think he has ADHD too.’”

At this point quite a few members of the group laughed, made exclamatory noises: “Whoouah, Really? No way!” and a sense of surprise and excitement was clearly palpable. As Keith was speaking I had noticed how he was very fidgety, his legs were shaking up and down, sometimes he sat

on his hands to stop them moving too. He seemed to be experiencing this more than most members I had seen so far. Yet no one in the group commented on that; instead Anna asked: “Oh my god, what did you say?” Keith elaborated on his feelings:

“Well I didn’t know what to say, I was like feeling really awkward and embarrassed. And then the psychiatrist carried on explaining what kind of treatment she was going to prescribe, what difference it should make and how often Billy should come to see her. But really I did not pay attention; I was like, in shock, it was like having vertigo. On our way home I kept wondering about what had happened, what did she mean I had ADHD as well? The thing is, I could not really remember what she had said about the meds so I had to ring her again and that’s how she explained that adults can also have ADHD, I didn’t know that, I thought it was only children that could have ADHD. She told me I could go and talk to my GP about it but I didn’t do that. I have not been to see my doctor yet.”

Very quickly, members one by one started to ask questions and to give advice to Keith: which GP did he have what he should do to get an appointment with a specialist doctor. After the session, I had the chance to have another conversation with Keith, and he explained to me that the event with the psychiatrist had happened nearly a year ago:

“I haven’t done anything about it, because with my wife we needed to get our head round the idea of Billy being on medication. We weren’t sure about the side-effects and how if this would make it harder at school for him. At the time the doctor told me she thought I had ADHD, my wife was pretty convinced that I had it and I should do something about it. To be honest, I felt a bit offended by the idea, not sure why, but it’s probably why I didn’t do anything about it for a long time. It’s only when I went to a follow up appointment with Billy that I asked more questions and thought I should find out more about it. So I went online got more information and started to see how Billy was so much like me, or was it the other way round? I know that I used to have bad times at school, lots of detention and thinking back they let me down really, so I don’t want that for him.”

The Future in the mirror

Keith's is an exemplary story which I heard in slightly different variations in all of the groups I attended, as well as in some of the clinical assessment I observed. The entrance and arrival of a psychiatric diagnosis within a family both reshapes individuals' life trajectories, and provokes parents into a re-examination of their past and present difficulties. Family stories are told and retold describing the similarities between childhood experiences at school and at home between generations. For some, like Keith, it takes time to come to terms and decide to take a passing comment seriously, as if the resonance of that moment required amplification. For others it is just like the flashbulb moment of recognition I described earlier, seeing oneself in another as if in a mirror. Roger, from another group, explained how he could see himself in his son, always climbing trees, getting into trouble at school and falling about all the time. In fact, he continued, he recalled how, as a child, he was always covered in bruises, knocking into things, and he broke his arm when he was ten and then his leg two years later. His son had had similar injuries and scars, which Roger thought was a little strange. At first he did not think that this was anything but 'boys being boys', even though his son was more frequently injured than most of his peers; but when his son was diagnosed, he thought, 'that explains a lot'. As my conversation with Roger was diverted to different subjects with other group members, I took it to mean that the diagnosis of his child explained a lot about himself, and that viewed through that lens, it appeared that he had been hyperactive as a child. The recognition that took place between himself and his son brought a new understanding, a new insight; it was not like seeing an exact mirror image but it brought the strangeness out of the familiar.

In his musing on time, art and things past, Berger (2005) describes how some painters have developed a technique in order to answer the searching question: when is a painting finished? According to Berger, they study their painting in a mirror, in a reversed reflection, a tactic which forces them to see through the familiar, to look with fresh eyes, and see anew. He concludes, 'What they glimpse in the mirror is perhaps a little like the look of their painting at that future moment to which it is being addressed' (ibid.: 27). The mirror reflection acts in this case as an intentional shift, a

disruption of what has been seen and worked on by the artist day after day, to then suggest what the end product will look like. Berger's mastery of time narration and his insight in finding the future in a mirror's reflection is also helpful to think with concerning the experience that people have of seeing themselves in their child as if in a mirror. Recognising behaviours and traits in one's children is quite common for parents, and it usually confirms one's sense of identity and of continuity. Weston also made use of mirrors as metaphors in exploring gay stories of coming out and suggested that 'seeking one's own reflection often symbolises an effort to affirm a coherent self in a situation that promises (or threatens) to transform identity' (Weston, 2013: 139). But in the cases I have described, parents, rather than seeking, were enforced and compelled to reconsider, and question who they were in relation to their child. What they saw and caught a glimpse of, in that moment of recognition, is the sameness in difference, the same yet not the same, and it propelled them along an unexpected trajectory. The familiar, what was seen every day, as a parent saw their child, was suddenly displaced to reveal other aspects of resemblance that had previously gone unnoticed⁸⁷.

A different visual metaphor, the Rabbit-Duck picture famously used by Wittgenstein (1972), can also help to envisage what takes place in this moment. One has to be familiar with the rabbit to see it in the picture, and the same goes for the duck, but only one can be seen at a time. Furthermore, the first time that we see this picture, only one of the two, rabbit or duck, can be seen and it takes a shift, a visual displacement, a change of focus, to see the other. Wittgenstein describes this in terms of a distinction between 'continuous seeing of an aspect and the dawning of an aspect' (ibid.: §194), hinting that the object being seen influences what is seen, and emerges in a kind of 'materialisation' (ibid: §199). No conclusion is given by Wittgenstein about what causes the shift, nor is my interest in explaining it. Instead I am interested by the fact there is a change of perception of the familiar that becomes something other and that this glimpse, caught in a moment, leaves an impression. Once we have seen and apprehended the picture of the duck in the rabbit, that possibility remains with us. Furthermore as noted by Cavell 'the flip from one reading to another is due solely to you, the change

⁸⁷ Lacan's theory of the mirror stage (1968) is influential in the mirror metaphors used above which suggest an objectification process associated in seeing oneself in a mirror; my interest here is in the way that a mirror image calls upon notions of reciprocity – that if I can look at another person and see myself in them, that is what I look like to somebody else.

is in you' (Cavell, 1979: 354)⁸⁸. In a similar way, for Roger and Keith, once they saw themselves in their sons, not only in terms of sharing the colour of their eyes or hair, but also in the bruises, scars and broken limbs, they knew that something had changed and they could not ignore it. But there are other reasons why recognising themselves in their children made a lasting impression which required acting upon, reasons directly linked to their relationship as kin. Marilyn Strathern showed how kinship knowledge has certain intrinsic qualities that make it difficult to ignore due to its 'cultural coupling with identity' (Strathern, 1999:68).

'For English-speakers, a peculiarity of knowing in kinship terms is that information about origins is already grasped as knowledge. Parentage implies relatedness; facts about birth imply parentage and people who find things about their ancestry, and thus about their relations with others, acquire identity by that very discovery. The information constitutes what they know about themselves.' (Strathern, 2005:69).

The contemporary scientific discourse of ADHD, which now describes it as a lifespan condition, also emphasises that ADHD has a high familial risk of 'clustering both within and across generations' (Franke et al., 2012: 961). Information of this kind that calls upon genetic ideas of kinship is widespread and not confined to ADHD. For the parents of children with ADHD I have met, it adds a new dimension to recognising and seeing themselves in their child. Can they ignore this information? What would be at stake if they did? In addition, the memories of childhood events that are triggered through this recognition also bring to the fore the persistent difficulties they have experienced. As Strathern described, they cannot ignore the information that their child is likely to have a neurodevelopmental disorder. To do so would potentially render the child as 'other', as not the same, not part of the family: it may deny the parent/child relation altogether. The experience of being stigmatised and ostracised for behaviours associated with ADHD is, unfortunately, widespread for children (Singh, 2012, 2013). Parents are well aware of this, having to deal with the impact and

⁸⁸ Cavell's analysis of the duck-rabbit picture emphasised the wide range of concepts that could be extracted from such an image; he lists seven. Following the moment of recognition I introduced in Chapter Five, my interest in the duck-rabbit picture is on the dawning, the appearance and new way of seeing something that had been there all along.

aftermath of the problem. For parents to act on the information that ADHD clusters in families, and to seek and accept a diagnosis of ADHD and treatment, is also to recognise one's kin as genuine relations. Acknowledging their sameness in being different, adults also open the way for the possibility of new kinds of kinship relations based on the sharing of similar difficulties, bringing adult and child closer together. Further on I will explore the reverberation on 'kinship imaginaries', to use Rapp and Ginsburg's phrase (2011a); but I wonder if the recognition of one's kin may not be particularly germane for the men I have met. Fathers have always had a lot more to prove in regard to their biological relations with children than mothers. Thus, to admit the possibility of the heredity of ADHD as pertinent for one's life, is to recognise and affirm a legitimate filiation. Keith had felt quite offended that his wife thought that, like their child, he too had ADHD, and that he should do something about it. Yet, after months of not acting on the information given to him in passing by the psychiatrist, his wife's comment may well have been a crucial factor in Keith's decision to finally make contact with the support group. Clearly that comment had also made an impression on him.

Strathern discusses kinship knowledge and the impossibility of refusing information in the context of reproductive medicine in the western world. She asks what impact new technologies have in producing new kinds of kinship relations from knowledge of the past. But the narratives I have encountered in the context of adult ADHD suggest a disruption to the natural flow of kinship knowledge that we have come to expect – namely a flow from parent to child whereby the sense of self and identity is passed on downward to the child. Instead the adults I met found themselves reformulating their identity from information about their descendants, not their ancestors, adding an upstream flow of knowledge from the child to the adult. For the adults I met, this is knowledge about their past, that is their own childhood, as well as about their present, knowledge they acquire through their child, their future. It is as if the child generates the adult: the child with ADHD begets the ADHD in the adult. As I have described, this situation is the result of a particular historical context whereby adults could not be diagnosed with ADHD until quite recently. In this way it could be

considered peculiar to the scientific and cognitive context of Euro-American⁸⁹ kinship knowledge. It is another permutation of the way that individuals within families either connect or do not connect with each other, which is due to new technology, albeit in this case not reproductive technology. But I wonder if this does not attribute to new technology, and genetics in particular, a place of importance that can obscure other understandings of kinship relations.

The parent of a child with ADHD

I found Bloch's ethnographic examples (1993, 2006) helpful as a way to further examine notions of relations that may be counter-intuitive to the dominant biological and western mode of conceiving kinship. Bloch's work with the Zafimaniry is far reaching and comprehensive, in that it covers wide aspects of the social life of the Malagasy people, and here I want to draw on his concerns with their kinship system. The main point that Bloch makes in this respect is that the Zafimaniry do not pay particular attention to biological inheritance when considering the formation of personhood in their society⁹⁰. In other words, births, and all of the relations we associate with it in terms of societal status, do not play an important role in the process of becoming a social person. Instead, as he suggests, it is through the making of a household that individuals become social beings, which entails house building, marriage and reproduction. The making of the household, which includes changing modes of living from hunting to cultivating food as well as giving birth to a child, marks the entrance of the couple into the social world. The child herself does not become a full member of the society by the sheer fact of her birth, instead she is considered as lacking 'moral responsibility' and treated like a loved pet. What the birth does not do to the baby born, it does to the parents as the child generates and

⁸⁹ Whilst my study is situated in the UK, the term used by Strathern (2005) to describe the western world's cultural sphere (Euro-American) can be helpful to describe the entanglement of Euro and Americans when it comes to ADHD. But it may be more precise to term it 'North Euro-American', as in both continents ADHD is particularly recognised and diagnosed in that part of their geography (Ginsberg, 2014).

⁹⁰ The peculiarity of the Zafimaniry people's conception of kin relations is part of the broader geography of South East Asia and Madagascar 'where birth is more like, "the launching of a ship"' and the individual remains malleable and open to influence through the relationship developed in life (Bloch, 2001: 48). Bloch's work also suggests that biological concepts of transmission are not incompatible with the notions described above (ibid.: 61).

creates parents as full social beings. The transformation of the parents into full social being goes further still at the point of the name-giving ceremony for the child. In contrast to Christian baptism ceremonies, where naming a child is a ritual entrance into the world as an individual, the Zafimaniry people hold a ceremony that, by naming a child, has the outcome of renaming the parents as well.

The practice of naming the parents from the child, defined and named by Tylor as 'teknonymy' (1889), is common in many parts of the world, even if it varies according to social context. According to Bloch, the Zafimaniry parents are renamed after their first child. More often than not their birth-name is abandoned completely, making 'the name-giving ritual a celebration of the entry into society of the parents not of the child' (1993: 128). Teknonymy is the sign of the growth of individuals in society, but following Geertz (1964), Bloch suggests that it is also a move towards losing some individuality. In effect, losing one's name for another that is descriptive of the role one has in society, in this case as a parent, is clearly depersonalising. Geertz goes further in describing the Balinese teknonymy system as causing 'genealogical amnesia' as names of ancestors are forgotten. Yet what Bloch shows is that a teknonym contains a proposition, therefore it is used with a purpose in mind, to show respect, or to strengthen relations and this purpose depends on the specific context of the relationships.

In the next section, I want to examine how the insights Bloch drew from the Zafimaniry kinship processes may be relevant to my interest in parents of children with ADHD; what kind of proposition is made by identifying oneself as a parent of a child with ADHD? I will answer this by drawing on assessments I observed in the clinic, where adults in the process of demonstrating the presence of ADHD symptoms in their childhood, also reveal its presence in their kin. I found that in support groups, conversations rarely revolved around relations with children when determining the validity of an adult's diagnosis. Mostly it would be in a 'newcomer's tale' that such reference would be found, as in the case of Keith's story. Instead, the focus of shared stories was laid on an individual's experiences, what ADHD meant to them. In contrast, the clinic was an environment where I observed issues of genealogy, kinship and heredity discussed explicitly, and for good reasons, but sometimes with unexpected outcomes as I will show.

The paradox of kinship

Bridget came in for her assessment with a large file that she had compiled herself, comprising school reports but also medical reports from psychologists, GPs and psychiatrists. In her mid-thirties, Bridget started to describe how she already had a number of diagnoses which she believed to be wrong. She had been diagnosed with depression and anxiety whilst she was still a teenager; then more recently she had some difficult times and doctors had diagnosed her with Personality Disorders for which treatment did nothing. The clinician, who was looking at the file Bridget had brought with her, started asking questions about what kind of problems she had and when they had started. Bridget explained how her main problems were about getting organised, that her mind wandered off, day-dreaming, so it makes it very difficult to get anything done, and with two young children that is really difficult. These problems had got her in debt. She forgot to pay bills, lost things all the time and was unable to control herself with online shopping and bought things she did not need.

By this point in the assessment, fifteen minutes had passed, and I was very aware of the visible aspect of Bridget's symptoms, and I am sure the clinician was too. Bridget was barely able to sit still and regularly got up and walked round the room for a few minutes. The clinician offered her the chance to take a break, but Bridget was not so sure, and looked towards the person accompanying her for reassurance and both agreed to carry on. Usually patients bring relatives or partners, but Bridget had brought along her child's support worker, Carry, herself diagnosed with ADHD. Bridget went on to explain how helpful Carry had been when her oldest child had been diagnosed; "she is just like my sister and she knows what I am going through because she has it too." Carry had reassured her and explained what ADHD was and encouraged her to go to the ADHD course that was run for informing and supporting parents. When she was there, she started to see how a lot of the behaviours that were described for children, were present in her too. Suddenly, she recalled, she could see herself in her child, the impulsive behaviours and constant fidgeting. Carry explained that when Bridget's boy started medication, it made such a big difference and he was able to catch up with his school work. Bridget described how her son also had "drug holidays" in school holidays and sometimes at week-

ends, when he did not take his Ritalin. It was in those moments that she recognised herself in him.

That was why, Bridget went on to explain, she was hoping for treatment because she saw what it did for him; she said “when you have that treatment, you can see the person that should be.”

Neither the clinician, nor I, had said a word for quite a while as Bridget and Carry were telling her story, jumping from one subject to another, the meds, the school, the debts, and then back again to the school. The clinician then steered the assessment back to his initial question: how was Bridget’s childhood, did she have any difficulties? At first she talked of her childhood, not in terms of problems with inattention or hyperactivity, but in terms of being neglected; she was in a special school and so had extra support, no more than five per class, so everything was well organised, just as for her son who gets lots of help. As the clinician asked more searching questions, Bridget explained that she had been taken into care after a number of years of being neglected by her mother who suffered with mental health problems. When she was not in school, she was always getting into trouble. As the clinician was looking into the file Bridget had brought with her, she explained that she had tried to get her mother to fill in the forms for this assessment. But because of the bad memories it brought up for her, bringing all those bad times back again, she got her sister and Carry to help her fill in the forms instead. By doing that she had found out a lot about her family, things that her mother had been ashamed of and did not want to discuss. She had contacted relatives who were abroad and she told me how she had found out that:

“My maternal cousin in New Zealand was diagnosed with ADHD as an adult; another maternal cousin committed suicide whilst in her 40s; another maternal cousin had some Learning Disability and had always been in his own world as a kid; one paternal cousin had murdered his wife.”

She had written this list down and after reading it, she wondered aloud about how hereditary and genetic ADHD might be. The clinician responded briefly that it was complicated, but that research showed that it was often found within families. As the assessment came to a conclusion, Bridget seemed exhausted and was barely able to listen to the last few comments regarding treatments; the

two-part session had lasted nearly three hours. The clinician made sure to explain that, in her opinion, Bridget had ADHD, that a full written report would be sent to her GP, and that she should make contact with her doctor in the next couple of weeks to start medication. At that, Bridget was clearly relieved.

The moment of recognition that something was wrong in her and that it could be remedied came through her son's diagnosis and treatment. Now she was hoping to share with him another way of being, where she would be more in control, more organised, and able to become 'the person that should be'. At that point of the assessment I perceived the sense of hope that Bridget attached to her son's transformation after starting his treatment. He could become someone other than a turbulent child who got into trouble. 'The person that should be' seemed to me to encompass Bridget's feeling of lack of control over what happened to her, and to suggest that there might well be another person within her who needed help to come out. The verb 'should' is loaded with a sense of obligation, of duty, but it also indicates something desirable. In view of Bridget's persistent restlessness and sleeplessness, the combination of hope and obligation produced a poignant image for me, one of someone striving to change, and to be somebody who could have rest. Her son, who had been suffering in the same way, would ask her 'to stop the thinking that was going on in his head'. During the assessment, she explained how she blamed herself for that, for the ADHD in him, saying; "it must have come from me."

On the one hand, Bridget could see how her son had benefited from being treated for ADHD, being able to sustain focus. She started to look forward to the future – to share with her son a new way of experiencing the world, something that her son already had access to, as if she was looking to emulate him, as if he was setting an example, and acting as a role model for her. On the other hand, Bridget was reminded that she is the parent of a child with ADHD, she attended a course for parents, she found out unhappy family stories and discovered that ADHD may be hereditary which suggested the role she may have played in producing her son's condition. It is as if these orientations were the two sides of the same kinship coin; one side is looking up towards her descendant for changes in her life, the other is looking down towards herself as an ancestor who has changed her son's life. To carry on

the coin metaphor of kinship, the latter side, the one representing the genealogical line of ascent, can be thought of in biological terms, as the natural flow of kinship knowledge. On this side, Bridget has passed on her traits to her son. On the other side of the coin, the genealogical line of descent is what might be thought of in social terms, what I called the upstream flow of kinship knowledge. On this side Bridget looks to her son to pass new traits and modes of existence on to her. The point I am making here is that the social and biological aspects of kinship are not separated, but contingent on one another. They overlap over one another and both require work in order to bring them into being, but the biological transmission downward, her genetic responsibility to her child, is experienced as more natural than the social effort to be recognised as the parent of a child with ADHD. In Bridget's as well as Keith's cases, the tekronym proposition (Bloch 1993) which is made by being called the parent of a child with ADHD, does not seem to depersonalise them. It does not reduce them to being merely the transmitters of ADHD, but also brings the possibility for change in themselves and the opportunity to become 'the person that should be'. It opens the way for becoming another kind of individual, albeit through treatment for ADHD. In addition, the sharing of the same remedy may also reveal other dimensions in relationships. As long as patients are prepared to undergo all the effort required and have the resources necessary to do so, then the hope and the relief from disabling symptoms that medicine can bring may be shared with family members and so become part of everyday family relationships.

The difficulty involved in maintaining any kind of relationship was a very common topic of conversation in support groups. Diagnostic manuals also highlight this inability to maintain relationships as a specific ADHD impairment if it is experienced to such a degree that it affects social functioning (NICE, 2009; UKAAN, 2013). Support group members described how they tried to make and maintain relationships, and spoke of their hope of not becoming cut off from other people. This concern was felt at home too with close kin, through the difficulties of caring for young children when one suffers from forgetfulness or disorganisation, as Bridget explained. Another member of a support group also explained how, when his son started medication, he saw how the boy organised his room and homework, and could not help but feel ashamed at his own pile of unpaid bills on the kitchen

table. He was worried that he could not care properly for his family, as his disorganisation and lack of attention to his finances was getting the family into debt. In his case and in others I encountered, the sense of responsibility to care and to provide good care is entangled with and related to the need to look after one's self and receive help. Kinship consists in caring and being cared for as Borneman has shown (2001). Bridget and Keith, in recognising themselves in their ADHD diagnosed children made positive moves to seek recognition and care for themselves in the clinic. What they found in the clinic is that to be recognised and diagnosed can be closely related to being called 'the parent of' someone already diagnosed with ADHD. Often 'parentage' is understood in its broader sense, not reduced to first line descent alone, but also extending to other branches of relatives as Bridget demonstrated in her family résumé.

The forms that Bridget filled in with help from her sister and Carry asked direct questions about family history: does anyone in your family (for example, parents, siblings, aunts, uncles, children) have features of ADHD? Has anyone been diagnosed with ADHD? Has anyone been diagnosed with a psychiatric disorder? The responses that Bridget brought with her covered all these options and more as she found out about distant relatives. The content of such questionnaires is indicative of the importance which is often ascribed to heredity and genealogy in modern medicine (including psychiatry) as a broad proposition that, statistically, traits and characteristics are often clustered in families. But it is worth asking how the information on that form is helpful, and what it does ?

During all the assessments I observed and in conversations with clinicians during my fieldwork, the family information provided by patients was never directly acted upon, checked or tested. By that I mean that no genetic testing is made on that basis. If there was some positive response to the questionnaire, then we can assume that it would, in the mind of the clinicians, increase the probability of them making an ADHD diagnosis for the patient. However, the questionnaire also highlighted to the patient that looking into their family history can be of importance for their own future health.

My purpose here is not to question the veracity of scientific assertions as to the role of genetics and heredity, but rather to ask how its impact on the way kinship is then conceived. In the cases of Bridget and Keith, how do notions of genes and heredity affect them when thinking about their difficulties?

From my conversations with them, I formed the impression that it increased their sense of genetic responsibility for their child's difficulties, and simultaneously raised the hope, that in sharing that same connection, they might be able to share the burden of their common difficulties. Yet heredity is defined in medicine as the genetic transmission from parent to offspring, not the other way round. Maybe there is another element that is implicit in this counter-intuitive logic of child to parent transmission of difficulties, one that is posited and accepted by patients and clinicians, and defined by Strathern thus: 'To see a child is ... to "recognise" a natural fact. Whether socially or legally, by contrast with the child, parenthood is thus always constructed as an object of knowledge' (Strathern, 1992: 148). Writing in her investigations on new reproductive technologies, Strathern argued that a child is defined in itself and by itself, we do not need to see proof that she has a parent, it is presumed. But on the other hand it takes a child to make a parent; we cannot assume when we see an adult that it is a parent; thus parenthood is constructed.

I am interested here in Strathern's suggestion that the relationship between the child and parent, which is grounded in both nature and culture, is an 'amalgam of different orders of fact' (ibid). In other words, the child is added to the parent to make it so, and so is the parent made by the addition of a child. It is the relation between the two separate entities child/parent (nature/culture), that makes something new, a hybrid in which part of one is found in the other. Strathern named these relations, merographic connections in that 'anything may be part of something else' yet 'nothing is in fact ever simply part of a whole because another view, another perspective or domain, may re-describe it as part of something else' (1992a:73; see also Franklin, 2003; Mol, 2014). The plural perspectives on kinship relations can also be seen in the work put in to keep two separate wholes together; the biological and the social aspects of kinship. Thus Bridget was holding together potentially contradictory notions of kinship connection: she combined being a parent of a child with ADHD with the idea that she might find solace and treatment for herself because of it, yet she also felt responsible for the ADHD in her son, as well as other newly discovered connections with distant relatives. Similarly Keith had to adjust and push away the sense of genealogical displacement when he was presented with the origin of his problems in his progeny, then consider treatment for his son as well as

support for himself. Such is the 'kinship thinking' (Strathern, 1992a) that takes place in order to keep together different elements that are in their connections constitutive of kin relations. Crucially, it is holding and mixing together the different elements that makes kinship what it is for Bridget and Keith: 'Thus the logic of the totality is not necessarily to be found in the logic of the parts, but in principles, forces, relations that exist beyond the parts.' (ibid.: 76).

Running wild in the family

Towards the end of my fieldwork, I was invited by the clinicians to make a presentation at a scientific conference on the work I had been doing with support groups. I asked the groups directly: what would they like scientists and clinicians to hear of their experiences? The three groups responded with similar points, such as training GPs to recognise ADHD and easier referral systems. One group also highlighted the need to treat the whole family, not just the child. When I asked what they meant, one of the facilitators made a gesture with her hand across the room, as if to say "there is your answer". In the room, around twenty people were sitting together, most of them aged over 30, mostly undiagnosed but describing themselves as having ADHD and its symptoms. I also knew that quite a few were parents and that some of their children had been diagnosed with ADHD. Yet they still had to convince the GPs and their funders of their need to be seen by a specialist clinician. Alan, one of the members explained:

"I am 52 now, and I've gone through all kinds of hell, I have been addicted to drugs and alcohol, I did a stint inside, I lost my family and, now I have found them again, I don't want to lose them. My youngest was diagnosed nearly five years ago now, and we know it runs in the family, so why can't they assess me and see if that's what's causing me all these problems?"

Another member interjected: "Yeah you can say that, it's like ADHD is running wild in the family."

Once the laughter had subsided, Tessa brought the conversation back to the topic of treating the whole family. Other members agreed, it would save a lot of time and misery to be assessing other members

of the family if one person had ADHD. By treating the family, they meant literally providing treatment, but also treating family members in the same way and providing access to assessment for adults as well as children. They wanted to be treated as whole individuals, not just as the parent of a child with ADHD. The conversations I observed in groups rarely referred specifically to genetics to explain the causes for ADHD. Instead, as in Alan's example, discussion would refer to it as 'running in the family'.

On the face of it, the phrase seems a rather vague statement, but to some extent it does express what matters to people when it comes to understanding the impact of presumed genetics in their lives. This was expressed succinctly by a member of another group: "Well until someone comes up with new treatments, [genetics] is of no interest to people trying to manage their daily lives". The scientific fact that ADHD is hereditary and 'aggregates in families ... as a result of genetic factors' (UKAAN, 2013:25) is experienced directly by people through living with their kin; siblings, parents, grand-parents, cousins and hyperactive children running wild in the family, as referred to in the joke. The expression is not used only with reference to ADHD and studies have discussed this in relation to genetic testing and risks factors (Lock et al., 2006; Lock and Nguyen, 2010). But rather than thinking of heredity in terms of risk or even genetics, it seemed that the support group members, were talking about the clustering of ADHD in families, in evidential and existential terms. The reasons are as follows: firstly as a possible means to support the case that they may themselves have ADHD; secondly, individuals can remember and observe how family members behave in ways that resemble the description of ADHD. Rather than genetics, these are family traits and characteristics, in other words, family resemblances⁹¹.

In her assessment, Bridget made reference to her two cousins in response to the questions on the form, when she described by the tragedy in their lives (committing suicide and murder) rather than by mentioning any signs of mental health problems. It is not clear why that would be, and my interest is not in speculating about the associations that Bridget may have made between ADHD and these tragic

⁹¹ For an extended argument on the importance of family resemblance over genetic links in adoptive families, see (Marre and Bestard, 2009).

events. Instead, it seems to point out how her notions of heredity seemed nebulous and vague. I do not mean that she did not have a sense of what heredity and the transmission of ADHD might be, but that her conceptualisations did not fit precisely with the genealogical and linear description found in the clinic. Indeed she also included Carry as her kin, just like a sister, on the basis of the care Carry showed to her and her son, and possibly because she also had ADHD: Carry knew just what Bridget was going through. I have touched on notions of kinship as caring and being cared for earlier and I want to conclude this section now by discussing how sharing experiences, which may be described as empathetic relations, may also be the basis for a certain kind of kinship.

During the assessments I observed in the clinic, I was often surprised by unexpected ideas of kinship connections that were presented by patients. I suspect this was because of the genealogical assumptions that form the basis of clinical family history-taking which conceive connections on a biological basis, and not in any other ways. My observational notes of one assessment illustrate this:

‘Connor, Young man late twenties, comes in with an informant, Lisa, describing herself as family friend. Dr Gomez asks her who filled in the pre assessment forms, Lisa explains that his mother did the childhood scales and she did the current and adult ones. Dr Gomez asks Connor who was his Sister in Law. Both Connor and Lisa look at each other. Lisa says that she kind of is and explains that she was adopted by her uncle and aunt, who had a daughter, her cousin. This cousin has been Connor’s girlfriend for the last four to five years. Her uncle and aunt (her adopted parents) are family friends of Connor’s parents. That’s why, she said, family friends and sister-in-law on the forms. Dr Gomez asks how well she knows Connor. She explains that she herself has ADHD and so has her son. She also knows someone who is working in an Autism and ADHD service and because she had to care for her son, she knows a lot about it. Dr Gomez carries on with the assessment.’

After the assessment, Dr Gomez and I shared notes and discussed the confusion that we felt about the relationships that were described. As we worked out how Lisa was related to Connor, Dr Gomez explained that her input as an informant was not very useful because she had possibly only known Connor for about four to five years. He was also clear that the fact she had ADHD and a son with

ADHD was not relevant as far as his diagnosis was concerned, because there was no direct biological link between them. Even though the prototypical mode of diagnosing was used in the clinic⁹², for Dr Gomez, in this case, biological connections trumped family resemblance. As it happened, this differentiation was not crucial for Connor as, according to the assessment and scales, he was showing definite traits of ADHD and was diagnosed as such on the day. But from Lisa's point of view, and we can assume for Connor too, her personal experience with ADHD in herself and her son was an important link between them. It gave her the ability to recognise herself in Connor, and to see that they were sharing similar difficulties and ways of being. I came across the very same sense of relating to another when, as shown in Chapter Four, Clara described seeing herself in a stranger, who was more like herself than her own twin. It was as if the chaotic and unfocused ways she approached the world, something she shared with the stranger, were stronger than the resemblance and familiarity that she may have shared with her twin. Of course we could call upon the common adage that 'we can choose our friends, not our family' to explain that Clara felt a stronger link outside her family. But in ways that are similar to Weston's (2013) description for gay and lesbian couples, the concept of choice does not accurately describe what happens in these situations.

The stories that were shared with me all indicated a lack of choice in that moment of recognition; it was unexpected and similar to kinship knowledge as described above by Strathern (2005); impossible to ignore. Recognising kinfolk in this way, means recognising that one belongs to the same world and shares the same experiences of the world, some good, some bad. This seems a similar description of kinship to the one Sahlins put forward recently, defining it as:

'mutuality of being: kinfolk are members of one another, intrinsic to each other's identity and existence. Coming in various degrees and forms, such intersubjective relations of being, I argued, will account for performative or "made" kinship as well as relations of procreation.' (Sahlins, 2013:62).

Sahlins' definition has the benefit of being inclusive, emphasising that it is what people do together that makes them kinfolk. It also seemingly allows the space for biological kinship to be conceived on

⁹² Albeit not formally recognised as such as described in Chapter Five.

the basis of sharing experience of life, such as birth and death. Yet as becomes clearer further on, his argument is really that the biological representations of kinship are exactly that, *representation and therefore cultural*. In other words kinship is first and foremost cultural in that kin relations can always be imagined through cultural actions: '[w]hatever is construed genealogically may also be constructed socially... Kinship is not given by birth, since human birth is not a pre-discursive fact.' (2013: 3)

Through this lens, kinship is therefore culture and nature, but as nature is made through culture, kinship is all culture. 'Mutuality of being' suggests an idea of kinship as living with and caring for one another, and in that sense I find Sahlins' definition helpful. Yet Sahlins' proposition seems to be lacking in any of the negative things that may be part of kinship relations. When kinship is examined in the details of relations rather than as an abstract concept, then the dependency, oppression and vulnerability contained in the relations, are sometimes revealed (Strathern, 2014). The darker side of relationships was visible in the clinic as patients shared stories of abuse and hurt received from relatives and partners. Whilst I described cross-generational recognition in relation to ADHD earlier in this chapter, I also came across group members who were not acknowledged by their parents as having ADHD. On one occasion a member described, visibly upset, how his parents, who held very strong religious beliefs, did not accept that he had ADHD, thinking it was an excuse for laziness. This was despite his being formally diagnosed, and they disapproved of him taking the medication prescribed. He explained he had a strong attachment to his dad in particular, but was torn and thrown into turmoil by his father's demand to comply with church life, to marry someone from a church background and by his constant remarks about 'pulling his socks up' and 'doing something with his life'.

Overall the patients and support group members who shared their stories seemed to have a very fluid idea of kinship, one moment based on their biology and sharing bodily experiences with others, and the next moment based on their 'mutuality of being', their empathetic relationships. They called upon the biology of ADHD to describe how certain characteristics and traits ran in the family and, at the same time, claimed kin relations with strangers on the basis of resemblance and shared vulnerability. Cultural and natural kinship were experienced simultaneously in that their mutuality of being was

always discussed through their biology, and their reinvented biology was described in terms of belonging to a particular group. At home, in support groups and in the clinic, the ways of being that they shared with others were understood through physicality and the senses – the constant fidgeting, the intrusive mental restlessness. Biomedical explanations have clearly been very influential in shaping these understandings, bringing in their wake critiques of psychiatry for its role in the medicalisation of everyday life. Nevertheless, psychiatric classifications have provided for the support group members I met a way to recognise and be recognised and to actively engage in everyday life, through their own attempts to change and help themselves and their kin.

In this chapter I have explored the roles that kinship relations played in the diagnostic process for adult ADHD. By presenting the unexpected recognition of parents in their own children, I have described how it triggered memories of their own childhood, and that the child's present brings to the fore the adult's past. Whilst this kind of collapsing of time is a common experience of parenthood, I argued that additional elements caused Keith to experience a feeling of vertigo when recognising himself in his child. I have suggested a co-existing ascendant and descendant transmission, whereby parents are made by children through the diagnostic criteria as well as through an upstream flow of knowledge, and I have shown how parents simultaneously feel the reverberation of their biological responsibility for their child's affliction. For these parents, the reconstruction of their own childhood that is required in order to be diagnosed with ADHD is combined and comes together with the recognition of themselves in their child; in other words the kinship bond between parent and child becomes an extension of the diagnostic process. The kinship relations described were based on sharing the same medication, the same biology, but not necessarily the same genealogical descent. Through Strathern's concept of merographic connections I have explored how the separate parts of social kinship and biological kinship are kept together so as to make something new, a kind of kinship whose practice is dependent on this moment in time. To note the paradox of recognition (Rapp and Ginsburg, 2011b) that combines a positive force for becoming 'the person that should be' with the controlling force exerted by institutions, be they medical, pharmaceutical or educational, is also helpful to describe the entanglement of lived kinship. The paradox of kinship, as I saw it, was that it

functioned as much as a creative and positive force, a mutuality of being, as it figured as something that was controlling and to be endured. Bridget, Keith and others, who shared their stories with me, showed how they reformulated and re-imagined the biological explanations given to them, and in that process, how they reached out for new kinship relations. Rapp and Ginsburg (2011a, 2001) examined this phenomenon in the context of American families who transformed their lives as a result of living with a child with disability. They suggest that these new kinship imaginaries also extended outside the family unit to form the basis for wider societal acceptance of disability. How this was done by families has been hinted at by Bridget's widened kin relations to others who are not biologically related to her, but who nevertheless experience similar ways of being in the world. It is also indicated by Keith, Clara and others who experienced a moment of recognition with others in the support groups and thereafter sought to be recognised as belonging to a category as much as to a community. The process of teknonymy I described earlier, naming the parent after the child, therefore only applied in this way to some of the adults I met in the support groups and clinic. There were many adults who were not parents attending the groups, whose interest and orientation was not to think of ADHD through children. Yet, the role of regulating social relations, performed through the renaming process of teknonyms, as described by Bloch, is also found in the act of naming oneself and others in the support groups as 'an adult with ADHD' (Bodenhorn and Bruck, 2006) in order to be known and recognised by that description. In my next chapter, I want to explore how recognising and being recognised as being an adult with ADHD involves the extension of kinship relations through biological traits that are not necessarily genealogical. I describe how adults with ADHD build communities which are sometimes defined as neurodiverse, sometimes not, but whose members are always active in their attempt to make their different ways of being accepted by others.

Chapter Seven Extended kinship: diversity in the support groups

“My butterfly brain is a curse and a blessing”⁹³

In May 2011, Rory Bremner, a well-known comedian and impressionist, made a programme on BBC Radio 4 entitled *ADHD and me*⁹⁴. I first heard of this programme through Jack, a support group member who I introduced in Chapter Five. Jack felt a strong sense of identification with the stories the programme told which led him to first seek information about ADHD and then to find the support group. In this programme, Rory Bremner explained that as a child he was always on the go; he never could stay still, and whilst he was often called ‘scatty’ and ‘flibbertigibbet’ by his mother, he never had a sense that he was suffering from a condition. When a member of his family was diagnosed, he became curious and in this programme, he interviewed parents of children with ADHD as well as adults attending support groups. In his interview with a renowned psychiatrist, Rory Bremner explored some of the issues relevant to his personal life, especially those in which recognition played a central role.

Prof Taylor: “People with ADHD can concentrate very hard, their focus can be excellent. It’s more a problem of waiting, in organising things, thinking ahead, planning, all that kind of thing you can’t do quickly. And the hyperactivity side is acting without thinking, going into a situation before you fully understood it, jumping in with both feet, getting things wrong as a result, but sometimes getting it right as a result, in an interesting and creative way.”

Rory Bremner: “It’s just like you have been watching me on CCTV for the last 49 years, because I mean, this rings such bells with me... It frustrates me when I can’t concentrate, when my lines wander or I am not able to read because I am reading the same words again and again. So there is a weakness in that respect, but there is strength in another respect. In a sense, it makes it easier for me to spot analogies, to make illogical jumps to think in terms of

⁹³ Rory Bremner in The Express <http://tinyurl.com/kuxm2hv> Accessed 7/06/2011.

⁹⁴ The radio programme can be accessed here: <http://tinyurl.com/pnh2zen>. The programme and subsequent interviews by Bremner have been widely shared and discussed on neurodiverse and ADHD websites and blogs.

comparison, and to think laterally but in a comedian's sense, but I have absolutely no common sense whatsoever.”

Professor Taylor's description of inattention and hyperactivity was also implying that the effect of these symptoms may not always be negative. This was a familiar concept for Rory, as he provided his own description in terms of strengths and weaknesses whereby his difficulties could also give him an advantage for professional comedic purposes. On the one hand, he struggles to focus and remain attentive when reading texts but on the other, his wandering mind can lead him to make unexpected connections, an ability which is central to comic techniques.

Following his exploration of how ADHD might be affecting him, Rory asked a direct question of Professor Taylor:

Rory Bremner: “So do you recognise in me symptoms of ADHD?”

Prof Taylor: “I do, I do”

Rory Bremner: [laughter]

Prof Taylor: “I recognise the switching from one thing to another, very quickly, and I recognise you occasionally losing the thread of your thoughts, and pausing and retracting.”

Rory Bremner: “What happens? Do you see my eyeballs going off?”

Prof Taylor: “No, no, no, just in your speech and when you stop. And yes occasionally you're looking away and another thought has clearly come into your mind.”

Rory Bremner and Prof Taylor: [laughter]

Rory Bremner: “I am thinking – have I got enough milk in the fridge?”

The positive answer led to some laughter, some confusion too as Rory wondered how ADHD could be observed in him, and in what kind of physical signs. To some extent ADHD was observable, not through rolling eyes as Rory suggested, but as Professor Taylor recognised and interpreted, more

through a loss of attention and certain speech mannerisms. In a voice-over conclusion to the programme, Rory Bremner returned to considering how ADHD affected his life:

Rory Bremner: “I quite like the fact that I am a bit scatty sometimes, I quite like being me, but there are times when I hate being me. What is interesting is that when I started out doing this, it was because I knew from the experience of other members of my family, the kind of effect that ADHD can have. And I felt there must be thousands of families who really struggle when they have people in their extended families who have this disorder. And the rest of the world is saying, “oh well it's bad behaviour and it's bad parenting or whatever”, and it isn't. It's taken me five decades to get recognition that I may have a medical condition.”

The radio programme became very popular on ADHD and neurodiversity websites and blogs and captured the central role that recognition played in the lives of the people I met. In the conversations I participated in and witnessed, it was this term, recognition, that was used to describe the process people went through, in relation to themselves and to others when grappling with their experience of ADHD. Chapter Six asked what role kinship might play in the diagnostic process by focusing on familial relations, and it showed that recognition was one element of kinship in the way that relations require an acknowledgement of the other, recognising the connections, be they biological, moral or otherwise. Kinship bonds outside the filial connections were hinted at in the clinical assessments I described earlier, and this chapter will examine how, in the process of identifying ADHD, the people I met described their relationship with strangers in kinship terms. Here, I am concerned with relations that people forged outside their immediate families, not in the realm of reproduction, but in the world of work or other institutions and, more specifically, in the support groups I attended. Recognition in this context acquired a political connotation that involved mutual acknowledgement between members as well as assertions of rights in the context of a contested disorder. The links between recognition and identity politics have been masterfully critiqued (Taylor, 1994 amongst others) but my interest, guided by my participants' discussion of these issues, is in the movement from 'recognition' to 'being recognised'. In my understanding, notions of identity and associated politics emphasise the activism of groups and social movements, whereas the term 'recognition' allows for a

more subtle examination of individuals' and groups' relations with the world. The need for ADHD to be recognised – or not – was part of the debates, arguments and controversies that circulated in the media and academia at the time of my research. Rory Bremner echoed many of the people I met as he explained that he had waited five decades to have his problems accepted and to be offered treatment; his radio contribution to the topic can be understood as a kind of activism towards the recognition of ADHD.

In this chapter I want to examine how support group members relate to two dominant perspectives of ADHD that influence its overall conception. On the one hand there is the critique of medicalisation which denounces the over-involvement of medicine in everyday life. In this version of ADHD, adults, parents and children with symptoms of inattention or hyperactivity are experiencing 'problems that used to be an expected and tolerated part of life [and] are now diagnosed and treated as mental disorder' (Frances, 2013: 82). In other words, these are not real symptoms and ADHD has only recently been invented. In this way, theories of medicalisation run the risk of claiming one single reality for ADHD and thereby leading to the experiences of many people being ignored.

On the other hand, a movement has developed in the last two decades that has promoted the idea of 'special differences' and reimagined the political recognition in health, and autism in particular in terms of the acceptance of difference and of diversity, that is, neurodiversity (Ginsburg and Rapp, 2013; Panitch, 2008; Silverman, 2011; Solomon, 2010). In this version, ADHD is not considered a disorder but an alternative way of experiencing the world within 'the limitless potential and neurodiversity of the human mind' (Solomon, 2010: 241).

I found that in the support groups neither discourse was totally accepted or rejected and that people did not entirely identify with either perspective, yet they drew on elements of both in their discussions. For example support groups showed ambivalence toward pharmaceutical treatments and their side effects but members explained that, accompanied with other support, medication may be necessary to bring change in one's life. Similarly, some people described to me how the concept of 'neurodiversity' helped in emphasising the creative and positive aspects of living with ADHD,

sometimes described as a gift, but they were also aware that such a description can obscure and undermine the difficulties they experience.

Following a fuller description the remainder of this chapter will explore how people's understandings are shaped by these perspectives but that when used on their own, neither the medicalisation critique nor the concept of 'neurodiversity' succeed in fully capturing the experiences that people described. In particular, I will suggest that the use of the term 'neurodiversity' could be seen as an attempt by patients and group members to reclaim their experience and distance it from some of the more reductive representations of neuroscience, popular and medical critiques of ADHD. I look at how this re-appropriation is played out within the groups through recounting the stories that individuals offered of the successes they had achieved because of ADHD rather than despite it. Thus, I enquire into the kind of bonds that are formed on the basis of sharing a particular way of evolving within the world, such as being forgetful and disorganised, and I ask, in the context of adult ADHD support groups in the UK, if neurodiversity can represent a form of extended kinship. I explore how sometimes the empowering force of the word 'neurodiversity' might be found in the notion of gift that is associated with it and I suggest that success, achievement and productivity may be neurodiversity's counter-gift. As many people told me, the gift of neurodiversity was perceived with ambivalence because of the obligation and the exhausting work required for transforming their idiosyncrasies into positive actions.

I found that the language of neurodiversity was often substituted with that of kinship. For example, notions of family, belonging, reciprocity and inclusivity as well as terms used in groups such as, caring, sharing, we, us, brought an emphasis on the grouping of people together, on their actions together, rather than on their neurone activities. I conclude this chapter by suggesting that as the notions of being 'wired in an atypical way' (Ortega, 2009: 427), of 'brainhood' (Vidal, 2009) and of 'being neurodiverse' were tweaked and adapted within the support groups and at times individualistic concerns were augmented, extended and enacted in caring relationships which resembled kinship bonds. My account does not seek to romanticise the relations formed in the support groups, and just

as in filial kinship relations, the web of obligations thus created in the groups (Stack, 1975) is as much about inclusion and exclusion, as one group member's experience showed.

Although Rory Bremner felt able to tell the world that his public success was related to ADHD, many support group members felt unable to take that step, feeling too vulnerable to do so. In other words the stigma associated with ADHD felt too powerful for individuals to 'come out' and risk being denied recognition. Not being recognised as suffering from a genuine disorder is still a very common experience discussed in the support groups and I want to turn to this topic now. As Dumit (2006) described so accurately, recognition by institutions and their gatekeepers is required if one wants access to treatment and, when it is denied, it is more than resources that are refused. To deny recognition is to question the validity of the suffering itself, with the implication that the person is faking an illness or even malingering. At least this is how some of the support group members described how they felt when they were faced with the situation. For most, the first port of call in the UK in seeking recognition is their GP and, as ADHD is considered a medical condition, only a medical doctor's diagnosis can lead to the prescription of treatments (UKAAN, 2014), or to the release of higher education resources (SASC, 2013)⁹⁵. There is evidence that a negative encounter with a GP regarding adult ADHD is a common experience (Ginsberg et al., 2014; Matheson et al., 2013). In the support groups, GPs were described as being unaware that the formal medical diagnosis had been extended to adults, and that they needed to be educated by their own patients. At other times, people described their GPs as 'sceptical', saying that ADHD was 'an American disease' or that the individual was far too successful professionally to consider that there might be anything out of the ordinary. Voices contesting the validity of the diagnosis of adult ADHD and portraying it as a merely social construction are common in the UK media and, like the rest of us, GPs do not work in a vacuum. As Rafalovich showed, the general scepticism towards and controversies that surround ADHD influence the way practitioners approach an unfamiliar diagnosis (2005). I found a similar sceptical approach amongst some of the clinicians attending the training course I described in Chapter Two; they suggested that ADHD was not seen as a sound medical classification. Such distrust is

⁹⁵SASC Guidance <http://tinyurl.com/nngrkzz> Accessed on 13/12/14.

partly due to the effect of the broader discourse exposing ADHD in terms of the medicalisation of everyday life, the side effects of medicalisation as it were, which in turn made it more or less likely for the support group members I met to be given the recognition they sought.

The side effects of medicalisation

Ivan Illich (1977) is often given credit for coining the term ‘medicalisation’ in the 1970s, but there were others, such as Zola (1972) and Szasz (1972) who also exposed the intrusive power of medical encroachment into everyday life. More recently, authors such as Conrad (1992; 2007; 2000) and Moynihan (2002; 2012) have added to this critique such concepts as disease-mongering and they have identified the role of marketisation and commercialisation as engines of medicalisation. At face value, the term ‘medicalisation’ expresses the process of turning a problem into a medical concern, and arguably, visiting one’s GP rather than, for example, a priest in order to have a health problem identified, diagnosed and treated is exactly that. But the 1970s zeitgeist of critiquing authority within which the term appeared explains why, from the start, the term was used as a social critique of and a resistance to the medical establishment. Medicalisation in this sense is to be understood as if in between speech marks, suggesting that something else lies behind this word, and that using it would reveal something hidden. The historical context of the term’s emergence is also the reason for its limitations, as many things have changed since the 1970s – medicine for one thing and patients for another. The premise that patients are passive subjects onto whom medical treatments are imposed is arguably redundant, as patient’s engagement in healthcare bears no resemblance to what it was 40 years ago. As Rose explains:

‘Medicalisation implies passivity on the part of the medicalised. One example is when people claim that disease-awareness campaigns persuade potential customers to “recode” their unease and dissatisfaction in the form of a diagnostic category to extend the market for pharmaceutical products and the remit of medical practitioners. With notable exceptions

(children, prisoners, people deemed mentally ill and admitted to hospital under compulsion), doctors do not force diagnostic labels on resistant individuals.’ (2007: 702).

As I have described throughout the previous chapters, support group members are anything but passive in the way they relate not only to each other, but also to their doctors, health commissioners or other health officials. Similarly the clinicians I met in the clinic did not harbour any plans to recruit patients against their will. The same could be said of the pharmaceutical company representatives who I met in conferences. Yet medicalisation, in the form of denouncing the role of the medical and pharmaceutical establishment in imposing their will on the rest of us, is now part of everyday language and, as I have suggested, it affects the lives of people directly when recognition is denied⁹⁶. Furthermore, by locating the responsibility for these seemingly oppressive actions on the medical and pharmaceutical establishment, the term medicalisation obfuscates the role that we all play in engaging with this process. The term becomes a slogan, a rallying cry to denounce the wrong doing of a particular kind of people. As Stengers suggested in the context of disease-mongering (Nathan and Stengers, 2004) and capitalism (Pignarre and Stengers, 2005), denouncing is not only ineffective, but counter-productive. It is not effective in the sense that, if denouncing the harmful role of Big Pharma or the medical establishment were to make a difference, it would have done so by now, after decades of accusations. It is also counter-productive to blame medicalisation for the over involvement of medicine in our lives because ‘it can give the impression that there is a [big capitalist] machinery, constituted once and for all and that over-determines everything’ (2005:42 *my translation*). If the process of medicalisation is so easily defined and precisely located in the medical and pharmaceutical establishments, then it suggests that it could easily be undone and reversed. Consequently we are moved further from examining the details, variations and different ways that we implicate medicine in our lives. Stengers also points out how the process of denouncing disease-mongering also denounces the activity of groups of people actively working to increase resources, or to introduce new treatments for contested illnesses:

⁹⁶ In defence of the medicalisation critique of the 1960s and 1970s, it would have been difficult to anticipate that patients would turn themselves into expert consumers in the following decades and assert choices and claims.

‘Thus, the claims of these lobbies can be described as destabilising the landscape of health provision, their passionate interest can be perceived as a problem. In brief, the fact that incompetent individuals are mobilised and meddle in what does not concern them, can be denounced. And the outcome may well be that the definition of the illness must rest solely in the hand of the clinicians’ (2012: 191 *my translation*).

Denouncing the role of Big Pharma and the medical establishment also has the consequence of posing questions about the motivation of individuals and activists in seeking recognition. Their interest and their role in participating in ‘informal alliances’ becomes suspect; (see amongst others Moynihan and Henry, 2006). This is what I have called the side effect of medicalisation: a health warning that medicine may not be good for individuals that has, in itself, an unexpected and harmful effect as people are not able to get recognition of their suffering⁹⁷.

Instead of looking at this unidirectional process, flowing from powerful institutions towards passive patients, both Stengers and Rose encourage us to examine the entangled relations involved in our engagement with medicine, and to accept our own involvement in seeking treatment and medical explanation, as ‘[medicalisation] has made us what we are’ (Rose, 2007: 700). Rose summarises this in the following way and his example of depression can easily be substituted by the experience of my participants:

‘It is this process of mutual construction, the intertwining of products, expectations, ethics and forms of life, that we observe in the development and spread of psychiatric drugs such as those for depression. This process is not a brute attempt to impose a way of recoding miseries, but the creation of delicate affiliations between subjective hopes and dissatisfactions and the alleged capacities of the drug. In engaging with these formulae in inventive ways, individuals play their own part in the spread of the diagnosis of depression and shaping new conceptions of the self’ (Ibid.:702).

⁹⁷ None of the support groups I attended had any direct connections with pharmaceutical companies, financial or otherwise; two of the groups received funding from their local council and raised funds through charity work. The patient organisation AADD-UK had no connections with pharmaceutical companies and no regular funding of any kind that I was made aware of. ADDISS received grants from the Department of Health and educational grants from pharmaceutical companies towards organising their national conferences.

Medical and health advancement are naturally attractive to us; why wouldn't we hope for less suffering or an improved sense of well-being? Of course these advances and improvements are put forward, advertised and recommended, but not only by drug companies or doctors. We all contribute in this process, discussing and sharing our health concerns and advice with our families and colleagues, attempting to discern the benefits and disadvantages of particular treatments. Mostly, we engage in a process of 'self-diagnosing', trying to make sense of the pain and discomfort, or to paraphrase a well-known quote from René Leriche, attempting to decipher the noise of our organs that threatens our health⁹⁸. Canguilhem used this quote and the work of Leriche in his study of the normal and the pathological in order to put forward the notion that 'health' is something that concerns the patient and that illness is the concern of doctors. Canguilhem states:

'Thus it is first and foremost because men feel sick that a medicine exists. It is only secondarily that men know, because medicine exists, in what way they are sick.' (1991: 229).

The point made here is that it is only through the relations with a patient that a clinician can consider something pathological; 'the pathologist's intention is not that his object be a matter without subjectivity' (ibid.: 229).

In his further reflections on the topic of the normal and the pathological twenty years later, Canguilhem extended the proposition that sickness starts with the patient, by examining how in health, we are made aware of norms through their opposites: 'Norms are recognized as such only when they are broken' (1991: 209). It is only when our health is threatened that we understand what it was, hence 'it is not paradoxical to say that the abnormal, while logically second, is existentially first' (1991: 243). Canguilhem's rich and dense text has much to offer for a conception of health as a dynamic process, when 'to be in good health means being able to fall sick and recover, it is a biological luxury.' (1991: 198). I will return to this aspect of his thinking, defining health as the ability to adapt and create new forms of life further on in the chapter, but for now Canguilhem can help us understand how noting the deviance in our state of health is also part of our recovery.

⁹⁸ 'La santé, c'est la vie dans le silence des organes'. (Leriche, 1936: 6)

In her research on self-medication, Fainzang (2013) asks the pertinent question: when an individual self-medicates, who does the medicalisation? She notes that medicalisation is mostly described as an ‘act of intrusion into the lives of individuals’, that is doctors impose their solutions and remedies onto people's problems. She argues that this concept of medicalisation is limited because people engage in treating their ailments and problems with pharmaceutical medicine without being directed by a doctor. At some point the individual notices a problem, ‘a bodily sign [that] is converted into a symptom, whereas the symptom is in turn converted into a sign of a pathological state, leading to the need to medicalise the problem’ (ibid.: 495). The transformation from symptom to pathological sign is not made by individuals working in isolation from other influences, and some inputs may be more invasive than others⁹⁹. But it is still normally through an initial recognition and identification of a sign that something is not right that an individual reconceptualises the problem as a symptom. It may be because of its duration or its persistence, or it may be because of its acuteness, but the symptom is then deemed to be pathological and requires acting upon. Fainzang suggests that the norms that control what is pathological are not confined to the medical establishment, as Canguilhem suggested, but that individuals set their own norms that may be ‘juxtaposed with - or possibly superimposed on- those established by biomedical discourse...’ (ibid.: 495). In other words, choosing to access medication, with or without consulting a doctor, requires first conceptualising the problem as requiring medical intervention, that is self-medicalisation.¹⁰⁰

In this way we could say that medicalisation, taken at face value as the process of involving medicine in our daily lives, is and has always been attractive to us as it offers help towards recovery. Our present situation in the 21st century, with the proliferation of interventions, pharmaceutical and otherwise, may have given a darker shade to this lure and ‘medicalisation’ as a social critique has set about warning us of the risks. But one cannot be without the other. That is the paradox of medicalisation in that it provides undeniable benefits whilst at the same time changing us in the

⁹⁹ ‘Direct to Consumer’ advertising of medication in the USA comes to mind. See Dumit (2012) and Singer and Baer (2008) among others.

¹⁰⁰ Fainzang concludes that ‘self-medication is the acting out of self-medicalisation’ (ibid.: 500). We could also talk of a de-medicalisation process in which patients interrupt or stop their treatment as some support group members did, as I show in Chapter Eight.

process, taking us into a perilous unknown. It is both creative and controlling, limiting access to alternatives and creating new forms of life. Crucially this process is undertaken in relation to others, in a network of relations, between doctors and patients, pharmaceutical representatives and scientists, between individuals in the support groups. Contrary to the argument that medicalisation contributes to ‘the individualisation of social problems’ (Conrad and Schneider, 1992: 250), medicalisation can be understood as a collective process which is both reliant and dependant on relations. Without the encounters and exchanges between all the actors involved in this process, including virtual encounters through internet forums, medicine would not exert the influence that it does on individuals seeking relief. The situations I came across in the clinic and the support group suggested that ADHD is made across both sets of sites by medical and lay experts and that they are equally conflicted about involving medicine in the details of people’s lives. I have found clinicians, like Dr Goodman or Warren, to be cautious in the use of labels and aware of the potential negative effect of diagnosing. Similarly, I met members of support groups, like Maria, who was hoping to be diagnosed yet did not want pharmaceutical treatments. Without denying the positions of power that continue to be contested, I am suggesting that the polarisation that may be found theoretically between anti- and pro-medicalisation was not so evident in the practices found in the clinic and support groups.¹⁰¹ I want to turn next to a recent concept, neurodiversity, which represents an unexpected move in involving medicine in everyday life, in that it suggests biological and neurological conditions that are identified by medicine yet for which no cures are sought; in other words medicine is called upon to detect and initiate a process of social acknowledgement and, ultimately, of empowerment.

‘Diversity is not disease; the anomalous is not the pathological.’

(Canguilhem, 1991: 137)

Neurodiversity is a concept developed in the late 1990s by advocates and self-advocacy groups who have reconsidered disabilities such as dyslexia, ADHD and autism figuring them as acceptable and

¹⁰¹ The methodological decision to work across clinical and support groups has influenced my approach to these two perspectives. By holding together sites that are often kept apart, similarities became apparent that would otherwise have remained invisible.

seeing them as ‘alternative forms of natural human difference’ (Armstrong, 2011:8). Spearheaded by activists with autistic spectrum disorder (Singer, 1999)¹⁰², the term rapidly grew to encompass a range of neurological conditions such as Asperger’s syndrome, ADHD, Dyslexia, Dyspraxia and Tourette’s syndrome. As with other sciences, neuroscientific concepts have influenced the way notions of selfhood are imagined and they have foregrounded how biological and natural metaphors may be applied to the workings of the brain (O’Connor and Joffe, 2013; Vidal, 2009; Weisberg et al., 2008). Thus, the brain is compared to an ecosystem that adapts and changes like a ‘unique rainforest, teeming with growth, decay, competition, diversity and selection’ (Edelman 1992, quoted in Armstrong 2011:10). Following Carrithers (2005), we can consider how the word ‘neurodiversity’ may be used by activists for its rhetorical force as it contains implicit references to both scientific and cultural concepts. Through its wide circulation in the media, films and academia, the term ‘neurodiversity’ spreads a message of change, of departure from concepts of disability towards ideas of creativity. It is used by activists, in the broad sense of the word, to advance the idea that a new era has come, in which brain sciences can lead to a more tolerant and accepting society. The circulation of the word also suggests its participation in making and forging communities based on the principle of sharing the same neurological make up, of being the same in being different (Bagatell, 2010). Thus the rhetorical work of the term ‘neurodiversity’ combines a message for tolerance based on science and the possibility for kinship bonds which are based on being different.

The emphasis in the neurodiversity literature is laid on the positive elements that diversity and plasticity bring to the lives of people with the conditions listed above. Just as in the rain forest, diversity is an asset; it nurtures possibilities, variations and different versions of entities that enrich the whole system. Neurodiverse activists also suggest that in order to turn this internal diversity into an advantage, the surrounding environment must be adapted and moulded, something described as ‘niche construction’, a notion borrowed from biology to describe the work of an organism in adapting its environment to its needs. The suggestion that adaptation is taking place within an active and changing milieu, not in relation to ‘a static, fixed or normal environment’ (Armstrong 2011:17)

¹⁰² For further details on the history of the neurodiversity movement see Baker, 2011; Cascio, 2012; Orsini, 2012; Ortega, 2009; Silverman, 2011; Solomon, 2010.

echoes Canguilhem's definition of health as dynamic, which I referred to earlier. The interaction and interdependence between organism and environment was, in his view, crucial because life is not only changed by its milieu but makes it its own environment too, what he called 'biological normativity' (1991:228). '[T]he organism is not thrown into an environment to which he submits, but he structures his environment at the same time that he develops his capacities as an organism' (1991:284). In other words, norms are not fixed but are fluid and changing, and normativity becomes an activity, not a state (Rabinow in Canguilhem 2000). Such a concept speaks directly to the concerns of the people I met in the support groups as they described to me their constant activity in relation to norms, including social norms, that they experience as restrictive throughout their lifecourse. The norms around them change and as I will describe, if they can adapt to this fluid environment and adapt those norms according to their own ways of being in the world, then despite being 'untypically wired', they can live not only 'normal' lives, but successful ones too.

A psychiatrist specialising in ADHD in a private clinic told me of two of his patients, both well-known comedians, who were taking stimulant medication to relieve some of their symptoms some of the time. One was taking stimulant medication during the day so that he could focus effectively on his chores, administrative tasks and even his writing but, he would never take medication prior to performing as he explained that he wanted the benefits of his excitability. The other man did the reverse and always medicated prior to going on stage in order to help him deal with the nervousness, anxiety and over-excitement of performing. There are more examples in the public domain, of athletes in particular who, whilst not apparently taking stimulants as these are banned for use during competitions, also find ways to make their excess energy an advantage¹⁰³. I would suggest that this is a kind of re-appropriation of ADHD whereby what has been described in medical and moral contexts as a deficit, a lack or an excess, is reclaimed as a different way of being that can be positive, given the right environment and nurturing. As I mentioned, the language of neurodiversity calls upon the notion of niche construction and, as well as ecology, self-help literature makes numerous references to

¹⁰³ Ashley McKenzie, Bronze Olympic Medallist, appeared at the ADDISS conference 2013 and UKAAN conference 2014 to share his experience of living with hyperactivity and taking alternative treatments to stimulants.

business endeavours. The character of the entrepreneur is often used as an exemplar for the art of turning a deficit into a productive result (Hartmann, 2002; Martin, 2000).

I came across the model of the entrepreneur in some groups more than others, and saw how it sometimes created tension between group members. On one occasion, in April 2013, a professionally successful individual identifying himself as having ADHD presented a suggestion to set up a crowdfunding venture. He described the project as social innovation which was intended to “make people with ADHD the drivers, not the passengers, in their lives”. The aim was to raise money to fund a research project and services that ranged from a directory of private ADHD specialists (‘Docfinder’, that would “beat the long waiting time in the NHS”), to a mentoring project for offenders within prisons. As the presentation went on, the energy of the presenter was visible and it was clear that the project was ambitious. The reaction of the group was mixed and, whilst some were clearly impressed and wanted to be involved, others were questioning the presenter’s financial motivations. Terms such as investment, shares and funds were not well received by some of the members, and a tense discussion ensued as to the value of support, and how people should help one another. On another occasion, I had a conversation with the presenter of the project and, with the same energy and excitement, he started telling me how his social enterprise and crowdfunding project had been inspired by a Danish individual. When his son was diagnosed with Autism Spectrum Disorder (ASD), Thorkil Sonne started a charity organisation, Specialistern, in order to provide work suited to adults with ASD by utilising their skills. As Mr Sonne was an IT manager, the work on offer was IT related ‘with technically oriented tasks and jobs, such as data management, software testing and quality control’ (for more details see Wareham and Sonne, 2008). As my interlocutor saw it, individuals with ADHD have an even wider range of skills to offer: He said, “knowledge is not the problem with ADHD, it is turning it into action that is difficult. It is also unfortunate that most ADHD people don’t get on with each other, as you saw when I did my presentation.” Whilst I agreed with him that the group was heterogeneous in its membership, it was not clear to me that the disagreement I witnessed was related to ADHD characteristics. Instead it seemed that, amongst group members, conceptions of self-help and enterprise differed.

What I observed in the support groups, in the main, was another kind of re-appropriation, not one based on turning deficit into capital, including social capital, but something that was less visible, less assertive and, most of all, coloured with ambivalence. The literature and websites discussing neurodiversity use powerful language to emphasise a hidden potential in ADHD that can be turned into success: ‘unlocking the power of ADHD’, ‘celebrating the opportunities’, ‘tapping the inner muse’, ‘I will be the best me I can be’, ‘succeeding with ADHD’¹⁰⁴. As many of these authors explain, there is a great deal written about ADHD and other neurological disorders that lists the problems, the difficulties and impairments. It is therefore important, they argue, to provide another vision of and perspective on ADHD. Neurodiversity, when presented in this way, is directly influenced by neuroscientific concepts and language; descriptions of natural variations in the neurological make-up of humans are discussed as though these have a direct relation to the special abilities experienced by individuals. Whilst the material quoted above is all written in the self-help style, that is, providing explanations, guidance and tips for readers to make changes to their lives, the articles are written by individuals who identify themselves as neurodiverse, and these writers often provide an abridged version of their own stories. As Hacking (2009) suggests when discussing autistic autobiographies, the stories told in this way have less to do with describing the life of people with ADHD than they have to do with creating a new language, albeit an ordinary one, to enable the rest of us, neurotypicals, to grasp the experiences of the neurodiverse. The distinction is important for neurological conditions, Hacking continues, because if we read these texts as straightforward descriptions of a way of being, then many other autistic or ADHD individuals with either less or more severe impairments will not recognise themselves in them. The concept of a *spectrum* for autism is also valid for ADHD and is accepted, in that some individuals will experience some but not all of the ADHD symptoms and to varying degrees of severity¹⁰⁵. But in contrast to the autobiographies Hacking is discussing, the language used in the narratives of adult ADHD self-help literature stems from neuroscientific discourse and hardly qualifies as ordinary language. This is quite an important

¹⁰⁴ (Kelly, Ramundo, and Ledingham, 1997; Levrini and Prevatt, 2012; Potgieter, 2014; Roberts, 2012; Weiss, 1997).

¹⁰⁵ ADHD is described in the scientific literature as ‘the extreme and impairing tail of continuous traits of inattentive and hyperactive-impulsive symptoms and behaviours’ (UKAAN, 2013). Thus individuals may have more or less of the symptoms and be more or less impaired than others.

distinction. If we take Hacking's main point, that a language is being created to describe the experience of being neurodiverse which in turn affects the way neurodiverse individuals live, the now well-known looping effect, then how is this played out within the adult ADHD support groups I attended?

The gift of neurodiversity

In one of the support groups I attended, a young man in his late twenties had a motto of his own to describe his relation to ADHD. He called it 'the 3D rule: not a Disorder, not a Disability, just Different.' He used it regularly in the course of the group sessions and just like a slogan in a rally, it had a political ring to it, saying what ADHD wasn't and what it was. Yet in conversation with him, I was surprised to find out that he was not so familiar with the neurodiversity movement. Instead he explained that the 3D rule was something he had heard somewhere and he liked the fact that he was different from other people and thought he should not be stigmatised for it. In this conversation, he referred to the group of people around him as untypical, and as I asked him if he meant neurotypical or neurodiverse, he looked bemused for a moment and told me they were just different to other people. The more I attended support group sessions the more obvious it became that members did not often use the term neurodiversity or its derivatives. At most it was used to describe the difference between a variation, a divergence from the norms, and it allowed for discussions of normality and abnormality yet without using such loaded terms, something quite important if one finds oneself described 'abnormal'. But as this person put it, being different did not necessarily have to be associated with the brain; being untypical can replace being neurodiverse and still denote a commonality with others. I found that the word neurodiverse was used not for representing a different neurological make up, or to explain particular behaviours, but to describe a group of people who felt similar to each other, yet who were, as a group different, in contrast to others. Furthermore, when in the support groups ADHD was defined by the benefits it can provide, it was usually with ambivalence just as when Rory Bremner described his brain simultaneously as a curse and a gift. I introduced Ray

in an earlier section of this thesis, when he described how being outside of the norm, which he called his 'bounciness', helped him to be where he was. When I asked him if there were positive aspects of having ADHD, he responded:

Ray: "I retired at the age of 36, I am a millionaire, I was a millionaire at 30, I reached a stage where I was increasingly unhappy doing my job. I was at the point of burn out, which is something ADHD people do anyway, but I stopped working two years ago, yeah I don't need to work, but actually I reached the point where work is important, for the purpose it gives, I am a lot more ADD when I am not working. I put down my success in business... I don't consider money as a major success and people are very funny about money success, but I would not have been in my [financial] situation if I had not been able to tune in when I find something interesting and focus. Is it a pathology?"

Claude: "What do you mean?"

Ray: "So would you define somebody in my situation as having ADHD, when it can be argued that I am who I am, I am where I am and I have achieved what I have achieved largely due to the characteristics that are on that DSM list. And if they are not having a negative effect, then is it a disorder at all? You know what I mean?"

The reason why Ray had been successful, he told me, is linked to his ability to hyperfocus and to have extra energy, that is hyperactivity. Yet it is also why he is not sure that this can be a disorder if he is not suffering any negative effects. In a roundabout way, Ray echoes the neurodiversity literature I referred to earlier, as unleashing his potential and constructing the right niche and environment to suit his way of being. Yet in the many hours that we talked, he never used the term 'neurodiversity', even though I am sure he was aware of it. Nevertheless, it seemed that Ray had doubts that ADHD as a diagnosis was helpful; similarly he was not sure that its symptoms could be useful. His ambivalence towards the psychiatric term and its negative depiction extended to the overtly optimistic vision of neurodiversity. As I asked him if he had experienced ADHD symptoms in his childhood he responded:

“As a child in school I was very disruptive and I was diagnosed as gifted, my IQ was around 150-160. My hyperactivity was attributed to being bored, so I had to get up and do something, entertain myself and get into trouble. But it’s not really much of a gift. It’s a gift I would happily leave under somebody else’s Christmas tree. What gets me, is when I come to the group and see some very dysfunctional people, and I can see some of them in me, and the characteristics that were helpful to me are eating these people apart.”

Ray concluded his interview with me by expressing his ambivalence in the following terms:

“If you take anything from this, is that I am still dazed and confused, about the diagnosis, the identity, the tribalism and more or less what constitutes a disorder, because at a lot of levels ADHD is associated with success, but success which is a small margin away from failure.”

Sonia¹⁰⁶, who attended a different support group, also talked to me about her mixed feelings towards the creativity and gifts that are associated with ADHD through the discourse of neurodiversity. She was a professional performing artist, successful in that she had built a career, making recordings and going on tour, even though, as she explained, she felt she should be doing better. When I met her she had recently started attending the support group, and during the year of my fieldwork she attended all the sessions without fail, becoming an active member of the group. In an interview we discussed how she had been diagnosed a few years earlier when already in her early forties and how prescribed medication had helped her with the chaos and disorganisation in her life. When I asked her if she felt that ADHD had anything positive to offer in her life, she responded at length:

Sonia: “I probably would get rid of it [ADHD] if I could, because it causes more problems than it causes goodness. My theory about all that, is that, errrrm, you know, necessity being the mother of all invention. The quality of the problem that we carry with us means that we get inventive, we develop. I don't think ADHD automatically brings along extra creativity or that kind of thing. We need those resources of improvisation. This was true when I was quite young, if I left my homework too late, then I had to think of a way, and I got quite clever at

¹⁰⁶ I met Sonia on ten occasions in support group sessions and in an interview lasting approximately one and a half hour. We also met on two occasions during patient organisation conferences.

doing that, because I had to. So we put ourselves in a position where we learn skills and tricks because we leave ourselves in the position where that is all we've got. Maybe the fact that we are distracted means that we do make connections that other people may not make, but I don't think that we are superwired for that. So maybe that would be something I would miss, but frankly I don't think I would."

Claude: "You are working in a creative industry, but you don't think of ADHD in terms of creativity?"

Sonia: "No, I mean, I remember reading about all that before [I was diagnosed], and I wondered if I would want to stay un-medicated while performing. But that went out of the window, because with the medication I could be more focused and more in the role. So it helps me be less distracted, as long as I am not over medicated. Because without meds it is too scatty so even brainstorming is no good, because what's the point of having good ideas if I can't hold on to them long enough to use them. No I think this creative special thing, is over-inflated a lot. There is nothing wrong in highlighting that, you know, I like my personality, ADHD and all, but I want bigger things. I want to make things, may it be music or changes, but I feel trapped on a kind of treadmill of effort that does not get me anywhere."

As with Rory Bremner, Ray and others, Sonia felt that if there were positive aspects in having ADHD, such as the unusual connections and the inventiveness, these were marred by the toil and hard work required to deal with her other experiences of ADHD. If ADHD was a gift, then for Sonia and Ray, its cost was too high and what came in exchange turned it into something they did not want.

In asking what kind of a gift this might be, I make reference to Marcel Mauss and his seminal work, *Essai sur le don* (1923) which explored the many facets of social practices associated with the exchange of gifts; his work showed that a gift is accompanied with an obligation to reciprocate. In the first instance Mauss tells us in his examination of Germanic law that, through particular

contractual practices associated with gages and guarantees, the word ‘gift’ in German acquired the double meaning of gift and poison, denoting that there is an intrinsic danger in the thing given. In Ray’s case, being a child with a gift was experienced as toxic. As another member described it, ADHD was ‘polluting him’, it had harmful effects, such as the inability to keep still and focus, that got him into trouble and turned the gift into something he did not want. Seen through this lens, neurodiversity is both a curse and a gift.

I want to briefly explore what kind of gift neurodiversity might be and how the gift might be contained in the word itself. As I described above, ‘neurodiversity’ is a concept that has been circulating widely in the western world and it has accumulated connections with different communities such as autism, ADHD, Dyslexia, Asperger’s and more. I have suggested that one of the rhetorical forces of the term is the portrayal of creativity and adaptability and these attributes are often coupled with the word gift, as in ‘the gift of neurodiversity’. Can the circulation of words have the same characteristics as the exchange system of goods described by Mauss and others? Might we see in the rhetorical force of ‘neurodiversity’ an equivalence with the life force (*la force des choses*) that Mauss described in the *Hau of the Maori* (2012)? Just as goods gain value with every exchange, ‘neurodiversity’ circulates and confers an increased sense of empowerment for those that use it to describe themselves, offering self-worth where previously there was deficit. Following Mauss’ proposition that the gift consists of ‘three obligations: giving, receiving, repaying.’ (ibid.: 142) in order to close the circle of exchange, one has to ask – what may be given in return for the concept of neurodiversity? One possible answer, can be found in the descriptions contained in the self-help literature mentioned above, where achievement, success and performance become the counter-gifts for the rhetorical force of ‘neurodiversity’. Thus one is obligated to make the most of the gifts given, “to be drivers, not passengers”. And just as the denial of reciprocity in the exchange of goods, described by Mauss, brings dishonour and loss of face (ibid.: 151), the failure to construct an ecological niche where hyperactivity or distractibility are turned into assets and skills brings shame and stigma.

Situating responsibility onto individuals for their successes and failures within the context of societal productivity is a feature of neoliberal ideology which the combination of the terms ‘neurodiversity’ and ‘gift’ seems to endorse. The assertion made by ‘neurodiversity’ for tolerance and acceptance of different ways of being also promotes self-improvement and progress as part of the neoliberal vision of rational, self-reliant and productive citizens. The limits of the ‘politics of neurodiversity’ have been critiqued by Runswick-Cole who showed how ‘neoliberalism tolerates those who can mimic the neoliberal ideal type’ (2014: 1126). She has also suggested that the limits are intrinsic to identity politics’ reliance on making categories of ‘us’ and ‘them’. The discourse of neurodiversity associated with success and gifts that I have discussed provides a means to promote self-worth and creativity where there was deficit and disability, yet it does so at the risk of excluding those who may not be able to sustain employment or relationships, something that may explain the low uptake of the term in the groups I attended. I want to juxtapose the circulation of abstract concepts, as described above, with a return to the local groups I attended and to examine how ‘neurodiversity’ featured there. I have already suggested that the term was used loosely, if at all, and often with ambivalence, yet it seemed nevertheless to play a role in people’s ability to create bonds with each other, and this last point is the one that I want to explore next; how is ‘neurodiversity’ enacted in the support groups?

Autism is the second cousin of ADHD

I have described the social events and activities (in Chapter Four) and the archival work support group members pursued to define what ADHD meant to them (in Chapter Three), which contributed to the formation of relationships and bonds between members of the group. In Chapter Eight I will expand on the webs of obligation thus created in which ‘individuals risk trusting others because they want to change their lives’ (Stack, 1975: 39). I found that the collective actions that made relationships and bonds between strangers possible were augmented by an implicit inclusiveness in the membership of the groups, something that took me by surprise. All the groups I attended advertised and presented themselves as ‘adult ADHD’ support groups, but half way through my fieldwork, it became clear that

they were open to a far broader membership than adults with ADHD. They welcomed the relatives and partners of adults with ADHD, and also of people who presented themselves as having Asperger's or Tourette's syndromes.¹⁰⁷ It was only as I attended Group B in March 2013 that I came to notice what had been there all along. On that day, some members recounted their attendance at a conference in which a workshop had been set up to provide a 'near experience' of what it may be like to have Asperger's syndrome. Participants were asked to button and unbutton their shirts with gloves on, or to put fizzy sweets in their mouth whilst blocking their ears. These 'experiments' aimed to replicate the way in which sensory information is processed and experienced by people with autism (Solomon, 2010). As the conversation grew around me, I recalled how in previous sessions a number of members had presented themselves as having Asperger's, and these people were now very much engaged in the conversation. On the same day I noted a poster, hand drawn, that was stuck on the outside of the door of the meeting room. It joined the letters of ADHD with ASPIE, a diminutive of Asperger's.

ASPIE

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Later on that day I told one of the facilitators, Caroline, about my surprise, and asked her if this was something the group had started to do recently. She explained that it had always been the case that people who might have been diagnosed with Asperger's came to the group, sometimes because they were relatives of other members, but also because there were no other places for them to receive support and advice. She went on to discuss how they had found that what made the two conditions so different, concreteness and order (Asperger's), and chaos and flexibility (ADHD), can become a strength when shared and brought together. In her view, Caroline continued, both were part of the same family, which did not mean that people were the same; people shared some differences and that

¹⁰⁷ The DSM-IV criteria specifically made Asperger's syndrome an exclusion criteria for diagnosing ADHD, therefore little data has been available on the comorbidity of the two disorders. Clinical practice has suggested that both are often diagnosed together and the possibility of co-occurrence of ADHD and ASD in DSM-5 will likely increase research in this area (UKAAN, 2013). ADHD has been reported as the most common comorbid disorder with Tourette Syndrome (TS) with 60% to 80% co-occurrence; the percentage of TS comorbid with ADHD, whilst much lower, remains significant, 8% to 10% (Rizzo et al., 2013)

was why they could get on here in the group. She pointed out that there were also one or two people who I had met suspected of having Tourette's syndrome, and they were waiting to see a psychiatrist.

The practices of the group, discursive and otherwise, took place within a context where diversity and difference were valued and encouraged. Yet this was rarely expressed in terms of neurodiversity, of brainhood or other neurological grouping. Instead group members enacted neurodiversity, or at least one kind of neurodiversity, by making it possible to have in one place 'alternative human differences' (Armstrong 2011). In all the support groups I found notions of neurodiversity and the purchase of its language to be both changeable and interchangeable with the language of kinship, of family, groups, us and we. Such diversity was enacted in the relations between people attending the groups, not between neurones and synapses, but between people who recognised each other as being different from the norm. Paraphrasing Rapp and Ginsburg, I suggest that the members of the support groups became pragmatic philosophers of human diversity (2011a: 406), because diversity and their attitude towards diversity was expressed in actions rather than words. In this way, rather than re-imagining the narratives of neurodiversity, they have reimagined it through their practices and relationships. Neurodiversity was put in practice not through loud lobbying or activism, but through kinship practices that extended family resemblance beyond psychiatric boundaries. In line with the caveat I provided in Chapter Six regarding the familial context, kinship relations formed with strangers should not be romanticised, as they can be double-edged, comprising of positive and negative qualities (Carsten, 2013). Within the reciprocity and the sense of belonging I observed between members, there were also tensions, reprimands, and sometimes mistrust and rejection.

One incident in particular highlighted how belonging to a support group relied on being accepted by other members. Whilst it was never made explicit why Mark did not fit in on his first visit, it seemed to me that he was being excluded. Mark, as he described himself, was in his early sixties, from a professional background and had lived in the USA before returning to settle in the UK after retiring. He had been diagnosed with ADHD in the USA in the mid-1990s following his son's diagnosis, and had tried a number of medications, most of which could not be prescribed in the UK. Throughout the meeting he contributed in a soft voice and with a gentle manner but he interjected when others spoke

by referring to psychiatric criteria, the DSM or to his experience in America. At one such interruption, another member jumped up and angrily pointed his finger right in Mark's face, shouting at him to shut up with all his nonsense. This incident was followed by the facilitator taking the young man outside the room to calm him down. Meanwhile the other facilitator told Mark how his behaviour was too disruptive for the group and that he needed to listen to other people, saying that 'sharing was like taking medicine through the ears'; Mark was visibly upset and crying. Eventually the other member returned to the group, shook hands with Mark without saying a word, and the group discussion resumed whilst I felt that the tensions had not been resolved. Mark attended once more, the following month, and he expressed his confusion about advice he was given by the facilitators; on the one hand he was told to find closure about being diagnosed, on the other he was constantly asked questions about the past, which re-opened old wounds. Tearful, he concluded with a question: should he come to the support group if it brought back painful memories? There was no direct response from other members and the conversation moved on. Mark did not join any more sessions for the remaining nine months that I attended, nor did I have any further contact with him.

In this situation, my thoughts as to why Mark did not return, why he might not have fitted in and possibly excluded by the group, are speculative. Yet it seemed to me that his age, his professional background, his deferential acceptance of psychiatry, were all in stark contrast with other members. Most of the others were young and their main focus was on training for employment. More importantly, through his mild manners, Mark seemed to refuse to take the listening medicine as prescribed by the facilitators. For each piece of advice he was given, he would respond with questions and would not readily accept the memory practices that were at the heart of the 'sharing' in the support group. Somehow the resemblance that he may have had with members of the group in relation to his symptoms of inattention and hyperactivity was not enough to develop bonds and connections. Similarly, this incident showed limits to the inclusivity and sense of belonging that might be generated by support groups. Importantly, it also highlighted the importance for members of this group to accept rules and hierarchy in order to fit in. In the 31 support group sessions I attended during my fieldwork, this was the only occasion that I came across what appeared to be the rejection

of a new member, a reminder of the limits of tolerance and acceptance suggested by ‘neurodiversity’. That said, the incident should not obscure or negate the kinship bonds and connections that I observed and described above.

Conclusion

The last two chapters have been concerned with the role that kinship plays in the diagnostic process of ADHD in adults and they have queried the kind of bonds and connections that may be formed due to ADHD as well as exploring the basis on which such connections are made. Recognition and resemblance featured in my analysis of this process on two counts; firstly, I have discussed how recognition implied the notion of kinship bonds in that recognising someone is already to acknowledge their existence. I have shown how this acknowledgement may be withdrawn and have illustrated the impact that this might have on people with symptoms of ADHD, including that of becoming accidental activists (Panitch, 2008). The self-recognition of parents in their children showed an unexpected flow of knowledge from child to adult and suggested that, currently, adults with ADHD are made by their children. Secondly, the concept of family resemblance (Wittgenstein, 1972) that was applied concretely between child and father in Chapter Six became relevant to describe the relations between strangers which were based on neuro-biological resemblance and not on filial links. Not only could the people I met recognise themselves in strangers, but their resemblance became a classificatory mode for describing themselves as belonging to the same family. I described how kinship relations based on sharing common symptoms related to neurological conditions, on being the same by being different, has been coined as ‘neurodiversity’ and I have shown that in the groups I attended, the term was used loosely to distinguish between those resembling each other as neurodiverse with others who were seen as neurotypical. More importantly I have found that the support groups, rather than being influenced by neuroscientific vocabulary to discuss their experiences, used kinship-like language to talk about it – belonging, caring, sharing, reciprocity – and they enacted diversity by stretching family resemblances to include people other than those with

ADHD. I have suggested that the webs of obligations which were formed in the support groups transformed the individualistic concerns of self-improvement into extended kinship relations that were evoked through familial care.

We could conceive the basis on which these relations are formed in a number of ways; as biosocial (Rabinow, 1992) whereby our social worlds and relations are made and unmade on the basis of our biology; or as kinship and genealogies of afflictions (Rapp, 1995; Rapp et al., 2001) emphasising the relations formed on the basis of some form of disability. Through my encounters in support groups, I found that biology, genes or disability did not fully capture the basis on which people made connections and bonds. The sharing that took such a central place in the activity of the groups, was centred on sharing those experiences that showed peoples' vulnerability. The general unpredictability of life or a lack of attention could result in their taking a disastrous wrong turn: as Ray put it, "success is a small margin away from failure." Similarly, Sonia described how relying on inventing and improvising solutions as a necessity and last resort left the future uncertain, as if precariously walking a tight rope. In previous chapters and the forthcoming one, Bridget, Jack and others in describing their struggles to keep their work, housing and relationships going also opened their vulnerability to be reciprocated with care, attention and support by clinicians and support group members. What I have described might be kinship based on vulnerability as a shared condition (Han, 2012), which does not restrict sharing to particular disorders or classifications, but extends family resemblance to a mutual lived experience of precariousness.

To some extent, if there is a gift in neurodiversity, maybe it is found in the way that the circulation of the term has enabled helpful social interaction between people who might not otherwise have had any relationships. As I observed, it was possible not only for people with ADHD, Tourette's and Asperger's, but also their parents and relatives to exchange support and care in the groups in the hope of making their lives better. More than that, it seems that re-appropriating ADHD and other conditions as their own, and seeing these conditions not as discrete and unconnected experiences or classifications, but as mutuality of being, was in itself a kind of activism, an ontological politic (Mol, 1999). As I saw it, the support groups assembled and affirmed ways of being, or 'forms of life' as

Canguilhem would have it, celebrating their diversity, building a community on their existential experience of vulnerability – acts which gave people a voice, and by extension, the chance of being recognised by others. The next chapter will explore this activism to show that it was not directly engaged in changing policies or influencing research (Rabeharisoa et al, 2014), but was instead concerned with producing pragmatic knowledge for living every day with ADHD.

Chapter Eight Ordinary problems: living with ADHD

Specialist training for an ordinary disorder

In November 2012 I attended a three day training course for clinicians delivered by UKAAN. The course taught specialist skills for diagnosing ADHD and covered such topics as DSM criteria, neurobiology of ADHD, recognising co-morbidity, and it included a whole day dedicated to treatments, pharmaceutical and otherwise. It was mostly attended by 30 or so psychiatrists¹⁰⁸ working within adult psychiatric services in different parts of England and Wales, whose daily practice in the NHS was orientated towards diagnosing and treating psychotic and depressive disorders. From them, I found out that ADHD had not been part of their training in psychiatry, but that they were coming across it more often in their practice. Referrals from GPs and other health professionals were becoming more frequent and most felt ill-equipped to diagnose let alone initiate treatment that involved controlled drugs. It is a NICE recommendation that adults ‘should be referred for assessment by a mental health specialist trained in the diagnosis and treatment of ADHD’ (2009: 19) and the clinicians attending the course were there for that purpose.

After registration, we brought coffee into the training room and the first session started, led by two psychiatrists who began by explaining how the course would not be engaging with debates on the validity of the diagnosis nor would it question whether ADHD symptoms were part of ordinary life; this had been done in other forums¹⁰⁹. Instead we were told that the course would go through a diagnostic process which was based on evidence and good practice. The presenters continued by describing how diagnosing ADHD was ordinary and in line with diagnosing any other psychiatric disorder. A film of an assessment was then played, showing how the Mental State Examination interview was conducted; questionnaires were also mentioned as a way to access detailed history. ADHD was defined as a common disorder, with a prevalence of 2.5% in adults in the UK, affecting

¹⁰⁸ My presence led clinicians to raise several questions, all out of curiosity and interest as to my research projects. These questions triggered useful discussions, some of which I described in Chapter Two.

¹⁰⁹ See (Asherson, 2010; Timimi and Moncrieff, 2010).

approximately 1.5 million people. In terms of diagnostic practice and statistics, ADHD was therefore presented as regular and ordinary. Yet during the three days, there were many statements and conversations that gave the opposite picture of this disorder, as something out of the ordinary and unusual. Some comments pointed out how ADHD was still controversial; pharmaceutical treatments, such as stimulants, were very contentious as well as complicated to titrate and establish at the right dosage. Other conversations highlighted how particularly difficult ADHD was to diagnose because its symptoms overlapped with many other disorders, hence the specialist skills required and provided by the training. As I saw it, this group of specialist clinicians running the course were in a bind. On the one hand, one way to face the controversies of ADHD was to normalise it, bring out its ordinariness, and work towards integrating ADHD within regular adult mental health services. On the other hand, to recognise ADHD, clinicians needed special skills to discern in their patients the differences between normal and pathological experience of everyday life. Specialised skills and knowledge were also needed to prescribe medications that, unusually, came under the controlled drug legislation and were unlicensed for adults. Thus ADHD in this forum was presented simultaneously as ‘ordinary’ in order to be accepted in society, and yet ‘out of the ordinary’ to treat.

In this chapter I will explore how people I met in support groups and in clinical settings described what living with a diagnosis of ADHD was like. Previous chapters have followed the diagnostic process from the clinic into the groups, tracing different moments on that path when patients and clinicians found out about ADHD, how they recognised similarities with others and how they accumulated evidence of symptoms. The diagnostic process highlighted various practices that enacted ADHD in adults, amongst which some were related to remembering and forgetting through administrative work or old documents; others called upon kinship relations in unexpected ways. This chapter is a pause in the reverse chronology offered by this thesis and its focus on the experience of living with a diagnosis will target two elements; diagnosis as a category, and treatment as its outcome (Blaxter, 1978; Jutel, 2011). In so doing, the chapter will suggest that the diagnosis of ADHD may be characterised negatively and that people labelled with it may be stigmatised when it is described as a lifelong disorder. My focus on treatment will show how receiving treatments, far from being a passive

activity, involved active engagement and that, in my analysis, stimulant medications emerge as important actors and participators in living with a diagnosis.

Through observations and conversations I conducted in all settings, a central theme revolving around the complex and contradictory use of the word ‘ordinary’ became apparent. The ordinary could be summarised as something which can be sought after (ordinary is the norm) or something to be avoided (this is extra-ordinary) and may need to be protected from medical intrusion (this is *just* ordinary). Thus the specialist clinicians I met in the clinic and in the training course were holding together the first two propositions, ADHD is ordinary/extraordinary and they were well aware of the third proposition that presents ADHD as an exemplar for the medicalisation of ordinary life. To disentangle the different uses of the word ‘ordinary’ I am inspired by Wittgenstein’s morphological method for clarifying concepts, exploring the use of a word in its variations as a ‘pole of a description, not the ground floor of a theory’ (Wittgenstein, 1988 : § 633). Thus, examining the familiar use of the word ordinary in context will show the complex ways in which ADHD was discussed and will start to unravel some of the opposite and seemingly intractable positions held in regard to this disorder. As much as anthropology provoked Wittgenstein’s thinking (Hacker, 2009; Wittgenstein, 2015), anthropologists have been inspired by his reflections (see amongst others Csordas, 2004; Das, 1998; Whitaker, 1996). Das in particular cites the philosopher as an influence on her work: ‘people in their lives articulate his questions. It is not a theoretical claim; I just let it be shown in my work. People are *living* certain philosophical questions, however different the languages in which these are thought.’ (DiFruscia, 2010, emphasis in original text).

Das’ work on the ordinary (Das, 2007; 2010; 2012) advocates that we look for the ethics in everyday practices rather than in the height of philosophical reasoning. From what she calls ‘a simple proposition that everyday life is the site in which the life of the other is engaged’ (Das 2010: 376), Das argues that the work it takes to live every day is not only done in order to fit with society's norms, but that it is made of moral actions, actions to live well with one’s self and others. In this way she highlights that life in the ordinary is not to be taken for granted, that it is threatened by what happens around us all the time, and ‘to secure the everyday...might be thought of as an achievement’ (ibid.) .

There are obvious differences between her ethnographic sites and the one I am concerned with – differences which are also represented in our approach to the ordinary. I am interested in the way that Das has been concerned with capturing how, in the face of extreme communal violence, people can not only pick up the pieces, but that through the very act of maintaining everyday habits and gestures that are required for staying alive, such as cooking, washing, they start social worlds anew. She calls this movement forward, from the actual to the eventual everyday (2012), ‘the descent into the ordinary’.

In contrast to Das’ participants, the people I met in support groups and clinics have not been faced with extreme and large-scale violence. Yet, within the context of the UK, I am suggesting that my participants have encountered those moments where the ordinary life that they build and maintain through routines, strategies and habits has been threatened, shaken, maybe undermined. The scale of threat and destruction are worlds apart from Das’, but crucially as I have described, and echoing Das’ notion of the work of time (2000), the problems they face are lifelong and require constant work; this work is part of their lives. Rather than a descent into the ordinary which was triggered by an extreme event, my participants described an accumulation of the quotidian that made life unbearable, an accrual of everyday events that had gone wrong. As discussed in previous chapters, each singular event considered in isolation could be perceived as an ordinary problem, but I have argued that through accumulation these events become problems of the ordinary. Time, in this way, is both part of the problem and a means for evolving solutions. Das’ concerns with describing the struggles and the work required for people to live alongside one another provides a frame for thinking about the way people I met described how they made and remade their ordinary over and over again. I heard of such continuous toil, with uncertain outcomes, described in their everyday lives as a combination of routines and habits; their potentials were tinged by doubt and anxiety and marred by the effect of tiredness that resulted from the unrelenting attention required.

Following the word ‘ordinary’ into support groups and clinics, this chapter will explore descriptions of living with the diagnosis of ADHD that were shared with me; some gave insights into the stigma people had to face through practices related to treatments. I will explore the work of medication, how

stimulants affected peoples' relationship with the world directly, not only through their pharmaceutical properties, but also in the way that they were taken and could be moulded to the uniqueness of people's lives. Sometimes called 'lifestyle drugs' (Kadison, 2005; Racine and Forlini, 2010) as if such practices were a mis-use of the drug, I argue instead that stimulants are actants in that they do different things depending on when, how and where they are used (Goodfellow, 2008; Han, 2012; Latour, 2005). I will conclude by discussing how carrying on living with ADHD is related to a notion of endurance due to the work that it takes to maintain relations with the world. Through group observations I show that enduring involves being active, in the form of caring for one another, but it can also mean withdrawing to recuperate.

People with ADHD are extra-normal because being normal is too ordinary

I arrived at 11am at the community centre on the edge of the town centre where support group B used a large room that could accommodate 30 or more individuals. The room was divided into a relaxing area with armchairs and sofas, set up in a circle. Tables and chairs were set out near a small adjoining kitchen area. People were already there, sitting in different parts of the room and, as Jim came towards me, I introduced myself. Jim had been a speaker at the Patient Organisation's conference where he had given a very emotional testimony of his struggles with ADHD and of the way that the support groups had helped to turn his life around. As he explained to me later that day, he was now 'giving back' and helping run the support groups so that others could benefit. The two facilitators and founders of the group had not arrived yet, but Jim was quite happy to start the meeting and introduced me to the members. As people started sitting in a circle in the main part of the room, I noticed that one wall of the room had a dedicated space for images and photos that were related to ADHD, some were well-known such as the famous logo of the hard rock band AC/DC revamped into AD/HD, others less so.

A poster showed a large fish in a small bowl with a smaller fish leaping out towards a larger bowl.

During another group session I met the person who brought this poster and she explained that she had bought it for the group to thank them for what they did for her. She said,

“That’s me, I went from the little bowl, being restricted and crowded, to the big bowl where I could move better. Before I attended the group, I didn’t know how to deal with my problems, I did not fit in there, in that bowl, now I can be myself”.

On the same side of the room was a wall of fame, with signed pictures of personalities, actors and football players who supported the work of the group, as well as pictures of politicians and civil servants with the founders of the group, Caroline and Tessa¹¹⁰. This montage constituted a record of lobbying and advocacy work over many years that led the two founders to raise a petition, and as one picture shows, to hand it to the Deputy Prime Minister of the time, Harriet Harman. Later on, when recounting this episode, Caroline and Tessa emphasised with delight how they ensured that group members attending Downing Street with them were those with the most visible and uncontrollable ADHD symptoms, which made a great impact, but also shortened the meeting as it became rather chaotic. One of the posters showed the logo of the organisation representing a smiley face made of the 4 letters ADHD surrounded by the phrase ‘don’t judge me, understand me’. Through the following month, I noticed this logo in the room, not only on mugs and leaflets but also on drawings and stationary. It was always accompanied with the © symbol to signify that it was copyright protected as the product of this particular organisation.

A few months later, Tessa explained how her experience of being diagnosed had been very difficult. When she had discussed her problems with her doctor, describing how the continuous disorganisation which she associated with ADHD affected her family including her diagnosed son, he responded that there was no such thing as ADHD. He added that what she needed was parental advice and support. It was as if he were judging her a bad parent and she were trying to use ADHD as an excuse. Other people I met in different groups had similar stories, whereby they felt certain that something was not

¹¹⁰ The wall on the other side of the room was covered with handwritten posters as described in Chapter Three.

normal in their behaviour, something they could not control or moderate, and it was no ordinary forgetfulness or run of the mill inattention. In their experience, GPs were either not informed about ADHD or were unwilling to make referrals to specialists. Such attitudes were exacerbated by the media's use of stigmatising headlines such as 'Is lazy parenting to blame for Britain's addiction to Ritalin?'¹¹¹. Tessa explained that the logo was a reaction to that stigmatisation. It was asking people not to jump to conclusions but to take the time to hear the full stories that showed the impact of ADHD on everyday life. She went on to explain that in her experience the suggestion that single parenthood could explain a rise in ADHD (Hjern et al., 2010) is a totally lopsided view of what it is like to live with these problems. She felt that ADHD was more likely to cause single parenthood due to the sheer difficulty of living every day with problems that do not go away. Her marriage had survived, but went through a lot of difficult periods. As for the copyright, she told me that in 2010 they had decided to constitute themselves as a social enterprise so that they could get some funding for the courses they were delivering.

Let me return to the support group session of that day. Jim asked everyone to settle down and the session finally started as he asked one member to share his story. Michael was in his early 40s, he explained that he was diagnosed a year ago and that his stimulant medication really helped at first: it was like heaven, he had never felt that calm. But then he crashed into depression and could not get out of the house, so he had six weeks off work. After that, he recalled, it was up and down with the medication, which he finally stopped a couple of months ago. He described how he thought the tablets were flattening his mood; he could not be bothered to do anything; he lost his 'joie de vivre', no jokes, no messing about. He could do his work better but that was boring. Up to that point, the other members just listened, sipping their teas or coffees, some checking their mobiles. I noticed that some people, three or four, were restless, fidgety; Michael was one of them. His legs were shaking uncontrollably and he was not trying to control them either, nor did he seem affected by the movements. As he was sitting on a low settee, he seemed to combine a very relaxed upper body and a

¹¹¹ (Atkinson-Small, 2012); and more recently such headlines as 'How many illnesses of modern childhood are excuses for bad behaviour, stupidity and parental neurosis?' (Liddle, 2014); and 'ADHD and why we, working mums need to look in the mirror' (Vine, 2014).

very tense, active lower part. Graeme interjected to tell Michael how he understood him, as his own life was definitely more boring when on treatment but that, for him, the meds kept him out of trouble, out of prison. As he put it, “I just did a stint of 12 months in jail, so taking the meds is the price to pay”. Michael responded that he had tried to balance the pros and cons of being on medication but had decided that he would rather live with his ADHD than with his meds, because he felt he was more aware of his symptoms now. He said, “if it’s what it’s like to be normal, well I’d rather not, thank you very much”. When the laughter had subsided, Jim opportunely reminded Michael that he had not attended the group for weeks, jokingly calling him, AWOL (Absent Without Official Leave) and saying that he would benefit from more frequent attendance. He then moved on the space for sharing and gave another member her turn to talk.

What I came across in my first visit to this support group, I encountered again and again in other groups too, sometimes with slightly different wording but with the following main theme that I paraphrase in the following way:

ADHD is part of ordinary everyday life, it does not go away and you have to learn to live with it; yet ADHD is not ordinary because most people don’t have it and because ordinary is boring, whereas ADHD is anything but boring.

That ADHD is described by many as both ‘ordinary’ and ‘not ordinary’ may seem a contradiction; how can it be both? It is also related to an earlier description I made of the multiplicity of ADHD, that it may be more than one thing and yet less than many. Through this lens, being ordinary/not ordinary is more of a co-habitation than a contradiction, co-existing in one person’s lived experience of ADHD.

But the entanglement of the opposed propositions should not obscure the fact that different scales of comparison are being applied in this juxtaposition of ordinary/not ordinary. On one scale, norms are compared between an individual and others – how do I compare with others, using social and external norms? On the other scale, norms are applied within one individual over time using biological and internal norms.

In regard to social norms, what is ordinary comes from comparing one's problems to others, or for that matter, being compared. At this end of the scale, the comparison can be painful and distressing and Tessa described the way she felt blamed and stigmatised for having ADHD and being a parent of a child with ADHD. The logo of the support group is a reaction to this, 'don't judge me, understand me'; a request to broaden the criteria for comparison and a plea to accept uniqueness. It is also what Michael suggested when he stated that "if being ordinary was boring, then being different was good" or as another member put it; "people with ADHD are extra-normal". The comparison with others and being out of the ordinary can be turned to your advantage, that is, if it does not get you into trouble or into prison. Nick, who I met in Group C, talked to me in an interview about meeting people who had been helpful to him in living with ADHD and of the benefits of attending support groups. I asked him:

Claude: "Are people helpful to you because they are more knowledgeable about ADHD than you?"

Nick: "It's more than that, much more. The reason that the support group is helpful is because, [silence] because [silence] it brings a sense of normality. [silence] Before, you feel not normal, not part of society, [silence] something's wrong."

Claude: "Hmmm"

Nick: "In a support group, I feel normal, you and Anna you're the abnormal one if you can understand, [laughter], so being in the support group it gives a sense of brotherhood, community, like belonging."

Nick was referring directly to the sense of being ordinary, normal, because he was amongst people like him, with the same difficulties that can be nurtured into a sense of belonging and of solidarity, something I described in Chapter 7 as extended kinship¹¹².

Support group members also applied a normative framework in relation to themselves, internally, and they evaluated their own experience in duration, from one day to another. They often recounted their

¹¹² Anna, the facilitator of the group, and I were the only individuals in the group who did not have ADHD, so according to Nick we were neurotypicals, whilst the group members were neurodiverse.

first awareness of ADHD in themselves as problems that were constant, day by day and which never went away. As Michael became more aware of his symptoms, he also learned to differentiate and recognise triggers, or periods of the day when his problems were exacerbated. He noticed that alcohol either made things worse, or instead helped him go to sleep. By referring to his bodily norms, what felt normal, he could choose to affect his problems of hyperactivity or inattention, through medical or non-medical means, as he decided. What the treatments were doing for him could be thought of in terms of chemical side effects, the flatness of mood, the loss of drive, but his decision not to continue with medication was related to how life felt whilst taking them; boring, no messing about, no jokes. That's how life had been, that was normal and so it was better to live with the side effects of ADHD than the side effects of the medication.

The argument inspired by Canguilhem (1991) that I put forward earlier is of relevance here; Canguilhem showed that organisms created norms as part of their lived reality, and did this in interaction with an environment, what he termed biological normativity. In other words bodily and social norms are entangled and so are the comparisons therein. Thus it may be that my focus is affected when in a busy and buzzy room and it is harder to keep on task; on the other hand it may be that being very fidgety makes me a better comic, or that my ability to hyperfocus ensures that I can work long hours. One clinician described ADHD as context-dependent, so we can think of the comparisons based on biological and social norms as intertwined even though they do not always fit together – a situation with the potential for causing distress and stigma. In the next section I want to return to Michael's dilemma about his treatment, and look at this issue from the point of view of the medication, as it were, so that I can examine what stimulants do and what kind of ADHD might be enacted through the actions of stimulants themselves.

Pills don't build skills

The meeting in Group C that I attended on a December night was well attended, some people were making cups of tea, others setting up a table with finger food and Christmas treats to which I added mince pies. As usual, there were slightly more men than women present and I started chatting with those I had met already, mostly about mundane things like the very cold weather spell the UK was going through, or the latest movies that people had seen. Anna asked people to settle down and started the meeting, explaining that this would be a shorter session than usual so that we could have more informal time afterwards. She then drew up a list of people prioritised to talk on that evening, ensuring that the couple of new members were given an opportunity. The first new member started describing her difficulties in being diagnosed, having been referred by her GP and then waiting for a number of months to be seen by the specialist psychiatrist. She was not receiving any treatment for ADHD and was curious as to what might be on offer once she was diagnosed. The facilitator described different types of medication and psychological treatments and was keen to emphasise that medication was not going to solve all her problems. She said, “meds may help but you will need to learn a lot and look after yourself” and she told the group, “pills don't build skills”. Chris, who had been attending for a few months, asked what the medication actually did; how did this tablet make you feel? He had only recently been prescribed stimulants about a month ago, and it was still very much, as he described, “hit and miss”. The dosage was still being adjusted but he was not sure that this was the right medication for him because the effect was really good but only for a very short period and then he felt rather awful. Another member, himself a GP, started to provide some details of the way the main medication worked:

“There are two main forms of medication, stimulants and non-stimulants. Stimulants come in different forms, like Methylphenidate or Dexamphetamine and the non-stimulants are things like Atomoxetine and Bupropion. The stimulants are the most widely prescribed and they come in different brands like Ritalin or Concerta. The difference between the brands is to do with how

long they take to act and how long they last in your system. Ritalin is fast but short acting¹¹³, it kicks in within 30 minutes but its effect is gone after three to four hours. Concerta has a smoother start and lasts around eight hours¹¹⁴. The non-stimulant medications are more like antidepressants in that they take a while to take effect, a few weeks, and they remain in your system longer too.”

Some people were taking notes, and I could see those next to me googling for this kind of information. Chris was clearly interested and asked where Medikinet, the medicine he was prescribed, fitted in all this. Lindsey, who was a long-standing member, explained that it sounded like Chris was prescribed the short acting kind of meds and that was why the effect disappeared quite quickly. “This can be a real problem”, Lindsey continued, “because you can get a real dip in your energy, in your focus and the rest, just when you need it the most, half way through your working day. Suddenly, maybe in a meeting or something, you just feel really lousy, you just can’t focus on what people are saying and you just feel like getting up and walking.” Lindsey then described how he talked to his doctor so that he could have a dosage combining long and short lasting stimulants. He was then able to take one pill in the morning whose effects would last until about three or four in the afternoon, and take a short acting tablet if he needed to focus or work late into the evening.

Chris, who started this discussion, continued and put forward a suggestion:

“Why don’t we put this information down, between us we have lots of experience that could be helpful. I know that there are websites and forums but really I haven’t found them useful, they are either too technical or too brash. What I would find useful is a list of people’s experience of different drugs. How do they take them, do they have breaks from the drugs, what are the side effects, can you break the pills to change the dosage?”

¹¹³ Also known as Immediate Release (IR).

¹¹⁴ Extended Release (ER).

The conversation rapidly jumped from one person to another; a sense of excitement was palpable, people adding their thoughts, or agreeing with the main point that what would be useful was not manual or textbook explanations, but real people's experiences. But how to go about it? How to collate this information and how to make it available to each other? Chris suggested that they could start with people who were interested in emailing each other and it might take separate meetings to agree a format to write these experiences down. Three other members agreed to get involved with this and email addresses were exchanged, whilst the conversation moved on to other people, their circumstances and concerns¹¹⁵.

I had witnessed similar conversations in other support groups that were more inclined to discuss medication, often using scientific descriptions and comparing what was available in the UK and the USA. In particular the flexibility of stimulant treatments was often discussed, how this kind of medication can be adapted to what is going on in your life, sometimes taking a break, and at other times making sure you function at your best, for a job interview, or other special occasions. There was at times an assertive feel to these conversations, in which the right to be functioning to the best of their potential was claimed; why would it be wrong to take a pill if it would help you to work better, be a better parent, or partner? Of course people were prescribed stimulant medication for a purpose, to treat ADHD, but the way stimulants act blurs the boundaries between the relief and the enhancement of the individual's functioning. As I described earlier, the scientific position is that ADHD is something that cannot be cured; treatments can only help in reducing symptoms and for short periods at a time. Whilst the individual is burdened with ingesting medication a few times a day, as Chris described, it seems that for some at least this provides an opportunity to adapt and choose the way that medication will make a difference in their lives. If inattention is relieved then focus is enhanced; if hyperactivity is contained, then calmness and moments of rest are enhanced. This ambiguity between treatment and enhancement is at the heart of the controversies associated with ADHD, linking

¹¹⁵ I did not participate in this conversation as the feeling in the room, led by Chris, was that this was a topic for the group to discuss with each other, adults with direct experience of ADHD in themselves or their relatives. The expertise they sought was their own, not textbooks. Not that I ever felt unwelcome in this group, or any other, quite the contrary, but I was often reminded, directly and indirectly, that my position of expertise, if I had one at all, was not experiential. I was a neurotypical amongst the neurodiverse.

treatment with lifestyle choices as well as with the extension of medicalisation of everyday life (Conrad, 2007; Donnelly, 2013; Edwards, 2013; Frances, 2013; Racine and Forlini, 2010; Schermer, 2007).

As we tucked into the dips and the mince pies, the conversations remained on issues related to ADHD, about articles and books people had read. A conversation began about a film that had been released earlier that year, 'Limitless', addressing the issue of enhancement directly. The story line can be summarised thus: a man on the verge of unemployment tries a mysterious pill that enhances his cognitive ability to the point that he rises to the top of the finance world. Problems arise when he runs out of pills and he experiences dangerous side-effects, sending him on a roller-coaster of highs and lows but, by learning to control the drug, its production and potency, his life settles into success. Our conversation, beyond noticing the good-looking actor, or the special effects, revolved around experiences that people could relate to. One person explained how she would take her stimulant meds only when she felt she needed them, that is, not every day as prescribed, which meant that she could keep a stash in case she had difficulties getting a repeat prescription as had been the case in the past. Others concurred and Chris returned to the subject of adapting the dosage to fit his needs specifically so that he would not be over-stimulated and then unable to sleep. The issue for him was how to control the action of stimulant medication to meet his needs, having enough, but not too much.

Stimulant medications, described like this, have agency: they are entangled in public life in many ways, they have a history, mostly turbulent and controversial, and act not only on the brain's neurotransmitters but also on everyday events (Whyte, Geest, and Hardon, 2002). As Latour demonstrated, scientific discoveries are often named after their actions, what they do is what is observed first, before they are described in terms of their competence (Latour, 2014; Latour and Woolgar, 1979). None more so than the stimulants which were defined by their actions in the 1930s in a moment often described as 'serendipity' (Barkley, 2006; Connors, 2000; Lange et al., 2010)¹¹⁶.

¹¹⁶ The research on the use of stimulants for the treatment of headaches in child patients showed little impact 'but to [Bradley's] astonishment the teachers reported major improvements in learning and behaviour in a number of the children that lasted until the Bensedrine regimen was withdrawn' (Gross, 1995). Discovering a

These drugs were observed to increase focus and attention, boost up energy and repress hunger. We can see how the emphasis on the medication's action remains in the vocabulary clinicians and support group members use when discussing it; 'fast acting', 'slow release', 'stimulate', 'focus', 'control'. Stimulants give control, yet their activity needs to be controlled: stimulants are 'controlled drugs' after all and come under strict legislation for their prescribing, management and use as medication (DoH, 2013)¹¹⁷. What I am suggesting is that the specific pharmacokinetic of stimulant medication, what the body does to the drug, the speed at which the drug is absorbed and distributed, makes the co-constitutive role of this medicine in the lives of patients more potent than that of other medication.

Beyond the direct effects that stimulant medications have on the body, they act directly on the relations shared with others, as hinted by Lindsey. At another group meeting, a member described how she and her son were prescribed the same medication and shared days without taking it, described as 'drug holidays'¹¹⁸. Whether they chose to take medication or not depended on what was going on in their lives; for example not taking medication before a football tournament so that both mother on the side of the field and son on the pitch could be as exuberant and active as they wished. In contrast, the parents' evening at school required them both to be fully focused and composed so as to pay attention. Through their presence or absence, stimulant medications facilitate relations with others; they help shape those relations and participate in helping patients engage with the world in positive ways, or so the person who shared this story hoped. Other stories, such as the strategic use of stimulants to improve work performance, as in the case of the comedians described in Chapter Seven, also show how taking or not taking stimulant medications acted on the relations that people had with others. We could think of stimulants and patients as co-producers of relationships which have, in the

drug's actions in this way is common, for an overview see (Ban, 2006). See (Rasmussen, 2008) for a comprehensive cultural history of amphetamines.

¹¹⁷ Stimulant medications also require a license, 'a marketing authorisation', issued by the Medicine and Healthcare products Regulatory Agency (MHRA) on the basis of evaluating the beneficial or harmful effects of medicine. Despite being NICE's first line recommended treatment for adults with ADHD, stimulants are licensed for children, but not for adults. The one and only licensed medication for adults with ADHD was approved during my fieldwork in 2013 and significantly it is a non-stimulant medication. For DoH document see <http://tinyurl.com/px6z7g2> Accessed on 9/07/14.

¹¹⁸ In support groups drug holidays were described as allowing parts of one's personality to come through, as bringing the 'real' person out. Thus, taking no treatment brings out the normal state of being and taking medication becomes, in contrast and by definition, an altered state.

stories shared with me at least, a positive effect. By paying attention to the details of how stimulant medications are used, the agency of both pills and the individuals is revealed. In contrast, the next section examines the concerns expressed by some psychiatrists, that stimulant medication among others, are a means of intruding into people's everyday lives for the benefits of the pharmaceutical industry.

What's in a word

'The question "what is a word really?" is analogous to "what is a piece in chess?"'

(Wittgenstein, 1972: §108).

'Real psychiatric disorders require prompt diagnosis and active treatment - they don't get better by themselves and become harder to treat the longer they are allowed to persist. In contrast, unavoidable everyday problems of life are best resolved through our natural resilience and the healing powers of time' (Frances, 2013: xix).

This quote from Allen Frances' recent book, *Saving Normal* (2013), is at the heart of the controversies associated with ADHD; how much of a problem is it to be inattentive, forgetful or even over active? The book's subtitle is worth quoting fully: *An insider's revolt against out-of-control psychiatric diagnosis, DSM, Big Pharma, and the medicalisation of ordinary life*. An eminent American psychiatrist, Dr Frances had been involved in the editing of the DSM-III and was head of the DSM-IV task force. By the time work towards the publication of the DSM-5 had started over a decade ago, he had retired but, as he described, he felt compelled to come back into the public arena and 'take sides in what has become a civil war for the heart of psychiatry – fighting a mostly losing battle to protect normality from medicalisation and psychiatry from overexpansion' (ibid.: xii).

In contrast to the medicalisation literature that I have introduced earlier in this thesis, which mostly offered a sociological critique on the construction of illness, the critical voices of psychiatrists have

focused on issues of boundaries and the delimitation of disorders. When does a behaviour become a symptom of pathology? By doing so, their attention is not on disputing that ADHD is real, but that, for most people, the behaviours associated with ADHD, inattention, hyperactivity and impulsivity, are just ordinary problems that are best left to resolve without medical intervention.

So far I have suggested that the word ‘ordinary’ had a fluctuating meaning when used by support group members as part of a normative frame; comparing themselves with others as well as evaluating their own behaviours over the passing of time. But the word ordinary has further nuances. When we use the word, as Wittgenstein’s quote suggests, it also plays a role and participates in the making of a reality; the reality of having problems deemed too ordinary to be real disorders, or the reality of having problems in ordinary, day to day life that do not get better. For a start, ordinary is both a noun and an adjective, it can define or be defined; its role in a speech act can shift from being the main point of attention to being out of the ordinary for example, or it can act to describe or transform something else, for instance behaviours that are deemed ordinary and that may be mistaken for ADHD. To switch from one sense to another is common and therefore can be confusing, as I experienced in the training course mentioned above.

The etymology of ‘ordinary’ points us towards other derivations such as: a quantifying sense that resides in the words ‘average’, ‘standard’ and ‘commonplace’, as well a meaning of order, ordering and possibly ranking too (Roget, 2012). In the first instance ordinary may be used to describe something that may be usual, traditional, familiar, even natural. This is what Dr Frances was referring to when he described ADHD as being an exemplar of the medicalisation of ordinary life: ‘Problems that used to be an expected and tolerated part of life are now diagnosed and treated as mental disorder’ (Frances, 2013: 82). In this view, forgetfulness and impulsivity are part of our nature, and should be endured, letting time heal as Dr Frances suggests by quoting Voltaire: ‘the art of medicine consists in amusing the patient while nature cures the disease (ibid.: 100). In this sense, ordinary is unexceptional and a hierarchical connotation is present too, in which our object of interest, by being ordinary, can be conceived as tolerable, passable and acceptable. Of course what appear to be neutral categorisations are also tainted by other traces that impart negative values. Ordinary can easily

become too ordinary, trivial, not worthwhile and possibly, mediocre¹¹⁹. I came across a portrayal of negative links between the ordinary and ADHD amongst support group members such as Michael and Maria (introduced in Chapter Five). Maria described with good humour how she first came to see the relevance of ADHD in her life. In the same conversation she also described how the ordinary in life had always been a problem and caused her difficulties:

Maria: “Although I am very bright, I'm not good at – you know – at life, at the ordinary things in life. I can do extra-ordinary things sometimes, but I can't do ordinary things. I had a job as a waitress, and I – I was hopeless [laughter] it was really really difficult, because I couldn't keep track of the people eating, you know, people would have just left. So I quickly found I couldn't do that. And I often think actually that if I had been able to be a better waitress I would have had a better career in the theatre, because I would have been able to support myself doing that. But anyway, the very thing of turning up on time every day, doing a boring job and earning a salary is impossible so I have been constantly poor. I thought that if I could get diagnosed, then, it may help, it may help to do the jobs I am not able to do.”

Claude: “So you have not been able to keep jobs, or get jobs?”

Maria: “I get jobs but they get boring and I can't bear it, it becomes insufferable, and I get depressed and so I leave.”

Maria talked about how she thought her main problem was, and had always been, forgetfulness; losing things, not attending appointments and not paying attention. She recounted childhood stories, of being always in a dream, and getting into trouble for losing things like lunch passes or forgetting school bags, not once but many times.

Maria: “You just add that to the way you think of yourself as a person, as part of your personality. The leaving things behind, the dreaming away, it's always, always happened.”

¹¹⁹ Dr Frances does not describe ADHD as trivial or not worthy of attention and he openly recognises the need to treat ADHD when experienced in extreme ways, that is when it is extra-ordinary.

For Maria, it is not ADHD that is negatively linked to the word ordinary, but the actual lived experience of ordinary life that makes her feel negative about herself. There are things, tasks in her daily life that, if she were able to do them, then her life might be better; she might not be so poor, for one thing and her career might have flourished. Ordinary life of this kind is not tolerable, it is not natural, instead it is insufferable and requires remediation, which for Maria, took the form of getting diagnosed and treated for ADHD. Yet, as with Michael, she was not interested in ‘doing ordinary’ as others did it, particularly not through medication, ADHD was an intrinsic part of herself, her personality.

In talking about her ambivalence towards pharmaceutical treatments for ADHD, she explained why she sought a diagnosis. She told me,

“So I thought it would make me feel better about myself if I had an explanation. I have a slight handicap in life, but I have lots of other things to make up for it, so I still hang on to that. Some people might be [silence] ashamed, but I don’t feel that at all. Because if I know what’s going on, if I understand what is going on, then I might have a way to cope with it. So meditation is helpful, primrose oil also I think helps me too. It is also real fun to be the clown, to make people laugh which is all to do with having ADHD and I wouldn’t want that to go.”

When I met Ray he was keen to explain where he saw himself in the abnormal/normal continuum. He said,

“There’s no doubt I’m not normal, and I am quite happy about the fact that I am not normal. My not normalness, my abnormality – I call it my bounciness – gets me in trouble sometimes, but without my bounciness I would not be where I am.”

Both Michael and Maria expressed ambivalence about being ordinary due to the negative connotations I have listed earlier; they even embraced being outside the norm, something I touched upon in Chapter Seven. But what interests me here is the oscillation between the two poles, abnormal/normal, as part of everyday life with ADHD.

Allen Frances applied ADHD-like symptoms to his own life to illustrate how ordinary life should not be medicalised into ADHD:

‘It is 6.00 am, dark and rainy and I am driving to the airport. I can’t put up the top of my convertible because it had been broken for months but I keep forgetting to get it fixed. I arrive, double park to check my bags, leaving the lights on and the radio blaring golden oldies from the 1960s. On returning a week later I can’t find my car in the garage. This is surprising to me but it shouldn’t be, because I never parked it there. I forgot it altogether, just checked the bags and blithely boarded the plane. Good-humoured security officers call in their buddies to enjoy a hearty laugh at my expense. My secretary, Tammy, has similarly found her life enriched by the delectation of my magical ability to lose papers going the ten feet from her office to mine...and my capacity to forget meetings and appointments. My life has been a kind of sheltered workshop. The kindness of friends and strangers has protected me from any serious impairment. Am I an absentminded professor or psychiatrically sick? In the old days I was a normal, if sometimes ridiculous, person. But things are different now. ADHD is spreading like wildfire’ (Frances, 2013: 140-1).

Whilst the strategies described by Maria and others I met were often linked to techniques of the self, betterment of oneself, here they are enacted through other people; secretary, wife, friends and even strangers are able to remediate the effect of losing and forgetting things. Of course one could point out that without his status and secretary, things at work might be different for Dr Frances, or that both wife and friends might not be able to shelter him from impairments indefinitely. But my concern with the way that the word ‘ordinary’ is put to work, is that Dr Frances emphasises its connection with the natural, the normal and more importantly the familiar. His own familiarity with some of the listed criteria for ADHD, forgetfulness and distraction, renders them ordinary and common. By extension, the implication is that these symptoms are not worth paying undue attention to: that these problems are unimpressive and to be expected.

In a counter-intuitive way, his call upon an empathetic connection for ADHD symptoms – ‘I have experienced this myself’ – removes a potentially sympathetic response. As noted with chronic illnesses, when milder versions of symptoms are experienced in a large part of a population, it renders claims of illness problematic (Bury, 1991; Richardson, 2005). Because diagnosing ADHD relies entirely on the description of symptoms by individuals, and because there are no biological tests available, the stories of lateness, forgetfulness and inattention, all play a crucial part towards receiving help. To declare that problems of inattention and hyperactivity are ordinary human problems may have for effect the denial that individuals might have their own experience within their specific context. Not everyone might have access to the social scaffolding described by Dr Frances, to keep them sheltered, propped up and prevented from falling.

Words, as Wittgenstein put it, may be seen as chess pieces (1972: § 108), they do things, they exude webs of influence, on this part of the board, rather than this one, supporting or threatening, changing the configuration of the initial set up. The word ordinary, in particular as an adjective used and applied in the varied contexts I have noted, does exactly that. It appears self-contained, one word, yet under this cover it does more than one thing. Just as the tools in a tool-box have different uses, so it is with the word ordinary (Wittgenstein, 1972: § 11). In the field of controversies in which Dr Frances’ book, *Saving Normal* is situated, a question remains, what kind of ordinary life is being threatened and needs saving?

Implicit in many of the uses of ‘ordinary’ described above is a temporal element, in terms of occurrence, day to day, usual and continuous. When applied to ADHD symptoms, ‘ordinary’ has affinity with ‘persistence’ and ‘lifelong disorder’, as in the NHS Choices’ online advice:

‘There is no cure for attention deficit hyperactivity disorder (ADHD), but treatment can help relieve the symptoms and make the condition much less of a problem in day-to-day life.’ (NHS Choices¹²⁰)

¹²⁰ The NHS choices website is described as the ‘front door’ of NHS services and its mission is to give online information to the public to facilitate making choices about their health. See <http://tinyurl.com/ngwyruw> Accessed 9/06/14.

The implication is that if you were to stop treatment, either pharmaceuticals and/or psychological ones, then the symptoms would reappear, unchanged. In other words, once you are diagnosed with ADHD, you may be able to alleviate its effect but it won't go away, it will remain part of you. This is what is meant when ADHD is described in psychiatric manuals as 'lifelong': it is part of your ordinary, everyday experience of life, from birth onwards (UKAAN, 2013). It is also more than that, as it is defined as a trait, a characteristic, something integral to your person which persists over time¹²¹. During the three years I attended scientific conferences in the UK where the concept of lifelong disorder was discussed, I noted the increased use of the term 'chronic disorder' to describe ADHD. What are the implications for the 'chronopolitics' (Ferzacca, 2010) of realigning and representing ADHD through a chronic paradigm? Estroff classically exposed the view that chronicity 'consists of a fusion of identity with diagnosis' which transforms individuals, through time, from having a diagnosis to being that diagnosis and thus associated negatively with a concept of chronic illness (1993). The association of chronicity with mental health problems in particular has been shown to stigmatise and mark individuals for life through being excluded, devalued, discriminated against and humiliated (Link and Phelan, 2001; Estroff, Penn et al., 2004; Good, 2010). Thus, labelling an illness as chronic conceals the nuances and range of experiences; moments of ill health and moments of wellness, moments of hope and moments of despair. As well as reflecting medicine's temporal concept based on the linear chronology of human life, referring to ADHD as chronic reflects what medicine can or cannot do; caring – yes, medicating – yes, but not curing, and it follows that ADHD is then considered in terms of its duration. Can this 'chronicisation' of ADHD equate to Estroff's definition of chronicity as the 'stabilisation, exacerbation and perpetuation of the sick role and thereby of sickness?' (1993: 274). Diabetes is often cited as an exemplar of chronic illness, as it was in the ADHD conference I attended (UKAAN, 2012), yet when the detailed practice of doctoring and of living with diabetes is studied, a different picture emerges, more fragmented, with multiple ways of being with diabetes, requiring work by all parties involved; in other words there is nothing typical in diabetes's chronicity (see Mol, 2009). And so I found that in regard to living with ADHD over a

¹²¹ With Serres (1995) we could think of 'trait' as the line drawn between two points, connecting and linking the events in a person's life through time.

lifetime, support group members and patients described a myriad of ways of living with their symptoms, and in some of those stigma played a role, sometimes as a motivator, as with Tessa, and sometimes as a dark shadow to be endured.

« Les gens vulnérables n'ont rien d'exceptionnel »¹²²

This chapter asked how people live with the diagnosis of ADHD. It has answered this question by examining the multiple and often contradictory ways that the word 'ordinary' is used, focusing on two aspects: being labelled and taking treatments. People in support groups explained how ADHD and its symptoms constituted their normal way of life as they had experienced hyperactivity and inattention throughout their lives. They also described how, by taking stimulant medications in order to bring their symptoms within norms, they found being ordinary to be boring and not worthwhile. When people did use stimulant medications, they told me that a great deal of work was required to adapt the treatment to their individual lives. Their descriptions revealed how stimulants acted on people's lives, swaying relations one way or another, exerting influence by either their absence or their presence in making life fast or slow, exuberant or focused. In contrast, the concern that pharmaceutical companies may be imposing their treatments to solve ordinary problems suggested that symptoms of ADHD might need to be endured without any medication and let the 'tincture of time' do its work (Frances, 2013:98). As I attempted to show, people I met often felt outside the norm; sometimes that was something experienced negatively and they felt stigmatised, yet at other times, being outside the norm made them feel alive. Either way, living with ADHD involved some tweaking, tinkering, experimenting, including with medication, and suggests an active engagement. Nevertheless, when addressing the question – how do people live with a diagnosis of a lifelong disorder? – the trope of endurance looms large. In contrast to its use to denote a passive tolerance and acceptance of a state of being as suggested by Dr Frances, people I met described 'enduring' as punctuated with actions, rests and exhausting repetitions. As Povinelli (2011) showed, endurance is not equally distributed and we

¹²² 'There is nothing exceptional about vulnerable people.' (Paperman, 2011, *my translation*).

could ask why some people sustain the effort to endure and live with ADHD and its symptoms while others do not. Jack's contribution to a support group session showed how the stories he recalled consisted of ordinary events of forgetting, but these had dire consequences, so much so that his account remained as poignant as when I first heard it.

Jack was in his forties, tall, with a gentle kind face, and calm manners when speaking. He explained how he was a carer for his wife who had a serious and debilitating medical condition, for which she needed to go into care on a regular basis. Jack was not formally diagnosed with ADHD at that point, and was working towards a referral from his GP to a specialist. He shared with the group how he suffered with forgetfulness and inattention which affected his life to such an extent that he needed to do something about it. For example, being disorganised meant that he often forgot to give his wife her medication, which led on one occasion to her hospitalisation and got him into trouble with social services who deemed this to be neglectful, and a form of abuse. My fieldnotes recorded how I was struck by the contrast between his calm and upbeat tone and his situation which seemed to me very difficult. Jack was a civil engineer by profession, but ended up demoted at work due to numerous incidents, all related to being disorganised and forgetful. On the occasion that led to his demotion, he was managing part of a very large civil engineering project, which required some tight coordination between different teams. As he put it, if one cog in the machine is missing, the whole project would grind to halt. Jack described how one night, he got a call from the building site as he was about to go to bed. They were missing the equipment essential for the work planned. Jack had forgotten to organise its delivery and attend the site to oversee the work. The work had to be postponed causing financial loss to the company and one of the longest traffic jams in that part of England. The comments of other members were highlighting how bad he must have felt, how awful it would have been, that maybe he should have asked for help from his work. Very quickly the conversation moved towards pragmatic advice and suggestions; one man suggested that he joined him and a friend in meeting weekly in each other's houses and help each other keeping on top of chores and tasks. Jack was obviously interested; his house, as he described it, was in a real mess, falling apart, and he wasn't

able to bring it back to order. One of the facilitators offered to meet with him in order to chase the GP for the referral, and suggested that the discussion moved to the person next to Jack.

The question of how some people endure and others do not has to be situated within the lifespan; thus people sometimes endure and carry on and at other times become overwhelmed, reducing their relations and contact with others or even stopping them altogether. ‘To live with ADHD’ may mean withdrawal from the tiring activities and the perseverance for a while. It may mean not being able to sustain employment, being demoted, being out of work, or isolating oneself and neglecting friendships as some of the people I met described. Beatrice, a support group facilitator who had been actively campaigning nationally for many years, described how she had found herself worn down by the expectation of government institutions on patient organisations to be representative. She explained how, without resources and with ADHD, her symptoms could not always be kept under control. She had not been able to carry on being involved in consultations and other public activities; she dropped all that for six months and, with the help of her husband, gradually felt able to resume with running the local support group. Beatrice shared with me the darker side of running a group, explaining that behind the caring space, there are demands, expectations and endless challenges which limited her ability to care. It seems that endurance in this case is made and remade; things stop and start again, as ADHD and its problems, private and public, do not get resolved, it is experienced as a never-ending and exhausting cycle. In Chapter 7 I introduced Sonia, a performing artist who was not entirely convinced of ADHD’s positive attributes. She described how she felt ADHD was holding her back,

“I want to make things, may it be music or changes. Still I feel trapped on a kind of treadmill of effort that does not get me anywhere. So unless things are set up for me I don’t make things happen, I have to concentrate really hard and be helped by my partner. It doesn’t mean that I have not done anything, but even then, like getting my diagnosis, it took me years to click-on to what was not going well, what to do about it. With my career I still don’t know what to do, it’s horrible, much worse than I could imagine ten years ago. It is true that you’re going to get a propensity of people with ADHD that are resilient because there is something about dealing with ADHD that you need to pick yourself up, over and over again. So it

teaches us – we can try again – until we get diffraction of course, but it teaches us [silence] to [silence]... It's not all due to ADHD but without it I don't think it would have happened this way. It's the, I don't know, the 30% that makes the difference, it's awful, I don't like that, and it's still there.”

In this interview and through conversations in the support group, Sonia made reference to ADHD as an enduring problem that lasted and required resilience because finding solutions or remediation had to be repeated over and over again. Sonia told me how making decisions was often done off the cuff, by improvisation rather than based on calculated choices. Of course, such an approach had disadvantages, and when I met her she felt that it had held her back in her career. During one group conversation, this aspect was discussed directly by older members of the group advising younger ones, suggesting that things did not get easier with age and still required the same amount of effort and attention. I recall Sonia explaining that it gets harder to find the motivation and stubbornness required to deal with ADHD as years went by. That is one lens through which we can see endurance as life-draining, but accompanying it there is a parallel vision that suggests endurance to be life-forming. A lens through which '[w]e see a multiplicity of life forms each with their own immanent forms of belonging, enduring, disregard and obligation' (Povinelli quoted in Reimóndez, 2013: 441). Over the fourteen months that I attended Group C, Sonia developed a stronger role, asking questions and making suggestions to other members and, on one occasion, putting forward a proposal to organise support between the group meetings.

She explained her difficulties with keeping on track with tasks, procrastinating and being distracted away from the calendars and other lists she had set up. She wondered if she could pair with someone in the group and create what she called an 'ad-hoc link for activation', causing both laughter and puzzlement amongst the other members. What would be helpful, she explained, would be to have regular contact by emails, phone or other digital media from someone to remind her and check if she was on track with that day's tasks. Someone said, "You need a PA, a personal assistant, that's what you need". Sonia persisted and suggested that she would reciprocate with something that would be helpful to the other person; "what I need is somebody to be accountable to, who can chase me, and

remind me of what I promised I would do". Nina agreed that she could do with some help too in chasing her doctor's appointment, as she had been on the waiting list for an assessment for too long. They exchanged contact details and as other 'ad-hoc links' were being explored, such as going jogging, helping with tax returns, Sonia suggested that she would email group members and people could start organising themselves¹²³.

By exposing the fragility of ordinary life and her vulnerability to things going wrong, Sonia was also creating a possibility to receive the caring attention of others. The forgetting or impulsive actions that were frowned upon, or even disciplined at work or at home, were as a result likely to be denied or hidden by those who experienced them. In contrast, the support groups offered the space to express, to verbalise, to voice the idea that forgetting and being hyperactive happens in ordinary life cannot be ignored, and needs paying attention to. Within the space of the support group, Sonia was aiming to form webs of obligations between members, reciprocal arrangements, risking to trust each other in order to change their lives (Stack, 1975: 39). When taking care of each other in the groups, members paid attention to each other and reached out to one another by working with the thought that: we are both disorganised; how can we help each other? We are too active; would you come running with me? In *Saving Normal*, Frances (2013) suggested that the prevalence of these symptoms was often a reason for not acting, for enduring quietly, but I have suggested that, on the contrary, the familiarity of this experience is the basis for group members reaching out and caring for each other. In other words, the fragility of ordinary life becomes the loci of creative possibilities. Sonia's experiment revolved around an 'activation' which I took to be the activation of reciprocal attention and care, emphasising that care was not to be taken for granted, but actively practiced and purposefully done. In this way care is the tinkering, interfering and attentive experimentation as proposed by Mol (2010) and, in a broader sense, it is 'everything we do to continue, repair, and maintain ourselves so that we can live in the world as well as possible' (Fisher and Tronto, 1990: 511). Whilst the ethics of care has a clear genealogy in feminist theory (Fisher and Tronto, 1990; Gilligan, 1982), Laugier shows how it has a

¹²³ It remains unclear to me if the arrangements made came to fruition; in conversation members sometimes described going to the cinema or the gym with other members. I did not have the opportunity to ask Sonia directly after the meeting described here.

broader purchase on life as lived by all, by proposing that ‘dependence and vulnerability are traits of a condition common to all, not of a special category – the “vulnerable”’(Laugier, 2013). In other words vulnerability is part of ordinary life and this thesis has attempted to show how, in regard to ADHD within its multiple versions and life forms, vulnerability can also act as a life affirming counterbalance to the darker side of the condition.

Chapter Nine An open window

This thesis has explored the diagnostic practices through which ADHD in adults was enacted in a clinic and in support groups in the UK. I have shown that there were features particular to the diagnostic process and these were due to the opening of an historical window that rendered the diagnosis of ADHD newly available to adults. This move encouraged specific practices aimed at enabling the remembering of childhood events. I found that these elements had implications for the people I met as they deployed various forms of memory practices through acts of recognition, recollection and archiving as well as in the way that they conceived their relations to others, whether family kin or strangers.

The practices I have described are continually changing and the findings of this thesis do not suggest otherwise. Some elements that have changed the practices of diagnosing adult ADHD since I was last in the field include the publication of the DSM-5, the introduction of a new diagnostic tool (DIVA) and the rapid expansion of support groups meetings in both frequency and numbers. Furthermore, it may be that as the diagnosis of ADHD in children becomes more widespread, the cohort of individuals being diagnosed in adulthood will reduce – a change which may alter the diagnostic practices too. For that reason I am cautious about drawing definitive conclusions and instead aim in this chapter to re-trace the praxes that I came across, to explore what they might be pointing towards and finally to suggest what areas would bear further exploration.

A window of time

The questions raised in this research project reach back to when I first came across the diagnosis of ADHD in adults, in the late 2000s, when the academic literature and popular media were reporting a binary opposition in views. On the one hand, the controversies associated with ADHD were presenting the expansion of the diagnosis into adulthood as a prime example of the medicalisation of

the everyday (Conrad, 2007; Timimi and Moncrieff, 2010). On the other hand, scientists were revisiting the claims that children with ADHD could grow out of it, suggesting instead that it was a lifelong and persistent disorder (Asherson, 2010). Given my background of working in mental health services, including campaigning groups in the UK for a number of years, I was intrigued to understand how these two contradictory propositions would manifest themselves in the lives of individuals. What did this mean for the adults concerned; had they remained undiagnosed and untreated since childhood, or did they develop ADHD later in life? If the former was true, then what was the impact on their lives? I also wondered how the diagnostic criteria applied to children would be adapted for adults. Were the symptoms in adults similar to those seen in children and did that make adults equivalent to children; did they regress into childhood? What, if any, was the role of 'Big Pharma'? Was adult ADHD a modern disorder, as some claimed, and what benefits might there be in claiming to have this disorder? I did not cover all of these questions during fieldwork and opportunities to meet adults diagnosed with ADHD helped me narrow my field of interest prior to commencing my fieldwork. In particular, the stories people shared with me suggested that the practice of diagnosing children in the UK that grew from the mid-1990s onwards meant that they could not have been diagnosed in their childhood, despite their ability to recollect severe difficulties related to hyperactivity and inattention.

In other words, this is a unique window of time, when adults over the age of 30 years old, for whom no diagnostic opportunities had existed during childhood now have the possibility of re-imagining and/or confirming their lifelong difficulties in the light of the diagnosis of ADHD. The rates of diagnosing children in the UK, combined with the increased awareness of the diagnosis, suggest the situation will change within the next five to ten years (NICE 2009)¹²⁴. This is not to suggest that ADHD will no longer need to be treated in adults but that it is more likely to be detected in childhood

¹²⁴ NICE guidance described the situation thus: 'There has also been a large increase in recognition of the problem and a corresponding rise in the numbers treated: from an estimate of 0.5 per 1,000 children diagnosed in the UK 30 years ago (Taylor, 1986) , to more than 3 per 1,000 receiving medication for ADHD in the late 1990s' (2009: 16).

and that if symptoms are persistent, treatment will continue into adulthood¹²⁵. The window remains open to further changes and new practices, but what remains specific to the present moment in time is the large number of individuals who may experience the detection, recognition and identification of their difficulties as ADHD in their adulthood. For that reason my research questions focused on exploring how the diagnosis might be carried out to respond to this specific historical context. Furthermore, the concerns expressed by the people I met suggested that the work required for diagnosing ADHD in adults was not restricted to clinicians but that, in line with other disorders (Dumit, 2006), it involved efforts and advocacy from the affected adults themselves. By examining the diagnostic process, my intention has not been to ask, what is ADHD? Instead, I have explored how people develop knowledge about working and living with ADHD whilst the controversies and debates about the condition continue.

Influential methodologies and concepts

Probably due to its being a recent phenomenon, social scientists' attention to ADHD in adults has been scarce. Mostly work has been based in the USA, Australia, Canada and it has adopted either a theoretical approach, often related to medicalisation (Conrad, 1975, 2007; Conrad and Potter, 2000; Tait, 2003, 2006, 2009) or a historical one (Lakoff, 2000; Smith, 2011, 2012; Rafalovich, 2001a, 2001b). Ethnographic explorations of ADHD are rare and this section highlights some that have been influential to my research. Emily Martin, who touched upon ADHD as part of a fuller examination of Bipolar Disorder as a diagnosis enmeshed in American culture, noted it sometimes as a pathology and at other times as a quality (Martin, 2000, 2007). In a brief autobiographical text focusing on ADHD, *Attention*, Martin explored the controversies associated with stimulant medications and suggested that norms of attention are being set in children, only to be broken down in adulthood:

¹²⁵ The prevalence of ADHD in adults in the UK and Europe is estimated as ranging between 2% and 5% (Kooij, 2010; Matheson et al., 2013b).

‘We are creating a notion of an ideal child who is disciplined and attentive to adults. This child then ideally becomes an adult whose attention is creatively dispersed and fragmented. The goal of marketing campaigns can then ironically come to be capturing a good market share of those fragmented adult attention spans.’ (Martin, 2002: 36 -37).

Goodwin (2010), who produced another autobiographically inspired project, specifically explored Hyperactivity in the San Francisco Bay, in children and adults. He argued for a notion of hyperactivity which transcended the condition’s medical and pathological definition so as to encompass dynamic and creative aspects of life. In the UK Sarrami Froushani (2009) explored clinicians’ approach to diagnosing ADHD in adults and found high variations in diagnostic outcome due to lack of awareness and training as well as varying social factors, for example media and public controversies which influenced clinicians (on this theme see also Rafalovic, 2005).

The work conducted by EPOKS (European Patients’ Organizations in Knowledge Society)¹²⁶ was influential in the development of my research. Vololona Rabeharisoa and Madeleine Akrich and their colleagues examined the contributions of patient organisations in influencing the governance and delivery of health issues across five countries in Europe and in regard to four health conditions, including ADHD (Akrich et al., 2014; Rabeharisoa and O’Donovan, 2013). Together they have put forward the concept of ‘evidence-based activism’ to describe the knowledge production activities that patient organisations engage with, not in opposition to the medical establishment but ‘from within’ (2014). They suggest that “‘evidence-based activism’ entails a collective inquiry associating patients/activists and specialists/professionals in the conjoint fabrics of scientific statements and political claims’ (ibid.: 2). Some of the specific circumstances and particular demographics related to the patient organisations studied¹²⁷ might undermine the possible generalisation of the concept, nevertheless ‘evidence-based activism’ questions and challenges the notion of evidence that circulates in biomedicine. Chapters Eight and Five of this thesis discussed the kind of experiential knowledge that is produced in support groups and explored how collective experience circulates when there are

¹²⁶ See <http://www.csi.ensmp.fr/WebCSI/EPOKSWebSite/> Accessed 05/03/2013.

¹²⁷ The Rare Diseases Organisation is particularly interesting for the impact it had at European Policy level despite the numbers involved, (see Rabeharisoa, Callon, et al., 2014).

no explicit collaborations between patients and clinicians/scientists. I showed that in some cases the collated experiences are subsequently shared online on forums that are also visited by clinicians who engage in professional debate. In other cases I have discussed how support groups may seek to establish collaborations not only with clinicians and their institutions but they also, at times, favour making closer links with non-medical bodies, such as the employment agency and criminal justice systems. In this respect, the use of the knowledge produced by support groups is strategically and often simultaneously deployed across different sites in the public domain for different reasons.

Exploring and exposing the complexity of living with and being treated for ADHD is also at the core of Ilina Singh's work and has promoted the voice of children in the debates surrounding stimulant medication. In particular, Singh has shown how the importance of considering biological alongside familial and social factors which influence children with ADHD, a model she described as the 'ecological niche' (Singh, 2012b). Singh argues that 'children's behavioural development must be seen as a fundamentally situated and relational process in which there is an ongoing and mutual process of shaping and of transformation between child actors and their immediate and proximal social and physical spaces.' (Singh, 2011: 890). By emphasising the agency of children, and at the same time the constraints surrounding them, Singh shows that the impact of treatment should be considered within a 'whole system method', through a 'social efficacy approach' (see also Van der Geest, et al., 1996; Whyte et al , 2002). Thus Singh contends that stimulant medication does not change children's sense of self at a crucial time in their development per se; she argues that dialogues with children show that most children do not feel that their 'authentic self' is at risk, but that there are circumstances, often dependent on the socio-political environment that might impact negatively on the efficacy of the treatment (Singh, 2012a).¹²⁸In Chapter Eight of this thesis, the role of stimulant medication is explored in the lives of adults, who described how their pharmaceutical treatment was neither all good nor all bad, but changed depending on the situation they found themselves in. I have found it helpful to think of stimulant medications as 'actants' (Latour, 2005) in that they are the

¹²⁸ The Voices Report (2012b) provides examples of the impact of 'playground ethics' on treatment, such as the way a bullying environment might undermine the role that stimulant medication might have in containing impulsive behaviour.

source of actions beyond their pharmacological properties; stimulants acts on people's lives and their use can be moulded to the uniqueness of an individual's everyday life. Thus the fast and short acting element of the medication's compound, its pharmacokinetic property, provides flexibility for its ingestion; in other words medication can be taken strategically for optimum effect on people's social, professional and family lives. Paying attention to the details of how stimulants were used revealed the agency of both the pills and the individuals.

Collaboration

My research project and its design started in the conversations I had over a number of years with members of the patient organisation AADD-UK which eventually led to a formal collaborative intent. How this would be translated into practice was left quite open and undefined and remained so throughout my fieldwork. It was clear that my research benefited from access to support groups and conversations with the organisation's founders but how that was beneficial to their aim was not always clear. For example, the survey I conducted provided helpful data for my research and it was published on AADD-UK's website, but its collaborative value remains unclear. In contrast, the agreement I had with the clinicians and scientists was clear and explicitly formulated through the bureaucratic procedures required for ethical approval; these spelt out my role and position at least in broad terms.

The fact that collaboration with the patient organisation was easier said than done and did not need further spelling out in the clinic, took me by surprise but, on reflection, this may be indicative of asymmetrical relations within collaborative networks. In a recent collection of essays, Konrad (2012) noted how calls for collaborative work were ubiquitous in all kinds of research arenas, including the bio-medical and the social sciences, due, in part to collaboration having an inherent positive attribute attached to it. Thus to collaborate is to open opportunities for exchanging knowledge, expertise and resources from different sources in the belief that this accumulation of views will bring positive outcomes including the resolution to a common problem. Such a vision of collaboration is particularly

evident in health-related research as it provides the means to include different contributors and often different disciplines in the hope of alleviating suffering. This representation applied directly to my research as it found itself at the intersection of an already-existing collaborative network, some arrangements being more formalised than others, for the purpose of understanding adult ADHD, biologically and otherwise. UKAAN and AADD-UK are both organisations that engage in collaborative networks, including with each other, which could be described as ‘dispersed collaboration’ (Konrad 2012). This collaborative mode favours virtual and fluid connections and forms what Callon has called ‘hybrid forums’ (2009) where lay and specialist experts debate and discuss common issues. Yet all is not always what it seems as the moral reward for those entering collaborative agreements has the potential to render the actual collaborative practices obsolete (Strathern 2012). The contrast between the collaborative expectations of the clinic and the patient organisation, one unsaid but acted upon and the other formalised yet stumbling to get concretised, leads me to reflect on how the rhetorical force of collaboration affected my position in the field.

Through the numerous conversations and questions that I engaged with in the support groups and the clinic, it became evident that initially I was perceived by all parties as an outsider bringing in some expertise. The ethnographer as an outsider is a classic trope in anthropology, which, in the context of my fieldwork, requires some nuancing. In the first instance this trope calls upon the image of the anthropologist who comes from afar, spatially and culturally, who studies a group of people through becoming sufficiently familiar with the language and ways of life, and yet remains distant enough to formulate some theoretical conceptions of a particular situation. Being an insider-outsider has been part of the knowledge toolbox and methodological orientation of anthropologists since ethnography was theorised (Malinowski, 2002; Nader, 2011; Stocking, 1984). The latter end of the 20th century saw some challenges to this ‘exotic anthropology’, and ‘the distances between ethnologists and the people they observed – once seen as informants – have constantly decreased’ (Peirano, 1998: 105) and thus anthropologists turned to study at home. Anthropologists do this within their unique circumstances and the home element of their research varies from one person to another depending on their connection with it, leading some to describe themselves as native anthropologists (Ohnuki-

Tierney, 1984), or as partial insiders (Narayan, 1993). A number of factors in my circumstances rendered these categories inadequate; I was born and brought up in France but have lived for 32 years in London; I have worked in the field of mental health for twenty years, but never in an ADHD related field¹²⁹; I was a non-clinician in the clinic and a neurotypical in the support groups.

In *Partial Connections*, Marilyn Strathern (2004) described herself as feminist and anthropologist, explaining that each separate identity was contained in the other and connected, not fully but at least partially. Similarly I found it hard to position myself into separate identities of outsider and insider as I am always both, to myself and others and my presence in the field was no different. Inspired by Mol's call for research to improve care practices, rather than proving them right or wrong (2006), I have striven to contribute to the debates I found in support groups and clinic. In practice, this has meant that I attempted to establish a symmetrical positionality (Latour, 2012) that required the suspension of value judgements, a kind of reflexivity that offered opportunity for negotiation and, most importantly, considered that participants might know more about the phenomena at hand than I did. It also involved learning 'the art of speaking well to people about things that really matter to them' (ibid.: 58 *my translation*), requiring me to enter into dialogues so as to check my understandings before suggesting ways to resolve difficulties. The collaborative process I have described was always negotiated and re-negotiated in the different sites of my fieldwork. Sometimes it led to nothing discernible or even to disagreements, but at other times it has informed my argument.

In this collaborative spirit, this thesis aims to contribute to an anthropology of ADHD by exploring how the condition is made in the social and political contexts of the UK at the beginning of the 21st century. My research is conceived as an opening for further explorations and is intended to be complementary to other medical and non-medical studies.

¹²⁹ My familiarity with the mechanics of the NHS proved to be very useful and significantly simplified the process for being awarded an honorary contract which allowed my presence in the clinic.

Widening the diagnostic process

Ray : “There isn't one ADHD. Look at genetics, they were hoping to find a gene, but they are many, and it makes me think it isn't one condition. And a spectrum idea is more useful for having strategies, sometimes my ADHD is a pain, other times I don't mind it, it can even be helpful.”

Nader's clarification of her classic concerns from 'studying up' to 'studying up, down, sideways simultaneously' (2008), encouraged me to retain an open mind as to how the diagnosis might be done and I decided to work across clinic and patient organisations (see also Bowman, 2009; Hannerz, 2003). At the point of formulating my research project, I was warned of the complications associated with extending my fieldwork across clinical and non-clinical sites; for example there might be practical and ethical problems of access, but also of positionality as an ethnographer. I found those complications aplenty. Yet this strategy opened possibilities for me to move beyond the seemingly stubborn divisions between these sites. Rather than confronting head-on and statically the intractable and polarised positions taken towards ADHD – for/against, real/not real, experts/non-experts – (Asherson, 2010; Timimi and Moncrieff, 2010), I moved back and forth, at times within the space of a day, between a range of support groups and clinics. Sometimes they were at odds with each other, and my position became uncomfortable. Sometimes I was regarded with suspicion or, on the contrary, I was sought as an ally¹³⁰. At other times I found the clinic and the support groups to be in accord with each other, even supportive of each other, sometimes from a distance or via virtual means, but at other times engaged in close face to face encounters¹³¹.

Veena Das and colleagues (1998) showed the clinic to be an extension of other spaces where caring and looking after others also take place, albeit through other modes and practices. Rather than a flow of techniques and discourse that would proceed from the clinic to permeate other domains of work, or

¹³⁰ In such situations I aimed to develop what Van Der Geest (2007) described as 'permanent sensitivity', which I experienced as providing patient listening, sometimes avoiding thorny topics, and not jumping to conclusions.

¹³¹ Patient organisations were invited to contribute to all scientific conferences during my fieldwork, as well as to more expert forums and policy working groups. Some support groups invited their local NHS psychiatrists, not always with comfortable results; nevertheless, dialogues were initiated.

the home, I suggest that there is more of a looping connection, within which practices and concepts circulate, albeit the origin of such exchanges remains an object of speculation. Extending the diagnostic process in space and time outside its traditional clinical context also provided a means to include the voices and concerns of ‘experts by experience’ alongside those of the ‘experts by profession’. Chapter Seven discussed some of the ways that support group members re-appropriated ADHD for themselves, transforming deficits into skills adapted to their environment as well as making the condition the basis for connecting and making kin with strangers.

It has been the aim of this thesis to describe the actants involved in making ADHD from a variety of sites so as to dispel the binaries listed above that represent ADHD as field of contestation (Crossley, 2006). Recognising that power imbalances exist between the parties involved should not obfuscate the complexities of their relations, but the practices that I observed have highlighted the connections that can be found between biomedicine, patient activism and pharmaceuticals. Thus I described in Chapter Eight, how the distinction between expert and lay knowledge became blurred, as support group members charted their experience of taking medication, in terms of dosage and timing, activities which in time influenced clinicians in their prescribing practices. In Chapter Four, pharmaceutical medications were described as one option out of an array of strategies for living better with symptoms. I showed how such strategies were neither an easy solution nor a ‘magic pill’ imposed through a medicalisation process, but an act that would engender engagement and adaptation. Similarly, the notion of activism in relation to contested illness was shown in Chapter Two to be nuanced by the actions and determination of clinicians towards a broader recognition of ADHD in adults. I have aimed to show how support groups contributed to the diagnostic process by producing knowledge concerned about living with ADHD; sometimes this knowledge worked in accord, in parallel or in dispute with medical and administrative institutions. Widening the lens of the diagnostic process and including non-clinical actors is to attend to the voices of those directly concerned with health as well as those concerned with illness (Canguilhem, 1991). It is also an attempt to redress the balance of representation of knowledge production in matters of health and to suggest a transformation of ‘a political landscape that is defined as much by existing scholarship as it is by the

exclusion of those that are defined as incapable of producing knowledge that matters.’ (Nathan and Stengers, 2004: 191 *my translation*).

By listening to and bringing together the voices and actions of clinicians, patients, stimulant medications, support groups and old documents, this thesis has shown the complexity and multiplicity of the relations between them which arguably make different versions of ADHD and ‘facilitate different realities’ (Van de Port and Mol, 2015). In as much as this is my argument, the same idea was partially present in the conversations and interviews I had with by the people I met. Ray’s quote above was one example, showing how the multiplicity of ADHD seemed to be accepted; it was made of many genes, it had many realities and ways of being experienced by one person, yet it remained ADHD. Similarly the conversations with clinicians documented in Chapters Two and Five highlight the many ways that ADHD was categorised; for example, as Specific Learning Disability in the education milieu, as neurodevelopmental disorder in the mental health clinic and previously as neuropsychiatric disorder or Minimal Brain Damage. The important element here is not the different realities that are enacted in living ADHD in these different contexts, which could suggest that they are mutually exclusive or as if moving in separate worlds. Instead my research shows how the different versions/realities of ADHD made through diagnostic practices can be connected to one another, and how they are often experienced simultaneously. In the preceding chapters, I documented how people described the way that they lived with ADHD in ambivalent terms; it is never all bad, nor all good, but changes from one day to another, often more rapidly than that, and ADHD is experienced through relations with others. Thus school reports, themselves records of good or turbulent relations, were able to bring useful biographical continuity whilst at the same time negatively colouring memories of childhood. In other words, the multiple realities of ADHD are connected through the continuously changing webs of relations between people and/or things.

‘Remembering is the discovery of kinship connections’

(Lambek, 2007:220-221)

My account of the diagnostic process outside the clinic highlighted the network of relations and practices across sites which in turn enabled this thesis to draw out two interrelated themes concerning memory and kinship. The chapters in this thesis have followed a temporal organisation starting from the point at which a clinical diagnosis is confirmed and they have then moved back in time through the journey described by the people I met inside and outside of the clinic. Chapters Two to Five have examined the central role that remembering and forgetting played in the clinic and the support groups in order to identify ADHD. By examining the emergence of the neurodevelopmental concept, I asked how normative notions of progress could impact on the way adults with ADHD might narrate their life stories as part of the diagnostic process. I have shown that in both sites people used structures to support and aid the process of remembering childhood events by using questionnaires and old documents, or by creating archives for reference and by devising appointment systems which functioned as caring practices. I have suggested that their purpose in doing so, was to create particular versions of ADHD, some more authoritative than others but not necessarily in opposition. Practices of remembering were also shown to be exercised towards the present in order not to forget daily tasks. Support group members called these practices ‘strategies’ which I described with reference to Foucault (1988) as transformative practices. Members regarded such strategies as requiring repetition in order to achieve the aim of living a better life.

In contrast the flash-like ‘moment of recognition’ identified by many support group members happened when they saw themselves reflected in another as if in a mirror. Their first encounters with ADHD were recounted to me as the unveiling of a knowledge that had already been with them, a ‘recognition’, which the morphology of the word suggests in this case to be a combination of identifying and taking to be true. Such moments of recognition figured in the narratives of many support group members and provided them with a sense of continuity in their lives. Just as old documents could be seen as evidence that hyperactivity and/or inattention had been present throughout their lives, the flashes of recognition were discussed as triggers and turning points. Other stories suggested that it

took the interventions of others, relatives or clinicians, in order for individuals to consider that their difficulties might be related to ADHD. I found that clinicians also discussed the process of identifying and discerning ADHD from other possibilities in terms of recognising something that was familiar. The interviews, informal conversations and observations in the clinic suggested that diagnosing was based on pragmatic and practical clinical skills that are developed over time. As I saw it, the face-to-face encounters with patients over months and years helped clinicians develop a repertoire of case studies from which to draw and recognise symptoms. Similarly to the ways that people in the support groups explained how they recognised themselves in others – the way they moved or talked – the clinicians described recognising traits and signs in patients that fitted with the typology they had built. In other words, memory as recognition played a central role in the diagnostic practices of ADHD, in and out of the clinic, as clinicians and support group members relied on recollection and recognition in order to make ADHD. Thus I have shown that the practices for identifying and diagnosing ADHD in adults in the different settings were part of a family of practice that sought the whole picture of an individual rather than focusing on a singular essence for the disorder itself (Wittgenstein, 1972).

It is important to note that for clinicians and support group members alike, recognising and diagnosing could still leave them in doubt and uncertain that the difficulties being experienced would best be explained by the concept of ADHD. Thus clinicians often brought complicated cases to ‘case formulation’ meetings where colleagues were encouraged to contribute to the hypotheses. Similarly, support group members may have recognised themselves in another diagnosed with ADHD yet remained ambivalent and not sure if ADHD encapsulated what might be wrong with them. Just as clinicians referred to their peers, so individuals attended support groups for the same purpose, putting their suppositions to the test. By highlighting the common diagnostic practices between clinicians and patients, this thesis is contributing to a better understanding of ‘self-diagnosis’, a non-medical process which is often portrayed negatively¹³². In line with Canguilhem (2009), I suggest that the process of

¹³² My argument is that the specific moment in time of my fieldwork highlighted common diagnostic practices, but there are of course many practices that differ between the clinic and support group; I have described the formal, statutory and gatekeeping role that the clinic played, and the informal and voluntary organisational

identifying ill health starts with the lived experience of the patient, which as I have shown, is hypothesised and tested, often before any contact with formal medicine is initiated. It is further proposed that when this process is misunderstood by clinicians, the clinical encounter is rendered ineffective (Matheson et al., 2013a).

The connections between remembering and kinship were explored more specifically in Chapters Six and Seven of this thesis. I have suggested that recognition was a part of memory, but it is also a part of kinship, in that kin can be recognised or disowned, accepted or rejected. In line with Lambek's (2007) suggestion that kinship should be thought of as a verb, as a set of practices, just as remembering is, I explored the unexpected recognition that can occur between a parent and child through ADHD. Whereas the moment of recognition described previously concerned strangers, Chapter Six explored how parents with children who are diagnosed with ADHD found themselves re-examining their past through their own childhood memories and their child's stories. In this way I suggest that memories of childhood associated with ADHD were triggered upstream from a child to its parents, as parents recognised themselves in their child. Whereas common traits and characteristics are usually seen to flow downstream from parent to child, confirming a sense of identity and belonging, here a new sense of identity is suggested through a descendant. In line with the notion of 'teknonymy', where parents are named after their child (Bloch, 1993), the parents I met were made into adults with ADHD through their child's involvement with the condition. Thus parents adapted their family life to living with ADHD and embarked on re-imagining kinship relations with their own children whilst in the process of being diagnosed. The clinical practices for diagnosing ADHD in adults encouraged the movement of memories and stories between generations and traced a lineage that was also understood through biomedical paradigms in terms of the causation of ADHD. In the context of the stigmatisation of ADHD for both children and adults, I found that for some of the adults I met, the need to share a different way of being with their child provided a sense of empowerment

position the support group occupied, each with their distinct administrative and bureaucratic practices. At times clinic and support groups were clearly not in agreement; waiting times was one such an issue, and generally access to resources caused disagreement. I have described the complicated and at times uneasy collaboration attempted between these actors.

and solidarity which unexpectedly turned them into activists, advocating for resources and more broadly for an acceptance of diversity (Rapp and Ginsburg, 2011). Re-imagining kinship relations in view of the unexpected recognition in their children, was for some an experience imbued with contradictions, as they felt both relieved about having treatments for their symptoms, and yet guilty that their child's difficulty was probably due to them.

In the support groups, I found that the recognition given to biological kin was also exercised towards strangers on the basis of a biology grounded on difference, described in this context as neurodiversity. Thus the vertical biological links were augmented by horizontal relations described through kinship language. People described how their similar 'brain wiring' marked them as different from other people and from the norm. As I saw it, sharing a particular biology and sharing stories and memories became practices through which kinship was forged. I found that discussion about neurodiversity took place, more often than not, with language depicting relationships and a sense of belonging, rather than neuroscientific discourse. As in other parts of this thesis, the heterogeneity of the people I met brought certain nuances to the notion that kin relations were being shaped on the basis of a neurological diversity; they highlighted how the description of ADHD as 'gift' was often experienced at the same time as a curse. Yet, as the membership of all the ADHD groups included individuals who had other neurodevelopmental disorders, principally Aspergers'¹³³ and Tourette's, I suggest that diversity is celebrated through the relations between people who share being different, rather than because of the connections between neurones and synapses. The mutual recognition that members gave each other in the support groups gave a voice directed towards the re-appropriation of ADHD, a call for caring and paying attention to ordinary problems. As invisible and quiet as it may be, the on-going care and sharing taking place in the support group formed a kind of activism, an ontological politic based on the making of pragmatic knowledge directed towards alleviating suffering which in turn shaped a particular reality.

¹³³ This nomenclature is no longer formally used since the publication of the DSM-5 at the end of my fieldwork. Aspergers' syndrome forms now part of the Autistic Spectrum Disorder (DSM-5, 2013).

Vulnerability as a shared condition

I have described the journey that led to getting a diagnosis, from the kinship relations that were formed through recognising a different kind of biology, as well as memory practices in the support groups and the clinic. If I have presented the process by starting at the end, it is partly to recognise that my own starting point in the research inquiry was the clinical diagnosis. To start my inquiry in the clinic allowed me to unpack what seemed to be a finished, complete category, stabilised through a number of DSM editions over the last 35 years. The reversed chronology of the chapters also paralleled the retrospective work undertaken by the people I met. Collectively the chapters suggest that giving and receiving a diagnosis does not bring solutions in itself and that living with ADHD is on-going and requires persistence and endurance. In Chapter Eight I showed how treatments, which can alleviate symptoms rather than effect a cure, required attention and effort in order to make them 'work' for individual needs. Thus people adapted their stimulant treatments to meet their life demands, as much as they had to adapt to the properties of the chemical compound. As a result I have suggested that stimulant treatments acted on people's lives beyond their physiological affect. When they were ingested, just as often when they were not, these treatments co-produced and participated in the making and maintaining of relationships with others. The presence and absence of treatments in people's lives were parts of the balancing act that was described to me; being able to do ordinary things that made for a better life, whilst wanting to keep all that is 'extra-normal' with living with ADHD. Paying attention to the contradictory use of the word 'ordinary', as used by support group members and 'opponents' of the concept of ADHD, helped me to show the complex practices that people put in place and worked to maintain in order to live with ADHD. The notions of never-ending effort and repetition were often used when people discussed the fact that there was no cure for ADHD as it was lifelong. For the cohort of adults aged 40 plus, the condition was often accompanied by a sense of unremitting exhaustion.

Whilst they are part of enduring, bearing with and carrying on living with ADHD, the caring practices I described in support groups suggested that endurance itself can also be life-forming and empowering. The activation of reciprocal attention that Sonia was hoping to put in place was one such caring practice which showed how vulnerability and dependency were part of enduring. In this thesis I have provided glimpses of the care given by partners, relatives, doctors, parents and have illustrated the difference such care made to enduring and living with ADHD. I have highlighted in detail the care-exchange practices which I am suggesting followed from a shared vulnerability, for example the archival and classificatory work described in Chapter Three and the clinic's appointment system documented in Chapter Two. As I saw it, such activities were initiated through the acknowledgement and disclosure of vulnerability to others; sometimes the sharing of confidences made in despair opened an opportunity for being cared for. By contrasting the different kind of relations and exchanges taking place between neighbours or relatives in her neighbourhood, Han (2012) showed that neighbours did not share and gave to each other on the basis of a shared intimacy, but instead on the basis of vulnerability as a shared condition. Han suggested that neighbours concealed their acts of kindness and giving so as not to openly acknowledge the crisis that each person might be facing. Through quoting Cavell 'We are endlessly separate, for no reason. But then we are answerable for everything that comes between us.' (ibid.: 88), Han argued that acknowledging another's vulnerability generates a responsibility to respond¹³⁴. Sonia and the other members of the support group were seeking that accountability and reciprocity through sharing their vulnerability, precisely because it was a shared condition in that space. Other conversations taught me that at work or in other public spaces, members of the group concealed their vulnerability, possibly for the reasons suggested by Han but also in view of the stigma attached to the diagnosis. Whilst vulnerability can be theorised as part of the human condition and of ordinary life, exposing it to others poses a risk that it

¹³⁴ This is reminiscent of the reciprocity and obligation implied in the exchange of gifts described by Mauss (1923) and discussed in Chapter Seven. To follow this trope, Han's argument posits the disclosure of vulnerability as a gift to another, requiring a response that is experienced as a burden by the person acknowledging. The example I provided situates the disclosure of vulnerability as a pre-requisite for attending support groups with the expectation of exchange that is often named 'sharing'. The burden linked to such obligation has been hinted in different part of this thesis; such as when Beatrice was overwhelmed by her role of facilitator or when Michael was reprimanded for not attending the group more regularly (in Chapter Eight).

may not be recognised or acknowledged¹³⁵, as I described in the ‘coming out’ stories in Chapter Five. The support groups, as I saw them, were networks of relations that recognised and acknowledged that vulnerability was at the core of living with ADHD and that maintaining relations with the world was a fragile balancing act, which if it failed could leave people isolated or bankrupted. In this thesis I have attempted to show the variety of practices that people deployed in the context of acknowledging the vulnerability in their lives, such as practices of remembering, of making kin at home as well as with strangers, and taking care/paying attention to each other in support groups.

Memory and kinship are concepts which are difficult to distinguish from one another when embedded in everyday life. The way in which they were experienced was not named or discussed using those terms within the support groups and clinic. Lambek offers a convincing argument when describing the word ‘care’ as capturing the entanglement of memory and kinship in everyday life.

‘To *remember* is to *care*...to care for and to care about; but also to take care of someone; to take care, as in to be careful; to have cares, as to be full of care; and to be vulnerable, to care what other say and do. Caring is the form of remembering generally characteristic of the ethos and practice of kinship everywhere.’ (Lambek, 2007: 220)

Throughout this thesis the diagnostic process I have described has been enacted through caring practices that called upon remembering and recollecting whilst making kinship relations; for example Chapters Seven and Eight showed how the relations forged in the support groups were described using the language of kinship, an extended kinship based on the shared condition of being vulnerable; Chapter Six described how a father recognised himself in his son, calling upon practices of remembering his own childhood, of caring for his son and being cared for by his partner. The chapter also showed how the father re-imagined his kinship relations to his son and family on that basis. An important element arises from my exploration of memory and kinship practices in the making of ADHD: adults with ADHD are made by children. I have noted in Chapter Six, drawing on Strathern (1992), that adulthood is always a constructed concept which requires social and legal intervention,

¹³⁵ Vulnerability is theorised in many ways and sometimes not as part of the human condition, but as a result of specific economic and political conditions (Quesada, Hart, and Bourgois, 2011).

whereas childhood is accepted as a natural fact, in itself. I demonstrated that such a notion was enacted in the ethnographic example of the Zafimaniry who only became social beings at the point of building a house and giving birth to a child (Bloch, 1993, 2006).

The role that reproduction plays in making adults into full members of society can also be recognised in UK society in a general sense, but I want to suggest conversely that during my fieldwork there were practices specific to the concept of ADHD which position children as makers of adults¹³⁶. Firstly, there were institutional practices, in particular within psychiatric institutions, which have clustered symptoms under the category 'ADHD' and theorised it as being lifelong. As I described in Chapter Two, it followed from this recent reconceptualisation that, in order for adults to satisfy the diagnostic criteria, the presence and persistence of symptoms in their childhood must be demonstrated. Such a conception has placed the act of remembering childhood as central to the diagnostic process, and has located memory practices within the individual patient, thereby making them good or bad historians. Secondly, diagnostic practices in the clinic have augmented the identification of symptoms through a list of criteria with a prototypical mode, in which resemblance and recognition have extended the location of both memory and kinship. Thus it became possible to remember turbulent childhood events with the aid of old documents and family friends, but importantly this process served to find the origin of an adult in his or her childhood. The prescribing practices have strangely emulated this image as adults could only be prescribed with licenced treatment intended for children as there were no stimulant medications licenced for adults. Finally, in support groups, children diagnosed with ADHD made 'accidental activists' of their parents, leading them to seek support, resources and, ultimately, for some to be diagnosed and so become adults with ADHD.

The practices for remembering and making kin were enacted in various ways but always remained central to the way of identifying ADHD. Kinship relations developed and were maintained with strangers on the basis of vulnerability as a shared condition; remembering was done collectively in making archives and classifications, and memories were triggered upstream from child to parent, in a

¹³⁶ Strathern suggested that the Euro-American concept of kinship imagines that parents create children in reality, and that children create parents metaphorically (2011). Here I am bridging both propositions in suggesting that in our window of time, adults with ADHD are created in reality by children with ADHD.

cross-generational version of Wordsworth's line. As in the clinic, remembering and making kin in the support group was stimulated and mediated by and through objects, such as medication, mobile phones and archives. I have argued that it is the recent changes in classification from which clinical practices were developed to diagnose adults that has created a specific moment in time when a large cohort of individuals rendered visible how it is that parents can be made by children.

By showing that children made adults with ADHD, the expanded diagnostic process I proposed highlighted that identifying and diagnosing ADHD in adults required a range of caring practices. These included developing kin relations with strangers and mapping memories of lived and shared experience of symptoms; such actions evolved within networks of relations, between actants, people and objects, family members and medication, doctors and employers, as well as between formal and informal classifications and between parents and their children.

What next?

‘The strength of the anthropological approach, certainly when it attempts to come closer to the experience of pain, illness, and suffering, is not that it can pride itself on capturing exactly what the other experiences. Its strength, rather, lies in its modesty and in the awareness of the incompleteness of the attempt. The anthropologist, who sincerely tries to participate, has done what he can; there is no better option.’ (Van der Geest, 2007)

I started this chapter by pointing out how this study does not claim to offer a finite description of the diagnostic process of adult ADHD in the UK in view of continuing changes in that field. There are also limitations to the areas of inquiry that this study has engaged with, in particular through the limited access to the greater part of the everyday life of the people I met. I was able to observe and participate fully in the life of the clinic, albeit this setting was bounded in time and space. In contrast, it was only on rare occasions that I was able to interact with support group members in the rest of their daily lives. Sometimes I met with them in groups, conferences and cafes but no opportunities

arose to visit them at home or at work during my fieldwork. Further study could involve people diagnosed with ADHD in research at home and at work¹³⁷ which would require an entirely different research design, as well as a different ethical and theoretical emphasis than the one I applied. Below I suggest other avenues for research that may contribute to the growing field of the anthropology of health, and the studies of narration and lifecourse.

Within the constraints of my study, a number of issues I came across during my fieldwork were left unexplored, mostly due to lack of time and difficulty of access. One case in point concerns my interest in stimulant medications and the multi-faceted controversies associated with them. It has been remarked that an inside perspective of pharmaceutical companies' activities is rare and research in such contexts could provide better understanding of the logics, principles and values which underpin such organisations (Petryna et al, 2006; Van der Geest, 2006; Van der Geest et al., 1996). I was struck in my fieldwork by the fact that stimulants, recognised as the most efficacious treatments and recommended by the NICE guidance are licensed for prescribing to children, but not to adults. Regulatory bodies have in the last ten years turned down a number of applications by pharmaceutical companies for licensing their product for adults, despite these medications already being licensed for children¹³⁸. Whilst I engaged in informal conversations with scientists and pharmaceutical company representatives on this topic, the complexity of the administrative, ethical and economic issues involved in the European-wide process of drug regulation required more resources than this study could provide. A research focusing on the political, economic, social and clinical process for the regulation of Class A drug treatments for adults would contribute to a better understanding of the forces in play that render some treatments available and others not.

I have touched upon the implications of defining lifelong difficulties related to hyperactivity and inattention in terms of chronicity, a term associated, in regard to mental health, with stigma and

¹³⁷ The medical view is that ADHD is not observable in the clinic as the artificial context there leads patients to compensate and hide symptoms. If this is true, any outside observer/researcher may have the same effect regardless of the setting.

¹³⁸ See the Medicines & Healthcare products Regulatory Agency websites for public assessment reports: <http://tinyurl.com/owt629g>. Accessed 18/07/2014. Also see Abraham and Lewis (1999) for an examination of the harmonisation of drug regulations process between European countries.

exclusion. By focusing on a cohort of adults over the age of 30 who could not have been diagnosed as children, this study has mainly examined retrospective accounts of difficulties. In view of the fact that diagnosing and treating of ADHD in adults potentially requires very few medical interventions and patients can initiate and maintain on-going self-management strategies including medication, future study might valuably undertake long-term tracking of the experience of living with the diagnosis of ADHD. Qualitative longitudinal research could provide the means to capture both social and biographical change over time, and could delineate changes in formal discourse and personal narration, and provide insights on the development of ADHD through the life course. I would suggest that intergenerational research would be of particular relevance for the topic discussed in this research, as the emergence of the diagnostic in adults in the UK would make it possible to examine how, at any one moment in time, ADHD may be enacted across three generations simultaneously whilst also providing an historical perspective.

Finally, revisiting studies by other researchers, or adopting the classical anthropological tactic of revisiting field sites, could engage directly with questions that arise in regard to the potential proliferation of ADHD in the UK. There are present concerns in the media and in some academic circles that ADHD will become part of an over-diagnosis trend which may medicalise all aspects of everyday life (Donnelly, 2013; Moynihan et al, 2012; Press Association, 2013; Radcliffe and Timimi, 2004) . My study has argued for an approach that seriously considers the local determinants in health (Lock and Nguyen, 2010) through examining the range of practices and actants involved in the making of ADHD. Thus the stability of the present practices and institutions, formal and informal, cannot be taken for granted, nor can their progression in line with the USA be speculated upon. A repeat study could re-examine such topics as activist practices and prescribing practices as well as the impact of the DSM-5 criteria and it could support a better understanding of how the diagnosis of ADHD in adult fares in the forthcoming years in the UK.

This study has aimed to broaden the sites of medicine in relation to diagnosis beyond the clinical encounter and has sought collaboration practices with various partners in the clinic, the support groups and patient organisations. There are many more collaborations and partners to call upon in

future than those who participated in this study and I hope that such alliances will spur further research (Viney, Callard, and Woods, 2015). In participating in the range of actions and situations described in this thesis, I worked to promote respect for all involved and in the hope of making a positive impact against the stigmatisation of ADHD.

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