Mapping the social geographies of autism – online and off-line narratives of neuro-shared and separate spaces

How to cite:

© 2012 Taylor Francis
Version: Accepted Manuscript
Link(s) to article on publisher’s website:
http://dx.doi.org/doi:10.1080/09687599.2012.714257

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.
Points of Interest

• We use the term ‘space’ to mean the places where people can talk with each other and meet. Spaces can either be accessible or not for people with autism.

• On-line spaces are where people meet and talk through the internet. Research has shown that on-line spaces can be a helpful way for people with autism to communicate.

• Off-line spaces are where people meet face to face. Off-line spaces are often where people with autism have difficulty communicating. We argue that off-line spaces need to be transformed so that they are accessible for people with autism.

• The research explores the meaning of off- and on-line spaces among people with autism.

• In our research we found that people with autism want to meet in ‘autism only’ spaces and at times may want to meet in spaces with both autistic and non autistic people.
Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces

Title: Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces

Hanna Bertilsdotter Rosqvist, Charlotte Brownlow, Lindsay O’Dell

The final word count for the whole of the article: 6825

Authors’ name:
Hanna Bertilsdotter Rosqvist (corresponding author)
Affiliation: Department of Sociology & Umeå Centre for Gender Studies, Umeå University
Address: Department of Sociology, Umeå University, S-901 87 Umeå, Sweden
E-mail: Hanna.Bertilsdotter@soc.umu.se

Charlotte Brownlow
Affiliation: Department of Psychology, University of Southern Queensland
Address: Department of Psychology, University of Southern Queensland, Toowoomba, 4350, Australia
E-mail: charlotte.brownlow@usq.edu.au

Lindsay O’Dell
Affiliation: Faculty of Health and Social Care, The Open University.
Address: Faculty of Health and Social Care, The Open University, Walton Hall, Milton Keynes, MK7 6AA, UK
E-mail: l.odell@open.ac.uk
Biographical Note

Hanna Bertilsdotter Rosqvist has a PhD in Sociology and is a Research Fellow in Sociology and Gender studies at Umeå University, Sweden. Her research interests include autism politics and identity constructions among adults with autism. Other areas of interest are homonormativity and representations of bisexuality among men with bisexual experiences and in the Swedish straight and gay press.

Charlotte Brownlow has a PhD in Psychology and is a Lecturer in Psychology at the University of Southern Queensland, Australia. Her research interests include a focus on exploring understandings of ‘difference’, particularly with relation to the fields of autism and developmental psychology more broadly.

Lindsey O’Dell has a PhD in Psychology and is Director of Post Graduate Studies in the Faculty of Health and Social Care at the Open University, UK. Her research interests focus on children and young people who are in some way ‘different’ including neurological difference, working children, young carers and language brokers.
Abstract

This paper draws together empirical work that has been produced by the authors in two different autistic spaces: The Swedish paper *Empowerment* produced by and aimed at adults with autism, and English-speaking autistic communities on-line. While the two points of data collection are quite different, there are important points of commonality which enable us to explore central issues concerning autistic and neurotypical space and the meanings assigned to these in different contexts. The paper aims to introduce the notion of social geographies of autism, based on talks among adults with autism and a social movement to promote autistic identities, giving examples from our previous work that has spanned both on- and off-line spaces. Key issues discussed in the paper include a focus on autistic political platforms and the carving out of both social and political spaces for people with autism. In doing so, neuro-separate and neuro-shared spaces must be negotiated.

Keywords: disability geography, people with autism, neuro-separate space, neuro-shared space, on-line communities, self advocacy press


**Introduction**

On the first page on the first issue of the Swedish magazine *Empowerment* there is a picture of two young women. They are standing close to each other, smiling and looking in the camera. One of them has her hand on the other’s shoulder. They are standing in front of the buildings where the first *Projekt Empowerment* summer camp and conference took place, in Sweden 2002. Projekt Empowerment was part of the Swedish autistic self-advocacy movement. This image of autistic friendship, framed within an enabling autistic physical environment, was an important goal for the movement and a theme for much discussion in the accompanying magazine *Empowerment*. The stories in the magazine, presenting images such as this, explore ideas about an enabling autistic physical environment and enabling spaces for autistic people. In these spaces people with autism make friends, have intimate partners and feel a sense of belonging to a community.

Online communities can be thought of as another enabling space for people with autism. Here people with autism can traverse geographical boundaries and interact with ‘like-minded’ others. It is in these online communities that people with autism can become the majority rather than the ‘othered’ minority, and therefore interactions between individuals can take place in an autism-friendly environment. Equally, these environments provide an opportunity to interact with neurologically typical individuals, without the complexities of non-verbal cues to negotiate in exchanges.
This paper contributes to ongoing debates within disability geographies about enabling spaces, the possibility of inclusionary spaces and the issues involved in maintaining separate spaces. We draw on notions of neuro-separate spaces and neuro-shared spaces to explore how socio-spatial inclusion and exclusion is experienced by people with autism (c.f. Holt, 2003). This will be explored through an examination of the meanings of off-line and on-line spaces that are inhabited by people with autism.

**Introducing the notion of separate and shared spaces**

In this paper, space is considered as actively produced through repetitive performances and through governing what are seen to be appropriate ways to behave (c.f. ex Valentine, 1996, 1997). The importance of a sociospatial analysis has been addressed by researchers (such as Valentine 1996; 997) within the field of disability geography who argue for the importance of a spatial analysis which focuses on the relationship between space and disability on both a structural, individual and political level; how social and spatial processes are used to disable rather than enable people with impairments (Gleeson, 1999).

From sexual geographies we borrow the concepts of (sexually) *shared and separate spaces* (c.f. Chauncey, 1994; Bachhofer, 2006). Shared spaces are often linked to notions of ambiguity and mix (c.f. Bachhofer, 2006), and can be experienced as hostile and threatening where one group dominates the space. “Separate spaces”, such as either ‘heterosexual space’ or ‘gay and lesbian space’, are recurrently positioned, firstly, as ‘disclosed spaces’ (c.f. Bertilsdotter Rosqvist & Arnberg, forthcoming) and secondly, as ‘safe spaces’ (Binnie, 1995:187) for the group members (see Valentine, 2002). It is clear that separate spaces offer
Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces

places of safety and inclusion, however they may also reproduce exclusion and marginalization (cf Davidson and Parr, 2010). Engagement with the majority culture is often necessary to enable broad cultural change and, potentially, acceptance. A third space identified in the sexual geographies literature can be defined as an ‘inclusionary space’ or ‘shared public spaces’ (Parr, 1999; McGrath et al, 2008), which attempt to accommodate to the needs of all participants in the space. The tensions between separate spaces and attempts to manage inclusionary shared spaces are explored in this paper with reference to two particular examples of autistic communities.

We also draw on developments in the neurodiversity movement to address our work, and start from a position of valuing difference in neurological functioning rather than positioning people with autism as deficient (see Brownlow 2010). Hence, the concepts of Neurologically Typical (NT) and ‘people with autism’ are used when referring to people without and with autistic traits respectively. While we have chosen to use the phrase ‘people with autism’ in this article, it is not without ambivalence. The use of language is being debated in Western autistic communities (including the Swedish autistic community) with some preferring the use of “autistic person” (or “aspie” or “asperger”) rather than “person with autism” (see Duffy & Dorner, 2011). Following Davidson (2008), we are not suggesting that there is necessarily one ‘autistic identity’, in the same way that it would be inappropriate to suggest that there is one ‘NT identity’. The use of language reflects that. We are therefore mindful that identity is multiple and that identities are related to the spaces that we inhabit at any particular time. Inspired by the concepts of shared and separate spaces we argue it is possible for spaces to be experienced as either neuro-separate or neuro-shared spaces. Neuro-separate spaces can either
be dominated by NTs or people with autism. Neuro-shared spaces are mixed spaces, or spaces made socially and physically accessible for both NTs and people with autism.

**Neuro-separate and neuroshared spaces**

A neuro-separate space dominated by NTs, which we refer to as *NT space*, can be defined as part of ‘the Land of the Normate’ (Smith, 2005), ‘normal’ spaces (Hall, 2005) or ‘mainstream’ cultural spaces (Milner & Kelly, 2009). Following researchers within the field of disability geographies, NT-spaces can be seen as socially produced to exclude people with autism in two main ways. They can be exclusionary practices which actively keep people with autism ‘in their place’ (Kitchin, 1998: 345) such as special spaces for people with disabilities (group homes, sheltered employments). They can also be “social texts that convey to disabled people that they are `out of place’” (Kitchin, 1998: 345). Inaccessible social interaction for people with autism exemplifies this; such as joking among NTs, coffee breaks or work meetings at the work space dominated by NTs where people with autism may not be enabled to take an active part due to lack of social accessibility (c.f. Bertilsdotter Rosqvist, 2012).

Disability geographers have explored how people with disabilities have been excluded from public spaces and “sequestered in private or institutional spaces” (Freund, 2001:697). It can be argued that they become socio-spatially constructed as ‘other’ in the mainstream able bodied world (c.f. Kitchin, 1998; Holt, 2003). For example, researchers exploring NT (public) spaces have focused upon parents’ (mostly mothers’) experiences of the reactions of others in public spaces towards their children with autism or learning disabilities (see Gray, 1993, 2002, 2006; Ryan, 2005, 2008, 2006). There has been some work that has explored the
experience of NT space for adults with autism. NT space is often experienced as hostile by people with autism. It is in the mainstream NT environment that disabled people are required to conform to this dominant construction of ‘normality’. For people with autism, this may mean that they are constrained to act in a way that maintains and conforms to NT ideals (c.f. Bagatell, 2007). NT spaces may therefore be inaccessible in a more direct way for people with autism (c.f. Ryan & Räisänena, 2008: 141).

There has been research exploring the concept of ‘safe spaces’ for people with learning disabilities and people with autism (see for example, Kruse, 2002; Hall, 2005; Ryan and Räisänena, 2008). In the safe spaces there is the possibility “to move from coping with everyday exclusionary experiences to asserting their own needs and identities” (Hall, 2005:111). Referring specifically about engaging in NT spaces, people with autism who took part in Ryan and Räisänenas’ study (2008) talked about spaces they felt safe in, where safety was linked to the type of interactions and their predictability. Examples of such safe spaces also discussed by participants in Ryan & Räisänen’s study included online spaces and off-line face-to-face support groups (see also the work of Bagatell, 2007, 2010). Indeed, previous research has argued that the internet may provide an important opportunity for some people with autism to escape from the constraints of face to face communication and the non verbal complexities that accompany such exchanges (see for example; Blume, 1997; Brownlow and O’Dell, 2006). Online communication may offer an alternative way in which people with autism can exchange information and develop relationships in an enabling forum. The role of the internet may therefore be that of a leveling device (cf Davidson 2008), which enables people with autism to interact with each other and affords the possibility to interact with NTs in a less stressful and more appropriate way.
In addition to separate spaces there have been efforts to create safe shared spaces for people with autism and NTs. In our work we refer to these as a neuro-shared space. This space is not, however, without tensions and ambiguities. Inclusionary spaces can be mainstream social spaces such as cafes and pubs where people with learning disabilities may feel welcome (c.f. Hall, 2005). However, these spaces need to constantly be struggled for. For example Milner and Kelly (2009) discuss how people with intellectual disabilities experience different kinds of ‘community’ (public) settings as spaces occupied by both disabled and non-disabled people, where it is important to go out, partly in order to affirm the right to be in the community, but where they may encounter both acceptance and challenge. Similarly in an online setting, Singer (1999) and Brownlow (2010) argue that the internet has the potential to bind together groups of people with autism, which may enable them to claim a position and role within a given community. Therefore it can be argued that online spaces (and some offline spaces) offer the potential for a shared social space for NTs and people with autism to inhabit together.

**Introducing materials and methodologies**

This paper draws together empirical work that has been produced by the authors in two different contexts: one in a magazine, *Empowerment*, produced by and aimed at adults with autism. The second consists of English-speaking discussion forums that take place in online communities focused on autism. The online communities spanned across the English speaking world (although the research was based in the UK).
The *Empowerment* magazine

All issues of the magazine have been included in this analysis with the permission of the editor, Hanna Danmo. The analysis of the Swedish data is based on a textual reading of articles in the magazine *Empowerment* where different spaces, among them the Swedish summer camp mentioned in the introduction, were discussed. *Empowerment* was published with two issues in 2002, thereafter with four issues every year until 2009 as a part of Projekt *Empowerment* by The National Society of Autism and Asperger in Sweden (RFA). The paper *Empowerment* was sent to all members with autism in RFA. Projekt Empowerment and the paper *Empowerment* is part of an emerging self-advocacy movement in Sweden among adults with autism. The aim of the Project Empowerment was to develop a model enabling adults with autism to meet and discuss issues of importance for them, to enable them to gain more influence and participation within the organization and in its external work. In short the aim of the project and the paper was to make RFA a neuro-shared space. The initiative to the project was taken by adults with autism who were experiencing RFA as dominated by parents of children with autism, often directly excluding adults with autism from the work and activities within the organization. The editing committee and writers of the paper consisted of adults with autism and one supporting NT-assistant. 47 adults with autism contributed at least one signed article in the paper during the publication period. The paper consisted of interviews with adults with autism on different issues, reportage on events and issues directed to or relevant for adults with autism, letters to the editor and pictures of adults with autism.

Online autistic communities

This project aimed to explore ways in which online communities interested in autism represented autistic issues and identity. The project was approved by a university human
ethics board before commencement of research. Online groups which discussed issues surrounding autism were then identified through online searches. This led to the identification of a large number of groups (addressing a wider range of issues) that pre-existed the research, with a potential sample pool of 430 groups. The groups were reduced in number through several steps. Firstly, all those groups that had a very specific focus, such as the links between autism and MMR, were removed. A second criterion for group selection was evidence of recent posting activity within the group and the number of members of the discussion list. Groups were therefore initially selected and approached for inclusion in the project if they firstly comprised of members predominantly consisting of people with autism, and displayed evidence of recent exchanges on the discussion list, and comprised of more than five members in order to maximize the opportunity for exchanges to be made between participants in the course of the research period. Based on these criteria, 16 groups were initially contacted to take part in the research. Secondly, list owners were approached individually by the researchers for permission to join the groups. This provided details concerning what the research entailed and a proposed time limit of four months for membership. Self-selection amongst the groups therefore played an important role in the make-up of the final groups contributing to the research data.

The final research project comprised of contributions from four online discussion groups. The four groups consisted of primarily people with autism, people who self-diagnosed as having autism, parents of people with autism, and professionals working with people with autism. Therefore, the groups represent both shared and separate spaces for people with autism and for NTs. The data presented in this paper draws on contributions by people with autism and those self-identified as autistic in forums that were designed to be autistic spaces, run and
moderated by people with autism. During the four month’s in which we were given access to the forums, 998 postings were made to the groups.

**Approach to data analysis**

The data we discuss in this paper is drawn from examples of newly formed autistic spaces in either the online or offline environment. The data was initially generated for different purposes and has been brought together here to enable a broader and nuanced picture of autistic spaces in both online and offline communities. There are many differences as well as points of intersection between the two datasets. The data produced in the online study was of individual contributors mainly talking about their own lives. In the Empowerment project data was produced from newspaper reports of various social events such as a Summer camp, including published reports by individual people with autism discussing their lives, and a commentary (by one of the authors of this paper) on the progress and development of the social movement itself. Points of intersection between the two datasets include discussions of NT and autistic worlds, with a focus on the strengths and positive qualities of autistic spaces and of autistic traits. The aim of our reading of these texts is to offer a broad commentary on key themes in relation to separate and inclusive spaces.

**Autistic political platforms: Carving out social and political spaces**

In this section we examine autistic and neurotypical space through three key issues: the development and use of separate autistic spaces; tensions between social and political space; and the possibility of shared or inclusionary space.
Separate spaces

In our two examples both provided opportunities for people with autism to construct separate space; as a physical place in which to meet face to face and as a virtual space in which to interact. For the online communities, a strategic decision was made by two of the groups to create separate spaces, and in order to be a member of the list, individuals identified themselves as autistic. By creating neuro-separate spaces, opportunity was created to focus on ‘autistic issues’ with a shifting majority/minority focus from other shared face-to-face spaces.

Between 2002 and 2004, Project Empowerment arranged week-long summer camp sessions annually at Almåsa, a Swedish training centre by the sea. The newspaper Empowerment published reports by participants who consistently describe the camp experience as a success. The stories about the week-long camps emphasise the changes made in order for them to be accessible, and the participants’ expectations prior to and experiences of the camps. The narratives also emphasise that “almost everyone who was involved with organising the camp and the conference personally had a disability.”. Another contributor to the Empowerment paper writes:

People established both new friendships and love relationships at the camp. It is empowering to meet others in a similar situation and exchange ideas and experiences. The adapted and structured environment allowed people to have enough energy and initiative left over to be social. At the camp people were accepted despite (or thanks to) the fact that they were different. … The week at camp was an opportunity for many to make new friends and gain self-
confidence. It’s nice to be accepted for who you are. No one felt disabled at the Almåsa camp. The factors that otherwise turn a physical disability into a handicap, poor treatment and the wrong environment did not exist.

The camps are described, in line with a social model way of thinking, as adapting to the special needs of persons with autism, and, as a result, social interaction among them was successful. This enabled people with autism to finally meet like-minded people and to be able to reflect on how autistic separate spaces such as the camps could contribute to empowerment. For instance, in several reports participants explain how the camps provided them with renewed energy to deal with their problems at home, how they dared to do things at the camps that they never dared do before, and the fact that they interacted socially with others. The camps are also described as an experience that raised the participants’ quality of life—one that “keeps the participants going all year long.”

Online discussion groups have also been identified as potentially useful ways for adults with autism to communicate with each other. Unlike the camp where the everyday physical and social environment is arranged in order to be accessible, online space moves away from the focus on face-to-face negotiations, and instead creates a virtual geographically dispersed space in which people with autism can interact. The discussions often focus on the benefits of an autistic space, often by noting the problems with NT behaviours and society. For example, Edward exemplifies these discussions in his views of NT behaviour as ‘primitive’ and the undesirable nature of NT society:
Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces

“… one would find it good curiosity to study the NT society, but not to live in it.

The NT lifestyle appears either totally incoherent or rather primitive

Edward, online discussion list

In both the examples we have drawn on there is an articulated need for and valuing of an autistic separate space.

**Negotiating alternative social spaces**

We argue that autistic spaces allow those involved to have distance from the mainstream NT world, which is seen as chaotic and alien. Meeting like-minded people was a key benefit for members of the Empowerment project and for members of the online discussion groups. This separate space served to provide support and friendship and also the opportunity to create collective resistance to the dominating NT world. However at times there was a tension between different uses of the spaces as an arena to develop an empowered political voice and as a place to interact with friends.

The *Empowerment* project illustrates the tension in the groups managing a social and a political aspect of their work. Between 2005 and 2009, “education camps” and conferences were arranged instead of summer camps. Although the stories surrounding these courses and conferences published in the magazine *Empowerment* continue to express the significance of meeting like-minded people and the value of socialising among people with autism, the reports in *Empowerment* from the camps and courses also increasingly focused on the educational aspects of these spaces. The shift from summer camp to educational experience can be seen as both an expression of financial limitations (it was easier to get funding for
Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces

camps and courses with an educational focus) but these tensions were also reflected in
Empowerment between the political and the social aspects of their work. Along with the social aspect, the essential goal of the summer camps as well as other activities organized was over time increasingly emphasised as a way to involve more people, ultimately changing the work in RFA (networking and starting local discussion groups, so called “Träffgrupper”). An expression of this tension is an article published in one of the final Empowerment magazine’s in which the social is seen as less important than the political. The discussion takes place in a review article that looks back at the life of the magazine, it is concluded that “the number of local groups has decreased and those that remain rarely discuss policy; instead, people talk about relationships and other things that are closer to daily life.”

A somewhat alternative meaning of autistic space is to be found in data from the online discussion forum. A common assumption articulated by the forum members was that the only safe autistic spaces were online spaces. An important function of the forum was friendship and discussion with like minded people, but this frequently focused on reflections about the NT dominated world and the need to remain separate from it. The online discussion groups allowed participants opportunities to question the negative portrayal of autism by NTs and to articulate an ‘autistic identity’ that is different but equal to NTs, and in some cases portrayed as better than, a neurologically typical state. In the online discussion groups forum members considered that offline, face to face spaces were seen to be neurotypical spaces which were largely hostile or unaccommodating to people with autism.

I have attended a conference for AS adults. It was held at [place name] UK last year. It was about as much use as a chocolate fire guard. We were told that to fit in we had to become more like normal people. Quite how we were supposed to
do this remained unsaid….There were some interesting talks by people with AS, but the experts would not answer questions, no time apparently…The AS people there were treated like children too, the attitude was “we know what’s best for you.”

Robert, online discussion list.

There is some discussion amongst our contributing participants about the mutually exclusive nature of the two constructed spaces. One of the ways that forum members considered this exchange was through understanding the two spaces and those who interacted within them as being either ‘social’ or ‘non-social’. The constructed differences between social and non-social people inverts the ‘problem’ of sociability, rather than making physical and social environments accessible for people with autism it is the social neurotypicals (NTs) who need help in interpreting the world. For example:

My personal vision statement is: I want to create a world where people with autism can live on their own terms. As social interpreter could interpret that for social people. If the world was filled with only people with autism how could a social person cope?

Ronald, online discussion list

At times the social people are not open to an autistic interaction

Ronald, online discussion list

The importance of such an autistic space is therefore in providing a space within which to develop autistic identities and advocacy narratives. The purpose is not to develop social skills
for face to face (NT dominated) environments but to offer a challenge to the need to ‘fit in’ to the NT world.

Whilst there was broad consensus in the online discussion forum that autistic separate space was important, there were some strongly articulated discussions between group members about the need to be inclusive and to engage with the NT world.

I can’t blame the people that are affected with neurotypicality, but that does not mean that i am obligated to change my views to see value in traits I dislike. I am not trying to get them to be anything they are not...my diatribes are directed toward aspies that hate their affliction and would give anything to be normal.

Archie, online discussion list

The online autistic spaces therefore serve several purposes for individuals contributing and operating within them. One element of the space is as a means through which to prioritize autistic thinking and ‘autistic issues’, and therefore enable the development of an empowering autistic discourse through which questions and challenges can be posed to the wider neurotypical society. A second element of the space is as an arena in which autistic individuals can interact with confidence in a ‘safe’ space. However, this separate space may not be considered ‘safe’ to some group members, particularly those who sought to engage with an NT world.
This raises several questions about the impact of the wider neurotypical community and the ways in which NT- and autistic spaces are constructed as mutually exclusive, offering limited potential to move between autistic and neurotypical spaces.

**Travels between NT and autistic spaces?**

Some contributors to both projects were clear that an exclusively autistic space was the best place for them. In *Empowerment* the camps, courses and rap groups were temporary autistic off-line spaces, which were sometimes presented in published articles in the Empowerment magazine as an ideal option for a permanent space to inhabit. For example, one participant describes the 2002 summer camp as more like a home, explaining that he “wanted to give notice at the group home and move to Almåsa training centre.” A recurrent theme in reports in the magazine, and a common reference point in *Empowerment* as a movement, is that the summer camps are a symbol for both the possibility of and an actual off-line autistic space in itself.

As has been discussed earlier, online contributors also talked about their preference for an autistic world and skepticism of the NT world. However, there are also some discussions amongst contributing forum participants about separate NT and autistic worlds and fluidity of membership in the two arenas. People with autism who participated in the online discussions questioned the need for autistic individuals to ‘fit in’ to a neurotypical world. While implicit in this argument is the acknowledgement that people with autism need to interact with neurotypical spaces, it remains clear that the needs of autistic individuals need to be upheld and the social world should accommodate to them. In the *Empowerment* magazine the focus
in several articles is on how to make physical and social adjustments in order to make neurotypical off-line spaces accessible (such as RFA, workspaces and living arrangements in group homes) and to educate people with autism how to navigate in the NT world (through courses and educational camps). However in the online discussion forums there remains a firm sense that a full entry into neurotypical off-line space is not necessarily desirable for all. For example:

“If you are an adult with Autism Diagnosis you have to have experience with medicine. Applied Behavioural Analysis is a way to bring you completely into the social world and I do not want to go. I want to stay in my world and just visit the social world.”

Ronald, online discussion list

**Discussion and conclusion**

In the two types of data presented here in this paper, there are both differences and commonalities. Both datasets emphasize the difference between NT-spaces and autistic spaces. In the data from the on-line forums there was little discussion of a neuro-shared space, or the need for an inclusionary space, rather a strong distinction is made between NT- and autistic spaces. The data from the Empowerment magazine stress both the importance of the social and physical adaption of off-line spaces in order to make them accessible for people with autism, i.e. remake a NT-space (such as RFA) into a neuro-shared space, and the importance of separate autistic spaces (for love and friendships and a sense of an autistic community). The Empowerment magazine must be understood as a negotiation between different aims, firstly, in relationship to its place within RFA and as part of the aim of Projekt
Empowerment to make RFA a more autistic inclusive space, a neuro-shared space. Secondly, the paper became an autistic space in itself with a community feeling about it comparable to papers of other social movements, such as the gay movement (Bertilsdotter Rosqvist, 2009). This could be seen as an indirect second aim of *Empowerment*; an aim not planned for but that occurred through activities such as the summer camps and the paper in itself. The aim of the movement to be an alternative autistic space was mourned and when Empowerment ended it merged with Ögonblick in 2010.

The data from the on-line forums stress that online spaces do not need any adaption in order to be accessible for many people with autism. The forums were not part of an organized disability movement and therefore did not need to negotiate between different aims, cooperate or integrate with NTs. This lends the on-line space to a more separatist construction of autistic identities, which promoted a separate autistic lifestyle and identity outside of a society dominated by NTs. Such a position strongly challenges actions aimed at making people with autism ‘fit’ in the NT world.

Work by Davidson (2008) suggests that there may be important implications for the offline world of online autistic advocacy, and such online social movements need to be treated seriously by practitioners and policy makers. Indeed research by Valentine and Skelton (2008) examining the relationship between online and offline communities of Deaf people pose some interesting considerations. Valentine and Skelton argue that technologies enable the development of a more global community and facilitate the linking together of communities which may otherwise be isolated geographically. This joining of communities and the
Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces

possibilities that it provides for the wider dissemination of information may be crucial for autistic communities, who can now form collective movements without the challenges presented by more face to face forms of communication. This could be in terms of the development of online advocacy groups, discussing and prioritizing ‘autistic issues’, but equally in terms of disseminating information concerning ‘safe’ AS groups and activities, such as the camps drawn upon in this paper. For people with autism, the constraints of space may not be primarily in a physical sense but a product of restricting social activities (cf Kitchin 1998). It is possible to produce a social space that has the flexibility to facilitate an autistic friendly environment in an otherwise NT dominated world in a way that can embrace and celebrate positions of neurodiversity. However, examples from our work point to groups of people with autism who may be reluctant to travel to a more neurodiverse space with NT constituents.

Previous literature examining the role that technologies may play in providing a more level playing field in terms of exchanges online have also raised some key points in terms of the potential ‘ghettoising’ effect of online groups in keeping talk separate from the mainstream understandings. For example, Seymour and Lupton (2004) consider that while the online space may provide an important forum for people with disabilities to ‘talk among their selves’, this has the danger of potentially isolating such talk and these understandings becoming part of the ‘special world’ of disability. Seymour and Lupton query what significance and impact such discussions will have on the public domain, if they continue to be enacted in a forum which is largely removed from the wider society. Therefore while online spaces may fulfill an important role in enabling the development of more empowering
identities for autistic people, and the generation of a more active self-advocacy movement by autistic people, do these developments translate to the NT-dominated offline world?

In order to create and maintain neuro-shared spaces in both online and offline spaces, a take up of the principles of neurodiversity must be witnessed, which present autism as a difference rather than a deficit. Further, it is through the examination of questions of space, drawing on a range of spaces such as in this paper, that such issues can be more thoroughly considered and debated.

References


Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces


Mapping the social geographies of autism – on- and off-line narratives of neuro-shared and separate spaces


