

## **Autism and social movements in France: exploring cross-cultural differences**

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CHAPTER TEN:  
Autism and Social Movements in France: Exploring Cross-cultural Differences

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**Introduction**

Social movements in the field of health have emerged to challenge healthcare access and quality of care, as well as advocate for broader social change (Brown and Zavestoski 2004). Scholars interested in health social movements explore the dynamics that propel actors to mobilize collectively around health issues and examine, as well, the links between ‘health’ and other social movements organized around cleavages such as race, gender and class, among others (Barnett and Steuernagel 2007).

This chapter provides a comparative perspective on autism advocacy using insights gleaned from the study of health social movements. In the field of autism advocacy and activism, there are deep divisions between parents’ groups and autistic persons’ organizations (sometimes referred to in the U.S. context as self-advocates) about how to best represent autism and advocate for autistic people. In addition, these actors clash over views about the fundamental nature of autism itself. As such, autism advocacy incorporates all of the characteristics of an embodied health movement (EHM), one of the three types of health social movements identified by Brown and Zavestoski (Orsini 2008). EHMs are typically organized around conditions for which scientific agreement on aetiology, diagnosis and treatment has not been reached (Brown and Zavestoski 2004).

Until recently only parents’ associations expressed their grievances and challenged representations of autism, mainly by adopting a biomedical model of autism. These parent-led associations, many of which promote a deficit-model of autism are assuming an increasingly

important role in shaping public policy in the field of autism (Chamak 2008a). Today, however, newly formed associations of autistic individuals are taking parents' associations to task for speaking on their behalf, and challenging the medical model of autism (Chamak 2008a; Ne'eman 2006; Orsini 2008; Ortega 2009; Silverman 2008; Sinclair 2005).

In recent decades, the medical definition of autism has also changed. The widening of the diagnostic criteria for autism introduced in the early 1990s in the international and American classifications of diseases redefined boundaries between normality and abnormality (Chamak 2008a; Eyal 2010; Grinker 2007; Hacking 2002; Silverman 2008). By including verbal persons in the autism category, the classifications enabled more people to fit the diagnosis of autism.

Autistic self-advocates begin from the premise that autistic adults *are* able to communicate to others what autism is like from the inside (Dekker 1999). Several published autobiographical and other first-hand accounts by persons with autism spectrum disorder (ASD) provide valuable insights into both the nature and the subjective experience of autism (Chamak 2008b; Hacking 2007; Murray, this volume; Peeters, 2002). People who recognise themselves as autistic have begun to campaign against being labelled as suffering from a mental disease, shifting the discourse from victim-blaming to system-blaming (Chamak 2008a). The success of their mobilisation efforts rests in part on changes brought about in the way their potential members view not only their life situation, but also themselves. At the international level, the historical dynamics of this mobilization shows that the people concerned refuse the representation of autism as a disease and criticize a society in which autism is solely understood according to a deficit model (Chamak 2008a, 2010; Murray, this volume). The first association of autistic persons, Autism Network International (ANI), set up in 1991 in the U.S., defends the idea that autism is neither a disease nor a disability, but a different mode of cognitive functioning.

The neurodiversity concept, which rallies individuals who view autistics as having a different mode of cognitive functioning, was first developed by Judy Singer (1999), an Australian whose mother and daughter have Asperger's Syndrome and who is on the spectrum herself. She argued: "the key significance of the 'autistic spectrum' lies in its call for and anticipation of a politics of neurological diversity, or neurodiversity. The 'neurologically different' represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability" (Singer 1999, 64). In the foreword to the edited collection Women from another planet (Miller 2003), Singer asserted: "We are the first wave of a new liberation movement, a very late wave, and a big one, just when you thought the storm of identity politics, with its different minorities jockeying for recognition, was surely over. We are part of the ground swell of what I want to call neurological liberation" (p. xii). The neurodiversity concept has spread successfully via the Internet as illustrated by the accounts of autistic persons (Meyerding 1998; Ne'eman 2006; Nelson 2004) and through the development of the website, neurodiversity.com. The autism rights movement adopts the neurodiversity concept and encourages autistic and non-autistic people to accept autism as a variation in functioning rather than a mental disorder to be cured.

The aim of this chapter is to analyse the different forms of activism among autistic persons in a variety of contexts and especially to explore the particularities of the French case as compared with movement organizing based mainly at the international level. The disability movement and awareness of the significance of gender dynamics in autism are not as developed in France as elsewhere (Chamak 2010) and this context influences the form of activism. In a previous work, one of the authors has identified differences between the international movement and the French one, as the latter does not refer to neurodiversity and rejects the idea of an autistic community (Chamak 2010).

In preparing this chapter, we analyzed first hand accounts written by autistic persons, including 29 autobiographies<sup>1</sup> and 25 accounts published in edited collections (e.g. Sinclair 1992) or posted online (For example see Dekker 1999; Meyerding 2010; Ne'eman 2006; Shelly 2004; Sinclair 1993, 2005). Discourse produced from Websites, newsletters, publications and colloquia from the associations, mostly ANI, ASAN (the Autistic Self-Advocacy Network) and 'Aspies for Freedom' was also analysed. For the French case, we focused on Satedi, the only association that exists in France for autistics. Satedi has French, Belgian and Canadian members. In addition to analysis of the website and forum exchanges, 15 in-depth interviews were conducted with French, Belgian and Canadian respondents diagnosed as autistic or as having Asperger's Syndrome. Unlike the international movement, Satedi does not challenge the medical and deficit models. They do challenge, however, the definition of autism as a mental disease. A comparison of the international autism rights movement with the French case allows us to demonstrate the heterogeneity of movements for autistic people and illustrates the need to examine how historical and cultural factors influence how social movements express their grievances, and challenge society and the state.

### **Autism Advocacy at the International Level: the Emergence of an Autistic Community**

By publishing autobiographical books in which they give their personal view of what it is like to be autistic, the American Temple Grandin (1986) and the Australian Donna Williams (1992) took part in the development of an identity politics around autism, allowing other people to recognize themselves in their accounts (Chamak 2008a). Temple Grandin and Donna Williams were the first ones to express themselves through the medium of autobiography and have been followed by other autistic authors including the Swedish Gunilla Gerland (1997) and the Americans Liane Holliday Willey (1999) and Edgar Schneider (1999).

The self-advocacy movement developed in the North American context when Jim Sinclair and other autistic persons participated in the Autism Society of America (ASA) national conference in 1991 and decided to found ANI, an association interested in stimulating autism self-advocacy, autistic peer support and empowerment. Sinclair, Williams and Kathy Grant co-founded ANI, which has grown from a small group to an international community (Sinclair 2010). Sinclair has played a leading role in organizing the movement and developing the idea that being autistic means being different and different does not necessarily mean defective (Sinclair 1992, 295):

Being autistic does not mean being inhuman. But it does mean being alien. It means that what is normal for other people is not normal for me, and what is normal for me is not normal for other people. . . . But my personhood is intact. My selfhood is undamaged. I find great value and meaning in my life, and I have no wish to be cured of being myself. If you would help me, don't try to change me to fit your world.

His presentation at the International Conference on Autism, a joint conference of the Autism Society of America and the Autism Society of Canada, held in July 1993 in Toronto, directly challenged the 'autism as tragedy' narrative and drew a lot of attention to ANI (Sinclair 1993). It led to a dramatic increase of exchanges on the online parents' forum, the only public forum about autism at that time. While some people strongly disagreed with Sinclair's presentation, most of the responses were positive (Sinclair 2005). Autistic persons became particularly active on the forum and parents launched attacks against these interventions. In response to these attacks, ANI decided to create an autistic cyberspace. At that time there were not yet any public Internet sites such as yahooogroups to host email forums. ANI had to use a listserv on an academic server. In 1994, ANI launched its own forum and in 1996 the Autism Network International listserv (ANI-L) moved to its current home on the Syracuse University server.<sup>ii</sup> The influence of ANI increased and blazed a trail for autistic people from other countries to found a national movement (Dekker 1999; Shelly 2004; Sinclair 2005).

In previous research, one of the authors analysed the historical dynamics of ANI (Chamak 2008a). Findings revealed that its members share certain values and have developed their own terminology using the word ‘neurotypical’ (NT) (or normies) for non-autistic persons, ‘aspie’ to refer to a person diagnosed with Aspergers’s Syndrome, ‘autie’ to refer to a person diagnosed with autism and the term ‘cousin’ is used to refer to a non-autistic person who has some other significant social and communication differences (Sinclair 2005). They have their own set phrases and in-jokes, each of which is part of an autistic culture that facilitates the mobilization of a collective identity. Certain testimonies of autistic persons show that this movement enables them to share experiences, to avoid loneliness and to have a more positive view of their condition (Lawson 2005; Newport 2001; Schneider 2003). ANI challenges representations of autism by contesting negative cultural representations of autism and celebrates an alternative collective identity based on abilities rather than deficiencies.

Not only does ANI take a leading role in bringing together and representing autistic people, it also structures different social spaces, such as a space for collective learning (in the form of a forum, a newsletter and conferences). When Sinclair, Williams and Grant decided that their “mission was to advocate for civil rights and self-determination for all autistic people” (Sinclair 2005, website of Autism Network International), they set boundaries between the private autistic connections and the exchanges with parents and non-autistic people. Distinguishing ‘us’ from ‘them’, the forum has been subdivided into an ‘AC’ section for messages of interest to autistic people and cousins, and a ‘Parents’ Auxiliary’ (PA) section for messages about parenting. Jim Sinclair (2005) explained that the idea of an exclusively ‘autistic space’ was a guiding theme when they decided to create their own autistic conference in 1996: Autreat. Most Autreat attendees live in North America but people also come from different regions of the world (Canada, Australia, Finland, Israel, Japan, New Zealand, Norway and others) (Dekker 1999; Shelly 2004; Sinclair 2005). ANI and Autreat conferences

enabled autistic persons from different countries, including Martijn Dekker in the Netherlands and Sola Shelly in Israel, to set up new online communities and associations around the world.

Sola Shelly, one of the founders of the Autistic community of Israel (ACI), explained at an Autreat meeting in 2004 that she had been formally diagnosed and is also the mother of an autistic adult. In her view, “[a]utistic culture expresses the special way that autistic people perceive the physical, emotional and social world” (Shelly 2004). She was surprised to learn that much of the writing about autistic culture was produced by female authors and quoted the book: Women from another planet? Our lives in the Universe of Autism [an anthology initiated and edited by Jean Kearns Miller (2003)]. This book focused on the interplay between the roles of women in society and their characteristics as auties or aspies (Shelly 2004). It provided a framework for advocacy as well as recommendations for the development of positive autistic identities. Building on insights provided by this book, Kristin Bumiller (2008) analysed the broader implications of grassroots autism rights activism for women and for the feminist movement and showed that gender identity matters for the experience of autism. Girls are much less likely to be diagnosed and to gain access to services, especially if they are not on the severe end of the spectrum (Davidson 2007). Conversely, males with autism are more likely to be stereotyped as violent. Females might receive more encouragement to develop the kinds of social skills that render them better able to compensate for the problems that they have than males. However, being better able to compensate for a problem does not mean one does not have the problem (Dekker 1999). As a group whose identity is based on difficulties conforming to social norms, autistic people are likely targets for social discrimination and resistance towards this discrimination is essential for participation in society (Bumiller 2008).



At the international level, the Autism Rights Movement (see <http://www.autism-help.org/points-autism-rights-movement.htm>), which includes organizations such as ANI, ASAN and Aspies for Freedom, has contributed to building a positive collective identity for autistic people and has been pivotal in mobilizing against discrimination. The valuing of genuinely autistic traits and persons comes with certain risks, however, and may be coupled with a devaluation of non-autistic characteristics and individuals. For example, the Institute for the Study of the Neurologically Typical, the satirical web site created by Muskie, a high-functioning autistic woman, defines “neurotypical syndrome as a neurobiological disorder characterized by preoccupation with social concerns, delusions of superiority, and obsession with conformity” (Website, Institute for the Study of the Neurologically Typical, <http://isnt.autistics.org>). The negative picture of non-autistic people mirrors the more familiar devaluation of autistic people encountered throughout popular culture. At times, the strategy fuels conflict between non-autistic and autistic persons, as well as among autistic persons, because the descriptions of non-autistic persons are caricatured:

Neurotypical individuals often assume that their experience of the world is either the only one, or the only correct one. NTs find it difficult to be alone. NTs are often intolerant of seemingly minor differences in others. When in groups NTs are socially and behaviorally rigid, and frequently insist upon the performance of dysfunctional, destructive, and even impossible rituals as a way of maintaining group identity. NTs find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum (<http://isnt.autistics.org>)

Analysis of the forum exchanges suggests that certain autistic persons may use these negative descriptions, but not in a metaphorical way. Some of them believe quite firmly that as autistic persons, they are genuinely superior to non-autistics. For example, Fistfullo1337 wrote in Aspies For Freedom forum in 04/04/2007: “I have never suffered from this gift, I cherish it, nourish it, make it so I have solace in knowing that I am biologically superior to NTs, you should do” (sic). In the same forum, Scandy007 wrote in 09/02/2010: “Autistic people and

people with Asperger's are a mental evolution of humankind with (possibly) the highest natural intelligence there is". One might interpret these characterizations and excessive generalizations just as inappropriate as negative depictions of autistic persons.

The Internet has played a crucial role in the emergence of the autistic community by facilitating exchanges and by promoting positive self-identification for autistics. As Martijn Dekker explains (1999), the Internet is, for many autistics, what sign language is for Deaf people. Dekker set up a mailing list server on his computer in the Netherlands called Independent Living on the Autistic Spectrum (InLv). In 1997, Dekker travelled to the U.S. where he met several autistic persons and concluded that autistic communication appears to occur without much protocol and in a direct way with less non-verbal communication. Davidson (2008) explored the distinctive styles of autistic communication and referred to the Wittgensteinian concepts of 'language games' and 'family resemblances': "You might not be able to say exactly what these features are, but you tend to recognize them when you see them" (Wittgenstein 1988, 66). The notion of shared experiential background led Davidson (2008) to argue that a place on the spectrum could constitute membership of an autistic 'form of life,' "a shared background and cultural association among members who tend to respond to and communicate about situations in certain ways rather than others" (Davidson 2008, 794).

Ari Ne'eman, the president of the Autistic Self Advocacy Network (ASAN), has been active in the autistic culture and disability rights movements for a number of years. On the ASAN website, Ari Ne'eman (2006) explains:

Society has developed a tendency to examine things from the point of view of a bell curve. How far away am I from normal? What can I do to fit in better? But what is on the top of the bell curve? The answer is mediocrity. That is the fate of American society if we insist upon pathologizing difference and seek to 'cure' it. The person who is socially isolated because he views the world in a different light may use that difference in perception to invent something revolutionary.

On December 16, 2009 President Barack Obama announced that Ari Ne'eman would be appointed to the National Council of Disability, a federal agency charged with advising Congress and the President on disability policy issues. In April 2010, he was appointed as a public member to the Interagency Autism Coordinating Committee, a Federal advisory committee that coordinates all efforts within the Department of Health and Human Services concerning autism. The fact that a proponent of autistic culture is a member of this committee might be taken to suggest that the highest political authorities in the U.S. are open to recognizing the existence of an 'autistic community'.

### **The French-speaking Association: the Notion of a Community is Rejected**

The lone association of autistic persons in France, Satedi, was set up in December 2003, 12 years after ANI. At the outset, Satedi was closely related to Autisme France, a parents' association and it adopted the claims and positions of this association. Currently, Satedi has distanced itself from the parent association and acquired more autonomy, but the aims remain different from those encountered in the international context. Whereas the international movement campaigns against the biomedical model of autism, Satedi has accepted the definition of autism as a neurodevelopmental disease. In the French context, the persistence of psychoanalytical interpretations of autism in the professional milieu may influence the adoption of the neurological hypothesis by Satedi. The analysis of the forum exchanges, the website content and the interviews with French autistic persons suggests that most Satedi members have internalized the notion of disability and the definition of autism as a dysfunction of the brain. In the forum, Yoyo wrote: "I know well that it is a disability without curing. There are those who were born deaf or blind, we were born autistic" (15 October 2010). For Kikuta: "If I had to put a name on my problem, I would have defined it as a dysfunction of the brain" (2 April 2010) and Gib explained: "My memory is very selective

and I do not understand its functioning. All is complicated. It is not easy to have a queer brain” (24 December 2008).

Satedi’s main aims are to help autistic persons and their families, and influence autism research and government autism policy. It explicitly does not associate with the broader international autism rights movement. The leaders of Satedi reject the notion of community, nor do they refer to the notion of neurodiversity. Exchanges on the forum illustrate the differences between French and Canadian members of Satedi, with the latter referencing the notions of community and neurodiversity, and expressing hostility with the notion of disability. In July 2009, when Dorry and Idlem (both pseudonyms) from the Canadian province of Quebec intervened to promote the neurodiversity concept and refused the definition of autism as a disability, some French participants responded that they preferred the term ‘disability’ rather than being stigmatised as having a psychiatric disease. The adoption of the notion of disability is also a means to get services and help. In December 1996, autism was officially recognized as a disability by law in France (n°96-1076). Changing the status of autism from a psychiatric disease to a disability enabled autistic persons to be granted rights and to receive disability benefits provided by the 1975 law (and now by the 2005-102 law for the equality of rights of the disabled persons).

Idlem argued in July 2009: “Autism is not a disability. Autism tends to be viewed as a disease only because people refer to and so help to construct it as a disease”. According to Idlem, “the autistic persons are closer to the better way of evolution than the NTs”. When Idlem defined autism as a “racial advantage”, the president of Satedi intervened and threatened to exclude him from the forum. The president of Satedi, who moderates the forum, is hostile to the notion of community and views the concept of neurodiversity as a product of “folklore”.<sup>iii</sup> He disagrees with Idlem’s idea that autism should be seen as an advantage rather than a disability. Another French member (Samoju) responded to Idlem in August 2009: “If

autism is a racial advantage, why do you exchange in a forum for people who describe their difficulties?”

The leaders of Satedi have staked out a moderate position, one that enables them to be taken seriously by professionals, parents and political authorities, many of whom often consult them about autism. They participated in the elaboration of the Plan Autisme (2008-2010), a government program which aimed to improve services for autistic persons by offering earlier diagnosis, better integration in school for autistic children and services for autistic adults. The National Ethics Advisory Committee called on Satedi for opinions on ethical issues regarding autism. Two Satedi members were invited to participate in the working group for the elaboration of guidelines for professionals concerning therapies and services for autistic persons. Had Satedi embraced the concept of neurodiversity and the notion of an autistic ‘community’, its autistic members would most likely have been excluded from the discussions with professionals, parents and political authorities. Interviews with parents, professionals and autistic persons (Chamak 2005) evidence this drastic difference from other countries like U.S., Australia or Sweden.

### **Socio-cultural and Political Differences**

In order to understand the differences between the ideas and claims of the international movement and those of the French movement, it is important to analyse aspects of the historical, political and socio-cultural context in France. The French system is characterized by a partnership between the State and the parent associations and by historical and cultural features, such as the longstanding opposition towards communitarianism (Saunders 2008). The French model contrasts with the American model in which communities play a crucial role in social organization (Donzelot 2003). With reference to the universalistic ideas of the Age of Enlightenment, French society accords priority to universal rights over communal bonds and particularistic values. The French model favours ‘universalism’, which treats all

citizens in the same manner and rejects ‘particularism’, according to which people are to be treated differently based on the group to which they belong (Etzioni 2004). Proponents argue that disabled persons are better served by a model of universalism than by a civil rights or ‘minority group’ approach (Bickenbach 1999).

The French preference for universalism and its resistance towards cultural diversity inhibits public recognition of groups, minorities or communities, although not completely. The French Constitution (one nation, one language, one state) proclaims that “France is an indivisible, secular, democratic and social Republic” that shall guarantee equality before the law of all citizens without distinction according to origin, race or religion. This principle is not always applied, however, since gender, ethnic origin and disabilities are often used as grounds for discrimination.

Anti-communitarianism is enforced by state institutions, including the High Council for Integration (Haut Conseil à l’Intégration) established in 1998 and the High Authority for the Struggle against Discrimination and for Equality (Haute Autorité de Lutte contre les Discriminations et pour l’Egalité, HALDE). The legal setting for this institutional activity is provided by two laws: the 1901 law on associations and the 1905 law on the Separation of Church and State. The ‘Observatoire du communautarisme’ was established in August 2003 and has adopted the anti-communitarianism goal of defending the Republic and the universalism of republican citizenship against the particularism of identities attached to all forms of communitarianism. It opposes long-lasting as well as more recent communitarianist identity campaigns, ranging from Breton regionalism to gender-based community campaigns (Saunders 2008).

Modern-day Anglo-American communitarianism began in the 1970s and 1980s in reaction to John Rawls’ book A Theory of Justice (Rawls 1971). Their proponents question the universalistic claims of liberal theory and critique notions of individualism and advocate

the social nature of the self (Sandel 1981; Walzer 1983). Community is closely associated with symbolic boundary construction. In the United States, community can be a symbol for egalitarianism, the quest for a place where every individual is recognized as an equal member of the community. Yet the idea of community is ubiquitous and versatile. It is a potentially powerful idea for crafting diverse political projects (Collins 2009). French anti-communitarianism opposes “a political order that must view individuals first of all through the communitarian prism that is assigned to them” (Saunders 2008, 166).

Unlike the United States, Canada, or other European countries, in France social movements demanding autonomy for disabled people eschew the language of civil rights (Galli and Ravaud 2000). Civil society forces rally around the management of specialised structures directed by parent associations. This method of organization enables delegation of public services to the associations managing structures set up for disabled people and constitutes the foundation of the partnership between the State and the associations (Barral 2007). In some cases, the institutionalisation of the relationships between the State and the associations has taken on personalized forms, with circulation between services of the State and associations. For instance, high-ranking civil servants join the boards of the associations and some administrators of associations become civil servants (Barral 2007).

Recently, the French government labeled autism the “Great National Cause for 2012.” This label gave the French parents’ associations the benefit of free publicity for campaigns on public TV and radio channels, and enabled them to raise awareness of their demands. They present the autism situation in France as a scandal (as illustrated by numerous articles in the French newspapers), criticize the persistence of psychoanalytical frameworks associated with certain French psychiatrists, and highlight the need for access to free behavioral treatments.

However, the parents’ associations do not always adopt positions considered satisfactory by those most directly concerned: autistic people. Regarding the differences

between the parents' associations and those representing autistic persons, Clarke and van Amerom (2007, 772) noted that:

Organizations, sometimes called charities, certainly have more power and economic suasion than diagnosed individuals. Their construction of problems clearly represents a more powerful perspective than do the blogs of one or even many individuals. Moreover, in order to exist and to justify their continued existence, charities constantly have to seek financial support by claiming to be helping those in need.

In their recent book, The Autism Matrix, Eyal et al. (2010, 4) argue that the new institutional matrix (community treatment, special education, and early intervention programs), following the deinstitutionalization of mental retardation, signalled a massive change in the social organization of expertise: "It was pushed forward by challenges to psychiatry from relatively marginal groups--special educators, occupational therapists, behavioural psychologists, activist social scientists identified with the anti-psychiatric movement--and parents". In the U.S, the National Association for Retarded Children (NARC) played a crucial role and so did the National Society for Autistic children (NSAC)--both parent groups. They all sought to undermine the dominance of the psychiatric profession, which had in the past ignored or belittled their expertise. In the new network of expertise, parents were recognized as credible experts.

At the international level, the aims of the autistic rights movement are very different from those of the parents' associations, since they aim to deconstruct the notion of disability and the deficit model. In their review and critique of models of disability, Bickenbach et al. (1999) argue that while disability movements were correct to criticize the medical model for turning a socially-constructed disadvantage into a problem with a person's body or mind, they suggest that the extreme position they advocate is equally problematic. Bickenbach et al. (1999, 1178-1179) conclude that:



the politics of disablement will be torn by an internal struggle between two antagonistic political strategies. The first characterizes disabled people as a social minority group who must seek out their basic civil rights and fight against discrimination in order to correct the injustices of the past and the present. The second insists that disablement is a universal human phenomenon that has been systematically ignored with dire and unjust social consequences.

In France, the autistic rights movement is almost absent, since the cultural influence and especially the hostility to communitarianism, prevails among French autistic persons (Chamak 2010). The deficit model is relatively well accepted and the distance from the international trend favours relations with the State, parents and professionals. The radical discourse produced at the international level by some autistic persons such as Amy Nelson (2004) is badly received in France. If reference to the brain is widespread in France, as in other countries, the notion of an ‘autistic community’ is flatly rejected by political authorities and professionals, as well as autistic persons themselves.

### **Neurodiversity and the Brain**

In November 2004, Amy Nelson (2004), one of the founders of Aspies for Freedom, drafted a proposal for the autistic community to be considered a social minority group by the United Nations. From her point of view, “it could help to end discrimination for those who have this neurological difference”. For Kathleen Seidel, who owns and operates the website neurodiversity.com, diagnosis is an aid because “we could make sense out of things that had been inexplicable to us; we felt validated. I encountered the word neurodiversity, and it just sang to me. I thought, ‘What a beautiful word that encompasses the reality that God has many different ways to build a brain’” (Solomon 2008).

Such references to the brain and differences regarding cerebral functioning are widespread in the recent discourse of autistic persons, as well as in society at large. The neurodiversity concept and reference to the brain are used by the Autism Rights Movement to construct a collective identity redefining autism as a difference and not as a disease. A

symposium entitled ‘Personhood in a neurobiological age. Brain, self and society’ held in London in 2010<sup>iv</sup>, questioned: “To what extent neuroscience is reshaping our understanding of human beings? To what extent people are going to recognize themselves in brain language?” Alain Ehrenberg (2010) answered that 1°) “Neuroscience does not change anything about our concept of person, either descriptive or normative” and 2°) “If people are moving towards recognizing themselves in their brain, this will be a social process, not a biological truth that everybody will eventually recognize as a truth based on proof established on an empirical basis coming from the laboratory. This claim means it will be learned: these are not neurobiological facts that are at stake, but their transformations into social and moral references to act in social life. From this perspective, this recognition is a new language game . . .”. Many authors (including Ehrenberg 2004; Ortega 2009; and Vidal 2009) emphasised the present-day diffusion of neuroscientific concepts beyond the laboratory and their penetration in society. Discourse about the brain and its illustration using brain-imaging influence the way we talk about ourselves. Researchers in the social sciences and humanities have investigated the role of neurological vocabulary in the elaboration of identities (Ortega, this volume) and found that the widespread use of brain metaphors and analogies is changing the way people understand their own subjectivities (Hacking 2007). The functioning of the brain is used as an explanation for the functioning of the person, as illustrated by Jane Meyerding. When she discovered she was autistic, she thought: “It’s my brain that doesn’t fit” (Meyerding 2003, 169). She describes herself as being ‘differently brained’ (Meyerding 1998). This is the new language adopted by some advocates for autistic persons.

## **Conclusion**

The neurodiversity concept has helped to shape for autistic persons a collective identity, “a perception of a shared status which may be imagined rather than experienced directly” (Polletta and Jasper 2001, 285). Beyond recruitment, identity work is crucial to sustaining

solidarity and commitment (Polletta and Jasper 2001). The question of collective identity is central when studying social movements. Indeed, a social movement process is in place when collective identities that go beyond specific campaigns and initiatives develop. Collective identity is a process that is strongly associated with recognition and the creation of connectedness (Diani and Bison 2004). How is collective identity constructed in the course of mobilization? How are common interests defined? How has an autistic culture developed within that community? Who is accepted in the group? Who is not? At the international level, an autistic community emerged from a group including those with Asperger's Syndrome, autistic persons and 'cousins'. Non-autistic people can participate, but decision-making power and organizational leadership rest in the hands of autistic people. ANI is aligned with the disability rights movement whereas Satedi is not. The French-speaking association has accepted the notion of disability and the biomedical model. It favoured the constitution of a network, but not a community, a concept that has a negative connotation for French people. The collective identity of the French autistic persons is focused on sharing experiences but not on using the neurodiversity concept. Activists may define their identities in different ways depending on the strategic situation. In the context of the massive contemporary changes, refocusing attention on contested perspectives of community organization sheds light on how people organize themselves and others for diverse political ends.

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## Appendix

*List of books by autistic persons analyzed for this research:*

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<sup>i</sup> The book references are listed in the appendix.

<sup>ii</sup> Syracuse University is known for stimulating the development of disability studies.

<http://disabilitystudies.syr.edu/what/disabilitystudiesatsu.aspx#tradition>.

<sup>iii</sup> Intervention in the seminar “Comment classifier/déclassifier sans stigmatiser?”, November 24 2010, Paris.

<sup>iv</sup> Personhood in a neurobiological age. ‘Brain, self and society ’symposium. The London School of Economics and Political Science, London, September 13 2010. <http://www.lse.ac.uk/collections/brainSelfSociety/>.