HØGSKOLEN I BERGEN

Autreat and Autscape: informing and challenging the neurotypical will and ability to include

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Abstract

Master's Thesis in Community work:
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Despite vast research efforts concerning autism, there is insufficient knowledge about what barriers to participation autistic people themselves experience, and how such barriers may be built down. Such knowledge may be crucial to creating an accessible society with equal opportunity to access for example public spaces, work and school environments.

This study provides insight into physical and social conditions at two conference events where autistic people are in majority, in charge, and conditions are adapted to their needs and preferences. Using a qualitative approach and relevant sociological theory, I have analyzed the content of openly available online text material written by conference organizers and participants. The study design privileged the voices of autistic people.

Findings highlight three vital elements in creating the accessible conditions at these conferences: Firstly, accommodating sensory issues through general adaptations plus enabling individual self-regulation. Secondly, facilitating an autistic style sociality by establishing autistic social rules. Thirdly, protecting the boundaries of the space itself. For community workers, the findings about how these conditions are created may be a knowledge resource both in relation to helping develop other autistic spaces and to avoid colonialist practices.

Findings cannot be generalized to the whole autistic population, but point beyond the conference events in question. Based on how conference conditions are created, the study casts doubt on the will and ability of a non-autistic majority to provide full and effective participation for an autistic minority. Still, treating these conferences as examples of "best practices" suggests some ways of enhancing accessibility. More research is needed about how many autistic people experience the kind of barriers to participation counteracted by adaptations at these conferences, and how such barriers may be built down in mainstream society.

Key words: autistic spaces, neurodiverse spaces, sensory issues, autistic people, participation

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Appendix A: Letter from NSD concerning my research project
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1 Introduction

1.1 Point of departure

1.1.1 Being autistic

I am not autistic. In the words of the people whose writings hold centre place in this thesis, I am neurotypical, or "NT". I am also a Norwegian health and social professional and college lecturer. This thesis reports from a study of physical and social conditions at two conference events defined as *autistic spaces* - spaces where autistic people are in majority, in charge, and conditions are adapted to autistic needs and preferences.

Autism is a complex phenomenon, and since the first comprehensive description of autism by Kanner (1943), speculation has abounded. Controversies still rage, for example over what causes it. I do not touch on this, as causation is not relevant to my study. Another controversy rages over how autism is to be understood. Is it a deficiency that should be counteracted? Or a human variation, a difference that should be respected as other differences, for example gender, race or sexual orientation? Some stakeholders see autism as a tragedy that has befallen them or their children, while others embrace their autism with pride. I do not attempt to resolve this. I simply note that autism is profoundly multidimensional: Among the autistic, one finds the accomplished scientists, the doctors, the outspoken self-advocates. But also the nonverbal, the self-injurious, the people in need of continuous help and support in daily life because they in addition to being autistic have intellectual impairments. Accepting the diversity of the autistic community, I also accept that there are many nuances and possible answers to the question of how autism is to be understood. However, the autistic spaces I focus on are largely created and frequented by autistic people who embrace their autism as a difference. A basic premise of my study has been that the people whose voices I harness do not speak for all people in some way affected by autism. But they certainly speak for themselves. One aspect that seems generally accepted by stakeholders is that autism is *pervasive;* a feature of people's functioning in all situations (WHO 2010). In the words of autistic American Jim Sinclair (1993), it "colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence".

1.1.2 Two autistic spaces

Autistic spaces can be "online", as when a discussion forum is declared to be autistic space. An example is the internet portal Aspies for Freedom, which currently has 70194 members. Since it was established in 2004 members have generated a total of 512430 posts in 22590 different discussion threads (AFF 2013). Autistic spaces can also be "offline". In my study I have focused only on offline autistic spaces, of which I have chosen to explore two in particular:

Autreat is described by Sinclair (2010) as "a retreat-style conference run by and for autistic people, designed to accommodate autistic people as much as possible". Autreat has been arranged annually since 1996 (except in 2001) and in 2012 was held 2-6 July in Johnstown, Pennsylvania, USA (ANI 2013).

Autscape is run by unpaid volunteers, most of whom are autistic. It has been arranged annually since 2005, and in 2012 was held 23-26 July in Ditchingham, East Anglia, UK (Autscape 2013). Autscape presents itself as "an escape to autistic-friendly space", a "retreat from the demands of mainstream society", an "educational conference, a social gathering, and an opportunity for advocacy and networking" (Autscape 2013). At Autscape

> presentations are targeted specifically for autistic people, autistic behaviour and communication styles will be the norm, and autistic needs are taken into account in every aspect of planning (Autscape 2013).

Both Autreat and Autscape are defined by their organizers as autistic spaces (ANI 2013, Autscape 2013). In the thesis I use the categories "autistic" and "neurotypical" people. This categorical dichotomy is an almost universal feature of the texts from which I have compiled my data material, written by people who identify themselves as autistic and experience themselves as fundamentally different from people who are not autistic. I maintain this dichotomy throughout the first seven chapters before relating to these categories in a more nuanced way in the last chapter. This is not only a way of showing respect for the standpoints and values of the authors, but also reflects my attempt to access their perspective, something I discuss in more depth in chapter 3. As far as I know, no community workers have been involved in developing these autistic spaces, but I have conducted my study from a community work perspective.

1.1.3 Community work

The term "community work" overlaps with and is largely used interchangeably with terms like “community development” (Ledwith 2011) and “community organization and building” (Minkler & Wallerstein 2005), though some approaches have more of a "grassroots mobilization/bottom-up" flavor, others more of an administrative "community planning/top-down" flavor. Community work can be described as

> the process by which community groups are helped to identify common problems or goals, mobilize resources, and develop and implement strategies for reaching the goals they have collectively set (Minkler & Wallerstein 2005, p. 26).

Twelvetrees writes that essentially, community work is about helping people, as members of various geographical or non-geographical communities, get a "better deal". Equally important is that they bring this about themselves, largely through collective action, gaining skills and confidence in the process (Twelvetrees 2008, p. 2). Thus, social justice is a central value in community work. Why else would community workers help people get a "better deal", if not as part of an effort to create a more just society? On a group level as well as an individual level, theories of social justice

> help to identify and classify different aspects of a person’s life with which we should be concerned: the extent to which their basic needs are met, the resources available to them relative to others, their negative and positive freedoms, their status, and the degree of recognition they receive, to name just a few (Burchardt & Craig 2008, pp. 11-12).

On a more macro level, community work can be seen as taking place within a human rights framework. Not only does community work and human rights share common ground and can contribute to each other, to a great extent they cannot do without each other (Ife 2010, p. 1).

1.1.4 My research interests

My first meeting with the idea of embracing autism as a difference was in 2007. Doing research for an essay, I stumbled upon the web site of autistic American Joel Smith (2006a), who stated that he was happy to be autistic, describing it as a way of life that was "a bit different but just as valuable”. He wrote:

> I am an autistic adult who wants to see my people succeed and prosper in this world. Unfortunately, there are a lot of difficulties we experience, only some of which have anything to do with our actual autism. Many of them deal with the way society sees and treats us (Smith 2006).

To me Smith's perspectives were eye-opening, and I was happy to incorporate them in my essay, where I was questioning the motives of a staff member in insisting an autistic resident of a group home should put on a type of footwear he was objecting violently to (Owren 2008). Early in my study I noted that in some ways the conditions of Autreat and Autscape resembled conditions that I as a health and social professional have been involved in creating for autistic clients in need of services and support in daily life. The spaces we created were never autistic spaces, though. To the best of our ability and understanding, we created physical and social conditions adapted to the clients' needs and preferences. But in these spaces I and other neurotypical staff members were in majority and in charge, and thus by definition they were not autistic spaces.

Part of my interest in Autreat and Autscape was related to how they presented themselves as a *retreat* and an *escape,* prompting the question of what the participants were retreating and escaping *from*, as well as what they were retreating and escaping *to*. Resonating with Smith's claim that many of the difficulties autistic people experience have nothing to do with their actual autism, this made me curious. Autreat presenting itself as "designed to accommodate autistic people as much as possible" seemed to promise conditions noticeably different from mainstream society. Autscape presenting itself as "an escape to autistic-friendly space" seemed to imply that conditions outside this space was *not* autistic-friendly.

In an accessibility perspective, anything that may contribute to building down barriers to participation is of interest, because the ultimate goal is a society for all. My main focus in this study is barriers to inclusion and participation and how they may be countered though universal and special adaptations. This does not mean that I consider enhancing individual capacity and skills as less relevant or irrelevant. Individual coping skills are no less important for autistic citizens than for other citizens, but this is not the focus of my study.

1.1.5 Research questions

The research questions I attempt to answer in this thesis are:

1) *What are the specific conditions that constitute Autreat and Autscape as autistic spaces, and how are these conditions created?*
2) *In what ways does this knowledge inform and challenge current efforts to promote inclusion and accessibility for all?*

My findings are provided in chapters 4 to 7 and summarized in chapter 9. In this chapter I go on to explain my use of the term "autistic people", present a description of autism, take a closer look at the concepts *community* and *spaces*, review existing research based knowledge about autistic spaces, draw a line from the concept *disability* to autistic spaces and goals on a societal level, and give an overview of the thesis.

1.2 Autism understood as a difference

1.2.1 Why I don’t use "people-first language"

Throughout the thesis I use the term "autistic people", mainly because this is the preferred terminology among the people I write about. In mainstream society, a more common form of referring to them would be as "people with autism", or, in medical terms, "people with autism spectrum disorders". Both forms are generally considered offensive by the communities I write about:

Saying “people with autism” is an example of “people first-language”, a form many consider to be a more respectful way of referring to people with impairments, because it places the impairment as a secondary attribute, not as a characteristic of a person's identity (Wikipedia 2013). Arguing against this, Sinclair states that it is neither possible nor desirable to separate the autism from the person:

> Autism isn't something a person *has*, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. [ ] It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with (Sinclair 1993, emphasis in original).

Furthermore, Sinclair (1999) claims, it is only when someone has decided that the characteristic being referred to is negative they would want to separate it from the person. But to Sinclair, autism is not negative:

> I know that autism is not a terrible thing, and that it does not make me any less a person. If other people have trouble remembering that autism doesn't make me any less a person, then that's their problem, not mine. Let them find a way to remind themselves that I'm a person, without trying to define an essential feature of my personhood as something bad. I am autistic because I accept and value myself the way I am (Sinclair 1999).

The sentiments expressed by Sinclair are common in the communities of Autreat and Autscape, both among the autistic organizers and the participants, of which most either are autistic themselves, have an autistic child, or both.

When it comes to saying “people with autism spectrum disorders”, a key point is that in the communities of Autreat and Autscape, autism is not considered a disorder. In general, autistic self-advocates perceive autism as a developmental difference, a neurological variation (Sinclair 1993, Robertson 2010, ASAN 2013a, ANI 2013, AFF 2013). Ari Ne’eman, a highly profiled autistic American self-advocate, explains this position:

> The neurodiversity movement takes the concepts of self-determination and equal legitimacy that we as a society have applied to differences of race, religion, gender, sexual orientation, and other disabilities, and applies them to the fact that people are born with different types of minds as well (interviewed by Silberman 2010).

1.2.2 A description of autism

On their web site the Autistic Self Advocacy Network (ASAN) provides a description of autism that highlights seven differences between autistic and non-autistic people. It states that while autistic people are as unique as any other human beings, they have some characteristics in common:

> *1. Different sensory experiences.* For example, heightened sensitivity to light, difficulty interpreting internal physical sensations, hearing loud sounds as soft and soft sounds as loud, or synesthesia.
>
> *2. Non-standard ways of learning and approaching problem solving.* For example, learning ‘difficult’ tasks (e.g. calculus) before ‘simple’ tasks (e.g. addition), difficulty with ‘executive functions’, or being simultaneously gifted at tasks requiring fluid intelligence and intellectually disabled at tasks requiring verbal skills.
>
> *3. Deeply focused thinking and passionate interests in specific subjects.* ‘Narrow but deep’, these ‘special interests’ could be anything from mathematics to ballet, from doorknobs to physics, and from politics to bits of shiny paper.
>
> *4. Atypical, sometimes repetitive, movement.* This includes ‘stereotyped’ and ‘self-stimulatory’ behavior such as rocking or flapping, and also the difficulties with motor skills and motor planning associated with apraxia or dyspraxia.
>
> *5. Need for consistency, routine, and order.* For example, holidays may be experienced more with anxiety than pleasure, as they mean time off from school and the disruption of the usual order of things. People on the autistic spectrum may take great pleasure in organizing and arranging items.
>
> *6. Difficulties in understanding and expressing language as used in typical communication, both verbal and non-verbal.* This may manifest similarly to semantic-pragmatic language disorder. It's often because a young child does not seem to be developing language that a parent first seeks to have a child evaluated. As adults, people with an autism spectrum diagnosis often continue to struggle to use language to explain their emotions and internal state, and to articulate concepts (which is not to say they do not experience and understand these).
>
> *7. Difficulties in understanding and expressing typical social interaction.* For example, preferring parallel interaction, having delayed responses to social stimulus, or behaving in an ‘inappropriate’ manner to the norms of a given social context (for example, not saying ‘hi’ immediately after another person says ‘hi’) (ASAN 2013b, emphases added).

Outside the neurodiversity movement, autism is usually described in medical terms as a "pervasive developmental disorder", a group of conditions

> characterized by qualitative abnormalities in reciprocal social interactions and in patterns of communications, and by restricted, stereotyped, repetitive repertoire of interests and activities (WHO 2010).

When it comes to the characteristics themselves, I perceive ASAN's description as being fundamentally in agreement with mainstream descriptions of autism (in which I include what is known as Asperger's syndrome) as a disorder, though it seems to provide a more nuanced picture. The main difference seems to lie in the perception of the relationship between "autistic" and "non-autistic": In mainstream descriptions autism is considered a deficiency because it deviates from typical functioning. That typical functioning is best seems to be taken for granted. Not sharing this assumption, ASAN explicitly contrasts autistic functioning to the typical: Paragraphs 6 and 7 state that autistics have difficulty understanding and expressing language as used in *typical* communication, and *typical* social interaction. This is different to saying "autistic people have difficulty understanding and expressing language, communication or social interaction", in that ASAN's description does not take for granted that there is only one fundamental way of understanding and expressing language, communication and interaction. Likewise, paragraph 2 contrasts "standard" and "non-standard" learning and problem solving, expressing that autistics have *non-standard* ways of learning and solving problems, not "difficulties in learning and problem solving". Paragraph 4 mentions *atypical* movement, explicitly contrasting the autistic and the typical. Less explicitly, paragraph 1 states that autistic people have *different* sensory experiences, begging the question "different from whom?", as "heightened sensitivity to light" begs asking “compared to whom?” In both cases the implicit answer is "neurotypicals". In referring to "deeply focused thinking and passionate interests in specific subjects", paragraph 3 also implicitly also compares autistic and neurotypical people, because characterizing some ways of thinking as "deeply focused" and some ways of being interested as "passionate" only makes sense in contrast to *other* ways of thinking and being interested.

1.3 The concepts "community" and "space"

1.3.1 Community

The term *community* implies people acting together as a group, not just a collection of individuals, but each as a part of something bigger which has meaning for them (Ife 2010, p. 11). It "refers to those things which people have in common, which bind them together, and give them a sense of belonging with one another", Day (2006, p. 1) writes, adding "this is a fundamental aspect of society, perhaps its very core". At the same time, a sense of belonging with someone carries within it the sense of *not* belonging with someone else:

> As humans, we are boundary-drawing animals, and we erect barriers between ourselves and others, quite as much as we identify with them. The idea of community captures these elements of inclusion and exclusion, pointing towards those who belong together, and those who are held apart (Day 2006, p. 2).

In community work it is common to distinguish between geographical communities, defined by geographical location, and functional communities, defined on another basis, as in the Italian community, Christian community or business community (Ife 2010, p. 13). Community may also be established on the grounds of common interests (Henriksbø & Sudmann 2011). The communities of Autreat and Autscape may be considered part of a larger community, the neurodiversity movement, which can be understood both as a functional community and a community established on the grounds of common interests. Autreat and Autscape are also examples of the "new communities", communities that come to exist through peoples' choices and actions, based largely on their tastes and interests (Day 2006, p. 24, 215). This is of course a common feature of many peoples' lives, not only autistic people. With the advent of the internet, it has generally become much easier for all to transcend geographical limitations to become part of communities established on the grounds of shared tastes, interests, situations, chosen identities and self-perceptions.

Community can also be seen as a process where individuals and groups strive to realize their potential. Here one can distinguish between "communities of struggle", involving people fighting for their economic and political rights, and "mutualities of the oppressed", more defensive social arrangements involving people who find themselves pushed to the margins of society (Williams 1975 in Day 2006, p. 20). If I were to characterize the communities of Autreat and Autscape according to this, I would describe them as having elements both of being "communities of struggle" and "mutualities of the oppressed": They aim to function as "escapes" or "retreats" for autistic people, positing mainstream neurotypical society as something to be escaped or retreated from. Their conditions are described as "hospitable" (ANI 2013), a "haven" (Autscape 2013), and escaping or retreating to hospitable havens may certainly be considered defensive moves. At the same time, as the findings I present in later chapters show, in these spaces many autistic people experience a sense of community, some for the very first time. Many develop new and positive understandings of being autistic as, opposed to the universally bleak understandings held forth by mainstream society. In these spaces they may find strength to go out and face the world of "overwhelming sensation", as Singer (1999, p. 63) terms it. Many describe that being in these spaces helps them develop a sense of pride in being autistic. Furthermore the people gathering at Autreat and Autscape are clearly inspired by and express the idea of neurodiversity, a controversial idea that flies in the face of public perceptions and much of the autism-related knowledge produced in the medical and professional community. It is certainly an idea that requires struggle to promote outside autistic spaces, and the very existence of such spaces may depend upon generating a certain acceptance for this idea.

1.3.2 Space

What are "spaces" as opposed to "places"? Conceptually, spaces are more abstract and defined more in terms of areas and volume, whereas places tend to have concrete form. The most straightforward and common definition of "place" is that of "a meaningful location", a specific spot on the Earth to which people attach meaning (Cresswell 2004, p. 7-8). Going back to the autistic spaces of Autreat and Autscape, they certainly are meaningful, but, as both events have been arranged in a number of different places, they do not seem to depend on specific location. However, the concepts of spaces and places defy such simple differentiation. The term "space" can mean "places where people can talk with each other and meet", but may also refer to the social relations that transpire in these places. Space "is considered actively produced through repetitive performances and through governing what is seen to be appropriate ways to behave” (Rosqvist, Brownlow & O’Dell 2012, p. 1-2). But "place" can also be expanded to be used as an "analytic concept that involves the process of shaping meaning and practice in material space" (Cresswell 2004, p. 81) which brings it closer to "space". Still, I have chosen to use the term "autistic spaces". Firstly, it signals a sense of independence of location. In principle an autistic space might be created in many different locations. And secondly, "spaces" is the term already in use in the communities of Autreat and Autscape.

Both of the aspects Rosqvist, Brownlow & O’Dell mention seem to be present at Autreat and Autscape: Both are places where people talk and meet. But not anybody may enter these spaces: autistic people must be in majority, and those who enter are expected to behave in certain ways, defined by autistic people. Thus, both in the sense of people acting together as part of something bigger that is meaningful for them, and of being produced by repetitive performances and governing what is seen to be appropriate ways to behave, Autreat and Autscape may be considered both communities and spaces.

1.4 Current research knowledge about autistic spaces

1.4.1 Rosqvist, Brownlow & O’Dell (2012)

A recent study explored "neurodiverse spaces", spaces where autistic people can "make friends, have intimate partners, feel belonging/part of a community, live, work, study" (O’Dell, Brownlow & Rosqvist 2011). A paper reporting from this study draws together empirical work produced by the authors in two different spaces: a Swedish magazine produced by and aimed at autistic adults, and English-speaking autistic communities online (Rosqvist, Brownlow & O’Dell 2012). Reporting that off-line spaces are often where autistic people have the most difficulty communicating, the authors argue that off-line spaces need to be transformed so that they are accessible for autistic people (Rosqvist, Brownlow & O’Dell 2012, p. 1). The authors stress "the importance of the social and physical adaption of off-line spaces in order to make them accessible" for autistic people and "the importance of separate autistic spaces (for love and friendships and a sense of an autistic community)” (Rosqvist, Brownlow & O’Dell 2012, p. 10). They also argue that "autistic spaces allow those involved to have distance from the mainstream NT world, which is seen as chaotic and alien" (Rosqvist, Brownlow & O'Dell 2012, p. 7). The authors call for a further examination of spaces departing from the principles of neurodiversity, so that these issues can be more thoroughly considered and debated (Rosqvist, Brownlow & O'Dell 2012, p. 11).

1.4.2 King (2009)

In his 2009 PhD thesis examining the rhetorics of online autism advocacy, King (2009) refers to autistic spaces while describing the development of Autism Network International:

> Because people on the autism spectrum often have difficulty with typical methods of communicating and socializing, Sinclair and others began cultivating modified "spaces" around autism conferences which were sensitive to this kind of embodiment. In these spaces—which were often hotel rooms or unused conference rooms— autistic people could meet each other in more comfortable environments which were not only modified for their sensory needs (e.g. no bright lights and less noise), but were spaces where they would not feel pressure to curtail the manifestations of their autism (i.e. "stimming" and vocalizations) (King 2009, p. 146).

King does not go further in exploring autistic spaces though, and his source for this description of autistic spaces is Sinclair's essay "History of ANI" (Sinclair 2005), which is also part of my data material.

1.4.3 Davidson (2008)

In a research based article about autistic culture online Davidson (2008) quotes an unpublished article by autistic Dutchman Martijn Dekker, who

> 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' (Davidson 2008, p. 801-802),

However, Davidson does not touch further on the concept of autistic spaces.

1.4.4 Bagatell (2010)

In a research based article by Bagatell, she quotes an Autreat participant telling her that at Autreat:

> ‘For the first time - at a conference - I wasn’t bombarded with florescent lights and noisy rooms and so much information. And if I needed to do my stimming or didn’t want to talk to anyone, you know, it was okay. You know, I could hang out. And, and I liked it’ (Bagatell 2010, p. 41).

"Stimming" is short for "self-stimulation". The Autistic Self Advocacy Network mentioned atypical, sometimes repetitive, movement, including "stereotyped" and "self-stimulatory" behavior (such as rocking or flapping) as one of the characteristics of autism (ASAN 2013b). Evidently, for autistic people stimming can express many different things. As autistic American blogger Leah Jane Grantham writes:

> Stimming, for me, is a form of physical, emotional, and intellectual catharsis. When I stim, all of the threads of my thoughts come together to form a grand design. The revelation is so exciting and overwhelming I have to rid myself of the excess energy caused by this epiphany through, you guessed it, more stimming. Not everybody stims for the same reasons I do, an individual autie may have a million different reasons for doing so. It could be a self-soother, a means of concentrating, a release of pent-up anxieties, a chance to think, or a means of warding off boredom (Grantham 2012).

For some, stimming can also be a coping mechanism, a way to ward off sensory overload. "Overload" is a state of overstimulation where the person is exposed to more sensory information than he or she is able to process. This can be painful and cause one or more senses to shut down (Bogdashina 2003). Based on autistic sources, Caldwell writes that for autistic people in a state of overstimulation, concentrating on the simple sensations of repetitive movement may alleviate the overload and stop it escalating into "fragmentation/meltdown", a state associated with pain, confusion, and a number of unpleasant and terrifying sensations (Caldwell 2006, pp. 27-28).

1.4.5 More casual mentions of Autreat and Autscape

Autscape and Autreat are both mentioned in research studies, book chapters, papers and articles about autistic self-advocacy, and some researchers have focused on the history of ANI in a way that extends to Autreat (mostly citing Sinclair’s 2005 essay), but none seem to have explored the specific adaptations that constitute Autscape or Autreat as autistic spaces.

1.4.6 Summing up

So far there seems to be a paucity of research based knowledge about autistic spaces, and what exists do not offer many specific details. The glimpses provided by Rosqvist, Brownlow & O’Dell, King, and Bagatell were the most concrete research based insights into autistic spaces I was able to find. Meager as they were, they nonetheless suggested that transforming spaces into autistic spaces requires attention to both physical and social aspects, and that I in my further exploration needed to be on the lookout for both.

1.5 The relevance for community work

1.5.1 Autistic-friendly versus "autistic-unfriendly" spaces

King noted that the autistic spaces Sinclair and other autistic people created were modified to have "no bright lights and less noise" in order to accommodate their sensory needs. This suggests that normal spaces tend to be too bright and noisy. The Autreat participant described the experience of not being bombarded with lights and noise and information as unique, suggesting that usually he is. Rosqvist, Brownlow & O’Dell noted that autistic people often perceive the mainstream world as chaotic and alien. Autscape's claim to be an autistic-friendly space where autistic needs are taken into consideration suggests that spaces tend not to be autistic-friendly and that autistic needs tend not to be taken into consideration. Autreat's claim to be designed to accommodate autistic people suggests that other spaces tend not to be. A factor that may contribute to this are neurotypical perceptions of the manifestations of autism: when King noted that in their autistic spaces, Sinclair and the others did not feel pressure to curtail manifestations such as stimming and vocalizations, the implication was that normally in the mainstream world, they did feel such pressure. Supporting this is the comment by the Autreat participant that if he needed to do his stimming or didn’t want to talk to anyone, "it was okay". From Caldwell we know that for some autistic people being able to stim is relevant for physical accessibility, because it can be a way of compensating for the overload typical environments may cause. Thus pressure to curtail stimming may exacerbate the difficulties some autistic people experience in typical environments.

1.5.2 Human rights and perceptions of disability

All of the above makes it clear that many autistic people have difficulty functioning in daily life. What is less clear is *why.* Traditionally, the difficulties autistic people experience in daily life have been attributed solely to their autism, as regrettable but highly natural consequences of having a neurological disorder/impairment. But either autism is seen as an impairment or a difference, this is a rather untenable position in the face of human rights ambitions in the countries where Autreat and Autscape are located. In clarifying this, I will start with the perspective of seeing autism as an impairment:

Both the United States and United Kingdom are signatory states of CRPD, the United Nation's Convention on the Rights of Persons with Disabilities (UN 2013), characterized as "the most recent, and the most extensive recognition of the human rights of persons with disabilities" (WHO 2011, p. 9). The convention draws a line between impairment and disability, stating that

> disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (UN 2006, p. 4).

Defining disability as an interaction means that disability is not an attribute of the person, and that social participation can be improved by addressing the barriers which hinder persons with disabilities in their day to day lives (WHO 2011, p. 4). So that each and every citizen may "fully enjoy all human rights and fundamental freedoms", the CRPD recognizes the "importance of accessibility to the physical, social, economic and cultural environment, to health and education and to information and communication" (UN 2006, p. 3).

This negates the traditional perception of disability, where the impairment is perceived as the problem and sole source of the hindrances to disabled peoples' full and effective participation. Still, both the CRPD and WHO use the term "disability" in an ambiguous way. On one hand, disability is defined as a result of the interaction between persons with impairments and attitudinal and environmental barriers, and not an attribute of the person. On the other hand, people may "have disabilities". I draw a sharper line between "impairment", as an attribute of the person, and "disability", as a result of attitudinal and environmental barriers that hinder people’s participation. I do not use the term disability in the plural, and I do not understand disability as something people may "have". This aligns me with what is called "the social model of disability", which can be understood as a

> deliberate attempt to shift attention away from the functional limitations of individuals with impairments onto the problems caused by disabling environments, barriers and cultures (Barnes 2012, p. 18).

The point is distinguishing between problems that can be solved through action on an individual level and problems that only can be solved through action on a collective, political level. In what he states is his "final word" on the subject (Oliver 2009, p. 1), one of the architects of the social model writes:

> In the broadest sense, the social model of disability is about nothing more complicated than a clear focus on the economic, environmental and cultural barriers encountered by people who are viewed by others as having some form of impairment (Oliver 2009, p. 47).

In 1976, in their Fundamental Principles of Disability, the starting point of the social model, the Union of the Physically Impaired Against Segregation characterized disability as a burden that was imposed on top of their impairments by the way they were unnecessarily isolated and excluded from full participation in society (UPIAS 1976, p. 4-5). This also resonates with a community work stance. As early as 1989 Asbjørn Kaasa, a veteran of Norwegian community work, wrote that in the exercise of community work there lies a protest against explaining people’s problems solely through factors related to themselves (Kaasa 1989, p. 29).

Seen from the traditional perspective, often called the “medical” or “individual model of disability”, the problem lies in the functional limitations of the individual, and the solution is helping people with impairments adapt to society as it is, as best they can. Tøssebro comments that few defend the medical model, and suggests that this equation of functional limitations with hindrances to accessibility is a way of perceiving disability that mainly lives on in the realm of what "goes without saying", what is taken for granted (Tøssebro 2010, p. 8). The social model of disability does not deny the value of appropriate individually based interventions in the lives of people with impairment (Barnes 2012, p. 18), and

> endorsement of the social model does not mean that individually based interventions in the lives of disabled people, whether they are based on medicine, rehabilitation, education or employment, are of no use or always counter-productive (Oliver 2009, p. 45).

From this perspective, the problem is that society does not accommodate the full range of human diversity, and the solution is creating a society that does (Tøssebro 2010, p. 20). It may not be possible to eradicate impairment, but disability may be eradicated through changes to the way society is organized, the social model posits (Oliver 2009, p. 44). But where the line goes between problems caused by disabling environments and problems caused by personal limitations can be unclear, though. One outspoken critic of the social model claims that "even in the most accessible world, there will always be residual disadvantage attached to many impairments" (Shakespeare 2006, p. 50), though "replacing a traditional deficit model with a social oppression model understanding was and remains very liberating for disabled people" (Shakespeare 2006, p. 30).

Some struggle to see the relevance of the environment at all. Jonathan Mitchell (2010a) describes himself as a "54-year-old man with mild autism". The troubles he has faced in his life makes him wish a cure for autism could be found. He rejects the idea of neurodiversity outright, which is made clear by his blog's subtitle: “We don’t need no stinkin’ neurodiversity” (Mitchell 2013). Mitchell does not feel that the neurodiversity proponents speak for him, a "veteran" of special education who has been fired from multiple jobs. He asks what societal accommodations have to do with his problems of applying himself, staying on task, his perceptual motor impairments and bad handwriting (Mitchell 2007). I return to his question in chapter 8.

1.5.3 Inaccessibility as discrimination

Thus in light of disability theory we can say that if autistic spaces are more accessible for some autistic people, the adaptations that make these spaces more accessible may be seen as pointers to

- attitudinal and environmental barriers in neurotypical space that hinder their full and effective participation in society on an equal basis with others (UN 2006),
- how they are excluded by barriers that hinder them in their day to day lives (WHO 2011),
- how they are disabled by the way society or local communities currently is organized (Oliver 2009 and Tøssebro 2010),
- in what ways disability is imposed as an added burden on top of their impairments (UPIAS 1976).

What makes these pointers particularly relevant, is that such barriers and forms of disablement may be considered acts of discrimination. For example, the British Equality Act 2010 considers a provision, criterion or practice to be discriminatory if it puts persons with a relevant protected characteristic at a particular disadvantage when compared to persons without this characteristic (Equality Act 2010, p. 10). In providing goods, facilities and services to the public, a rule, policy or practice that applies to everyone but particularly disadvantages people with an impairment may be considered an act of indirect discrimination (Government Equalities Office 2010, p. 6). ADA, the Americans with Disabilities Act (1990) does not use the term indirect discrimination, but some of the forms of discrimination it refers to are "the discriminatory effects of architectural, transportation, and communication barriers", "overprotective rules and policies" and "failure to make modifications to existing facilities and practices" (The Americans with Disabilities Act 1990, Section 12101).

The Autistic Self Advocacy Network (ASAN) states that it “seeks to bring about a world in which Autistic people enjoy the same access, rights, and opportunities as all other citizens” (ASAN 2013). From a traditional perspective this goal may be perceived as utopian or self-contradictory. In light of newer understandings of disability, as those of the UN, WHO and UPIAS and the goals of anti-discriminatory legislation, it makes perfect sense. At the same time I find a certain ambiguity in the network's position. In one position statement it posits “social acceptance of neurological difference as part of the broad landscape of human diversity”, in another it notes that it "regularly works with other disability rights organizations" (ASAN 2013a). I understand this ambiguity, where they on one hand define autism as a difference, on the other align themselves with the disability rights movement, as a strategic compromise. Rights springing from having impairments or "disabilities" are well established both in declarations of human rights and US legislation, whereas the position of seeing autism as a difference on par with race, gender and sexual orientation can so far at best be described as tenuous.

1.5.4 A minority status for autistic people?

What difference would it make for the above argument if autism was commonly perceived as a developmental difference? I cannot see that would not change the basic principles involved. If the same concepts of self-determination and equal legitimacy that are applied to differences of race, gender and sexual orientation were applied to autism, it can be reasonably assumed that autistic people would be offered the same legislative protection and practical considerations that is offered on these grounds. What might be lost in such a perceptual transformation? Discussing deafness, Solvang suggests that for a group where many depend on support, claiming a minority status might be detrimental to established rights to support. For example, if such support comes through having a client status in charity or welfare systems on the basis of the impairment, achieving a minority status might mean having to look for alternate means of support (Solvang 2000). At the same time, in a world that did not see autism as a problem in itself, and where environmental barriers to autistic peoples' participation were addressed, fewer autistic people might depend on support. Furthermore a minority status would hardly rob them of the right to support on other grounds, and there are many other grounds that might make support necessary. Many impairments and medical conditions appear more frequently in autistic people. For example intellectual impairment, epilepsy, attention-deficit/hyperactivity disorder, obsessive compulsive disorder, bipolar disorder, anxiety disorders, depressive disorders, anorexia nervosa, Kleine-Levin Syndrome, osteoporosis, juvenile myelomonocytic leukemia, sleep disorders, self-injurious behavior, food and gastrointestinal problems, and catatonia (Coleman & Gillberg 2012).

1.6 The structure of the thesis

In *Chapter 2. Theoretical framework*, I present the theoretical elements I draw upon to analyze and make sense of my data material. Some are from Structuration theory as formulated by Giddens (1979, 1984, 1993) and Stones (2005), where I have found the distinctions between *external and internal structures, enabling and constraining aspects of structures* and *practical and discursive consciousness* of particular relevance. I also present some of Goffman's (1959) perspectives on impression management in social encounters. In showcasing the part nonverbal and contextual communication plays, his perspectives make it possible to pinpoint more exactly how neurotypical style interaction may exclude autistic people. The last element I present is Universal design, a strategy for inclusion that has gained widespread acceptance in the Western world.

In *Chapter 3. Research methodology,* I describe how I have gone about producing answers to my research questions and choices I have made along the way, and consider issues of validity. My data material was compiled through four online searches, my goal being to access as much as possible of what was available online about autistic spaces written by organizers and participants of Autreat and Autscape. I analyzed my material using a social science qualitative content analysis approach to create a set of categories, then using theoretical elements from chapter 2 to analyze the content of each category.

In *Chapter 4. First aspect: Accommodating sensory issues,* I present and analyze the content of the first category of findings - confirming and expanding on existing research knowledge of the physical and sensory conditions of autistic spaces, and giving details about how these conditions are created. I discuss and analyze my findings, particularly drawing upon the concepts *material constraint, internal dimensions of structure, practical and discursive consciousness,* and *knowledge of structural context* as well as other relevant studies that privilege autistic voices.

In *Chapter 5. Second aspect: Facilitating autistic style sociality,* I present and analyze the content of the second category of findings - confirming and expanding on the previous research knowledge that making spaces autistic spaces also requires attention to social aspects, and giving details about how autistic behavior and communication styles are facilitated and established as the norm at Autreat and Autscape. I discuss and analyze my findings, particularly drawing upon the structuration theory concepts *structural constraint* and *constraint based on sanctions,* as well as other relevant studies that privilege autistic voices. I also draw upon Goffman's perspectives on impression management in order to tease out some differences between neurotypical style sociality and the sociality at Autreat and Autscape.

Regulating who may enter autistic spaces and on what conditions they may enter, may be seen as a necessary precondition for achieving the conditions that constitute spaces as autistic spaces. In *Chapter 6. Third aspect: Protecting the boundaries of the space,* I present and discuss my findings about how these aspects seem to be managed at Autreat and Autscape, including a few perceivable differences between Autreat and Autscape.

In *Chapter 7. Informing and challenging current efforts to promote inclusion and accessibility for all,* I discuss the findings from previous chapters in light of the strategy called Universal design, looking first at sensory related barriers before moving on to those related to social interaction. I discuss some consequences of my findings, make a few practical observations and suggestions, and examine to what extent the barriers highlighted in my study may be called discriminatory.

In *Chapter 8. Beyond and between categories,* I review my use of the categories "autistic people" and "neurotypicals". In matters of equality, any act of categorization is questionable, because processes of categorization may in themselves contribute to sustaining inequalities. Acknowledging that, provisionally adopting existing analytical categories may still be necessary in order to document relationships of inequality among social groups (McCall 2005), which is what I have attempted to do in my study.

In *Chapter 9. Relevance for community work,* I suggest some ways my study may be relevant in relation to community work.

In *Chapter 10. Conclusions,* I summarize and draw some conclusions from my findings, and suggest some possible avenues of future research.

2 Theoretical framework

2.1 Chapter overview

In this chapter I present my theoretical framework, first describing some elements from structuration theory as formulated by Anthony Giddens and Rob Stones. According to Stones, Giddens has complained that researchers tend to import too large portions of structuration theory, in ways that unnecessarily clutter and burden their studies (Stones 2005, p. 2), instead preferring those who use his concepts selectively, "in a spare and critical fashion" (Giddens 1991 in Stones 2005, p. 2). In my study, I have selected a small bundle of concepts that seemed to fit my subject matter.

Secondly, I present some of Goffman's theoretical perspectives on face-to-face interaction and the performed character of social encounters.

Thirdly, I describe the basic principles of the strategy for inclusion known as Universal design, and some of the ways it intersects with anti-discriminatory legislation in the US and UK.

2.2 Structuration theory

2.2.1 The duality of structure

Structuration theory was formulated by Giddens during the 1970s and 1980s, as a response to a long-standing debate in sociology about the relationship between agency and structure. According to Aakvaag (2008, pp. 128-130), the debate has revolved around the question: Are social structures constituted by the actions of individuals, or are the actions of individuals constituted by social structures? This question is an example of dualism, a mode of thinking which

> sets up a confrontation between two entities and forces one to choose in terms of this opposition: either this side or that side. It does not allow for the possibility that each of the terms of the "opposition" in fact requires and draws upon its supposed opposite (Fay 1996, p. 224).

Giddens rejects the dualism of agency or structure, claiming it fails to provide a proper starting point for theoretical reflection (Giddens 1993, p. 4). Refusing to give primacy either to social structures or individuals, structuration theory focuses on what Giddens terms "the duality of structure": On one hand, social structures and individuals' knowledge of these structures enable them to participate successfully in social settings. On the other, social structures can only be said to have existence to the extent they are drawn upon and reproduced in the day-to-day social activities of individuals. Social structures are at the same time both medium and outcome of practices (Giddens 1984). Explaining the process of structuration, Stones writes that

> agents draw on structures to produce actions that change or reproduce structures. This is the cycle of structuration. It is what is meant by the term 'structuration'. Neither structures nor agents are given primacy. Both require the other. It is not one or the other but both that are involved in social processes (Stones 2005, p. 20).

Giddens (1984, p. 377) defines a social system as the "patterning of social relations across time-space, understood as reproduced practices". The smallest type of social system is dyadic, i.e. involving two people (Giddens 1979, p. 73). But all social systems, "no matter how grand or far-flung, both express and are expressed in the routines of social life, mediating the physical and sensory properties of the human body" (Giddens 1984, p. 36).

2.2.2 External structures

External structures are the conditions of action, the context people find themselves in, the patterning of social relations in which they attempt to maneuver, and these structures have an existence autonomous from the agent-in-focus (Stones 2005, p. 84). Stones sets out to remedy what he sees as a "relative lack of attention" paid by Giddens to external structures (Stones 2005, p. 86). As conditions of action vis-a-vis individual actors, external structures both enable and constrain. Structuration theory rejects equaling structure with constraint: structure is always at the same time enabling and constraining

(Giddens 1979, p. 69; Giddens 1984, p. 25), but regarding the constraining aspects of external structures, Giddens distinguishes between material constraint, constraint based on (negative) sanction, and structural constraint (Giddens 1984, p. 176):

Material constraint can be understood as constraint "deriving from the character of the material world and from the physical qualities of the body" (Giddens 1984, p. 176). This concerns the "limits which the physical capacities of the human body, plus relevant features of the physical environment, place upon the feasible options open to the agent", including those set by the "sensory and communicative capabilities of the human body" (Giddens 1984, p. 174).

Constraint represented by *sanctions* can be understood as "deriving from punitive responses on the part of some agents towards others", responses that first and foremost appear when some form of transgression occurs or is perceived as likely to occur (Giddens 1984, p. 176).

Structural constraint can be understood as constraint "deriving from the contextuality of action" meaning "from the ‘given’ character of structural properties *vis-à-vis* situated actors" (Giddens 1984, p. 176, original emphasis). Here Giddens tangents Bourdieu’s concept of *doxa*, the body of common knowledge that is taken for granted, accepted as "a self-evident and natural order which goes without saying and therefore goes unquestioned" (Bourdieu 1977, p. 166). In this also lies the "conventional" and "ordinary". As Giddens notes, "we will not ordinarily ask another person why he or she engages in an activity which is conventional for the group or culture of which that individual is a member" (Giddens 1984, p. 6). A central point from structuration theory is that the external structures facing actors are largely created and upheld by other actors. Stones notes that "constraining external structures are socially produced and sustained by agents" who "are themselves socially situated" and subject to "pressures and constraints" (Stones 2005, p. 60). Accordingly, participants in any social setting may be seen as mutually upholding the social structures that simultaneously enable and constrain action and interaction. Going back to the definition of disability as a result of interaction with attitudinal and environmental barriers, the World Report on Disability states that both public policies, the way service delivery systems are organized, and the understandings held by other people in society also may be obstacles for participation and inclusion (WHO 2011, pp. 3-4). And to the extent that such obstacles are not to be understood as expressions of ill will, it seems reasonable to see them as examples of structural constraint. As Tøssebro (2010, p. 8) suggested, the continued equation of individual functional limitations with disability may be best understood as a perception living on in the realm of what is taken for granted.

This also points to the malleability of social structures and systems: If they are being continuously being reproduced through participants' choices and actions, then principally, change should be no further away than a new understanding resulting in a new choice resulting in a new action. Regarding this, Fay writes:

> As agents we appropriate culture, and as members of a society we continually produce and reproduce it by the way we interpret its meanings and embody its rules. Consequently cultures and societies are forever changing through the creative and innovative power of their members (Fay 1996, p. 68).

2.2.3 Internal dimensions of structure

Not only are people always inevitably rooted in a structural context, they are "always and inevitably drawing upon their knowledge of that structural context when they engage in any sort of purposeful action" (Stones 2005, p. 17). It is this *knowledgeability* that enables them to act successfully in social encounters, and at the core of it is the awareness of social rules (Giddens 1984, p. 21), the awareness of

> what is appropriate at this social moment in this room with these people, and why that would not be appropriate in the same room at another moment with the same group of people, or in the next room with the same or another group, and so on (Stones 2005, p. 23).

People do not necessarily think about the skills they use to maneuver a given social encounter. The knowledgeability to which Giddens refers, the "knowledge of social conventions, of oneself and of other human beings, presumed in being able to 'go on' in the diversity of contexts of social life", is founded less on discursive than on practical consciousness (Giddens 1984, p. 26). There are no special barriers between these two forms of consciousness. What is known on a practical level can be lifted to a discursive level. If asked, people are normally able to verbally express the social rules by which they maneuver. The distinction is mainly based on the difference between what is talked about and what characteristically is simply done (Giddens 1984, p. 7).

This knowledgeability is not specialist knowledge. Giddens refers to all "competent members of society" as "expert sociologists" who are "vastly skilled in the practical accomplishments of social activities", and the "knowledge they possess is not incidental to the persistent patterning of social life but is integral to it" (Giddens 1984, p. 26).

Following Giddens' claim that knowledge of social conventions is integral to the persistent patterning of social life, creating alternate patternings would seem to require establishing an alternate form of knowledgeability. In turn, this would seem to require raising to a discursive level a number of social considerations that are typically left at the level of practical consciousness and taken for granted. Again we may turn to Bourdieu, who writes about the power of discourse to expose the arbitrariness of what is taken for granted, to push back the limits of doxa (Bourdieu 1977, p. 169). This suggests that changing knowledge of social conventions, for example through questioning and re-interpreting their meanings and the way rules are to be embodied, is likely to require a critically reflective stance on the part of those seeking such a change. Without this, it seems reasonable to believe that they would simply accept the limitations placed on the range of options open to them, perhaps as a regrettable but inevitable result of their own characteristics.

Such analyses go to the heart of community work. Ledwith (2011, p. 34) notes that community work involves analyzing how people's particular experiences are "linked to the forces of power that are embedded in the structures of society, and understanding how these forces reach into communities to impact on personal lives". In Freirian terms, encouraging a critically reflective stance is a crucial part of breaking the "culture of silence" among people who have come to see their marginalized situation as inevitable through having adopted dominant cultural descriptions of themselves as faulty and deficient. But critical consciousness, the understanding of how one's personal life is impacted by the structures of society, cannot be taught as a curriculum. An understanding of their situation as historically situated, which as historically situated also can be transformed, must stem from people's own reflection upon their world (Freire 1970, 1993), their interrogation of culturally and historically situated "truths" (White, Fook and Gardner 2006, p. 19).

2.3 Erving Goffman on face-to-face interaction

Goffman provides a more dramaturgically oriented perspective on social encounters, focusing on “face-to-face interaction”, “the reciprocal influence of individuals upon one another’s actions when in one another’s immediate presence” (Goffman 1959, p. 26). Harnessing the imagery and language of the stage, Goffman describes everyday social encounters as performances where people continually foster impressions in one another through the verbal and symbolic expressions they *give* and the range of nonverbal expressions they *give off* (Goffman 1959, p. 14). His point is not that people are insincere, but rather that being perceived as sincere may require an equal amount of care and consideration as a contrived performance meant to mislead:

> Whether an honest performer wishes to convey the truth or whether a dishonest performer wishes to convey a falsehood, both must take care to enliven their performances with appropriate expressions, exclude from performances expressions that might discredit the impression being fostered, and take care lest the audience impute unintended meanings (Goffman 1959, p. 73).

Accordingly, in order to succeed in typical social interaction the ability to give and give off expressions that are sufficiently attuned to other people’s expectations will be crucial. This requires the ability to interpret their verbal and nonverbal reactions during the encounter, judge what kind of impression one is making, and adjust one’s deportment accordingly. Also vital is managing of one’s own nonverbal expressions so that others may perceive them as being aligned with the verbal ones, as they often are used as a check of the validity of what is conveyed verbally (Goffman 1959, 18).

In the initial phase of any social encounter, each person will project a definition of the situation, in effect making a bid for how both they and the situation should be understood (Goffman 1959, p. 23), for their version of reality (Goffman 1959, p. 90). Thus how social situations and each participant's role in them are to be understood can be seen as a matter of negotiation. But ordinarily participants’ definitions and respective roles are sufficiently attuned to one another so that open contradiction does not occur (Goffman 1959, p. 20). These initial and largely silent negotiations at the start of a social encounter creates a shared understanding, a projection of what kind of encounter this is to be and what role each participant will have. It is crucial to the success of the encounter that the interaction that follows is sufficiently attuned to this initial understanding. Participants must play their part in a way that does not contradict, discredit or cast doubt on the mutually projected over-all definition of the situation (Goffman 1959, p. 23 and 59). But the “impression of reality fostered by a performance is a delicate, fragile thing that can be shattered by very minor mishaps”, Goffman (1959, p. 63) writes. And when such

> disruptive events occur, the interaction itself may come to a confused and embarrassed halt [ ]. At such moments the individual whose presentation has been discredited may feel ashamed while the others present may feel hostile, and all the participants may come to feel ill at ease, nonplussed, out of countenance, embarrassed, experiencing the kind of anomaly that is generated when the minute social system of face-to-face interaction breaks down (Goffman 1959, pp. 23-24).

Such disruptions may have different consequences. One is the disorganization of the interaction described above (Goffman 1959, p. 235). But there is also a tendency to see a flawed performance as a negation of people’s capacity as performers, and it may also reflect negatively on categories they are perceived as belonging to (Goffman 1959, p. 235). Lastly, causing such disruptions may discredit people in their own eyes, making it harder to conceive of themselves as competent social actors (Goffman 1959, p. 236).

Goffman identifies some common defensive measures used by performers to save their own show. Being able to control one’s emotions, face and voice is “the crucial test of one’s ability as a performer. Actual affective response must be concealed and an appropriate affective response must be displayed” (Goffman 1959, p. 211). Other defensive measures are remembering one’s part, prudence in what one lets others see or understand, being disassociated enough to monitor the interaction and deal with any contingencies that arise, the ability to meet any potentially disruptive event with a plausible explanation, a joking manner, or a suitable apology (Goffman 1959, pp. 210-211). Lastly, the performer must have a flexible relationship to the truth of the matter, being willing for the sake of the performance to accentuate certain aspects and suppress aspects which might discredit the fostered impression (Goffman 1959, p. 114). In social interaction, Goffman warns, “a rigid incapacity to part from one’s inward view of reality may at times endanger one’s performance” (Goffman 1959, p. 77).

2.4 Universal design

The concept of universal design emerged from the disability rights movement but goes beyond accessibility for groups with "special needs". Rather, it is a search for design strategies that bring benefits for all (Steinfeld & Maisel 2012, pp. xiv-xv).

> Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design (Mace quoted by Center for Universal Design 2008).
>
> The intent of universal design is to simplify life for everyone by making products, communications, and the built environment more usable by as many people as possible at little or no extra cost. Universal design benefits people of all ages and abilities (Center for Universal Design 2008).

The underlying rationale is human diversity (Steinfeld & Maisel 2012, pp. 62-63). Steinfeld & Maisel (2012, p. 21) writes that many societies are moving towards the goal of having "an architecture of social participation" and "equality in opportunity through universal design", and note that "design for diversity is concerned with social justice for all" (Steinfeld & Maisel 2012, p. 40). Such ambitions require looking beyond the traditional target populations for whom we create measures to enhance accessibility - people with mobility, sensory, and intellectual impairments. Designers must know their demographics and target groups (Steinfeld & Maisel 2012, p. 51). A central thought is that design that secures accessibility for some also benefits others: An elevator that makes a building more accessible for wheelchair users will also benefit others for whom a staircase represents a barrier, for example elderly persons or people with baby carriages.

Universal design intersects with the anti-discriminatory legislation mentioned in chapter 1, both the Americans with Disabilities Act (1990) and Equality Act 2010 in the UK. The Americans with Disabilities Act (1990, Section 12102) covers those who have "a physical or mental impairment that substantially limits one or more of the major life activities", have "a record of such an impairment" or are "regarded as having such an impairment", and

> prohibits discrimination on the basis of disability in employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications (U.S. Department of Justice 2009).

In the UK, the Equality Act 2010 aims to ban unfair treatment and help achieve equal opportunities in the workplace and in wider society (Home Office 2013). It

> prohibits unfair treatment in the workplace, when providing goods, facilities and services, when exercising public functions, in the disposal and management of premises, in education and by associations (such as private clubs) (Home Office 2013).

The Act defines nine "protected characteristics". One is having an impairment with substantial and long-term adverse effects on the ability to carry out normal day-to-day activities (Equality Act 2010). The act prohibits both direct and indirect forms of discrimination. Direct discrimination is being treated worse than people without impairment. Indirect discrimination happens when there is a rule, policy or practice that applies to everyone but particularly disadvantages people with a particular impairment (Government Equalities Office 2010, pp. 4-6).

Barriers are significant in more ways than simply blocking people out. Barriers may slow people down, divert them from their goals, cause them fatigue, limit their opportunities, or restrict their ability to express themselves (Steinfeld & Maisel 2012, p. 4). At the same time, barriers are an integral part of creating social order, as can be shown by the simple example of sidewalk curbs. One of their contributions to social order is separating cars and pedestrians, reducing the risk of the latter being hit by the former. Often sidewalks are raised from road level, providing the edge known as the curb. Curbs make crossing the road more difficult for wheelchair users. One solution has been to build curb ramps, short ramps cutting through curbs or building up to them. But this requires also incorporating features that can function as detectable warnings for pedestrians who are blind or have low vision (Department of Justice 2007). A barrier for wheelchair users, curbs have traditionally helped pedestrians who are blind or have low vision know when they were about to enter the street. This is an example of how removing barriers for one group may create new barriers for another. In the same way, bright lighting may enable some people to see contrasts, but worsen the situation for others who are light-sensitive (Tøssebro 2010, p. 22).

Universal design seems to hold out the prospect of a better future for all, as when Steinfeld & Maisel (2012, p. 57) proclaims that it "benefits everyone". But in practice it means negotiating between different, and in some cases incompatible, needs. In working towards more inclusive environments,

> a major question for all of us is what barriers are created in the process and what they represent for society. Negotiated spatial orders define the differences between individuals: Who is in, who is out, who has access to resources, who is denied access, who wins, who loses, who is empowered, and who is neglected? The experience of barriers is universal, but not everyone has the same ability to overcome barriers that may restrict independence, social engagement, and the communication of a positive identity (Steinfeld & Maisel 2012, p. 13).

Steinfeld & Maisel specify eight goals of Universal design:

> 1. *Body fit.* Accommodating a wide a range of body sizes and abilities
> 2. *Comfort.* Keeping demands within desirable limits of body function
> 3. *Awareness.* Ensuring that critical information for use is easily perceived
> 4. *Understanding.* Making methods of operation and use intuitive, clear, and unambiguous
> 5. *Wellness.* Contributing to health promotion, avoidance of disease, and prevention of injury
> 6. *Social integration.* Treating all groups with dignity and respect
> 7. *Personalization.* Incorporating opportunities for choice and the expression of individual preferences
> 8. *Cultural appropriateness.* Respecting and reinforcing cultural values and the social and environmental context of any design project (Steinfeld & Maisel 2012, p. 90, emphases in original).

3 Research methodology

3.1 Chapter overview

In this chapter I describe how I have gone about producing answers to my research questions, my *methodology*. More than mere method, the term also encompasses the philosophical underpinnings of a research approach on one hand, its more mundane and practical techniques on the other. Ideally, McCall (2005, p. 1774) notes, "methodology is a coherent set of ideas about the philosophy, methods, and data that underlie the research process and the production of knowledge".

My research interests made it clear that my approach would be qualitative and interpretive, the challenge being to work "out how the things that people do make sense from their perspective" (Ezzy 2002, p. xii) and in turn making sense of this in a larger perspective informed by theories of social science and justice. That my preconceptions would influence findings and interpretations was inevitable (Ezzy 2002, p. 53). In contemporary theory of knowledge the effect of researchers' positions and perspectives is acknowledged. The onus has shifted from attempting neutrality to a commitment to reflexivity: assessing and accounting for these effects (Malterud 2001, p. 484). The alternative to attempting neutrality is not "haphazard subjectivity". In any scientific endeavor the knowledge that is produced should be the fruit of a "systematic and reflective process" (Malterud 2001, p. 483). In this chapter I describe how I have attempted to make my research process systematic and reflective, tracing the stages chronologically. Underway, I had a number of considerations: some practical, some ethical, some concerning research rigor, some grounded in the philosophy of science. These considerations were intertwined, and as such I treat them here.

In 3.2, I describe the searches that enabled me to describe the current research based knowledge about autistic spaces in chapter 1.

In 3.3, I describe how I came to choose an interpretive, non-participatory research approach using texts from online sources.

In 3.4, I describe how my data material was compiled through internet searches and a process of screening results and identifying relevant content.

In 3.5, I describe the process of analyzing the data, first doing a content analysis of the data material to develop categories, and a theoretically informed analysis of the material in each category, resulting in chapters 4, 5 and 6. Then moving on to analyzing and discussing results in light of current efforts to promote inclusion and accessibility, resulting in chapter 7, discussing some issues of categorization, resulting in chapter 8, and discussing the relevance of my findings to community work, resulting in chapter 9.

In 3.6 I discuss issues of preconceptions, bias and validity

3.2 Searching for previous research

To find previous research I searched a number of data bases: Academic Search Elite, Amed, Cinahl, Ebscohost, Embase, ERIC, MeSH, PsycINFO, PubMed, PubMed Health, ScienceDirect, Social Care Online, SocIndex, SpringerLink and Teachers Reference Centre. I also used Google Scholar with no limitations on year of publication. In each data base I used the search terms "autistic space", "autistic spaces", "Autreat", "Autscape", "autist space", "asperger space" and "aspie space". Because there was so little to be found, I also searched Google Books and Google using the search term “autistic space” in the hope of finding references to research.

The sparsity of results is not because of lack of research interest. Matson & LoVullo (2009) notes that the field of autism research is expanding at an exponential rate. Based on their overview of autism research, they report that the most frequently studied topics include genetics, perception and cognition, neurobiology, physiology and nosology. But of the 18 top categories they list, not one suggests the inclusion of autistic adults’ own voices, experiences and concerns. Generally, autism research has been dominated by approaches seeking to discover causes and develop treatments, focusing mainly on children. As autistic American researcher Scott Robertson (2010) points out, only “a tiny fraction of scholarly articles about autism in the academic literature have examined real-life concerns presently impacting autistic adults”.

3.3 Choosing a research approach

3.3.1 Choosing an interpretive approach

On the philosophical side, an important consideration was that community work has its tenets in the social sciences, and is committed to understanding human actions as expressions of agency, creativity and competence (Bergen University College 2010, p. 5). Thus, beyond studying the adaptations that constitute autistic spaces, I must also access the experiences and intentions of those involved that lead them to make these adaptations. This effectively ruled out all approaches of a positivist nature, approaches that favor the study of observable behavior, emphasizing techniques of observation, measurement and quantification (Fay 1996, p. 72). Positivism

> is an approach to social research that seeks to apply the natural science model of research to investigations of social phenomena and explanations of the social world (Denscombe 2002, p. 14).

The last five decades a range of approaches that reject some of the positivist premises has come together under the umbrella term *interpretivism* (Denscombe 2002, p. 18). A shared view is that social realities cannot be observed or measured in the same way as material realities, because the realities of the social world only exist through the ways people believe in them, relate to them and interpret them (Denscombe 2002, p. 18). My need to access the experiences and intentions of the people creating the social realities of Autreat and Autscape suggested an interpretive approach. In support of this was community work's agenda of privileging community voices as a safeguard against colonialist practices (Ife & Fiske 2006, p. 304, Ife 2010, p. 46). Ledwith warns against using positivist approaches in community work, writing:

> If we fall into a positivist approach to research that encourages research *on* people rather *with* people, we will certainly overlook vital aspects of community life (Ledwith 2005, pp. 34-35, original emphases).

3.3.2 Choosing an non-participatory approach

A practical consideration was that I wished to study a phenomenon that primarily exists respectively 5800 and 914 kilometers from where I live. It seemed infeasible to do a fieldwork study, also because at master level there is no research funding. But if I could have gone, would these communities, exploring “what it means to lay claim to one’s environment without a domineering culture breathing down one’s neck” as autistic American Valerie Paradiž (2005) puts it, have welcomed me? They might. Both open for some forms of research, and contingent on advance approval from a Planning Committee (Autreat) or an Organisation's board (Autscape), their guidelines are no stricter than typical research ethics requirements of securing informed consent (ensuring participants have full knowledge of research purposes and procedures, participate voluntarily and know they may withdraw at any time), respecting confidentiality and privacy and so forth. On the other hand the organizers of Autreat have been fiercely protective of their autistic spaces when it comes to researchers, for example their online discussion list, ANI-L. The first paragraph of the Principles and policies section read:

> This list is "autistic space." Autistics and cousins are here to participate for our own benefit, not to put ourselves on display for the benefit of parents or professionals. Non-autistic people who wish to participate with us as fellow human beings, with respect for our dignity and our privacy, are welcome. People wanting to study us are encouraged to look for study material elsewhere (ANI 2013).

As a community worker I would have preferred to do the research as community-based participatory research, inviting members of these communities to join me in each step of the research process. Practically this might have been done using online shared spaces and e-mails. But, being unsure whether I would be capable of both fulfilling my moral and formal obligations towards them *and* ensuring that my thesis fit the requirements of the master’s program, I decided to not do it as a participatory project. But without a partnership with the communities in defining the focus and research questions, I could not be sure that my study would have any value to them. Hence, a second decision was that I would conduct it with the least possible amount of involvement and potential burden to them.

These decisions led me to focus on archival sources, data material generated without the active participation of community members, an approach that also may be called nonreactive data collection (Janetzko 2008, p. 161). In considering possible sources of such data, the internet was an obvious choice.

3.3.3 Choosing to use online sources

Online, I would be entering an arena that in many ways is the home ground of the neurodiversity movement. Bagatell (2010, p. 35) links its very emergence to the "explosion of computer technology, specifically the Internet", and describes that many autistic participants in her study "were more comfortable communicating in writing than orally" (Bagatell 2010, p. 37). She quotes one as saying:

> "I just feel more free writing. It’s like I can look at the keyboard and the words just come together. I don’t get the same word freeze that I do when I’m talking. And if I do, well, timing doesn’t matter so much" (Bagatell 2010, p. 37).

"Clearly", Bagatell (2010, p. 37) states, "the Internet has given autistic people a voice". In 1999, the Autistic Australian sociologist Judy Singer noted that the

> internet has 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, p. 67).

After researching chat rooms for autistic people, Brownlow and O'Dell (2006, p. 315) noted that autistic people are "finding a voice in an online environment". As Blume claimed in a New York Times article:

> The impact of the Internet on autistics may one day be compared in magnitude to the spread of sign language among the deaf. By filtering out the sensory overload that impedes communication among autistics, the Internet opens vast new opportunities for exchange (Blume 1997).

My conclusion was that if I wished to access autistic voices speaking for themselves, online sources could be a good choice, in addition to having the benefit of an international scope. I would lose the opportunity to immerse myself in the social practices at the center of my attention; on the other hand I would be accessing autistic voices communicating in a medium that for many is more comfortable than face-to-face communication. Discussing techniques, procedures, tools and issues in internet research, Hewson & Laurent (2008, p. 61) note that "the lack of extra-linguistic cues (e.g. tone of voice, facial expression, body language) could lead to ambiguities in the communication process". In this case the "lack of extra-linguistic cues" might be an advantage. Sinclair writes that

> many of the communication pitfalls we encounter in face-to-face communication with NTs — being expected to understand nonverbal signals, having people try to read meaning into our own appearance and nonverbal behavior — don't exist in text-only communication. (It still boggles my mind when NT people complain about this as a *drawback* of online communication!) (Sinclair 2010, emphasis in original).

Reporting from a study involving autistic participants, Ryan & Räisänen noted:

> Communicating electronically removed difficulties around understanding body language and facial expressions and there was less chance of misunderstandings (Ryan & Räisänen 2008, p. 141).

Thus relating only to autistic peoples' written words might actually help me focus on their message. These considerations made it clear that the internet might be a more that adequate source. I had also done preliminary online searches showing that there was material to be found. But how would I restrict the scope of my study? The internet is a place of few natural boundaries where in research, as Hine (2009, p. 2) notes, "the possible connections to pursue multiply". In pondering this, I had already reached the initial steps of a qualitative content analysis, a method of data collection characterized by systematically going through documents to find relevant information about the matter under study (Grønmo 2004, p. 187).

3.3.4 Initial qualitative content analysis

Two steps in the preliminary stages of a qualitative content analysis are defining what themes should be given priority and considering what kind of texts may hold relevant information (Grønmo 2004, p. 189). My best guess was texts containing the terms

Autreat, Autscape, autistic space or autistic spaces. Thus, I decided to search the internet for web pages or documents containing at least one of these words.

At this stage I also had the opportunity to limit my level of intrusion into the privacy of the people whose voices I was trying to access, and to restrict the scope of my study. My solution, which also was approved by the NSD, the Norwegian Data Protection Official for Research (see Appendix A), was that I would limit myself to texts collected from sources openly available on the internet and therefore in the public domain. This ruled out forums requiring registration and login. Among such texts I would distinguish between a) texts published for general readership (which I would use freely, and refer to following ordinary academic citing practices), b) personal texts that seemed directed towards an larger audience (where I would ask the author's permission and adhere to the answer), and c) personal texts that seemed directed towards a more limited audience (which I would refrain from using).

3.4 Compiling the data material

3.4.1 Four internet searches

Another step in the preliminary stages of a qualitative content analysis is finding the documents that are to be analyzed (Grønmo 2004, p. 189). Sinclair (2010) mentions four gatherings of autistic people: Autreat (USA), Autscape (UK), Empowerment-Päivät (Finland) and Aspies e. V. Sommercamp (Germany), and that Autreat is the largest autistic-run organization to have regular gatherings of autistic people. Because of this and my limitations concerning Finnish and German, I narrowed my focus to Autreat and Autscape. My search strategy was simple: I did four internet searches using the search terms "Autreat”, "Autscape", "autistic space" and "autistic spaces", one at a time.

The search using the term Autreat generated approximately 9900 results. I screened the 590 results that Google presented as unique.

The search using the term Autscape generated approximately 5500 results. I screened the 330 results that Google presented as unique.

The search using "autistic space" generated 3470 results, of which Google only would show the first 1000. I screened all 1000. All items that eventually were included in my data material were among the first 680 results, after which the results were mainly repeating themselves.

The search using "autistic spaces" generated 310 results. I screened all 310.

3.4.2 Screening the search results

In a qualitative content analysis, a primary goal is to identify and register content that is relevant to the matters under study. Judging relevance is an essential part of this (Grønmo 2004, p. 190). Screening search results I found it relatively easy to judge relevance. "Autscape" and "Autreat" was consistently used to refer to the events in question. On the other hand, the terms "autistic space" and "autistic spaces" were used in a variety of meanings other than the one I was focusing on:

- In the psychoanalytical tradition "autistic space" refers to a type of internal “mental functioning” (McClelland 1993 is an example).
- Hacking (2006) proposes "autistic space" as an alternative term to “autistic spectrum”.
- "Autistic space" and "autistic spaces" are used as figures of speech in disciplines like art and political theory to denote a state of “withdrawal” or “aloneness”, a “closed silence”, an “isolated mode of functioning” (e.g. Fung 2008, Ikeda 2010, Watanabe 2001).
- Finally, "autistic space" is used by autistic American Ian Ford in the sense of a place “one can step back into” in order to see something from the perspective of autistic people (Ford 2010, p. 37).

No material using "autistic space" and "autistic spaces" in these other meanings was included. In some cases results referred to autistic space in the sense I was after, but were not included because they did not have direct relevance to my questions. In the clearest example, autistic Finnish activist Heta Pukki states:

> I also felt we should have a forum for public debate, not so much the separate ‘autistic space’ of Autreat. I believe there is a need for that too, sometimes, but I felt we needed effective dissemination of information more than anything else (quoted in Williams 2008).

3.4.3 Identifying relevant content

I printed out all the material included in my first compilation. Going through this, I removed pages that did not have content with relevance to my questions. This left me with 165 pages, of which 163 were written by people identifying themselves as autistic.

In screening the results, I had distinguished between the three categories of text mentioned in 3.3.4. Even if they were openly available, I defined comments to blogs, or postings or comments in discussion forums as belonging to category c) personal texts that seemed directed towards a more limited audience, and refrained from using them. Thus my 165 pages were compiled solely from the first two categories, according to the following principles:

Books, web sites and online articles were considered examples of category a), texts published for general readership. In this category I collected the following:

- 36 pages from Jim Sinclair's internet essay “Autism Network International: The Development of a Community and its Culture” (Sinclair 2005)
- 24 pages from Jim Sinclair's article “Cultural Commentary: Being Autistic Together” (Sinclair 2010)
- 5 pages from interviews with Sinclair (Ashkenazy 2009 and Ellerman 2011)
- 2 pages from the brochure for Autreat 2010 from the ANI (2013) web site
- 2 pages from information about Autreat 2012 on the ANI (2013) web site
- 3 pages from the Autreat 2012 Call for proposals (ANI 2013)
- 10 pages from an account of being at Autreat 2004 by Jane Meyerding (2004) (posted on the Autreat web site, therefore considered published for general readership)
- 4 pages from an account of being at Autreat 2007 by Stan (s0) (2007) (posted on the Autreat web site, therefore considered published for general readership)
- 6 pages from a book by autistic American researcher and parent of an autistic child, Valerie Paradiž (2005)
- 1 page from a item in the ASAN Newsletter, by Sarah Pripas (2011)
- 2 pages from an interview with neurotypical American writer Steve Silberman (Lehrer 2012)
- 35 pages from the Autscape (2013) web site

- 2 pages from a item from ASAN UK (2009), which included an anonymous personal experience from Autscape
- 2 pages from an item by Charles Burns (2005) in Taimyo, The Magazine for British Shintaido
- 1 page from an item by Charles Burns (2007) in Taimyo, The Magazine for British Shintaido

All of these are posted in my list of literature references.

Blogs were considered as an example of category b), personal texts that seemed directed towards a larger audience. Blogs are personal and may be diary-like, a place where people records or comments on their own activity or beliefs, including perspectives on current events (Fielding, Lee & Blank 2008, p. 550). They are literally published for all to see. But, boyd notes,

> just because people's expressions on the internet are *public* in the sense that they can be viewed by anyone does not mean that people are behaving as though their audience consists of billions of people across all space and all time (boyd 2009, p. 31, emphasis in original).

It is questionable to what extent this applies to bloggers. Still, the NSD required me to ask their permission. They also ruled that if I was unable to reach the authors, I could still use the material in anonymized form if I made it impossible to trace back to its original online source. Anonymizing online sources poses a special challenge. Any quote from a web page can be used as a search term in online search engines and instantly bring up the web page. This makes anonymity harder to achieve and easier to break:

> The same easy access to online data and the ease of matching individual respondents to other datasets that make online data collection so much simpler also make it much easier for someone to break anonymity and discover the identity of individual respondents (Blank 2008, p. 541).

I collected the following material from blogs by people identifying themselves as autistic:

- 1 page from Blogger A, Karen Boyd: “On Autistic Space” (permission granted, wished to be cited as Karen Boyd 2011)
- 1 page from Blogger B, Nico: “feeling a little isolated”) (permission granted, wished to be cited as Savannah Logsdon-Breakstone 2011)
- 2 pages from Blogger C, who attended Autreat 2010 (unable to reach, anonymized)
- 2 pages from Blogger D, who attended Autreat 2007 (unable to reach, anonymized)
- 2 pages from Blogger E, who attended Autreat (I was unable to tell what year) (unable to reach, anonymized)
- 4 pages from Blogger F, Estée Klar, who attended Autreat 2007 (permission granted, wished to be cited as Estée Klar 2007)
- 2 pages from Blogger G, who attended Autreat 2007 (permission granted, wished to be cited as Jonah 2007)
- 1 page from Blogger H, Alexander Cheezem, who attended Autreat 2009 (permission granted, wished to be cited as Alexander Cheezem 2009)
- 7 pages from Blogger I, Jerry W (2010): "Autreat2010PoorPitifulMeAndTheTreatments IRantOn” (permission granted, but without specifying how I should cite him, therefore I used Jerry W 2010)
- 2 pages from an article by Valerie Paradiz (2010) titled “Growing Up Grassroots” (cited as Paradiz 2010)
- 1 page from Blogger J, commenting critically on an incident at Autreat (unable to reach, anonymized)
- 2 pages from Blogger K, who attended Autreat 2010 (unable to reach, anonymized)
- 2 pages from Blogger L, who attended Autscape 2005 (unable to reach, anonymized)
- 1 page from Blogger M, who attended Autscape 2010 (unable to reach, anonymized)

I contacted a total of twelve blog authors to ask their permission, in each case specifying the blog post and what parts I was interested in using. I also asked how to cite them (full name, a pseudonym of their choice, or anonymously) if they granted me permission. My wording varied a little, but the content is covered by the sample letter in Appendices, Appendix B. Where I found an email address, I used that. With others I left a comment on their blog or sent a personal message. In one case I found no way to make contact. In the above list, seven blog authors are referred to only by a letter, which means I could not reach them or they haven't responded. Where I have used material from them, I have anonymized it by rewriting it until I could use my text as a search term without the original web page showing up in the first few search result pages, while still, I believe, retaining the intended meaning. Six bloggers responded, all giving their permission. Most of them instructed me to use their full name. One requested that I not use some parts of his blog post, and I haven't.

3.5 Analyzing the data and presenting my findings

3.5.1 Further qualitative content analysis

In a qualitative content analysis researchers systematically go through the material either manually or with computer software, marking or extracting relevant content for the purpose of finding information about the matters under study (Grønmo 2004, p. 191). I chose to do this manually, making two identical sets of the 165 pages so that I could cut text fragments from one and have one intact version for reference. During the next following two weeks I went through the material, cutting out text fragments that seemed relevant to my questions. Numbering each fragment and marking the corresponding place in the intact version, I extracted 347 fragments, ranging in size from a single sentence to several pages. In chapter 4, 5 and 6, where I present the main body of my findings, I mainly cite the fragment number. The source of each fragment may be found in Appendix C: Fragment numbers and sources.

The purpose of extracting text fragments is to be able to compare different parts of the material, identifying common traits among them and grouping different parts according to such common traits, establishing categories. During the process these categories can be revised, refined and nuanced (Grønmo 2004, p. 191). It was obvious from the start that the distinction between physical and social aspects environmental aspects would be relevant. The following preliminary categories emerged (of which most later were collapsed into one of the three categories represented in chapters 4, 5 and 6):

- sensory issues and adaptations (> chapter 4)
- social interaction and communication issues (> chapter 5)
- non-acceptance versus acceptance of autistic traits and behavior (> chapter 5)
- degree of individual choice (> chapter 5)
- access to information, quality of information (> chapter 5)
- interaction that becomes possible in autistic space (> chapter 5)
- peer support
- critical consciousness
- sharing interests
- diversity in autistic space (> chapter 6)
- managing the inclusion of neurotypical people (> chapter 6)
- transitions in and out of autistic space
- challenges in autistic space for autistic people and neurotypicals

3.5.2 Theoretical analysis and discussion

Going through the material in these preliminary categories several times, attempting to see it in light of the concepts and distinctions from structuration theory, it became clear that the categories *accommodating sensory issues*, *facilitating autistic style sociality* and *protecting the boundaries* would fathom a majority of the preliminary categories. It would also enable me to highlight *material constraint* related to sensory issues (chapter 4), and *constraint represented by sanctions* and *structural constraint* related to autistic sociality (chapter 5). When it came to *protecting the boundaries* (chapter 6), findings resonated less with my theoretical framework, but had obvious practical importance as a precondition for achieving the conditions described in chapters 4 and 5. In each chapter I chose to present findings before discussing them in light of my theoretical framework.

In the theoretically informed analyses and discussions in chapters 5 and 7, I found myself increasingly drawing upon my personal practical knowledge of neurotypical style sociality. For example in discussing how the statement "I don't want to talk to you" typically might be interpreted, I suggest that in many cases it might be understood as carrying the relational subtext "I don't like you". Struggling to see what might be an authoritative source for neurotypical style subtexts, I explored my practical knowledge and consciousness as a neurotypical. I took care to pick examples and interpretations that I perceived as common and uncontroversial, so that any reader with a practical knowledge of neurotypical style sociality might assess their validity.

This also reflects my attempt to make my process as transparent as possible, an important factor in research (Malterud 2001, p. 484). I believe that one of the strong points of my study is the level of detail I provide about how I compiled the material, combined with the accessibility of my sources. My steps up to the point of theoretical analysis can be retraced by anyone with access to the internet. Online content changes day by day, and my searches were done in April 2012, but at least for a while anybody retracing my steps should be able to form an opinion of the soundness of my process, even if they might have made some different choices in how to make sense of the data material. Doing so might also be a reflection of having a different set of preconceptions regarding autism.

3.6 Preconceptions, bias and validity

I entered the process with a considerable willingness to accept autism as a difference, though I both then and now follow Baker (2006, p. 27), who asserts that public sector programs should accommodate both autistic people who value their autism and people who want to overcome it as far as possible, and that for some, for example people with severe self-injurious behavior, behavioral therapy may be life-enriching.

I had a resolve to privilege the voices of the communities I was exploring, as well as to make some guidelines for myself that might reduce some of the drawback of being neurotypical in understanding how the things they were describing made sense from their perspective. In presenting findings, I have tried to preserve their words by using quotes instead of condensing meaning into my words. I have not entered into close reading of text, focusing instead on concrete content, as my questions guided me to. Where I had a choice I have used the preferred terminology of the autistic communities. I have given priority to relevant research studies privileging autistic people's voices. I have also used theoretical elements developed by autistic people. By doing this, I have also adopted elements of what is known as "standpoint epistemology", a methodology developed by feminist scholars that "rejects the idea that there is one true standpoint" (Ezzy 2002, p. 23), building on the argument that "knowledge is always situated, and what is known is influenced by the shared experiences and political orientations of the standpoint of the person who knows" (Ezzy 2002, p. 20).

The communities I have explored are part of the neurodiversity movement. In privileging their voices, I also contribute to validating the neurodiversity standpoint. Some might consider this a bias. But opening the door to seeing autism as a human variation is no more of a bias than not doing so. Whether autism is a deficiency to be counteracted or difference to be respected is not a question that can be answered by science any more than science could provide an answer to the similar question about same-sex orientation. Ultimately, these are questions that can only find their answers though dialogues and decisions on cultural and political levels. Furthermore, autism is so profoundly multidimensional, researchers are starting to refer to it as "the autisms" (Coleman and Gillberg 2012). In other words, an open mind seems appropriate.

Regarding preconceptions, Malterud (2001, p. 484) notes: "Preconceptions are not the same as bias, unless the researcher fails to mention them". Furthermore, "to suggest that something is biased suggests that there is an 'unbiased' interpretation" (Ezzy 2002, p. 57). But in research, there is no such thing. Research is always conducted within the framework of a set of assumptions about the world and phenomenons in the world. This also makes research political. As Ezzy (2002, p. 48) puts it: "To pretend that research is not political is to be supportive of current structures and practices without saying so explicitly". Political decisions should be informed decisions. Research that identifies, describes and explains the experiences of stakeholders and explores how they correspond to overreaching cultural and political goals may contribute to better informed decisions.

Regarding validity, Malterud notes: "Internal validity asks whether the study investigates what it is meant to, whereas external validity asks in what contexts the findings can be applied". I believe my study investigates what it sets out to. I have let the questions guide my choice of methods. I have compiled a data material with the utmost attention, well aware of the ease with which my steps could be retraced. I have obviously looked for similarities in my data material, as my categories show, but I have also looked for discrepancies. When I have conflated data from Autreat and Autscape to the extent that I have, it is because of their consistent similarity and because my focus was not explicitly comparative. In analyses, when I found they were taking me in other directions than I expected, I followed their lead. I have challenged my findings along the way, for example through recontextualizing each fragment I quoted in the findings chapters to see if anything in the context contradicted my interpretation, and through reading through the whole intact version of the data material after finishing chapter 4, 5 and 6, looking for anything that could contradict my findings. I have also considered my extensive use of Jim Sinclair's texts. On one hand they provide rich detail, and it can be argued that they reflect many years of experience in creating autistic spaces, and distill the experiences of many Autreat participants. On the other hand Sinclair is still only one person, and I know nothing about the rigor with which participants' experiences have been collected, what voices may have been left out, or with what level of accuracy the rest are represented.

The aim of research is to produce information that can be applied beyond the study setting (Malterud 2001, p. 485). I believe many of my findings have relevance beyond the setting of my study. But in all cases such transfers will require an active, responsible role on the part of the person considering the transfer. This is typical of qualitative research:

> The qualitative researcher can enhance transferability by doing a thorough job of describing the research context and the assumptions that were central to the research. The person who wishes to "transfer" the results to a different context is then responsible for making the judgment of how sensible the transfer is (Trochim 2006).

4 First aspect: Accommodating sensory issues

4.1 Chapter overview

In this chapter I describe, discuss and analyze the adaptations at Autreat and Autscape that concern sensory issues. As mentioned in 1.2, many autistic people report having sensory experiences that differ greatly from those of neurotypicals (ASAN 2013b). Autistic Australian sociologist Judy Singer claims that to most autistic people, “the autistic spectrum is above all a hypersensitivity to sensory stimuli, which necessitates the withdrawal from a world of overwhelming sensation” (Singer 1999, p. 63). My findings support this, at least among the autistic people who organize and frequent Autreat and Autscape. The findings from both spaces are very consistent with each other, though I also point out some differences. From previous research I knew that transforming spaces into autistic spaces required attention to physical aspects, as when ANI started creating spaces with “no bright lights and less noise” and an Autreat participant noted that for once, he was not “bombarded” with lights, noise and information. My findings confirm and expand on this knowledge in three ways: Firstly, through providing more specific details about what sensory stimuli are addressed and how. Secondly, through showing how many sensory issues are related to other people's behavior and thus only can be solved through addressing all participants' behavior. And thirdly, through showing that both events have a strategy that combines a set of general adaptations with adaptations that facilitate self-regulation of exposure to stimulation and recovery from stimulation.

In this chapter I describe first the general adaptations, then those facilitating self-regulation, before moving on to sort and discuss these findings in light of the analytical categories I draw upon from structuration theory. I refer to findings using fragment numbers, as for example by writing *(243)* behind a statement or quote. As noted in chapter 3, the source of each fragment can be found in Appendix C.

4.2 General adaptations concerning light, noise, smells and touching

4.2.1 What is the problem?

In mainstream society, leaving home can mean going out into “noisy crowded public places” where autistic people risk “uncontrollable sensory assaults” *(104)*. In neurotypical spaces, autistic people may have to accept “being subjected to noxious sensory stimuli as the price of social participation” *(97)*. A normal conference venue can be a “sensory nightmare” *(95*) with “sensory bombardment” *(148)*. There can be “too much going on - too many people, too much movement, too much noise” *(1)*. “Most of the world”, autistic American Pripas writes, “has loud noises, bright lights, unwanted social interactions, and a general atmosphere of chaos which often invokes overload” *(228)*.

4.2.2 Lighting

Some of the general accommodations for sensory issues at both Autreat and Autscape concern lighting. Evidently, fluorescent lights is considered particularly troublesome: On the Autscape web site, the organizers apologize for there being some fluorescent lighting at the current venue, but promise to do their best to reduce exposure *(276)*. Fluorescent lights are listed as one of the reasons mainstream conferences tend not to be good places for autistic people to connect meaningfully with each other *(1)*. The Autscape web site notes that: “Good natural lighting (so fluorescent can be avoided)” is an absolute requirement for Autscape venues *(299)*. Similarly, a member of the Autreat Planning Committee writes: "Part of the selection of the venues for Autreat is the selection of a presentation hall ANI looks for some combination of natural light and acceptable artificial lighting" *(172)*. But any bright light can be troublesome. For example, normal daylight can be blinding *(241)*. One of the benefits of being in one’s personal space at home, is being free to “replace eye-stabbing bright lights with low-wattage bulbs” *(99)*. And indoors, a camera flash can “assault those with visual sensitivities” *(177)*. Concerning appropriate ways to behave, Autreat participants are urged to be careful with camera flashes: "Flashes of light can hurt people. Before using a camera with a flash, you should get the permission of everyone in the area who will be affected by the flash, even if they will not be in the picture" *(143)*.

4.2.3 Noises

When it comes to noise, a “very quiet setting” is a required feature for arranging Autscape *(299)*. Noises can also be troublesome either they are the “wrong kind”, like echoes, many people talking at the same time, or the sound of eating *(199)*, or simply loud: loud noises can be terrifying or cause nausea *(241)*. Two strategies at Autscape are choosing venues in a "quiet location away from busy road or other noise” and asking the "venue to stop other noisy activities” *(312)*. Organizers promise to do their best to keep things "orderly and calm” *(280)*. At Autreat, rooms in the conference area have a sign on the door showing the level of noise permitted in that room *(341)*. But the success of this depends on establishing appropriate ways to behave among participants. The Autreat brochure informs: "Many people at Autreat have auditory sensitivities and can be hurt by noises that are loud, unexpected, or at a frequency that is painful to the hearer. Please try to avoid making unnecessary loud noise" *(143)*. "Being in a shared space means being required to modify our own behavior to accommodate other people’s needs”, Sinclair comments *(104)*. After spending a few days at Autreat, neurotypical American writer Steve Silberman commented that "instead of erupting into applause after a presentation Autreat folks raise their hands in the air and flap them. It’s a wonderful way of expressing appreciation without creating a burst of noise, and also of destigmatizing behavior for which they were punished and bullied as kids" *(242)*. In the orientation session at the start of Autreat, organizers also issue warnings about a number of auditory hazards: "(at both camp venues we had to endure tests of the fire alarm system, so we told people when that would happen and suggested places to go to be as far as possible from the alarm when it went off; in the university residence hall the room doors will slam loudly if not handled carefully, and the halls carry a lot of sound and echoes, so we ask people to be careful with the doors and to be quiet in the halls)" *(81)*.

4.2.4 Smells

Smells can also be troublesome. For example cigarette smoke, the smell of cigarette smoke on other people’s breath or clothing, or the smell of perfume, aftershave, food or coffee *(290)*. Autscape has a rule banning use of scented products *(310)*. Perfume and aftershave is mentioned specifically. Participants are also asked to not bring “food or drink (other than water) in the meeting rooms as some autistic people are sensitive to food and drink smells such as coffee” *(290)*. Similarly, Autreat participants are urged to be considerate: "Many people are sensitive to scents. Please do not use scented products at Autreat. If you smoke in designated smoking areas, please be considerate about tobacco odors. If you use products that make it hard for other people to breathe, you may be asked to leave events" *(143)*.

4.2.5 Touching

When it comes to touching, being touched by others can be troublesome for some autistic people: "This includes 'routine' (in NT society) touching such as tapping people on the shoulder to get their attention. Many people at Autreat find it startling or unpleasant to be touched" *(143)*. The Autreat Orientation Guide states: "Please do not touch other people without their permission! [ ] If you already know a particular person and you know that person is comfortable with certain kinds of touch, that is fine. But do not touch people unless you know it’s okay with them" *(143)*. Sinclair comments: "People who don’t want to be touched can be secure in the knowledge that nobody is likely to touch them (and that if anyone does touch them, they’re allowed to protest)" *(132)*.

4.2.6 The limitations of general adaptations

What also became apparent is that general adaptations are not sufficient, mainly because the great autistic variability makes it necessary to enable adaptations on an individual level. Sinclair comments that a common stereotype is that all autistic people are sensory defensive, and if that had been so, creating autistic spaces would simply be a matter of reducing sensory stimulation *(103)*. However, "there are also low-registering autistic people who tolerate — even *need* — more intense stimulation than the most sensory-seeking NTs would find comfortable *(103)*. Furthermore, autistic people cannot be neatly compartmentalized into “sensory-defensive” or “sensation-seeking”: "It is possible, for example, for someone to be easily overwhelmed by auditory stimuli but to seek out intense visual stimulation, or to be extremely tactile defensive but crave (and also create) a lot of loud sounds, or to avoid some types or ranges of visual/auditory/tactile/olfactory/gustatory stimuli while seeking out other types or ranges of stimuli, or any number of other combinations of sensory defensiveness and sensation-seeking within the same person. This extreme autistic variability presents challenges in accommodating sensory needs in autistic space. The kinds of sensory stimuli that are hurtful to some autistic people may be necessary for others" *(103)*.

As I will discuss in a later chapter, this also points to one of the ways Autreat and Autscape cannot be said to include and be accessible to all autistic people. Here in this chapter I move on to the fact that to make their spaces accessible to as many as possible, in addition to these general adaptations, Autreat and Autscape also have implemented a number of adaptations that aim to facilitate self-regulation of exposure to and recovery from sensory stimulation.

4.3 Adaptations to facilitate self-regulation

4.3.1 Providing low-stimulation rooms

Both Autscape and Autreat provide low-stimulation rooms participants may withdraw to. At Autscape, a "quiet room, in which no interaction or unnecessary noise is allowed, is available at all times" *(294)*. Here participants may retreat to “relax and ‘chill out’ if things are getting too much” *(279)*. At Autreat this room is called the “crash room”.

For ANI, the practice of providing low-stimulation rooms originated when they started having exhibit tables at mainstream autism conferences: "We requested that the conference organizers provide a room for autistic people to retreat to during the conference, to take a break from sensory overload and from NT social pressures. We placed a lamp with an incandescent bulb in the room, and kept the overhead fluorescent lights turned off" *(61)*.

In the orientation session at the start of Autreat, as part of clarifying options in the use of the Autreat space, participants also receive information about the location of the crash room *(81)*. Apart from providing a low-stimulation room that any participant may withdraw to, Autscape also focuses on how people may regulate their level of exposure without necessarily withdrawing from the situations:

4.3.2 Reducing impact of sensory issues

Autscape participants are urged to bring "ear-plugs, headphones, sunglasses or whatever" they "require to reduce the impact of sensory issues" *(280)*. For the same purpose, organizers provide a variety of multi-sensory objects suitable for stimming. In addition to the customary notepads and pens, participants can help themselves to a glow stick, a glitter ball, a small shimmering rainbow torch, a plastic container with oozing fluid in vivid colors, a multi-colored spinning top, or another a similar gadget *(340).*

4.3.3 Regulating the balance between rest and activity

Even with the above mentioned adaptations, overload and exhaustion is acknowledged as a common hazard both at Autreat and Autscape. Being together “inevitably means being exposed to the behaviors and sensory stimuli that other people produce” *(104).* Any "group gathering of this size will be difficult for most autistic people” the Autscape web site warns *(274)*. Participants bear this out, in their reports of being short on energy after being at Autreat *(192)*, being exhausted after Autscape *(337)*, having low energy levels, sleeping and being tired at Autreat *(219)*. One reports: "besides needing quiet I also need at least one hour to 'decompress' from even the slightest social contact before I can relax enough for sleep. And yet I was so avid for contact with the people and activities at Autreat that I virtually condemned myself to insomnia as effects of the sustained contact accumulated day after day" *(163)*. Autreat participants are warned that they should pace themselves, choosing the things that are most important to them and making sure they are sufficiently rested to enjoy them *(134)*. Autscape organizers admonish participants to get enough quiet time: "In the busy and people-filled days at Autscape, don’t forget to take some low-stimulus time to rest, relax, and gather yourself for the next activity. The venue and its environs have areas to walk in. There is enough space that if you need some time alone, it is possible to get far enough away from everyone for a while" *(294)*.

4.3.4 Providing access to outdoor spaces

Access to outdoor spaces also seems important: As part of trying to make Autscape as accessible as possible, organizers also try to accommodate participants who need “extra personal space and interaction free space” by choosing venues "with lots of open space (indoors and out)" *(313)*. The current venue has "plenty of outdoor space for physical activities" *(295)*. Early in the process of planning an autistic retreat, ANI "members pointed out the importance of having not just a building, but also outdoor spaces where people could move around" *(73)*. The present location for Autreat has "outdoor space for roaming” *(75)*, and “plenty of open space for walking, recreation, and enjoying the outdoors" *(149)*. One participant specifically mentions using exercise "to deal with the social stuff" by going to "bike in the early morning valley fog" *(235)*.

4.5 Easing material constraints

Reviewing my findings about the conditions in the two autistic spaces, it was striking to note how terms like "assault", "noxious stimuli", "nightmare" and "bombardment" were used to describe conditions that I believe most neurotypicals would consider acceptable or at least tolerable. Attempting to theorize this aspect of neurotypical functioning, Autistic American Ian Ford claims that between infancy and adulthood neurotypicals go through a process of sensory desensitizing and emotional dulling, in which they

> cut back on detailed observation, emotional observation, and emotional response to stimuli. A desensitized NT adult can walk by blaring speakers, sirens, blinking lights and other strong stimuli without anxiety or pain (Ford 2010, pp. 19-20).

My findings suggest that to many autistic people, a number of sensory stimuli that most neurotypicals consider normal may have considerable aversive effects: Normal indoor lighting may be blinding or “eye-stabbing”. Loud noises may be terrifying or cause nausea. Unexpected noises or sounds at certain frequencies may be painful. Touch may be startling or unpleasant. The environments at Autreat and Autscape are clearly designed to prevent or reduce such effects. Regarding the sensory issues discussed in this chapter, related to lighting, noises, smells and touching, they all lie within the area of the *material*. Giddens described *material constraints* as limits placed on the feasible options open to the agent by the combination of the physical capacities of the human body, including its sensory and communicative capabilities, and relevant features of the physical environment (Giddens 1984, p. 174). Thus, all the adaptations I have described so far may be understood to ease a number of material constraints for the participants of Autreat and Autscape.

Some material constraints are reduced or avoided through choice of venue, others through changing features of the physical environment, for example through replacing fluorescent lights with a combination of natural light and acceptable artificial lighting, or asking the venue to stop other noisy activities. But many of the relevant features of the physical environment are inextricably linked to the behavior of other participants. In order to avoid or reduce such material constraints for some participants, organizers must address all participants' behavior. In structuration theory, this takes us from the *external* to the *internal* dimensions of structure, and also to considerations of space as "actively produced through repetitive performances and through governing what is seen to be appropriate ways to behave” (Rosqvist, Brownlow & O’Dell 2012, p. 1-2).

Stones (2005, p. 17) noted that people "always and inevitably" draw "upon their knowledge of that structural context" in "any sort of purposeful action". Because the actions of participants to such an extent constitute each other's external structures through their actions, creating the autistic spaces of Autreat and Autscape seems to require establishing in participants a knowledge of structural context specific to these places. Simply, the generalized knowledge accumulated from neurotypical spaces will either not be sufficient or not applicable. And not only must new knowledge be established, participants must also modify previous knowledge and practical skills. Things that may be taken for granted in other settings cannot be taken for granted in autistic spaces. Thus, creating autistic spaces seem to require raising a number of issues to a discursive level that normally are allowed to reside at the level of practical consciousness.

The distinction between practical and discursive consciousness was based on the difference between what is talked about and what characteristically is simply done (Giddens 1984, p. 7). But, as I believe has been demonstrated in this chapter, many of the troublesome sensory issues that autistic people report are caused by features of the environment that in mainstream society are largely taken for granted. Contributing to creating autistic spaces may require participants to remember not to use camera flashes as they are accustomed to when taking pictures, not to clap their hands when they wish to applaud, not to just let go of the hall doors after they pass through them, not to bring food and drink into meeting rooms, not to use scented products, not to go directly from smoking a cigarette into a meeting room without appraising their clothes for smell, and not to touch other people without their express permission. And even if participants are autistic themselves, the bulk of their learning experiences may be from neurotypical spaces, therefore requiring all these considerations to be learned. Furthermore, all these considerations may require raising to a discursive level issues that in mainstream society are left at the level of practical consciousness and taken for granted. In order to gain the knowledge that can enable them to participate in creating autistic spaces, both neurotypicals and autistic people may need to reconsider their previous learning. Another aspect of this, is that to the extent that breaking these rules, for example by bringing coffee into a meeting room or touching somebody's shoulder to get their attention, is not a result of ill will or disdain for the rule, it probably may be understood as an expression of structural constraint, deriving from the given character of structural properties vis-à-vis situated actors (Giddens 1984, p. 176).

4.6 Establishing knowledge of structural context

Going back to my findings: How is this alternative knowledge of structural context established?

Firstly, it seems, an alternative knowledge of structural context is established through information to participants beforehand: Both events provide extensive and detailed information on their web sites, with detailed descriptions both of what participants may expect and what is expected from them.

Secondly, on arrival participants receive both oral and written information, as in the orientation session at the start of Autreat and the Autreat Orientation Guide. The information presented both beforehand is both detailed and explicit. In autistic spaces "the rules and the expectations are clearly and explicitly spelled out, sometimes in excruciating detail" *(125)*.

Thirdly, through the organizers' willingness to answer questions at length: "Experience has taught the leaders of ANI and Autreat that taking time to answer people's questions is a necessary part of organizing autistic activities", Sinclair notes *(124)*.

Fourthly, organizers may intervene if they observe or suspect that rules or guidelines have been broken, if participants behave in ways that "jeopardizes someone else's safety, comfort or enjoyment" *(301)*. Thus, on one hand organizers take an active part in regulating participants' behavior, and on the other hand, to the extent that they succeed in this, participants may come to be secure in the knowledge that they will receive feedback if they are out of line, and, by extension, as long as they do not receive such feedback, they are not.

A sentence in my material also points out that this alternative knowledgeability has two separate dimensions: In autistic spaces, "participants who don’t want to be touched can be secure in the knowledge that nobody is likely to touch them" *(132)*. But also, they know that "if anyone does touch them, they’re allowed to protest" *(132)*. To the extent that this is a contrast to "neurotypical spaces", it implies something about general conditions in neurotypical spaces (one is more likely to experience invasions of personal boundaries in neurotypical space) and about the possibility of regulating conditions at an individual level (in neurotypical space, protesting against being touched is less feasible or less effective). Assuming this applies also to the other sensory modalities, it might be inferred that for autistic participants, in a situation in autistic spaces where they are being troubled by lights, noises or smells, protesting will generally be a more feasible and effective option than in neurotypical spaces. In autistic spaces, they can expect their personal needs and boundaries to be respected in ways that provide them with more feasible options. And should they experience transgressions, others behaving in ways that jeopardizes their "safety, comfort or enjoyment", they will have more feasible options to do something about it, and they will have knowledge of these options. This brings us to the next aspect of creating autistic spaces, facilitating autistic sociality

5 Second aspect: Facilitating autistic style sociality

5.1 Chapter overview

In this chapter I describe, discuss and analyze adaptations at Autreat and Autscape that aim to facilitate autistic style sociality. From previous research I knew that transforming spaces into autistic spaces also requires attention to social aspects (Rosqvist, Brownlow and O'Dell 2012, p. 1) and that some autistic people report feeling less pressure to hide or curtail outward signs of their autism in such spaces - as the Autreat participant quoted by Bagatell (2010) as saying that if he needed to stim or did not wish to talk to anyone it was accepted. Also from King (2009, p. 146) I knew that creating autistic spaces might involve facilitating forms of interaction better suited to autistic people than neurotypical style interaction and sociality tends to be. My findings both confirm and expand on this knowledge. In addition to providing more details about the social aspects of Autreat and Autscape, my material enables me to describe three strategies used to facilitate autistic style sociality: 1) fulfilling information and structure needs, 2) providing material cues to guide interaction, and 3) establishing a set of autistic social rules. Research-wise, this is new knowledge.

In this chapter I first present my findings about these strategies, including the reasons given for their implementation. Thereafter I sort these findings according to the analytical categories I draw upon from structuration theory and discuss them in light of both findings from other relevant studies that privileges autistic voices and Goffman's descriptions of face-to-face interactions.

5.2 Fulfilling needs for consistency, routine and order

Compared to neurotypicals, a common autistic characteristic is a need for greater consistency, routine and order (ASAN 2013b). At the start of Autscape, participants are provided with a schedule that also indicates where each event on the schedule will take place, and a map of the venue. Such schedules are also posted in strategic places around the venue. Also, the name of the rooms and a schedule of what is happening there is posted on the door of each room *(286).* Regarding meals, menus are posted near the dining room so that participants can consider their food choices in advance *(281).*

Large amounts of unstructured time, especially in an unfamiliar place, can be a problem *(284)*, therefore each of the main days at Autscape follow a similar pattern, and leisure time is also scheduled *(318).*

In periods defined as leisure time, there are provisions for both unstructured and structured activity. Those "who like socialising with a little more structure and a little less intensity" are directed to "board games such as chess or card games", and urged to bring their own favorite games *(298).*

As an adaption for participants for which unstructured time is a problem Autscape organizers try to keep "large blocks of totally unstructured time to a minimum", and there are "opportunities to suggest or sign up for structured or semi-structured activities for most of the time there" *(284)*. Furthermore, they urge participants who know that unstructured time is a problem for them to plan ahead how they will occupy themselves in the evenings, bring their own entertainment such as books, music, electronic devices, games to share, musical instruments, or other interests and hobbies, or consider running a structured discussion one evening and think ahead of some topics they would like to discuss with others *(284).*

The schedule also contains *structured discussions (320)*, discussions that are "structured and facilitated to help more reluctant communicators have their say on issues" *(304)* with a "facilitator who has some information to share on the topic and will help participants each have their say" *(320).*

5.3 Providing material cues to guide interaction

In chapter 4, unwanted social interactions was mentioned as a factor contributing to an “atmosphere of chaos" that may cause overload in NT spaces *(228).* The background for some of the innovations for autistic accessibility at Autreat is that: "Even verbal autistic people are likely to have difficulty being verbal all the time, especially under conditions of sensory overload such as are likely to occur at a conference. Many of us had found ourselves struggling with speech shutdown at conferences. Non-autistic people would want to talk to us, when we needed to be left alone for a while" *(61).* Thus, for some autistic people unwanted social interaction can be a problematic feature of neurotypical style sociality. This may also be a problem in autistic spaces, as "many autistic people do not generate automatic nonverbal signals to indicate their interaction-readiness, nor pick up on such signals from other people" *(130).* Autistic people often "do not pick up on vaguely described, implied, or unspoken behavioral expectations” *(125).* Also, some autistic people may want interaction but have difficulty initiating it *(311).*

As part of facilitating autistic style sociality, both conference events provide a system of color coded interaction guide badges involving the use of red, green and yellow cards in plastic badge holders. Through placing a certain color card in front, participants may indicate to what extent they wish to socialize. This is easy for “autistic people to use, and easy for both autistic and non-autistic people to understand” (62):

Red color means: “Please do not initiate any interaction with me” *(275, Autscape),* the bearer does not want to be approached at all by anyone *(151, Autreat).*

Yellow color means: “Please do not initiate unless I have already given you permission to approach me” *(275, Autscape),* that the bearer wants to be approached only by people he or she already knows *(151, Autreat).*

Green color means: “I would like to socialise, but I have difficulty initiating. Please initiate with me” *(275, Autscape)*, that: “I want to interact but am having trouble initiating, so please initiate an interaction with me” *(62, Autreat).*

No badge, or at Autscape, **white color,** means: “I am able to regulate my own interaction” *(275).*

Several Autreat participants blog about these color coded interaction guide badges, expressing admiration for this system *(195),* or wishing that such badges also existed outside of autistic spaces *(207).* Meyerding writes: "I appreciate the help given by the badges worn by other people. It is relaxing to know instantly (without words or even much attention) that person X will be relieved rather than upset if you pass by without speaking, and that person Y, just entering the dining room with his tray, will be happy to be invited to join your table" *(159).* On the other hand, one blogger comments that wearing the red badge didn’t stop people from talking to him and communicating in ways he didn’t want *(215).* One Autscape participant reports that the badge system worked *(338).* Another writes about the relief of being able to use the yellow badge without anybody questioning her, other participants just accepting that at this moment in time she didn’t feel able to talk. Later, feeling better after eating dinner in at a no-interaction table facing a wall, she was comfortable exchanging the yellow badge for a green *(342).*

Sinclair comments that this interaction guide badge system makes it possible for people to listen to presentations or to be around others even if they are not up to having interactions *(61),* which he claims is "an important factor for some autistic people’s ability to be comfortable in autistic space. Many of us need undisturbed time to observe people and activities before we can decide whether or not we want to join in. Some we’ll decide to start participating after we’ve watched for a while. Sometimes we decide we don’t want to participate, but we’re still interested in watching what other people are doing. It’s a great relief to be able to be among people, partaking of whatever aspects of the situation we’re interested in, without pressure to do more socializing" *(111).* This principle of providing opportunity, but not pressure to socialize is also one of the important autistic social rules.

5.4 Establishing a set of autistic social rules

5.4.1 Providing opportunity, but not pressure for interaction

“Autreat is meant to provide opportunity, but not pressure, for social interactions”, the ANI web site states: “If you want to come but do not want to meet or talk to people, you are still welcome” *(151).* Similarly, at Autscape: “There is no requirement to socialise at all, and there will be no implicit or explicit disapproval of those who choose not to interact with others" *(275).* An Autreat participant wrote: "Respect for solitude was key. Each autistic participant had a cabin to retreat to, alone or with support people and family members, and no one would be forced to participate in activities. It was perfectly legitimate in this environment to isolate oneself as a means of preventing or recovering from sensory shutdown or social overwhelm" *(177).* Thus, a central social rule is respecting other peoples' choice if they do not wish to interact or choose to withdraw. This also seems to contribute to better self-regulation of exposure to and recovery from sensory stimulation: At Autreat “I was able to recover from my anxiety and sensory issues much quicker then I normally can - people left you alone when you were having problems” *(200).* An Autscape participant writes: “It was wonderful to be able to wander off on my own for a while without people following me to ask if I was OK” *(322).* The rule also seems to have another effect. The "absence of any expectation or pressure to socialize, and the knowledge that they’re free to withdraw at any time, seem to free many autistic people to want to socialize" *(85):* As they grow more secure in the acceptance of peers and the freedom to opt out of activities in autistic space, it becomes less scary to consider deciding to opt in *(132).*

5.4.2 Being more explicit

Another autistic social rule proscribes communicating needs or wishes explicitly, neither relying on nor expecting others to understand nonverbally communicated or contextually implied meaning. In many cases, neurotypical style sociality does not provide autistic people with enough information to understand what is expected of them *(97).* In autistic spaces each person is responsible for explicitly communicating his or her wishes regarding interaction *(114).* Interviewed by Ashkenazy, Sinclair states: "The #1 rule is NEVER ASSUME, ALWAYS ASK. The same goes for communication, especially nonverbal communication: Don’t try to interpret facial expressions, body language, or tone of voice, because if you don’t know this person very well, your interpretations are pretty much guaranteed to be wrong" *(142).* After attending Autreat, one blogger that it was nice to have a more obvious way of communicating, without the "normal hidden messages”. It was a relief not to have to try and figure out what "really was being said" through examining the social context, especially knowing when other people did not wish to talk *(195)*. Also, at Autreat, it is “acceptable, and expected, to say what you mean”, for example "to tell someone else to stop talking to you” *(114).*

5.4.3 Accepting autistic behavior

A third social rule is that autistic behavior is not only acceptable, but expected. Describing a presentation at Autreat, one blogger notes that the "audience waved their hands in the air", that there "were others who rocked back and forth" and yet "other adults who gracefully flapped their hands" *(202).* The Autreat Orientation Guide specifies: "We do not expect you to 'act normal' or to behave like a neurotypical person at Autreat. It is perfectly acceptable at Autreat to rock, stim, echo, perseverate, and engage in other 'autistic behaviors'" *(81).* Under the heading Autistic Behaviour, the Autscape web site states: "Stimming (repetitive movements), echolalia, distractibility, different or impaired conversation skills, avoidance of eye contact, perseveration (obsessiveness), are expected and accepted as part of an autistic conference. Appearing (or, indeed, being) completely NT is also perfectly acceptable" *(277).*

This also seems to enable self-regulation. One blogger writes that at Autreat she didn't "have to be appropriate": she could say when she had to leave "without a guilty fuss", and no one would judge her *(210).* In the Autistic Needs section, the Autscape web site reassures participants: "Sensory issues, and mechanisms to reduce them, are totally acceptable. No one will think it odd if you wear tinted glasses, ear-plugs, headphones, or whatever you may require" *(276).*

Most events lack the necessary degree of individual choice and program adjustability, Sinclair states. The solution is to provide a variety of different options and allow people to make their own personal choices *(123).* "Autreat offers a selection of presentations on topics we know to be of interest to many autistic people. No one is required to attend any of those presentations, and if someone does attend one and finds it uninteresting, it's perfectly acceptable to get up and leave. We offer informal group discussions and recreational activities. No one is obliged to attend any of these, and if someone chooses not to join in, Autreat social rules specifically proscribe pressuring people to participate" *(123).* Again, this shows how the enabling of self-regulation and facilitating autistic sociality are intertwined. Similarly, the Autscape web site promises:

"You always have the choice not to do a particular activity, or to leave early if you're feeling stressed. Only you can decide what you would like to do with your time at Autscape" *(283).*

Evidently, for many participants the acceptance of autistic behavior makes a noticeable difference to the world outside. "I am fortified by being here," the son of one of the bloggers "wrote on his Lightwriter, a keyboard with a small screen that speaks for him after he types his sentence" *(204).* Another blogger writes that: "For the past several years I've been going to Autreat. This year I haven't, and I feel less for it, for not being in an Autistic Space, for not getting to spend a week surrounded by fellow Autistics" and: "It's just harder to be in non-autistic space when I don't get a chance to really spend time in Autistic space" *(186).* A member of the Autreat Planning Committee notes that "Autreat is a place where we are among our own, with all our differences" *(168).* Another mother writes about Autreat that: "The camp had an aura of acceptance about it. It was a rarefied place. Elijah and I played all day long without concealing our repetitions or interrupting them before he wanted to stop. We didn't have to go off to an isolated field to commit our unconventional acts as we did back home in Woodstock with our balloon routine. We stood outside the main lodge, playing shadow games for hours" *(181).* Another blogger notes that not having to hide his differences feels like being set free from oppression *(198).* At Autreat, Meyerding writes, "you don't have to devote energy (the way you usually do) to appearing non-autistic. You don't have to be anxious that your autisticness will be stigmatized by those who hear you speaking (or not speaking) or see you ticcing or stimming. It's amazingly comfortable" *(161).* Sinclair writes: "The real 'magic' of inclusive autistic spaces, such as we strive for in ANI, is not that every autistic person can automatically expect to find other people who are like him or her. The real 'magic' is that almost every autistic person — everyone who is able to participate without violating other people's boundaries — can expect to be accepted for who he or she is" *(108).* Some common descriptions of this experience are: "This was the first place I wasn't criticized for being different." "It showed me that being me was okay, and that my ways of doing things weren't 'wrong' or 'defective,' just different, and perfectly all right". "For the first time, I had my less than 'normal' attempts at communication recognized, and also accepted." *(108).* One Autscape participant described Autscape as a space where autistic people may behave in an autistic way without fear of judgement *(321).* Another expresses that Autscape is a good place to be, and represents an example of how life could have been if individual differences were accommodated and appreciated *(344).*

5.4.4 Establishing the rules

How are these autistic social rules established? As with sensory related issues, three strategies seem to be giving participants detailed information beforehand, enabling them to ask questions as part of preparing to come, and providing them with oral and written information when they arrive: "Many autistic people need to know ahead of time what they will encounter and what will be expected of them", and people "planning to attend Autreat often have a lot of questions about anything from general social conditions to minutiae about the physical space" *(87).* "People who register for Autreat are sent a collection of files before they attend, providing extensive details about the venue, daily schedule, and Autreat customs and social expectations. There is an Autreat Information forum online where people can ask questions and share information and pre-plan their Autreat experience. There is an orientation session on the first evening of Autreat where non-readers can hear the information that was sent in advance to read, and everyone has a chance to ask questions" *(124).* Autreat participants are urged to understand that some of the others will not want social interaction, and that their choice must be respected *(151).* In addition to the detailed information on their web site, Autscape provides the opportunity to put questions to previous participants through a chat list. If people have specific questions about anything to do with the facilities, service, or program, they may ask the organizers *(273).*

A fourth strategy, as with sensory issues, is that organizers may intervene if they observe or suspect that rules are broken, for example if participants behave in ways that "jeopardizes someone else's safety, comfort or enjoyment" *(301).* It also seems important to explain the social rules:

"Some autistic people scrupulously, even rigidly, follow rules simply because they’ve been told that they’re rules. Other autistic people care nothing at all for rules unless the rules make sense to them. At both extremes of the rule-following spectrum, as well as for autistic people in between, it is helpful to have clear explanations of the reasons for rules. If we know why something is a rule, and we can understand that the rule makes sense, then those of us who require logical explanations are more likely to respect and follow the rule, while those of us who tend toward rigid rule-following are better able to be flexible when necessary. In autistic space, asking 'Why?' is a perfectly normal and acceptable response to a rule, and is not considered impudent or disrespectful. Autistic community leaders who create rules must be prepared to explain and justify those rules" *(125).*

When it comes to interfacing with neurotypical staff, the Autscape web site notes that the venue must have an "understanding and accommodating staff willing to be asked literally hundreds of highly detailed questions" *(299).*

5.5 Easing constraint by sanctions

The acceptance of autistic behavior stands out as one of the fundamental (and striking) features of these autistic spaces. Meyerding notes that at Autreat she doesn't have to be anxious that her autisticness will be stigmatized by others who hear her speaking (or not speaking) or see her ticcing or stimming, and that this is amazingly comfortable. This seems to speak of an experience of being less constrained by negative sanctions. For autistic people, "ticcing and stimming" may be an important part of regulating their exposure to or recovery from sensory stimuli, as well as being an expression of joy, "a self-soother, a means of concentrating, a release of pent-up anxieties, a chance to think, or a means of warding off boredom" (Grantham 2012). The experience of being less constrained by negative sanctions also shines through when Autreat participants state that not having to hide their differences there feels like being set free from oppression, that there they can behave in an autistic way without fear of judgement, they do not have to conceal repetitions or go to an isolated place to commit unconventional acts, their ways of doing things are not defined as "wrong" or "defective", and they are not criticized for being different.

Similarly, when Autscape reassures potential participants that "there will be no explicit or implicit disapproval of those who choose not to interact" it seems to be the promise of less constraint by negative sanctions they are holding out. The same when they promise that no one will think it odd if participants use sunglasses, earplugs, headphones or other material means to protect themselves from sensory overload. When one of the bloggers tells of her relief of using the yellow badge without anybody questioning her and telling her that she functions too well for that, it also suggests that in other settings she often is questioned and that this questioning is not approving.

It seems that to a larger extent than in mainstream society, in autistic spaces people may be explicit without fear of punitive responses. Certainly, in neurotypical style sociality, explicitness may cause trouble. Many neurotypicals would interpret statements like "I don't want to talk to you" or "please stop talking" as saying more than just what the words themselves mean. In the absence of an explicit agreement to the contrary (and perhaps even then), in everyday conversation such statements would probably be perceived as conveying meaning also on a relational level. The relational subtext might for example be interpreted as "I don't like you" or "you are boring". In order to avoid this, a neurotypical might be less explicit, find an excuse, or lie. As Goffman notes (1959, p. 114), succeeding in social encounters requires a "flexible relationship to the truth", a willingness to "accentuate certain aspects and suppress aspects which might discredit the fostered impression", and a "rigid incapacity to part from one’s inward view of reality" may endanger the performance (Goffman 1959, p. 77). As Ford (2010, p. 132-133) bluntly notes: "Lying is considered a normal and acceptable thing to do among NT's", though NTs "usually distinguish levels of lying". To illustrate this, Ford lists a range of neurotypical style answers to a question like "do I look fat in this dress?" that would be used to avoid saying a direct truth like "yes, you do" (Ford 2010, p. 133). From this it may seem that many autistic people have a "less flexible relationship to the truth", and prefer others to be honest too. In a study done by Abrahamson & Behlic, an autistic participant told them that she preferred others to "tell things as they are", "straightforward and honest all the time, that is the most important thing" (Abrahamson & Behlic 2005, p. 30, my translation). Joe, an autistic participant in a study by Hurlbutt & Chalmers (2002, p. 106-107) was more uncompromising, saying that: "I can conclude that other people's inability to accept me is not my problem. Is that our problem, that others can't handle the truth?" Thus, it seems that part of what causes some autistic people to meet negative sanctions in the form of punitive responses in mainstream society, is that they have a less flexible relationship to the truth and are less willing to "accentuate certain aspects" and suppress others. Goffman's ambition was to describe and theorize face-to-face-interaction in general. But what he was generalizing *from* was in fact neurotypical interaction. Had he been studying autistic style sociality, it seems reasonable to assume he might have concluded differently.

Autistic American James Williams (2005) comments in an essay on principles of autistic interaction, that autistic people may develop friendships based on social rules that are unique to autistic relationships. And many autistic people report that they find it easier to interact with other autistic people (Williams 1994, Ford 2010). Some of this seems to be related to more matter-of-fact styles of communication, where what people say mean only what the words mean in themselves. And, should they find a presentation uninteresting and leave, it is not necessarily a value judgement of the presenter or the theme, or a relational statement. This also seems to illustrate the implicit and ingrained nature of some of the barriers autistic people meet: In a setting where neurotypical style sociality was the norm, for someone to explain that they are leaving because they find the presentation uninteresting, but that it is not a value judgement of the presenter or a relational statement, might not help much. Even with such an explanation, it might still be interpreted as a value judgement or relational statement. Furthermore, the very act of explaining might in itself disrupt the presenter's performance as well as the performance of appropriate "listener behavior".

5.6 Easing structural constraint

I have described a number of ways the patterning of social relations at Autreat and Autscape differ from "neurotypical style sociality". In these spaces there seems to be a certain shift from nonverbal to material cues on one hand, from nonverbal to explicit verbal cues, including a higher level of social scripting, on the other. Here I discuss these shifts in light of the concept of structural constraint, and other relevant studies privileging autistic voices. Evidently, for some participants the patternings of social relations at Autreat and Autscape ease a number of constraints and provide them with more feasible options. One describes her relief over not having to devote energy to appearing non-autistic the way she usually do. One notes feeling "less" for not going to Autreat this year, and that being in non-autistic space is harder when she doesn't get to spend time in autistic space. One describes being there as "being among our own". One reports that for the first time his/her communication was recognized and accepted. So far in this chapter I have described three different strategies for facilitating autistic style sociality, and all of them seem to contribute to easing of structural constraint, constraint deriving from what has become so commonplace in social structures that it is taken for granted. In 5.2, I described how the schedule, physical environment and the activities at Autscape are designed to provide a higher level of structure, enabling more people to participate. The structured discussions have a defined theme, and are moderated by a facilitator who makes sure everyone has their say. In neurotypical style sociality this is a well known way of organizing discussions, but one that typically is reserved for more formal occasions - like meetings, educational settings, court proceedings and different ceremonies. Mainly, I believe, because it is not considered necessary in interaction at the level of formality that after-dinner discussions represent. At this level the interaction typically would be regulated in more implicit ways, largely relying on nonverbal and contextual cues. But many autistic people prefer a more structured and explicit "social scripting" where the interaction is regulated with more explicit definitions of purpose or theme, of "who does what when", of what is expected of each person present. Müller, Schuler & Yates writes that many of the autistic participants in their study mentioned structured social activities as ideal contexts for interacting with others. The activities they referred to as comfortable and enjoyable were all predictable with a high level of social scripting, whether they were Catholic masses, 12-step programs, speaking clubs with strict protocol, school choirs or bands, or dance classes - in contrast to small talk and other "unstructured conversation" (Müller, Schuler & Yates 2008, p. 182). I believe few neurotypicals will be conscious of, or specifically reflect over, the level of social scripting they are following while in a typical after-dinner discussion. I also believe few would be able to describe how the turn-taking was being regulated without stopping to think. If this is correct, it would place the knowledge of structural context that they were drawing upon as they were going along at the level of practical consciousness, of what characteristically is simply done (Giddens 1984, p. 7). Thus when Autscape organizers make it easier for autistic people to participate in activities through making them more predictable with a high level of social scripting, they can be said to be easing structural constraint.

Secondly, regarding the shift from nonverbal to material cues, the prime example is the system of interaction guide badges. As the heightened level of social scripting they also seem to ease structural constraint, but this time by providing material cues for matters that in neurotypical style interaction mostly are regulated through nonverbal and contextual cues. As with social scripting, these matters are also typically left at the level of practical consciousness. The badges seem to enable participants who usually struggle to initiate social interaction, but with the help of their badge may signal an interaction-readiness and at least heighten their chances of interaction. The badges clearly enable Meyerding, who can know that one person wishes to be left alone, but that another may welcome an invitation to her table. When she characterizes this as "relaxing", it suggests an easing of constraint, and as I understand it, the main component of this is being freed from having to pick up on "vaguely described, implied, or unspoken behavioral expectations" in order to succeed in social encounters. The badges certainly represent an easing of structural constraint for those who can use them to protect themselves from unwanted social initiatives, or reduce the number of occurrences. At least - this is the case if these initiatives are not expressions of ill will, but well meant, conducted by people who do not realize beforehand that their social initiatives is unwanted, in settings where they consider it natural to take such initiatives. The badges also seem to enable some participants to recover faster from anxiety and sensory issues by making it more likely they are left alone. Combined with the rule of not pressuring anyone to socialize and the knowledge that they are free to withdraw at any time, the badge system also seems to make it easier for some to opt into activities and choose to interact.

Thirdly, the norm of explicitness also seems to free participants from having to pick up on "vaguely described, implied, or unspoken behavioral expectations" in order to succeed in social encounters. In Goffman's descriptions of face-to-face interaction, he described the ability to attune a performance to unspoken expectations of interaction partners as crucial for the success of encounters. But not only may this make much of the meaning content inaccessible to autistic people, in many cases access to what is not being said would have been the only way to understand what the conversation was about. As Ford notes in his "field guide" to understanding neurotypical behavior: talking with neurotypicals, he has often made the mistake of believing the conversation was about the things being mentioned, when it evidently was not (Ford 2010, p. 49). The style of sociality in autistic spaces seems to counteract this, as illustrated by the blogger who was relieved over not having to try and figure out what "really was being said". In a study by Müller, Schuler & Yates (2008, p. 179), an autistic participant noted being unable to understand that "in-between-the-lines stuff". Needing explicit communication was a common theme among those who participated in the study. As one put it: Autistic people are "just going to need you to spell it out literally. Not metaphorically. Not in a roundabout way. They're going to need a literal explanation" (Müller, Schuler & Yates 2008, p. 184). Thus a social norm of explicitness in autistic spaces makes sense. If more expectations are explicitly stated, it may give those who struggle with understanding the "in-between-the-lines stuff" better grounds for maneuvering the interactions, perhaps causing fewer disruptions. And again, to the extent that these features of neurotypical style interaction function as barriers and burdens to autistic people are not expressions of ill will, they may be considered instances of structural constraint, constraint deriving from what is generally taken for granted in mainstream society. The experience of being free to withdraw from interaction or activity at any time suggests that ordinarily, it is not so. If it is "wonderful" to be able to wander off alone without anybody following to ask whether you are OK, this suggests that well meant social expressions of concern may be a burden to autistic people in some instances. If access to more information before and during events may enable autistic people to participate, it raises a question: What is an adequate level of information? Or rather: For who is a given level of information adequate? And if that is the level that is built into social norms that typically regulate how much information one may ask for without risking punitive responses, this also suggests one way typical social norms create barriers inclusion and participation for some citizens. Similarly, if being able to ask "why" may be an important factor in enabling some autistic people's participation, this will be a much less feasible option in neurotypical style interaction, where asking "why" beyond a certain degree often will be perceived as impudent, as a challenging of the rule or the authority of the person stating the rule. Such matters can be learnt. But where neurotypicals largely learn social rules though social interaction, many autistic people have to learn them explicitly and may never integrate the knowledge on an intuitive level as practical knowledge. In its turn this may contribute to all kinds of interaction, but perhaps especially neurotypical style sociality, forever being taxing. Reporting from their study, Ryan & Raïsänen writes about

> the learnt rather than lived way participants' experienced social life. Because social rules are not internalised or felt, they have to be constantly re-learnt over and over and this is a harder task if there is a gap between experiencing particular situations. [ ] the inability to reach the stage of taken for grantedness meant that interactions remained conscious activity – 'conscious work' as Richard called it – a process that had limitations and was tiring, draining and constant (Ryan & Raïsänen 2008, p. 140).

6 Third aspect: Protecting the boundaries of the space

6.1 Chapter Overview

In chapter 4 and 5 I showed the extent to which the conditions of autistic spaces are socially produced, how much they depend on a majority of participants following a set of rules. Presumably this also necessitates managing a) who are allowed to enter these spaces and b) on what terms. I understand this as a clear prerequisite for creating these conditions that may constitute spaces as autistic spaces. In this chapter I present my findings about how these aspects seem to be managed at Autreat and Autscape.

6.2 Autreat and Autscape as inclusive spaces

The autistic spaces of Autreat and Autscape are inclusive spaces. The Autreat 2012 Call for Proposals states: "Autreat aims to be welcoming and relevant to the broadest possible cross-section of the autistic population: Autreat is attended by autistic people who speak and by autistic people who do not speak; by autistic people who communicate fluently and by autistic people who have limited communication; by autistic people who live independently and by autistic people who need intensive support with daily living; by autistic people who have jobs and by autistic people who live on disability benefits; by autistic people who are able to present as 'socially acceptable' and by autistic people who require support to help them manage their behavior; by autistic people who have been labeled 'high-functioning' and by autistic people who have been labeled 'low-functioning' including some autistic people who have had both labels, at different times or under different circumstances" *(152).*

At Autreat, "'High-functioning' and 'low-functioning' became inconsequential here. There was no hierarchy of who was 'more abled' and who was not. Some people talked. Some didn't. Some sat at keyboards in wheelchairs. Some had stereotypies, like hand flapping or tics with the head. Some were mentally retarded" *(178).* Sinclair quotes the father of a non-speaking autistic adult as saying of the first Autreat in 1996: "Here people who could paint and draw equally shared experiences with those who can't hold a pencil or a brush. People who are very articulate equally shared experiences and understood those who could only jump or clap their hands or point to letters on a letter board or picture board to respond to a question" *(77).* Upon founding ANI, the three co-founders decided their mission was to "advocate for civil rights and self-determination for all autistic people, regardless of whether they were labeled 'high-' or 'low-functioning'" *(20).* And further, Sinclair notes, "we had all fit descriptions of 'low-functioning' autistic people when we were younger. We all recognized commonalities between ourselves and autistic people who were still considered 'low-functioning'. We also recognized abilities and strengths in many autistic people who just didn't happen to share our skills in using language" *(20).* They had already proven themselves to be a resource to parents of autistic children *(14).* Finding ways to include and educate parents and professionals was the only way they "could hope to affect the lives of autistic people who weren't able to participate on their own" *(20).* Professionals are welcome at Autreat as long as they participate on autistic terms *(148).*

Autscape also focuses on diversity, welcoming "participants from across the spectrum" *(269).* "All varieties of autistic people from all parts of the spectrum are welcome, whether diagnosed or not. Diversity enriches the experience for everyone *(251).* Neurotypicals are also welcome: "Non-autistic people, be they family members, professionals, friends, relatives or interested others, are very welcome. All we ask is tolerance, respect for 'autistic space' and an open mind" *(248).* An Autscape participant wrote: "There are a huge range of abilities among the 50-60 people who attend Autscape each year, from people who really can hardly speak at all, and seem very disconnected from the world around them (and yet, given access to a computer, sometimes turn out to be quite intellectual and taking university degrees!) to others who would quite easily pass as 'normal' in the outside world" *(345).*

Neither Autreat nor Autscape are segregationist communities. Both seem to strive to find a balance between activism and creating empowering spaces for autistic people. ANI is "not as politically intense as some autistic activist organizations" *(38).* Similarly, the Autscape web site claims that: "Autistic activism is important", but "activism is not what Autscape does. Autscape exists to create a positive and accepting environment in which autistics can truly be ourselves amongst others who are fundamentally similar" *(268).*

Both conference events are clear that presenters must commit to presenting autism as acceptable, a legitimate difference. The Autreat 2012 Call for Proposals states: "We are not interested in presentations about how to cure, prevent, or overcome autism. We do not appreciate having non-autistic people come into our space to talk to each other about how difficult we are to deal with, or how heroic they are for putting up with us" *(152).* Likewise the Autscape web site states: "We do insist that presenters acknowledge the right of autistics to exist (so we would not accept presentations focussed on cures or how to make us normal for example)". But, and in this I perceive a somewhat different stance than ANI and Autreat, they go on to say: "We welcome all autistics whatever their personal views on autism politics (issues such as whether there should be a cure for autism or whether autism is a disability or a difference)" *(268).*

6.3 Defining the terms of inclusion

Securing autistic majority is evidently an important part of creating the autistic spaces of Autreat and Autscape, and of creating the empowering effects of being there that many of the bloggers report. A majority of neurotypicals could have not created this effect, even if they had fulfilled all rules and terms of inclusion. At the same time, just being autistic does not suffice, because autistic people's needs and preferences vary so much. Autreat and Autscape are designed to accommodate some autistic needs and preferences at the expense of not accommodating others. Sinclair notes that some of the common characteristics among the founders of ANI have influenced conditions at Autreat:

"We were all highly verbal (though not necessarily fluent with oral speech) and comfortable with written communication (a built-in selection factor when most contact was via email); we tended to be more sensory-defensive than sensation-seeking; more prone to shutdown than to meltdown when overloaded; most of us did not have major difficulties with impulse control; we understood and respected personal and property boundaries. Whatever difficulties we had in functioning — and those difficulties might be quite severe, limiting our abilities to feed and care for ourselves — our difficulties did not generally interfere with other people around us. The ANI community has thus developed to have a high reliance on written language as a means of communication, and to have customs and rules that place greater emphasis on protecting people's boundaries than on allowing complete freedom of self-expression. People who need to protect themselves from sensory and social overload are more likely to feel comfortable and supported by ANI's rules and customs, while people who need intense stimulation, and/or who struggle with impulse control, may find some of our rules uncomfortably restrictive" *(96).* Inspired by Autreat, Autscape seems to have adopted largely the same type of accommodations and cater to about the same segment of the autistic population. Thus, it is possible to imagine autistic spaces designed to accommodate other needs and preferences and catering to other segments of the autistic population. But creating any kind of autistic space may require attention to "governing what is seen to be appropriate ways to behave", as Rosqvist, Brownlow & O'Dell (2012, p. 1-2) puts it. In any kind of autistic space, allowing too many people to enter who are not able or willing to abide by certain given rules and reproduce certain practices may make it impossible to uphold the conditions that make it an autistic space.

This challenge is acknowledged both at Autreat and Autscape: "People can be, and occasionally have been, excluded from participation in ANI functions — on the basis of behavior that victimizes other people, not merely for being too different or too severely disabled", Sinclair writes *(108).* The Autreat Orientations Guide notes: "The only behaviors that are not acceptable are actions that infringe on the rights of others: by violating their personal boundaries or their property boundaries, or by preventing them from participating in Autreat activities, or by causing undue distress through physical, verbal, or sensory assault" *(81).* But one autistic blogger, self described as a friend of an autistic woman whose registration for Autreat was rejected, harshly attacks Sinclair, claiming Sinclair gave a libelous and false reason for this rejection, that the real cause was Sinclair's disagreement with the woman's opinions and politics, and that Autreat would profit from more room for differences of opinion *(239).*

The Autscape web site includes a detailed protocol for managing boundaries/ challenging behavior. The protocol states that Autscape wishes to avoid prescribing how participants should behave, but notes three sources of limitations: English law, internal Autscape guidelines to ensure that the environment is safe and comfortable for all participants, and venue guidelines *(301).* The protocol suggests ten steps to be followed if "a matter comes to the attention of the committee in which guidelines arising from any of these areas have (or are suspected to have) been broken" *(301).* A committee member should attempt to solve the matter at the lowest possible level by clarifying any misunderstanding, or informing the person of what guideline has been broken and the consequences that may arise from continuing to do so. If this does not resolve things, the matter should be lifted to the attention of the committee, who then decides how it will be dealt with. After it has been dealt with, the committee should convene in order to review what happened and examine the guidelines that have been broken to see if they should be amended. If a participant has engaged in serious or repeated infringements, the committee may ask him/ her to agree to a behavioral contract. If it should prove to be impossible for a participant to remain at Autscape, the leave taking is to be handled with sensitivity for his or her vulnerability and safety in traveling. Also, provision must be made to explain the situation to the other participants and ensure them that they are safe and not at risk of removal *(301).*

It seems obvious that creating autistic space depends on reserving the right to not include or to remove participants who are not able or willing to behave in ways defined as appropriate for the space. This is not special for autistic spaces. On the contrary, it is a right any conference or venue would claim. The difference lies in what is considered inappropriate. Some disqualifying behaviors at Autreat or Autscape might be considered inappropriate also in other venues and mainstream society. But some such disqualifying behaviors might be considered quite normal in other settings, which would probably make a decision to exclude the person harder to understand and easier to attack outside the autistic space. It seems that in some respects it may be important to create a certain understanding and acceptance for the rules of autistic spaces also outside of the spaces themselves.

Ife addresses another aspect of building communities, the issue of sameness and difference. Often communities are built on commonality, as when "people have sought community membership on the basis of some common element" or the community is "built around a cultural identity" (Ife 2010, p. 14). This certainly seems to be the case in both Autreat and Autscape. A danger is the "natural and inevitable connection between strong communities built around commonality and the practice of exclusion and 'border protection'" (Ife 2010, p. 14). In comparison, communities built on difference can be far more resilient and viable. Ife recommends never regarding the boundaries around the community as settled, always questioning them, always challenging the capacity of the community to embrace rather than spurn people and ideas from the outside (Ife 2010, p. 16). The communities of Autreat and Autscape are certainly diverse. At the same time it is interesting to note how the blogger attributes the decision of rejecting the woman's registration for Autreat solely to Sinclair, not to Autreat or to the Planning Committee. This may be a coincidence. It still makes me wonder about the style of decision making in ANI and how well internal decision processes are publicized outside ANI. I could not find anything on the ANI web site similar to the Autscape protocol. I wonder whether this also reflects differences in how decisions are made in the two communities. In any case, the Autscape protocol resonates well with Ife's recommendation of questioning the boundaries, in that after infringements has been dealt with, the committee examines the guidelines that have been broken to see if they need to be amended.

6.4 Managing the terms of inclusion

My research questions also ask how the conditions at Autreat and Autscape are created. Building on chapter 4 and adding the findings from this chapter, I believe I can piece together an outline of how the terms of inclusion, how "governing what is seen to be appropriate ways to behave”, are managed at Autreat and Autscape.

The first step of inclusion management seems to involve attracting the type of participants who will both enjoy the event and fit in and making others understand that they either may not enjoy the event or not fit in. Autreat and Autscape provide extensive and detailed information on their web sites, with detailed descriptions of what potential participants may expect and what is expected of them. Also, both make provisions so that people who may be interested in participating can pose questions both to previous participants and organizers. The goal at this step may perhaps be called *enable accurate self-selection among potential participants.*

The second step seems to involve making sure all participants, especially new participants, receive so much information at an early stage, that it is likely they will be able to contribute to reproducing the conditions of the autistic space. For example, on arrival Autreat participants receive oral and written information through the orientation session and Orientation Guide. The goal at this step may perhaps be called *at the outset, provide all participants with an information "starter pack".*

The third step seems to involve monitoring participants closely enough so that a sufficient number of the infringements against rules/guidelines that happen are picked up by some of those in charge. This will be a prerequisite for providing feedback. The goal at this step may perhaps be called *pick up instances of rule-breaking.*

The fourth step seems to involve having a system in place that ensures that participants who break rules/guidelines receive feedback, enabling them to change their behavior to make it compatible with reproducing the conditions of the autistic space. At Autscape this covers several defined levels of intervention, from providing explanations and warnings to behavioral contracts. The goal at this step may perhaps be called *provide sufficient feedback and behavioral support*

The fifth step seems to involve reserving the right to exclude people after fair warning and support has been given, having a system in place that allows the exclusion of participants who are not able or willing to behave in ways defined as appropriate. Such exclusion is a feature of both Autreat and Autscape. The goal at this step may perhaps be called *exclude participants who threaten the conditions of the autistic space.*

7 Informing and challenging current efforts to promote inclusion and accessibility for all

7.1 Chapter overview

In chapters 4 and 5, I showed how the physical and social adaptations at Autreat and Autscape ease a number of constraints for some autistic people. In this chapter I review and discuss these constraints in light of the concept of Universal design, general aspects of legislation related to disability and discrimination, and studies that privilege autistic voices. In the first part I look at constraints related to sensory issues, before moving on to constraining effects related to social interaction. Exploring some examples of such effects more closely, I discuss some consequences of the present situation and draw a few practical conclusions. Towards the end I examine the extent to which the constraints highlighted by my study may be called discriminatory.

7.2 Physical aspects of environments

The sensory issues being accommodated at Autreat and Autscape seem primarily related to light, noise, smell and touch. Sensory issues related to autism are well documented. For example, after studying forty-five autobiographical texts by autistic authors, Davidson concluded that they provided

> good reasons and recommendations for toning down ‘toxic’ stimuli – such as fluorescent lights – and for redesigning or reorganizing the shared sensory ‘furniture’ of social space (Davidson 2010, p. 305).

Davidson uses the word "toxic". In chapter 4 I noted autistic people's use of words like "assault, "noxious stimuli", "nightmare" and "bombardment" about experiences in conditions that I believe most neurotypicals would consider normal. Many of my sources refer to sensory overload. Caldwell (2006) notes that unchecked, sensory overload in autistic people may lead to the painful, confusing and potentially terrifying state called fragmentation/meltdown. It seems clear that typical environments cause some autistic people to have experiences most people would find intolerable, and that this hinders their participation in society. The fact that most people do not have such experiences in typical environments does not make this acceptable, if the goal is "an architecture of social participation" to quote Steinfeld & Maisel (2012, p. 21), or, as the Americans with Disabilities Act (1990) states: "equality in opportunity". That light can be "blinding" or "eye-stabbing" is not special for autistic people, as can be readily demonstrated with a 300 watt light bulb. Hence, the difference does not lie in the need for suitable light levels, but in what can be considered to be suitable. It seems clear that levels and types of light that may be well adapted to the average neurotypical, are not suitable for many autistic people. This does not seem to be common knowledge in Universal design. It is not within the scope of my study to ascertain *how* common it is - but it seems significant that no autistic needs regarding lighting are mentioned in the Internal Environment "best practice" guidance booklet from The Centre for Excellence in Universal Design in Ireland. The sole reservation about fluorescent lighting is the danger of interference with hearing enhancement systems (Centre for Excellence in Universal Design 2013). In the guidance booklet *noise* is amply mentioned and discussed, but only generally, as if same considerations apply for everybody. Also here the only exception is related to hearing enhancement systems (Centre for Excellence in Universal Design 2013). Yet, a number of studies have described sensory issues in autistic people. Apart from Davidson (2010) there is for example the UK study done by Beardon & Edmonds (2007): Among 237 autistic people, 60 reported that sensory issues and/or crowding made it difficult to use public transportation. For 6 it was impossible. Enduring the sounds and smells (smoke, perfume) of other passengers was especially taxing. Other studies have also highlighted crowds, sounds and smells as obstacles to autistic people's participation (Madriaga 2010, Ryan & Räisänen 2008).

One might ask: in what society would these sensory issues not be issues? Can such a society be envisioned, a society where autistic people maneuver shared and public spaces with the same ease as most neurotypicals do at present? Such a society is implied by goals like "full and effective participation in society on an equal basis with others" (UN 2006, p. 4) and the ADA goal of "equality in opportunity". How far such issues can be accommodated within a Universal design framework is certainly a matter for further research. But, if one accedes that for some autistic people these issues will continue to be issues in the foreseeable future, and given current ambitions to create inclusive and accessible societies, it seems reasonable to fall back on the goal of creating accessibility in less universal ways. And perhaps here the range of adaptations at Autreat and Autscape that enable autistic participants to self-regulate exposure to and recovery from sensory stimulation may be considered current "best practices". As shown in chapter 4 and 5, in both these autistic spaces accessibility is achieved through a combination of general adaptations and enabling participant to self-regulate. One of these "best practices" that enable self-regulation is providing access to low-stimulation rooms. And to the extent that it is not possible to create universal sensory accessibility for autistic people in mainstream society, one of the ways of bringing shared and public spaces closer to the goal of universal accessibility might be to ensure that autistic people maneuvering them could be secure in the knowledge that a low-stimulation area was never far away. Considering the consequences of fragmentation/meltdown for the autistic person and for others, providing access to low-stimulation areas for autistic people to use at their discretion seems reasonable. This may perhaps be compared to having access to toilets, which is near universally accommodated in shared and public spaces. Secondly, enabling self-regulation without having to withdraw, which also is a reasonable expectation, may require heightening public awareness of such sensory issues. A goal would be that autistic people who need to reduce levels of stimulation in public, for example by using ear-plugs, headphones, sunglasses or different forms of stimming, may do so without punitive responses from other people. In creating such awareness, it might also be favorable to focus on *why* some autistic people need such adaptations, namely the failure of society to create environments that accommodate all.

Smell is not mentioned by The Centre for Excellence in Universal Design, nor in Steinfeld & Maisel (2012) but clearly is an accessibility issue for some autistic people. For example, Casanova cites a court case involving an autistic van driver who

> refused to drive a company van because she smelled deodorant in it and could not stand it. When reproached by a supervisor, she threw a fit and kicked a chair across the hall. She was fired the next day. Anyone familiar with autism knows that sensory responses can be particularly acute in persons with ASD. For Cathleen, the very prospect of being stuck in a smelly vehicle with closed windows was probably enough to trigger a break-down. Nonetheless, Cathleen was found not entitled to ADA protection and the case ended in summary judgment for the employer (Casanova 2010, pp. 46-47, citations removed).

Though this is only a single case, it does suggest that accepting smells that most neurotypicals find acceptable or tolerable as grounds for ADA protection may still be a way off. Yet, in the spirit of Universal design one could ask: might other groups also benefit from being less exposed to smells in shared and public spaces? Here the answer is yes, for example people with allergies, pregnant women in the first trimester, or people undergoing chemotherapy. When it comes to the smell of smoke, the problems it causes some autistic people adds to the already considerable case against smoking as a health hazard. Perfume, deodorant and other scented products is another matter, though. To quote from a publishing house's advertising for a book about perfume:

> Perfume is a cutthroat, secretive, multibillion-dollar industry, symbolizing glamour, beauty, and status. Jean-Claude Ellena, the superstar of the perfume world, opens the doors to his laboratory and explains the process of creating precious fragrances, revealing the key methods and recipes involved in this mysterious alchemy along the way (Hamilton Book 2012).

The question is, given the value that so many people give to using "precious fragrances" as well as deodorants and scented skin products, and the fact that unlike smoking, using such products is not a known health hazard: would the majority be willing to give up using scented products in order to make public transportation, schools, workplaces and commercial facilities more accessible to a small group who now are excluded? I find that unlikely. And, given the unlikeliness of that, is it possible to make it easier for all kinds of people to protect themselves from smell if they so wish? Again this may be a matter of both providing people with the means to protect themselves, and of creating greater acceptance for using them. Enabling self-regulation in relation to sensory issues tangents the Universal design goal of "*Personalization.* Incorporating opportunities for choice and the expression of individual preferences" (Steinfeld & Maisel 2012, p. 90, emphasis in original). How such self-regulation can be enabled and what products might help autistic people self-regulate more effectively in shared and public spaces, is an area that obviously would benefit from further research.

Regarding these issues, it seems worth repeating that the needs in themselves are quite normal. Both in the USA and UK, ensuring that levels of sensory exposure and stimulation in transportation, schools, work places and commercial facilities are held within certain ranges is the subject of numerous laws and regulations. The difference lies in what levels of exposure and stimulation are considered suitable or safe.

Autreat and Autscape demonstrate how inextricably linked the sensory aspect of environments is to the behavior of other people: In order to ease constraints for some participants, organizers need to address the behavior of all. To increase the options for participants with visual sensitivities, others participants must be careful with camera flashes. To increase the options for participants with auditory sensitivities, other participants must restrict the nature and volume of the sounds they make or cause to happen. To increase the options for participants with olfactory sensitivities, other participants must be careful about what smells they bring into shared spaces. This is of course not particular to Autreat and Autscape. At any mainstream conference, organizers will ensure that participants' behavior do not unreasonably limit other participants' options. Any participant introducing sensory stimuli experienced as aversive by other participants will attract the attention of organizers. Whether it is a matter of causing instances of light that are blinding or eye-stabbing to other participants, noises that cause terror or pain in other participants, introducing smells that make it hard for other participants to breathe, or touching other participants in ways they find startling or unpleasant, such behavior will be regulated also in typical spaces. Again the differences are related to differences in tolerance and suitability. But there also other differences. For example, the outcome of the case where a person refused to drive a van smelling of deodorant might have been different, if the case instead had been that she

> refused to drive a company van because she smelled excrement in it and could not stand it. When reproached by a supervisor, she threw a fit and kicked a chair across the hall. She was fired the next day.

Would she still have been fired, and would the court still not have found her not entitled to ADA protection? My point is that smell touches on both neurological and cultural levels of experience, and that neurological differences between autistic and non-autistic people make it hard to rule out that to some citizens, the smell of deodorant may be as bad as the smell of excrement to most. And again, if the goal is equality in opportunity, the fact that most people do not experience the smell of deodorant as intolerable does not make it acceptable to pressure those who do to endure it. This also illustrates the magnitude of the changes that might be necessary to create a truly inclusive society seen from the perspective of autistic people: In order to build down barriers for some autistic citizens, all citizens' behavior would have to be addressed. This is also the case when it comes to the last sensory issue, *touch*. After a study involving a qualitative analysis of autobiographies written by autistic people, a group of researchers found that

> sensitivity to touch was a reoccurring theme in these authors' autobiographies. The ways that individuals experienced touch, and at times feared it, was considered a barrier to interaction with others (Causton-Theoharis, Ashby & Cosier 2009, p. 90).

Issues related to noise and touch bring us into the realm of socially produced barriers, the performed aspects of environments that go beyond the scope of Universal design.

7.3 Performed aspects of environments

7.3.1 Sensory issues

The performed aspects of environments concern the ways external structures facing actors to a large extent are created and upheld by other actors. For example through practices such as expressing approval by clapping. Well within the tolerance levels of most people, to some autistic people it represents a threat of sensory overload. Thus, to them, being applauded in this way might be aversive, an expression of ignorance or disrespect rather than approval. As noted by several bloggers, at Autreat people wave or "gracefully flap" their hands instead of clapping *(202, 242).* In settings where this is the norm, those sensitive to sound will be able to go places where they know there may be expressions of approval, secure in the knowledge that there will not be clapping. But, another example of a dilemma in Universal design, if this was the norm in society, it would exclude people who are blind or have low vision.

To the extent that not touching others is the norm in autistic spaces, people can be reasonably secure of not being touched by strangers. But what is considered appropriate ways of touching strangers in public spaces varies between different cultures, ethnic and social groups. In Western societies, tapping somebody's shoulder to get their attention is common, and often is done by a light touch. Ironically this may make it worse. Autistic American Temple Grandin writes that to her, light touch feels like a cattle prod (Grandin & Scariano 1986). To elaborate on this point, it means that in going to a mainstream public event, Grandin can never be sure of not being touched in ways that to her feels like a cattle prod. Even if she protests, the damage will already be done. She will be surrounded by people who can neither be expected to recognize her as an autistic person, as an autistic person especially sensitive to light touching, or to possess the highly specialized knowledge that would enable them to meet her appropriately. To avoid being touched, she would have had to explain her need to every person in her vicinity. But even after doing so, she could not be sure of not being touched. Many women experience being touched in public by strangers in ways they find inappropriate, and presumably, those touching them have had an infinitely better opportunity of being informed in such matters than the people surrounding Grandin would have had of being informed about autistic people's sensory issues. And even if she could have explained her need in a way that made people refrain from touching her, having to explain would already have put her at a disadvantage compared to people who can attend public events without having to explain their needs. The same also applies to noises and smells: No matter how much the general public can be brought to respect autistic sensory issues, the challenge of identifying who in their vicinity may be autistic, and what their specific issues may be, will remain. This suggests that autistic people with sensory issues may never experience "full and effective participation in society on an equal basis with others" (UN 2006, p. 4) in a society where neurotypicals are in majority.

7.3.2 Issues concerning styles of sociality

As established in chapter 4, the interaction badge system at Autreat and Autscape represents an easing of structural constraint for those who can use it to deter unwanted social initiatives. It enables some to recover faster from anxiety and sensory issues, and can make it easier to opt into activities and choose to interact. As established in chapter 5, the social rule of explicitness at Autreat seems to free some from having to pick up on "implied, or unspoken behavioral expectations" in order to succeed in social encounters. At Autscape, activities tend to have a higher level of structure and social scripting, enabling more people to participate. To do this, organizers use relatively ordinary means that are used to fulfill the same needs in neurotypical style interaction, but are typically reserved for more formal occasions. In each case, again, the needs are normal, the differences primarily related to levels of tolerance and suitability. All people need to be able to regulate their interaction. All people need activities to have a sufficient level of structure. And all people need to be able to pick up on interaction cues. As Goffman points out, the success of any encounter depends on participants being able to read each others' cues, both verbal and symbolic expressions "given" and nonverbal expressions "given off" (Goffman 1959, p. 14). But cues that many neurotypicals consider "loud and clear" do not meet the level of clarity required by many autistic people. This tangents another Universal design goal: "*Awareness.* Ensuring that critical information for use is easily perceived" (Steinfeld & Maisel 2012, p. 90, emphasis in original). It does not seem unreasonable to refer to cues that enable people to interact successfully with others as "critical information", even though this may not be what Steinfeld & Maisel had in mind. At the same time, the level of explicitness that, if universally implemented, would make the world more accessible for many autistic people is also something that a neurotypical majority probably would not be willing to provide on a universal level. On one hand, many neurotypicals might profit from being more explicit and from others being more explicit, as can be illustrated by the extensive focus in couples therapy on getting partners to state their needs and expectations more explicitly, not relying on the other to pick up on "vaguely described, implied, or unspoken behavioral expectations". At the same time, what would be lost? Large parts of what may be some of the most treasured areas of communication: the art of innuendo, the double meaning at the heart of much comedy, irony, the implied meaning at the heart of so much poetry, the whole genres of flirtation and of "feeling each other out" before committing to something that cannot be retracted if it proves to be unwelcome. These are not things the neurotypical majority would give up easily.

But taken together, these differences suggest that the levels of cues, structure and social scripting that is adequate for most neurotypicals and therefore permeate social structures in a society dominated by neurotypicals, are inadequate for many autistic people and may be understood as barriers to their inclusion and participation. At the same time, current efforts to promote inclusion and accessibility seem to address this form of barriers to a very limited degree. When it comes to the performed aspects of environments, such efforts seem mainly to consider "attitudinal barriers" (UN 2006, p. 4). This suggests a number of avenues for future research, as well as political debate: Regarding the kinds of performed aspects of environment that do not come under the heading "attitudinal barriers", to what extent can such aspects be integrated into the theory and practices of inclusion? To what extent is it desirable? And, where the line gets drawn, how can drawing the line there be justified? On another tack: as the list of groups claiming to be discriminated against grows, each and every group calling for more awareness: How many minority issues should each and every citizen be aware of and have skills in accommodating? How much knowledge of special considerations is it possible to instill in the average public servant, or reasonable to expect?

One of the challenges of such debates is to hold on to a social justice perspective. That autistic people may profit from a heightened level of cues, structure and social scripting is well known both in special education and among providers of health and social services and support in daily life. But to the best of my knowledge, this is mainly defined as accommodation for "special needs", not accommodations that may contribute to securing autistic peoples' civil rights, for example to inclusion and participation. This is also an area that might profit from further research. What understandings drive the adaptations already being done? What differences does it make if adaptations are made on the grounds of all citizens' right to inclusion rather than "special needs"?

Moving from the kinds of performed aspects of environment that do not come under the heading "attitudinal barriers" to the ones that do, it is evident that the lack of acceptance of autistic social behavior in mainstream society also constitutes a barrier to some autistic people's inclusion and participation. For many participants, the contrast between being at Autreat or Autscape and their everyday experiences in mainstream society seems profound. An Autreat participant writes that "so many autistic people, myself included, find the social experience at Autreat revelatory. For many of us, Autreat is simply full of kindred spirits” *(230).* Some of the participant statements from chapter 5 bear witness to the existence of practices in mainstream society that are clearly detrimental to "independence, social engagement, and the communication of a positive identity" (Steinfeld & Maisel 2012, p. 13) for the persons subjected to them. For example: "This was the first place I wasn't criticized for being different", and being here "showed me that being me was okay, and that my ways of doing things weren't 'wrong' or 'defective,' just different". This also applies when Meyerding comments that at Autreat she doesn't have to be anxious her autisticness will be stigmatized by others who hear her speaking or see her ticcing or stimming, and that this is amazingly comfortable *(161).* Being stigmatized can be understood as being "pejoratively regarded" in broader society, to be "devalued, shunned or otherwise lessened in their life chances" (Alonzo and Collins 1995 in Green 2009, p. 13). In social and political science the term *stigma* denotes a "distinguishing mark of social disgrace" (Collins 2000 in Green 2009, p. 14). In light of such definitions, to state that it is amazingly comfortable not to be stigmatized seems modest.

These participant statements also bear witness to just how profoundly autistic needs, preferences, interests and behavior may challenge neurotypical taken-for-granted assumptions of everyday life. On one hand, a number of researchers sympathetic to the autistic way of life are generating studies that value autistic people's contributions to, in Bourdieu's (1977, p. 169) terms, pushing back the limits of doxa. For example, Bagatell (2010), reporting from her study in a support group for autistic adults, noted that one of her surprises was discovering the highly social nature of the support group meetings. However, they involved social practices that she did not originally perceive as social, as they did not occur in the conventional way with eye contact, small talk, and back-and-forth dialogue. Not only may autistic sociality be hard for neurotypicals to understand, she comments, they may have difficulty recognizing it as sociality (Bagatell 2010, p. 39). In a similar vein, Ochs & Solomon (2010, p. 70) writes that autistic sociality brings clarity to the understanding of foundational properties of human sociality, for example by highlighting other possibilities in interaction, like the "side-by-side" and "oblique" orientations (Ochs & Solomon 2010, p. 81). On the other hand, autistic people report being abused and mistreated by neurotypicals and neurotypical daily practices on many levels. For example, the Autistic Self Advocacy Network claims that autistic children and adults often are the targets of abuse and bullying in schools and elsewhere (ASAN 2013a). Autistic American Julia Bascom, founder and organizer of The Loud Hands Project, refers to autistic people as a community who are routinely silenced, as people living in an unsafe and abusive world where cultural processes and ghettoization contribute to making them strangers to themselves (Bascom 2012, pp. 7-8). Several autistic sources refer to autistic people being abused, tortured or murdered, in many cases by family members (Smith 2006b, Oakley 2011, the dedication in Bascom 2012). On the more subtle side of abuse, Bascom notes:

> One of the cruelest tricks our culture plays on autistic people is that it makes us strangers to ourselves. We grow up knowing we’re different, but that difference is defined for us in terms of an absence of neurotypicality, not as the presence of another equally valid way of being. We wind up internalizing a lot of hateful, damaging, and inaccurate things about ourselves, and that makes it harder to know who we really are or what we really can and cannot do (Bascom 2012, p. 7).

7.3.3 A question of discrimination

It is not a stretch to say that autistic people are discriminated against, both directly and indirectly, in the sense that conditions in much of mainstream society puts autistic people at a particular disadvantage compared to neurotypicals. In many cases both the built and performed environment privileges neurotypicals, but how well this is covered by current legislation seems to vary. As noted in previous chapters, under the Americans with Disabilities Act of 1990, citizens can expect a degree of protection in matters of "employment, State and local government, public accommodations, commercial facilities, transportation, and telecommunications" (U.S. Department of Justice 2009). Similarly, the British Equality Act 2010 covers employment, education, the provision of goods, facilities and services, management of premises and exercise of public functions (Equality Act 2010), and considers a practice to be discriminatory if it puts persons with a "protected characteristic" at particular disadvantage compared to persons without this characteristic (Equality Act 2010, p. 10). Indirect discrimination is linked to rules, policies or practices that apply to everyone but particularly disadvantages people with a particular impairment (Government Equalities Office 2010, pp. 4-6).

Obviously, direct discrimination in all its forms should be counteracted. This is a goal that perhaps may be reached through more acceptance of differences, greater will to accommodate, and more accommodations on both general and individual levels. But my study does not really enter the realm of direct discrimination, primarily contributing to shed some light on barriers that may be regarded as indirect discrimination. And, as I believe I have shown, the forms of discrimination that limit autistic people's options in daily life run so deep into the fabric of institutionalized neurotypical values and taken-for-granted assumptions, that it is an open question how far the majority is willing and able to go in order to change established patternings of social relations and practices in order to more fully include an autistic minority. The ambition of assuring "equality of opportunity, full participation, independent living, and economic self-sufficiency" as the Americans with Disabilities Act (1990) states "the Nation's proper goals regarding individuals with disabilities" to be, may simply prove to be more feasible in relation to other groups than autistic people.

It may be that a more attainable initial goal on a societal level regarding autistic people might be implementing the principle "first, do no harm". Reaching such a goal would require more research. By exploring the writings of some autistic people, I have highlighted some issues. But how common these issues are in the autistic population is yet to be known, as is what other issues exist that has not shown up in my material. But I am confident that that best way to develop such knowledge is through harnessing the knowledge and resources of autistic people themselves. If the issues highlighted in my study should prove common among the autistic population, and given the challenges involved in accommodating such issues universally, this would be a strong argument for enabling the development of autistic spaces in far more places on a far more permanent basis. Perhaps a Universal design that also took account of the needs of autistic people would proscribe building autistic spaces, "neurodiverse spaces" as O’Dell, Brownlow & Rosqvist (2011) calls them, in every local community, for the benefit of all.

8 Beyond and between categories

8.1 Chapter overview

In the previous chapters I have done my best to access the perspective of the texts from which I have compiled my data material and to privilege the authors' voices. At the same time, as Ezzy notes

> it is impossible to understand the reality of the other person entirely on his or her own terms. On the other hand, the meanings of the other person are never entirely reduced to our own preconceptions. Thus, interpretation involves an ongoing circular process of moving between one's own perspective and the perspective of the other person (Ezzy 2002, p. 27).

In this chapter I take a more solid step back into my own perspective to look at the two categories I have operated with, "autistic people" and "neurotypicals".

8.2 About categories

I opened this thesis with remarking "I am not autistic". This is true. I am a neurotypical, though I may not be the most neurotypical of neurotypicals. But any category spanning me, Justin Beiber and Prince Charles is bound to have limited explanatory value. We are also all male, another hopelessly wide category. Neither of these two categories are capable of saying much about our needs, values and commitments in life, even when taken together. Yet, in our respective societies they will have a certain relevance to how others see us, meet us and treat us. And perhaps we can bring in further categories into which all three may be placed, such as "white", "heterosexual", and perhaps "abled" (as opposed to "disabled"). Looking at the ways such categories are made relevant in the societies in which we live as male, white heterosexuals, it becomes possible to see some common features in our options in daily life. Such an analysis might gain more depth by bringing in how "counter-categories" as "autistic", "female", "black", "homosexual"/ "transsexual"/"asexual", and "disabled" are made relevant in the societies in which we live. And even more depth, if we were to look at how all these different categories intersect, as is the focus of the research perspective called *intersectionality*.

As a perspective in research, intersectionality not only rejects single analytical categories as insufficient, but goes beyond the simple additive effects of belonging to several "disadvantaged" or "advantaged" categories, to study the complex patterns created through the combination of these different categories (Söder & Grönvik 2008, p. 15). For example in the life of an autistic black woman, studying the way each of these categories are made relevant in society as well as how they interact and influence each other in her life and self-understanding may enable much more precise descriptions of her situation. Such an approach may also contribute to make differences within single categories clearer. A classic example is the critique raised by black feminists in the 1970s, when they claimed that white middle-class feminists were universalizing their perspectives and experiences in ways that contributed to veiling oppression based on race and class (Söder & Grönvik 2008, pp. 11-12).

8.3 Identity politics and dialogue

Mobilizing on the grounds of a common characteristic in order to change the way this characteristic is understood and evaluated in society is the essence of what is known as *identity politics* (Söder & Grönvik 2008, p. 16). But, as feminist theory has taught us, one of the pitfalls of focusing on a sole characteristic is the downplaying of differences within the movement in ways that obscure how some members are being impacted by how other characteristics are made relevant in the societies in which they live. There is always a danger of some members being in a position to define both the situation and the goals in ways that silence or alienate other members through invalidating their experiences and perspectives. Regarding the neurodiversity movement, this might for example be the case if more verbal and outspoken advocates and activists define an autistic platform and agenda through universalizing their perspectives and experiences to the detriment of less verbal and outspoken autistic people, or in ways that alienate people for whom autism is a less manageable difference. In his doctoral thesis, King (2009) explores discourses in autism advocacy - in which he includes organizations where parents and professionals unite to "fight autism" as well as organizations like Autism Network International, who fight for the right to be autistic. King notes the "defensiveness which is a common thread across all types of autism advocacy" (King 2009, p. 191), one of its most palpable effects being "the disavowal of other autism advocacy communities and their respective beliefs" (King 2009, p. 192). This may have the unfortunate side effect of shutting down dialogue: "leading to stalemate among stakeholders; it does not cultivate possibilities for finding shared ground and sustained dialogue" (King 2009, p. 195). One example of autistic advocates alienating people for whom autism is a less manageable difference, is the "turning away" of the outspoken critic of neurodiversity mentioned in chapter 1, Jonathan Mitchell. Once part of Autism Network International and publishing two articles in their newsletter, Mitchell writes that for him the turning point was when Sinclair

> wrote an editorial opposing medical funding of autism. This was sort of a turning point in my career as an autism gadfly as this was my first exposure to neurodiversity and the "we don't need no stinkin' cure" mentality (Mitchell 2010b).

This can be understood as an example of how rhetorics meant to stimulate rallying around a cause, an important part of mobilization, also may entail the turning away of people who could have been resources but are put off by too singular stances. Another problematic aspect is that shutting down dialogue also inhibits people's willingness to explore their own taken-for-granted assumptions. As mentioned in chapter 1, Mitchell (2007) asks what societal accommodations have to do with his problems of applying himself, staying on task, his perceptual motor impairments and bad handwriting. This is a highly relevant question, but as I believe to have shown in this thesis, it is a question to which there are relevant answers, starting with the UN's definition of disability. In this thesis, chapters 4 to 7 provide several examples of how seemingly personal problems can be analyzed as a result of people's interaction with attitudinal and environmental barriers.

The question of what society has to do with personal problems, whether posed by Mitchell or someone else, may be interpreted as an expression of having come to accept a marginalized situation as inevitable through adopting dominant cultural descriptions of themselves as faulty and deficient, the phenomenon which Freire (1970, 1993) calls a “culture of silence” and other traditions refer to as "false consciousness",

> the unquestioning view of the world in which subordinate groups accept their reality in passive and fatalistic ways, leaving the power and privilege of dominant groups unchallenged (Ledwith 2011, p. xiii).

Inviting any stakeholders to explore taken-for-granted assumptions about themselves and others requires moving away from stalemate positions that involves dismissing each other' arguments as flawed, which only perpetuates the stalemate. It requires a willingness to acknowledge other stakeholders' perspectives as legitimate, listening openly and long enough to understand their position and concerns (King 2009, p. 198). Ledwith (2005, p. 34) claims that the foundation of community work lies in "listening, valuing and understanding people’s particular experiences". Ford provides an example of the value of "listening, valuing and understanding people’s particular experiences", but from an autistic perspective, in relation to neurotypicals:

> In the past I have seen NTs negatively as just a weak-minded herd of clones who waste all their time pointlessly talking about nothing, but I've begun to see them more positively as a result of understanding their "wiring" (Ford 2010, p. 9).

8.4 An intercategorical perspective

Söder & Grönvik point to another pitfall of mobilizing on the grounds of one characteristic: the struggle that revolves around this single characteristic may become more important than establishing dialogue and exploring common interests with people with other characteristics that find themselves being impacted by the same forces in society. From the perspective of intersectionality, the question of what may unite different marginalized groups and provide grounds for alliances across differences becomes important (Söder & Grönvik 2008, p. 16).

I have not conducted an intersectionality study. On the contrary, I have tightly held on to the dichotomy of "autistic people" and "neurotypicals", quite consistently ignoring other characteristics. This is an approach that would be regarded with deep suspicion in some intersectionality approaches, but may be defendable in light of others. McCall differentiates between three approaches. The first she calls *anticategorical,* an approach that has been influential both in fragmenting a number of existing categories and rendering suspect not only categorization itself, but also any form of research based on categorization (McCall 2005, p. 1777). The second she calls *intracategorical.* Although maintaining a critical stance towards categories, researchers will often try to capture the experiences of "particular social groups at neglected points of intersection" (McCall 2005, p. 1774). The third approach she calls *intercategorical.* Here researchers may "provisionally adopt existing analytical categories to document relationships of inequality among social groups" (McCall 2005, p. 1773). The intercategorical approach

> begins with the observation that there are relationships of inequality among already constituted social groups, as imperfect and ever changing as they are, and takes those relationships as the center of analysis (McCall 2005, p. 1784).

In this thesis I have adopted a categorical distinction almost universally promoted by the neurodiversity movement. As autistic people, they claim, they have a set of common characteristics that sets them apart from non-autistic people. This may be understood as part of an attempt to establish *being autistic,* (as opposed to *having autism)* as a new category of difference (Singer 1999). So far only a handful of researchers have taken this category of difference seriously, and I have mentioned many of them in this thesis. As imperfect and permeable as the categories of "autistic people" and "neurotypicals" may be, I have provisionally adopted and sustained them throughout my study, in an attempt to contribute to a growing body of documentation of a relationship of inequality that seems to exist between people who are defined as autistic and people who are not. I would also like to believe that I along the way have contributed a little to strengthening the category of *being autistic* as a relevant analytical category for research. Thus my study may perhaps be understood as operating at a kind of "proto-stage" of doing an actual intersectionality study, where being autistic is included as a fully relevant analytical category among the more established analytical categories.

9 Relevance for community work

9.1 Chapter overview

In this chapter I explore the relevance of my findings for community work, focusing on three distinct ways I believe they may be relevant: As a knowledge resource in creating other autistic spaces in other places (and perhaps also in creating other spaces for people with other characteristics), as a knowledge resource to help avoid colonialist practices, and lastly, as an illustration of the value of systematic self-reflexivity.

9.2 Pointers to help develop autistic spaces

My first research question concerns the specific conditions that constitute Autreat and Autscape as autistic spaces and how they are created. I provide a detailed description of this in chapters 4, 5 and 6, as well as a shorter version in chapter 10. I believe these descriptions may be a knowledge resource to community workers in three ways:

Firstly, a neurotypical community worker wishing to be of assistance to autistic people in a local community, or to a fledgling autistic community or organization, might use them as a knowledge resource in the collaboration. Perhaps the local community is discussing ways to include autistic community members in their neurotypical spaces, or wishes to provide an autistic space, a neurodiverse space where autistic people are in majority, in charge, and conditions are adapted to their needs and preferences. If so, in some cases, as when people's needs and preferences resemble those of the participants at Autreat and Autscape, my descriptions might be used almost as a blueprint. In any case this would be a matter to be decided in a collaborative way between stakeholders:

> The work process in community work is based on a democratic ideal of voluntariness, equity and partnership between those concerned and the professional(s) (Bergen University College 2010, p. 5).

In such a joint assessment of my descriptions, their potential value may lie as much in enabling a sufficiently detailed discussion about how the conditions of such an autistic space should be and how its boundaries should be protected, as in providing a blueprint for it.

Secondly, by using them to extract the principles of how the conditions at Autreat and Autscape are created, I believe my descriptions also may be a resource in creating autistic spaces with different conditions from those at Autreat and Autscape. These two spaces are largely formed to accommodate the "sensory defensive", as Sinclair put it. But any autistic people, whether they may be called "sensory defensive", "sensory-seekers", or any combination of these two, may benefit from accommodation of their sensory issues. The needs and preferences of the autistic people that are involved may perhaps require facilitating a different flavor of autistic sociality. Some communities may wish for even more "autistic" forms of sociality in their spaces, others may wish the interaction to be more "neurotypical" with only a few adaptations. Perhaps some communities wish to create separatist spaces. Others may wish to bring in a larger number of neurotypicals to assist participants (which might require even stricter enforcement of rules, in order to help the neurotypical assistants "behave"). Thus my descriptions may be a resource through suggesting a number of aspects that should be examined in collaboration with those concerned - or with their representatives, if the dialogue that may be established directly with them is insufficient to ascertain their needs and preferences and give them enough influence. It is reasonable to expect that conditions in autistic spaces designed for different autistic communities may be quite different from each other, and perhaps what is needed now is a variety of detailed descriptions of different ways autistic spaces may be created.

Thirdly, the descriptions in chapters 4, 5, 6 and 10 may perhaps also be a resource to community workers working with people and communities who are not autistic, but still have needs and preferences that differ from the majority, by suggesting aspects to be discussed with them. For example: How do features of the environment, combined with their physical, sensory and communicative capacities limit the options open to them? To what extent are these features created by the built environment, and to what extent are they created by the behavior of other people, the performed environment? Is it possible, within defined geographical spaces, to change such features to a sufficient degree? And when it comes to *issues of sociality:* Might establishing a set of special social rules in defined spaces be useful to the people in question? If so, what should the content of these rules be? Might changing information and structure levels in activities enable more of people in the community to participate in them? In what ways do those concerned experience negative sanctions from other people? How can an atmosphere of acceptance be created within defined spaces? How can the community mobilize in order to create greater acceptance outside these spaces? In what ways do the people involved experience structural constraint, from other people's practices or how social systems function? Exploring this, one will have entered the grounds of what Freire (1970, 1993) calls *conscientisation*, breaking the "culture of silence". On the grounds of their stories from everyday life, with the community worker in a catalyst role, this involves analyzing how their

> experiences are linked to the forces of power that are embedded in the structures of society, and understanding how these forces reach into communities to impact on personal lives (Ledwith 2011, p. 34).

Based on what emerges, is it possible within defined geographical spaces to establish social practices and systems that counteract such forces, the same way such forces are counteracted at Autreat and Autscape? And when it comes to the need to *protect the boundaries of such a space*, how may a self-selection among potential participants be achieved? How may participants be provided with sufficient information at the outset? In the space itself, how may enough instances of rule-breaking be picked up? How may all participants receive enough feedback and behavioral support to be able to participate in the reproduction of the conditions of the space? And, lastly, as a last resort, how may the need to exclude participants who threaten the conditions of the space be handled?

To the last point, in the matter of control there is always the question of which of the involved actors are in a position to exert control over other involved actors. Here it may be useful to bear in mind that autistic spaces are spaces where autistic people are in charge. Similarly, spaces for other defined groups or communities should be established as spaces where they are in charge. But it may also be useful to bear in mind that being in charge does not mean doing and handling everything alone without assistance. Rather it means having a final say on how things should be, what should be done, and how it should be done. Thus, a challenge of any community worker offering assistance to any category of people, any group, organization or community, is to find ways of assisting them without taking charge or being perceived by them as taking charge. The alternative is simply not compatible with giving primacy to the wisdom of the grassroots level (Ife & Fiske 2006, p. 304) and safeguarding against “colonialist practices”, imposing one's world view on the community (Ife 2010, p. 46).

9.3 Pointers to help avoid colonialist practices

A neurotypical community worker wishing to be of assistance to autistic people in a local community or to a fledgling autistic community or organization, might perhaps also use my findings as a knowledge resource in other ways:

Collaboration and partnership means interaction. But on whose terms are the interaction between community worker and community members based? Concerning the liberating experience of communicating with other autistic people when they first started gathering in physical space, Sinclair writes:

> It was an amazing and powerful experience to be able to communicate with someone in my own language. I had sometimes been able to establish meaningful communication with people before, but it always involved my having to learn the other person's language and do constant laborious translating. (Sinclair, 1988) Here, with people who shared my language, meaning flowed freely and easily (Sinclair 2005).

For a community worker, to insist that community members should learn "his/her language" in order to establish meaningful communication would not be consistent with the ethos of community work. Accordingly, I believe my findings about accommodating sensory issues and facilitating autistic style sociality may function as a resource to a neurotypical community worker also through suggesting ways to adapt his/her verbal and nonverbal behavior and expectations. Knowing that some autistic people prefer to interact in writing, perhaps community members may prefer to channel more of the communication through email, chat rooms and social media? Knowing that autistic people may need others to be extraordinarily explicit (from a neurotypical point of view), is this something the community worker with the help of community members, may learn to do? If so, it may require actively seeking feedback and evaluation from them. That the community worker perceives him/herself as being explicit will not be sufficient. The real test is whether the community worker is experienced as explicit by community members. But being sufficiently explicit may be a challenge, because it may require the community worker to express him/herself in ways that in neurotypical style sociality is considered offending and rude because of the "relational subtext" (chapter 5). It may require that the community worker learns to have a "less flexible relationship to the truth" in order to not be "just another lying neurotypical". It may require that the community worker accepts community members' honesty without being taking offense, perhaps even learning to value it, discovering that the option of being more explicit may also be useful in his/her own life beyond being in the community worker role.

All this points to the simple fact that a neurotypical community worker may have quite a lot of learning to do in order to function in a non-discriminatory way vis-à-vis an autistic community. The community worker may stand in danger of communicating in ways that puts them at a disadvantage. What seems like a natural agenda to him/her may be irrelevant to them. Their goals or needs may be so alien to him/her that the danger of attempting to impose his or her world view on them is overhanging. Furthermore, as a neurotypical, the community worker may be so much a part of the "reality that challenges them" and puts them at a disadvantage, or may take this reality so much for granted, that he or she may initiate or promote action that does nothing to lessen their disadvantage, or, worse, exacerbates it. Furthermore, this also points to the need to challenge one's own taken-for-granted assumptions, to push back the limits of doxa, as Bourdieu (1977, p. 169) termed it, in order to take conscious, value-based choices.

9.4 Illustrating the value of systematic self-reflexivity

I believe my study may serve to illustrate how insufficient good intentions alone are for a community worker and the value of systematic self-reflexivity: the challenging of our own taken-for-granted assumptions. Without laying down and following some ground rules for myself, I would not have been able to enter my sources' perspectives to the extent I have. I probably would have missed how interwoven "autistic needs" are with neurotypical practices and taken-for-granted values and assumptions, and to a much larger extent might have remained in the comfort zone of my "tried and true" understandings.

It seems that as community workers, we might be well advised to work from the assumption that the more pronounced relevant differences between us and community members are, the more rigorously we may need to challenge our own taken-for-granted values and assumptions. Also because taken-for-granted practices, as shown in chapter 7, may play an instrumental role in social exclusion. This shifts the focus onto us and the privileges that derive from being neurotypical in a society where the majority is neurotypical. Concerning the role privilege plays in matters of social exclusion, Pease writes that

> while the concept of social exclusion has been important in illustrating the structural dimensions of unequal social relations and examining the costs of those relations for excluded groups, it has done little to address those of us who benefit most from existing social divisions and inequalities. Nor do most of the writings on social exclusion examine how these inequalities are reproduced by and through the daily practices and life-style pursuits of privileged groups (Pease 2009, p. 37).

Based on my study, I believe that in approaching the question of privilege, we may need analyses that approach the "nuts and bolts" of daily life at very close range, at least as close as the analyses I do in subchapters 7.2 and 7.3 regarding sensory and social issues. It was first when I focused that close I could start unraveling my practical knowledge. Assuming I am not alone in that, it also suggests that in order to unravel some of the ways that we stand in danger of reproducing inequality, we may need to conduct such investigations with a certain rigor.

In the matter of social inequalities based on race/ethnicity, in a classic essay called "White Privilege: Unpacking the Invisible Knapsack", McIntosh (1990) lists 26 things she as a white person can take for granted in her daily life, but that a black person cannot. She describes having been taught about racism as something that puts others at a disadvantage, but not been taught to see one of its corollary aspects, the privileges that puts her as a white person at an advantage. Furthermore, she writes:

> Describing white privilege makes one newly accountable. As we in women's studies work to reveal male privilege and ask men to give up some of their power, so one who writes about having white privilege must ask, "having described it, what will I do to lessen or end it?" (McIntosh 1990).

In the same vein, autistic American Beverly Harp has, in a joint effort with other autistic activists, compiled a "Checklist of Neurotypical privilege", listing 275 things a neurotypical can take for granted in their daily life that an autistic person cannot. The first one reads: "My teachers are not labeled bad teachers if they allow me to be myself" (Harp 2009).

Hence, in the case of me or other neurotypical community workers wishing to be of assistance to autistic people, a fledgling autistic community or autistic organization: on one hand, if we look, we will find many resources within the community, or in other communities of people sharing some of the same characteristics, to help us unravel the assumptions that puts us at an advantage. On the other hand, gaining knowledge of one's unearned privilege also makes one accountable. To paraphrase McIntosh, as one who writes about having neurotypical privilege I must ask myself: having described it, what will I do to lessen it?

10 Conclusions

10.1 Chapter overview

My research questions concerned the specific physical and social conditions that constitute Autreat and Autscape as autistic spaces, how these conditions are created, and in what ways knowledge of this may inform and challenge current efforts to promote inclusion and accessibility for all. In this chapter I summarize my findings, draw some conclusions, point to issues that should be taken into consideration when discussing how to promote inclusion and accessibility, and suggest some avenues for future research. When I suggest future research, I mean forms where autistic people are actively involved, for example by being in charge, by being fully integrated in the research team as equal partners, or have been offered the chance of such involvement.

10.2 Accommodating sensory issues

Conditions at Autreat and Autscape are designed to accommodate an untypical set of tolerance levels for light, noise, smells and touching. This is done through general adaptations that both aim to provide autistic participants with conditions that are as favorable as possible, and enable autistic participants to regulate their exposure to and recovery from aversive sensory stimulation on an individual level. Aversive or exhausting sensory stimulation may be caused both by features of the built and the performed environment. The general adaptations in place at Autreat and Autscape are created through both changing features of the built environment and establishing rules for participant behavior. Both events provide low-stimulation rooms that enable participants to take a break from sensory stimulation. But establishing these rooms as low-stimulation spaces require all participants to respect them as such. Participants are also encouraged to bring and use products or objects that help them regulate sensory exposure or recover from it, but this requires establishing as a universal norm that autistic behavior, including stimming, is acceptable. Reducing aversive exposure to light may entail replacing fluorescent lights, dimming bright lights and making all participants be careful with camera flashes. Reducing aversive exposure to noise may entail making all participants be more careful about the level and kind of noises they make or cause to happen. Reducing aversive exposure to smells may entail making all participants refrain from using scented products such as perfume, aftershave and deodorant, and be careful about bringing smells of food or smoke into shared spaces. Reducing aversive exposure to touching may entail making all participants refrain from touching other participants without permission.

These examples show that in order to avoid or reduce sensory overload for some participants, organizers must address the behavior of all. Informing about what is considered appropriate behavior in these spaces is crucial. All participants must have specific knowledge about the possibilities the spaces provide, what is expected of them, and what they may expect from others. In turn this requires raising to a discursive level a number of considerations that in mainstream society generally are left at the level of practical consciousness and taken for granted. Equally important for creating the conditions at Autreat and Autscape is exercising control over who are allowed to enter these spaces and on what terms, in order to ensure that enough of the participants behave in accordance with the rules.

Considering the adaptations in these two autistic spaces and the reasons for them, it seems clear that both the built and performed environment in mainstream society produces sensory stimuli that many Autreat and Autscape organizers and participants experience as aversive. Besides causing sensory overload, if regulating their exposure to sensory stimulation is not possible, conditions in mainstream settings may put them at risk of the painful, confusing and potentially terrifying state called "meltdown". Such sensory issues, caused by the interaction between them and environmental features in mainstream society, constitute barriers to participation. These sensory issues may be termed *disability* in the sense of being added burdens imposed on top of an impairment/ imposed on a group with minority characteristics. As barriers to participation caused by features of the environment, in light of current legislation many of the sensory issues that are described may also be understood as examples of indirect discrimination.

It seems clear that such sensory issues are not taken enough account of in the strategy for inclusion and social justice called Universal design or in the legislation regulating accessibility. It also seems clear that a non-autistic majority may not be willing to abstain from using scented products or adhere to the kind of behavioral restrictions required to universally avoid the sensory issues and aversive conditions in mainstream society that organizers and participants at Autreat and Autscape report. In other words, both now and in the future, vis-á-vis some autistic citizens, a certain level of indirect discrimination seems unavoidable. In light of this, it seems reasonable that a research priority should be to find out how many among the autistic population experience such sensory issues and aversive conditions in mainstream settings and what issues they experience. Another research priority might be to broadly document autistic citizens' experience and skills in countering the effects of such sensory issues, in order to inform efforts to enhance accessibility on a universal level. Here, the conditions at Autreat and Autscape might be treated as examples of "best practices" that may suggest strategies for enhancing accessibility and reducing sensory issues in a larger scale. One strategy might be to incorporate into Universal design the practice of providing access to low-stimulation areas in mainstream settings. Another might be to create more public acceptance of autistic behaviors like stimming, which seems to help many autistic people reduce the impact of aversive sensory stimuli and avoid meltdown. This may require research among non-autistic people, in order to ascertain the level of acceptance today and how it may be influenced. Apart from that, another avenue of inquiry might be to explore whether autistic people's existing means of reducing the impact of aversive sensory stimuli can become more effective. This might involve research on the spectrum of practical methods autistic people use to reduce the impact of aversive sensory stimuli. Some of the goals might be to gain an overview over methods in use, identify what methods seem to be the most effective, find ways to make them more effective, and explore whether any products could be developed that might be helpful. The goal in all cases would be to enable autistic people to protect themselves against the sensory burdens of living in a society that privileges neurotypical sensory needs and preferences. In their turn, such research efforts might inform policies aiming to ensure that methods of self-protection against such sensory burdens are made available throughout the autistic population.

10.3 Facilitating autistic style sociality

Aside from accommodating sensory issues, at both Autreat and Autscape a crucial part is facilitating autistic style sociality, a sociality which, by organizers' and participants' accounts, is severely negatively sanctioned in mainstream settings. Some vital elements are providing a higher level of structure and social scripting in activities, providing plentiful and detailed information before and during activities, eliminating some of the need to understand non-verbal signals, and establishing a set of autistic social rules.

A higher level of structure and social scripting in activities enable more people to participate, as does making sure participants receive plentiful information, and are free to ask literally "hundreds of questions" without negative sanctions. Both events have implemented a system of "interaction guide badges" that participants may use to signal non-verbally to other participants whether they wish to interact, wish only to interact with people they already know, or not at all. This frees them from having to pick up on unstated expectations, and from unwanted social interactions. Participants describe this as a clear contrast to mainstream settings, where such factors often contribute to sensory overload. It also enables some participants to recover faster from anxiety and sensory issues by making it more likely they are left alone when they need to be left alone.

Equally important to creating the autistic spaces is establishing a set of autistic social rules: providing opportunity but not pressure for interaction, being verbally explicit and expecting others to be verbally explicit, and accepting autistic behavior. Providing opportunity but not pressure for interaction also protects participants from unwanted interaction. The combination of the badges, the reduction of pressure to socialize, and knowledge of being free to withdraw at any time seems to make it easier to opt into social activities. The rule of being explicit seems to enable participants to interact on premises they understand and like. The explicit truthfulness that is allowed and cherished in these spaces seems to be one reason autistic people are negatively sanctioned in mainstream settings where neurotypical style sociality is the norm. The difference seems to be that participants neither intend nor read any "relational subtexts" into statements, taking statements at face value and treasuring not having to figure out what is "really being said" by examining the social context. They also treasure not having to employ the level of impression management and selective truthfulness that neurotypical style sociality demands.

The elements mentioned above contributes to an easing of constraints, where participants are freed from a number of barriers to social participation that are part of their daily life among non-autistic people in mainstream settings. If judged by the same standards as physical barriers to participation, these barriers might have been the subject of accessibility legislation. But the public's face-to-face interaction cannot be regulated and "universally designed" in the same way as the matters regulated by for example the Americans with Disabilities Act or the British Equality Act. On the other hand, barriers created by "practices" are taken account for in anti-discriminatory legislation. Hardly to the extent of the needs signaled by Autreat and Autscape, but at least to the extent that these "best practices" might well be used to inform and challenge practices in a number of public services and functions, including transportation, schools, work places, and not the least: professionals and staff who provide services and support to autistic people who depend on continuous help and support in daily life.

This becomes even more pronounced when taking into account the third of the autistic rules implemented at Autreat and Autscape: accepting all autistic behavior that does not threaten others participants' boundaries or needs. In these spaces, stimming, hand-flapping, rocking, echoing, avoiding eye contact is perfectly acceptable.

The acceptance of autistic behavior at Autreat and Autscape is relevant in two ways. Firstly, it is an absolute requirement for creating the accessible conditions of Autreat and Autscape. If organizers and participants did not accept and respect autistic behavior, needs and preferences, none of the elements that constitute these autistic spaces as autistic spaces would come to be. Secondly, it is also relevant to enhancing accessibility in mainstream society, which seems largely to hinge on the perception of autism. Accepting autistic behaviors that do not jeopardize or impinge on other people's rights or boundaries seems a precondition for building down the barriers represented by neurotypical style sociality as well as by sensory issues. But when it comes to autistic behavior, how much the barriers represented by neurotypical style sociality can be built down will be more limited. Some of the barriers to participation are deeply entrenched in neurotypical practices and taken-for-granted values and assumptions. Even more than with sensory issues, full and effective participation is unlikely. Discrimination or abuse is not acceptable. But regarding the indirect discrimination and barriers that result from vast numbers of neurotypical people engaging in neurotypical style sociality, there are limits to how much they can be built down. Given the impossibility of offering autistic citizens full and effective participation and given the goal of an accessible society, it seems reasonable to think that making autistic spaces much more common may be a way to compensate. The autistic spaces of Autreat and Autscape are living testimony to the value some autistic people attach to meeting autistic peers and having a chance to develop a positive autistic identity, as well as how these spaces provides respite from "the world of overwhelming sensation" as Singer (1999, p. 63), puts it.

I see two ways the principles from Autreat and Autscape may be harnessed to enhance accessibility by creating "enclaves" of autistic space. One is a community work practice of developing autistic spaces in local communities. Here I see an important role for community workers in any local community: in helping neurotypical community members understand the issues, enhancing their willingness and practical ability to include autistic community members in their plans, and helping them explore how the inclusion of autistic community members may benefit the community as a whole. On the other hand, assisting autistic people get organized and get a "better deal", largely bringing it about themselves through collective action, gaining skills and confidence in the process, as Twelvetrees (2008, p. 2) puts it. In such processes, developing an autistic space in the community might be both goal and a means of reaching the goal.

For a neurotypical community worker, one challenge may be to rigorously enough challenge his/her taken-for-granted values, not only examining how autistic community members are put at a disadvantage, but also how his/her neurotypicality privileges and puts him/her at an advantage. In such processes my findings may be a knowledge resource in avoiding colonialist practices as well as developing autistic spaces.

Another way to harness the principles from Autreat and Autscape is in service provision to autistic people who are dependent on help and support in daily life. Armed with the knowledge of sensory issues and the barriers that neurotypical style sociality can represent for autistic people, neurotypical staff providing services and support to an autistic person with limited communication abilities might declare his/her apartment to be autistic space. Recognizing the danger of discriminatory practices based on their own taken-for-granted values and assumptions, they might develop rules for themselves that to the best of their knowledge could enable them to respect the autistic person's needs and preferences as an autistic person, and uphold them to the best of their ability.

10.4 Protecting the boundaries of the space

In all cases, establishing an autistic space requires protecting the boundaries. A space defined by autistic people being in majority, in charge, and conditions being adapted to autistic needs and preferences, will dissolve or be corrupted if autistic people no longer are in majority or in charge, and if conditions gradually or suddenly become governed by neurotypical needs and preferences. My findings about how the terms of inclusion are managed at Autreat and Autscape, of how the boundaries of the spaces themselves seem to be protected, may be summed up in five steps:

Enable accurate self-selection among potential participants. Attract the type of participants who will enjoy being in the space and fit in, make the others understand that they either may not enjoy being there or not fit in. This can done with extensive, detailed information and descriptions of what potential participants may expect and what is expected of them, as well as providing the opportunity to ask questions.

At the outset, provide all participants with an information "starter pack". Make sure all participants, especially new ones, receive so much information that it is likely they will be able to contribute to reproducing the conditions of the autistic space.

Pick up instances of rule-breaking. Participants must be monitored closely enough by the people in charge of the space so that a sufficient number of the infringements against rules/guidelines that happen are picked up.

Provide sufficient feedback and behavioral support. Have a system in place that ensures that participants who break rules receive feedback enabling them to make their behavior more compatible with reproducing the conditions of the autistic space.

Exclude participants who threaten the conditions of the autistic space. Reserve the right to exclude people after fair warning and support has been given. Have a system in place that allows the exclusion of participants who are not able or willing to behave in ways defined as appropriate.

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Norsk samfunnsvitenskapelig datatjeneste AS
NORWEGIAN SOCIAL SCIENCE DATA SERVICES

Appendix A

NSD

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Vår dato: 06.08.2012 Vår ref:26731 / 7 / LMR Deres dato: Deres ref:

TILBAKEMELDING PÅ MELDING OM BEHANDLING AV PERSONOPPLYSNINGER

Vi viser til melding om behandling av personopplysninger, mottatt 15.03.2011. Meldingen gjelder prosjektet:

26731	*Normalt å funksjonshemme? En analyse av autistiske personers beskrivelser av samfunnsflertallets sosiale og kommunikative praksiser*
Behandlingsansvarlig	*Høgskolen i Bergen, ved institusjonens øverste leder*
Daglig ansvarlig	*Anne-Mette Magnussen*
Student	*Thomas Owren*

Personvernombudet har vurdert prosjektet, og finner at behandlingen av personopplysninger vil være regulert av § 7-27 i personopplysningsforskriften. Personvernombudet tilrår at prosjektet gjennomføres.

Personvernombudets tilråding forutsetter at prosjektet gjennomføres i tråd med opplysningene gitt i meldeskjemaet, korrespondanse med ombudet, eventuelle kommentarer samt personopplysningsloven og helseregisterloven med forskrifter. Behandlingen av personopplysninger kan settes i gang.

Det gjøres oppmerksom på at det skal gis ny melding dersom behandlingen endres i forhold til de opplysninger som ligger til grunn for personvernombudets vurdering. Endringsmeldinger gis via et eget skjema, http://www.nsd.uib.no/personvern/forsk_stud/skjema.html. Det skal også gis melding etter tre år dersom prosjektet fortsatt pågår. Meldinger skal skje skriftlig til ombudet.

Personvernombudet har lagt ut opplysninger om prosjektet i en offentlig database, http://www.nsd.uib.no/personvern/prosjektoversikt.jsp.

Personvernombudet vil ved prosjektets avslutning, 01.03.2013, rette en henvendelse angående status for behandlingen av personopplysninger.

Vennlig hilsen

Vigdis Namtvedt Kvalheim

Linn-Merethe Rød

Kontaktperson: Linn-Merethe Rød tlf: 55 58 89 11
Vedlegg: Prosjektvurdering

Prosjektnr: 26731

Utvalget består av 4-12 medlemmer av en aktivitetsgruppe for personer med Asperger syndrom. Data samles inn via gruppeintervju.

Førstegangskontakt foretas via aktivitetsgruppens tilrettelegger, som har invitert prosjektleder til å informere om studien på en gruppesamling. Utvalget gis skriftlig informasjon som de tar med seg hjem. De som ønsker å delta, dukker opp på gruppeintervju med underskrevet erklæring. Fokusgruppene avholdes slik at de ikke berører aktivitetstilbudet til dem som ikke ønsker å delta.

Prosjektleder bekrefter at utvalget er samtykkekompetent, jf. telefonsamtale med prosjektleder av 14.04.2011. Informasjonsskrivet vedlagt meldeskjemaet, finnes tilfredsstillende.

I tillegg skal prosjektleder benytte internettblogger og åpne diskusjonsforum på nettet som datagrunnlag. Prosjektleder opplyser at dette datagrunnlaget kan deles i to grupper, jf. e-post av 30.06.2011: Den ene gruppen vil bestå av bloggforfattere som mottar informasjon om studien og som det innhentes samtykke fra til bruk av, og referering til, blogg. Behandlingen kan således hjemles i personopplysningsloven §§ 8 første ledd og 9 a.

Den andre gruppen vil være internettkilder der det ikke er mulig å gi informasjon eller innhente samtykke (eksempelvis grunnet gamle diskusjonsinnlegg). Prosjektleder vil ved bruk av slike datakilder omgjøre sitater og lignende i endelig oppgave, slik at enkeltpersoner ikke kan identifiseres. Ombudet vurderer at ettersom det i slike tilfeller er umulig å nå utvalget med informasjon om studien, samt siden det ikke publiseres personidentifiserende opplysninger i endelig oppgave, kan man unntas fra informasjonsplikten jf. personopplysningsloven § 20 c, samt hjemle behandlingen i pol. §§ 8 d, 9 h.

Prosjektet skal avsluttes 07.07.2012. Lydopptak skal da slettes, og øvrig materiale skal anonymiseres, bortsett fra personopplysningene i den endelige oppgaven (identifisering av blogger) som informantene har samtykket til at kan stå der. Anonymisering innebærer at direkte personidentifiserende opplysninger som navn/e-postadresser slettes, og at indirekte personidentifiserende opplysninger (sammenstilling av bakgrunnsopplysninger som f.eks. bosted, alder, kjønn) fjernes eller endres.

Appendix B: Letter to blog authors

Hi!

I'm a neurotypical Norwegian master student of community work, doing research for my master thesis: "Examining autistic space from a community work perspective".

I am writing about "autistic space", for example the conditions at Autreat (US) and Autscape (UK), based on texts written by autistic people published online (Jim Sinclair's articles, information from the autreat.com and autscape.org web sites, and blog posts by a number of people identifying themselves as autistic). Only a few pages of my material is written by neurotypicals (like for example Steve Silberman)

My question: May I use your blog post as part of my data material?

[Here I specified what part of the blog post I was interested in using]

A community work perspective means actively privileging autistic people's voices and experiences, along with a social justice perspective. One of my thoughts is that the way autistic space is designed will point out some of the disabling barriers that autistics come up against as a minority in a predominately neurotypical society. I am writing my thesis in English. I will publish it online when it is finished, and will be happy to send you an email when I do, if you want.

If I may use your blog post, I need to know how I should refer to you. You may also remain anonymous, if you wish. And you may withdraw your contribution at any time if you wish, without giving any reason.

My regards,
Thomas Owren

Appendix C: Fragment numbers and sources

[1-91]	From autistic American Jim Sinclair's internet essay "Autism Network International: The Development of a Community and its Culture" (Sinclair 2005)
[92-138]	From Jim Sinclair's article "Cultural Commentary: Being Autistic Together" (Sinclair 2010)
[139-143]	From interviews with Jim Sinclair (Ashkenazy 2009 and Ellerman 2011)
[144-147]	From the brochure for Autreat 2010 from the ANI (2013) web site
[148-151]	From information about Autreat 2012 on the ANI (2013) web site
[152-153]	From The Autreat 2012 Call for proposals (ANI 2013)
[154-165]	From an account of being at Autreat 2004 by autistic American Jane Meyerding (2004)
[166-175]	From an account of being at Autreat 2007 by autistic American Stan (s0) (2007)
[176-182]	From the book "Elijah's Cup: A Family's Journey into the Community and Culture of High-Functioning Autism and Asperger's syndrome" by autistic American researcher and parent of an autistic child, Valerie Paradiž (2005)
[183-185]	From a blog by Blogger A, Karen Boyd: "On Autistic Space" (permission granted, wished to be cited as Karen Boyd 2011)
[186]	From a blog by Blogger B, Nico: "feeling a little isolated") (permission granted, wished to be cited as Savannah Logsdon-Breakstone 2011)

[187-192]	From a blog by Blogger C, who attended Autreat 2010 (unable to reach, anonymized)
[193]	From a blog by Blogger D, who attended Autreat 2007 (unable to reach, anonymized)
[194-201]	From a blog by Blogger E, who attended Autreat (unknown year) (unable to reach, anonymized)
[202-213]	From a blog by Blogger F, Estée Klar, who attended Autreat 2007 (permission granted, wished to be cited as Estée Klar 2007)
[214-226]	From a blog by Blogger G, who attended Autreat 2007 (permission granted, wished to be cited as Jonah 2007)
[227]	From a blog by Blogger H, Alexander Cheezem, who attended Autreat 2009 (permission granted, wished to be cited as Alexander Cheezem 2009)
[228-232]	From a item in the ASAN Newsletter by autistic American Sarah Pripas (2011)
[233-235]	From a blog by Blogger I, Jerry W (2010): "Autreat2010PoorPitifulMeAnd-TheTreatmentsIRantOn" (permission granted, but without specifying how I should cite him, therefore I used Jerry W)
[236-238]	From an article by Valerie Paradiz (2010) titled "Growing Up Grassroots"
[239]	From a blog by Blogger J, commenting critically on an incident at Autreat (unable to reach, anonymized)
[240-241]	From a blog by Blogger K, who attended Autreat 2010 (unable to reach, anonymized)

[242]	From an interview with neurotypical American writer Steve Silberman (Lehrer 2012)
[243-320]	From information about Autscape on the Autscape (2012) web site
[321-325]	From an item in ASAN UK (2009)
[326-333]	From an item by Charles Burns (2005) in Taimyo, The Magazine for British Shintaido
[334-338]	From a blog by Blogger L, who attended Autscape 2005 (unable to reach, anonymized)
[339-344]	From a blog by Blogger M, who attended Autscape 2010 (unable to reach, anonymized)
[345-347]	From an item by Charles Burns (2007) in Taimyo, The Magazine for British Shintaido