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parents' groups' scientific and political framing of an unsettled
condition

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**Attention Deficit Hyperactivity Disorder in France and Ireland:
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Claire Edwards, Etaoine Howlett, Madeleine Akrich, Vololona Rabeharisoa

Abstract

Attention Deficit Hyperactivity Disorder (ADHD) is an unsettled condition whose history is characterised by controversy amongst medical professionals. Its emergence has frequently been interpreted as an example of the growing 'medicalisation' of society and the individualisation of social issues. This paper examines how groups representing children with ADHD in France and Ireland engage within this contested medical domain, and challenges the frequently made association between the process of 'medicalisation' and 'de-politicisation'. We argue that through the weighing up of different bodies of knowledge, parents' groups redefine issues of significance requiring action at both an individual and a collective level.

Parents' organisations have developed different politics of knowledge around ADHD, which become visible in their 'epistemic efforts'. In Ireland, organisations remain committed to a biomedical approach to ADHD, although their practical efforts are oriented towards complementing medication with non-pharmaceutical treatments. In France, the key parents' group opposes any paradigm that focuses exclusively on one aspect of the disorder: social, psychological or neurological. It struggles to 'open up' the scientific domain of ADHD. We demonstrate how these contrasting engagements with knowledge lead parents' organisations to politicise and act on the area of ADHD in different ways within their respective countries.

Keywords: Attention Deficit Hyperactivity Disorder (ADHD), parents' groups, France, Ireland, evidence, medicalisation, politicisation.

Introduction

The development of patients' and parents' groups around 'unsettled' conditions has attracted much attention from social scientists in recent years. These groups arguably reflect forms of activism that stretch beyond traditional health movements (Brown et al. 2004), foregrounding contestations between lay and credentialised knowledge in defining these conditions, as well as in health and social policies affecting their recognition and treatment as legitimate 'patients'.

Attention Deficit Hyperactivity Disorder (ADHD) is one of these unsettled conditions. Since the beginning of the twentieth century, its medical history has been characterised by controversy within and between the medical profession and related professional groupings, including neuroscientists, psychiatrists, psychologists and psychotherapists (Rafalovich 2001; Conrad & Potter 2000; Singh 2002). There are no definitive biological or clinical markers 'proving' the existence of ADHD, but parents of children with the disorder have little doubt that a set of behaviours exist that can cause extreme stress to the child and family relationships.

In this article, we examine how parents' groups in France (HyperSupers) and Ireland (INCADDS and its member organisations) problematise their situations, with a particular focus on the types of evidence that they carve out and deploy in shaping and defending their causes. Indeed, the two groups strive to 'state the fact of ADHD' and in so doing engage with contentious medical knowledge about the disorder. Over the duration of our project (2009-2012), we interviewed members and leaders of the two groups, attended meetings they organised, analysed their websites and publications, and investigated their pronouncements and activities on knowledge about ADHD. Our objective in this paper is to unpack the ready-

made expression ‘stating the fact of ADHD’ by exploring what ‘stating’ entails, which ‘facts’ the two groups deem relevant and legitimate, and what scientific and political meanings ‘ADHD’ holds for them and for the various actors who intervene in this condition area.

We start with an overview of the literature on patient and parent activism on ADHD. Many commentators have linked the emergence of ADHD to processes of medicalisation. The converging interests of three categories of actors have been identified in driving these processes: the pharmaceutical industry, the school system, and patients and parents. Posing more or less explicitly the *cui bono* question, a number of studies have suggested that one of the consequences of medicalisation is the increasing abstraction of health issues from their social and political context, such that different conditions are interpreted and treated as problems within the individual. This process of individualisation, it is argued, has the potential to de-politicise the arena of health and medicine by removing the focus from “the social forces that influence well-being” (Conrad, 2007: 152). In this paper, we seek to challenge this narrative, by arguing that it is through the staging and weighing up of different bodies of knowledge that HyperSupers France and INCADDS redefine the significant issues requiring action at both individual *and* collective levels.

Section two explores how the two groups stage and confront knowledge and know-how from various fields, reflect on their robustness and relevance, weigh up expert knowledge in light of parents’ experience and vice-versa, circulate articles and summaries, draft documents for parents, teachers, the media and the public to raise awareness of the disorder, and exchange experience and information about what it is to have ADHD. Through this intense and reflexive engagement with knowledge, the two groups progressively transform patients

and families, their medical, educational and social environment, as well as definitions of the condition itself.

In section three, we argue that medicalisation is not a ready-made solution to children's and parents' problems; it is a compound process in which families evaluate and negotiate what counts as relevant. The level of consensus/discord that exists in each country amongst professionals regarding the nature of ADHD shapes how the two groups involve themselves in different forms and degrees of epistemic and political effort. In the Irish context, INCADDS tends to align itself with the biomedical approach to ADHD. Its concern is pragmatic: to marshal 'undone science' (Hess 2009; Frickel et al. 2010) in relation to treatment options, with a view to expanding the number of therapeutic routes available beyond medication, and at promoting a multimodal approach to care that includes medical and educational solutions alike. HyperSupers France opposes any paradigm that focuses exclusively on one aspect of ADHD (social, psychological, neurological), notably the dominant psychodynamic model, and struggles to open up scientific domains on the disorder. This has recently led the group to articulate its multidimensional definition of ADHD in the context of French disability legislation. We conclude the paper by considering the politics of knowledge developed by parents' groups and their impact on the network of expertise and issues related to ADHD.

Medicalisation of contested illnesses and the issue of politicisation

Interpreting ADHD: contested condition narratives

ADHD is a condition mired in uncertainty about the process of diagnosis, causes (genetic, biological, cultural, socio-environmental), and treatment (Rafalovich 2001; Singh 2008,

2011). Typical symptoms associated with the condition include impulsivity, inattention and hyperactivity, but children with ADHD are often deemed to exhibit co-morbidities, including oppositional defiance disorder and conduct disorder. It has been suggested that rates of ADHD are increasing significantly across the globe (Singh 2011). However, Singh (2006) points to the need to investigate the national, local, social, and cultural contexts which shape how the disorder is constructed and treated if one is to make sense of the divergence in rates between different countries and in rates of prescribing of stimulant medications as treatments.

There are a number of different interpretive narratives which seek to explain the condition. Rafalovich (2001) discusses the dominance of three particular approaches: (i) the psychodynamic approach, which explains the disorder in terms of behavioural difficulties which children have in responding to their environment (such as the school, family and so on); (ii) the psychological approach, which suggests that an organic problem causes some dysfunction which in and of itself provokes anxiety resulting in behavioural disorders; and (iii) the neurodevelopmental approach, which takes its lead from brain science, and proposes a direct organic cause for the disorder. In the first model, individual and/or family psychotherapies are the key therapeutic route. In the second, psychologists privilege behavioural interventions (with or without stimulant medication), whilst practitioners working out of a neurodevelopmental perspective have tended to advocate stimulant medication as the primary form of treatment, albeit in conjunction with other therapies.

Internationally, dispute remains amongst professionals regarding the existence of ADHD as a consistent category. For example, a Working Party of the British Psychological Association stated that “cultural expectations have been far too influential in determining the presence of ADHD, perhaps pathologising individual differences rather than making accurate

diagnosis” (Rafalovich 2001: 414). Proponents of the neurological perspective have reacted against such claims. In 2002, a group of 75 international psychiatrists and psychologists, led by Russell Barkley, a leading US proponent of the neurological perspective on ADHD, issued an *International Consensus Statement on ADHD* in which they set out to dismantle “myths” about ADHD and assert its diagnostic validity. As the statement reads, “We cannot overemphasize the point that, as a matter of science, the notion that ADHD does not exist is simply wrong” (Barkley et al. 2002: 89). This statement has been criticised by an opposing group of psychiatrists and psychologists as circumscribing scientific debate about ADHD; they ask why, if the evidence on ADHD is so indisputable, is there a need for a consensus statement in the first place (Timimi et al. 2004)?

The medical status of ADHD, then, is characterised by a fragmentation of knowledge (Mol & Berg 1998). This also translates into differences between countries according to national traditions in psychiatry. In their study on ADHD and Ritalin use in Italy, for example, Frazetto et al (2007: 397) note that “while American professionals interpreted the clinical issues within an organic and biological framework, the Italian professionals interpreted the same case information within a psychodynamic and socio-environmental framework”. With different psychiatric interpretations come different diagnostic pathways and treatment approaches: the dominant professional perspective in terms of diagnosing and treating ADHD in Ireland has been that of bio-psychiatry resulting in the referral of children suspected of having ADHD to their local child and adolescent mental health team, headed by a child psychiatrist; in France, psychodynamic understandings have had a greater role to play and have led to children undergoing long-term psychotherapeutic interventions.

‘Stating the fact of ADHD’ through medicalisation

In a context characterised by a great diversity of understandings and approaches, social scientists have explored the processes through which ADHD has emerged. Since the 1930s, the move that led to the constitution of ADHD as a category has been associated with medication: the MBD (Micro Brain Dysfunction) category which was adopted in the 1960s to replace other denominations such as Hyperkinesis – and was later replaced by ADD and ADHD – developed in a context where patients responded positively to treatments based initially on amphetamine and more recently, methylphenidate (Ritalin) (Rafalovich 2001; Singh 2006; Comstock 2011); thus, success of the medication has been seen to validate the existence of the condition, in an example of what Barker (2011) terms “pharmaceutical determinism”. In its search for ever-expanding markets, the pharmaceutical industry has been perceived as complicit in the medicalisation of ADHD, a dynamic which commentators argue is evidenced by rising prescriptions of drugs such as Ritalin (Conrad 2007).

The school system has also been described as a “mediating mechanism to diagnosis” (Singh 2006: 445): a formative site in which cultural norms and practices are played out, with knowledge about children’s behaviours and expectations regarding child development and performance providing teachers and educators with the capacity and motivation to discriminate between different categories of children (Graham 2007). Depending on the resources available to schools to manage the behaviours associated with ADHD (Malacrida 2004), the school system has the potential to promote the process of diagnosis and therapeutic intervention, including medication.

Lastly, parents are portrayed as having played a major role in the expansion of the ADHD category. Confronted with narratives of parental blame which have frequently characterised

ADHD in psychodynamic discourse as well as in the popular media (Singh 2004; Bennett 2007; Malacrida 2002), parents seek medical recognition as a means of gaining validity and legitimacy: it enables them to ‘state the fact’ of the disorder (Barker 2011) even if, for some analysts, it does not resolve the parental “blame game” (Singh 2004; Peters 2008; Taylor et al. 2006). Participation of parents in self-help groups allows them to reduce doubt and uncertainty in the context of a ‘contested illness’ (Barker 2011), to construct a shared view on the disorder and to circulate knowledge on therapeutic possibilities. Such exchanges may have a performative effect (Barker 2005) and contribute to the reification of the disorder through an alignment with a specific medical approach (Chamak 2011); according to Conrad and Potter (2000) these converging efforts lead to a ‘naturalisation’ of ADHD.

All together, it is suggested that these actors contribute to medicalisation, i.e. to “defining behavior as a medical problem or illness and mandating or licensing the medical profession to provide some type of treatment for it” (Conrad 1975: 12). This conceptualisation of medicalisation is a commonly shared framework of analysis amongst social scientists who have studied ADHD. However, there are some divergences in their positioning of social ‘causes’ vis-à-vis organic or psychological causes of ADHD. Some commentators have suggested that the behaviours associated with ADHD do not constitute a medical disorder and that to label children with the diagnosis is a form of stigmatisation and social control (Conrad 1976, 2007). Rather, they point to the fact that ADHD is particularly seen to manifest itself within structured settings such as the classroom, sites where certain norms or codes of behaviour are expected to apply (Graham 2007, 2008). In contrast, Singh (2006) calls for an integration of the “social” and the “biological”, or for “biology in context” (Singh 2002) within the research frame on ADHD: for instance, the assessment of medication should take

into consideration the socio-cultural context surrounding the prescription and the specific care setting including all forms of associated therapies.

Medicalisation and the issue of politicisation

A key issue highlighted by Conrad (2007) and of a number of other authors is the association of medicalisation with de-politicisation. Medicalisation is said to lead to the individualisation of social problems, to allow the use of certain techniques (medication) for social control, to remove problems from the public realm and to give medical experts a monopoly on their resolution (Conrad 2005). Once children with deviant behaviours have been medicalised, there is no room left for discussion on the organisation of schooling, on the way, together with a number of devices, it produces social norms, or on legitimate forms of social control. Moreover, it is suggested that acceptance of medicalisation reinforces the existing tendency of people to become intolerant to minor troubles or underperformance, and legitimises the generalisation of ‘enhancement techniques’ (such as “technological fixes”, that Conrad (2007: 152-3) refers to), all issues that might be interpreted in the context of social structures and norms that impinge on individuals.

In contrast to these authors, our fieldwork enables us to argue that gaining medical recognition and legitimacy for ADHD (which encompasses more than securing access to medication), provides a means through which parents can challenge and question the way their children are treated at school and in other life situations; thus medicalisation does not hinder politicisation, but rather may enable it. Moreover, ADHD groups are actively (re)shaping the meaning of the condition and, to a certain extent, expanding it beyond the domain of what is considered ‘core’ medical knowledge, although they do this in different

ways in France and Ireland. It is this complex interplay between medicalisation and politicisation that we will examine in the following sections.

HyperSupers and INCADDS' engagement with knowledge and know-how: transforming the individual, the environment and the disorder

HyperSupers' and INCADDS¹ (and member organisations) motives for engaging with knowledge and know-how are first and foremost pragmatic. In both France and Ireland, parents turn to the two organisations when they face critical problems: when their children are about to be excluded from school, for example, or when they can no longer cope with their children's behaviour. Parents also contact the two organisations to ask what to do and what to expect after receiving a diagnosis. They come in search of a listening ear and for help. Welcoming like-minded people who share the same problem is a classic mission of support groups. However, this mission takes on a particularly salient meaning in the case of ADHD; the condition is contested by certain health professionals whose suspicion accentuates families' hopelessness.

¹ HyperSupers was formed in 2002 by parents of children suffering from ADHD in France. It formalised initial contacts between parents through an electronic discussion list that constituted, and still constitutes, a strategic means of running the association. In 2009, HyperSupers had 820 family members, and more than 800 enlisted participants on its online group, be they members of the association or not. INCADDS, the Irish National Council of AD/HD Support Groups, was created in 1999. It emerged out of a network of AD/HD support groups that mushroomed during the 1990s and the early 2000s in Ireland. Today, INCADDS has some 22 local member groups.

HyperSupers and INCADDS arguably translate parents' experiences into a basis for action. The coordinator of an INCADDS member group, HADD Cork, explained how local ADHD support groups in Ireland emerged in response to parents' refusal to accept their children's exclusion from the school system. Recasting the subjectivities of ADHD children and their parents as 'sufferers' has been central to the work of INCADDS and its member groups. This, however, was not just a matter of 'identity politics' (Johnston, Larana and Gusfield 1994); it was also a matter of 'real life' politics. Many interviewees emphasised that, from the outset, and to some extent still, they were fighting the prevailing child psychiatry "disease regime" (Klawiter 2004), a regime that demonised them as bad parents, especially bad mothers, and their children as "brats". Drawing on ADHD understandings in other contexts, most notably the USA and UK where parents often had to travel to obtain a diagnosis, Irish support groups voiced the fact that ADHD is a "treatable chronic condition", and that children and their parents are not 'deviant'.

In the context of an illness "you have to fight to get" (Dumit 2006), Irish ADHD organisations progressively equipped patients and parents with members' experience, knowledge and know-how, to enable them to tell the 'truth' (sic) about the disorder and to address their situation. Like INCADDS, HyperSupers also augments families' experiences with knowledge and know-how, and aims to offer children and parents resources for a better understanding of ADHD and for acting on their situation.

HypersSupers' and INCADDS' knowledge-related activities are both inwardly and outwardly focused. They target patients and families as much as health professionals, teachers, and other institutional actors. For the two organisations, equipping professionals to

understand what it is to have ADHD and how it can be managed is a strategic move towards a better recognition and care for children with the condition.

HyperSupers and INCADDS engage with these knowledge-related activities in a strongly reflexive way, continuously questioning the species of evidence brought in by various specialists in light of families' experience and vice-versa. For the two organisations, 'stating the fact of ADHD' does not simply entail alleging its 'medical reality'; it is also stating its complexity and advocating for a multimodal therapeutic approach to the disorder.

Transforming children and parents

As in many support groups, parents of children with ADHD come together to share their feelings about the experience of the condition, as well as their 'home-made solutions' to the challenges it presents. Drawing on these exchanges, the two organisations actively contribute to the structuring of families' experience and provide a narrative to help them make sense of their chaotic lives. HyperSupers for instance reorders mothers' testimonies and publicises them on its website with a view to narrating the 'standard' pathway or trajectory of a child with ADHD who exhausts her/his parents and teachers at school. As the narrative goes, ADHD behaviours result in poor relationships with teachers for both the child and parents, with the child feeling increasingly frustrated regarding the negativity surrounding her/his behaviour in the classroom. When the child receives a diagnosis, parents initially experience it as a catastrophe (see for example Taylor et al. 2006), but then as a relief because it facilitates the start of therapeutic intervention(s) and supports, including drug treatment (which proves that the child has a serious condition and does not deserve to be blamed for her/his behavior), and specific pedagogical methods to manage the child's behaviours. This sort of stylised narration points to the fact that ADHD is a 'real' disorder whose

manifestations can be acted upon. Parents call for the constitution of such a corpus of “experiential knowledge” (Borkman 1976) and know-how, as the following excerpt from HyperSupers’ online forum illustrates:

“I read in the archives that some of you had tried several months ago to use Omega 3 as an alternative treatment. What improvements did you notice if any?”

INCADDS also equips children and parents with members’ experience on the management of the disorder. For instance, INCADDS member group HADD runs groups for young people diagnosed with ADHD. The stated purpose of the program is to encourage these young people to utilise Solutions Focussed Brief Therapy, “a short term approach that focuses on setting goals rather than dwelling on problems” (<http://www.hadd.ie/youthgroup.html>). This kind of approach echoes parents’ experience: parents have learnt that when their children start to “fly off the handle”, the best thing to do is to divert their attention rather than enter into lengthy argument. All these ‘clues’, acquired through mutual learning, are made available through booklets and brochures targeted not only to families but also to their interlocutors, notably teachers. We will return to this issue later on.

The dissemination of families’ experience goes hand in hand with the circulation of formal knowledge and know-how on the complex mechanisms and multiple manifestations of ADHD, as well as on various therapeutic strategies. One is struck by the continuously updated flow of knowledge that fuels the two organisations’ websites, organised around questions, such as “What is ADHD/ADD?” “What are the symptoms?” “What to expect? Best practice guidelines”. Recommended books written by specialists, videos, links to academic research, recent articles on ADHD with full-texts or abstracts, are also listed.

Various bodies of expertise are mobilised – neuroscience, behavioural science, child psychiatry, psychology, psychotherapies, parenting therapies, pharmacology, educational expertise, judicial knowledge – rendering the two organisations’ websites multidisciplinary centres of documentation on ADHD. In addition, INCADDS member groups and HyperSupers regularly organise meetings at which expert knowledge is presented and shared, often coupled with their general assemblies of families. From 2009 to 2011, HyperSupers’ volunteers organised more than 30 symposiums across France. During the 2010 conference that followed the association’s general assembly, topics such as bipolar disorder and other co-morbidities of ADHD, dysfunction of certain neurotransmitters in ADHD, the “Barkley method” (a parenting therapy), were addressed. INCADDS and its member organisations frequently hold events at which they bring together different ‘experts’ – such as child psychiatrists, or occupational therapists – to talk to parents about medication and other issues. For instance, as part of the 2010 ADHD Awareness Week, an information evening brought together a panel of ‘experts’, including educational and clinical psychologists, a child and adolescent psychiatrist, and another psychologist who was also the mother of a child with ADHD. This event was clearly envisaged as an opportunity for parents and carers to be recipients of advice from ‘experts’ within the field. Nonetheless, it also exhibited a high degree of circulation of experiential knowledge, with parents in the audience sharing their experiences of managing issues relating to ADHD, such as accessing and negotiating services.

Indeed, formal knowledge is not thought of as exogenous to parents’ experience: it is mobilised as an interpretive resource to help them make sense of, and organise what, though intimately felt, remains difficult to express, notably because professionals hold conflicting understandings of the disorder. Organisations therefore engage in an intensive process of

sorting, confronting and articulating experiential knowledge and credentialed expertise. On HyperSupers' online forum for instance, most discussions start with a message from a person seeking advice on how to manage a problem s/he is confronted with. Answers come in various forms: 'tips' that work although they remain unexplained, but also references to articles, books, and conferences that echo the person's preoccupation. The President of HyperSupers is particularly active in posting such references. As she explained, she has spent, and still spends, a lot of time "shopping around", with families' experience as her compass. In the same vein, the organisation's website proposes various therapeutic strategies, such as the 'Token economy method', advising parents to reward their children when they are doing well, and to draw their attention to alternative small tasks when they are "going into a spin". As stated on the website, this method is simultaneously nurtured by parents' experience and by psychological theories which show that children with ADHD tend to lose self-esteem because of the constant denigration of their behaviour. Much like Brown et al.'s (2004) embodied health movements, then, for INCADDS and HyperSupers, formal knowledge and parents' experience intertwine in such a way that boundaries between the two become significantly blurred (see also Akrich 2010).

The intense and continuous work that HyperSupers and INCADDS engage in as regards medical, psychological, educational knowledge and practices, and parents' experience, provides evidence of the crucial role played by various bodies of knowledge and know-how in these two organisations: both organisations offer knowledge and experience as cognitive and material resources to help families better understand and act upon their situations. Moreover, knowledge-related activities contribute to a move from a situation where parents' experience has been relatively silent, to one where it is progressively becoming part and parcel of a web of expertise on the disorder.

Transforming the environment

Knowledge-related activities are not exclusively directed towards children and parents. They also target the public realm and various social and professional arenas to create an environment in which families' actions can be effective. Thus, HyperSupers and INCADDS heavily publicise ADHD, as part of their mission to 'state the fact' of the disorder. For example, in 2008, a committee member of INCADDS, along with her son and another parent of a child with ADHD, took part in a radio programme broadcast by RTÉ Radio 1, and referred listeners to HADD (an INCADDS member organisation) for advice. Anglin (1997) demonstrated how crucial activists' 'outing' was for the recognition of breast cancer and women's suffering in the early days of the movement in the USA. HyperSupers and INCADDS have pursued similar strategies with an aim of educating the public and correcting popular views on ADHD. Recent actions included press releases about symposiums they organised during ADHD Awareness Weeks in collaboration with ADHD Europe. After the 2009 Awareness Week, INCADDS released the following information:

"ADHD is a neurobiological condition affecting 3-7% of school children, roughly two children in every classroom."

In addition to these 'public understanding of ADHD' initiatives, HyperSupers and INCADDS set up a variety of actions tailored for professionals. During the scientific meeting organised by HyperSupers in 2010 as one of its contributions to the European Awareness Week on ADHD, the President presented the results of a survey she conducted on the online forum of the organisation on the time taken to receive a diagnosis, specialists who deliver the diagnosis, medications they recommend if any, and so on. Her communication was explicitly

intended to provide data on families' situation in France to researchers and clinicians from all over Europe attending the symposium.

Teachers in particular have been the targets of much of the two organisations' knowledge-related activities. This targeting is consistent with the understanding of ADHD as a 'disorder of educational performance' and the observation that internationally, teachers have been constructed as "sickness brokers" (Phillips 2006). The two organisations provide training sessions and various materials to teachers (booklets, CD-ROMs, 'Tips' published on their websites), outlining what they should do if they suspect a child has the disorder. Training sessions and materials come in various formats. A conference organised by ADD Midwest in October 2009, primarily targeted at teachers, involved a series of didactic and non-participative presentations from experts on ADHD. Moreover, Irish ADHD organisations have compiled publications, such as *ADHD and Education: A Resource for Teachers*, specifically aimed at providing school staff with information about ADHD to "redress the absence of a widely available written resource for schools on this subject" (HADD 2005: 6). In association with ADHD Action, a multidisciplinary team including medics in child and adult psychiatry, paediatricians, as well as representatives from the National Education Psychological Services, the Irish Primary Principals Network and HADD, Irish ADHD organisations were involved in a survey of Irish children with ADHD (ADHD Action 2007) which was launched to mark Ireland's first ADHD awareness week in 2008. HyperSupers puts parents to the fore during its "SOS Back to School Operation", which was introduced a few years ago. The initiative consists of telephone hotlines at that time of the year: parents are asked to report on their difficulties, and are provided with advice and materials to share with the teachers. The brochure *TDAH et l'école* (ADHD and the school) is one of these materials. It describes, in plain language, what ADHD is, what problems children with the

disorder encounter at school, how to help them to overcome their difficulties, and what tools and methods to use. It was ‘imported’ by HyperSupers from its Spanish sister organisation, and was rewritten by three mothers, in collaboration with one speech therapist, one child psychiatrist and two teachers.

By and large, these sorts of initiatives linking parents and professionals enact the collective action that parents’ groups strive to develop in making children with ADHD visible, and included, in a reshaped school environment.

Transforming the disorder

HyperSupers’ and INCADDS’ approach to credentialed knowledge and professional practices is pragmatic. It is also eclectic and reflexive: the two organisations tirelessly stage and weigh up various species of evidence in light of families’ experience. This approach imposes itself in a configuration where ADHD has long been, and still is, subject to contestation.

As argued above, in Ireland ADHD was marked by the “blame culture” of child psychiatry and psychology. Support groups emerged against this understanding of the disorder, thanks to a couple of psychiatrists and psychologists who moved to Ireland from the USA, and promoted ADHD as:

“[A] disorder that is genetically transmitted (often runs in families), and is caused by a chemical imbalance or deficiency in certain neurotransmitters (chemicals that regulate the efficiency with the brain controls behaviors)²”

² <http://www.incadds.ie/what-is-adhd-add.html> accessed 17 June 2010

One can easily understand how appealing this ‘genetic foundation’ of ADHD, and the “somatic self” (Novas and Rose 2000) it represents, was to parents facing accusations of ‘bad parenting’. Up until this point, the story of INCADDS support groups was one of typical biologisation that removes the ‘fault’ from parents, and restores their responsibility and ability to re-act.

However, this is just part of the story. Parents learn by experience that ADHD is a complex disorder, whose manifestations are multiple and variable from one patient to another. This translates into INCADDS support groups using various labels: ADHD, ADD, HADD. The disorder is also said to come with various co-morbidities, such as oppositional defiance disorder, conduct disorder, dyslexia and dyspraxia: these co-existing disorders were featured in a media report on a 2002 conference organised by the Sligo support group (Judge 2002), and appeared again in a 2010 issue of HADD Cork newsletter (HADD Cork 2010). Moreover, ADHD evolves over time: if it is not subject to early diagnosis and intervention, some commentators have suggested that children with ADHD may be more likely to engage in criminal activity in later life. A key champion of the ADHD cause in Ireland is the (recently retired) governor of the country’s largest prison. He has been a speaker at public information meetings organised by INCADDS support groups, and for many years, has made public pronouncements about how untreated ADHD can lead to violent and criminal behaviours (Maguire 2004). All these aspects of ADHD are fraught with scientific uncertainty: although an ‘etiological consensus’, grounded in the neurobiological, has progressively become established in Ireland, there is, so far, no agreement on the most appropriate treatments and on their long term effectiveness. This has prompted Irish support groups to uncover and evaluate complementary approaches to biomedicine, with a view to

crafting a multimodal approach to treatment and care for ADHD children and adults, as illustrated earlier on.

The contextualization of ADHD by HyperSupers in France follows an even more radical path. Denial or suspicion of the ‘reality’ of ADHD still looms large in certain expert as well as lay discourses. The President of HyperSupers explained that certain child psychiatrists, drawing on a psychodynamic approach, refuse to provide psychotherapies for children on Ritalin©. *L’Information Psychiatrique*, a professional journal in psychiatry, recently published a special issue after a one-day meeting devoted to the revision of the 10th International Classification of Diseases in child psychiatry launched by the WHO. In the introductory statements to the special issue, Vincent Garcin (2011), a child psychiatrist, reported on the difficulties of applying the DSM nosological categories to ADHD, and warned against the “risks of over diagnosis due to pressures for medication and for education efficiency”. At the other end of the spectrum, certain neuroscientists hold a purely neurological understanding of the disorder, pushing forward a reductionist view of ADHD as a ‘brain disease’ (see for example, Rapp 2011).

HyperSupers makes itself part and parcel of this web of confrontational expertise. In the issue of *L’Information Psychiatrique* mentioned above, as well as in every single public arena that she actively strives to access, the President of the association pictures ADHD as a multi-factorial and multi-dimensional disorder that defies any monolithic understanding (Gétin, 2011). In many of her writings and talks, she agrees that ADHD is a neurodevelopmental disorder, but strongly opposes reducing it to a ‘brain disease’: drawing on families’ experience, she voices the fact that the child’s environment does impact on the development of the disorder. She rejects the idea that ADHD is a strictly ‘behavioral disorder’, but

recognizes that children with ADHD have serious difficulties coping with ‘normal’ social functioning due to cognitive impairments (lack of attention, impulsivity). HyperSupers forcefully asserts the complexity of ADHD: for the association, stating the fact of ADHD does not make much sense if it ends up singling out any one dimension; stating its complexity is the only relevant way for advocating a multidisciplinary epistemic understanding of the disorder and a multimodal therapeutic approach which can only begin to address the multiple and variable dysfunctions that characterise ADHD.

To recap, it would be tempting to portray the two organisations as players in the game of medicalisation, as a way of parents avoiding ‘blame’ for their children’s challenging behaviours. The situation we have reported on, however, does not fit this model. Firstly, medicalisation is not an end in itself; it is a detour that allows parents to act upon a range of different actors, including teachers and children themselves. Secondly, medicalisation is not sufficient in and of itself; it has to be accompanied by patients’ organisations’ work on, and with, knowledge and experience, an action rendered invisible in much literature on ADHD. It is this work undertaken by patients’ organisations, together with medicalisation, which enables the conception and implementation of alternative actions on ADHD.

It should be reiterated also that the role that a medical diagnosis plays in easing the ‘suffering’ experienced by parents and their children is not self-evident. As we have noted, medical knowledge around the condition is fragmented, and often controversial. Here, we see differences in national contexts: as we demonstrate in the next section, the networks of expertise that exist around ADHD in each country have consequences for the way in which the organisations politicise the condition position themselves.

Acting upon the network of expertise and issues around ADHD

Becoming part and parcel of the web of expertise on ADHD by introducing patients' and parents' experiences and by carefully scrutinizing formal knowledge stands at the core of INCADDS' and HyperSupers' activities. As amply demonstrated by a number of studies (see for instance Rabeharisoa 2006a), patients' groups do not engage in knowledge for the sake of knowledge: they do so with a view to transforming understanding of their conditions and to acting upon 'the system' so that they can be medically, as well as socially, treated the way they feel they should be. Depending on the content and scope of the network of expertise on ADHD in their countries, INCADDS and HyperSupers will act differently upon 'the system'. Because of the persistence of specialists' divergence on the 'reality' of ADHD in France, HyperSupers has decided to support the multiplicity of expertise with an aim of defending a multidimensional epistemic model of the disorder, not only in patients and families' everyday life, but also in social policies and practices on ADHD. The relative consensus on ADHD in Ireland, where the condition is now regarded as neurodevelopmental, has prompted INCADDS to delegate further scientific investigation on the disorder to recognised specialists, and to focus on research or studies on complementary treatments to medication. Hence, we see the different politics that the two organisations develop.

INCADDS: mainstreaming ADHD in the biomedical realm and pushing research towards 'problem-solving'

Voices opposing biomedical models are very much in the minority in Ireland, both in the professional and public spheres. This was illustrated in a recent controversy whereby a prominent media psychologist practicing within the psychoanalytic tradition (and who had in the past questioned the legitimacy of ADHD), was forced to retract comments he made questioning the neurobiological basis for autism, due to strong criticisms from parents, the

Minister for Health, and even the Psychological Society of Ireland (Rogers 2012). The articulation of a neurodevelopmental understanding of ADHD has been central to INCADDS' awareness-raising about the condition. Efforts to recast the identities of children with the disorder and their parents were central to the work of Irish ADHD organisations when they were first established in the 1990s. In challenging the prevailing child psychiatric regime, seeking out medical 'allies' (Arksey 1994) was key to INCADDS' promotion of their cause and to the 'stating of the fact' of ADHD.

A key figure in this battle of truth and fiction was Professor Michael Fitzgerald, a psychiatrist based in Trinity College Dublin who was the first professor of child psychiatry in Ireland, and is identified by Irish ADHD organisations as having made a significant contribution to the formation of a professional discourse about the disorder. Since its outset, INCADDS has had strong links with Fitzgerald, who is described on the INCADDS website as "the leading expert on ADHD in Ireland³". Moreover, he has been variously described by INCADDS members in interviews as "our saviour" and a "great friend of the group".

Another significant feature of the story of ADHD organising in Ireland has been the instrumental role that a number of key international allies have played. Relations with a small number of health professionals from the USA and elsewhere played an important role in the international diffusion of recognition of ADHD as a psychiatric condition. For instance, the INCADDS website is dedicated to the memory of a US clinical psychologist, Deirdre Killelea, who is identified as having made a significant contribution to the establishment of the national organisation. A member of one of the support groups described her as a

³ <http://www.incadds.ie/useful-links.php>

“visionary of hope” for children diagnosed with ADHD and their parents, and noted that, without her knowledge of the condition, “we would not know how our children would or could shine⁴”.

The “culture of action” (Klawiter 2004: 848) around ADHD in Ireland, then, is such that key (biomedical) experts (certain clinical psychologists and psychiatrists) have become part of the activist landscape, drawn on and deployed by groups to support them in the media, for example, or to speak at events aimed at parents. As a result of the close alignment between Irish ADHD organisations and the biomedical world, parents’ groups have not been interested in shaping or influencing the nature of research being conducted within this arena. Their knowledge production enterprise is instead more applied, focusing on the provision of services, or providing information to parents of children with ADHD. This has led INCADDS and its member groups to push the boundaries of research by drawing on their own embodied experience to challenge current diagnosis and treatment strategies, while remaining committed to the biomedical understanding of the *causes* of ADHD. In their quest for a multimodal treatment model, groups have been keen to diversify treatment options beyond medication; they have been highly critical of the lack of provision of services in the Irish public health service, and the singular approach to the treatment of ADHD in Ireland, where children are typically assessed and diagnosed by a consultant psychiatrist in a care context which was described by one interviewee as “very strongly biological, medical model”. In response to this, two ADHD groups commissioned evaluations of different therapeutic modalities, one focusing on a family therapy based programme, the other on neurofeedback. Neurofeedback is a type of biofeedback which focuses on the brain and

⁴ <http://www.incadds.ie/dedicated.html>

central nervous system: by placing sensors on a person's head, it provides a display of brain activity, or 'brainwaves' that can be monitored and potentially retrained. This therapy is not necessarily perceived as a legitimate or evidence-based intervention by the wider medical community as an intervention. As the evaluator of one of the interventions noted of the impetus for the research:

"... assessment, diagnosis and treatment by using a medical model is not the full picture. You need to have other components in place... [the parents] weren't demeaning the medical intervention. They were saying that it's step one and, in their experience, all the other steps were missing."

In the case of both evaluations, the aim was not only to provide informed recommendations to other groups' members, but to lobby their local health service should the interventions be successful. Significantly, in the context of psychotherapeutic intervention, the personal experiences of the parents involved provided a key impetus for the evaluation, with the study emerging from an expressed need for an intervention to help them develop "coping strategies" for their children's behaviour.

At the level of diagnosis and treatment then, INCADDS has arguably broadened the professional terrain involved in the ADHD field, and has sought to extricate ADHD from the exclusive realm of psychiatry and medication. However, these interventions operate at a different level to that of 'mainstream science'. The findings of both evaluations were aimed at local policymakers in the health service, rather than at 'peer-reviewed' academics or journals. Both groups did however recognise that if their claims were to be taken seriously by policymakers and other healthcare professionals, credentialised findings would be required, hence the need for evaluation. In case of the study concerning the family therapy

intervention, the evaluation acted expressly as a mechanism for validating and formalising parents' experiential knowledge in order for it become deployable for lobbying purposes.

In summary, the epistemic work of Irish ADHD organisations can be characterised as principally orientated towards 'solving problems' (i.e. identifying effective interventions to facilitate families to live with ADHD) and impacting on service and policy arenas.

HyperSupers: opening up the scientific domain on ADHD

Like INCADDS, HyperSupers is also keen on promoting a multimodal diagnosis and therapeutic approach to ADHD. But in contrast to its Irish counterpart, HyperSupers makes itself part and parcel of a network of expertise on the disorder which is much more confrontational in France than in Ireland. As mentioned earlier, certain experts, notably neuroscientists and child psychiatrists who have a psychodynamic background, regularly oppose each other on the 'reality' of ADHD, and come to hold univocal views on the disorder: the psychodynamic approach to ADHD and other disorders like autism for example, is still prominent, if not dominant in France, and is often opposed by patients' and parents' groups which feel not only unrecognized but also badly treated (Méadel 2006; Rabeharisoa 2006b). Rather than taking sides for or against one or the other, the President of HyperSupers soon realised that both approaches might undermine the complexity of the disorder that parents experience in their everyday life. Quite pragmatically then, HyperSupers refused to be caught up in specialists' disputes and tried to create open spaces for them to dialogue, or at least, to listen to each other under the supervision of the organisation.

This mediating role of HyperSupers in the expansion of the scientific domain on ADHD took on a particularly salient form during the "Journée Ribot-Dugas" it organised in

collaboration with its scientific committee in 2011. This one-day symposium, named after two French psychologists, gathered specialists from a variety of backgrounds. In addition, the President of HyperSupers succeeded in securing an invitation from the organisation's scientific committee to a speaker who talked about the role of Omega 3 fatty acids, a heated issue not only within the medical milieu but also in the public realm. This openness does not mean that 'anything goes' however: the President of the organisation carefully looks at the 'evidence-base' of the various approaches, and points to the lack of robust data and methodologies for some of them. Indeed, certain bodies of knowledge and know-how are not only questioned in the medical arena, but also by families: on the online forum of HyperSupers, a heated debate arose about Neurofeedback, with a mother denouncing therapies that have not yet been backed up with scientific evidence, whilst others voiced the need for alternative/ complementary therapies to medication and opposed the subsuming of experiential knowledge to EBM-like evaluations. In this context, HyperSupers tries to hold its moderate line, i.e. not only to delve deeper into the scientific domain on ADHD, but also to increase the scientific validity of certain approaches which are not yet recognised by credentialised experts, but which echo families' experience.

Thus, in contrast to INCADDS which delegates research on ADHD to its allied experts, HyperSupers questions the nature and shape of the network of expertise on the disorder, enlarging and organising multidisciplinary exchanges between specialists that it feels better fit its multidimensional conception of ADHD. This willingness to transform the domain of competences on ADHD is not exclusively directed towards scientific and medical expertise, but also, and in the same move, towards social and educational expertise on the disorder. This is translated in HyperSupers' contribution to the development of the category of "cognitive disability".

From 2008 to 2010, HyperSupers was member of a working group on “cognitive disability” set up by the French Delegation for People with Disability, an inter-departmental service whose objective is to implement the French 2005 Disability Act. At first, HyperSupers’ family members did not favour considering ADHD as a disability: discussion that arose around the mid-2000s on the organisation’s online forum displayed parents’ reluctance to engage with ‘disability talk’, for they feared this might bring a stigmatised identity to their children. However, the 2005 Act brought in substantive modification to the definition of disability with which the President of HyperSupers felt quite comfortable. Indeed, the Act referred to the 2001 WHO Classification, which proposed an interactive and dynamic conception of disability. In contrast to the medical and individual approach to disability dating back to the 1989 WHO Classification⁵, the 2001 one defined disability as an interaction of both biological and societal phenomena which combine to impact on disabled people’s participation in daily life. It is this new international classification that underlies the French 2005 Disability Act, also labelled “Equal Access to Opportunities Act”.

The Act recognised “cognitive disability”, alongside “mental disability” and “psychiatric disability”⁶. However, its content was still to be delineated. Seizing this opportunity, a

⁵ Disability studies (Albrecht et al. 2001) and activists played a crucial role by promoting an alternative social model for many years, which eventually led to the revision of the 1989 WHO Classification.

⁶ According to participants in the group, as well as an interview we conducted with one of them, all these three categories are embedded in the French history of disability organizations and do not exist as such in other countries. “Mental disability” mainly refers to intellectual disability, whereas “psychiatric disability” denotes disability related to mental illnesses, and notably psychosis.

coalition of associations concerned with dysfunctions like dyslexia, dysorthographia, and dyscalculia, of which HyperSupers is a member, provided a description of their conditions in terms of “cognitive disorders”. Soon after, the working group mentioned above was set up to reflect on the links between “cognitive functions”, “cognitive disorders”, and “cognitive disability”; in addition, participants were asked to characterise dysfunctions and rate their severity according to the 2001 WHO Classification. HyperSupers joined the group, within which one member of its scientific committee played a very active role in drafting the chapter on ADHD.

What is interesting in the debates which emerged in the drafting of the final document, is the effort made by HyperSupers’ spokesperson in differentiating ADHD from classic learning disabilities (such as dysorthographia or dyscalculia), considering that the latter involve dysfunctions in acquiring certain competences required by the school system (acquisition of written language notably), whereas ADHD involves much more fundamental cognitive functions such as attention and executive functions. By the same token, his proposal also provided an ‘operational’ foundation to the category of “cognitive disability”.

For HyperSupers, “cognitive disability” may arguably serve as a political category for claiming additional care and compensation: Conrad and Potter (2000: 574) have suggested that, once diagnosed, individuals may use disability legislation in order to claim additional resources: “Not only are individuals with ADHD the potential beneficiaries of a "medical excuse" for their life problems, but they may be eligible for specific benefits under the ADA

“Cognitive disability”, the most recent category, refers to disability related to the alteration of all, or specific, cognitive functions.

[Americans with Disabilities Act]. Individuals who, prior to diagnosis, would not have seen themselves having a disability find themselves reaping the benefits of disability legislation”. But their interest in the framing of “cognitive disability” cannot be reduced to this: it is an opportunity to produce a validated description of what the disorder entails in all aspects of life, and to specify ADHD within the spectrum of a whole range of dysfunctions. This description work can be understood as the pulling together, and translation of, different kinds of knowledge, i.e. medical, psychological, pedagogical, and experiential knowledge. It produces effects on the emerging category of “cognitive disability” itself as well as on the definition and understanding of ADHD; in addition, it is intended to constitute a mediating – non-medical – language between a set of actors that include parents, medical professionals, the education milieu, and social services. So, the work done within the Disability Act framework can be seen as the construction of a tool adjusted to the multifaceted definition of ADHD that HyperSupers wants to promote, and one which is resistant to, rather than convergent with, any kind of medical reductionism, as Conrad’s interpretation would suggest.

To sum up, we can say that it is not the pragmatic approach to knowledge that distinguishes HyperSupers and INCADDS: their knowledge-related activities stem from patients’ and parents’ demands for action around specific ‘problems’. What distinguishes the two organisations is the sort of knowledge that they mobilise for crafting their conceptions of ADHD and for shaping issues of significance. In this regard, their strategies depend on the network of expertise on ADHD in their countries. But, and more significantly, through their knowledge-related activities, they also (attempt to) impact on the very nature and shape of the webs of expertise and issues of which they are part and parcel.

Conclusion

ADHD is often cited by social scientists as a prime example of the increasing medicalisation of society (Conrad 2007). Parents, along with the pharmaceutical industry, have been implicated in playing a key role in driving the search for a validating medical label. Yet the processes through which this happens, and the outcomes, are complex and incomplete; medical recognition does not signal an end to parents' battles nor does it presuppose a (solely) biomedical response to treatment (i.e. medication).

Our study leads us to reflect on some of these complexities and the role that knowledge plays within the 'medicalising' agenda. Whilst parents' organisations can be seen as one of a number of actors 'promoting' the medicalisation of ADHD, what medicalisation means in this context needs to be reframed. For the two groups we studied, gaining a medical label does not mean denying the potential social causes of the condition, or closing off therapeutic avenues other than medication; it does not engender a retreat to individualised understandings of health and illness, but rather, as our analysis of the two groups demonstrates, may open up an arena for negotiation and action in which social structures and processes (such as schooling) are often a target for critique.

Our analysis also leads us to concur with Rose (2007: 701-2) who suggests that "the term medicalisation might be the starting point of an analysis, a sign of the need for an analysis, but it should not be the conclusion of an analysis". Medicalisation, in and of itself, is associated with dilemmas and uncertainties about the status of knowledge around those conditions deemed to be 'unsettled'. Unsurprisingly, then, knowledge forms a key focus for parents' organisations, as it is through their participation in debates about the very nature of the condition and potential treatments that they can enforce their claims and find practical

solutions to the challenges they are confronted with. Medicalisation in the context of ADHD is not a (pharmaceutical) end point; it is a basis for action in which parents' engagement in knowledge activities seeks to highlight, and enact, the complexity of the condition. In addressing this complexity, patients' and parents' groups open themselves up to multiple bodies of expertise in seeking to avoid medical reductionism, particularly in the treatment of the condition.

The strategies and actions that groups deploy depend on the nature and scope of the networks of expertise which they make themselves part and parcel of, and which they seek to influence. In France, for example, medicalisation might best be described as an on-going plural process, in which various conceptions and understandings of the condition – sustained by different groups of professionals – are addressed and evaluated. HyperSupers does not align itself with one particular category of actor, nor does it remain on the periphery of debates about the condition. Rather, it actively promotes a knowledge policy consistent with its pragmatic experience of the disorder, a policy which consists of bringing various streams of investigation together within the same arena, to be scrutinised by parents. In contrast, the relative medical consensus about ADHD in Ireland leads INCADDS to adopt a different kind of knowledge policy: instead of participating in 'mainstream' science debates about the disorder, they situate themselves on the margins of the scientific community, and devote specific effort to expanding the therapeutic domain beyond the dominant biomedical arena. In both cases, then, parents' organisations actively participate in shaping the 'web of expertise' that exists around ADHD in each country, and cannot simply be seen as hostages of actors who want to extend their influence by gaining parents' support.

Thus, parents' organisations' engagement with knowledge questions the very meaning of 'medicalisation', as well as its relevance in relation to families' experiences and preoccupations. This questioning is both epistemic – what *is* ADHD? –, and political – what does it entail *to have* ADHD in France and in Ireland? Our analysis enables us to show that parents' groups' production and dissemination of knowledge provides them with evidence for bringing the complexity of the disorder to the fore, and for grounding their claims for specific social and medical treatment accordingly. Conversely, our fieldwork demonstrates that parents' groups' social and political activism targeted at the inclusion of children with ADHD enacts their definition of the condition as a complex disorder that requires a multidisciplinary epistemic approach. INCADDS and its member groups, although aligned with the dominant biomedical understanding of ADHD, develop a politics of care that seeks to operationalise families' expectations of ADHD as a multidimensional disorder. HyperSupers' advocacy for ADHD to be recognised as a "cognitive disability" not only aims to secure rights for children with the disorder, but also, and more significantly, to perform the organisation's understanding of ADHD as a complex condition.

Finally, we can reasonably argue that the form of activism with which parents' groups engage potentially fuels the formulation of a new understanding of the self. As stated earlier, ADHD is puzzling for professionals and for parents alike. The condition indeed raises questions regarding what it entails to have/live with ADHD. In some circumstances, the behaviours associated with ADHD come to be seen as positive attributes; one of the often cited ones is increased creativity, for example. Parents' groups' knowledge-related activities thus imply more than science and politics; they bring in intimate evidence of the self with which children and their families hope to live better lives.

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