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Lobbying by association:

The case of autism and the controversy over packing therapy in France

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Abstract

The controversy over packing therapy used in psychiatry was studied here to illustrate how leading associations can influence public health policies. The main French associations of parents with autistic children succeeded in obtaining the prohibition of packing, announced by the French Secretary of State to the Ministry of Health in April 2016. Parents and professionals who had observed the positive effects of packing when nothing else worked for their part wondered what could be done for self-harming patients. The political authorities followed the opinion of the main associations of parents with autistic children at the expense of that of professionals. In this paper, the actions and discourse of the associations against packing are explored, as are the arguments of the psychiatrists who defend packing therapy. The different phases in the controversy from the first opposition in 2005 and the role of opinion leaders in associations are analyzed. The strategies to discredit psychiatry and to promote behavioral methods are also studied to understand the shift in the balance of power from professionals to association leaders. The mobilization of the associations prompted some psychiatrists to conduct evidence-based research and to formalize their practice. The controversy over packing, involving political decision-making processes, ethical issues and clinical questions, enables us to illustrate a case of lobbying by associations.

Key words: France; social movements; lobbying; controversy; autism; psychiatry; packing; association leaders.

1. Introduction

Social movements are increasingly contributing to the production of public action, and health social movements are an important political force for health access and quality of care (Brown & Zavestoski, 2004). Some of these movements have acquired a growing influence and have contributed to shaping the relationships between health professionals, politicians, and economic markets (Callon & Rabeharisoa, 2008; Epstein, 2011). On the basis of their claim for collective representation, associations have gained increasing recognition in most Western countries in the last few decades (Raz et al. 2018). However, a representation gap between associations of people with disabilities and associations intended to support them has been evidenced (Chamak, 2008; Chamak & Bonniau, 2013; Raz et al. 2018). There is a great heterogeneity across the different associations, from those that are powerful and well-established to newly-born associations. The most powerful organizations in some cases conduct lobbying activities with the government authorities, as already illustrated in the USA (Caruso, 2010).

Lobbying, once the preserve of economic and financial groups, is now currently used by a diversity of players, including associations (Saurugger, 2003). A recent theoretical model conceptualizes lobbying as a mechanism of persuasion (Hall & Deardorff, 2006). Only a few studies have focused on the changes occurring in the associations of parents with autistic children, and the development of political lobbying (Caruso, 2010; Chamak, 2008; Rios & Costa Andrada, 2015). Yet these changes provide useful information in understanding global changes in society, and the role of health social movements (Brown & Zavestoski, 2004; Snow et al., 2004). How do they succeed in influencing political decisions? Does this mean it is participative democracy, or is it political lobbying? In this paper, the controversy over packing in France has been used to provide an empirical starting point to scrutinize these issues.

1. 1. Lobbying by associations in autism

Eyal et al. (2010) and Silverman (2011) stressed the crucial role of the parent movement in blurring the boundaries between experts and laypersons, and in extending the category of autism to include less typical manifestations. Eyal et al. (2010) underlined the central position of Bernard Rimland, a psychologist and parent of an autistic child, in a nascent parent movement, in a network of expertise around the parent-researcher-activist-therapist, and in the alliance with behavioral therapists. They showed how Rimland promoted alternative biomedical interventions in autism, in particular vitamin therapy, supplements, and special diets, and how he favored a coalition of parents, health practitioners and researchers interested in biomedical treatments for autism. This led to the formation of *Defeat Autism Now!* the main proponent of the link between autism and vaccination. Silverman (2011) focused on the role of parent advocates in autism research, and their efforts to mobilize networks for information-sharing and lobbying. In the USA, the close working relationship between the Congressional Autism Caucus (known as CARE) and autism advocacy groups played a crucial role in this influence (Baker & Steuernagel, 2009).

Currently, large organizations such as *Autism Society of America* and *Autism Speaks* are at the center of autism activism in the USA. *Autism Speaks* set up a very active fund-raising strategy using the power of celebrities to draw attention to the condition (Caruso, 2010). The fact that media moguls such as Bob Right have become personally involved in issues around autism has certainly changed the movement. Most funds collected for autism have been devoted to research. By depicting autism as a mainstream public health threat, the main lobbyist for *Autism Speaks*, Craig Snyder, persuaded the public authorities to devote a substantial amount of money to autism research (Wayne, 2007). The 2006 Combating Autism Act allocated nearly one billion dollars over five years, approximately doubling expenditures on existing programs, including a significant increase in spending for biomedical research in autism. In addition, the US Department of Defense has established its own Autism research program (Caruso, 2010). For Alex Wayne (2007), "Spending surge on autism outpaces understanding" and "the reason lies in an increasingly effective lobbying campaign" by parent associations. Following the declaration of a prominent parent-lobbyist: "This bill is a federal declaration of war on the epidemic of autism", Ari Ne'eman, the president of *Autistic Self Advocacy Network* (ASAN), criticized the Combating Autism Act, considering that the "War on Autism" approach is not in the interests of people on the spectrum. It offends and alienates the autistic community" (ASAN, 2007). However, the Combating Autism Reauthorization Act was voted in 2011 (900 million dollars), and the Autism CARES Act of 2014 authorized 1.3 billion dollars to fund autism research for the fiscal years 2015-2019 (Marcos, 2014).

1. 2. Parent associations and the context in France

Associations are historically linked to political actions, and are considered as spaces for mobilization, engagement, learning about collective action, and training of citizens. In France, the mobilization of parent associations followed different orientations. In the 1960s, the associations denounced the lack of funding and facilities devoted to autism, and set up the first day hospital for children in Paris (Chamak, 2008). Since then, the proliferation of medico-social establishments for disabled people managed by associations receiving public funding has characterized the French system (currently, associations manage 87% of this non-profit sector) (Barreyre, 2013; Robelet, 2017). For a long time, autism expertise was the monopoly of psychiatry and psychoanalysis in France. Most French psychiatrists have favored a psychodynamic approach involving different professionals with the aim of fostering exchanges through different interventions in the fields of therapy, education, social interaction, sport and cultural activities (Hochmann, et al., 2011). However, more and more parents have denounced the psychoanalytical approach as favoring feelings of guilt among parents (Méadel, 2006). Etiological conceptions linking autism to maternal depression, such as the “refrigerator mother” theory, played a crucial role in parent mobilization to counter the stigmatization of mothers, and to promote intensive educational and behavioral methods (Chamak, 2008; Méadel, 2006; Demailly, 2019).

In the 1980s associations of parents founded institutions oriented towards educational programs (Chamak, 2008). The adoption of the new American and international classifications of autism with enlarged diagnostic criteria in the 1990s and the development of behavioral methods in the USA gave rise to a large-scale mobilization around the changes in the definition of autism and related interventions in many countries. The psychoanalytic influence has persisted much longer in France than in the USA with a gap of approximately 20 years between the generalization of cognitive and behavioral methods in the USA compared to France (Chamak, 2008). This context has induced a shift in the attitudes of the parent associations from an alliance with certain psychiatrists to an offensive posture against psychiatrists who draw on psychoanalysis (Chamak, 2008). A new generation of associations that emerged in the 1990s and 2000s depicted autism as a major health issue, denounced the psychiatric monopoly by the French psychiatrists, refused the definition of autism as a psychosis, and the psychoanalytic orientation (Chamak, 2008; Borelle, 2017). The redefinition of autism as an organic condition was an important strategy to counteract the psychoanalytic hypotheses. Political lobbying by parent activist associations succeeded in gaining recognition of autism as a “disability” in 1996 (Chossy act of 11 December 1996), not only to guarantee social benefits but above all to move away from psychiatry, and enable the generalization of cognitive and behavioral methods (Chamak, 2008). The same process and antagonism with mental health professionals was described in Brazil in 2012 (Rios & Costa Andrada, 2015).

1. 3. The controversy over packing therapy

The controversy over packing therapy that started in the mid-2000s is studied here to illustrate the role of the parent associations in influencing public health policies. Packing therapy consists in wrapping the patient in wet towels (cold or not), and then wrapping them in blankets to help the body warm up in a few minutes. This procedure lasts about one hour, and involves two to four therapists. Packing therapy is used in a few French or Swiss hospital units to treat catatonia, anorexia or severe self-injury, and when usual psychotropic drugs are not working (Cohen, et al., 2009; Consoli, et al., 2010; Delion, et al., 2018; Goeb, et al., 2009; Opsommer et al., 2016). Violence among mental health patients and the treatment of severe auto/hetero-aggressive behaviors is a complex issue in psychiatry, thus creating tension between care and control (Brodwin and Velpry, 2014; Gansel and Lézé, 2015; Lobry, et al., 2011). Suffering, manifestations of extreme distress, and self-harm are difficult issues for professionals trying to relieve their patients, and packing therapy is sometimes prescribed to treat these symptoms.

However, recent controversies have emerged (Spinney, 2007). The main French associations of parents with autistic children are fiercely opposed to packing therapy (Borelle, 2016). They consider that it is an unethical approach that lacks evidence-based studies to support the treatment. Despite the testimonies of parents who observed a real benefit for their children (Allione, 2013; Emeyé, 2015), hostility toward packing spread and the parent associations called for a ban. They succeeded in obtaining it in April 2016. The aim of this paper was to analyze the controversy over packing therapy, and the role of key association leaders in the ban on packing in France. We explored their actions and their discourse describing the packing method as horrible and risky. We also looked at the arguments of the psychiatrists who defend packing therapy as a useful tool when nothing else works. This controversy, involving political decision-making processes, ethical issues and clinical questions, enables us to illustrate a case of lobbying by associations.

2. Methodology

The controversy over packing was investigated through press coverage obtained using “packing” as the keyword in the main journals and magazines in France (about 60 press articles), on parent association websites (*Autisme France*, *Vaincre l’autisme*), and in 35 books by parents, as well as in discussions on an Internet Yahoo forum created for parents of children with autism (1327 email exchanges about packing from 2006 to 2017). On the Doctissimo forum (French-language website dedicated to health), the exchanges posted on the forum between 2007 and 2008 were followed on the topic: “What do you think of the practice of packing?” Preliminary coding involved reading the extracts multiple times to look for patterns in the data. Extracts, which talked about packing in a similar way, were grouped together. The most representative extracts of the exchanges have been quoted in the paper (part 3.3).

Reports produced by different institutions (Haut Conseil de la Santé Publique, 2010; Haute Autorité de Santé, 2012) were also analyzed. Videos of packing sessions carried out in different units (Bordeaux, Lille, Paris) were viewed. Twenty eight interviews were realized with psychiatrists. As the psychiatrists Pierre Delion and David Cohen were the most frequently attacked by parent associations, we examined their arguments in detail (emails exchanges from February to May 2016). The arguments against packing expressed by the association leaders were found on their websites and in the press.

The use of therapeutic wraps for mental health patients was investigated via a bibliographical search of articles published in scientific and historical journals and perusal of books by advocates of packing, to analyze the way psychiatrists and mental health professionals describe their practices. The bibliographical searches were carried out from February to May 2016 using the French data base cairn.info (only 40 references) while the other papers were found in books, article references, and two Master theses (Lefevre-Utile, 2014, 2015). The interviews with psychiatrists enabled us to gather and analyze papers on packing published in international scientific journals (10). For the historical perspective, papers from Harmon (2005, 2009) in *Issues in Mental Health Nursing* were helpful, and references from 1916 to 1990 (6 in French and 5 in English), were found in 12 books written by French professionals.

3. Results

3.1. The history of packing

Different forms of wrapping have been used therapeutically for centuries in hospitals for mental illnesses (Wright, 1932). This approach was considered as one of the main tools in psychiatry until the 1930s. In the first half of the 20th century, nurses were the primary practitioners of wrapping and hydrotherapy in the USA (Harmon, 2009). Whether the nurse applied hot or cold sheets depended on what the physician prescribed (Braslow, 1997). Harmon (2005) found that all the nurses who had administered wet sheet wraps concurred on their calming effect. The retired nurses interviewed for this research believed they were helping, not hurting, patients with these treatments (Harmon, 2005). However, the sheet wraps were sometimes used not only as sedative therapy, but also as a method of therapeutic restraint (Weiss, 1954). This approach declined in the middle of the last century, not due to a “lack of effectiveness” but because it was replaced by new pharmacological therapies that required fewer nursing staff (Braslow, 1997, p. 51).

In the 1950s, wrapping and hydrotherapy was viewed as a technological alternative to sedatives, barbiturates and more invasive methods. The American Michael Woodbury used wet sheet packs routinely at Chestnut Lodge, an asylum in Rockville, Maryland. The aim was to stimulate the body schema and to avoid self-injury without using drugs or isolation (Woodbury, 1966). The French psychoanalyst Paul-Claude Racamier (1992) remembered his first observation of wet sheet packs in 1961 when he was at Chestnut Lodge. He explained that no medication was used and “there was a need to cope with the agitation of some patients” (p. 286). At the end of the 1960s, Woodbury introduced the therapy to France and to Switzerland.

3.2. The arguments of the advocates of packing

In the 1980s, Pierre Delion, a child psychiatrist at Lille Regional University Hospital in northern France, pioneered packing for children, and especially for autistic children who self-harm. He explained that members of staff were constantly attentive to the patient during the packing session (Delion, 2012). He argued that the wrapping and the warming up following the initial chill helped the patient achieve a sense of containment (Delion, 2012). In order to explain the relief of symptoms obtained, he developed psychoanalytic interpretations. For him, packing reinforces the child’s awareness of his bodily limits, and decreases the sense of fragmentation. Once calmer and more aware of his surroundings, the child is able to listen and talk (Delion, 2012). Theoretical interpretations were developed in reference to the “Moi-peau” theory (Anzieu, 1985). Reference to the concept of holding and the idea of a restructuring of the body map is widespread among occupational therapists and psychoanalysts.

David Cohen is the head of the child and adolescent psychiatry department at La Pitié-Salpêtrière hospital in Paris, where packing is used alongside specialized education and medication for severely autistic and schizophrenic children (only a few cases). He considers packing not as a therapy for autism but as a form of “bodily mediation” used to relieve sensory problems and to prevent self-injury. For him, the history of packing is linked to the history of hydrotherapy (Alberne, 1992) and there is no need to call on psychoanalytic concepts to account for the improvement of patients who have experienced packing. David Cohen considers packing therapy as a sensory integration approach, useful for subjects who have a sensory integration dysfunction (autistic people, adolescents with catatonia). In his unit, occupational therapists and nurses carry out packing after having explained the procedure and obtained consent from parents and patients (Lefevre-Utile, 2015). David Cohen mentioned a 1988 paper published in the *American Journal of Psychiatry,* which concluded that the treatment was safe and had interesting and useful effects that went beyond mere restraint (Ross, et al., 1988).

Not only psychiatrists but also parents defend packing (Allione, 2013; Éméyé, 2015). The journalist Églantine Éméyé, mother of a disabled child with autism, wrote a book (Éméyé, 2015) and produced a film: "*Mon fils, un si long combat*" (France 5, January, 2014) in which she illustrated the difficulties in dealing with a child with a tendency to inflict severe self-harm, and the help of packing in this case. Her film triggered a backlash from parents and leading associations opposed to packing, as shown by the exchanges on the Internet Yahoo forum between January and February 2014. This example illustrates the tensions between parents who are convinced of the superiority of the cognitive and behavioral methods and parents who have not seen any improvement for their child with these methods, and experienced other approaches.

3.3. The arguments against packing

Various arguments have been put forward by presidents of associations and by parents on different forums (Yahoo group, Doctissimo). Ethical issues have been raised: 1) wrapping a patient in cold wet towels is perceived as ill-treatment; 2) children who cannot speak cannot give or withhold their consent; 3) some parents were not informed that packing was used for their children. Questions about health risks such as hypothermia or psychological risks have also been raised. Packing is particularly stigmatized as an archaic approach proposed by psychoanalytically oriented psychiatrists. Finally, the question of funding has been underlined: state money spent on packing would be better spent on educational and behavioral methods for teaching children to communicate. Applied Behavioral Analysis (ABA), conceived by Ivar Lovaas at the University of California, has been called for by parent associations. This method, used for young children, involves a professional who discourages behavior considered as bad, and reinforces anything good with smiles, sweets or other things the child enjoys (Schreibman, 2005). The behavioral method has evolved over time and more educative and cognitive approaches have been introduced.

3.3.1. Exchanges on Yahoo group: "an enemy that we must fight"

Since 2006, email exchanges between parents of children with autism on the Yahoo forum have illustrated the strong hostility toward packing and psychoanalysis. Parents, who are frequently members of associations such as *Autisme France* or *Vaincre l'autisme*, have used irony to discredit psychiatrists, psychoanalysts (referred to as "*psykk*") and packing. Anger was also expressed in terms such as "a revolting practice", "degrading treatment". In February 2006, the exchanges began with a question raised by a parent who asked what "packing" was. The response from another parent referred to the 2003 Delion book entitled "Packing with autistic and psychotic children" (FC, 02/13/2006). He criticized the title of the book and its author since "everybody should know that child psychosis does not exist". He was critical of the state funding of this technique which he considered "barbaric". All the exchanges were opposed to packing and when someone tried to have a more nuanced view, he was severely criticized. Merely indicating a website with psychoanalytical references launched aggressive responses discouraging any alternative view (exchanges from 13 to 16 February 2006). Some parents used the term "bullshit" to qualify the website indicated by a young woman who answered (E, 02/14/2006):

> I did not want to spark such anger […] I am neither a professional nor a parent, just a web user. I am only trying to get information for myself […] I regret that people are so rude…

Laurent explained to her (02/14/2006):

> In France, the interventions on autism are mainly psychoanalytic. This approach has failed and is damaging since its monopoly has prevented the setting up of efficient interventions. On this forum, we are all against psychoanalysis used for autism. This is why your mention on the forum of harmful methods that we thought had disappeared, we were dismayed.

A mother expressed her disapproval of the aggressive reactions (I 02/16/2006):

> Rather than jumping at her throat, we could have explained her why this website is so bad, and we could have suggested some books to get proper information. It is a mistake to say that this website is not useful because we have an enemy that we must fight and we need to know what it is. The psychoanalysts wanted the entire world to believe that we were responsible for our children's autism. Therefore, it is natural to want them to disappear. We are angry…

On March 3, 2006, a circular from the president of the *Léa pour Samy* association aimed to mobilize opinion against hospitalization and the use of packing for an 8-year-old boy. The administrator of this association used the forum to disseminate the information (10/03/2006). Throughout 2006, messages against packing were broadcast:

> There's no need to think much about packing to realize the horror of the method. I feel upset to know that this method still exists, that children can be tortured without being able to say: "stop torturing me!" Just thinking about it makes me feel sick (MCB 10/15/2006).

In November, parents suggested writing negative comments on the websites selling Delion's books.

On March 27, 2007, it was announced that a legal action against the French State was to be undertaken by parents for neglect and ill-treatment towards children with autism. On April 17, 2007, parents posted opinion on the forum to express their anger. They were shocked by the documentary on packing broadcast on the channel France 5. A representative from *Léa pour Samy* wrote:

> To respond to this shameful defense of incompetence and institutionalized sadism, we should write a letter to the editorial team of France 5. We also call parents to send letters to the Ministry of Health (K, 04/18/2007).

3.3.2. Exchanges on Doctissimo: "packing as an archaic method"

The forum about packing posted in May 2007 on Doctissimo involved parents and young professionals asking for information. Some parents who were also professionals in educational and behavioral methods explained what to do to other forum participants. One of them explained that behaviorism is the best approach to self-harm (Pos60wy, 05/30/2007). Other exchanges on the same issue, published from March 2008 to May 2008, involved parents, a psychiatric nurse and a psychoanalyst. Both parents of children with autism and the psychiatric nurse who exchanged on the forum considered packing as an archaic method associated with psychoanalysis. A mother who saw the video on packing used in a day-care hospital considered that the child was not being forced and appeared calm and relaxed. She wondered whether this artificially initiated intimate moment might not be a good thing, but the other parents intervened to compare packing to a cold shower and to ill-treatment. Thus the interpretation of images differs with personal views and beliefs. When a psychoanalyst explained that packing had a calming effect on anxious children, one parent argued that there was no validation of this method. Those who expressed positive arguments on packing were criticized and mocked, and psychoanalysts were compared to gurus. Given the hostility towards their arguments, the advocates of packing rapidly gave up any attempt to argue.

3.4. The different phases of the controversy

No controversy over wet sheet packs was noted before the mid-2000s. The controversy was sparked when a short documentary (less than 8 min) was aired on French TV on 17 April

2007 (https://www.dailymotion.com/video/xpa9d7). A day-care hospital in Bordeaux using packing was the focus of this documentary, which triggered strong reaction from *Autisme France* and *Léa pour Samy*. *Autisme France* officially complained to the TV channel and to the French Health Minister in a letter entitled “Stop the ill-treatment of autistic children!” (18 April 2007).

Delion emphasized that parental consent was always sought, and that a psychiatrist would explain to the child what was going to happen, sometimes with the help of a doll. He argued that no child was forced to accept the pack. His book on packing was launched (Delion, 2007) and a French hospital clinical research program (PHRC) entitled “demonstration of the efficacy of packing treatments in children with autistic disorder with severe behavioral impairments” was accepted. The protocol was approved in 2008 by the ethics committee of the University Hospital Centre (CHU) of Lille, and the research was undertaken by Delion and his collaborators. After numerous difficulties caused by the fierce opposition of the leading associations and the mobilization of their members, the results have recently been published (Delion et al. 2018).

The mobilization of the associations against the use of packing spread (as illustrated by exchanges on the Yahoo forum). On 2 April 2009, the World Autism Awareness Day, M’Hammed Sajidi, the president of “*Léa pour Samy*” (in 2010, the association changed its name for *Vaincre l’autisme*), organized a demonstration on the Pont des Arts in Paris against packing, with demonstrators wrapped in sheets. He called for a moratorium on packing (see http://www.vaincrelautisme.org/content/action-contre-le-packing). In June 2009, the Health Minister, Roselyne Bachelot, asked for the opinion of the French High Council of Public Health, which in February 2010 published a report in favor of packing in controlled conditions, considering that to date packing did not pose any identified risk.

The parent associations were upset, and more and more letters were sent to the hospital directors to oppose packing. Evelyne Friedel, the president of Autism-Europe, seized the opportunity of the Autism-Europe International Congress in Sicily in October 2010 to recruit visiting specialists to publish a letter opposing packing in the *Journal of American Academy of Child & Adolescent Psychiatry* in February 2011. They "reached a consensus that practitioners and families around the world should consider this approach unethical" (Amaral, et al., 2011, p. 191).

In March 2011, on Sajidi's initiative, Pr. Christopher Gillberg, president of the scientific committee of *Vaincre l'autisme*, officially announced the launch of the Manifesto against packing at the Glasgow conference, "No Mind Left behind" (29-30 March). The participants were invited to sign the manifesto. In September 2011, a documentary about autism and against psychoanalysis, *Le Mur*, authored by Sophie Robert and funded by the association "*Autistes Sans Frontières*" was widely broadcast. This film was both an attack on psychoanalysis and a promotion of behavioral methods.

In December 2011, *Vaincre l'autisme* filed a procedure against Pierre Delion and David Cohen to the College of physicians. They were heard in April 2012. They explained their practices, and the case was closed. On 20 January 2012, a right-wing Member of Parliament, Daniel Fasquelle, who backed up the position of the associations, proposed a law to ban psychoanalysis for autism. On March 2012, the film against packing by *Vaincre l'autisme* (2012) was broadcast, with its horror-film overtones, despite the fact that the president of this association declared he had never witnessed, nor did he want to witness, any packing sessions (Vincent, 2012). Two days later, the Haute Autorité de Santé (HAS) (2012) published autism recommendations that classified packing as formally contra-indicated.

Testimonies from parents who were satisfied with the use of packing for their children had been published (Allione, 2013: Éméyé, 2015) but the parent associations criticized these testimonies. On a TV show (Canal +, 2016), Églantine Éméyé mentioned the criticisms and even the threats against her because of her testimony in favor of the packing for her son. She was accused of mistreating her son. The mobilization of Autism Europe succeeded in prompting a visit from inspectors of the European Committee for the Prevention of Torture in 2012 to La Pitié-Salpêtrière hospital. They concluded that "there was no need for further investigations" (interview with David Cohen, 01/31/2016). During their visit in November 2013 to La Pitié-Salpêtrière hospital, the inspectors sent by the "Contrôleur général des lieux de privation de liberté" (in charge of inspecting prisons and other places of internment) found that the rights of children and adolescents were respected, as were the therapeutic and ethical procedures prior to the use of packing, which was implemented on medical prescription only and with the parental consent. Two Master theses in ethics produced by a psychiatric nurse, illustrated the precautions taken in La Pitié-Salpêtrière hospital when packing was used (Lefevre-Utile, 2014, 2015).

Under the chapter: "The time of hatred", Pierre Delion (2013) addressed the controversy over packing and described the "adverse reactions" on the internet, the refusal of the right to reply by the *Journal of the American Academy of Child and Adolescent Psychiatry* after the publication of the letter in February 2011, and the harassment by the president of *Vaincre l'autisme* who sent letters against him and David Cohen to the directors of Lille Hospital and La Pitié-Salpêtrière hospital respectively. This same association assigned them before the Council of the Order of French physicians. The case was closed but at the National Committee on Autism on April 21, 2016, Ségolène Neuville, Secretary of State to the Ministry of Health, in charge of Disabled Persons, decided to ban packing (however, packing could be used for research in hospital with protocol approved by an ethical committee). Following the HAS recommendations, she adopted the UN position which considers packing as a form of maltreatment (The UN Committee on Children's Rights, 2016). On May 3, she addressed a circular to the regional public health agencies requesting them not to subsidize establishments that used packing, and to cancel any training or information sessions on packing. This decision was considered as a victory by the parent associations campaigning for the ban, but other parent associations, such as the RAAHP (*Rassemblement pour une approche des Autismes Humaniste et Plurielle*), and practitioners caring for patients rejected by schools and other services, were upset. The parents and the professionals who observed the positive effects of packing wondered what could be done for self-harming patients. Given the irreversibility of certain lesions and self-injuries, some medical practitioners took the view that banning packing treatment was a form of withdrawal of care.

The controversy and the mobilization of parent associations prompted psychiatrists to conduct “evidence-based research” and to formalize their practice. Since 2007, several papers have been published by authors who have investigated the use and efficacy of packing therapy among children and adolescents with severe self-harm behaviors or catatonia (Cohen, et al., 2009; Consoli, et al. 2010; Delion et al., 2018; Goeb, et al., 2009; Lobry, et al., 2011). These authors concluded that packing seemed to be a feasible and useful adjunct treatment for catatonia and could be effective in relieving auto and hetero-aggressive behaviors. A retrospective study on a cohort of 172 adult patients suffering from serious mental illness showed that body wraps were potentially associated with a reduction in the use of both anxiolytic and neuroleptic drugs (Opsommer, et al., 2016). Despite these publications, the public authorities did not revise the ban on packing. Recently, a psychiatrist received a dismissal letter (01/10/2019) from a medical-educational center run by an association in the Paris urban area for offering packing sessions for an autistic teenager who had broken an educator's nose. The teenager was also kicked out of the center.

3.5. The increasing influence of lobbying by opinion leaders in associations

The packing ban is the result of intense lobbying by a new generation of parent associations that questions psychiatric authority and knowledge. Lobbying involves media actions. These associations increased their impact through websites and contacts with the media. They undertook legal actions via Autism Europe (complaint to the European Committee on Social Rights), and developed lobbying strategies with the political authorities, the decision makers, and the scientific community. They have succeeded in being present in the various committees in charge of political action on autism (national Autism plans), and in charge of developing and implementing recommendations (HAS, Centres Ressources Autisme, Agences régionales de Santé). They are also in the committees of foundations that fund research on autism (Fondation de France, Fondation Orange, etc.), and in the research Institutes, such as INSERM Association network.

The influence of the associations increased in 2002 when Evelyne Friedel, a lawyer and mother of an adult with autism, drafted the collective complaint (n°13/2002) that Autism Europe lodged against the French Government. In November 2003 the European Committee on Social Rights concluded that France had failed to respect its educational duties concerning autistic children. The decision of the Council of Europe published in 2004 upheld the collective complaint and forced the French Government to elaborate the first national Autism plan (2005-2007).

Evelyne Friedel, a member of the international law firm Taylor Wessing and elected European Lawyer of the Year in 2016 and 2017, was the president of *Autisme France* from 2004 to 2006, and then president of Autism Europe from 2008 to 2011. Since 2003 she has been a member of the executive committee of Autism Europe. She is currently the Vice-President of Autism Europe. She organized the opposition to psychiatric care in autism, and has enabled private facilities to develop. Through a service management agency, *Association française de gestion de services et d'établissements pour personnes autistes* (AFG) founded in 2005 by Evelyne Friedel and her life partner, she has succeeded in generalizing the use of behavioral methods imposed in the structures managed by AFG.

Service management agencies, communication and lobbying companies, and training companies have been used by some leaders of parent associations in France to discredit psychiatry and to promote behavioral methods, inclusive education, and privately-run services. A collective of parent associations succeeded in making Autism the "Great national cause" in 2012. The president of this collective, the manager of a communication and lobbying company, was in charge of the communication campaign on autism financed by the government. Through the Internet and other media, the associations succeeded in mobilizing their members and other players beyond. Beyond the role of an associative leader with a law background and expertise, those who run powerful associations are middle- and upper-class parents, competent to mobilize legal resources, use the media and networks, and intervene with representatives (Demailly, 2019). Their way of thinking is similar to that of political and health authorities, with a tendency to promote performance, competition, evaluation, and efficiency, with the assumption that we only manage well what we measure. In the scientific community, their allies are researchers who are demanding more funding for neuroscience and genetic research (Demailly, 2019). There is a conjunction of interests between numerous actors: researchers in cognitive science, some psychologists and psychiatrists, certain geneticists, cognitive and behavioral methods practitioners, parents seeking solutions, political authorities who have to take decisions, and promote markets and job creation (private services).

Another lever was the training of parents and professionals in order to homogenize knowledge on autism. This training is a market, and some of the parents became professionals in autism. In the 2013-2017 Autism Plan, more than one million euros were devoted to parent training. The market for this training was however fraught with conflicts of interest, since the leader of one of the training companies financed by public funds is the life partner of the special advisor to the Secretary of State who prohibited packing.

Some association leaders succeeded in convincing the parents, the media, and the public authorities that their definition of the problem of autism was the right one. The associations referred to international classifications and scientific publications, giving their demands more credibility (Chamak, 2008). However, it is important to mention the great heterogeneity among associations. The local associations that collaborate with health care professionals are quite different from the associations engaged in the political lobbying described above. The objective of the local associations is to provide assistance for families and their children. However the new government policies aiming to restructure the sector and favoring the large management agencies may force them to call upon the services of these agencies, such as AFG. The parents who succeeded in creating establishments and services realized that the orientation of their services could be controlled by management agencies, or directly by new managers trained in business school, with the main aim of rationalizing costs. When they discredit the public services and promote private services, the association leaders contribute to reinforcing the management trend in the medical and social sectors.

4. Conclusion

4.1. How do leading associations succeed in influencing political decisions?

Media and legal actions, lobbying strategies with the political authorities, the decision makers, and the scientific community, service management agencies, and training of parents and professionals are various ways used to influence political decisions, and to homogenize knowledge on autism. Baker & Steuernagel (2009) explored the question of the success of parent associations in orientating public policies on autism in Canada and the USA. By promoting the idea of autism as a treatable disease, and the use of ABA, some parent associations have simplified the issue. In the case of issues that are technically or scientifically complex, “the public and other stakeholders are (consciously or not) especially interested in simplification of the issue” (Baker & Steuernagel, 2009, p. 235). Hansen (1991) argues that lobbies are influential “because they determine the kinds of information about constituents that are available and the kinds of information that are not” (p. 3). Lobbying is thus defined as a game with asymmetric information (Austen-Smith, 1997).

Why are some organizations more successful than others? The success of certain organizations compared to others is linked to their long-established links with the political authorities, public managers, and the media. The parent association supporting packing therapy is a new association founded in 2014, and their arguments are not in accordance with the main claims of the leading parent associations followed by the political authorities in designing policy. Thus, a different point of view is problematic because it introduces complexity and calls into question the relevance of the policy. Parents who are grateful to psychiatrists who used packing because they noticed the positive impact on their children rarely speak up, and when they do they face great hostility from other parents (through the websites exchanges, and in the media). In addition, the psychiatrists who defend packing have become less numerous, since the new generation of psychiatrists are often not trained in this method, and increasingly subscribe to cognitive and behavioral approaches (interviews and publications). At international level, cognitive and behavioral methods are gaining momentum and support all over the world, and their limitations are underestimated (Warren et al., 2011).

Exchanges between parents and professionals have long been characterized by asymmetrical relationships. However, certain well-organized parent associations have been involved in decision-making processes, as shown by the fact that various countries have legislated on patient and parent involvement in joint governmental committees dealing with health policies (Raz et al. 2018). Several studies have shown that patient associations have joined forces with established actors in the production of medical and scientific knowledge

(Epstein, 1995; Akrich, 2008, Rabeharisoa et al., 2014). The notion of “evidence-based activism” has been proposed to characterize the association between health activists and professionals in the production of scientific statements and political claims (Rabeharisoa et al., 2014). In our case study, association leaders joined genetic and cognitive science researchers in severely criticizing child psychiatrists who defend packing and a pluralistic approach to autism. These leaders have set up alternative mechanisms of data collection that by-pass the clinicians of the previous generation, and forge alliances with new generation psychiatrists.

With the example of autism and the controversy over packing, we have shown how leading associations were able to impose their points of view and to discredit alternative views from other parents and professionals, how they acted to mobilize their members, and how they influenced political decisions to alter the legislation. The absence of scientific demonstration of the efficiency of packing was one of the arguments pinpointed, but when positive results were published, the associations and the political authorities did not take them into account. For the public, parent associations have a positive image, and are not seen as having any conflict of interest. However, scrutiny of this controversy illustrates how some association leaders may use their professional training to impose their point of view on autism, and to gain professional benefit from their initiatives. They view themselves as fighters for the cause of autistic people. Yet the social construction of autism produced by parent associations does not always satisfy the people concerned (Chamak, 2008; Raz et al., 2018). Thus, Michelle Dawson considered that the parent associations had deprived autistic people of their right to speak, and she disapproved of the generalization of behavioral therapies (Dawson, 2004).

The complex issue of the treatment of severe auto/hetero-aggressive behaviors with no therapeutic options has not been addressed by the association leaders or the HAS. Some professionals have raised the issue of responsibility, and underlined the fact that medicine is first and foremost a practice that is supposed to relieve pain and suffering whilst taking into account individual specificities (Lefevre-Utile, 2015). French and Swiss professionals have been almost the only ones to use packing because they were trained for it. Paradoxically, the association leaders have been strongly critical of these professionals more respectful of the patients and the families than ever before. The success of the associations in the ban of packing may also be understood in the general context of the French psychiatry crisis with a lack of professionals and resources, especially for child psychiatry (Inspection générale des affaires sociales, 2017).

4.2. Participative democracy or political lobbying?

Unlike other French sociological studies, which emphasize the contributions of associations, and in particular health associations, to describe their role in the development of a health democracy (Akrich & Rabeharisoa, 2012), our study illustrates a case of lobbying by associations. This lobbying by associations of parents with autistic children has already been described in the USA by Caruso (2010) and Silverman (2011) and in Brazil by Rios & Costa Andrade (2015). In France, sociological studies tend to highlight the positive aspects of social movements (Laville & Salmon, 2015; Akrich & Rabeharisoa, 2012; Rabeharisoa et al. 2014). The association is perceived as the privileged place where many forms of public engagement are invented. Although Laville and Salmon (2015) recognize the instrumentalization of associations by the public administration as tools for dismantling public services, they choose to highlight positive experiences. In fact, the development of associations follows a plural dynamics with, on the one hand, centralized organized structures, a form of hybridization with the State and the market, and, on the other, associations of small size, with small budgets and small objectives, but where the people involved have a real power to direct the affairs that concern them.

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