

Hannah Ebben
Hallam University

Movement as language, signification as identity: Understanding and empowering the autistic community in online spaces

Abstract

This article is a contribution to ongoing research in online autistic culture by defining its overarching themes and presenting a new theoretical framework that could advance and empower both autism research and the autistic community itself. It studies autism as a concept that is constantly linguistically (re)produced in society rather than as a mental disorder. Focussing on YouTube as a platform for autistic identity, it features a review of existing academic literature about the autistic community on the internet and analyses two YouTube videos made by autistic people. After an exploration of the focus on geography and the performance of citizenship in the literature, it will introduce the notion of the counter-metaphor as a facilitator of new concepts on human diversity besides 'autism' for researchers and the autistic community. Its significance will be explained through a presentation of 'atopos' as one such concept. The overall aim of this paper is to affirm the notion of online space as a producer and platform of new language and conversations on autism. It considers analytical tools for the academic study of the geography of autistic people, but also encourages empowering negotiations of online and offline space within the autistic community.

Key words: autistic identity, online cultures, empowering technology, disability geography, voice, counter-metaphor, atopos

Introduction

Autism is a flexible concept, shaped in and outside the clinical world. Within a medical context, it has been conceptualized and defined as a disorder characterized

by impaired communication, social skills, and information processing. However, many stakeholders outside the clinical and scientific realm also attach words, signs, and metaphors to the concept. In this way, it becomes a dynamic interplay of meaning, subjective experiences and interpretations rather than a fixed, universal entity. For twenty years, there has been room for the previously unrecognized voices of autistic people, who had previously been seen as not being able to speak.¹ The arrival of the internet played a key role in the formation of the first autism self-advocacy organizations.² Autistic people now form and maintain online and offline communities and further shape and develop notions of divergence and diversity. For researchers, it is important to know how this new community negotiates identity and the word ‘autism’, and for autistic people, it is important to have a podium to develop further their own voices.

This article explores how to understand and further encourage the empowering potential of the internet, and YouTube in particular, for people who identify with the concept of autism. It considers literature on digital technology, autism, and empowerment, and presents terminology that affirms the free flow of enabling new ways to talk about human diversity. YouTube is a social networking site based on video sharing. Visitors may freely view uploaded videos, start a channel in order to upload videos, subscribe to other channels, comment on videos, and make playlists. Both companies and private citizens own YouTube channels, and both professional and homemade videos have become famous and widespread. Autistic people have posted and shared simulations of everyday sensory input, videos on social and political issues within the autism self-advocacy movements, and informal blogs about the notion of autism.

In order to understand the social and spatial conditions in which the flow of meaning on autism thrives, as well as the role of the internet in this process, it is important to acknowledge the close connection between technology and society. In their study of online Deaf culture, Valentine and Skelton refer to thinkers on the social science of technology like Bruno Latour and state, “society is produced in and through patterned networks of heterogeneous materials in which neither the properties of humans or non-humans are self-evident, rather they emerge in practice”.³ On the basis of this statement, this paper will adopt the stance that technology, society and identity are not static entities, but are unconsciously shaped by everyday practices of signification, mutually complementing each other.

It will consider the internet as a digital space in which these practices evolve. A literary review on the autistic community online⁴ will highlight the significance of

¹ Oliver Sacks, *An Anthropologist on Mars: Seven Paradoxical Tales*, (New York: Alfred A. Knopf) (1995).

² Martijn Dekker, “On Our Own Terms: Emerging autistic culture”, Presented at Autscope (1999).

³ Gill Valentine, Tracey Skelton, “Changing spaces: the role of the internet in shaping Deaf geographies”, *Social & Cultural Geography* 9:5 (2008), p. 471.

⁴ Martijn Dekker.

spatiality. With the help of literature that addresses the construction of citizenship, I will study two YouTube videos made by people who identify with the concept of autism: the 2006 video “In My Language”, posted on the YouTube channel “silentmiaow” from non-verbal autistic self-advocate Amelia Baggs (formerly Amanda; blogs as ‘Ballastexistenz’); and the video “What it’s like to walk down the street when you have autism or an ASD” by “Craig Thomson”. With this reading, I eventually consider the question how the online autistic community could be further empowered in and outside academia. I will suggest the ‘counter-metaphor’ as an academic theoretical framework that could facilitate inclusive practices of signification online based on the empowering qualities of digital technology. This specific term stems from my research into metaphors on autism in cultural representations. These are the themes that emerge from the narrative structure and stylistic qualities of film, literature and video that can be formulated as ‘autism as...’. In relation to such metaphors as found in culture, counter-metaphors are interventions made by people who consider these metaphors, in my case the researcher or eventually autistic people themselves. Inventing a counter-metaphor aims to enable a broader vocabulary and a free flow of signification to come into being in a way that further empowers autistic people. It aims to not only recognize but also support the way in which autistic people find their voice and how YouTube offers its platform online. A larger framework of counter-metaphors in and outside academia might eventually facilitate new sustainable structures of signification on human diversity. Digital media have been a platform for the creation of words and meaning to everyday experiences. YouTube is one of the social networking sites that can be explored to study how this creativity comes to the fore and the way it could be further acknowledged and encouraged.

The study and encouragement of empowering technologies exemplifies a Cultural Studies approach⁵ that stands for an open, interdisciplinary, and worldly engagement with multilateral themes addressing culture, meaning, and ideology.⁶ It not only studies cultural artefacts, but is more precisely focused on their “use” in everyday life in a given political context.⁷ This use indicates the way in which a political system is embedded in cultural objects that are produced and consumed daily and are usually left unnoticed. To research this, Cultural Studies scholars seek the social margins in order to strive for “demarginalization”, and regard for social diversity. Research that has been done in the field of Cultural Studies has had a very broad scope and is difficult to capture in one single methodological template. Nevertheless, it is important to consider its approach as it helps us to understand how to foster the process of demarginalization effectively.⁸ The Cultural Studies

⁵Mitzi Waltz, “Reading case studies of people with autistic spectrum disorders: a cultural studies approach to issues of disability representation”, *Disability & Society* 20:4 (2005).

⁶Mimi White, James Schwoch, “Introduction: The Questions of Method in Cultural Studies”, in *Questions of Method in Cultural Studies*, ed. idem, (Oxford: Blackwell Publishing) (2006), pp. 1-3.

⁷ Mimi White, James Schwoch, p. 5.

⁸ Mimi White, James Schwoch, p. 14.

approach in this particular inquiry strives to acknowledge the empowering qualities of YouTube for the autistic community as a group that has struggled to let their voices be heard. The field has borrowed its method of data collection from Media Studies, amongst other fields, but focuses more on the social contexts in which mediated artefacts has arisen.⁹ In order to grasp the empowering quality of YouTube for autistic persons comprehensively, I will address its interface and the style and content of its videos. Studying the use of video in society, my reading includes larger themes such as the construction of autistic identity and citizenship through a negotiation with the non-autistic ‘norm’ within the boundaries of the YouTube interface.

After a short description of autistic voices online and the research that has covered it, I will present a reading of the two videos. I will then introduce the counter-metaphor through an explanation of the atopos concept that I have employed in my own research. I will argue that other researchers and autistic people could also invent such terms as empowering tools. In keeping with most autistic people’s wishes, this article employs identity-first language. This means that I will speak about “autistic people” in order to refer to people who identify with the concept of autism.¹⁰ Note that this includes personal accounts on YouTube regardless of diagnoses. To maintain the integrity of the research, this article does not decide if the persons portrayed ‘actually’ have autism and only addresses discourse, although future analyses will cover online negative responses to Baggs’ work and claims.

Online and offline autistic community

Notions of affirmation and emancipation are often approached in terms of the voice: being able to speak, being enabled to speak, and being heard are necessary conditions for the production and recognition of knowledge.¹¹ For a long time, ‘autism’ was seen as a negation of a speaking self, as autistic people were not believed to be able to be introspective and retrospective because of their lack of understanding of the human mind.¹² This has been problematized by the emergence of autism self-advocacy, in which autistic people make themselves known as “actors with agency”¹³ because of a shared story of living with autism, which renders it political.¹⁴ Arising in

⁹ Mimi White, James Schwoch, p. 15.

¹⁰ Alicia Broderick, Ari Ne’eman, “Autism as metaphor: narrative and counter-narrative”, *International Journal of Inclusive Education* 12:5-6 (2008).

¹¹ Nick Couldry, *Why Voice Matters: Culture and Politics After Neoliberalism*, (London: Sage) (2010).

¹² Oliver Sacks.

¹³ Mitzi Waltz, *Autism. A Social and Medical History*, (Basingstoke: Palgrave Macmillan) (2013), p. 133.

¹⁴ Titchkosky Tanya, “Disability: A Rose by Any Other Name? ‘People-First’ Language in Canadian Society”, *Canadian Review of Sociology* 38:2 (2001), p. 136.

the early 1990s, autism self-advocacy has been greatly shaped out of an oppositional stance towards the stakeholders that traditionally had delimited what could be said and what could not be said about the concept of autism, like parents, charity funds, and therapists.¹⁵ The first *recognized* autistic people with a voice of their own still operated in the proximity of clinicians and parent groups. By contrast, the internet brought autistic people together as equal peers, which is a great factor of its empowering quality. Mailing lists formed its first online communication. A notable example is *Independent Living on the Autistic Spectrum*, which offered emotional support and a platform for activism. Due to their dissatisfaction with the emphasis on cures amongst parents, in 1992 Donna Williams and Jim Sinclair founded ANI, the first autism self-advocacy organization.¹⁶ Today, autistic voices are visibly recognized online; for example, autistic vlogger Amythest Schaber offers accessible resources on autism presented by an insider.¹⁷

Literature of the formation of autistic voices and identity often employ as a method of choice an ethnographic study¹⁸ or an analysis of questionnaires and autobiographical accounts¹⁹. These texts highlight the conscious and challenging choices of autistic people to disclose²⁰ and construct²¹ an autistic identity against a backdrop of the increasingly non-hierarchical practice of signifying autism as explained above and the shift in focus from autism as a condition in need of a cure to a potential community.²² The identity management of autistic people is influenced by the need to undermine stigma and stay safe²³ and is characterized by a dynamic process of negotiating a polyphony of voices from in and outside the autistic community.²⁴

Writings that specify autistic culture online critically approach the potential empowering effects of digital technology²⁵ and remarkably often focus on geography, that is, the way in which online and offline communication are negotiated as different

¹⁵Mitzi Waltz, (2013), pp. 134-143.

¹⁶Martijn Dekker.

¹⁷Amythest Schaber, "Ask an Autistic – What is Autism?", YouTube, <https://www.youtube.com/watch?v=Vju1EbVVgP8>, (2015), date accessed 11 April 2016.

¹⁸Nancy Bagatell, "Orchestrating voices: autism, identity and the power of discourse", *Disability & Society* 22:4 (2007), pp. 413-426.

¹⁹Joyce Davidson, Michael Orsini, "The Shifting Horizons of Autism Online", in *Worlds of Autism. Across the Spectrum of Neurological Difference*, ed. idem, (Minneapolis: The University of Minnesota Press) (2013), pp. 285-304.

²⁰Joyce Davidson, Victoria Henderson, "'Coming out' on the spectrum: autism, identity and disclosure", *Social & Cultural Geography* (2010), 11:2.

²¹Nancy Bagatell, (2007), pp. 413-414.

²²Nancy Bagatell, "From Cure to Community: Transforming Notions of Autism", *Ethos. Journal of the Society for Psychological Anthropology* (2010), 38:1.

²³Joyce Davidson, Victoria Henderson, p. 159.

²⁴Nancy Bagatell, (2007), pp. 422-425.

²⁵Joyce Davidson, "Autistic culture online: virtual communication and cultural expression on the spectrum", *Social & Cultural Geography*(2008), 9:7.

spaces.²⁶ The internet is significant for the autistic community and the research that studies it; literature addresses its status as a technology that could compensate autism-related communicative impairments. Jordan comments that online communication often lacks elements of face-to-face communication with which autistic people struggle.²⁷ In their study of questionnaires completed by autistic people, Davidson and Orsini quote one anonymous participant who states that the internet only offers “one dimension”: a text that can be read and written at any occasion, which fits their communicative style much better.²⁸ Others confirm that their social lives have been enriched by the accessibility of the internet.²⁹ The importance and innovation of the communicative possibilities that a website interface offers to autistic people is well known in the academic world: several articles refer to the belief that the internet might have the same significance for autistic people as sign language for Deaf people.³⁰ In addition, just like the Deaf community emerged out of a shared language and a shared space³¹, the communicative accessibility of the internet brought autistic people an increased proximity to their peers, regardless of bodily distance.³² In the case of Deaf culture, the internet offered more information and people to communicate with via text and sign language than did offline Deaf clubs. This meant that it formed a technology that, unlike cochlear implants, was not aimed at the normalization of Deaf people.³³ Similar to this, ANI-L, one of the first virtual spaces for autistic people, encouraged the affirmation of autistic identities rather than the search for a cure.³⁴ It therefore offered a space that was low in stimuli for people with communicative and sensory problems and did not pressure normalization. The close proximity amongst new people enables the formation of new communities, and in relation to empowering technology, the internet facilitates these communities and their unique communication.³⁵ Space is created through these shared activities.³⁶

The geography of the autistic community is thus heterogeneously localized in online and offline space and the exact relation between the two has been explored in literature. Rosqvist et al base their article on two research projects on specific online and offline communities (respectively a forum and a magazine with an accompanying

²⁶Hanna Rosqvist et al, “Mapping the social geographies of autism – online and off-line narratives of neuro-shared and separate spaces”, *Disability & Society*(2013), 28:3.

²⁷Chloë Jordan, “Evolution of Autism Support and Understanding Via the World Wide Web”, *Intellectual and Developmental Disabilities* 48:3 (2010), p. 220.

²⁸Joyce Davidson, Michael Orsini, p. 293.

²⁹Joyce Davidson, Michael Orsini, p. 294.

³⁰Joyce Davidson, (2008), p. 792.

³¹Gill Valentine, Tracey Skelton, p. 472.

³²Martijn Dekker.

³³Gill Valentine, Tracey Skelton, pp. 472-474.

³⁴Martijn Dekker.

³⁵Gill Valentine, Tracey Skelton, pp. 476.

³⁶ Hanna Rosqvist et al, p. 368.

summer camp) and consider both as enabling spaces for autistic people to enter.³⁷ Their geographical study of the autistic community distinguishes “neuro-separate spaces” from “neuro-shared spaces”.³⁸ In neuro-separated spaces, mainstream culture follows a non-autistic norm in which autistic people are either excluded or creating their own “safe spaces” of resistance.³⁹ Neuro-shared spaces attempt to accommodate anyone and are created when places are made accessible for disabled people. Through its empowering potential, the internet might be a leg up to a stronger offline position and thus a shared space with the majority culture.⁴⁰ In the online and offline alternative spaces studied, autistic people found a chance to find peers and benefited from the removal of the ‘problems’ of non-autistic society as their quality of life increased.⁴¹ However, divergent interest amongst the visitors often clashed: socializing predominated political ambitions or vice versa, and disagreements arose regarding the possibilities of contact with non-autistic society.⁴² The online forum studied especially displayed reluctance to transfer to non-autistic space.⁴³ Rosqvist et al state that the magazine project needed significantly more negotiation with non-autistic culture and was therefore more of a neuro-shared space aimed at wider inclusion than the forum. This made the latter more separatist and led to various discussions on identity that were less preoccupied with ‘fitting in’.⁴⁴ This research is interesting here because it considers the clustering of autistic voices into technologies and spaces that all facilitate a different type of identity construction with regard to mainstream culture.

Rosqvist et al mention concerns about a “ghettoization” of online autistic culture as an overly separated practice of signification and communication.⁴⁵ Jordan laments the potential ‘splintering’ of the autistic community caused by autistic self-advocates online who form a polar opposite to other interest groups. Such chasms could hamper the autism movement.⁴⁶ By contrast, Davidson and Orsini also address the fear of a diminished visibility of disability caused by online autistic culture and offer a nuanced study that carefully weighs up visions of the internet as a panacea versus the internet as separation for the autistic community.⁴⁷ In their analysis of questionnaires returned by autistic people, they study what their personal experiences of the internet can reveal about identity and negotiations of space. They argue on the basis of this study that “online activities are rarely entirely insular” and that the effects of these activities reach beyond autism, autistic persons, and skills that are solely

³⁷ Hanna Rosqvist et al, pp. 367-368.

³⁸ Hanna Rosqvist et al, pp. 368-369.

³⁹ Hanna Rosqvist et al, pp. 369-370.

⁴⁰ Hanna Rosqvist et al, p. 370.

⁴¹ Hanna Rosqvist et al, p. 373.

⁴² Hanna Rosqvist et al, pp. 374-375.

⁴³ Hanna Rosqvist et al, p. 375.

⁴⁴ Hanna Rosqvist et al, p. 376.

⁴⁵ Hanna Rosqvist et al, p. 377.

⁴⁶ Chloë Jordan, p. 22.

⁴⁷ Joyce Davidson, Michael Orsini, pp. 285-286.

useful on the internet.⁴⁸ This could indicate blurring boundaries between the online and offline world.⁴⁹ Some autistic research participants pointed out their overly long periods of time spent online, and some stated their preference for virtual and digital communication. Nevertheless, many indicated that their social lives and skills were improved outside the internet through online communication, with more overall empowerment and connection.⁵⁰ Social exclusion was decreased online as the autistic participants did not have to be confined to the space of their homes anymore with access to the internet.⁵¹ They easily adapted to quickly changing technologies, such as mobile internet access that extends beyond the home.⁵² Overall, many autistic people are shown to construct online spaces dynamically that are inclusive to their peers; they both confine a separate safe space online and improve their negotiations of space beyond those confinements and into the offline world.

Performing autistic voices on YouTube

The notions of autistic voices and geographies online and offline form the cause of the exploration of the imagery and geography of YouTube. The concept of autism (as well as Deaf culture) is being (re)defined and circulated online by heterogeneous peer groups in ways that do not necessarily reflect clinical understandings of pathological difference. The interfaces of digital technologies both facilitate communication amongst autistic people and shape the content of this communication. For example, autism forums only offer written dialogues and take away the additional challenging communicative and sensory input of face-to-face conversations.⁵³ At the same time, they might form spaces that are separated from mainstream culture, as the interface of a forum that is solely visited by autistic people does not require any negotiation with non-autistic voices and communication. This may result in discussions that regard mainstream culture as ‘alien’.⁵⁴ The performative nature of autistic identity—the notion that people ‘do’ identity through constant culturally specific practice—is key here and is closely related to space and technology. My own analysis presupposes the notion that the word ‘autism’ does not necessarily reflect a pre-linguistic, material reality that is based in the bodies of diagnosed people, but that it is actively being filled with meaning through all kinds of signifying practices. Using the word ‘autism’ brings a specific reality into being, just as if the declaration ‘I hereby apologize’ actualizes apologies. In the case of YouTube, a

⁴⁸Joyce Davidson, Michael Orsini, p. 299.

⁴⁹Gill Valentine, Tracey Skelton, p. 481.

⁵⁰Joyce Davidson, Michael Orsini, pp. 290-296.

⁵¹Joyce Davidson, Michael Orsini, p. 297.

⁵²Joyce Davidson, Michael Orsini, p. 298.

⁵³Martijn Dekker, Joyce Davidson, Michael Orsini.

⁵⁴Hanna Rosqvist et al.

specific video is such a performative utterance in itself.⁵⁵ It is important to note that performative expressions evolve *unconsciously*.

YouTube facilitates specific performative practices of signifying autism through its specific user interface. It is a platform for videos that are accessible through personalized channels, open to comments, and can be made easily using cameras and editing software. Even though the comment section uses written text and can be complemented by autistic people at their own convenience, making a video itself offers creative potential with more “elements” than text only.⁵⁶ Meaning can be constructed consciously or unconsciously through editing, camera work, intertitles, monologues in front of the camera, or annotations. Overall, YouTube is a digital space in which individual practices of producing and uploading content forms the “main vehicle of communication and of social connection” and most users use the site to watch and comment on this content.⁵⁷ The analysis of the two case studies, from now on referred to as “What it’s like...” and “In My Language”, will address all of these elements.

My approach to these case studies is informed by several texts. The field of Cultural Studies fits into the aim of exploring signifying practices of autism in and outside videos distributed by YouTube and to the role of the specific YouTube interface. The empirical study of two YouTube videos are considered as cultural ‘texts’⁵⁸; annotations, tags, and the video description from the poster as paratexts in which the video is presented to the audience⁵⁹ and comments from others as instances of reception of the video content. This highlights the use of cultural content in online practice⁶⁰ and thus opens up an approach that analyses the actions of autistic people on YouTube as an assemblage of video content and debates in textual commentary.

Additionally, the production of autistic identity and space on YouTube will be considered with the help of the literary review and the insights of van Zoonen et al’s 2010 article on the performance of citizenship on YouTube. In their exploration of citizenship in a multicultural society, van Zoonen et al read YouTube videos that react to the release of the Dutch far-right politician Geert Wilders’ anti-Islam film *Fitna*.⁶¹ Their research questions regarding the study of citizenship, that is, how the

⁵⁵ John Austin, *How to do Things with Words. The William James Lectures delivered at Harvard University in 1955*, (Oxford: Clarendon Press) (1962).

⁵⁶ Joyce Davidson & Michael Orsini, p. 293.

⁵⁷ Jean Burgess & Joshua Green, “Agency and Controversy in the YouTube Community”, in *Internet Research 9.0: Rethinking Community, Rethinking Place, Copenhagen* (15-18 October 2008).

⁵⁸ Mimi White, James Schwoch, p. 5.

⁵⁹ Gérard Genette, “Introduction to the Paratext”, *New Literary History* 22:2, “Probings: Art, Criticism, Genre” (1991), p. 261.

⁶⁰ Mimi White, James Schwoch, p. 5.

⁶¹ Liesbet van Zoonen et al, “Performing citizenship on YouTube: activism, satire and online debate around the anti-Islam video *Fitna*”, *Critical Discourse Studies*(2010), 7:4, p. 253.

videos claim their right to speak and who is the implied addressee⁶², are closely aligned with my own consideration of autistic voices as constructed practices. They problematize common theorizations of voices in academia in relation to YouTube, as the rear end of the communicative process is often ambiguous in videos. People or groups addressed in a video do not have to be part of its actual audience, and many videos that declare a message do not explicitly address someone at all.⁶³ Van Zoonen et al subvert the assumption that voices need a clear addressee with the help of a “performative” concept of voice: expressions that are significant in and of itself for themselves, no matter who is addressed and who listens. Within this view, one becomes a citizen by ‘doing’ citizenship.⁶⁴ The appealing factor of this definition for this study is the fact that it directs the study of voice to the “deed” of citizenship, that is, YouTube videos and comments, and its participants.⁶⁵ My readings of autistic identity and citizenship in “What it’s like...” and “In My Language” will also set the content of stylistic choices of the deed at the forefront, rather than the intention of the creators. The act of posting content itself already constitutes citizenship. The following analysis will also be based on assumed audiences and the occurrence of autistic voices and community.

Both “What it’s like...” and “In My Language” are divided into two segments: one that appeals to a normalized gaze to the world and to disabled people, and another that subverts this gaze and establishes autistic difference and voice. However, the two videos convey a very different message. Whereas “What it’s like...” is a more traditionally educative video that simulates a walk through the eyes of an archetypical autistic person, “In My Language” offers a translation to non-verbal communication as a breakdown of social expectations of autistic people. The assumed addressee in the videos is key here. “What it’s like...” features a ‘demonstration’ of autism as a difference in everyday sensory input. A fragment that displays a walk down a street from the point of view of a non-autistic “neurotypical” person is followed by a fragment of the same path that is now perceived by an autistic person. Both are introduced by intertitles that disclose the identity ‘archetype’ shown. The “neurotypical” walk is filmed with a steady camera; however, the “autistic” walk features increased brightness and city noise (added in postproduction), jerky camera movements, and superposed textual commentary. This commentary uses clinical language as the intensified stimuli is referred to as “sensory overload” that can cause a “flight or fight response”. The video description says more about its assumed audience: “It will hopefully give neurotypicals a rough idea about what it’s like to life (sic) with autism”. This gives the impression that the video is intended to educate non-autistic people about autistic sensory experience, about which he states that it

⁶²Liesbet van Zoonen et al, pp. 251-253.

⁶³Liesbet van Zoonen et al, p. 251.

⁶⁴ Liesbet van Zoonen et al, p. 252.

⁶⁵ Liesbet van Zoonen et al, pp. 252-252.

“does vary from person to person”.⁶⁶ Nevertheless, many comments come from people who disclose their identification with the concept of autism and state to which extent the content mirrors their own personal experiences. YouTube user “Arman Kody” posted such a reply in the form of a new video.⁶⁷ Even though the establishment of autistic sensory overload in “What it’s like...” is mostly unilateral, its comment section does form a platform for autistic people to talk about their personal life. The video thus ‘performs’ autism as it is established through a contrast between two fragments that show clear differences in stylistic choices. The shadow of the camera operator proves that ‘normalcy’ and ‘deviancy’ had to be staged in order to be portrayed on film. Its educative nature negotiates non-autistic society by assuming an audience that is oblivious to the peculiarity of autistic perceptions. The video could thus be seen as ‘neuro-shared’.

By contrast, “In My Language” does not reveal differences but offers its assumed audience a mirror to its prejudice. At first, Baggs moves and makes sounds in a domestic space, but after the intertitle “A translation” appears, Baggs says with a computer voice that the movements were her “native language”. Establishing her language, she incites the assumed audience to look at her movements and sensory contact as meaningful in and of itself, as non-verbal disabled people are often seen as unable to communicate and relate to the world. While “Craig Thomson” directed his video to “neurotypicals”, Baggs’ implied audience is much more subtly interwoven into her message. In her translated spoken message, she refers to “many people” and often speaks in the passive when talking about false preconceptions on disabled people. This makes clear that her assumed audience covers society generally: not necessarily individual stances towards disability and voice, but discriminatory social practices. Because of this, “In My Language” is a statement that consciously deconstructs common assumptions from mainstream culture and presents movement as another language. Its comment section mostly contains reactions to this particular statement without much identity disclosure. Overall, Baggs’ space in and surrounding her video is more ‘neuro-separated’ since societal prejudice is contrasted with “people like me”, even though she addresses a wider audience.⁶⁸ The rhetoric of the translation clearly establishes an alternative autistic voice that is filled with significance, more so than “What it’s like...”. The assumed audience of “What it’s like...” has a *lack* of knowledge on autism, whereas “In My Language” refers to an assumed audience that is *filled* with prejudice.

“Craig Thomson” and Baggs unite both autistic and non-autistic internet users by their posts. However, the very fact that they use YouTube as a platform to creatively present autism, perception, and voice already means that they are part of a

⁶⁶ Craig Thomson, “What it’s like to walk down a street when you have autism or an ASD”, YouTube, <http://www.youtube.com/watch?v=plPNhooUUuc> (2010), date accessed 18 May 2015.

⁶⁷ Arman Kody, “Re What it’s like to walk down a street when you have autism or an ASD”, YouTube, <https://www.youtube.com/watch?v=3Rj-s2gW3x4> (2011), date accessed 14 April 2016.

⁶⁸ silentmiaow, “In My Language”, YouTube. <https://www.youtube.com/watch?v=JnylM1hI2jc> (2006), date accessed 18 May 2015.

wider online autistic community. They actively shape and contribute to the online flow of new signs on the autistic condition through web pages. This already signifies a particular geography based on a creative structure of signification. It is exactly this geography that I hope to grasp better through further study and encouragement of new words on the concept of autism in the autistic community. In the next section, I will leave behind my position as a passive observer of an online community and will focus on my own textual inventions that helped me to understand representations of autism better. The nature of this invention, a *counter-metaphor*, could be transferred to performative citizenship itself in order to make an unconscious production of meaning conscious.

The counter-metaphor

We saw that the production of the autistic community revolves around an unconscious process of identity performance and this occurs on YouTube by sharing creative units. I would like to argue that YouTube is a fitting platform for me to develop further the notion of the counter-metaphor as a *conscious intervention* in the practice of signifying autism. A counter-metaphor is a discursive invention that is specifically *intended* to be a break with common normalized conceptualizations of autism. In and outside the clinical world, the process of meaning-making is so obscured that speech on autism is seen as a pre-discursive ‘truth’. Conversely, the counter-metaphor allows free signification outside the dominant pathology of the concept of autism. It thus *broadens* talk about human diversity, rather than *replaces* ‘autism’ when traditional words fail to bring everyday autistic experience affirmatively into words. New words that refer to this experience could also connote the lives of other minority groups, which could lead to new alliances outside the autistic community. In order to show how this signification process of the counter-metaphor works, I will now turn to my own academic practice: the invention of ‘atopos’ in my MA thesis.

My MA thesis focused on the representation of autism as a discourse and negotiations of space in literary and visual culture. I found that the word ‘autism’ failed to grasp adequately the way in which autistic characters and autistic people in personal accounts transgress the space that surrounds them. The word ‘autism’ has always been associated with a preoccupation with the self: it was first formulated by psychiatrist Eugen Bleuler in 1910 and stems from the Old Greek word ‘autos’, meaning ‘self’.⁶⁹ Ever since, imagery of autistic people locked in their own world has

⁶⁹Eugen Bleuler, *Dementia Praecox oder Gruppe der Schizophrenien*, (Leipzig: Franz Deuticke) (1910).

been dominant.⁷⁰ By contrast, my case studies, including the two YouTube videos discussed in this essay, showed autistic people who are preoccupied with space: they intensively transgress space and stimuli and are often absorbed by it in case of sensory overload. To enable myself to freely consider my case studies and their undermining subversion of the word ‘autism’, I decided to invent something new with the intention to empower my own analysis and the practice of signification by autistic people. I thus developed theory *out of* my data. I countered existing spatial metaphors of autism: a lot of language on autistic people is concerned with withdrawal from space (autism as a shell) or origins from another space (autism as alien).⁷¹ A *counter-metaphor* concerned with space does not reject such metaphors but makes something new out of it.

The concept of *atopos* does prioritize space and is a “virtual, hypothetical parallel to the actual etymology of ‘autism’”.⁷² It is also an Old Greek word that means ‘strange’ in the sense of being ‘out of *place*’ (a-topos: no space). In the same vein as Bleuler’s adaptation of an Old Greek word in his ‘autism’, ‘atopos’ forms the basis of words like ‘atopy’ in immunology, which refers to hypersensitivity to allergens⁷³ and ‘atopia’ in geography, which refers to a borderless world.⁷⁴ All of these terms touch upon lived experiences as told by many autistic people themselves. The sensation of sensory overload is a *hypersensitivity* to stimuli that can give a feeling of absorption by space and a *loss of boundaries* between space and the body. Atopos thus shakes off inherent ‘autism’ connotations and allows a whole new vocabulary of lived experience to come into being.

This vocabulary greatly informed my readings of “What it’s like...” and “In My Language”. It enriched my understanding of the representation of “sensory overload” in “What it’s like...” as I could analyze its jerky camera work as an atopic transgression of the autism archetype’s corporeal boundaries characterized by probing sounds and light. In the case of “In My Language”, the atopos term mirrors Baggs’ message. Her ‘translated voice’ states that it is ironic that her movements and touch are seen as indicative of a life in her own world; her conscious contact with space through movement already forms a language in itself. Whereas I rejected ‘autos’ and the idea of autistic people being in their own world to improve my analyses, Baggs retrieves her own voice in *the* world instead of *a* world because she transgresses and absorbs space with *agency*. ‘Atopos’ evolves into something new: into

⁷⁰ Davidson Joyce, “‘In a World of her Own...’: Re-presenting alienation and emotion in the lives and writings of women with autism”, *Gender, Place & Culture: A Journal of Feminist Geography*(2007), 14:6.

⁷¹ Alicia Broderick, Ari Ne’eman, pp. 463-466.

⁷² Hannah Ebben, “In constant encounter with one’s environment: Presenting counter-metaphors in the study of the discourse of autism and negotiations of space in literature and visual culture”, MA thesis supervised by László Munteán and Mitzi Waltz (2015).

⁷³ Arthur Coca, Robert Cooke, “On the classification of the phenomena of hypersensitiveness”, *Journal of Immunology*(1923), 8.

⁷⁴ Helmut Willke, *Atopia. Studien zur atopischen Gesellschaft*, (Frankfurt am Main: Suhrkamp) (2001).

a language. Baggs' term 'translation' might inspire new words and videos from autistic people who may build it into a completely new concept that breaks with rooted assumptions on autism and voice—a new counter-metaphor.

This is why I intended the notion of the counter-metaphor to be something that anyone could invent in order to broaden common language on human diversity and lived experience. My atopos counter-metaphor does not always help to understand a text from an autistic person better; in these cases, new concepts could be theorized in order to broaden language on human diversity beyond the predominant 'autism'. In research on the empowering potential of YouTube for the autistic community, 'atopos' is mostly usable for an analysis of video content itself, but not necessarily for the study of the unique geography that the online autistic community generates. Even though autistic people worldwide can meet each other online in a world without borders, atopia, it cannot fully address the full complexity of the autistic community. Based on my literary review on online autistic space, I would like to state that Michel Foucault's concept of *heterotopia*—as presented in his essay "Different Spaces",—might be more useful here. Foucault uses the term to name the contemporary presentation of space as various "relations of emplacements"⁷⁵, which means that different heterogeneous elements form a space through specific relations.⁷⁶ In the literature I discussed, the autistic community on the internet was addressed as an intricate web of relations between non-autistic people and autistic people, being shared and separated, online and offline. As I lack the space to elaborate this, it might be useful to adopt heterotopia as a new theoretical framework for autistic online geography. The notion of 'relation of emplacements' may also be useful for members of the autistic community itself if it helps to articulate their negotiation of the difference between online safe spaces and offline spaces in which non-autistic culture predominates. They might create new words out of this or another concept in a signifying process that is similar to my own creation of atopos as a researcher. The counter-metaphor process thus aims to facilitate new enabling words that together might form a new structure of signification on human diversity. As the invention of words stands for creativity, it may as well be a *conscious* construction of citizenship itself.

The counter-metaphor as a facilitator of a new structure of signification within the autistic community on YouTube confirms and builds on cultural anthropologist Ben Belek's findings of his 2013 ethnography of a community of vloggers who identify with the label of Asperger's Syndrome on YouTube. He concludes that the vloggers and the autistic people who comment do form a community, but states that it is not enough to say that they solely share a diagnosis.⁷⁷ He instead describes them

⁷⁵ Michel Foucault, "Different Spaces", in *Aesthetics, Method and Epistemology*, ed. James Faubion, (London: Penguin Books) (1984 [1976]). (1998), p. 177.

⁷⁶ Michel Foucault, p. 178.

⁷⁷ Ben Belek, "*I Believe It Can Change the Way Things Are*". *Identity Constructions Among Video-Bloggers with Asperger's Syndrome on Youtube*, (Diemen: AMB) (2013), pp. 45-46 .

as a “discourse community”, which is a community that is bound through a shared form of communication that is specific to the history of the group.⁷⁸ A discourse community is confined to its own words, but there is room for change as the linguistic possibilities of the community can be extended by choice.⁷⁹ Belek argues that the autistic vloggers contribute to a large stockpile of texts that shape and direct their discourse, often in ways that touch upon the most basal understandings of the ontology of autism.⁸⁰ He points out the constant intake of new terms, theories, and metaphors that the vloggers deliver.⁸¹ Based on these findings, he presents the autistic community on YouTube as a collective that could unite and develop a voice within the historical circumstances of the arrival of the internet.⁸² It could create an identity through the active social construction of the notion of autism by transforming its meaning.⁸³ The YouTube community studied thus reconstituted the very category of Asperger’s Syndrome as a positive identity through a creative employment of autism as a discourse.⁸⁴ A conscious process of signification intended to be an act of identity formation counters the unconscious performativity of the concept of autism in society. As I stated in my MA thesis, “The insight of the autism community as a discourse community teaches that its members belong to each other by negotiating the discourse of autism”.⁸⁵ This essay has presented a similar theorization of the autistic community on YouTube with its discussion of two case studies. It has created an additional concept that might form an enabling discursive tool for new terms and words to arise.

Conclusion

After the presentation of the ‘counter-metaphor’, it is wise to indicate the role of the researcher in its potential next steps. This article has laid the empowering potential of digital technology in language in and of itself. It reassures that it is okay to accept that the concept of autism is cultural and flexible. On the internet, it is a field for creativity and identity forming, and in the end this signifying process could eventually positively affect the geography of the autistic community. This does not pretend to neutralize the difference between offline and online space or to make each problematic element of autistic space obsolete. The internet offers many autistic people the advantages of a social space that is low in stimuli, bridges peers that are

⁷⁸Ben Belek, p. 46.

⁷⁹Ben Belek, pp. 46-47.

⁸⁰Ben Belek, p. 47.

⁸¹Ben Belek, p. 48.

⁸² Ben Belek, pp. 50-51 .

⁸³Ben Belek, pp. 52-53.

⁸⁴Ben Belek, pp. 66-68.

⁸⁵Hannah Ebben.

often from all over the world, and forms a platform for creative content. Within these circumstances, the geography of the autistic community could go in any direction. Even though concerns about ghettoization are understandable, in order to support the demarginalization of autistic people in research, it is important to try to understand *discourses* on autism. The interpretation of ‘autism’ and ‘identity’ is up to people identifying with autism themselves. In order to study the autistic community, allowing the free production of words and terms is key. This might ultimately lead to concepts that enable alliances with groups, spaces, or fields that now lie outside of the notion of autism, such as other marginalized groups with similar lived experiences.

This article has engaged with demarginalization through its combination of empirical research that induces its conclusions on the basis of observations of YouTube as a digital social network, and action research that aims to change the world it observes. Specifically, the counter-metaphor has both academic and inclusive implications as it interprets existing practices of meaning-making and encourages new words and concepts. I hope that my literary review and presentation of the notion of the counter-metaphor will inspire subsequent studies on the empowerment of autistic people. Considering technology as a bottom-up participative spread of information could be a starting point for rethinking ‘autism’ and facilitating the negotiation of meaning and identity, theorized here as the formulation of counter-metaphors.

References

- Austin John L., *How to do Things with Words. The William James Lectures delivered at Harvard University in 1955*, (Oxford: Clarendon Press) (1962).
- Bagatell Nancy, “Orchestrating voices: autism, identity and the power of discourse”, *Disability & Society* 22:4 (2007).
- Bagatell Nancy, “From Cure to Community: Transforming Notions of Autism”, *Ethos. Journal of the Society for Psychological Anthropology* 38:1 (2010).
- Belek Ben, “I Believe It Can Change the Way Things Are”. *Identity Constructions Among Video-Bloggers with Asperger’s Syndrome on Youtube*, (Diemen: AMB) (2013).
- Bleuler Eugen, *Dementia Praecox oder Gruppe der Schizophrenien*, (Leipzig: Franz Deuticke) (1910).
- Broderick Alicia. A., Ari Ne’eman, “Autism as metaphor: narrative and counter-narrative”, in *International Journal of Inclusive Education* 12:5-6 (2008).

- Burgess Jean & Joshua Green, “Agency and Controversy in the YouTube Community”, in *Internet Research 9.0: Rethinking Community, Rethinking Place*, Copenhagen(15-18 October 2008).
- Coca Arthur. F. & Robert A. Cooke, “On the classification of the phenomena of hypersensitiveness”, *Journal of Immunology* 8 (1923).
- Couldry Nick, *Why Voice Matters: Culture and Politics After Neoliberalism*, (London: Sage) (2010).
- Davidson Joyce, “‘In a World of her Own...’: Re-presenting alienation and emotion in the lives and writings of women with autism”, *Gender, Place & Culture: A Journal of Feminist Geography* 14:6 (2007).
- Davidson Joyce, “Autistic culture online: virtual communication and cultural expression on the spectrum”, *Social & Cultural Geography* 9:7 (2008).
- Davidson Joyce & Victoria L. Henderson, “‘Coming out’ on the spectrum: autism, identity and disclosure”, *Social & Cultural Geography* 11:2(2010).
- Davidson Joyce & Michael Orsini, “The Shifting Horizons of Autism Online”, in *Worlds of Autism. Across the Spectrum of Neurological Difference*, ed.idem, (Minneapolis: The University of Minnesota Press) (2013).
- Dekker Martijn, “On Our Own Terms: Emerging autistic culture” Presented at Autscape (1999).
- Ebben Hannah, “In constant encounter with one’s environment: Presenting counter-metaphors in the study of the discourse of autism and negotiations of space in literature and visual culture”, MA thesis supervised by László Munteán and Mitzi Waltz (2015).
- Foucault Michel, “Different Spaces”, in *Aesthetics, Method and Epistemology*, ed. James Faubion, (London: Penguin Books)(1984 [1976]). Volume 2 of the *Essential Works of Foucault 1954-1984* series edited by Paul Rabinow (1998).
- Genette Gérard, “Introduction to the Paratext”, *New Literary History* 22:2, “Probing: Art, Criticism, Genre”, Translated by M. Maclean (1991).
- Jordan Chloë J., “Evolution of Autism Support and Understanding Via the World Wide Web”, *Intellectual and Developmental Disabilities* 48:3 (2010).
- Rosqvist Hanna B., Charlotte Brownlow & Lindsay O’Dell “Mapping the social geographies of autism – online and off-line narratives of neuro-shared and separate spaces”, *Disability & Society* 28:3 (2013).
- Sacks Oliver, *An Anthropologist on Mars: Seven Paradoxical Tales*, (New York: Alfred A. Knopf) (1995).

- Titchkosky Tanya, “Disability: A Rose by Any Other Name? “People-First” Language in Canadian Society”, *Canadian Review of Sociology* 38:2 (2001).
- Valentine Gill & Tracey Skelton, “Changing spaces: the role of the internet in shaping Deaf geographies”, *Social & Cultural Geography* 9:5 (2008).
- Waltz Mitzi, “Reading case studies of people with autistic spectrum disorders: a cultural studies approach to issues of disability representation”, *Disability & Society* 20:4 (2005).
- Waltz Mitzi, *Autism. A Social and Medical History*, (Basingstoke: Palgrave Macmillan) (2013).
- Willke Helmut, *Atopia. Studien zur atopischen Gesellschaft*, (Frankfurt am Main: Suhrkamp) (2001).
- White Mimi and James Schwoch, “Introduction: The Questions of Method in Cultural Studies”, in *Questions of Method in Cultural Studies*, ed. idem, (Oxford: Blackwell Publishing) (2006).
- Zoonen Liesbet van, Farida Vis and Sabina Mihelj, “Performing citizenship on YouTube: activism, satire and online debate around the anti-Islam video Fitna”, *Critical Discourse Studies* 7:4 (2010).

Video material

- Arman Kody, “Re What it’s like to walk down a street when you have autism or an ASD”, YouTube, <https://www.youtube.com/watch?v=3Rj-s2gW3x4> (2011), date accessed 14 April 2016.
- Craig Thomson, “What it’s like to walk down a street when you have autism or an ASD”, YouTube, <http://www.youtube.com/watch?v=plPNhooUUuc> (2010), date accessed 18 May 2015.
- Amythest Schaber, “Ask an Autistic – What is Autism?”, YouTube, <https://www.youtube.com/watch?v=Vju1EbVVgP8>, (2015), date accessed 11 April 2016.
- silentmiaow, “In My Language”, YouTube, <https://www.youtube.com/watch?v=JnylM1hI2jc> (2006), date accessed 18 May 2015.