



The French ADHD landscape: Revisiting the “backwardness” of France

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Abstract

The purpose of this paper is to analyse the dynamics of problematization of ADHD in France and to understand how it emerged as a public issue in the last 15 years, drawing on the abundant production of reports related to the disorder during this period.

Until the end of the 1990s, the massive lack of academics' interest in ADHD, may have delayed its coming as an issue worth debating and enquiring about. As a consequence, ADHD emerged as a public issue in quite peculiar circumstances:

- Firstly, the INSERM collective expertises on various disorders, in which ADHD surfaced as an unsettled condition, provided high visibility to international bodies of literature and brought in a biological-oriented conception of these disorders, opening up debates on their very nature.
- Secondly, Hypersupers, the main French group of patients and families concerned with ADHD, took initiatives for assembling scientists and clinicians who manifested an interest in ADHD, though holding divergent views, an effort which culminated in the organization in 2009 of an international conference. Hypersupers also produced experiential knowledge on the disorder in order to "state the fact" of ADHD.
- Thirdly, working groups on disorders more or less associated to ADHD blossomed, which Hypersupers joined in some cases. All together, these successive groups sustained reflection over the last 15 years, and progressively constituted an epistemic community. Their enduring effort helps to understand the continuing elaboration and re-elaboration of public policies on these conditions.
- Fourthly, the 2005 French Disability Act led to the invention of the notion of "cognitive disability" which offered a conceptual framework for articulating medical care and education interventions that Hypersupers has long promoted, as much as it helped professionals working with disabled persons to enact such a multimodal approach.

The progressive emergence and installation of ADHD does not imply its univocal positing within the French scientific and medical landscape. The multimodal approach that Hypersupers and its network has been promoting from its beginnings is core to the French problematization of ADHD and led to ADHD care models integrating a variety of interventions, including psychotherapies.

We end the paper by some reflections on the issue of medicalization and the implications that the continuing problematization of ADHD as an unsettled condition have on public policies.

Keywords

ADHD – Learning impairments – France – public policies – patient organizations – research – neurosciences

1. Introduction

In 2009, Hypersupers, the main French group of patients and families concerned with ADHD, organized a conference entitled “Confronting European practices on ADHD” in Paris (Hypersupers TDAH France and CPPS 2010), gathering a bunch of world-renowned specialists such as Aribert Rothenberger, Eric Taylor or Tobias Banaschewski. Apart from being the very first international event on ADHD in France, it provided some participants the opportunity to reiterate publicly their concerns: Franck Baylé, a psychiatrist, stated that “the [French] situation can be considered as dramatic”; Diane Purper Ouakil, another psychiatrist, declared that in France, “treatments prescribed to children have not been evaluated, nor their efficacy proven”; she deplored that French contribution to research on this topic, as well as medical training on ADHD, are nearly non-existent. Talking to Christine Gétin, the president of Hypersupers, one of the eminent foreign guests had this joke: “I thought that France was years behind. I was wrong. France is only fifteen years behind” (interview).

Such considerations were not new; at the beginning of the 2000s, Carla Sept, a mother of a child with ADHD and one founder of Hypersupers, already made similar observations on her website:

“Applied research on neurological problems such as dyslexia, dysphasia, and of course hyperactivity barely exists. Professionals work in their own corner without confronting their knowledge, nor their practices. Speech pathologists don’t like neurologists intruding their domain and think they know best than them. Psychiatrists consider that they can take everything in charge and continue to apply psychoanalytical theories without taking neurosciences into account. Teachers distrust speech pathologists (...) and the latter often criticize learning techniques and think they are obliged to do teachers’ job.”

Such statements are still topical, as is illustrated by the framework paper (HAS 2012) published by the HAS (Haute Autorité de Santé, the French High Authority of Health equivalent of NICE in UK) for elaborating guidelines on ADHD illustrates, which draws upon the conclusions of the above-mentioned 2009 conference.

Should these declarations be taken seriously or should they be interpreted as a strategic and political use of the “backwardness” rhetoric? A closer examination of some available data shows that at least, French research efforts are indeed rather sparse compared to other countries, as revealed by the two graphs below.

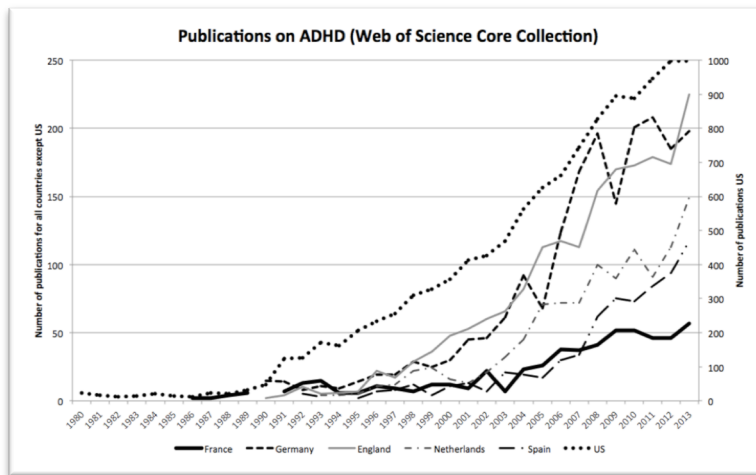


Figure 1: Evolution of publications on ADHD

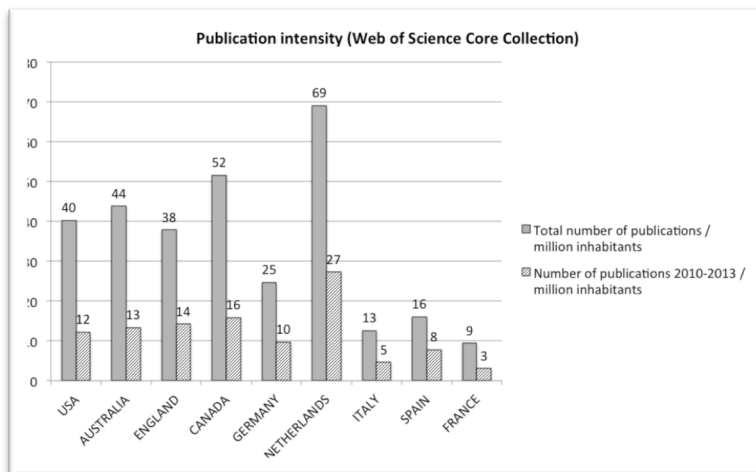


Figure 2: Publication intensity on ADHD

The number of French publications took off in the mid-2000s, i.e. more than 10 years after the US, and 6 to 8 years after England, Germany and the Netherlands. Moreover, the ratio of publications per inhabitant is four times lower than in most English-speaking countries, about three times lower than in Germany or Spain, and half the Italian ratio.

Besides, another figure helps figuring out the French situation: it has been estimated that 0,15% (HAS 2012) to 0,4%¹ of children receive a prescription for methylphenidate, the psychostimulant used for treating ADHD, which is by far a smaller proportion than in US and one of the world lowest rates according to the president of Hypersupers². This

¹ "Consommation de Ritaline + 70%", 30 mai 2013, <http://www.vivrefm.com/infos/lire/1331/consommation-de-ritaline-70> (accessed 2014, August 16th)

² "Hyperactivité: pourquoi autant de ventes de ritaline?", 30 mai 2013, <http://www.santemagazine.fr/hyperactivite-pourquoi-autant-de-ventes-de-ritaline-49900.html> (accessed on 2014, August 16th)

situation is put into relation with an underdiagnosis of ADHD, itself linked to the strength of psychodynamic approaches within the French psychiatric milieu, as pointed out by Franck Baylé during the 2009 conference:

“Psychoanalysis and social psychology approaches dating back to the 1970s still have a strong impact. Consequently, a psychogenetic understanding of the disorder is still prevalent, especially in child psychiatry.”

For most psychiatrists, the symptoms associated with ADHD are either the signs of psychological suffering or the effect of social / parenting problems. According to them, prescribing methylphenidate is a bad answer to the problem, for it shifts away from the search of psychological causes which has long been central – and still is – in the French psychiatric practice (Vallée 2011): “with Ritalin, the mystery remains unsolved since the meaning of the disorder still has to be worked out in regard to each child’s history” declared in 2005 Bernard Golse, Head of the Psychiatry Unit in a Parisian child hospital³. Some point to the risk of addiction, drawing a parallel - endlessly taken up by the press - between methylphenidate and substance abuse. Thus, the medicalization thesis has been used for many years by mainstream psychiatrists, and relayed by the mass media, to counter a minority of other psychiatrists who, together with neurologists and parents of children with ADHD, have been pleading for other approaches including methylphenidate, cognitive behavioural therapies and psychomotor rehabilitation.

However, despite the continuing opposition between psychodynamic-oriented psychiatrists and other specialists, the situation regarding ADHD has considerably changed over the last 15 years. Examination of press articles on this topic over the period reveals that two thirds of the papers published between 1998 and 2004 expressed doubts about the reality of ADHD, which one paper even ironically called American Democratic Deficit (ADD). In contrast, between 2005 and 2012, three papers out of four did not deny the existence of ADHD anymore, and often described the condition according to the neurobiological perspective. Another indicative change is the sales of methylphenidate, which have risen from around 50,000 boxes in 2000 to 280,000 boxes in 2013, reflecting an increase in the number of diagnosed children. Finally, ADHD has been taken into consideration in a number of official reports. In short, ADHD has been progressively recognized as a disorder in its own right in the public opinion, in medical practices and in public policies.

The purpose of this paper is to analyse the dynamics of problematization of ADHD in France and to understand how it emerged as a public issue in the last 15 years: as one can deduced from what precedes, this dynamics cannot be described as a long quiet river since it involves divergent conceptions of the disorder and of the ways it should be treated. However, we do not intend to produce an erudite history of ADHD in France: we

³ “Des enfants sages sur ordonnance”, *Le Monde*, 23 novembre 2005.

will proceed otherwise, by concentrating on a number of spaces of problematization (Laurent 2011) where concerned actors (families, specialists, institutions) have discussed the disorder, its very nature, and the appropriate actions to be conducted in order to solve the various problems it raises.

2. Material and methods

Our work on ADHD in France was first motivated by an interest into elucidating the role of patient organizations in the production and dissemination of knowledge and its mobilization into politics. We have shown elsewhere (Edwards et al. 2014) how Hypersupers, the French patient organization founded in 2002, has played a major role in the problematization of ADHD in France, struggling to open up treatment options and to deepen the scientific understanding of the disorder. Engaging in what we called “evidence-based activism”, (Rabeharisoa, Moreira, and Akrich 2014) they undertook surveys in order to produce data on patients’ paths to care; they organized conferences with specialists with an aim at confronting credentialed knowledge and families’ experiences; they participated to various working groups set up by French health institutions to elaborate reports, recommendations and guidelines; and they engaged with the media in order to make their voice heard. More significantly, Hypersupers has been, and still is instrumental in bringing specialists from various backgrounds to talk to each other, sometimes forcing the confrontation between different corpuses of knowledge and disciplines.

In order to trace more accurately the emergence of ADHD as a public issue, we broaden our perspective on the French ADHD landscape by looking at the abundant production of reports related to the disorder during the last 15 years. As several authors have demonstrated (Barthe 2006; Jasanoff 2005; Hilgartner 2000; Leclerc 2009), expert groups and reports are very interesting sites for capturing the articulation of knowledge to decision-making in a context of scientific uncertainty; reports highly contribute to the publicization of an issue while giving some insights into the fabrication of public policies.

Provided the pivotal role played by Hypersupers in assembling different specialists around ADHD, we start identifying a series of reports mentioned on its proliferating website, and supplement this initial material with other documents cited by these reports. We eventually come up with a dozen of reports published from 1999 onwards. Hypersupers was involved in five out of the seven reports published after the creation of the organization. We also look at comments on, and reactions to these reports in lay and expert publications.

These reports are of different kinds:

- The first one, a publication from the HCSP (Haut Comité de la santé publique, the French High Committee for Public Health) is not a report *per se*, but 40-page dossier on learning impairments, with a special section on ADHD (Vaivre-Douret and Tursz

1999) in the journal published by the HCSP, which aims at providing actors in the public health sector a complete information on one given topic.

- The INSERM (Institut national de la santé et de la recherche médicale, the French national institute for health and medical research) published four “collective expertises” between 2002 and 2009 on topics including ADHD. One of INSERM missions is to provide decision-makers in the public health sector an analysis of the scientific literature on a specific topic. These “collective expertise” obey to a strict methodology and are produced by a group of a dozen scientists. The French social insurance fund for self-employed workers commissioned four collective expertise with an aim: (i) to improve the screening and the prevention of mental disorders (INSERM 2002) and conduct disorder (INSERM 2005), and to foster the understanding of learning impairments (INSERM 2007); (ii) to provide ideas on how best to follow-up children with these disorders, especially as regards systematic health assessments and risk factors detection (INSERM 2009).
- Five reports have been elaborated by committees set up either by the Department of Health, the Department of Education, or both. The two first reports, commissioned by both Departments, concerned dysphasia and dyslexia: the first one (Ringard 2000) intended to describe the current state of knowledge and practices, whereas the second one (Veber and Ringard 2001) defined a national plan – that has been put into application shortly after its publication – for children with specific language impairments. The other three reports are: (i) a report defining and classifying “cognitive disabilities” (Cecchi Tenerini 2010); (ii) e-learning modules on learning impairments and conduct disorder for teachers (EDUSCOL 2012); and (iii) a position paper on the organization of screening and provision for children with learning impairments (Commission nationale de la naissance et de la santé de l’enfant 2013) – one of us had the opportunity to attend five out of the six meetings of the group in charge of preparing this position paper.
- Upon Hypersupers and five professional societies’ request, guidelines for actions to be implemented for children and teenagers with ADHD are currently under completion by the HAS.
- The ANSM (Agence Nationale de la Sécurité des Médicaments, The French national medicine agency) issued a report in 2013 on the use of methylphenidate (ANSM 2013).
- The CNSA (Caisse Nationale de Solidarité Active, the French national fund for dependent elderly persons and persons with disabilities) is currently elaborating a guide to help its professionals to manage learning disabilities; we have had access to a nearly completed version of the report.

3. Revisiting the “backwardness” of France

Taken altogether, the reports we studied display two main features around which we outline the remaining sections of this article.

Firstly, with the notable exception of the HAS framework plan for guidelines on ADHD, none of the other reports has ADHD as an exclusive focus. ADHD surfaced in these various contexts, sometimes quite marginally, other times more firmly after Hypersupers and sister organizations’ active lobbying. When scrutinizing the content of

the documents, one is struck by the uncertain positioning of ADHD either within or in-between different categories of disorders, namely mental disorders, conduct disorder, learning impairments, specific language impairments, and cognitive disabilities. This elusiveness of ADHD was a major preoccupation for the various expert groups, which continually discussed what ADHD is, i.e. what are its causes and effects, its significant manifestations, and the mechanisms underlying its “natural history”? This questioning is particularly prominent in the first three collective expertise conducted by INSERM on mental disorders, conduct disorder and learning impairments, which exclusively involved academics in contrast to the other expert groups which included private practitioners, members of the Health administration, the Education administration or the Disability administration, as well as education specialists and representatives of patients organizations. Section 4 is devoted to this enduring problematization of ADHD as an unsettled condition, which in turn leads experts to question the very nature of a series of disorders to which it is associated.

Secondly, there is a massive difference between the reports that question what ADHD is, and the reports that reflect on what to do for the people concerned with ADHD (children and families) and for those implied in the management of the disorder (teachers, primary health professionals, specialists, etc.). As stated above, the reports focusing on what ADHD is are sort of trapped into the complexity of the disorder, and do not bring in conclusive answers to the questions posed to them by the institutions. In contrast, the reports reflecting on what to do on and with ADHD strive not to forget but to put aside the multiple uncertainties on the definition of the disorder, and rather engage discussion on how to mutually accommodate ADHD and the existing health and school systems. Despite these differences, the reports highlight the deficiencies of the health and school systems when confronting complex and uncertain conditions, as much as it puts to the trial ADHD experts and decision-makers when it comes to “acting in an uncertain world”, to borrow from Callon, Lascoumes, and Barthe (2009). Section 5 digs around this problematization of ADHD as an undoable condition, whose treatment challenges the articulation of knowledge to action.

In light of our analysis, the conclusion reverts to the alleged “backwardness” of France. The reports we studied allow us to refine our initial observation. Apart from the weak presence of French scientists on ADHD and the historical importance of psychodynamic-oriented approaches, what best characterizes the French ADHD landscape is experts’ prevarications on what to do on and with this unsettled condition. The reports we studied clearly show that though ADHD has progressively raised its profile up to an issue that deserves collective and public attention in itself, the question of how to make the disorder an ordinary object of public health and educational interventions still remains largely open. This may not be specific to France, but at the very least, it is a pressing concern for families and for professionals who confront children with ADHD in their daily occupations.

4. The problematization of ADHD as an unsettled condition

The reports we studied do not simply constitute a list of independent and dispersed documents. As we stated above, these reports cite each other, and many of them are mentioned on Hypersupers website. The map below displays the citation links between these reports:

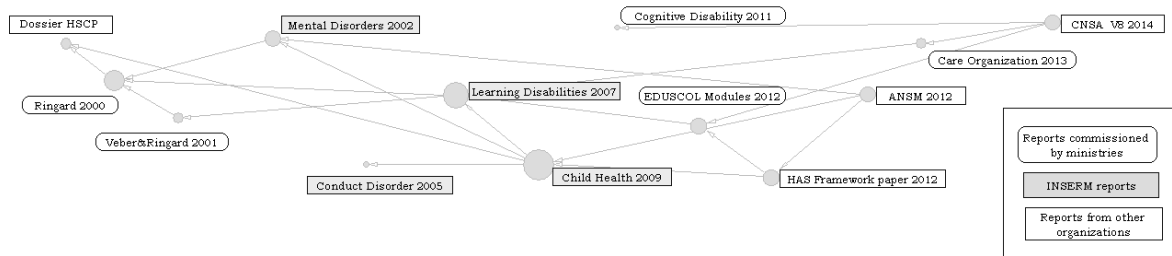


Figure 3: Citation links between the reports

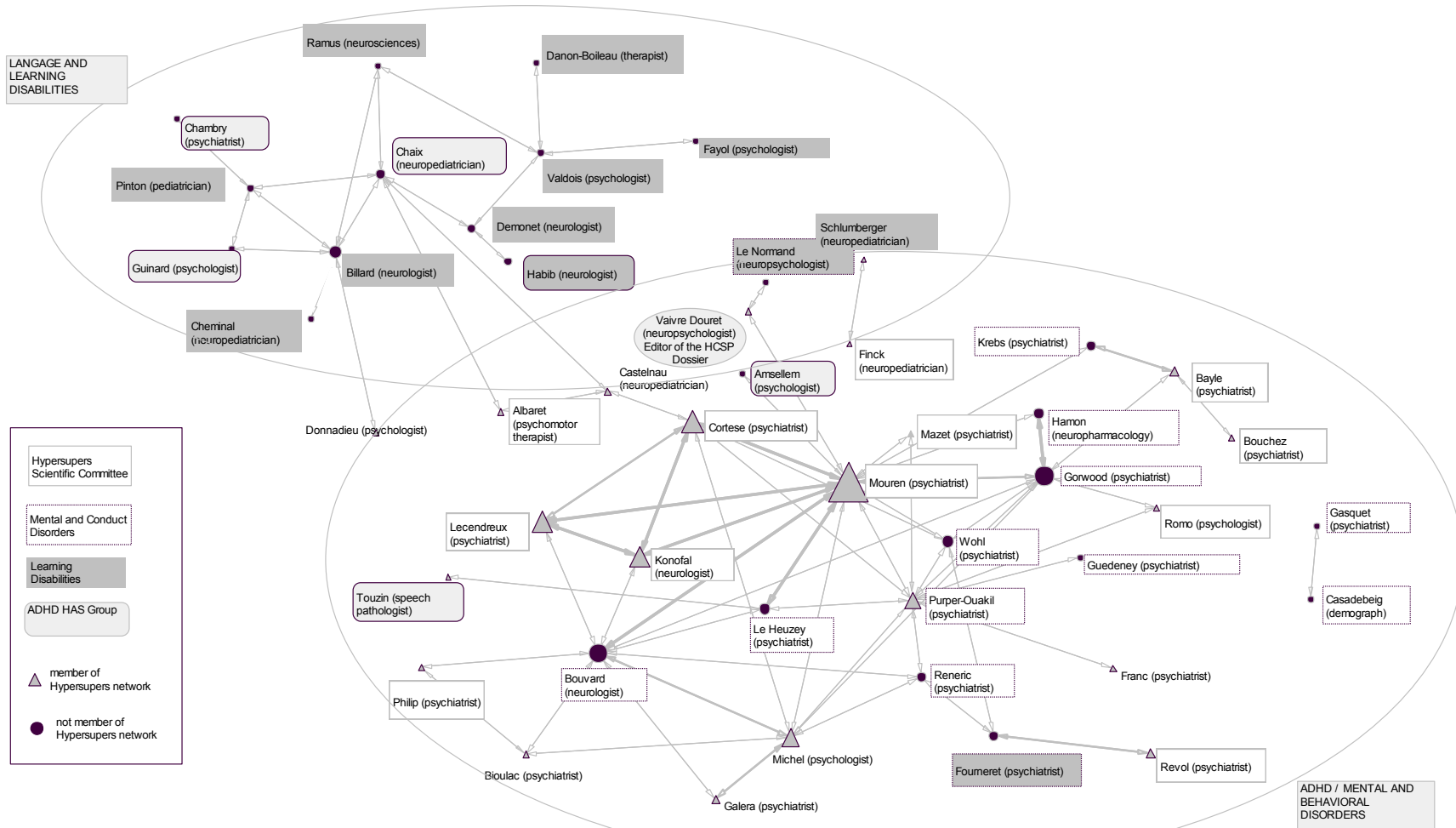
Besides, 21 experts participated to 2 to 5 reports, resulting in most working groups sharing members with 6 or 7 other groups. Over the years then, these experts have progressively formed a community contributing to the emergence and recognition of ADHD as a public issue, alongside other conditions.

Furthermore, since HyperSupers has been active in bridging different groups of specialists, we investigated the collaborations between the expert groups we explored and the scientific network to which Hypersupers allies (i.e. all clinicians-scientists who have either given a conference in one of Hypersupers meetings, who have been awarded a prize by Hypersupers, or who are members of Hypersupers scientific committee). We did this by tracing co-authorships within the expert groups and Hypersupers scientific network

For the sake of clarity, we grouped the reports into three categories: (i) the two INSERM reports on mental disorders and conduct disorder; (ii) the various reports on learning impairments; and (iii) the HAS guidelines on ADHD. About 60% of all academic experts mobilized in the various reports are represented on this map, which shows that: (i) there indeed exists a community of experts, including ADHD specialists, which have multiple bonds with each other; and (ii) that the scientific network of Hypersupers can reasonably be considered as partaking in this community. More precisely, the map helps to decipher the positioning of Hypersupers scientific network. Two groups can be clearly distinguished:

- The first one is mainly composed of psychiatrists who have been mobilized for the reports on mental disorders and on conduct disorder; despite the fact that none of the members of Hypersupers' scientific committee participated to these reports, Hypersupers scientific network is highly connected to this group of experts;
- The second one is mainly composed of neurologists who have been mobilized for the reports on learning impairments.

- A few individuals – almost all belonging to Hypersupers scientific network – bridge the gap between these two groups. Participants to the HAS group, the only one specifically dedicated to ADHD, belong to both groups.



This first examination of the reports leads us to two main conclusions. Firstly, taken altogether, the reports delineate a community that presents all characteristics which Haas (1992) associated to epistemic communities, i.e. “a network of professionals with recognized expertise and competence in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area.” (ibid: 3). This epistemic community does not represent all scientists, clinicians and professionals who either work on or manifest an interest in ADHD and associated conditions, some trenchantly opposing the conclusions of the one or the other report, as we will see. This epistemic community is rather a group of people from heterogeneous backgrounds, and occasionally conflicting views, which has been conferred epistemic credentials by the institutions and public authorities, and which has struggled to put various conditions, including ADHD, on the political agenda. Secondly, from an academic perspective, this community draws upon two subgroups, one more psychiatry-oriented, and the other more neurology-oriented and especially interested in learning impairments. Hypersupers plays a decisive role in connecting these two subgroups, a position which we will reflect on.

ADHD, a disorder with a multiple personality

The existence of an epistemic community around ADHD does not mean that its definition and characterization have been straightforward and consensual. Actually, up to the end of the 2000s, most efforts have been attempted to sort out the very nature of this disorder.

The variety of labels used in the reports is a first indicator of the prevailing uncertainty at that time. Whereas the dossier published by the HCSP in 1999 talked of attention deficit/hyperactivity disorder, the 2002 INSERM report on mental disorders provided a dozen of different names. In the chapter on epidemiology, the author related these names to various classifications and epistemic traditions: Hyperkinetic Syndrome in the European tradition, ADDH Attention deficit disorder with hyperactivity in the DSM III, ADHD Attention deficit/hyperactivity disorder in the DSM IV, Hyperkinetic Syndrome and Attention-Deficit Hyperactivity Disorder in the ICD-10. In other chapters, new denominations appeared without always being “traced”: attention deficit with hyperactivity/ without hyperactivity, hyperactivity-attention deficit, hyperactivity disorder with attention deficit, psychomotor instability, minimal brain dysfunction etc., thus synthesizing ADHD history (Conrad 1975; Rafalovich 2001) without really putting it in context. The report did not make any decision about the denomination that should be used: this probably indicates the lack of consensus within the group and even a confrontational atmosphere⁴. At about the same time, a special issue of *Le Carnet Psy*

⁴ As reported by Gérard Schmit in *La lettre de la psychiatrie Française*, n°162, février 2007, <http://www.psychiatrie-francaise.com/Data/Documents/files/LLPF%20162%20-%20f%C3%A9v%202007.pdf> (accessed on 2014, August 21st)

was published on *unstable children*; in its introduction titled “Instability of the instability”, the editor (July 2003) commented on this multiplicity: “There might be as many instabilities as unstable subjects, and under the label ADHD or hyperactive, we may talk of very diverse children (...) even if they display (...) the same triptych: hyperkinesis, inattention and impulsivity”. In this issue, maintaining this multiplicity appears as a way to preserve a plurality of approaches, including psychoanalysis, and to contain the “pervasive hegemonic trend of the American DSM IV”.

The multiplicity at stake here is a bit different from the one described by Mol (2002); it denotes the fact that different practitioners from different backgrounds enact different disorders which, at some point, are being grouped together, notably by parents who do not subscribe anymore to the dominant psychodynamic approach. In contrast to the case of arteriosclerosis studied by Mol, these approaches are in competition with one another; more precisely, the *Carnet Psy* issue provides evidence for the emergence of a space of negotiation: some people stand on their position, like Bernard Golse (2003) who declares: “Giving up on words, one eventually gives up on ideas... Giving up on theories, one eventually gives up on practices”; but others are calling for an integration of approaches: “Investigating child hyperactivity with a complex psychopathological perspective may result in more than a dispute between schools of thought: a deep reflection on a psychopathology that would neither ignore psychoanalytical intelligence (...) nor the neuro-bio-physiological substrate of any human singularity.” (July 2003).

The variety of denominations decreased in subsequent documents and eventually converged around TDAH (the French equivalent of ADHD), after a period when THADA (Hyperactivity with Attention Deficit Disorder) prevailed. Thus the focus moved from hyperactivity –the most disputed concept – to attention deficit. Even psychodynamic-oriented psychiatrists have come to use TDAH, though a limited variability remains in the psychodynamic literature: “psychomotor instability” (Metz and Thévenot 2010), “hyperkinetic disorder” (Raffy 2006). The use of such concepts always manifests a contestation of what “ADHD” entails.

Beyond the question of denomination, the definition of ADHD itself has been at the heart of a number of reports, especially the INSERM ones. Two main questions have been discussed: (i) to what category of disorders should ADHD be attached? and (ii) what are the links between ADHD and other disorders such as learning impairments and conduct disorder?

It seems that each of the three INSERM reports constituted in itself a space of problematization within which ADHD was positioned in a specific way: whereas the division between mental disorders, conduct disorder and learning impairments was supposed to constitute more or less exclusive categories, ADHD was the only disorder taken in consideration in the three categories/reports. Strikingly, in the report on mental disorders, ADHD was considered as pertaining to learning impairments in the

section entitled “biological and cognitive approach”, and as a category of its own, deserving a special sub-section in the section entitled “clinical approach”.

Moreover the issue of uniqueness/multiplicity of ADHD was raised in the 2002 report on mental disorders in relation to the various associations of THADA with other disorders:

“THADA is barely isolated. International epidemiological studies have shown a very high comorbidity, since more than half of children with THADA have received at least one additional diagnosis and especially a conduct disorder, an oppositional disorder, a mood disorder and/or an anxiety disorder. (...) Clinical studies also point to its co-occurrence with learning impairments (between 10 to 92% depending on the study...). It is estimated that 18% of children with THADA have tics. (...) Children with a comorbid form of THADA would present special clinical characteristics. (...) Comorbidity of THADA with bipolar disorder represents a specific clinical form which is still currently discussed.”

The INSERM reports questioned the very nature of the links between ADHD and other disorders: is ADHD a precursor of conduct disorder, “suggesting that these two disorders are part of a same clinical entity”? Or is it a different kind of disorder that co-occurs with conduct disorder? More precisely, what is the role of executive dysfunctions in both disorders? Are they common to them, or specific to ADHD? In the conclusion of the report, it is suggested that the “real” antisocial behaviour is the one that includes ADHD, and deduces that ADHD seems to be constitutive of conduct disorder. And what about the comorbidity between ADHD and learning impairments? Is ADHD a conduct disorder that worsens the consequences of learning impairments, or is it in itself a learning impairment?

May have the commissioners of the reports been expecting to get definitive answers on the investigated topics, they would have been deeply disappointed as regards ADHD, as the experts let a variety of interpretations proliferate without taking a stand for one or another, except the fact that they all agreed on a biological origin of ADHD, possibly a genetic one. ADHD looks like a chameleon, transforming itself while being plunged in various epistemic environments; even more, it seems difficult to discern ADHD from other entities: is ADHD delineating the frontier between different disorders, or are other disorders exploding the ADHD entity? The experts left all these questions open, working to the joint problematization of ADHD and its associated disorders, and producing a picture which put to the fore the complexity of the involved mechanisms and the multiple uncertainties as regards causes and effects.

An elusive and disputed prevalence

Calculating the prevalence of a pathology implies that the pathology is recognized as such and that there is an agreement on the diagnostic criteria: considering the state of discussion on ADHD in France, it is hardly surprising that until very recently, no data was available on this matter, which did not prevent this topic to be discussed in a variety of arenas.

The INSERM reports echoed the lability of ADHD and presented a set of thresholds, each corresponding to the definition of the disorder according to one given classification:

“Studies drawing upon DSM produce rates ranging from 0,4% to 16,6%, generally comprised between 5 and 10%. Conversely, studies drawing upon the ICD definition of the hyperkinetic syndrome result into much lower rates ranging from 0,4% to 4,2%, with an average around 2%.”

The prevalence of comorbidities was discussed in similar terms, with an emphasis on the diversity of methodologies used in the literature.

The press also reflected this uncertainty; more precisely, depending on their source of information, papers displayed different rates: commenting on the 2002 report by INSERM, *Le Monde* and *La Croix* estimated the figure at 1 to 2%; a year later, interviewing Christine Gétin, the president of Hypersupers, *La Croix* quoted her estimation – 3 to 5% – but mentioned that according to some specialists, the prevalence is only about 1%. A few years later, in 2009, *Le Monde* published a paper on adults with ADHD, stating that “according to various studies, it is estimated that out of the 3 to 8% of children suffering from this disorder, 60% still suffer from the disorder as adults”; but at the end of the paper, they quoted Bernard Golse’s reaction: “3 to 8%, I consider that it is a big joke and that there is only a few children out of a thousand. The society cannot stand restless children, thus the problem is eliminated by prescribing amphetamines rather than getting interested in the symptoms”, an argument which illustrates the finely-grained analysis proposed by Singh (2006) on the social and cultural understanding of ADHD.

In 2010, Michel Lecendreux and Eric Konofal – two of the most faithful allies of Hypersupers – together with Stephen Faraone, an international “star” of ADHD research, published the first epidemiological study on ADHD in France (Lecendreux, Konofal, and Faraone 2011). Carried out by phone with a sample of about 1,000 families, it resulted in a prevalence threshold comprised between 3,5 and 5,6%, allowing the authors to conclude that: “The epidemiology of ADHD in French children is similar to the epidemiology of ADHD in other countries”, thus reinforcing the “reality” of the disorder.

Thus, in less than 15 years, ADHD status has dramatically changed: considered as an American invention in the late 1990s, it is now recognized as a real disorder, even if still controversial. Concerned people and professionals continue to face a burdening problem however: what actions should be collectively undertaken for facilitating patients, families and professionals’ management of the disorder in a context where multiple uncertainties still loom large in expert discourses on ADHD? The following section turns to this question.

5. The problematization of ADHD as an undoable condition

Confronted to social exclusion, to accusations of bad parenting, and even to threats that their children will be removed from the ordinary school system, the recognition of ADHD as a “real” disorder is crucial for patients and families, though not enough: since

its inception, Hypersupers has been seeking a “complete” solution to the problems posed by ADHD, i.e. the possibility to get a diagnosis in a reasonable delay, to be offered a variety of treatment options – psychotherapies, rehabilitation, medicine –, and to benefit from school adaptations.

Sorting out the disorder from mere difficulties

Since its creation, Hypersupers has been in contact with an organization of families and professionals concerned with learning impairments called Coridys, provided the frequent association between the two conditions and the fact that children with ADHD and children with learning impairments are often facing similar sorts of problems. The president of Coridys was a member of the working groups elaborating the 2000 and 2001 reports commissioned by the Department of Health and the Department of Education on specific language impairments (SLI). He associated the president of Hypersupers to his strategic reflections and they both agreed on the fact that it would be relevant to put ADHD on the list of conditions concerned by the action plan, so that children with ADHD might benefit from it. So much so that in the *circulaire*⁵ published in order to implement the national plan resulting from these reports, ADHD was included into the broader category of learning impairments to which SLI also belong. By bringing ADHD closer to learning impairments, while sustaining bonds with specialists from other backgrounds, Hypersupers has found its way through the multifaceted landscape of ADHD and associated disorders for the benefit of patients and families.

The plan provided a series of landmarks in the domain:

- It stated that “specific learning impairments which comprise dyscalculia, dyspraxia and attention disorders with or without hyperactivity [in addition to SLI, concerned by this *circulaire*] are considered as primary disorders, i.e. their origin is supposed to be developmental, independent from the socio-cultural environment on the one hand, and different from a recognized mental impairment or psychic disorder on the other hand.”
- It set up a distinction between *difficulties* and *impairments*, given the fact that the identification of real SLI is not that easy, for they translate into “symptoms” which can be confused with those displayed by children with temporary school difficulties. Consequently, it insisted on the need for developing early screening taken in charge both by teachers and school doctors.
- It declared that, in most cases, children with SLI should stay in the ordinary school system, and that a schooling plan should be set up in order to define the adaptations and special means in terms of rehabilitation and educational support that children should benefit from.

⁵ *Mise en œuvre d'un plan d'action pour les enfants atteints d'un trouble spécifique du langage oral ou écrit*, circulaire du 31/1/2002, Encart Bulletin Officiel de l'Éducation Nationale n°6, 7 février 2002, <http://www.education.gouv.fr/bo/2002/6/default.htm> (accessed on 2014, August 25th).

- It advised for the creation of multidisciplinary centres of reference in university hospitals that would be in charge of elaborating precise diagnosis, of defining care and of conducting research.

The plan was clearly a watershed in the area of learning impairments, specific language impairments and ADHD, in stating that these disorders are serious medical problems which should not be regarded as mere temporary difficulties induced by the social or family environment, and which challenge the existing health and education systems. It notably drew attention to the issue of screening and diagnosis, whose rationale had been endlessly discussed by experts with few conclusive advices.

Organizing screening and diagnosis

Screening, has been, and still is, a contentious and difficult issue: indeed, the 2000 Ringard report suggested to proceed to systematic identification of 3 to 4 years-old children who display oral language delay. Despite paying a lot of compliments to the report, Jack Lang, the then Minister of Education, declared that he disagreed with this proposition, arguing that: “a too early diagnosis can be a catastrophe for a child, and a lot of learning difficulties can be handled by other means than a heavy medical management”.

But the massive controversy about screening arose in the aftermath of the publication of the 2005 INSERM report on conduct disorder. In the final chapter, the report drew a number of recommendations, amongst which a health examination for 3-years old children:

“At this age, it is possible to identify children with a difficult disposition, with hyperactivity and with the first symptoms of conduct disorder. This early identification allows to setting up preventive actions. (...) The items [to be added in the Child Health Record] may concern the various symptoms of conduct disorder: physical aggressions (fought, bit, hit, kicked); opposition (refuses to obey, no remorse, no conduct change); hyperactivity (can't stay quiet, is always fidgeting, can't await his/her turn).”

This measure sparked a public outcry, especially from a number of psychiatrists; it elicited the creation of a collective and the launching of a petition that eventually gathered nearly 200,000 signatures. The opponents denounced the INSERM report as instrumenting care practices to the benefit of the security policy of Nicolas Sarkozy, the then Minister of Home Affairs. This argument probably helped to gather signatures from people not especially aware of psychiatric issues. The opponents' attack did not stop there however; they considered that:

- The knowledge mobilized by the INSERM report was limited to “theories of behavioural neuropsychology that allow to identify any deviance according to a norm established in accordance with Anglo-Saxon scientific literature”.
- This approach leads to the “medicalization of educational, psychological, and social phenomena, and creates a confusion between social unrest and psychic suffering”: some leaders of the movement explicitly drew on social sciences to develop their argumentation

- It draws upon the use of medicines that might “induce a formatting of children behaviours” and “a form of infantile drug addiction”.

Though Hypersupers did not contribute to this report, its internet forum soon turned into a place of heated discussion: on one hand, some parents considered that the labelling resulting from early screening could lead to further stigmatization, and that associating ADHD to conduct disorder would make it even more difficult for the general public to understand its neurological dimension. On the other hand, other parents considered that at last, the report had set up the basis for an understanding of the disorder, and that it could be used as a leverage to get screening and diagnosis organized and professionals educated. They also pointed that it is important not to fight the wrong enemies, and that joining the collective “Ban zero mark for three-years old children’ s conduct”⁶ is to support those very psychiatrists who refuse to take ADHD seriously.

In the end, this latter line prevailed and a press release was issued on March 2006, insisting on the dramatic situation of children with ADHD in France and on the fact that, considering this situation, the report had made a number of welcomed recommendations such as the organization of early identification, the development of research on care, the involvement of parents in care, and the setting up of measures to support them. It concluded that the report should prompt a reflection leading to solutions appropriate to the field realities.

The controversy lasted several months: the INSERM was summoned by the Department of Health to organize a large conference gathering the main protagonists. Clearly different perspectives were exposed during the conference, but in the end, it seemed to result into a wishy-washy consensus about the need for combining different approaches as regards conduct disorder, and of being extremely cautious in the qualification of what is at stake when confronting children with behaviours evocative of conduct disorder. Probably owing to the press release, the president of Hypersupers was invited to give a paper (Vergnaud Gétin 2007), in which she criticized some formulations of the report which could be interpreted as validating the idea that ADHD leads to delinquency; but she also reaffirmed the press release statements as regards the necessity for developing a prevention, detection and care policy.

Thus, whereas Hypersupers endorsed the alignment between ADHD and learning impairments in the 2000 Ringard report, it implicitly accepted the juxtaposition of ADHD with conduct disorder in its reaction to the 2005 INSERM report. Actually, instead of remaining paralyzed by the uncertainties on ADHD, Hypersupers tried to take advantage of the fuzzy identity of the disorder and adapted its positioning whenever it felt that the context might be conducive to beneficial changes for patients and families. In the confrontational atmosphere induced by the INSERM report however, the

⁶ in French: Pas de zéro de conduite pour les moins de trois ans.

association between ADHD and conduct disorder proved to be a dead-end: no significant change followed, and the issue of screening and diagnosis was once again postponed until the most recent reports.

Going with a demonic and demonized medicine

Another reason explaining Hypersupers' intervention in this debate might be that the criticisms formulated by the opponents to the report were exactly the same that families had to face in everyday life: indeed, one important difference between learning impairments and ADHD lies in the existence of a supposedly "miraculous" medicine for the latter, which is not the case for the former. Thus, the "medicalization" thesis takes a flavour in the case of ADHD that is not in the air for learning impairments.

As already mentioned, Ritalin© has always been a "fixation abscess" in public discussions around ADHD: "symbol of the all-drug option in child psychiatry" for *Le Monde*, it is invariably associated to the drifts of American child psychiatry. It has been apparently prescribed in France for ADHD since the 1980s in the Child Psychiatry Unit (Wodon 2009) headed by Michel Dugas who trained most of the psychiatrists taking in charge ADHD in France in the early 2000s, though its use has been limited until the last ten years. Hypersupers and its expert network have always displayed a measured attitude towards this medicine: they consider that it might be a precondition to enter a therapeutic process: without it, it is simply not possible for some children to reflect on their behaviour, to learn to discipline themselves and to be receptive to school teaching.

Access to methylphenidate is complicate in France: it is classified in the list of narcotic drugs; the first prescription must be done by specialized hospital doctors; it has to be renewed every 28 days by the attending physician and every year by the specialist. Many parents told that pharmacists had horrified reactions while reading the prescription and often lectured them on their parental duties. So gaining access to methylphenidate has been inseparable from informing and raising awareness on the need for combined therapeutic approaches, including methylphenidate, among professionals and the general public.

To increase the credibility of this information, Hypersupers asked the French national medicine agency (ANSM) to elaborate a document for the general public and told the ANSM its preoccupation relative to the ignorance and prejudices of professionals. In 2013, the ANSM issued two documents: (i) a report on the current use of methylphenidate and on how to use it securely; and (ii) an information leaflet for parents.

The report showed that methylphenidate consumption increased a lot since 2004: it rose from 0,01 Defined Daily Dose (DDD) per 1000 inhabitants in 1996 to 0,18 in 2005 and 0,43 in 2012, but despite this augmentation, it remains very limited compared to most countries, and especially to the leaders, i.e. Iceland (13,5DDD), Canada (11,7DDD) and US (9,12DDD).

Hypersupers' intervention resulted in the ANSM publishing statistics that should transform debates around the medicine. The difficult access to methylphenidate remains a preoccupation for Hypersupers, but for them, this is only one aspect of the problem: in contrast to what has been described in US {Citation}Hypersupers has always been fighting against the drug reductionism, which implies that they have to negotiate a narrow path between psychoanalysts who refuse to consider the biological aspect of ADHD and some neurologists who consider that once the medicine prescribed, there is nothing to be done:

“The medicine has an effect limited in time and limited to specific functions, attention functions and work capacity. (...) But children with ADHD have difficulties in integrating social codes and living in society, and as the medicine comes late in their life, they need help. And that is part of school missions. (...) If we let some neurologists train teachers telling them that they should advice the parents to have their child on the drug, the very drift denounced by some psychiatrists will occur, with an excess of normalization. And I don't agree with that.” (interview with the president of Hypersupers)

Not only promoting the drug would expose Hypersupers to accusations of being manipulated by the industry and/or contributing to social control; it would also go against the multimodal approach to care which combines education, psychological and medical interventions that the organization has been defending together with its expert network: and that they had the opportunity to promote during the preparation of the 2005 Disability Act.

Lightning a bit of hope: the invention of the concept of “cognitive disability”

In 2002, the then French President Jacques Chirac initiated the long process of the elaboration of a new Disability Act: it took about three years and many meetings, commissions, reports to get to the final point. A number of meetings were held with the organizations representing disabled persons or parents of disabled children. In this context, Hypersupers and Coridys, the organization concerned with learning impairments mentioned earlier, together elaborated a strategy in order to put forward the new concept of “cognitive disability”. Christine Gétin, the president of Hypersupers, had to replace the president of Coridys on one of the meetings:

“It was the first time I was attending such a meeting. 70 organizations, some of them very big ones, represented by their directors, very educated people, they were discussing about the terms to be put in the law: physical disability, mental disability etc. I knew nobody. They were talking an abstruse language with acronyms I have never heard of. I made a first intervention on cognitive disability; they just stared at me, wondering who I was. I let them discuss. Then I came back, a discussion arose, I made arguments, somebody took up my intervention, it was settled!”

The 2005 Disability Act set up MDPH (Maison départementale des personnes handicapées, House for people with disability) at the level of each French department: MDPH have multidisciplinary teams in charge of elaborating a compensation plan for each individual; in the case of children, this plan includes a schooling plan as well as other types of interventions, such as rehabilitation. Their work is based upon the

International Classification of Functioning, Disability and Health (ICF) that promotes a bio-psycho-social approach to disability and articulates an analysis of alterations of functions with the determination of the limitations to activities and the restrictions to social participation that a person with disability may encounter. To evaluate the compensation, they need to know how to move from a diagnosis to a description of the altered functions and of their effects on everyday life. Considering the novelty of the concept of “cognitive disability”, the Inter-Ministry delegate for people with disability set up a working group in order to define the content of cognitive disability and to describe it according to the ICF.

During two years, starting in early 2008, the group comprising the main associations in the domain worked to produce a document, which detailed, for each diagnostic category, the nature of impairments, the main activity limitations and the usual restrictions to social participation. Discussions pointed out the specificities of the French disability categorization which offers a striking example of what Sheila Jasanoff (2005) called “civic epistemology”: the notions of “mental disability”, “psychic disability” and “cognitive disability” resulted from the work of various associations who, from the middle of the 20th century, fought to get some problems recognized by pushing forward new categories (Azéma et al. 2001; Barral et al. 2000; Chapireau 2011; Van Amerongen 2005); “cognitive disability” took place in an already long history of conceptual innovations.

Discussions resulted in the recognition of an epistemic positioning held by Hypersupers against other organizations: the expression “learning impairments” disappeared from the classification, in contrast to most documents in which this category is often used as an umbrella term encompassing ADHD on its margins. The argument put forward by Hypersupers was that a range of disorders such as dyspraxia, dysexecutive syndrome, dysgnosia, ADHD, etc. cannot be considered as resulting from a learning process, in contrast to dyslexia, dysorthographia and dyscalculia. The suggestion was to make a distinction between specific developmental specific impairments and specific acquired impairments. In the final version of the document, the distinction between these two categories does not clearly appear however, but all these entities are grouped under the “specific developmental specific cognitive impairments” heading, and nowhere does the expression “learning disabilities” appear.

Through this categorization, Hypersupers tried to overcome the fuzziness and ambiguity that have characterized previous positioning of ADHD within existing nosographies. At the same time, this categorization impacts on the mutual positioning of the disorders at stake by ordering them in a novel way, some disorders - like ADHD - being considered as of a more “fundamental” nature in the sense that they may contribute to other disorders linked to learning activities.

Shortly after the completion of the report, the Inter-Ministry delegation was suppressed. Consequently the report stayed in the administration cupboards. After two or three

years, the associations that worked on the report decided to make it public and to post it on their websites. It would seem that all this work has been wasted, but this appraisal would miss the fact that “learning disabilities” are associated to a compulsive policy making activity. In 2014, the CNSA, which is the organization managing the MDPH, decided to complete the elaboration of a guide for the MDPH professionals in order to help them dealing with “specific language and learning disabilities”: they brought together a group of experts, both professionals and patients’ representatives, who had for most of them participated to other working groups. The “cognitive disability” document came out of the discussions as a masterpiece that should be considered, if only because it had been produced exactly for this kind of purpose. The CNSA document, still in a validation process, not only takes up the classification of disorders, but also integrates most of the description of these disorders as it was set up in the previous document.

One of the innumerable texts produced by the administration which could have simply died before really being born was brought to the light by the community of people who contributed to its writing: the continuity of policy-making across time and across institutions results from the repeated interactions of a group of people who constituted itself while shaping and giving consistency to their matters of concern.

A care organization paralyzed by the lack of expertise

The shared acknowledgement that the system does not work properly underlies the CNSA process as well as the setting up of a working group on the organization of care for children with disabilities by the Department of Health.

Working sessions of these groups have been occasions for each category of actors, starting with patient organizations, to complain about various organizational dysfunctions.

The testimonies that Hypersupers had been receiving since its inception had prompted its board to undertake increasingly sophisticated surveys on families’ experience of the health system and of the school system; the last of these studies was initiated in 2011 and its main results have been published in a medical journal (Getin-Vergnaud and Angenon-Delerue 2011). It has also been presented on various occasions, and to the Department of Health working group. The survey showed that it took 31 months on average for a family to get a diagnosis, instead of 4 years at the beginning of Hypersupers activity, and that a half of the parents estimated that the first professional they consulted had no idea of ADHD or a poor level of knowledge. Once on the right track, the diagnosis process seemed satisfactory as 79% got a psychometric assessment, 70% a psychological assessment, 52% a detailed neuropsychological assessment, 62% a speech and language assessment and 53% a psychomotor assessment. A major issue was the cost of care evaluated at 200€ per month, since, according to the survey, 39% of them were engaged in a psychotherapy, 27% in a speech and language therapy, 19% in

psychomotor therapy, therapies which are not all taken in charge by the public health insurance system. Even if 44% of children benefited from a personalized schooling plan, they encountered a lot of difficulties: 20% had been excluded from school at least once, 30% had repeated at least a grade, and half of the parents had difficult or very difficult relations with teachers.

The contributions of other members of the working group pointed to a number of difficulties: because the MDPH are the entry point that allows to get a multimodal treatment, the elaboration of the schooling plan and the reimbursement of certain interventions, many parents engage into building a case to get recognition of their child's disability. The MDPH are thus overcrowded by demands that they don't know how to handle, given on the one hand their lack of expertise (hence the elaboration of a guide by the CNSA) and on the other hand, the heterogeneity of the documents they receive to assess the cases: facing what they consider as poorly justified demands, they challenge the competence of the doctors producing these documents. To overcome this difficulty, they ask parents to get a diagnosis from one of the few reference centres created by the 2002 national plan.

Consequently, the reference centres are overcrowded by demands that range from simple difficulties to extremely severe impairments: the active file population often represents an appointment delay from 12 to 18 months. A few doctors working in private practice have been trained to these disorders, but they cannot always proceed to all the necessary assessments, which require a multidisciplinary approach:

"We are confronted to children with school problems, and more and more often to complex cases, with an intermingling between various problems, including psychological problems. If we wait until the completion of assessments, it can take up to one year; and the child stays with his/her problems. We want them to start something before getting the diagnosis completed." (a paediatrician, working group)

Indeed, uncertainties, affecting medical knowledge as well as clinical situations, which are not specific to France (Rafalovich 2005), lie at the heart of the organizational dysfunctioning. The ideal organization described in the position paper would articulate three levels of care: (i) a first one in charge of detection and of making the difference between difficulties that call for light intervention and disorders; (ii) a second level in charge of elaborating a first diagnosis and handling the cases with medium severity; and (iii) a third level, the reference centre, taking charge of the most complex or severe cases. But as they themselves admitted over the discussion, stabilized knowledge and expertise that would allow for such a division of work are dramatically lacking: (i) training for doctors as well as teachers is still insufficient; and (ii) evidence on the efficacy of therapies are also too scarce:

"We need to reflect upon criteria for rehabilitation, and on criteria for stopping rehabilitation. (...) Once we have detected dyscalculia, what do we do? We are far from being at the top as regards recommendations for apraxia. And on psychomotor rehabilitation, cognitive remediation,

psychodynamic psychotherapies for attention deficit, we are at a stage where we need to do clinical research to be able to train other people.” (a neuro-paediatrician, working group)

Moreover, echoing Georgieff (2008) analysis on the discrepancies between research and clinical practices in psychiatry, it seems that the categories on which the diagnosis is supposed to be drawn are not that adjusted to the clinical situation, even leading to question the notion of diagnosis:

“Why not getting rid of the word diagnosis and replace it by ‘review of the situation’? So that we could adapt, not to an adult with hemiplegia consequences or a child with radiotherapy consequences due to leukemia, but to a developing being for whom the only thing we can tell today is: ‘We observe this; we don’t know more’, but what we know is that if we give him that for a certain time, it might change his life.” (a neuro-paediatrician, working group)

Lastly, social factors can enter into play in a complex way: children with disadvantaged backgrounds might be ignored, because their problems are mistakenly attributed to their situation, while children from privileged backgrounds can also be ignored because the support they receive from their environment conceals their problems until they simply collapse.

These various uncertainties lead to ambiguity and prevarications on what to propose. For instance, the president of Hypersupers has the following hesitation about methylphenidate prescription:

“It would be good to have prescriptions done in private practice. But the doses adjustment is something complicated, and we observe problems in private practice, doctors are not always well trained. They are very uneasy on this issue, and don’t know very well the drug. The only people we are sure can handle it are the specialized hospital doctors who did the first prescription. And it’s important because some treatments fail because of poor adjustment.” (working)

Moreover, the necessary multidisciplinary is difficult to achieve in everyday life: the various medical actors involved – GP, paediatrician, language pathologist, psychomotor therapist, psychotherapist – are working in different places, they cannot easily attend the meetings at school where the schooling plan is regularly re-evaluated, whereas all actors agree on the fact that “whatever its complexity and its performance on a medical point of view, without linking it to what’s going on in the classroom, any rehabilitation loses half of its efficacy.” (a neurologist, working group)

There exist about 400 centres for diagnosis and care for children with mental health problems in France, called CMPP (centres médico-psycho-pédagogiques), with a range of medical, psychological and education expertise. However, most of them apply psychodynamic approaches and are very opposed to the DSM. Statistical analysis of the Hypersupers survey mentioned above showed that the delay for getting a diagnosis is two and half longer for parents who consulted first in a CMPP than for parents who went to a private practitioner or a hospital. Whereas associations concerned with language impairments are clearly opposed to the recourse to CMPP, Hypersupers considers that psychotherapists with psychodynamic background have a unique expertise on listening

techniques which can help reduce the use of methylphenidate; consequently Hypersupers rather pleas for enrolling CMPP on ADHD.

Implementing a multimodal and multidisciplinary model of care is clearly not an easy task. Despite the creation of the concept of “cognitive disability”, major epistemic difficulties hinder the process: on one hand, uncertainties on the disorder, associated to the frequency of comorbidities, make it very difficult to delegate screening and diagnosis to “first level” practitioners; on the other hand, theoretical conflicts drastically reduce the number of “second level” practitioners who recognize ADHD as such, even though a number of practitioners are confident that various approaches could be reconciled (Cohen de Lara et al. 2007; de Barbot 2007; Georgieff 2008).

According to some authors, uncertainties around ADHD entice a two-fold attitude amongst practitioners: firstly, they maintain the contested status of the disorder and hinder its recognition (Jupille 2014); secondly, practitioners who recognize the existence of the disorder tend to play around the lability of the category, which has the effect of "facilitating" the diagnosis of ADHD and increasing methylphenidate prescription (Chamak 2011; Jupille 2011). Our material suggests that practitioners and families are well aware of this latter risk of misdiagnosis, due to the multiplicity of problems that may make one think of ADHD at first glance, and they refuse an uncontrolled expansion of the category (Conrad and Potter 2000), which, in the end, may threaten the emerging credibility of the disorder: in order to reduce uncertainties and avoid transforming ADHD into a "catch-all" category, they insist on the need for an expert view to get an accurate diagnosis.

6. Conclusion

We started this article with the often-reported “backwardness” of France on ADHD, due to the historical hegemony of psychoanalysis and psychodynamic approaches which deny the reality of the disorder and relate the observed symptoms to patients’ social and family environments. As Rafalovich (2001) showed, conflicts between psychodynamic and neurological perspectives on ADHD, and protagonists’ legitimizing strategies, were constitutive of the international ADHD clinics. Besides, he displayed the variety of conceptions on ADHD not only between, but also within these two and other approaches, and warned against an appraisal of neurology as a monolithic source of knowledge on the disorder. Somehow then, the 2000s French landscape on ADHD was not that unique, at least in regard to the existing opposition between psychodynamic and neurological perspectives. What is specific to France however, is the massive lack of academics’ interest in ADHD until the end of the 2000s, which may have delayed its coming as an issue worth debating and enquiring about. As a consequence, ADHD emerged as a public issue in quite peculiar circumstances:

- Firstly, the INSERM collective expertise on mental disorders, conduct disorder, and learning impairments, in which ADHD surfaced as an unsettled condition, provided high visibility to international bodies of literature, and notably to a significant

proportion of research work in neurology. This brought in a biological-oriented conception of these disorders, and opened up debates on their very nature. This biological approach and discussions it induced somehow marginalized the French psychodynamic “exception”, in a highly confrontational atmosphere.

- Secondly, Hypersupers, the main French group of patients and families concerned with ADHD, formed in 2002, took initiatives for assembling scientists and clinicians who manifested an interest in ADHD, though holding divergent views, an effort which culminated in the international conference on ADHD organized by the association in 2009. Hypersupers also produced experiential knowledge on the disorder, drawing on families’ testimonies, exchanges via its electronic forum, surveys, etc. in order to “state the fact” of ADHD.
- Thirdly, working groups on disorders more or less associated to ADHD blossomed, which Hypersupers joined in some cases. All together, these successive groups sustained reflection over the last 15 years, and progressively constituted an epistemic community. Their enduring effort helps to understand the continuing elaboration and re-elaboration of public policies on these conditions.
- Fourthly, the 2005 French Disability Act, which Hypersupers and sister organizations endorsed, led to the invention of the notion of “cognitive disability”. This notion offered a conceptual framework for articulating medical care and education interventions that Hypersupers has long promoted, as much as it helped professionals working with disabled persons to enact such a multimodal approach, though difficulties remain.

It was throughout this problematization work, undertaken by certain actors at certain moments and in certain settings, that the term TDAH (the French equivalent of ADHD), and epistemic discussions it opened up, eventually made it. In today’s France, this term is adopted by ADHD specialists including those who continue to oppose the neurobiological flavour it vehicles.

The progressive emergence and installation of ADHD does not imply its univocal positing within the French scientific and medical landscape. Rather, it comes with a shifting position of the disorder that in turn unfolds new relations between different specialties. Early research on ADHD in France was undertaken by Michel Dugas, who trained most of the psychiatrists who specialized on specific aspects of the disorder (associated sleep disorders, the role of iron deficiency, medications). Clinicians who allied with Hypersupers belong to this circle of psychiatrists. In the 2000s, INSERM reports problematized ADHD as an unsettled condition within and between mental disorders, conduct disorder, and learning impairments. When it came to care, Hypersupers rather partnered with sister organizations concerned with learning impairments, while developing contacts with neurologists. The maps we provided earlier displayed this multifaceted scientific and medical landscape of ADHD: (i) a scientific milieu drawing on two groups, one of psychiatrists and one of neurologists; and (ii) a medical milieu within which ADHD is tightly linked to learning impairments, an alliance which in turn repositions the latter within a new category of “neurodevelopmental disorders” very much like what DSM V actually does.

This being said, approaches to care are far from embracing an “all-neurological” perspective. The multimodal approach that Hypersupers and its network has been promoting from its beginnings is core to the reports we studied. This comes with two remarkable features:

- Firstly, psychotherapeutic approaches are far from being excluded. As we showed elsewhere (Edwards et al. 2014), though Hypersupers fully recognizes the biology of ADHD, it steps back from disputes on the causes and effects of the disorder when reflecting on what to do. Rather than the causes of ADHD, its preoccupation is with what ADHD is the cause of, i.e. what does the disorder do to children in their daily life (their learning, psychological and social problems). Consequently, Hypersupers is investigating a wide range of interventions, including psychotherapies. This makes a decisive difference between Hypersupers and organizations concerned with learning impairments, the latter aligning more firmly with neurological-oriented approaches to care.
- Secondly, health practitioners and education professionals also share the multimodal approach defended by Hypersupers and its network: as described by Vallée (2011), while psychoanalysis has had a continuing influence in France, many psychiatrists have adopted an “eclectic approach”, which led some of them to develop ADHD care models integrating a variety of interventions. Though the reports we studied are not as conclusive as decision-makers would probably have wished, they all reflected on how to organize multidisciplinary diagnosis and care, associating neurologists, paediatricians, child psychiatrists, paramedics, teachers, education specialists, and last but not least, families. To cite but one example, the EDUSCOL report (EDUSCOL 2012) argued for partnerships between the health and the school system, and explicitly publicized a series of education interventions.

This overview of the problematization of ADHD over the last 15 years in France allows us to make two final concluding remarks. Our first remark is on the issue of medicalization. One difficulty with this issue is that the notion of medicalization is an analytical category, as much as it is a category mobilized in political debate. As an analytical category, this notion depicts the process through which a social or a political issue is turned into a medical one, eventually leading to the individualization and de-politicization of the issue at stake (Conrad 1975). But this conceptual framework has been adopted by actors themselves, some of them quoting explicitly social sciences (Gori 2007); besides, some social scientists have been involved in controversies on the medicalization of certain disorders in the area of mental health (Chamak 2011; Ehrenberg 2006, 2007; Pignarre 2008). As a consequence, the notion of “medicalization” has been turned into a category for action, used to raise issues in political debate. Interestingly, by circulating the notion of medicalization from the academic arena to the political arena, social sciences have helped to enhance the actors’ reflexivity on their practices and positioning. The story we told offers a telling example: not only Hypersupers and professionals manifested much caution in the use of methylphenidate, but they also brought in issues such as how to articulate medical prescription and education interventions, when and how to begin and/or stop certain therapies, how to evaluate the efficiency of treatments associating medications and other therapies and

account for the different factors which impinge on the drug prescription (Singh 2002). Rather than closing debates and restricting the exploration of the disorder, the notion of “medicalization” raised concerns and sensitized different actors to a variety of problems which were not clearly on the map previously.

Handling such a variety of issues is far from straightforward however. Our second final remark is about the seemingly “paralyzing” effect of the continuing problematization of ADHD as an unsettled condition. By multiplying efforts for singularizing ADHD and associated disorders, specialists and concerned actors are plunging into the ever-complex bio-psycho-social make-up of these conditions, so much so that finding solutions to the problems they raise often appears out of reach. At present, ADHD is an undoable condition, in the sense that diagnosis and care cannot be accurately performed out of highly knowledgeable circles of clinicians and professionals. This raises an immense problem for public policies: what species of institutional arrangements and interventions should be designed to accommodate the multiple uncertainties into which certain conditions continue to be mired, due to the endless singularizing process they go through? No doubt that this will be the next step on ADHD’s path in France.

References

- ANSM. 2013. *Méthylphénidate : Données D'utilisation et de Sécurité D'emploi En France*. http://ansm.sante.fr/var/ansm_site/storage/original/application/8dd1277a3867155547b4dce58fc0db00.pdf.
- Azéma, Bernard, Jean-Yves Barreyre, François Chapiro, and Marcel Jaeger. 2001. *Classification Internationale Des Handicaps et Santé Mentale*. CTNERHI.
- Barral, Catherine, Florence Paterson, Henri-Jacques Stiker, and Michel Chauvière, eds. 2000. *L'institution Du Handicap. Le Rôle Des Associations*. Presses Universitaires de Rennes.
- Barthe, Yannick. 2006. *Le Pouvoir D'indécision. La Mise En Politique Des Déchets Nucléaires*. Coll. « Études Politiques ». Paris: Economica.
- Callon, Michel, Pierre Lascoumes, and Yannick Barthe. 2009. *Acting in an Uncertain World. An Essay on Technical Democracy*. MIT Press.
- Cecchi Tenerini, Roland. 2010. *Proposition D'écriture: Contribution À La Définition, À La Description et À La Classification Des Handicaps Cognitifs*. <http://www.coridys.asso.fr/pages/Coridys/definitioncognitif2010.pdf>.
- Chamak, Brigitte. 2011. “Troubles Des Conduites.” *L'information Psychiatrique* 87: 383–86.
- Chapiro, François. 2011. “Du Handicap Au Handicap Psychique : Itinéraire D'une Construction Sociale.” In *Usagers Ou Citoyens ? De L'usage Des Catégories En Action Sociale et Médico-Sociale*, edited by Marcel Jaeger. Paris: Dunod.

Cohen de Lara, Guinard, Lacaze, Pinton, Chambry, and Catherine Billard. 2007. "Hyperactivité et psychose de l'enfant : l'intérêt de la méthodologie projective dans l'affinement des diagnostics." *Psychologie clinique et projective* 13 (1): 173-96. doi:10.3917/pcp.013.0173.

Commission nationale de la naissance et de la santé de l'enfant. 2013. *Parcours de Soins Des Enfants et Des Adolescents Présentant Des Troubles Du Langage et Des Apprentissages*. Ministère de la Santé. http://www.sante.gouv.fr/IMG/pdf/Parcours_de_soins_des_enfants_atteints_de_troubles_des_apprentissages.pdf.

Conrad, Peter. 1975. "The Discovery of Hyperkinesis: Notes on the Medicalization of Deviant Behavior." *Social Problems* 23: 12-21.

Conrad, Peter, and Deborah Potter. 2000. "From Hyperactive Children to ADHD Adults: Observations on the Expansion of Medical Categories." *Social Problems* 47 (4): 559-82.

De Barbot, Françoise. 2007. "Les diverses approches des troubles de l'attention sont-elles conciliables?" *La lettre de l'enfance et de l'adolescence* 66 (4): 49-56. doi:10.3917/lett.066.0049.

EDUSCOL. 2012. *Scolariser Les Enfants Présentant Des Troubles Des Apprentissages*. Paris: Ministère de l'Éducation nationale. http://cache.media.eduscol.education.fr/file/Handicap/46/6/TSA_EDUSCOL_225466.pdf.

Edwards, Claire, Etaoine Howlett, Madeleine Akrich, and Vololona Rabeharisoa. 2014. "Attention Deficit Hyperactivity Disorder in France and Ireland: Parents' Groups' Scientific and Political Framing of an Unsettled Condition." *BioSocieties* 9 (2): 153-72. doi:10.1057/biosoc.2014.3.

Ehrenberg, A. 2007. "Épistémologie, Sociologie, Santé Publique : Tentative de Clarification." *Neuropsychiatrie de l'Enfance et de l'Adolescence* 55: 450-55. doi:10.1016/j.neurenf.2007.07.015.

Ehrenberg, Alain. 2006. "Dans Trois Rapports Qui Soulèvent La Controverse, l'Inserm Ignore L'action Menée En France et Brouille La Donne. Santé Mentale, Trouble de L'évaluation." *Libération*.

Georgieff, Nicolas. 2008. "À propos de l'expertise collective de l'INSERM sur le « trouble des conduites » : quelques problèmes critiques de la pédopsychiatrie contemporaine." *La psychiatrie de l'enfant* 51 (1): 5-42. doi:10.3917/psy.511.0005.

Getin-Vergnaud, C., and K. G. Angenon-Delerue. 2011. "Après 10 ans d'activité, HyperSupersTDAH France dresse un premier bilan de ses actions au travers des résultats d'une enquête menée durant l'été 2011 auprès des familles adhérentes." *ANAE. Approche neuropsychologique des apprentissages chez l'enfant*, no. 114: 358-64.

- Golse, Pr Bernard. 2003. "L'hyperactivité de l'enfant : un choix de société." *Le Carnet PSY* 78 (1): 26–28. doi:10.3917/lcp.078.0026.
- Gori, Roland. 2007. "La construction du trouble comme entreprise de normalisation." *La lettre de l'enfance et de l'adolescence* 66 (4): 31–41. doi:10.3917/lett.066.0031.
- Haas, Peter M. 1992. "Introduction: Epistemic Communities and International Policy Coordination." *International Organization* 46: 1–35.
- HAS. 2012. *Conduite À Tenir Devant Un Enfant Ou Un Adolescent Ayant Un Déficit de L'attention Et/ou Un Problème D'agitation, Note de Cadrage.*
- Hilgartner, Stephen. 2000. *Science on Stage. Expert Advice as Public Drama.* Stanford: Stanford University Press.
- Hypersupers TDAH France, and Centre Pédiatrique des Pathologies du Sommeil (CPPS) du CHU Robert Debré. 2010. *Confrontation Des Pratiques Européennes Au Sujet Du TDAH – Synthèse Des Débats.* <http://www.tdah-http://www.tdah-france.fr/confrontation-des-pratiques.html>.
- INSERM. 2002. *Troubles Mentaux. Dépistage et Prévention Chez L'enfant et L'adolescent.* Expertise collective. <http://www.ipubli.inserm.fr/handle/10608/46>.
- . 2005. *Trouble Des Conduites Chez L'enfant et L'adolescent.* Expertise collective. <http://www.ipubli.inserm.fr/handle/10608/60>.
- . 2007. *Dyslexie, Dysorthographe, Dyscalculie: Bilan Des Données Scientifiques.* Expertise collective. <http://www.ipubli.inserm.fr/handle/10608/73>.
- . 2009. *Santé de L'enfant: Propositions Pour Un Meilleur Suivi.* Expertise opérationnelle. <http://www.ipubli.inserm.fr/handle/10608/82>.
- Jasanoff, Sheila. 2005. *Designs on Nature: Science and Democracy in Europe and the United States.* Princeton University Press.
- Joly, Fabien. 2003. "Instabilité de l'instabilité..." *Le Carnet PSY* 78 (1): 12–12. doi:10.3917/lcp.078.0012.
- Jupille, Julien. 2011. "Hyperactivité et Troubles Des Conduites: Des Diagnostics Controversés." *L'information Psychiatrique* 87: 409–16.
- . 2014. "De « coupables » à « victimes actives ». Enjeux pour les familles d'un diagnostic de TDA/H." *Socio-logos. Revue de l'association française de sociologie*, no. 9 (February). <http://socio-logos.revues.org/2835>.
- Laurent, Brice. 2011. "Democracies on trial. Assembling nanotechnologies and their problems." Paris: MINES ParisTech.
- Lecendreux, Michel, Eric Konofal, and Stephen V. Faraone. 2011. "Prevalence of Attention Deficit Hyperactivity Disorder and Associated Features Among Children in France." *Journal of Attention Disorders* 15 (6): 516–24.

doi:10.1177/1087054710372491.

Leclerc, Olivier. 2009. "Les Règles de Production Des Énoncés Au Sein Du Groupe D'experts Intergouvernemental Sur L'évolution Du Climat." In *Expertise et Gouvernance Du Changement Climatique*, by Raphaël Encinas de Munagorri, 59–92. Paris: LGDJ.

Metz, Claire, and Anne Thévenot. 2010. "Instabilité psychomotrice des enfants : trouble ou symptôme ?" *Psychologie Clinique* 30 (2): 34–48.

Mol, A. 2002. *The Body Multiple. Ontology in Medical Practice*. Durham: Duke University Press.

Pignarre, Philippe. 2008. "Médicaliser/démédicaliser : développer l'expertise des patients." *Cliniques méditerranéennes* 77 (1): 125–36. doi:10.3917/cm.077.0125.

Rabeharisoa, Vololona, Tiago Moreira, and Madeleine Akrich. 2014. "Evidence-Based Activism: Patients', Users' and Activists' Groups in Knowledge Society." *BioSocieties* 9 (2): 111–28. doi:10.1057/biosoc.2014.2.

Rafalovich, Adam. 2001. "Psychodynamic and Neurological Perspectives on ADHD: Exploring Strategies for Defining a Phenomenon." *Journal for the Theory of Social Behaviour* 31: 397–418.

———. 2005. "Exploring Clinician Uncertainty in the Diagnosis and Treatment of Attention Deficit Hyperactivity Disorder." *Sociology of Health and Illness* 27: 305–23.

Raffy, Alex. 2006. "L'enfant des limites, l'enfant du DSM." *L'information psychiatrique* 82 (9): 723–30. doi:10.1684/ipe.2006.0054.

Ringard, Jean-Charles. 2000. *A Propos de L'enfant Dysphasique et de L'enfant Dyslexique*. Paris: Ministère de l'Education nationale. <http://media.education.gouv.fr/file/95/7/5957.pdf>.

Singh, Ilina. 2006. "A Framework for Understanding Trends in ADHD Diagnoses and Stimulant Drug Treatment: Schools and Schooling as a Case Study." *Biosocieties* 1: 439–52.

Vaivre-Douret, Laurence, and Anne Tursz, eds. 1999. "Les Troubles D'apprentissage Chez L'enfant. Un Problème de Santé Publique?" *ADSP*, no. 26 (March): 23–66.

Vallée, Manuel. 2011. "Resisting American Psychiatry: French Opposition to DSM-III, Biological Reductionism, and the Pharmaceutical Ethos." In *Advances in Medical Sociology*, 12:85–110. Bingley: Emerald Group Publishing. <https://researchspace.auckland.ac.nz/handle/2292/15627>.

Van Amerongen, A.-P. 2005. "Psychiatrie et histoire. Contribution d'une association de familles." *Annales Médico-psychologiques, revue psychiatrique* 163 (3-4): 250–54. doi:10.1016/j.amp.2005.03.005.

Veber, Florence, and Jean-Charles Ringard. 2001. *Plan D'action Pour Les Enfants Atteints*

D'un Trouble Spécifique Du Langage Écrit Ou Oral. Ministère de l'Education nationale, Ministère de la Santé, Secrétariat d'Etat aux personnes âgées et aux personnes handicapées. <http://www.sante.gouv.fr/IMG/pdf/plandysl.pdf>.

Vergnaud Gétin, C. 2007. "TDAH, Prédicatif Et/ou Facteur de Risque ?" *Neuropsychiatrie de l'Enfance et de l'Adolescence*, Trouble des conduites : de la pratique à la recherche Journée de l'INSERM - 14 novembre 2006, 55 (8): 495-96. doi:10.1016/j.neurenf.2007.07.014.

Wodon, Isabelle. 2009. *Déficit de L'attention et Hyperactivité Chez L'enfant et L'adolescent: Comprendre et Soigner Le TDAH Chez Les Jeunes.* Bruxelles: Editions Mardaga.

