The "rendez-vous manqués" of Francophone and Anglophone Disability Studies: the case of autism in cross-cultural context

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Les «Rendez-vous **manqués**» de **francophones et anglophones Disability Studies: le cas de l'autisme en contexte interculturel**

Résumé

Ces vingt dernières années, l'autisme a fait l'objet d'un intérêt énorme à travers un large éventail de disciplines, que ce soit la science, les sciences sociales ou même les études culturelles. Des m**étaphores de l'**autisme ont **été** de plus en plus diffusées dans des formes culturelles populaires, tels que les films grand public, les romans à succès, les mémoires et les articles de journaux. Mais cela a été, d'abord et avant tout, un phénomène anglophone. Cet article examine la nature de cet intérêt et les cadres, à la fois culturels et cliniques, à travers lesquels l'autisme pluriel a été construit depuis le milieu du XX**ème** siècle. Le contexte en France est très différent. Si les « Disability Studies » sont une solide formation pluridisciplinaire au Royaume-Uni, ce n'est pas le cas en France, malgré l'important travail mené dans le cadre de la Francophonie. Dans le même temps, la psychiatrie a été dominée par la psychanalyse avec des conséquences particulières pour l'autisme. La bataille actuelle et la crise en France sur les services pour l'autisme, pour les enfants et les adultes, requièrent une plus grande attention internationale. La nécessité d'**échanges interculturels entre la France et la Grande-Bretagne en particulier, et la recherche interdisciplinaire en** « Disability Studies » sont cruciales à cet égard.

Mots-clés : Disability Studies, l'autisme, handicap intellectuel, psychanalyse, *Le Mur*, les recherches interculturelles, les représentations culturelles de l'autisme

Summary

Autism has been the subject of enormous interest across a wide range of disciplines, across science, social science and cultural study in the last two decades. Metaphors of autism have increasingly circulated in popular cultural forms, from mainstream film and bestseller fiction, to memoir and journalism. But this has been an Anglophone phenomenon first and foremost. This article examines the nature of this interest and the frames, both cultural and clinical, through which autisms plural have been constructed since the mid 20th century. The context in France is strikingly different. Disability Studies is a strong, multidisciplinary formation in the UK but not in France, despite important work being conducted in the Francophone context. At the same time, psychiatry has been dominated by psychoanalysis, with particular consequences for autism. The current battle and crisis in France over autism services, for both children and adults, requires much greater international attention. The need for cross-cultural exchange between France and Britain in particular and interdisciplinary research in disability scholarship is crucial to this.

Keywords: Disability Studies, autism, intellectual disability, psychoanalysis, *Le Mur*,

cross-cultural research, cultural representations of autism

1. Introduction

Autism has been subject to an explosion of interest, of both cultural and scientific kinds, for a little while now in the Anglosphere. The kinds of interest to which it has been party are both culturally indicative and strongly constitutive at a discursive level and take various distinctive guises. Still lacking, though, in this picture, is research of a more cross-cultural nature, a project which some have called for and started to map initially (Grinker, 2008, 2009). The cultural context I will focus on here is that of the on-going dramatic political and institutional struggle taking place currently in France around autism. Autism remains in a highly unusual position in France, caught up in a "delay" that has ensued from an entirely different diagnostic approach to its causes and to clinical intervention. Disability Studies internationally has emerged strongly in the last two decades, challenging the so-called "medical model" of disability and arguing for a "social model", in which disability is thought about in terms of the social stigma and problems caused by lack of understanding and/or provision of appropriate services, rather than as, simply, a problem at the level of the individual concerned (French and Swain, 1993; Oliver, 1996; Linton, 1998; Corker and French, 1999; Corker and Shakespeare, 2002; Davis, 2002).

This powerful movement has taken hold both within and outside the academy, part interrogation and part activism, lodged primarily within the critical social sciences. More recently, cultural studies and humanities scholars have begun the work of examining cultural representations of disability and have started to bring about a series of shifts analogous to earlier transformations of teaching canons and bodies of theory with regard to race, gender and sexual orientation. But intercultural dialogue crossing language areas has so far been notably limited, particularly between France and the UK. Disability Studies is not a recognisable formation in the French academic context (Chamak, 2008: 78). Furthermore, the policy context has been marked by difficulties in formulating anti-discrimination legislation on a par with other European countries, due to the republican egalitarian model of rights-based citizenship. Arguments around "differentialist" versus universalist models are familiar with regard to multiculturalism, ethnicity and gender in the French context but are also pertinent here (Wieviorka, 2001). In a recent special issue of the *Scandinavian Journal of Disability Research* on French Disability Studies, the journal editors note the degree to which work in French is unknown to Anglophone researchers and set out the need for *"a richer exchange"* (Gustavvson and Barron, 2007, 137). Isabelle Ville and Jean-François Ravaud, the guest editors for the issue, provide an overview in their article "French Disability Studies: Differences and Similarities" (2007), of the development of disability research in France, which does not *"constitute a specific disciplinary field"*, as in "Anglo-Saxon" and Scandinavian countries (p. 138). They argue that the specificity of the French case needs to be understood in relation to three aspects: the historical emergence of disability as a social category, the political concept of equality and how academic research is organised in France (p. 138). Their historical

overview deals only with physical impairments, and the category of invalidity which came out of war-time injury or industrial accidents. They do not broach the psychiatric context of the same period of the late 19th to 20th centuries, which is usefully surveyed completely separately in Coffin (2005), in a chapter examining mental impairment to the exclusion of physical ones. This mind-body split, where physical and mental disability are treated separately, has been a troubling aspect of disability awareness and study as will be seen below.

To these remarks on the striking absence of "disability studies" as a distinctive formation in the French academy, either in terms of institutional organisation (where research is scattered) or in terms of publishing initiatives (notably absent, in comparison with British and American established series), should be added those of Henri-Jacques Stiker, himself a highly significant figure. Stiker's first major work in the area, *Corps infirmes et sociétés: essais d'anthropologie historique,* dates back to 1982. This was not translated in to English until 1999, when it came out in the book series *Corporealities: Discourses of Disability*, edited by the well-known scholars of disability and cultural representations, David T. Mitchell and Sharon L. Snyder ,for the University of Michigan Press, with a foreword by Mitchell (Mitchell, 1999). Even then, it did not noticeably impact on Anglophone disability studies. Stiker works as an historical anthropologist, based at the University of Paris VII, rather than at the *Centre national de la recherche scientifique* or at the *Institut national de la santé et de la recherche médicale*, as do many of those engaged in work in this area (Ville and Ravaud, 2007: 141). Writing in 2001, alongside Ravaud and Gary Albrecht, the American sociologist of disability (Albrecht, Ravaud, Stiker, 2001), Stiker notes the same clear parallel with women's studies and ethnicity studies mentioned already, in that disability studies has emerged in the UK , and also the US and Canada, anchored within a social movement. Like them too, its emergence

« *interpelle le milieu scientifique et justifie de s'interroger sur l'incapacité qu'ont eue les disciplines traditionnelles à prendre en compte la question du handicap au point que les disability studies ont dû s'autonomiser pour prendre leur véritable essor.* » (p. 44).

Disability Studies thus represents a critical counter-formation to existing modes of study, in particular in opposition to groupings in medical and rehabilitation sciences and their understanding of disability.

The use of the term "handicap" in France presents another potential stumbling block to Anglo-French dialogue. Ville and Ravaud present this as a linguistic obstacle primarily i.e. that it covers "impairment" and "disability" and is not derogatory. According to them, it remains the primary term in the French political and policy context, as well as academically, unlike in English, where it has been superseded by "disability", and where it is seen as unacceptably tainted by an "ableist" normativity. The view that this marks a language difference only and can be set aside seems not entirely convincing. In the light of some of the lags and deficiencies of French disability policy of recent years, it is regrettable that Julia Kristeva, appointed to head a *Conseil national handicap* by Jacques Chirac in 2002, before the European Year of Disability in 2003 (Haigh 2006, 2010), has continued to employ the term

unproblematically (Kristeva and Gardou, 2006; Calvez, 2007). Stiker sketches a useful series of key moments in British disability studies (Ravaud and Stiker, 2001) and, in a subsequent article, traces some of the conceptual orientations underlying his own work and that of others working in France on disability, including most notably the work of Foucault but also of Castel, Gauchet and Canguilhem (Stiker, 2007). As he wryly points out, French intellectual life is rarely interdisciplinary (p. 148), despite the longstanding reception and reworking of French philosophy and social theory, including the work of some of those he foregrounds, in the UK and US in to highly interdisciplinary work within both humanities and social sciences and the attendant misapprehension regarding the interdisciplinary nature of this work in its context of production.

Disability Studies in the UK is now presented as in its second phase (Longmore, 2003), moving on from the initial stage of self-definition to self-questioning, including of its own foundational models, in which *"attention moves in a complementary and reciprocal way from rights and access to culture and community"* (Walters, 2011; Goodley, 2011). Tom Shakespeare, one of the best-known British disability scholars, now positions himself as a "critical friend" to the social model (Shakespeare, 2006b; see Kristiansen and Kermit, 2007; Sheldon et al, 2007), rejecting the false dichotomies it entails between biological and social constructionist perspectives and demanding a more complex interactionist approach, even whilst acknowledging the value of a targeted simplicity in an unaccommodating political climate in which policy is formulated. The case of autism is particularly testing here, as it does not, and never has, clearly fitted in to either approach, even before the opposition came in to question. As such, how it has been framed and the historical evolution of this are important to understanding the kinds of attention, both lay and clinical, that it has attracted. Having noted the very different state of play in France and Anglophone research areas with regard to disability studies (what would once have been unproblematically encapsulated as a "dialogue of the deaf"), I will now turn to autism in particular.

2. Autism and cultural "fascination"

Disability Studies in the UK and in North America has, then, produced work of enormous political and cultural significance, moving across the range of social science and cultural studies disciplines. But, as the American literary critic, Mark Osteen, argues in his introduction to his edited collection, *Autism and Representation* (2007), in its emphasis on construction and necessary engagement in political confrontation, it has been slow to *"theorise the body itself"*, including pain and suffering. Perhaps, he suggests, this is *"because doing so would seem to yield the floor to medicine"* (p. 3). Too many distinct conditions have been *"swept together"* and crucially, cognitive, intellectual and neurological disabilities have been left out, an omission which itself *"disables"* disability scholarship (p. 4). Henri-Jacques Stiker also criticises the omission of the non-physical from UK and American disability studies (Stiker, 2007: 147). This has been particularly the case in the work of humanities scholars who have pursued projects in the wake of social science disability research. The

pioneering work, *Narrative Prosthesis. Disability and the Dependencies of Discourse* by David T. Mitchell and Sharon L. Snyder (2000), in setting out its exploration in literary texts of *"marked bodies"*, that is to say the array of identities that *"'marked' human bodies as Other"* (p. vii), is both typical and significant, given its deservedly core text status in the field (Murray, 2008). Even as the field failed to *"produce a systematic theory of the body"*, as Osteen states (p. 5), it has focused very strongly in its readings on the visible body. Intellectual disabilities (including in an unwieldy shorthand cognitive and neurological ones also) lie *"at the bottom of the disability hierarchy"*, in the academy as in society at large (Krentz, 2005: 555, cit. Osteen, 2007: 6). *"Unusual bodies are one thing; unusual minds, it seems, are quite something else,"* Osteen comments (p. 5). Autism clearly challenges the mind-body dualism implicit here and is finally beginning to garner significant interest in the UK context in terms of cultural representation, notably in the work of the literary scholar Stuart Murray (Murray, 2008, 2010, 2012). One of Murray's starting-points is the wider cultural fascination with "autism" (Murray, 2008). The term has become all-pervasive in non-academic contexts, used loosely and unrigorously, most starkly, as a marker for social subsets, on the one hand loner social misfit criminals, on the other, loner social misfit geniuses. The latter journalistic habit has given rise to a well-established parlour game, Great Autists of the Past, in which figures such as Wittgenstein, Newton and Einstein or artists and musicians from Van Gogh to Warhol to Glenn Gould are posthumously labelled as autistic, a pastime which is not without its academic proponents (Fitzgerald, 2003). The presence of autism as journalistic shorthand, or as a plot device that hinges on significant gifts or traits in popular cultural production, is a recent phenomenon in Britain and North America, dating back twenty years, but particularly striking in the last ten. The phenomenon of popular Hollywood films with characters with autism has begun to be examined (Conn and Bhugra, 2012). There is little equivalent to this in the Francophone sphere as yet, in terms of popular, frequently instructively erroneous usages. Autism has also been readily exploitable by the mid-market British press as a feeder of parental anxiety about developmental milestones in early childhood and subsequent educational profiling of a range of abilities, cognitive and social. The exponentially increasing diagnostic rate amongst children has itself become a media phenomenon, with "epidemic" scares and pseudo-scientific vaccination furores. More informed coverage and the phenomenon of autistic blogging have enabled some better insight, the latter a significant issue in itself (Hacking, 2009). Over this period, autism across a range of production and registers has become a seemingly inescapable reference point outside of the academy in the UK, a *"cultural obsession"* in the US, according to Broderick and Ne'eman (2008).

As Chloe Silverman, in her important recent study *Understanding Autism. Parents, Doctors and the History of a Disorder* (2012), points out, autism has been treated in the Anglo-American clinical context, as a psychological, neurological, behavioural and genetic disorder at different points, and sometimes at the same time, in step with current directions in medical research and popular interest (p. 32). The first description of autism only appeared in English in 1943, in the American journal *The Nervous Child*, by Leo Kanner, who came to Baltimore

from Berlin and before that the Austro-Hungarian area now part of Ukraine, in the early 1920s. His paper, "Autistic Disturbances of Affective Contact" (Kanner, 1943), began the modern clinical study and construction of autism. Kanner borrowed the term from the Swiss psychoanalyst, Eugen Bleuler, an origin still much insisted upon by the French psychoanalytic-pscyhiatric establishment, as we will see in due course. But Bleuler was using the term in relation to an exploration of childhood schizophrenia. At the same time, in late-1930s Vienna, Hans Asperger made use of the same term, though it remains disputed whether or not Kanner could have not known this, as a German speaker, and why he made no reference to Asperger's work (Feinstein, 2010: 9–11). Asperger remained unknown in Anglophone study for a long time and the circulation of the term Asperger's syndrome, to designate a specific range or group of individuals with autism, only took place in the UK from the late 1980s onwards, thanks to the translation work of Uta Frith (Frith, 1989; Wing, 1993; Wolff, 2004; Silverman, 2012). The third German-speaking psychologist who would shape the understanding and treatment of autism in America and Europe was Bruno Bettelheim, who came to Chicago from Austria in 1939. Bettelheim's work found favour in the States in the 1950s and 1960s, when psychoanalysis was both fashionable and used as an institutional career strategy by clinicians (Nadesan, 2005: 82–7; Eyal et al, 2010). Child psychoanalysis was popularised by childcare manuals and packaged as endless *"advice"* to mothers who must view themselves as responsible for developing *"normal personalities"* and must heed the advice of the new childcare *"experts"* (Nadesan, 2005: 83). The mother-infant relation came under intense scrutiny as a result of this and Bettelheim's use of the term *"refrigerator-mother"* took off from remarks by Kanner, which the latter subsequently regretted, implying that the families, and mothers in particular, might be causally responsible for child autism through their own dysfunctional remoteness and failure to bond with their babies (Nadesan, 2005; Silverman, 2012; Eyal et al, 2010).

Both Kanner and Asperger offered work which was cautiously descriptive in character, not attempting to posit causes definitively and leaving much open to interpretation. Kanner's work was responsible for the dominant understanding which took hold thenceforth of autism as a kind of *"aloneness"* (Kanner, 1943; Murray, 2008; Feinstein, 2010; Duffy and Dorner, 2011; Silverman, 2012). This apparent *refusal* of social exchange – as it was first widely understood by then psychoanalytically oriented psychiatry in the US – or inability to cope with social relations, in a later, distinct but overlapping version, is key to the cultural *"fascination"* with autism (Murray, 2008, 2010). As Alicia Broderick, an American education academic, and Ari Ne'eman, who writes as a person with autism, have argued in their article "Autism as metaphor: narrative and counter-narrative" (2008), the key metaphors most culturally available for autism in the last twenty years are those of the *"alien"*, of withdrawal, of being shut off from others, within a *"fortress"* (a term popularised by Bettelheim), a child within a *"shell"* (Broderick and Ne'eman, 2008: 463–4). The sense of radical difference and separateness has led to an idea of the autistic character offering a counterpoint sense of what is around (usually) him, a kind of defamiliarising "Martian" critique of our society. This was initiated most powerfully by the hugely influential Hollywood film *Rain Man*, starring Dustin Hoffmann, in 1988.

The idea that the autistic person can offer a different reading of the inhumanity or alienation of Western consumer society is implicit in the film. The "alien" defamiliarises the social configuration, delivering the potential for critique. The sense of *intentional* withdrawal, i.e. not innate, is particularly useful to this kind of presentation of a person with autism, as the British psychoanalyst and writer Adam Phillips suggests (Phillips, 2012). The fantasy of a cure for autism is less common now in mainstream films, genre fiction and novels which deploy characters with autism as a device. The huge success of Mark Haddon's novel, *The Curious Incident of the Dog in the Night-time* (2003), now a sell-out West End play in London and with set text status for both children and trainee teachers, has contributed very strikingly to awareness of the term in Britain and represents a much more valid attempt to give a sense to readers both with and without autism of what it is like to inhabit this neurological difference.

Clinical fascination with autism has also been various, controversy-driven and, at times, tendentious. The ever-increasing profile of autism here is due in part to its increased proportions, from being seen as a rare childhood disorder classified as a psychosis, linked to schizophrenia in childhood and treated as a mental illness (Chamak, 2008: 79), to being treated as a neurodevelopmental disorder of "epidemic" scale. The rise in diagnosis in America, as mapped in the recent sociological history, *The Autism Matrix. The Social Origins of the Autism Epidemic* (Eyal et al, 2010), is a result of the deinstitutionalisation of children. The relative absence of autism formerly was due to *"the insensitivity of the custodial sieve"* (p. 25), which failed to differentiate adequately between types of impairment and disorder. Strikingly though and unlike intellectual disability more generally, autism was always viewed as exciting for the clinician: *"a mysterious disorder through which he hoped to catch a glimpse of how the normal mind/brain works"* (p. 5). The expansion of diagnostic criteria has brought in the notion of a "spectrum disorder", itself subject to criticism as implying a linear scale (Hacking, 2006). The mapping of the disorder to include those with profound communication disabilities, on the one hand, and those with more subtle social interaction impairments, deemed to have Asperger syndrome, on the other, is currently at the heart of controversy in the States over the most recent DSM-V diagnostic criteria and remains without scientific consensus.

This use of autism as crucial in illuminating the "normal" in new ways is fundamental to the best-known clinical work in the UK at present, that of the Cambridge psychologist, Simon Baron-Cohen. Baron-Cohen has taken as his starting-point Hans Asperger's view that AS is predominantly a male disorder and developed from this the idea of the *"extreme male brain"* (Baron-Cohen, 2004, 2008). This fits very much with, and indeed explicitly employs, the popular idea of "super geek syndrome", of a certain kind of technically-skilled boy or man with autism, socially awkward but unusually able in "male" areas. The gender determinism here is highly suspect and it is unarguable that autism is being "constructed" here, based on a restricted set of very leading case studies and examples (Nadesan, 2005: 199; Murray, 2008: 156–7). This hyper-essentialised view of gender is made respectable by evolutionary biology and a theory of "the autistic mind". The "autistic brain" is reduced in to one type

as *the* dominant type, and savant skills are coupled with a deficit in social relations skills. As Victoria McGeer has argued, it seems much more plausible that *"neurotypical minds constitute a species of mind, whilst autistic minds remain exceptionally multiple and idiosyncratic"*, than the reverse (McGeer, 2010: 291). But in Baron-Cohen's unitary "Theory of Mind" hypothesis, the model is one of deficit. There is one core difference between neurotypical and autistic minds: the inability of the latter to *"recognise intentional states in others"* (Barnbaum, 2008: 5), that is to say, to have *"a theory of mind"*. This "mind-type", in Baron-Cohen's theorisation, is *"an extreme version of the male brain that tends to systematize information at the expense of empathizing with others"* (Solomon, 2010: 242). John Duffy and Rebecca Dorner, in their recent account of this, "The Pathos of 'Mindblindness'. Autism, Science and Sadness in 'Theory of Mind' Narratives" (2011), have shown how, despite the macho rhetoric of *"hard science"* deployed by cognitive psychology, this is a *"discourse of affect and values, or a rhetoric of scientific sadness"* (p. 202). As they point out, like Kanner and Asperger, psychologists such as Baron-Cohen still have no *"biological marker"* for autism and their practice remains one of description based on diagnosis *"through the subjective observations of behaviour and affect"* (p. 201). While Kanner remained cautious and refrained from categorical aetiological assertions, contemporary cognitive psychology and psychiatry are more likely to make strong causal assertions, based on the observation of "symptoms" or behaviours. Autistic aloneness is narrated, Duffy and Dorner argue, as the *"inability to relate to the self"* (p. 202) as well as to others, and the *"doubled pathos"* of the metaphor of mindblindness positions people with autism as tragic, poetically sad figures, who are *"mourned even as they are ostensibly explained"* (p. 203). The external behaviourist description of cases by clinicians is meticulous and aggregative – as they say, crucially, *"almost ethnographic"* (p. 203). The troubling ethical questions this poses will be explored in future work. Worth noting here is the terse rejoinder from Jim Sinclair of the American Autism Self-Advocacy Network, who warns that *"mourning for us"* is on a par with praying for a cure for the *"normal child"* locked in a fortress, trapped in a shell and does not embrace autism as a way of being (Sinclair 1993, 2005).

At the same time as the Theory of Mind approach has come to the fore in the UK, empathy itself has gained currency, in particular in the emerging formation of the medical humanities, as a category for dealing with, describing, reporting on and feeding in to diagnosis and or interventions (Jurecic, 2006; Barnbaum, 2008). The question raised by the autism self-advocacy movement, of who should speak for autism, is particularly complex. As Osteen argues (2007: 7), the nondisabled need to speak also. But even more significantly, in the case of the complex groupings of impairments that are brought together as autism spectrum disorders or ASDs, to insist on the primacy of the voices of those with autism leaves *"the more severely disabled – who constitute a significant portion of autistic people – doubly disenfranchised: first, by their disorder, and second, by the very community that should welcome them"* (p. 7). Historically, the working definition of "idiocy" was that of one deemed unfit to speak for him or her self (McDonagh, 2008). Even now, intellectual disabilities of these kinds are still only rarely the subject of work in disability studies.

Some American philosophers have recently started to take on the challenge of ID (intellectual disability) to philosophy itself – as that which is outlawed by the foundational self-understanding of philosophy. Those unable to speak for themselves are deemed to be unable to bear rights. As Licia Carlson has argued in her 2010 book *The Faces of Intellectual Disability: Philosophical Reflections*, and in the important collection edited with the feminist philosopher, Eva Feder Kittay, *Cognitive Disability and its Challenge to Moral Philosophy* (2010a), they are seen as *"the most marginal of marginal cases"*, philosophical pets who, as Michael Bérubé comments in his contribution to the collection, do not *"meet the performance criterion for being human"* (Bérubé, 2010; see also Rapley, 2004; Nussbaum, 2006, 2010). Osteen proposes the term *"empathetic scholarship"* to encapsulate the aim of combining the norms of scholarship with *"experiential knowledge gained as family members and friends of autistic persons"* (p. 8). The lack of empathy which Baron-Cohen proposes as *the* marker of autism in all its variants (Baron-Cohen, 2012) is turned in to the founding principle of investigation of the sub-field of autism within disability studies. Family members, argues Osteen, who writes like many scholars in the area, such as Kittay and Bérubé, as a parent of a child with autism and as an academic, learn empathy by their experience, by *"'becoming autistic', […] perceiving the world as another sees"* (p. 25). This does not simply confer moral improvement upon them, but gives validity to their knowledge, an important claim that Chloe Silverman develops at length in her study of the disorder (2012). As Adam Phillips comments, *"scientific expertise needs the experience and the knowledge of those who love these children as well as those who are just interested in them. Without this, scientific accounts of autism may be misleading, since no one, not even neuroscientists, knows their children better than parents do"* (Phillips, 2012). Conversely, relationality, the being in relation to another, typically, family member, is viewed as giving philosophical validity and human value to the ID person (Kittay, 2010). Silverman's attempt to revalidate the experiential work of families and their accounts is a crucial area in need of further examination. The activist work of parent groups and their positioning in the field is no less significant. This is now very strongly the case in the French context, particularly in the last ten years.

The work of the Canadian philosopher of science, Ian Hacking, has been immensely important to disability scholars in the Anglophone world interested in autism. Hacking held a chair in the Philosophy and History of Scientific Concepts at the Collège de France from 2000 until his retirement in 2006, the first English-speaking academic to do so. Despite his longstanding engagement with the work of Foucault and period at the Collège, this work has not attracted much attention in the same field in France, however. Hacking is a self-styled historical epistemologist (Saar, 2003). As a philosopher of science, he has a critical relationship to naïve social constructionist accounts of disability of the first wave, although in sympathy with their political objectives (Hacking, 1999). Hacking's interest, as stated in his 2006 article, "Making Up People", is in a kind of *"dynamic nominalism"* in the human sciences, broadly understood to encompass social science, psychiatry and some life sciences, where certain kinds of people are classified as part of the process of scientific enquiry (p. 23). In what he terms the *"looping effect of human kinds"*, the people thus

grouped are

"moving targets because our investigations interact with them, and change them. And since they are changed, they are not quite the same kind of people as before. The target has moved." (Hacking, 2006: 23).

So, on the one hand, *"classifying someone with a learning disability involves a way of being a person"* and from there, *"those classified interact with the classifying process"* (Davis, 2008: 442). As has been indicated already, the history of autism in the one hundred years since Bleuler coined the term in 1911 is, quite simply, the history of child psychiatry across a range of countries, disciplines in the process of emerging across the period and national traditions within them, with the various effects of delay, exchange and non-exchange, particularly across linguistic divides, which create radical differences so profound there is only antagonistic avoidance of dialogue left (Bourdieu, 1990). How these formations have posited causes and advocated treatment has varied, therefore. The crucial divide, however, has been between approaches grounded in psychoanalytically oriented psychology and psychiatry and approaches favouring behaviourist pedagogic therapies that posit neurodevelopmental disorders. How these have classified those with autism and where this has left their families is a crucial part of this. Again, we are dealing with different constructions of autism, but as Hacking has made clear, ones which have the most fundamental possible impact, determining not simply clinical outcomes and therapeutic possibilities, but "ways of being" themselves. This is the battleground for autism in France today in terms of policy and legislation and, in terms of the dominant intellectual understandings of the disorder which diverge fundamentally from counterpart North European and American frameworks.

3. Les "sans-droits" de la République

The American German studies scholar, Carol Poore, author of the ground-breaking study *Disablity in Twentieth Century German Culture* (2007), wrote in 2003, that *"comparative perspectives on disability across cultures and historical time periods can help us understand ways in which disability is a constructed category, thus demystifying a phenomenon that is often held to be natural and not in need of interpretation"* (Poore, 2003: 21). Her own starting point for her book was a reflection on the presence of visible physical disabilities in German language film of the early to mid 20th century. Where Martin Halliwell, in his 2004 study *Images of idiocy. The idiot figure in modern fiction and film*, listed 500 American films, she found only a very few over the same period in German. This led her on to an exploration of the place of disability in German society over that time. The relative absence of characters with autism, plots involving autism and autism as a journalistic shorthand indicating background scientific trends such as cognitive psychology and evolutionary biology with regard to gender, social relations and child development, is no less striking in France in comparison to the areas highlighted above in the UK and North America, and is worthy of further study in itself. Cross-cultural research on cultural representation needs to be developed, but also comparative work on

national cultural clinical traditions and on the cultural history of autism in the context of mid 20th-century Europe and America. As the American medical anthropologist, Roy Grinker, writes, there is little room for complacency in such research with regard to autism. The only "evidence" is still behaviour and there is *"little agreement even within a single culture, about exactly what it is or how to treat it"* (Grinker, 2008: 2). Scientific research is embryonic and conflicted still and the situation is not one of resolution or clear outcomes, in the Anglophone context, where scientific controversies, policy disagreements and the fight for resources continue increasingly bitterly. The situation in France is, at first glance, not structurally dissimilar to this. But the lack of an organised disability studies academic formation with activist moorings masks the specific problems and institutional situation to the casual observer.

At the end of 2011, a documentary was made by a young French anthropologist, Sophie Robert, which set out to understand the work of psychiatrists in the arena of autism diagnosis and care. Robert was sympathetic to, and interested in exploring further, the work of psychoanalysis in this clinical context. As Robert worked on her film over four years, her sense of her subject changed and her focus shifted radically. The final documentary, *Le Mur*, produced in conjunction with the parent activist group *Autistes sans frontières*, became a staged indictment of the role of psychoanalysis in the diagnosis and treatment of autistic people in France. The documentary consists of a series of interviews with various senior psychiatrists, all of whom defend and speak from a psychoanalytic approach, interspersed with clips of the home life of several families with autistic children, with parents explaining their experience of the psychiatric institution in France. This film was banned on 26th January 2012 at a hearing in Lille, as a result of action taken by three psychiatrists interviewed, Esthela Solana-Suarez, Eric Laurent and Alexandre Stevens. Certain parts were excised due to legal action by some of the interviewees and a campaign, "Support the Wall", has been mounted internationally in protest. The film cannot now be shown, although it is still available on the *Autism Rights Watch* site and on the site of *Autistes sans frontières*, which established the campaign and which enabled its presentation at the major international autism conference in Philadelphia in February 2012.

Psychoanalysis is still part of the training of psychiatrists in France and their careers are promoted by posts in hospitals that in turn dictate the kinds of treatment and care that they advocate primarily for autism. One major consequence of this is that an estimated 80% of children with autism have not been in school at all over the last thirty years in France, and 75% of them are cared for in psychiatric hospitals (Feinstein, 2010; Philip, 2012). A further short documentary, *Shameful,* has been made by two American filmmakers, Alex Plank and Noah Trevino, posted on YouTube in late 2012, on the educational aspect in particular. Some French parents have relocated to the north of France so that their children can attend schools in Belgium, rather than remain out of school in France. Adults often reside long-term in psychiatric hospitals. The response to *Le Mur* and to ensuing political debates has been intransigent from psychoanalytic and above all Lacanian quarters.

Prior to this legal decision and at the same time as a review of autism care

policy was drawing up a very unsatisfactory balance-sheet of objectives reached for the 2008–10 *Plan d'Autisme*, the then Prime Minister, François Fillon, of the right-wing UMP party, nominated autism as *"Grande cause nationale 2012"*. This label is given to a cause selected by the Prime Minister, to grant free media slots to particular not-for-profit organisations in a given period. Following on from this attempted PR calming measure, another UMP politician, Daniel Fasquelle, a member of parliament in the Pas-de-Calais region, demanded nothing short of a new law banning the involvement of psychoanalysis in autism care in France. In March, the *Haute autorité de santé* (*HAS*), the chief health authority, together with the evaluation and quality agency for social and medical-social services (the *Agence nationale de l'*évaluation *et de la qualité des* établissements *et services sociaux et médico-sociaux* (*ANESM*)), published a report criticising the use of psychoanalytic techniques in this area and recommending the use of behavioural and educational methods for autistic children. And in response to the controversy generated by *Le Mur*, the incoming Socialist Prime Minister, Jean Marc Ayrault was far more reluctant to offer support to Fasquelle and to parent associations and autism activist organisations. *Autismrightswatch* published a letter written in May 2012 by Ayrault to a Lacanian group, the *Union pour la Formation continue en Clinique Analytique* based at the University of Paris VIII under the direction of the celebrated Lacanian analyst, Jacques-Alain Miller (*Uforca pour l'Université Populaire Jacques Lacan*), in which Ayrault describes autism as, crucially, an illness and not a disability, amenable to "therapeutics" rather than behavioural and/or intensive educational approaches. In other words, this endorsed the terminological and clinical parameters of the psychoanalytic led psychiatric institution.

The crisis is complex and the result of years of struggle by parent groups. France was censured by the Committee of Ministers of the Council of Europe, which upheld the charge of failing to fulfil educational obligations to persons with autism under the European Social Charter. This complaint was brought against the French government by *Autism Europe* and upheld in November 2003, a decision made public in 2004. But this had little effect. The European Committee on Social Rights backed the parent associations by concluding that France had neglected its educational obligations concerning autistic children and had violated three articles of the Autism and Social Movements Social European Charter (Chamak, 2008: 85). The reasons given were *"a restrictive definition of autism compared to the international classification, the non-enrolment of autistic children in school and the chronic shortage of facilities for adults"* (Chamak, 2008: 65-6). France was censured again in 2007, 2008 and 2012, as outlined by Danièle Langloys (2013), president of the parent group *Autisme France* (*AF*) and representative to the *HAS* of service-users. *AF* sought, she states, to *"se mettre aux normes occidentales en matière d'autisme"* and to extricate autism services from *"un scandale typiquement français"*, that is to say *"les ravages des théories psychanalytiques de l'autisme"* (Langloys, 2013). Those with autism remain, in Langloys' designation, *"les sans-droits de la République"*, excluded from the cornerstone republican institution of the school (Philip, 2012). The *HAS* report was hailed as a death sentence for psychoanalysis by *Le Monde*, a reprieve by *Le Figaro*, and an entirely ineffective

contribution in *Rue 89*, "Autisme: entre psys et antipsys, un rapport qui ne tranche rien".

The educational situation seems barely credible to outsiders. As Christine Philip points out, in her overview of education and autism in France in recent years (2012), it has arisen as a result of an institutional and policy split between *"soin"* and *"éducation"*. Where *"soin"* is the domain of hospital-based psychiatry, *"éducation"* is not and the demarcation is rigidly policed by the former. A clear sense of this is given in Jacques Hochmann's account of the history of autism (Hochmann, 2009, 2012). Hochmann, who is a strong advocate of current French psychiatry with regard to autism, produces a national psychoanalytically oriented history of autism, from the *"sauvage d'Aveyron"* lost child of the late 18th century, through to Bleuler, whose coinage of the term enables a kind of psychoanalytic ownership of the concept, and on to child psychiatry in the 20th century. A kind of mock surprise that psychoanalysis can be "attacked" when, after all, autism specifically "belongs" to it is present repeatedly in the heated responses to the controversy engendered by Sophie Robert's film (Miller, 2012; Aflalo, 2012; *L'École de la cause freudienne*, 2012; *Université Populaire Jacques Lacan – Institut de l'Enfant* 4.3.12 press conference in response to *HAS* and to Fasquelle, 2012; *Centre interdisciplinaire de formation à la psychothérapie relationnelle* dossier, 2012). Autism is classified as a mental illness, not a disability nor a developmental disorder, and as a psychosis originating in childhood. French psychoanalysts, as evidenced by *Le Mur* amongst other defences, position themselves against an invading, all-conquering cognitive-behavioural "American model", which must be "seen off". The behaviourist techniques in question are those of the operant conditioning methods of Lovaas' ABA programme and the intense intervention of Schopler's TEACCH, examined historically by Laura Schreibman (2005). Instead, they advocate a *"psychodynamic approach founded on psychoanalysis and group psychology"* (Chamak, 2008: 78). Applied behaviourism can only *"produce robot attitudes"*, they warn, (p. 77), or, even more sinisterly, lend itself to the adoption of pharmaceutical solutions. The programmes favoured in the UK and the US with young children diagnosed with autism come on the side of *"éducation"* rather than *"soin"*, as Philip points out (2012) and are therefore disallowed. This is, they proclaim, a "witch-hunt" against psychoanalysis (Miller, 2012).

In the meantime, parent associations have become increasingly, and understandably, incensed by the institutional hegemony of psychoanalysis and its consequences for their children (Chamak, 2008). A further series of protests have been launched against the practice of "packing", or wrapping a child in wet sheets for several hours – *"la camisole glacée"* – as a psychiatric intervention for children with autism (Feinstein, 2010: 105). The sense of powerlessness of the parents is tangible, but the rage and despair evident in the associations' web dossiers and in *Le Mur*, come from the perceived culture of parent-blaming, which is seen as fundamental to French clinical practice. The child's "withdrawal" into aloneness described by Kanner and Asperger in the late 1930s and early 1940s is treated as *"acquired"* as a result of *"relational emptiness"* due to maternal depression (Widlocker in *Le Mur*; Rey-Flaud, 2008; Roudinesco, 2008). In place of the *"refrigerator-mother"*

we have the *"crocodile-mother"*, as the Lacanian analyst, Geneviève Loison discusses in her interviews in *Le Mur*. Maternal *"toxicity"* is causal and hence autistic children *"defend themselves from language"*, she explains. As Robert comments, blaming mothers is an open door, even before aetiological claims about child psychosis are at issue. In this version of autism it is still seen as a rare, severe psychosis, hence the demands for extended diagnostic criteria, a more *"unrestricted concept"* of autism (Chamak, 2008) and acceptance of its level of incidence on a par with elsewhere. French parent groups, as well as the self-advocacy group, SAtedI, have reacted to psychoanalytic intransigence with an uncritical espousal of "American" behavioural techniques. So far, however, they have not succeeded in countering these positions. This hyperpolarisation of the one true "good model" versus the pernicious, evil model is inevitable, given the policy crisis at stake. But it is worth noting that, from an intellectual perspective, the accounts given are unsatisfactory. British psychoanalysts in the UK, such as Tustin, Meltzer and also Adam Phillips, have produced interesting reflections on autism and Chloe Silverman's sympathetically nuanced account of Bettelheim (2012) enables a more subtle awareness of even his approach and its foundations, despite its anathematisation by French parent groups. But of course, in the UK there has been no psychiatric monopoly in the same way and the power over disabled children and their families is not on this scale. Interestingly, as Chamak points out, parent groups in France have increasingly empowered themselves as lay activists by using scientific research to reinforce their demands, refusing to let others have a simple monopoly of "expertise". But this has, of necessity, been done to reinforce a very stark opposition between models. Henri-Jacques Stiker, who remains intellectually open to the work of psychoanalysis, suggests that it is *"especially French to see violent opposition between analytical and cognitivist perspectives"* (Stiker, 2007: 148) and that there is *"a legitimate conflict of interpretations"* at stake. But on the ground, the lack of concrete impact of the parent groups and the controversies caused by European censure of France and Robert's film, mean that this is a battle that has to be won, before the complex intellectual work of questioning models and pursuing intellectual genealogies of the construction of autisms plural can be meaningfully engaged with by those same associations. Their own "lay-expertise", of the kind foregrounded by Osteen and Silverman, remains channelled in to the most acute fight for inclusion and empowerment.

4. Conclusions

The dire position of both children and adults with autism in France needs much wider international recognition and campaigning: *Le Mur* and *Shameful* are merely the beginning of what has to become a major international demand for change. The lack of an institutionally defined disability studies in France means that the very interesting work produced remains ineffectually scattered, little-known outside France and without political impact. This lack has contributed to the absence of successful activism and profile-raising of this issue. The *"rendez-vous manqués"* between British and French disability studies is potentially key to this. Greater awareness will foster international activism and, at the same time, lead to the possibility of better intellectual exchange.

Disability Studies in the UK is itself waking up to the need for a "global turn". The American cultural studies scholar, Benjamin Fraser, in his book-length study of Disability Studies and Spanish cultural production, *Disability Studies and Spanish Culture. Films, Novels, the Comic and the Public Exhibition* (2013), has argued that this *"new, international phase"* is already here, evidenced in, for example, the special issues of the British *Journal of Literary and Cultural Disability Studies*, or in the recent work on disability in the Spanish American work of Susan Antebi (Antebi, 2009; Fraser, 2013: xv). This is welcome but marks merely the very beginning of much larger-scale cross-cultural research projects with regard to disability, to cultural representation and to autism in particular. The bilingual journal *ALTER European Journal of Disability Research/ Journal européen de recherche sur le handicap*, launched by Stiker, Ravaud and others, is an important development and one which might successfully break down linguistic divides and closed national disciplinary circuits. Future research needs to be highly multi- and interdisciplinary across humanities and social sciences, as well as cross-cultural and comparative. The cultural, philosophical and aesthetic investigation of autism and cultural representation has started to be explored by Anglophone scholars: in addition to Stuart Murray and Benjamin Fraser, already mentioned, the work of Ato Quayson and Michael Davidson is relevant here (Quayson, 2007, 2010; Davidson, 2007). This work now needs to be taken further. Transnational film study of autism, the study of autism blogging internationally, the exploration of comparative psychiatric contexts and, not least, the revalidation of "experiential knowledge" will all add to the productiveness of the emerging field, and the impact must be both intellectual and political. In this way, cross-cultural research on autism will be able to make a strong contribution to the reworking of the place of cognitive, intellectual and neurological disabilities in the wider area of Disability Studies in Anglophone and Francophone spheres, and beyond.

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