

## Autistic culture online: virtual communication and cultural expression on the spectrum

Joyce Davidson

Department of Geography, Mackintosh-Corry Hall, Queen's University, Kingston, Ontario, Canada, K7L 3N6, joyce.davidson@queensu.ca

*Drawing on first-hand accounts of the Autism Spectrum (AS), this paper argues that there are distinctive autistic styles of communication. It suggests that these differences can usefully be conceptualized in Wittgensteinian terms as 'language games', and further, that these are associated with an autistic culture emerging alongside their practice, particularly online. The Internet is shown to be an appropriate, accommodating medium for those on the spectrum, given characteristic preferences for communication at a socio-spatial distance. The Internet has potential implications for AS social exclusion/inclusion, and hopes expressed in AS writings are high; one author claims that '[t]he impact of the Internet on autistics may one day be compared to the spread of sign language among the deaf' (Singer 1999: 67). This paper investigates such claims, and the extent to which those with autism describe using the Internet to connect with similar Others, not just for social support, but to organize and advocate for recognition of autistic cultural difference.*

**Key words:** autism, autobiographies, communication, disability cultures, Internet, social inclusion.

### Introduction: definitions beyond diagnosis

Questions of self-definition and self-advocacy have become increasingly important for people on the Autism Spectrum (AS). AS encompasses a wide array of neurodevelopmental conditions typically characterized by challenges in social interactions and communication skills, and the presence of repetitive behaviours and restricted interests (American Psychiatric Association 2000). Expert 'outsider' accounts of AS (e.g. clinical, popular, parental) have tended to reinforce stereotypical images of autistic individuals as a-social,

unemotional, and perhaps especially, uncommunicative (Szatmari 2004), thereby denying voice to individuals on the spectrum (Brownlow and O'Dell 2006). However, a large number of first-hand descriptions of AS have emerged in recent years, unsettling predominant views about the nature (and culture) of autism (see Davidson 2007).<sup>1</sup> In this paper, I draw on a collection of over forty autistic autobiographies<sup>2</sup> in order to explore what I believe to be distinctive autistic styles of communication. I suggest these communicative differences can be conceptualized in Wittgensteinian terms as 'language games',

and further, that they are associated with an autistic culture or ‘form of life’ that is emerging alongside their practice, particularly online. Building on existing scholarship with respect to cultural geographies of difference, I examine how interaction in virtual worlds enables recognition of complex Other ways of understanding and expressing experience that hold potential for ‘real world’ outcomes.

Given that autistic accounts repeatedly stress the extent to which the written word is preferred over other means of self-expression and communicative interaction, this paper takes a text-based approach to understanding autistic culture (see Smith 1996 for an exposition of similar methodology). I argue that autobiographies are an appropriate and accommodating means for researching autism in and on autistics’ own terms (Davidson 2008). Close reading of autobiographies allows the researcher to identify and investigate recurring themes and indeed pursue authors’ recommendations for further research. To date, my own effort in this regard includes research into the need for appropriate accommodation, gendered dynamics of diagnosis, and calls for recognition of autism as neurological *difference* rather than disability or deficit (Davidson under review).

While the primary sources informing this paper are conventionally published autobiographies, the analysis also benefits from the findings of recent social science research conducted online (including Clarke and van Amerom 2007; Jones, Zahl and Huws 2001). The ethical challenges surrounding such studies (discussed by Brownlow and O’Dell 2002) have thus far restricted my own work in new media. However, Brownlow and O’Dell’s (2006) approach is inspiring as well as exemplary, highlighting the need for further focused research on autism in virtual space. Secondary sources employed below also

include journalistic commentaries and semi-autobiographical writings by autistic academics and ‘cousins’ who identify with those on the spectrum.

In what follows, I take up an emerging theme regarding the implications of the Internet for individuals with autism. Popular periodicals and mainstream media report regularly on the conspicuous autistic presence online, as in the recent *New Scientist* article (Biever 2007: n.p.), which states that ‘Since the 1990s, people with autism have been communicating via chatrooms, email lists and online bulletin boards, including a suite of email lists called “Independent Living on the Autistic Spectrum” [InLv] created by Martijn Dekker’ (of which, much more below). Also coming to public notice is the autistic utilization of websites like Second Life—home of the Autism Island, ‘Brigadoon’<sup>3</sup>—and YouTube (e.g. Gajilan 2007), and the prevalence of groups like ‘Posautive’ and ‘Autism and Computing’ to raise awareness about and foster alternative, affirmative views of autism (Murray and Lesser 1999). Much of the work of advocacy takes place in virtual arenas, and lends weight to the claim that ‘the democratization of information flow which is the Internet has promoted the emergence of new ways of self-identification for autistics’ (Singer 1999: 64). Proclamations for the Net’s significance for autism are in fact often momentous; witness the same author’s oft-repeated statement that ‘The impact of the Internet on autistics may one day be compared to the spread of sign language among the deaf’ (Singer 1999: 67). In the decade since Singer’s statement was published its substance has been not only repeated but reinforced by several other autistic authors, some of whom emphasize the close yet complex connections between Internet usage and what they see as the emergence

of a distinctive autistic culture (Dekker 2006; Prince-Hughes 2004).

While what one means by ‘culture’ can be complex and contentious (Cresswell 1996), there are persuasive indications from AS authors that autism is emotionally, spatially—in every sense—*otherwise* (O’Neill 1999), such that recognition of a distinctive culture becomes not only reasonable, but almost inevitable. That is to say, autistic differences in perception and ‘processing’ tend to involve Other ways of being-in-the-world, separate senses of selves and space that give rise to distinctive cultural experience, and so also, cultural *expression*. The sense of phenomenally different perception on the spectrum has been explored in depth elsewhere (Davidson forthcoming). In this paper, I am concerned with expressly communicative aspects of difference and cultural distinction. As one AS author says, by telling and sharing stories, ‘[m]uch like the deaf community, we autistics are building an emergent culture. We individuals, with our cultures of one, are building a culture of many’ (Prince-Hughes 2004: 7).

### Cultural geographies of difference, and different ‘forms of life’

Critical (especially feminist and post-structuralist) geographers have argued persuasively that people and places, selves and spaces, are mutually constitutive, that they come into being relationally, produced and performed in interaction with each other (Kirby 1996; Rose 1999; also see Bondi and Davidson 2003, 2005). This is, in fact, the premise of online communities, wherein ‘individual participants can circumvent the geographical constraints of the material world and take a more proactive role in shaping their own virtual community

and their position within it’ (Kitchin and Dodge 2002: 342). While each individual partially creates and is created by her own unique personal geography, there are obviously elements shared among members of similar human and physical environments; after all, we are not free to construct just anything, but are limited by the realities (material, historical, political, etc.) of our embodied situations, interactions, and ‘horizons’.<sup>4</sup>

Similarities in circumstances generate potentially significant (if not always predictable) likenesses between and among various groupings. The sense of shared cultures that experiential affiliations create may differ across time and space, but they are also associated with less tangible ‘axes of identity’, as discussed by geographers of gender, ‘race’, sexuality and (dis)ability, among others (see Anderson, Domosh, Pile and Thrift 2003; Pile and Thrift 1995). Individuals might thus articulate an association or identification with ‘minoritized’ (Burman and Chantler 2004)—for example, Queer, Black or Deaf—cultures, referring to certain overlapping or parallel experiences, perhaps including experiential constellations around contestation of discrimination and geographies of exclusion (Sibley 1995).

Cultural associations need not, then, entail any ‘essential’ commonality, in biological, socio-cultural or indeed any other terms (Davidson and Smith 1999, after Wittgenstein 1988; also see Davidson 2003, chap. 3). Rather, individuals associated with such complexly constituted clusters might be described as presenting certain patterns of similarities that can usefully be conceptualized in terms of ‘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 significance of this *non-essentialist* notion for this paper can best be understood by considering two closely related (later) Wittgensteinian concepts; ‘language games’ and ‘form (or forms) of life’.

The concept of ‘language games’ is intended to link a particular *use* of language with the ‘actions into which it is woven’ (Wittgenstein 1988: 7), to connect communication with actual social and spatial project and circumstance. The uses and activities around language are arguably endless and fluid (Wittgenstein 1988: 23). To be able to ‘keep up’ and take part, to use language in ways meaningful for others, depends less on ‘definition’ than *context*, on shared expectations and understanding. ‘Background’, too, is important, and in what follows, I want to suggest that ‘autistic language games’ might be seen as emerging from partially shared experiential background and ‘identity’—that is, self-identification with a place on the spectrum.

The notion of shared experiential background leads us to consider the second key ‘cultural’ concept presented in this paper, Wittgenstein’s idea of a ‘form of life’, which is admittedly difficult to define or pin down, *precisely because* it is not intended to define essential features identical to all members of the ‘form of life’ (or cultural grouping), members who are ‘related’ in terms of the flexible notion of ‘family resemblance’. In discussing the possibility of and possibilities for ‘autistic culture’ I reject the notion that there is any such thing as an ‘essentially’ autistic identity. On the contrary, I want to make space for conceptualizing difference constructively, to enable recognition of complex Other ways of understanding and expressing experience. Questions of culture, identity and difference are delicate and difficult, and there are good reasons why geographers should be wary of their thornier

implications. However, the project undertaken by this paper is intended to investigate and advance arguments emerging from AS circles in a manner open and faithful to AS concerns. The following discussion of ‘autistic forms of life’ should, therefore, be read within the conditions of caution and respect intended.

Advancing a working definition of the concept at hand, Lynne Rudder Baker (1984: 278) argues that ‘forms of life rest finally on no more than the fact that we agree, find ourselves agreeing, in the ways that we size up and respond to what we encounter.’ Sharing a ‘form of life’ does not mean that we agree about or share everything, but that we tend to *understand* each other because of our *related* experiences. ‘Form of life’ is intended to designate ‘what it is about a community *that makes possible meaning*’ (Baker 1984:288, emphasis added). On this basis, it might thus be argued 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.<sup>5</sup>

One of the most important insights of cultural geographies of difference, and one that arguably enriches the Wittgensteinian notions employed here, is that no one(’s) identity can be *singularly* straightforward, and certainly never fixed in place (see, for example, Valentine and Skelton 2003a, 2003b). What this means for the project at hand is that, if there is an autistic culture/‘form of life’, it need not be understood to define or delimit the identities or geographies of individuals involved. Subjectivities exceed cultural frameworks, but such frames of reference can still be put to work for particular—perhaps especially *political*—purposes, as suggested immediately below, and elaborated with specific relation to autism towards the end of this paper.

Of necessity, we each negotiate more than one set of cultural spaces, and members of particularly subjugated groups can find it necessary to cloak an identity in order to pass through (or pass as ‘normal’ in) hegemonic social space. Performance in mainstream environments is restricted and restrictive by definition, and autistics have long felt pressure to study and copy majority social skills they do not ‘naturally’ possess (Grandin and Barron 2005). Social space is never equitably accessible, but constructed as more or less exclusive, racist or sexist, often hetero- (and arguably neuro-) *normative* in its affects. Challenging routes to acceptance in ‘public’ space by asserting an alternative or ‘abnormal’ identity, or signaling sense of belonging to an Other cultural group—say, being openly gay in a Deaf club, or being seen to prioritize one’s association with Deaf culture in space constructed as primarily queer—is an overtly political act that obviously risks consequences. Such consequences can be negative and destructive—as Valentine and Skelton’s (2003a, 2003b) research attests—but also empowering and liberating, particularly if cultural connections are made with similarly different others. Think of forceful ‘minority’ expression, from say, disability rights groups, in marches for gay pride (Butler 1999).

While those with autism have yet to literally take to the streets, increased literary presence in numerous public forums suggests that many are in fact ‘coming out’ with pride, asserting minority cultural status and strengthening common ties in (virtual) space. As Singer (1999: 61) explains (and with reference to non-figurative family resemblance), for years her experience and ‘personal struggle in the middle of three generations of women “on the spectrum”’ was ‘silenced’: ‘By now, groups of women, Blacks, queers, crips, had all found their voices, their communities. It seemed that

only my family was left without a group to belong to, who could speak for us and with us.’ Finally, however: ‘With our own communication medium, autistics are beginning to see ourselves not as blighted individuals, but as a different ethnicity’ (Singer 1999: 67).

### Communicating cultures of autism

Perceptual and ‘processing’ differences associated with autism hinder typical communication, with the result that words and actions—the ‘language games’—of others can be unpredictable, indecipherable and scary for those on the spectrum. It is not just linguistic articulations that can disturb, but even expressions of face intended to *smooth* social interaction and perhaps communicate pleasure. For Gunilla Gerland, others’ smiles were enough to confuse and ‘make me uncertain’, but laughter could be devastating, ‘sudden and horrible to me, as if their faces were cracking, huge mouths, with no previous warning. Suddenly a lot of teeth and loud noises’ (2003: 17). That facial expressions (neuro)typically considered so positive can be perceived so differently, *harmfully*, provides powerful illustration of why embodied interaction is often best avoided. Journalist Harvey Blume quotes an autistic individual he describes as ‘mordantly expressive on line’—‘so eloquent and brilliantly funny’ (1997a: n.p.)—explaining why it would be bad to meet in person. Blume’s correspondent states ‘that personal contact confounds more than it informs’, and that ‘reading faces is like looking into a rippling pond. I am too distracted by the edges, glints of light, to make much of it’ (quoted in Blume 1997a: n.p.; see also, Koborg Brøsen 2006).

Obtuse but neurotypical (NT) patterns of expression are alien to AS worlds: ‘I always said exactly what I meant, neither more nor less. That other people didn’t do that was very

confusing’ (Gerland 2003: 35; see also Williams 2005). Communications of typical others can be staggering for those on the spectrum, as stressed by the following quotation from a study conducted online:

One aspect of autism is that it is like a perpetual culture shock, no matter where I go or how long I stay. I don’t understand many of the basic social assumptions that others take for granted (often without even being consciously aware of it). (Mr. E, in Jones and Meldal 2001: 38)

A state of shock in the face of profound cultural difference could be described as an experientially defining ‘moment’—albeit long lasting—for members of a group forced to develop skills as sociologists (Dave, in Osborne 2002: 68) and anthropologists to ‘figure out the natives’ (Grandin, in Sacks 1995: 256). As numerous authors attest, AS speech tends to be clear, to the point, and to avoid any reference to extraneous information that might muddy the clarity of communicative intent: ‘NT conversations have a very fast-paced rhythm of little exchanges back and forth, whereas autistic people usually say what they have to say, in its entirety, then stop talking and wait for the other to respond’ (Dekker 2006: n.p.) ‘Language games’ among autistics are precisely straightforward and a seriously rule-based affair. Given such striking preference for precision, it is unsurprising that the transmission of information—especially *across cultures*—is best set in text. Some AS authors suggest ‘autistic communication could be comparable to written communication’ (Dekker 2006: n.p.), while others have taken a virtual leap, claiming that ‘for many autistics the Internet is Braille’ (Blume 1997b: n.p.).

There is evidence to suggest that the predictability of computers can compensate for AS challenges. As Shore explains:

computers are often particularly well suited for those on the autistic spectrum as they provide interactive consistency. A computer has the same response for a given input, so there is no body language or tone of voice messages that need to be decoded. (2001: 60)

Computer-generated communication is clear, satisfyingly straightforward and accurate, and can go a long way towards alleviating AS anxieties around social interaction. For Williams, type-writing also provides a valuable means of clarifying thoughts and ideas, for others as well as herself: ‘When I need to explain something at a level of complexity for which spoken words evade me, I still run off to the computer and let my fingers talk’ (Williams 2005: 252).

In sum, and to say the least, ‘computers can be very enabling’ (Murray and Lesser 1999: n.p.), particularly in slowing down the fast-paced rhythm typical of NT exchanges and creating more accommodating ‘language games’. Camille Clark, creator of the ‘Autism Diva’ blog explains: ‘Of those autistics on the internet who discuss its use, we all agree that it’s an amazing tool . . . because of the way that it allows for a delay in a response that is almost never allowed in real life’ (quoted in Biever 2007: n.p.). In the real world, explains Darius (2002: 25), ‘There is no such thing as adequate delayed social reactions. One either is quick enough to keep up, or one is weird and socially disabled.’

The comfort experienced online means it is often described as more than a ‘means of communication’ (Williams 2005: 119). The medium can itself be an accessible ‘meeting place’ (Williams 2005: 119), in surprisingly substantial ways; the following quotation is drawn by Singer (1999: 65) from an InLv thread about the ideal ‘country’ for autistics: ‘We’ve already got our own country. It’s

a cybercountry called InLv, and it's perfect. We can interact without getting on each other's nerves—gently, carefully'. Social spaces of the Internet might thus be in some senses Utopian—a literal 'no-place' where good things come to light. Adding depth and weight to the striking *yet shared* sense of a seemingly different life-form (or perhaps 'form of life'), Dekker writes:

autistic people often report that they have very few problems communicating with and understanding people 'of their own kind'... communication problems arise when the cultural border is crossed. (2006: n.p.)

### AS 'language games' online: social support, advocacy and activism

AS writings and others' research demonstrates that the Internet provides at least some of those on the spectrum with 'a means to develop and maintain social relationships' (Jones and Meldal 2001: 38). In addition, the opportunities for exchanging practical advice and information with other (non-professional) experts are considered extremely important (Parr 2008; Parr and Davidson 2008).

Thanks to the Internet, autistics are taking diagnosis, scientific speculation, experimentation with self-medication into their own hands. News travels fast on the net about what works and what doesn't, which practitioners are good and which are not. With this sense of empowerment, some autistics are in a position to speak with satisfaction about the medical partnerships they have been able to negotiate. (Singer 1999: 65)

As Clarke and van Amerom (2007) have found, resistance to the 'medicalization' and professional 'ownership' of autism

is a common discursive feature of AS sites, and others recognize that 'the use of the Internet by individuals with autism and related conditions is part of a movement of self-advocacy' (Brownlow and O'Dell 2002: 690). At the most basic level, 'the Internet has begun to challenge stereotypes surrounding the competence of people with autism to communicate effectively' (Brownlow and O'Dell 2006: 315). Put somewhat differently, and as we have seen, the Internet enables those with AS to participate in shared 'language games', and so to have a *voice*, a collective voice that is often confrontational in the sense of contesting and attempting to supplant predominant belittling constructions of autism. Clarke and van Amerom report that bloggers 'spoke of celebrating their differences and of anger at neurotypicals for stigmatizing them' (2007: 771); that they are 'proud of their differences and committed to the value of the uniqueness and the nuances of their experiences of AS' (2007: 772).<sup>6</sup> These statements stand in marked contrast to the views expressed in sites sympathetic to the notion of a 'cure' for autism, including the well-known 'Cure Autism Now Foundation' (CAN<sup>7</sup>), founded by the parents of an autistic child. The very existence of such sites is offensive in the extreme for many of those leading calls for recognition of difference (Davidson forthcoming). Amy Nelson (2004: n.p.), for example, describes the possibility of cure as an 'immanent threat' faced by those on the spectrum. In a statement posted online, another AS individual explains:

I won't use the term 'disability' to describe AS ... I do not feel disabled or impaired. I am not broken and I do not need to be fixed or cured. If I were to become NT, I would not be 'me' anymore, and a lot of my good qualities would disappear. (Person 5, in Brownlow and O'Dell 2006: 319)

Highlighting communicative difference as among the AS qualities she values most highly, Jeanette Purkis (2006: 192) states: 'If I had the choice to see the world the way most people see it and to have the understanding and communication skills of the majority, I would not take it'.

Such clear resistance to neuro-normative pressure is reminiscent of responses to hetero-normative mores of the (not so distant) past, where claims that homosexuality was an 'illness' or 'disorder' to be cured were clearly the result of professional and popular prejudice and misunderstanding. Many authors with AS feel responses to their own difference are similarly misplaced, and regularly draw comparisons with the experience and value of various other 'minoritized' groups. Nelson (2004: n.p.), for example, writes: 'In the same sense that this would be entirely unacceptable to cure someone's skin colour, we feel that our differences need to be respected and our minority group to be protected.' While moves towards acceptance of AS as difference rather than disability, disorder or deviancy, are at a comparatively early stage, resistant AS discourse is clearly gaining momentum, so much so such that some are beginning to speak of 'a movement' that parallels others like 'Disability Pride (e.g. deaf community) and Psychiatric Survivors movements' (Dekker 2006: n.p.). Dekker is among those who regularly point to correlations between AS and Other, perhaps especially, D/deaf experience and culture, and here he does so in a way that highlights the cultural significance of different 'language games': 'The parallel between deaf people and autistic people lies mainly herein that both populations have a communication style that is different from the norm.'

Dekker (2006: n.p.) suggests both groups face cross-cultural challenges, but 'With deaf people, this cultural border is much more clearly visible than with autistic people.' This

difference in visibility can be experientially significant in terms of others' willingness to accommodate or 'make allowances' for atypical communicative style (Prince-Hughes 2004). However, this significance largely evaporates online where autistic 'language games' can appear typical in a way that expands AS horizons. Blume, for example, quotes one respondent's claim that: 'The level of communication possible via the Internet is changing our lives, ending our isolation, and giving us the strength to insist on the validity of our own experiences and observations' (in Blume 1997b: n.p.).

Clearly, there are important differences between AS and other forms of activism. Perhaps most notable is the particular form of communicative media that enables members to organize. With AS, 'the movement did not really get off the ground until the Internet became widely available, as the Internet is essential in the facilitation of communication between adults on the autistic spectrum' (Dekker 2006: n.p.). Certainly, autobiographies have done much to challenge mainstream views of autism, but the pace of change in response to individual, albeit authoritative voices was slow. AS writings online (as well as recent offline commentaries) are indicative of an increasing awareness of potentially constructive political connections between pioneer organizations like Autism Network International (founded by Donna Williams and Jim Sinclair to promote acceptance of the autistic 'way of being') and well established and at least partially successful grassroots movements from whom important lessons might be learned. In mainstream circles, it is generally considered unacceptable to question the validity and rights to inclusion of minority peoples of all kinds, and that this is the case is largely the result of self-advocacy and activism on the parts of many who refused their



exclusion in the past. For the time being, however,

a culture and community for people on the autistic spectrum is still in the process of being established, currently lagging way behind other disability cultures ... Autistic culture today is largely where deaf culture was a century ago. (Dekker 2006: n.p.)

Most AS authors who comment on the movement do nevertheless insist that it is gathering pace, and this is evidenced by the increasingly forceful as well as frequent nature of statements appearing in various media, contributions ever more tricky for the mainstream to ignore. In an illustration of the escalating sense of self-worth and power of political will, Singer (2003: xii) recently exclaimed: '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.' This statement was made in the introduction to a published collection of autobiographical writings that began life on an AS Internet list-serve, and Singer is insistent in her hope that the edited book will advance moves to add 'a further intersection to the current framework of gender, class, ethnicity, race, sexual orientation, age and disability. I hope it will add *neurological difference* to the existing set of social variables' (Singer 2003: xii). The increasingly politicized nature of the movement is evidenced further by fellow contributors to the collection, who ask that the reader bear witness to 'violations of human rights' (Miller 2003) that authors have suffered as a result of their place on the spectrum. Similar senses of outrage at exclusion and maltreatment motivated two autistic women, Amanda Baggs and Laura Tisoncik, to form 'the autistic liberation front' within Second Life—a space

where autistic people can 'organize, educate and advocate for ourselves' (quoted in Biever 2007: n.p.). Their actions support calls for recognition of minority status for members of a group determined to assert cultural difference in positive, political terms, to demand rights to experience and express an arguably Other 'form of life'.

### Witnessing cultural difference

A 16 November 2004 submission to the UN by 'Aspies for freedom' is titled 'Declaration from the Autism Community that they are a Minority Group', and begins as follows:

We mean for this statement to begin a process of official recognition by the United Nations that we are indeed a minority group, and worthy of protection from discrimination, inhumane treatment, and that our differences are valid in their own right and not something that needs to be cured. (Nelson 2004: n.p.)

Significantly, for understandings of autism and for the argument this paper puts forth, one of the bases on which minority status is claimed, is that: 'People in the autism community have their own way of using language and communication that is different from the general population, is often misunderstood and can cause a bias against us.' Such communicative difference and misunderstanding between those of and off the spectrum calls to mind Baker's (1984: 288) loose definition of 'form of life' as simply 'what it is about a community that makes possible meaning.' Further illustrating the existence of 'meaningful' AS communities, Nelson writes:

People on the autism spectrum have a unique social network, this is primarily using communication

with text on the Internet. It is an invaluable community for many of us. There should be increased availability and recognition for this autism community online so that isolated members of the autism community can join and participate. (2004: n.p.)

The sentiments expressed here help us see something of the political *point* of claiming an identity, of asserting a sense of belonging to a particular cultural group, despite the inevitable potential for limitation associated with labeling practices. *Self*-identification as autistic—as opposed to being stuck with a label professionally applied—is crucial for the sense of empowerment and entitlement that can motivate movements for change. As Williams (2005: 7) has argued: ‘Nobody has the copyright on autism.’

Claiming an autistic identity enables contributions to the collective formulation of demands, not merely for others’ recognition or ‘tolerance’, but for accommodations that will facilitate appropriate forms of social inclusion. As we have seen, these may involve more imaginative alterations to environments, creative ways of making space for and legitimating autistic experience and expression that involve much more than adaptations for physical access. A geographical imagination might be employed to better enable *virtual* articulations of autistic ‘forms of life’, always in ways cognizant of difference *within* AS communities. As this paper has tried to show, the Internet is a crucial ‘place’ for challenging autistic exclusion, however and by whomever it is experienced, in always complex ways that shift with personal context and various other axes of difference.

Despite the seemingly reductive title of the ‘One Community Pledge’ issued by Autism Network International (ANI), those with autism are invited on the group’s website to sign up to a very inclusive assemblage:

I affirm that we on the autistic spectrum—Kanners and Aspergers, high functioning and low functioning, rich and poor, those of us with additional disabilities and those without, all of us of whatever age, race, creed, sex, sexual preference, or any other subgrouping—are one community. (quoted in Murray and Lesser 1999: n.p.)

In accordance with the difference embraced by this statement, the current study has found that even those most adamant about the existence and importance of autistic culture are acutely aware of the marked diversity among those on the spectrum. After all, ‘Autism is a spectrum disorder, and people with autism are a diverse culture’ (Grandin and Barron 2005: xvi). In a demonstration of such multiplicity, other AS authors resist references to autism as a ‘disorder’, preferring to speak of a ‘condition’ (Williams 2005), or simply a different ‘order of being’ (Shore 2001: v). Despite identifiable family resemblances, there are thus many very personal ways of describing life on the spectrum, and perhaps as many shades of autism as there are individuals concerned. In the words of Prince-Hughes (2002: xii): ‘We are all different and all the same; a cultural composite.’ Nevertheless, Prince-Hughes is emphatic that ‘People on the autistic spectrum do, indeed, have a culture—one separate from the “normal” world they must live in’ (2002: xiii). There are differences and similarities across and between different cultures, and cross-cultural interaction can—as we have seen—be challenging in the extreme.

As with any culture, we have social norms, unwritten rules and a thought perspective all our own. That people with autism have to exist within a different culture on a day-to-day basis in order to survive—one that often blindly insists on conformity rather than respecting our cultural diversity—makes functioning

in the world around us exceedingly difficult, often depressing and continually anxiety-laden. (Grandin and Barron 2005: xvi)

Despite such challenges, no author advocates anything other than multiculturalism as the most appropriate path for autistic ‘inclusion’. In a collection entitled *Voices from the Spectrum*, Shore writes ‘While it is important for people with autism to maintain our own identities as a culture and way of being, it is also important to learn how to interface with the vast majority of people who are not on the autism spectrum’ (2006: 201). The challenge is finding means to facilitate such interaction in ways more manageable and equitable.

Fortuitously, the communicative medium preferred by autistics is capable of facilitating interaction with those off the spectrum in ways comfortable and potentially enriching for all concerned. As we have seen, typical space is largely constructed as neuro-normative and exclusive of many other manifestations of difference; the hardest thing about living with autism, according to Baggs (quoted in Bieber 2007: n.p.) is ‘having to navigate a world that is, on all levels, built for the abilities and deficits of people who are not built remotely like me.’ In stark contrast:

On the Internet, freed from the constraints of NT timing, NT ways of interpreting body language, free from the information overwhelm of eye contact, the energy demands of managing body language, [those with AS] sound, simply, ‘normal’, and often, eloquent. (Singer 1999: 65)

Thus, rather than contributing further to marginalization and perhaps ‘ghettoization’ of those on the spectrum, as some might reasonably fear, there is considerable evidence to suggest that the Internet facilitates a degree of ‘social inclusion’, allowing productive

‘cross-cultural’ exchanges to take place more easily, and simply *more*, than ever before:

For centuries the environment has tended more and more widely to be autism incompatible. With computers a newly autism-compatible environment has emerged in the late twentieth century. People on the autistic spectrum have as much to contribute in this new environment as anyone. (Murray and Lesser 1999: n.p.)

Also stressing the Internet’s ‘leveling’ qualities, Bieber writes:

In recent years the Web has morphed from a place where a few technically minded people hang out to a mainstream hub of communication. That transformation has given autistic Web users a bigger, broader audience for the first time, and a chance to communicate on a level playing field with almost everyone. (2007: n.p.)

Crucially, there is also emerging evidence to suggest that AS voices ‘gathering force’ online *will be heard offline too*, that virtual communication has the potential to spill over into the ‘real world’, with further potential for political consequence. As one AS individual explains: ‘When the computer became able to connect me with others via the internet, my “real” world expanded also’ (in Blume 1997a: n.p.). Shore (2001: 142) provides rather more detail about the nature of such expansion, emphasizing opportunities to travel and socialize while ‘spreading the word’ about autism: ‘Cyberspace can be a good place for those on the autistic spectrum to meet others. For example, I have been invited to present at several conferences as a result of my cyberspace connections’. Dekker (2006: n.p.) too describes on/off line relations—in another (but also activist) sense—when he explains how the positive space of a virtual community takes

on real-world presence through ‘Autreat’, a three-day conference camp in New York State ‘that replicates the autistic space in 3D life’. AS cultures emerging online thus have the potential for real-world outcomes. The Internet facilitates cultural experience and expression, and enables those on the spectrum to participate in aspects of another’s culture, one from which they are typically excluded. This cross-cultural activity clearly has important implications for all concerned.

### Conclusions: expanding AS horizons

In a sense, autistics are constituting themselves as a new immigrant group on line, sailing to strange neurological shores on the Internet, and exchanging information about how to behave upon arrival. They want to be able to blend in, to pass, and are intently studying the ways of the natives in order to do so ... Yet, in trying to come to terms with an NT-dominated world, autistics are neither willing nor able to give up their own customs. Instead, they are proposing a new social compact, one emphasizing neurological pluralism. (Blume 1997a: n.p.)

In the decade since this statement was made, considerable evidence has emerged—largely from first-hand accounts of autism and others’ research on AS online—that has allowed me to argue that there are distinctive autistic styles of communication. I have suggested that these differences can usefully be conceptualized in Wittgensteinian terms as ‘language games’, and further, that these are associated with an autistic culture or ‘form of life’ that is emerging in association with the practice of these ‘language games’, particularly online. The Internet has been shown to be an appropriate and unusually accommodating medium for those on the spectrum, given characteristic preferences for

communication at a socio-spatial (and minimal *temporal*) distance. We have seen that many of those with autism are using the Internet to connect with similar Others, and not only for purposes of mutual social support; the Internet has indeed ‘begun to do what was thought impossible, to bind autistics together into groups, and it is this which will finally enable them to claim a voice in society’ (Singer 1999: 67).

Clearly, many individual autistic voices are actively contributing to the creation of a collective voice and ‘movement’, one that contests predominant constructions of AS difference as disorder or disability. There are thus parallels between the activities of AS movements and those of other ‘minoritized’ groups who have had some considerable success in challenging discrimination in the past; constructive comparisons have often been drawn with experience of D/deaf people and cultures, but there are similarities with those of many Others. While it seems that, to date, the place of autistic activism remains largely online, evidence is emerging that there are potentially powerful real-world consequences, and future research is required to assess the difference AS people online can make. The communicative and cultural significance of the Internet for autism should be taken very seriously indeed, and perhaps assist more imaginative construction of policies and provision of services to facilitate, not just recognition, but also social inclusion, for ‘new’ neurological minorities.

### Notes

- 1 The term AS is used here to reflect the preference of the majority of authors whose work contributes to this study. Many find the inclusive connotations of this diagnostic term preferable to other more contentious and potentially divisive labels in clinical circulation, such as ‘low-functioning’ or classic Kanner’s autism,

- or supposedly higher-functioning Asperger's Syndrome (Shore 2001). AS is seen to facilitate constructive focus on experiential commonalities across the spectrum in a manner faithful to the aims of advocacy many support. In this paper, the term 'autism' is at times used as shorthand, or to reflect original context, but is still intended to denote the full spectrum. However, I do not wish to suggest these terms are accepted by all, and controversies around labeling should be borne in mind: 'As befits a disability emerging for the first time in the postmodern era, the autistic spectrum has fuzzy boundaries. Not even its name has been agreed upon' (Singer 1999: 63). For other recent and insightful discussions of boundaries and self-definitions of autism, see Bagatell (2007), Baker (2006), Brownlow and O'Dell (2006), Clarke and van Amerom (2007), Gevers (2000), Jones, Zahl and Huws (2001) and Waltz (2005).
- 2 The study is funded by the Social Science and Humanities Research Council of Canada.
  - 3 Founder John Lester named Brigadoon after a fictional enchanted Scottish village—'a beautiful place full of magic' and explains that: 'Second Life is a commercial system (you pay a monthly charge to use their services), and although it is often classified as an "online game" (like The Sims Online), it really ISN'T a game. It's an online world, with no content or goals except those created by the people who use it ... [In Brigadoon, AS users can] build a world around themselves within which they could talk to each other and create a whole new kind of online community' (Lester 2005: n.p.).
  - 4 This term is used by philosopher Hans-Georg Gadamer (1998) to help conceptualize his sense of the peculiar possibilities and limitations of our cultural condition, the place from within which we interpret, inhabit and respond to our 'effective history' (*Wirkungsgeschichte*).
  - 5 See Davidson and Smith (1999) for more detailed elaboration of the concept of 'form(s) of life'.
  - 6 The current study, however, has found that very few of those writing about AS do so in ways that are straightforwardly celebratory (Davidson 2008, forthcoming).
  - 7 See <www.cureautismnow.org>.
- Anderson, K., Domosh, M., Pile, S. and Thrift, N. (eds) (2003) *Handbook of Cultural Geography*. London: Sage.
- Bagatell, N. (2007) Orchestrating voices: autism, identity and the power of discourse, *Disability and Society* 22: 413–426.
- Baker, D.L. (2006) Neurodiversity, neurological disability and the public sector: notes on the Autism Spectrum, *Disability and Society* 21: 15–29.
- Baker, L.R. (1984) On the very idea of a form of life, *Inquiry* 27: 277–289.
- Biever, C. (2007) Web removes social barriers for those with autism, *New Scientist*, 27 June, <<http://technology.newscientist.com/article/mg19426106.100>> .
- Blume, H. (1997a) Autistics, freed from face-to-face encounters, are communicating in cyberspace, *The New York Times*, 30 June, <<http://query.nytimes.com/gst/fullpage.html?res=9803E7DC1F31F933A05755C0A961958260&sec=&spn=&pagewanted=all>> (accessed 21 January 2008).
- Blume, H. (1997b) 'Autism & The Internet' or 'It's The Wiring, Stupid', Media In Transition, Massachusetts Institute of Technology, <[http://web.mit.edu/m-i-t/articles/index\\_blume.html](http://web.mit.edu/m-i-t/articles/index_blume.html)> (accessed 21 January 2008).
- Bondi, L. and Davidson, J. (2003) Troubling the place of gender, in Anderson, K., Domosh, M., Pile, S. and Thrift, N. (eds) *Handbook of Cultural Geography*. London: Sage, pp. 325–343.
- Bondi, L. and Davidson, J. (2005) Situating gender, in Lise Nelson and Joni Seager (eds) *A Companion to Feminist Geography*. Oxford: Blackwell Publishing, pp. 15–31.
- Brownlow, C. and O'Dell, L. (2002) Ethical issues in qualitative research in online communities, *Disability and Society* 17: 685–694.
- Brownlow, C. and O'Dell, L. (2006) Constructing an autistic identity: AS voices online, *Mental Retardation* 44: 315–321.
- Burman, E. and Chantler, K. (2004) There's no place like home: emotional geographies of researching 'race' and refuge provision in Britain, *Gender, Place and Culture* 11: 375–397.
- Butler, R. (1999) Double the trouble or twice the fun?: Disabled bodies in the gay community, in Butler, R. and Parr, H. (eds) *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. London and New York: Routledge, pp. 203–220.
- Clarke, J. and van Amerom, G. (2007) 'Surplus suffering': differences between organizational understandings of Asperger's syndrome and those people who claim the 'disorder', *Disability and Society* 22: 761–776.

## References

American Psychiatric Association (2000) *Diagnostic and Statistical Manual of Mental Disorders*. Washington, DC: American Psychiatric Association.

- Cresswell, T. (1996) *In Place, Out of Place: Geography, Ideology and Transgression*. Minneapolis and London: University of Minnesota Press.
- Darius (2002) in Prince-Hughes, D. (ed.) *Aquamarine Blue 5: Personal Stories of College Students with Autism*. Athens, OH: Swallow Press, pp. 9–42.
- Davidson, J. (2003) *Phobic Geographies: The Phenomenology and Spatiality of Identity*. Burlington, VT and Aldershot: Ashgate Press.
- Davidson, J. (2007) 'In a world of her own...': re-presentations of alienation in the lives and writings of women with autism, *Gender, Place and Culture* 14: 659–677.
- Davidson, J. (2008) 'More labels than a jam jar...': the gendered dynamics of diagnosis for girls and women with autism, in Moss, P. and Teghtsoonian, K. (eds) *Contesting Illness*. Toronto: University of Toronto Press, pp. 239–258.
- Davidson, J. (under review) Feeling different: sensory geographies of autism, [copies available from author].
- Davidson, J. and Smith, M. (1999) 'Wittgenstein and Irigaray: gender and philosophy in a language (game) of difference', *Hypatia: A Journal of Feminist Philosophy* 14(2): 72–96.
- Dekker, M. (2006) On our own terms: emerging autistic culture, *Autistic Culture*, <<http://autisticculture.com/index.php?page=articles>> (accessed 21 January 2008).
- Gadamer, H.-G. (1998) *Truth and Method*. New York: Continuum.
- Gajilan, A.C. (2007) Living with autism in a world made for others, <<http://www.cnn.com/2007/HEALTH/02/21/autism.amanda/index.html>> (accessed 7 January 2008).
- Gerland, G. (2003) *A Real Person: Life on the Outside*. London: Souvenir Press.
- Gevers, I. (2000) Subversive tactics of neurologically diverse cultures, *The Journal of Cognitive Liberties* 2(1): 43–60.
- Grandin, T. and Barron, S. (2005) *Unwritten Rules of Social Relationships: Understanding and Managing Social Challenges for those with Asperger's/Autism*. Arlington, TX: Future Horizons.
- Jones, R.S.P. and Meldal, T.O. (2001) Social relationships and Asperger's syndrome: a qualitative analysis of first-hand accounts, *Journal of Intellectual Disabilities* 5(1): 35–41.
- Jones, R.S.P., Zahl, A. and Huws, J.C. (2001) First-hand accounts of emotional experiences in Autism: a qualitative analysis, *Disability and Society* 16: 393–401.
- Kirby, K. (1996) *Indifferent Boundaries: Spatial Concepts of Human Subjectivity*. New York and London: Guilford Press.
- Kitchin, R. and Dodge, M. (2002) The emerging geographies of cyberspace, in Johnston, R.J., Taylor, P. and Watts, M. (eds) *Geographies of Global Change: Remapping the World*. Oxford: Blackwell, pp. 340–353.
- Koborg Brøsen, S. (2006) *Do You Understand Me? My Life, My Thoughts, My Autism Spectrum Disorder*. London and Philadelphia: Jessica Kingsley Publishers, [translated from Danish, *Kan I forstå mig?*].
- Lester, J. (2005) About Brigadoon, <[http://braintalk.blogspot.com/brigadoon/2005/01/about\\_brigadoon.html](http://braintalk.blogspot.com/brigadoon/2005/01/about_brigadoon.html)> (accessed 7 January 2008).
- Miller, J.K. (2003) *Women from Another Planet: Our Lives in the Universe of Autism*. Bloomington, IN: Dancing Minds.
- Murray, D. and Lesser, M. (1999) Autism and computing, <<http://autismandcomputing.org.uk/computing.en.html>> (accessed 7 January 2008).
- Nelson, A. (2004) Declaration from the Autism community that they are a minority group, *PRWeb: Press Release Newswire*, 18 Nov., <<http://www.prweb.com/releases/2004/11/prweb179444.htm>> (accessed 21 January 2008).
- O'Neill, J.L. (1999) *Through the Eyes of Aliens: A Book About Autistic People*. London: Jessica Kingsley Publishers.
- Osborne, L. (2002) *American Normal: The Hidden World of Asperger's Syndrome*. New York: Copernicus Books.
- Parr, H. (2008) *Mental Health and Social Space*. Oxford: Blackwell.
- Parr, H. and Davidson, J. (2008) 'Virtual trust': online emotional intimacies in mental health support, in Brownlie, J., Greene, A. and Howson, A. (eds) *Researching Trust and Health*. New York and London: Routledge, pp. 33–53.
- Pile, S. and Thrift, N. (eds) (1995) *Mapping the Subject: Geographies of Cultural Transformation*. London and New York: Routledge.
- Prince-Hughes, D. (ed.) (2002) *Aquamarine Blue 5: Personal Stories of College Students with Autism*. Athens, OH: Swallow Press.
- Prince-Hughes, D. (2004) *Songs of the Gorilla Nation: My Journey Through Autism*. New York: Harmony Books.
- Purkis, J. (2006) *Finding a Different Kind of Normal*. London and Philadelphia: Jessica Kingsley Publishers.
- Rose, G. (1999) Performing space, in Massey, D., Allen, J. and Sarre, P. (eds) *Human Geography Today*. Cambridge: Polity Press, pp. 247–259.

- Sacks, O. (1995) *An Anthropologist on Mars*. London: Picador.
- Sibley, D. (1995) *Geographies of Exclusion*. London and New York: Routledge.
- Singer, J. (1999) 'Why can't you be normal for once in your life?' From a 'problem with no name' to the emergence of a new category of difference, in Corker, M. and French, S. (eds) *Disability Discourse*. Buckingham: Open University Press, pp. 59–67.
- Singer, J. (2003) Foreword: Travels in parallel space: an invitation, in Miller, J.K. (ed.) *Women from Another Planet: Our Lives in the Universe of Autism*. Bloomington, IN: Dancing Minds, pp. xi–xiii.
- Shore, S. (2001) *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*, (second edition). Shawnee Mission, KS: Autism Asperger Publishing Company.
- Shore, S. (2006) The importance of parents in the success of people with autism, in Ariel, C.N. and Naseef, R.A. (eds) *Voices from the Spectrum*. London and Philadelphia: Jessica Kingsley Publishers, pp. 199–203.
- Smith, S. (1996) Taking it to a limit one more time: autobiography and autism, in Smith, S. and Watson, J. (eds) *Getting a Life: Everyday Uses of Autobiography*. Minneapolis: University of Minnesota Press, pp. 226–248.
- Szatmari, P. (2004) *A Mind Apart: Understanding Children with Autism and Asperger Syndrome*. New York and London: The Guilford Press.
- Valentine, G. and Skelton, T. (2003a) Living on the edge: the marginalization and resistance of D/deaf youth, *Environment and Planning A* 35: 301–321.
- Valentine, G. and Skelton, T. (2003b) Coming out and outcomes: negotiating lesbian and gay identities with/in the family, *Environment and Planning D* 21: 479–499.
- Waltz, M. (2005) Reading case studies of people with autistic spectrum disorders; a cultural studies approach to disability representation, *Disability and Society* 20: 421–435.
- Williams, D. (2005) *Autism: An Inside-out Approach: An Innovative Look at the Mechanics of Autism and its Developmental Cousins*. London and Philadelphia: Jessica Kingsley Publishers.
- Wittgenstein, L. (1988) *Philosophical Investigations*. Oxford: Blackwell.

### Abstract translations

*La culture de l'autisme en ligne: la communication virtuelle et l'expression culturelle dans le spectre*

À partir de récits personnels sur les troubles du spectre autistique (SA), cet article défend l'idée qu'il existe des modes autistiques de communication particuliers. Il laisse entendre que ces traits distinctifs peuvent être judicieusement conçus selon une perspective wittgensteinienne des «jeux de langage» et, qu'en outre, ils sont associés à une culture de l'autisme qui apparaît en même temps que leur pratique, notamment celle en ligne. L'Internet s'avère, pour les personnes souffrantes de troubles du spectre autistique, un véhicule de communication approprié et accommodant, compte tenu de leurs propres préférences au niveau social et spatial de la communication à distance. Internet est porteur d'incidences sur l'exclusion/l'inclusion en matière de SA, et les écrits sur le SA suscitent beaucoup d'espoir; un auteur affirme qu'«un jour, on pourra mettre en parallèle l'effet de l'Internet sur les autistes et la diffusion du langage des signes auprès des sourds» (Singer 1999: 67). Cet article vérifie ces affirmations et l'ampleur de l'utilisation d'Internet par les personnes atteintes d'autisme pour établir des liens avec d'autres personnes dans la même situation et ce, pas simplement dans le but de bénéficier d'un appui social, mais surtout dans celui d'organiser et de revendiquer une identité culturelle autiste à part entière.

**Mots-clefs:** autisme, autobiographies, communication, cultures de l'invalidité, inclusion sociale.

*La cultura autista en línea: comunicación y expresión cultural virtuales en el espectro*

Haciendo uso de descripciones de primera mano del Espectro del Autismo, este papel sugiere que hay distintos estilos de comunicarse propios del autismo. Sugiere que estas diferencias pueden ser utilmente conceptualizadas en los términos de Wittgenstein como 'juegos de lenguaje', y que además, éstas están asociadas con una cultura autista que va surgiendo al lado de su práctica, particularmente, en línea. El Internet constituye un medio adecuado para aquellos con espectro autista, dado su preferencia por la comunicación a una distancia socioespacial. El Internet tiene posibles consecuencias en cuanto a la inclusión/exclusión social de personas con espectro autista y estas

personas expresan altas esperanzas en sus textos escritos; un autor afirma que 'puede que algún día el impacto del Internet sobre las personas autistas sea comparado con la difusión de la lengua de signos entre los sordos' (Singer 1999: 67). Este papel investiga estas afirmaciones y hasta qué punto las personas con autismo utilizan el Internet para

conectarse con Otros semejantes, no sólo en busca de apoyo social, sino para organizar y abogar por el reconocimiento de diferencia cultural relacionada con el autismo.

**Palabras claves:** autismo, autobiografías, comunicación, culturas de discapacidades, inclusión social.



Copyright of *Social & Cultural Geography* is the property of Routledge and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.

Copyright of *Social & Cultural Geography* is the property of Routledge and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.