



**NANYANG
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UNIVERSITY**

**VOICE AND IDENTITY IN THE AUTISTIC SPACE OF THE
BLOGOSPHERE**

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ABSTRACT

The goal of this study is to explore how autistic identity is constructed through blogs, and, more broadly, to show how communication theory can provide new ways of looking at the communication behaviors of autistic persons in the autistic space of the blogosphere. This study was guided by the following three questions: (1) How do autistic people structure their identity as bloggers and how do they negotiate their identity through their blogs? (2) What does autistic identity mean to bloggers? (3) What are the underlying constructs of autistic identity?

To address these questions, a grounded theory approach was applied to organize the main data collection, which included intensive face-to-face interviews, email interviews with bloggers and textual analysis of 2,873 blog posts with more than 10,000 pages of blog pages from 16 blogs authored by bloggers in Australia, Israel, Singapore, United Kingdom and the United States of America.

Three main autistic-identity constructs emerged from the data: autism diagnosis, autistic agency and normality. Normality was found to be at the heart of a dialectic negotiation with the social world: rejection of the neurotypical perception of normality and adoption of autistic identity as identity of difference. Autistic diagnosis was found to be a formative construct for autistic identity. Autistic agency was found to be at the core of autistic identity, while self-stimulation-related behaviors were found to be at the core of the perception of autistic identity.

Overall, the study's findings demonstrate that the Internet has revolutionized the ability of autistic persons to communicate, create communities, promote social change through activism and communicate with the non-autistic world. In particular, the Internet has played a crucial role in the emergence of an international autistic community as well as the shaping of autistic identity at both

the community and individual level. The personal space of the blog provides an arena in which autistic persons can explore their autistic selves and negotiate their identity with followers and the social world. Blogs create a safe space in which autistic persons can redefine themselves using their own voice and construct an identity as an individual and member of a community. In this light, the Internet and blogging in particular are radically reshaping contemporary thinking about autism, moving away from the biomedical conceptualization of autism as "deficiency" or "deficit" toward a socio-cultural view of autism as a manifestation of neurodiversity.

The study offers several contributions to our evolving understanding of autistic identity. First, this is one of the first studies to explore autistic identity in the blogosphere, as previous communication studies focused on community platforms such as forums, chatrooms and community websites. Second, grounded in communication theory, and in particular the work of Manuel Castells and James Carey, this study provides a conceptual framework that helps explain the roles the Internet and social media play in evolutions of autistic identity. Finally, the study demonstrates that communication approaches provide an important basis for investigating identity negotiation processes with the social world through blogging.

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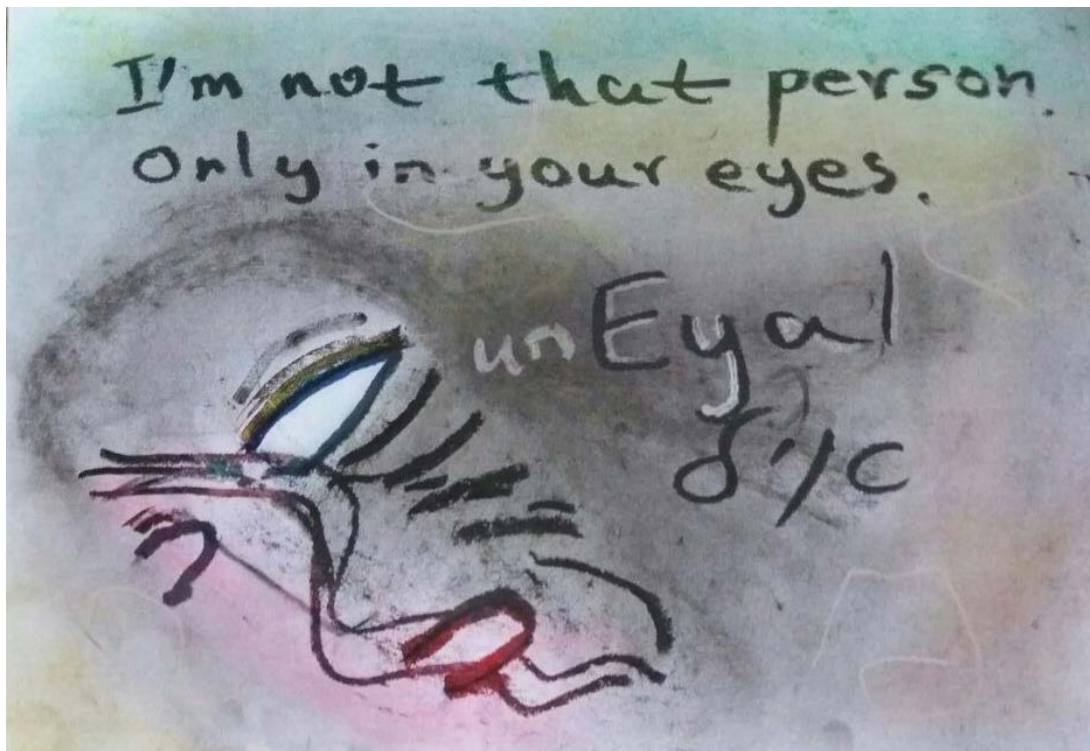
This thesis is dedicated to my mother, Michal, and my late father, David. I would have not been who I am without their love, support, values and intellectual curiosity.

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Eyal Shahal's art submitted to Autistic Speaking Day, Israel 2016

PROLOGUE

Autism, as a term, refers to a wide spectrum of people who differ in their needs, strengths and communication styles, as well as degrees of independence needed and realized. Thus, autistic people differ from each other significantly. Accordingly, throughout this research project, I was exposed to the bloggers' differing views on autism and studied their identity construction process.

In terms of autism, I learned that these bloggers oppose the tendency to view autism as disease, and instead call for social change that will enable individuals on the spectrum to be active partners in deciding about their lives. Among these

changes, they call for a shift from the focus on deficiencies and cure to emphases on the different needs of individuals on the spectrum and a move toward making both the medical and the social environments more accessible to autistic people.¹

The personal accounts of the blogs revealed that identity is very central to the definition of their ‘selves’ and is closely related to their meaning of personhood. The choice to study autistic identity through blogs was affected by distinctive features of the blogs: the personal space of the blogs allows the blogger to write relatively long narratives and provides the researcher potential access to the meaning-making process; the nature of the blog, as a space that is updated by the blogger with additional posts, emphasizes the identity construction as a process; and the virtual dimension of the blog provides the blogger with possibilities to negotiate his/her identity with the social world through the writings or through direct dialogue with blog followers.

Two Insightful Introductions

An Insightful Event

On October 28, 2016, Assaf Markowitz, an Israeli musician and autistic activist, published a Facebook post in a closed group of individuals on the autism spectrum calling for submissions about the autistic experience to celebrate Autistic Speaking Day.² This ‘Day’ is an online event initiated by the international autistic community in response to another event – ‘Communication Shutdown’ –initiated by non-autistics to show solidarity with communication difficulties faced by persons with autism.

¹ Autistic activists are very much aware of the fact that individuals on the spectrum who are officially diagnosed as severely low functioning may not be able to express themselves without some type of mediation, be it by their caregivers or professionals. They call for medical institutions to listen to them and learn from their experiences.

² The choice to refer to individuals on the spectrum as ‘autistic’, rather than ‘persons with autism’, has deep roots for people in the autistic community. Consonant with the findings of this study, I decided to use ‘autistic person’ or ‘individuals on the spectrum’, due to their preference by people in the community. This issue is discussed later as part of the discussion about ‘neurodiversity’.

Along with autistic persons I encountered in my study, I believe that although initiated with good intentions, ‘Communication Shutdown’ reinforces two key problems: first, the common stereotype of autistic people as being ‘trapped in their shell’; and, second, the assumptions of the ‘dominant tragedy model’ of autism. In response to these critiques, activists in the international autistic community protested by creating their own event; one that in their view emphasised their ‘non-mediated voice’³ by asking people in the non-autistic world to listen to what individuals on the spectrum *communicate* and how *they* experience autism, instead of focusing on their communication deficiencies. Autistic Speaking Day offers center stage to individuals on the spectrum by inviting them to express aspects of the autistic experience through submitting their own pieces, created specifically for the event in any format they prefer: text, photo, video, audio file or any other format that can be posted on the website. Since then, Autistic Speaking Day is celebrated every year on November 1st. The Israeli autistic community celebrated it locally for the first time in 2016.

The decision in Israel to celebrate locally and link it to the international celebration was significant. At that time, public discourse about autism in Israel had intensified, but the voices heard are typically those of parents and professionals rather than voices of autistic people themselves. In celebrating autism, the organizers hoped to achieve three aims: first, to raise awareness to the autists’ right to be heard in any shape and form; second, to be an active part in decisions that affect their lives; and, third, to advance the call for inclusiveness to the variety of voices and an end to the use of negative stereotypes about autistic people.

³ The voices of autistic people are rarely heard publicly. Therefore, public discourse about autism comes mostly from parents and professionals who chose to speak for autistic people. Autistic activists say that there is a great need *to hear* from autistic people directly, without the mediation of others who ‘speak on their behalf’.

Although ‘mediation’ in communication studies is used in reference to the medium of communication, the research reported here uses it to refer to the direct voice of individuals on the spectrum. In contrast, ‘non-mediated voice’ refers to mediation of parents and professionals.

Meet Daniel and Assaf

Though I have known his mother for many years, as we attended high school together, I only met Daniel when he was 12 years of age. Daniel is a non-speaking autistic person. He has a severe case of dyspraxia and is officially diagnosed on the low end of the spectrum. While Daniel needs help in many aspects of his daily routine, his cognitive ability is well above average. He is, in my opinion, a thinker and artist with significant capacities. The first official recognition of his capacities became apparent to Daniel's mother when he was 4 years old, when she realized his flipping pages in books was not random or some rigid repetitive behavior. Rather, it seemed to reflect understandings that he could not articulate. Her insight was confirmed when she took him to a professional and insisted that her son to be tested for reading ability.

Based on this affirmation, Daniel's mother started working with him on communicating through written language; first through Augmentative and Alternative Communication [AAC] and later through the computer and the Internet. But it was only when Daniel was 7.5 years old that he began to pronounce his first words. Today, his main media of communication are the Internet, mostly Facebook, and a printed board with the Hebrew alphabet carried in his mother's purse. His language is very rich and his thinking is highly sophisticated: He articulates his thoughts, his emotions and his point of view through poetry, paintings and written texts. He has written poetry since he was eight years old and posts it on his Facebook 'wall', together with other posts in which he shares his thoughts or tells others about his experiences. There Daniel asks many questions, writes about different aspects of the autistic self, social (in)justice, autism labelling and many other topics. Recent posts include writings about being autistic, about being different, about home schooling and the public educational system.

Assaf and Daniel are friends. They create together. Assaf sets Daniel's poems to music and performs them in public. Through their creativity they share many levels of their world views as well as advance their commitment to social change.

The announcement of the first Autistic Speaking Day in Israel sought to involve all individuals on the spectrum regardless of any defining label of functionality. The event celebrated autistic abilities, creativity, diverse communication styles and the right to be heard. For example, both Daniel and Assaf are dealing in their own ways with questions of personhood, community, belonging, culture and the autistic self. Furthermore, the two have chosen different forms of participation: While Assaf is part of the Israeli autistic community [ACI], Daniel did not join the community. Although he shares many of the community values, Daniel prefers to participate in discussions from outside.

Blogging the Autistic Self: On Identity, Voice and Exploration
Overview & Rationale for the Study

A forbidden tongue that cannot tell its tale to thee
A tongue torn between time that was and time that is to be
The Other tongue, prohibited to its speaker and lord
Permitted to God and only to God
Because He, who listens to the world
Can hear silence becoming words.

Eyal Shahal
(non-speaking autistic person)

Early mentions of autism and identity in scholarly work described individuals on the spectrum as lacking a sense of self and/or as a struggle with being recognized to be autistic (Bagatelle, 2003). Indeed, Sacks (1995) claims identity to be among autistic peoples' needs. For example, Donna Williams described her personal journey in search for identity as a two-decade long struggle to discover who she really is (Bagattel, 2003; Williams, 1992). Later studies explored aspects related to autistic community and culture, though in doing so they did not focus on identity, per se. These studies employed differing methodologies: individual stories found in

published autobiographies (Davidson, 2008); observations and interviews with individuals on the spectrum through traditional ethnographic research (Bagatell, 2003; 2010); observations of identity negotiation and neurodiversity in a role-playing game camp (Fein, 2015); as well as identity construction in community websites (Brownsberger, 2015; Sarrett, 2016), chat rooms (Brownlow and O'Dell, 2006), online discussion groups (Bertilsdotter Rosqvist, Brownlow and O'Dell, 2013) and online forums (Spillers, Sensui and Linton, 2014).

An alternative approach applied in studies of related phenomena proposes that self-exploration by an individual, voiced through personal expression, is a powerful source for identity construction. Doing so enables both author and readers to understand how autistic authors, in our case, make sense of their experiences and use narratives to communicate these experiences to others.

The underlying assumption is that the personal narrative, together with the negotiation of identity with the social world, are among the main means through which persons construct identity of the self (Bagatell, 2003). In this regard, Hacking, who analyzed autists' autobiographical stories, suggests:

A role for autism narratives internal to autism itself... is developing a language, or, if you will, a new language game, one that is being created before our eyes and ears. This speech is, in turn, creating or extending a way for very unusual people namely, autistic ones – to be, to exist, to live. (2009, p. 501)

Development of new 'language games', argued Davidson (2008) and Hacking (2009), is important, too, in empowering the autistic self as well as to create a sense of collective autistic pride.

The importance of narratives as a tool of expression has been identified and used for people with an illness (McGeekin-Heilferty, 2009), as well as, in studying hard-to-reach populations (Harvey, 2011). However, amidst efforts found in the literature on autism, I found that researchers focused less on narratives as a source of identity construction and more on authors' narrative abilities and representations, as well as narrative as intervention tool for use with/by autistic people. For example,

studies used the narrative as an intervention technique (Jones, Zahl and Huw, 2001) as a means to learn about the world of an autistic child (Kellman, 1999) or focused on the narrative abilities in High Functioning [HF] children with autism (Losh and Capps, 2003).

Digital and Social Media

Social media and other new technologies offer us a promising, relatively new domain of narrative study. Researchers are finding that these channels can be effective simply by providing useful ways to communicate with oneself in a personal domain along with others and, in doing so, enhance a sense of identity and community. One may also argue that authoring these texts empowers users. Chat rooms and forums, for example, provide opportunities for individuals as well as a community of people with autism to find their own voice and advocate about autism to the wider community of the neurotypical⁴ [NT] world (Bagatell, 2010, p.39; Brownlow and O’Dell, 2006). Community websites, too, host chat rooms and forums to facilitate communication of an opinion or post on personal blogs hosted by the community.

While dialogical communication is often an overt or implied expectation in chat rooms and forums, members of the autistic community differ in their definition in significant ways (Bertilsson Rosqvist, Brownlow and O’Dell, 2013). These researchers found that whereas ‘separate spaces’ are open for participation by autistic people only, ‘neuro-shared’ are shared spaces open to both NT and autistic people (ibid). Further, discussions in neuro-shared chat rooms and forums focus more on negotiating meanings, as autistic participants know they are open to the ‘NT eye’ and that, accordingly, their narratives may be affected by it.

⁴ Neurotypical (NT) is a concept used by autistic people to refer to the Typically Developed (TD) world. The term has developed as part of a wider perception of autism as defined by the neurodiversity movement, to be discussed in a later chapter. The label NT conveys political meanings for some people in the autistic community and, thus, is not always a fond reference to the NT world. Use of NT in this report is reference to the TD world.

Previous studies of autistic peoples' personal accounts analyzed personal websites (Jones, Zahl and Huws, 2001; Jones, Quigney and Huws, 2003). Overall, these studies found that autistic people focused on emotional and perceptual experiences. For example, they talk about emotional distress, frustration and a sense of alienation, sensory experiences and coping mechanisms.

Researchers who focused on social media and autistic identity construction included studies of community websites (Brownsberger, 2015; Sarrett, 2016), forums or chatrooms (Brownlow and O'Dell, 2006; Spillers, Sensui and Linton, 2014). Community websites can host blogs, forums, chatrooms, or publish relevant articles. Forums and chatrooms can be part of a community website or form communities themselves that evolve around the forum and are hosted by a portal that provides the technical means to create and manage a forum. Both community websites and forums emphasize dialogue between members, but only the website or forum administrators can control some of the technological features that allow them to delete posts or block members who do not follow written or unwritten codes of behavior.

Blogs, on the other hand, are designed to be individual oriented and allow, and often emphasize, more self-exploration and self-expression. Though located in virtual spaces, the identity construction process in the personal space of the blog can be reflected through potential dialogue between the 'thinking self' and the 'social self'.⁵ It is up to the blog owner to decide how much of the blog will be open to direct dialogue with others. Ortega (2013) considers the blogosphere as a major identity construction setting for people with disabilities. Yet, as Ortega points out, while scholars and self-advocates refer to the Internet as "an essential space of debate and identity development for autistic persons" (Ortega, 2013, p. 436), blogs have received inadequate attention in the study of autistic identity construction.

⁵ Bagatell (2003) discusses the role of the dialogical process with the social world in identity construction using Mead's (1934, appeared at Bagatell, 2003) definition of the 'thinking self' and the 'social self'. According to Bagatell, Mead referred to the interconnectedness between the two selves.

Why Blogs?

Scholars differ in their definition of blogs. One of the common definitions characterizes blogs as: an online diary that is updated frequently or on a regular basis, published in reversed chronological order and often include archives for earlier postings (Boniel-Nissim and Barak, 2008; Fullwood, Sheehan and Nicholls, 2009; McGeehin-Heilferty, 2009; Subrahmanyam, Garcia, Harsonon and Lipana, 2009). Hookway (2008), for his part, defines blogs as ‘self-narratives’ that allow the writer to post his/her intimate and private content on a daily basis or as frequent as the blogger desires. The blog serves as an on-line diary that focuses on the ‘drama’ of everyday lives, interactions and events and allows the writer to share with others his/her thoughts about the self.

Boyd (2006), on the other hand, rejects the definition of blog as online diary claiming that it “depletes blogs of any agency as a concept”. According to Boyd, a blog is social practice, which is at one and the same time a medium and a bi-product of expression. Sonja (2015) refers to blogs as one form of online digital storytelling that relies heavily but not exclusively on the written text.

Framed as digital storytelling and as a channel, the working assumption in this research project is that the blog space provides an arena for identity construction through self-exploration and negotiation with the social world. In the process of identity exploration, bloggers do not necessarily need to commit to one specific writing style and can either combine or shift between autobiographical memories, essays, hosting guest bloggers or interviewing people they find relevant to their blog.

Blogging, as cultural practice, is defined by Boyd as “producing digital content with the intention of sharing it asynchronously with a conceptualized audience” (2006). The blog’s features, as derived from this definition, include: ongoing expressions; content is captured locally; and although there are common values across blogs, the blogger is not bound to shared set of rules and meaning as the blog owner can set her/his own set of rules.

Autistic blogs, in summary, can be an interesting combination of personal diary, manifesto and text open to the public. Some bloggers use personal writing and focus on their own experiences; others use personal writing to solicit support but also to discuss the ‘bigger picture’ and topics related to autism in general; while others emphasize activism and their writing is less of a diary and aimed more at promoting awareness and social change.

Abductive Research Method

The focus on autistic identity and the early exposure to the blogger’s narratives challenged my pre-conceptions about autism, autistic people, social order, social interactions, communication, community and culture characteristic of much of the research conducted to date. Taking this into account, the study reported in this treatise employed a form of inductive, grounded theory that applies an abductive reasoning method offered by Charmaz (2006) throughout the research process. This method led to an investigatory approach that enabled me to search out answers to questions about the meanings of the alternative social order, the place of the autistic person in general and the autistic blogger specifically in the autistic social order as well as the connections between autistic identity and social order.

A preliminary analysis of blogs written by autistic people, conducted prior to the current research (Seidmann and Pang, 2013), revealed that the bloggers included in the study explored questions of identity and sought to promote awareness to autism through their writings. Further, they explored private issues, described inner processes undergone, discussed topics relevant to autistic people in general and promoted the neurodiversity agenda. They talked openly about social experiences and social interactions; they distinguished between loneliness which is the common stereotype of autistic people and between aloneness which is a place of choice and comfort; they talked about empathy; and they discussed the need for neurodiversity and inclusion of autistic people in society.

Similar to other studies that raised questions regarding the meaning of autism to autistic people and the neurodiversity claims, Seidmann and Pang (ibid) found

several key underlying assumptions: First, autistic bloggers tend to go against the common perception of autism as deficiency and the tendency to seek a 'cure' for people on the autism spectrum. Second, they thrive to accept themselves for who they are. Third, they assume that playing according to the NT rules in the NT world is a form of 'pretending' that accepts the dominant NT value of 'normality' (see also Bagatell, 2010; Browlow, 2010 about this point). Finally, by way of overarching theme, they advocate for the claim that society should focus on their uniqueness instead on their disability.

Advancing Empirical Research via Further Consultations with the Research Literature: Consistent with the 'Abductive Research Method', the conclusion of the pilot study suggested that further study of blogs must extend beyond the content to the practice of blogging; examine intentions and goals as well as the diverse styles within the blogs; and, these further investigations must be undertaken with guided by ongoing consultations with the extant research literature.

For example, the definition of the blog as online diary can only partially explain the functionality of the personal space of the blog to the identity construction of the autistic blogger and the bloggers meaning making process or quest for the autistic self. However, Boyd's conceptualization of the duality of the blog as a channel and at the same time as a cultural product provides a good framework to define the blog as autistic space and as cultural practice. The blog's features that derive from this duality add other features that can explain the functionality of the blog in the identity construction process. Thus, Boyd (2006) talks about the blog as 'extension of man'⁶ and refers to blogging performance as blurring textuality and orality.

Although Boyd's definition refers to blogs specifically and not to the Internet in general, these features are consistent with scholarly works about the role of the

⁶ Boyd (2006) uses McLuhan's definition for 'the medium as extension of man'.

Internet in the evolution of autistic community and autistic culture, as discussed above, and provides a theoretical framework that reinforces some of the autistic activists' perception of the Internet as "shaping a new kind of human society" (Dekker, 1997).

The social dimension of identity negotiation is manifest through Boyd's definition of the blogs as culture driven medium and the blogging practice as blurring between textuality and orality. The audience presence is manifest through the comments or "other communicated references to the blog material" (Boyd, 2006) and the blurring between textuality and orality is compatible with the definition of the autistic communication style as "language games" (Davidson, 2008; Hacking, 2009).

In summary, identity in the current research is defined as "thoughts and feelings about the self, or self-views" (Swann and Bosson, 2008, p. 448). Identity can be constructed through narrative and through the dialogue with the social world. Bloggers who use more personal writing may rely more on the narrative as a source for identity construction. Bloggers who use their blogs for social change and identify themselves as self-advocates may rely less on narratives and the social world may be more dominant in their quest for the autistic self. Boyd (2006) claims that the blog is the blogger's online identity and the blog is both a digital representation of the blogger and "a space for the embodied digital individual".

Although some bloggers may see the blog as means to reach a greater goal, others may very well see blogging as part of their identity. Viewing blogging as a possible part of the blogger's identity was reflected by one of the interviewees in the current study when he said that "blog is around the blogger, while forums are around topics; the interaction [with the readers] is around the blogger even if the content is not personal". The blogger is, therefore, at the center of the blog and the content or the dialogue evolve around the blogger. If the blog is the blogger's identity and it functions as the blogger's digital representation and a space for the embodied digital individual (Boyd, 2006), then its role in the identity construction process is greater than solely serving as a space for self-exploration. Consequentially, there is a need

to investigate more deeply into the characteristics of the blogger's techno-identity, a matter to be explained in detail later in this report.

Davidson, Edward and Hemsworth (2012), who studied the role of the Internet in the lives of individuals on the spectrum, found that the Internet is perceived by them as a safer place due to their ability to reveal their autism without revealing their true identity. In this sense, bloggers can explore their identity in the 'figured world' (Bagatell, 2010) of the Internet while controlling and shaping their "embodied digital self" (Boyd, 2006). The virtual environment and the space of the blogs provide the autistic bloggers the platform to negotiate their identity. Regardless of the self-definition of the blogger, the digital representation may take part in the identity negotiation process.

In conclusion, I explained why my working assumption is that the blog plays a significant role as a space for autistic identity construction. The blog as a medium and as cultural product provides the space in which the individual identity construction occurs. The formal features of the blogs provide the opportunity to explore the blogger's techno-identity and identity management (Schmidt, 2007) as well as the identity construction process. Therefore, the following research questions, which guided the research presented in this treatise, are related both to the identity construction process and to the personal space of the blog:

- How do autistic people structure their identity as bloggers, and how do they negotiate their identity through their blogs?
- What is autistic identity to the bloggers?
- What are the constructs of autistic identity?

CHAPTER ONE

INTRODUCTION

I was exposed to the non-mediated voice of autistic people almost by accident. In 2008, I was interested in studying autism and video games when one of my students at Michigan State University told me about a non-speaking autistic boy who communicated with his surroundings through video games. The idea that video games provided this child with the means to communicate encouraged me to look more deeply into the topic. I found that researchers, para-medical professionals (e.g., therapists, care-givers) and even parents create games designed to help autistic people learn social skills. Coming from a theoretical background and some experience in serious game design, I decided to study those games.

While working on my research proposal I found myself going ‘around’ autistic people; that is, planning to interview professionals, parents or other caregivers but not autistic people themselves. I knew I needed their perspective but I did not know how to approach them or even whether I could use a direct method such as interviewing with individuals on the spectrum.

My realization that I could have direct access to the autistic voice via blogs written by autistic bloggers became a major turning point in this project as I found in these blogs the rich, non-mediated voice of individuals on the spectrum. I started to learn how they perceive autism, what topics they find important to talk about and how they view the non-autistic world. Furthermore, I discovered that autism as portrayed in the media or in the medical model of autism was inconsistent with the way it was portrayed in their blogs. Thus, these blogs opened up a world of access to non-mediated and non-solicited texts that offered accounts of autism-related topics and an unfiltered perspective of the autistic experience.

Exposure to these bloggers’ texts strongly influenced my decision to change the focus of my research and to learn about autism from persons with autism rather than from people “around” autism. Thus, my research started with the broad question of what autism means to bloggers like Daniel and other autistic bloggers? As it

evolved, my investigations came to focus on autistic persons' conceptualizations of such core notions as autistic self, identity and experience.

Digital Media

The Internet challenges common stereotypes regarding the limitations of autistic people to communicate effectively (Brownlow and O'Dell, 2006). Indeed, as my research demonstrates, the still emergent digital world offers users technological tools that enable autistic people to find and communicate with each other or with the typical world, to form communities and to create personal spaces adapted to their communication needs. As a result, the development of the Internet opened the door for people who did not have the ability or the opportunity to express their voice without the mediation of a parent or para-medical professional; it enabled them to communicate through written language; and it promoted their political agenda as individuals or as members of a group.

An insightful entre to this claim can be found in a YouTube video, entitled *In My Language*, posted by Amanda Baggs in 2007 that has attracted more than 1.4 million viewers.⁷ Amanda Baggs is one of the activists who used Internet to vocalize autism, alongside such people as Temple Grandin, Jim Sinclair from the US and Donna Williams from Australia. Her film deals with her use of language as a non-verbal autistic person. In the first part of the video, Baggs introduces viewers to HER language by demonstrating several of her different routines. For example, the video begins with Baggs humming while she moves her fingers back and forth on a keyboard, playing with a rope, listening to a spinning top placed near her ear, playing with water, rubbing her face in book pages, playing with and looking through a yellow plastic spiral toy. Her point in such a presentation seems to challenge what could be interpreted as 'random actions', 'uncontrolled behaviors', 'pathological

⁷ <http://www.youtube.com/watch?v=JnylM1h12jc&hl=en-GB&gl=SG>. First accessed in 2013.

symptoms' or simply 'non-language' events. However, for Baggs, these are in fact different ways in which she converses.

The second part of the video is dedicated to explaining her language to other people. To do so, Baggs employs spoken language achieved through use of a special computer program that produces computerized voice vocalizing of her typed text. The verbal part of the video includes a manifesto about how she and people like her are perceived by NT society. Baggs says:

[...] the way I naturally think and respond to things looks and feels so different from standard concepts or even visualization that some people do not consider it thought at all but it is a way of thinking in its own right... I smell things, I listen to things, I feel things, I taste things, I look at things... their definition of thought defines their definition of personhood so ridiculously much they doubt that I am a real person as well (2007).

Baggs has her own blog, Facebook page as well as more videos she created and posted on YouTube to show aspects of her life. From her collective texts, we learn that, for Baggs, autism is an integral part of her personhood and her language is part of conversing with the environment. It defines who she is. Through her unique communication style, she talks not only about her language but about her personhood as being defined and perceived by NTs. Stated succinctly, Baggs claims that non-language in the eyes of NTs leads to a definition of non-personhood, and non-personhood leads to violence.

On the one hand, one might argue that Amanda Baggs is not necessarily a typical example of people on the autistic spectrum who express themselves on the Internet, as she is a non-speaking autistic person and as such, she is defined as low functioning while many of the other autistic people active on the Internet are defined as high-functioning autistic or Aspie.⁸ On the other hand, she is highly articulate in

⁸ Aspie refers to Asperger. Similar to seeing 'autistic people' as part of their identity, people with Asperger prefer being 'labelled' as Aspie. The latest clinical definition however moved away from distinguishing between different types of autism (like Asperger, PDD-NOS etc.) or the distinction between low and high functioning autistic people towards one spectrum of autism.

her written language. Thus, what she does represent is the broader phenomenon of autistic people who use the Internet and social media to express their voices through blogs and other social media, like Facebook, to communicate, to create, to advocate and to establish communities run by and for autistic people. The unique features of the Internet, in general, and of social media, specifically, provide autistic people with opportunities to express themselves, to learn about themselves, as well as to communicate with others through a medium that is more adaptive to their abilities and to their style of communication and social interaction.

One of the main contributions of Internet technology to the evolution of autistic identity involves providing the tools to construct what Sinclair (2010) refers to as ‘autistic space’. Autistic space is a virtual or physical space where people can safely explore, express or communicate and construct their identities as individuals or as part of a group. The current research project draws on this notion to explore the identity construction of individuals on the autism spectrum through their personal blogs.

The choice to focus on blogs as an arena for identity construction was influenced by several considerations. First, autistic identity construction has not been studied in the blogosphere, an omission noted by Ortega, a prominent scholar of neurodiversity and autistic identity (2009; 2013). In contrast, blogs have been found to be very useful for studies of self-exploration (Tan, 2008) for such phenomena as: adolescents (Boniel-Nissim and Barak, 2008; 2012; Subrahmanyam, Garcia, Harsonon and Lipana, 2009; Sun, 2010); illness (Mcgeehin-Heilferty, 2009); eating disorders (Guardiola-Wanden-Berghe, Sanz-Valero and Wanden-Berghe, 2010); and depression (Clarke and Van Ameron, 2008). Second, blogs can be considered as one type of autistic space as defined by Sinclair (2010) in which they can explore, communicate and construct their identity. Third, although blogs as personal spaces emphasize the individual blogger, in open blogs the blogger shares her/his experiences and opinions with others and negotiates autistic identity with the social world through her/his writings.

1.1. Studying Online Autistic Identity Construction

Internet and Identity

A series of studies found that Internet plays a significant role in the construction of autistic identity (Bagatell, 2007; 2010; Blume, 1997; Brownlow & O'Dell, 2006; Brownlo, 2010; Davidson, 2008; Davidson and Parr, 2012; Davidson, Edward and Hemsworth 2012; Dekker, 1997).

In turn, ethnographic studies of autism that focused on aspects relevant to autistic identity have referred to the Internet as mediating discussions about identity and emphasize the technological tools that enable the adaptation of the environment to the user's needs. For example, Markham (2011) discusses different aspects of the Internet and claims that the Internet, as a medium of communication, provides multiple means of interaction and performance of identity and community (p. 114) and functions as a context of social construction. The researcher defines three approaches to studying the Internet: Use the Internet as a research tool to study: (1) any existing social phenomenon; (2) socio-cultural phenomena mediated by the Internet or relying on it for their composition or function; and, (3) the Internet or aspects of it as a phenomenon itself (p. 112). Studying the autistic space and the autistic identity cannot be characterized as exclusively any one of these approaches.

Autism is considered to be, for the most part, a neurodevelopmental phenomenon, which exists as a social phenomenon regardless of the existence of the Internet. Yet, on one hand, evidence exists that the Internet mediates the evolution of autistic communities and can enable marginalized groups in society to give voice to their existence, needs and concerns. Activist groups of autistic people, community websites and autistic conferences are all part of a socio-cultural phenomenon that changes in front of our eyes and may have some implications on the society, in general, in terms of basic definitions of norms, values and inclusion. On the other hand, autistic communities are dependent in many ways on the virtual platform to

meet, to communicate, to converse and to create a collective identity. So, too, does the personal identity, explored and communicated on the Internet, exist in a way that otherwise would be difficult for many of them to do without it. As such, it is a phenomenon that is mediated by the Internet and relies on it for the composition and functions of the evolving unique identities.

Communication Theories and Identity

Moving more closely into autistic persons use of the Internet, from a research perspective, it is important to understand that the research reported here draws on three approaches from communication studies that helped us conceptualize the contextual processes through which autistic space and autistic identity are constructed, in particular via the Internet. Though in the chapters that follow I provide more in-depth presentations of these approaches, I summarize them here in order to frame for the reader the broad theoretical foundations of my research study and findings.

First, James W. Carey (1965, 1997), a leading figure of the American tradition of cultural studies, discusses the contribution of technological changes to the evolution of ‘speech communities’ among marginalized groups. In doing so, he offers a ‘ritualistic’ approach to communication as an alternative to the traditional ‘transmission’ approach (Carey, 1989). Although Carey focuses on mass media rather than Internet, *per se*, his view of communication as culture can be applied to one of the main aspects of the debate between the autistic activists and the dominant biomedical approach to autism: The latter perspective of autism as a communication disorder assumes a linear process of communication that echoes assumptions of communication as transmission. In contrast, Carey’s ritualistic approach to communication contextualizes some of the assumptions about autistic communication in ethnographic accounts of autism (Ochs, Kremer-Sadlik, Gainer Sirota and Solomon, 2004; Ochs and Solomon, 2010).

The second approach focuses on the cultural and social changes that emerged through the rise of Internet and social media. Here the claim made is that the

technological changes, which began in the 1990s, approximately, led to the shift from massive manufacturing of content to user-generated narratives and the circulation of content to massive audiences without aid of professional mediators. According to Jenkins (2006; Jenkins, Ford, and Green, 2013), these technological changes led to what he defines as the emergence of ‘participatory culture’. This concept can refer to and explain the evolution of blogs as cultural texts in autistic culture through the user-generated narratives of individuals on the spectrum that led to the emergence of common lexicon among activists as well as evolution and distribution of shared values and norms.

The third approach, advanced initially by Castells (2010), explains the evolution of identity construction as one of the new forms of social change occurring with the recent advent of network society. We will see later how his definition of the network society as collective individualism and the dynamics of identity construction processes among different communes enables us conceptualize the social dimension of the autistic identity construction.

Aims and Organization of the Thesis

These theoretical foundations, sketched here broadly, enable us to present an initial statement of the rationale, aims, context and need for the use of ethnographic research methods study employed in the research presented in this treatise.

Again, this study focuses on the meaning of autistic identity to autistic bloggers. In doing so, this research was guided by three main assumptions about identity developed from these theoretical foundations:

1. Identity construction is a dynamic and ongoing process.
2. Identity construction involves an exploration of the self as well as exploration of how the self is perceived by the social environment.
3. Autistic identity construction involves an ongoing dialogue with the autistic culture and common perceptions of autism both within the autistic community and through negotiating with the neurotypical world.

Accordingly, in order to set the stage for the exploration of autistic identity construction, one needs to understand (a) the different approaches to autism in research and (b) approaches that evolved from two semi-theoretic models of disability studies adopted by the autistic community. The discussion about these different research approaches affects the questions asked and investigations conducted in regard to autism and the distinction between studying “autism” versus “autistic people.” In addition, autistic identity needs to be explored through understanding the debate between autistic activists and proponents of the dominant bio-medical approach to autism research.

Organization of the Thesis

This research presentation is organized in seven chapters. Following this introductory chapter, the second chapter briefly reviews approaches to autism. The first part describes some of the leading theories in autism research developed by the predominant biomedical approach. In contrast, the second part introduces the anthropological approach applied in the research project presented in this treatise. The third part of this chapter discusses, briefly, two models evolving in disability studies, also involved in the research reported here.

The third chapter presents neurodiversity and the rise of the neurodiversity movement as well as its impact on the evolution of autistic identity and culture and the Internet.

The conceptual framework used to contextualize this research is presented in the fourth chapter, through the following sections. First, three communication approaches and the main concepts relevant to the exploration of autistic identity construction are presented. This is followed by descriptions of the evolution of: the ideas of autistic space; autism, identity and the Internet; the blog as a type of autistic space and bloggers’ community as type of collective individualism that provides part of the social aspect of negotiating the individual identity. Collectively, this chapter establishes the foundations and rationale for my focus on blogs as an arena for

identity construction. The chapter concludes with the research questions addressed in this research project.

The fifth chapter presents the methodology employed in this study, and discussion of various ethical considerations related to studying blogs written by autistic persons.

The sixth chapter presents the study's findings along with a discussion of their significance based on the existing literature. The finding's presentation begins with discussion of the blog as a personal autistic space, starting with descriptive information about the structural features in order to explore the bloggers' techno-identity and the blog as a space for identity negotiation. The next section presents an analysis of the meaning of autistic identity to the bloggers. In the third section, I probe more deeply into the constructs of autistic identity that emerged from the blogs and the interviews.

Finally, the seventh chapter includes a synthesis of the findings, discussion of implications, various limitations of this research study and suggestions for future research.

CHAPTER TWO

ALTERNATIVE APPROACHES TO THE STUDY OF AUTISM

Autism is a highly complex neurological condition that is considered to be both complex and enigmatic to many researchers, health professionals and caregivers. As a result, members of the global research community have been developing and applying multiple and, indeed, distinctly different approaches to study and understand autism. This chapter presents the following three of these research approaches.

The *biomedical approach*, the dominant research paradigm, considers autism to be a disorder, and focuses on neurological and psychological mechanisms that cause developmental impairments. Within this approach, evolving neurological and psychological theories explain different aspects of autism, as well as develop intervention plans and programs for people on the spectrum that apply these theories.

Anthropological studies investigate the socio-cultural context as well as discursive processes. Operatively, this means, for example, that this research literature could assist in providing clearer differentiations between communication and social skills in order to study the way autistic persons interact and communicate with others.

The *disability studies* and movement include two semi-theoretical and semi-ideological models of disability. These models had impact on the emerging concept of neurodiversity and the continuing evolution of autistic activist thought.

The remainder of this chapter presents and assesses each of these approaches, as the foundations for the conceptual framework developed in advancing the research reported in this treatise.

2.1. The Biomedical Approach

The Diagnostic and Statistical Manual of Mental Disorders (Fifth Edition, 2013 [DSM-5]) defines autism as a developmental disorder, and provides the following

diagnostic criteria: A person will be diagnosed as autistic if s/he: (a) shows deficits in social communication and social interaction across multiple contexts; and (b) shows restricted repetitive behaviors, interests or activities.⁹ This clinical definition of autism refers to it as a complex developmental disorder that “can cause significant social, communication and behavioral challenges”.¹⁰ Christensen, et. al. (2016) define Autism Spectrum Disorder as “a developmental disability characterized by social and communication impairments and by restricted interests and repetitive behaviors” (p. 2). According to the U.S. Centers for Disease Control and Prevention, 1 in 68 children are diagnosed with autism.¹¹

Although the spectrum of the disorders is wide and ranges from low to high functioning autistic people, some symptoms are shared and characterize most people on the spectrum. The biomedical approach, in general, and psychological analyses, in particular, identified deficits that characterize all people on the spectrum in varying degrees regardless of autistic severity (Baron-Cohen, Ashwin, Ashwin, Tavassoli and Bismadev, 2009; Beaumont and Newcombe, 2006; Booth, Charlton, Hughes and Happe, 2003; Boucher, 2012; Capps, Kehres and Sigman, 1998; Dawson, Munson, Estes, Osterling, McPartland, Toth, Carver and Abbot, 2002; Delinicolas and Young, 2007; Plaisted, Saksida, Alcantara and Weisblatt, 2003; Rajendran and Mitchell, 2007; Schietecatte, Roeyers and Warreyn, 2012). These deficits relate to social skills, verbal and non-verbal communication, social communication, delayed or absent language and lack of interest in other people (Durkin, 2010); as well as, different aspects related to mechanisms such as emotional information processing and identification, and processing of non-verbal cues.

⁹ Taken from Autism Speaks official website at <https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria> .

¹⁰ Definition is cited from the CDC (U.S. Centers for Disease Control and Prevention). <https://www.cdc.gov/ncbddd/autism/index.html> . See also the DSM-5 diagnostic criteria at the Autism Speaks website (<https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria>)

¹¹ <https://www.cdc.gov/ncbddd/autism/data.html>

Accordingly, autism research, conducted via the biomedical paradigm, aims to identify the relevant developmental deficits responsible for the symptoms that characterize and define autism. Theories developed within the paradigm describe the developmental deficiencies that characterize people on the spectrum and focus on impairments in social skills and communication skills. The deficit model employed by it emphasizes the following three dimensions: cognitive and neurological origins of autism symptoms; social skills impairments; and communication skill impairments. People on the spectrum - - from high functioning [HF] and Asperger's syndrome to low functioning [LF] autistic people - - are seen to have impairments in social and emotional information processing, identification of non-verbal cues, imitation of body movements, interpretation and use of non-verbal gestures (Dawson, Munson, Estes, Osterling, McPartland, Toth, Carver and Abbot, 2002; Rajendran and Mitchell, 2007).

Social skills impairment refers to a group of skills needed for healthy social development. These impairments characterize autism across a spectrum from low to high-functioning and people with Asperger's syndrome.

Communication skills are related to language processing and use, pragmatics and the ability to 'read' non-verbal cues. These social and communication impairments are intertwined in biomedical research; that is, they do not distinguish between how they affect people with autism in their functioning at home, in schools and in their communities (Boucher, 2012; Blinkoff, 2010; Capps, Kehres and Sigman, 1998; Delinicolas and Young, 2007; Murray, Lesser and Lawson, 2005; Rajendran and Mitchell, 2007; Sacks, 1995).

There are four main and/or associated theories *on* autism developed via the biomedical approach, delineated below: Theory of Mind (ToM), Joint Attention, Executive Dysfunction and Weak Central Coherence. Each of these theories focuses on different deficits in social and communicative development and inflexible behavioral patterns (Booth, Charlton, Hughes and Happe, 2003).

Theory of Mind

Theory of Mind [ToM] identifies cognitive mechanisms that affect social participation and communication. Among its major claims is that a deficit in even one of the many components of the social brain creates impairments in basic aspects of communication. The theory assumes that neurologically-based deficit leads to specific social impairments among autistic people which explains their social behavior (Hill and Frith, 2003). The theory refers to the cognitive deficits that limit someone/all persons on the spectrum's capabilities to understand somebody else's thoughts and feelings as well as predict others' behaviors (Baron-Cohen, 2009; Booth, Charlton, Hughes and Happe, 2003; Lacava, Rankin, Mahlios, Cook and Simpson, 2010; Rajendran and Mitchell, 2007).

Language is viewed as a means for sharing thoughts, information, feelings and beliefs with others and, therefore, communication is defined as the ability to express and interpret intended meaning. Accordingly, ToM assumes that impairment in the effective use of discourse impairs social participation and communication. Taken together, successful communication entails the understanding of the language as means to share with others (Hale and Tager-Flusberg, 2005). More specifically, individuals on the spectrum are characterized as lacking the effective use of pragmatics of language (e. g., irony, non-literal language and deception [Hale and Tager-Flusberg, 2005; Solomon, 2010]) and non-verbal social behaviors (e. g., facial and affect recognition [Hill and Frith, 2003; Solomon, 2010]).

Yet, Hale and Tager-Flusberg (2005) found that, unlike previous studies, children with autism do show improvement, in time, in social communication tasks. People with autism can potentially acquire a conscious 'ToM' (mostly HF persons or Aspergers), but lack the intuitive understanding and ability to mentalize other minds needed in everyday communication.¹²

¹² Frith (1989) introduced the term mentalizing referring to "the ability to represent mental states, whether perceptual, conative, emotional or epistemic" (Boucher, 2012, p. 229).

A later re-conceptualization of the theory argued that the autistic mind is not oriented to the social world and is incapable of interpreting verbal and nonverbal social cues, as is the mind of the NT person (Rajendran and Mitchell, 2007).

Theory of Joint Attention

Joint attention is defined as “the ability to coordinate attention between interactive social partners with respect to objects or events, or to share an awareness of the objects or events” (Dawson, et al, 2002, p. 346). For example, *joint attention* refers to the ability to jointly focus on the same object through the ability to follow someone else’s gaze, or through pointing or other verbal or non-verbal cues (Charman, 2003; Dawson, Munson, Estes, Osterling, McPartland, Toth, Carver and Abbot , 2002; Delinicolas and Young, 2007; Schietecatte, Roeyers and Warreyn, 2012).

Joint attention skills are important for development of language as well as cognition and social skills. Deficits in joint attention lead to difficulties in recognition of face and facial expression, significance of affective stimuli and understanding someone else’s feelings, thoughts and intentions (Dawson, Munson, Estes, Osterling, McPartland, Toth, Carver and Abbot, 2003; Schietecatte, Roeyers and Warreyn, 2012).

Two types of joint attention are commonly referenced: initiation of joint attention, related to social development; and response to joint attention as closely related to language development (Charman, 2003; Delinicolas and Young, 2007).

Theory of Executive Dysfunction

Executive dysfunction refers to “difficulties in inhibiting responses based on reality... and/or impaired generativity and imagination” (Boucher, 2012, p. 232). Executive functions are responsible for a variety of cognitive skills; such as, the ability to plan a series of behaviors; decision-making; ability to initiate, change or cease an activity; ability to inhibit irrelevant responses; ability to adapt to changes in the environment; judgement and self-perception (Blinkoff, 2010; Booth, et al., 2003; Durkin, 2010; Hill and Frith, 2003; Rajendran and Mitchell, 2007). The theory accounts for an autistic person’s stereotyped and rigid behavior in everyday life that may be

indirectly related to social and communicative interactions and also explain many of the non-social cognitive and motor aspects of autism like rigidity, repetitive behavior, rocking, etc.

However, executive difficulties are not exclusive to people with autism and autistic people have showed varying degrees in performance of executive function tasks. Although the theory can explain some of the deficits or the difficulties in performing tasks that could be related both to social and communication skills, it has difficulty explaining individual differences in performance especially among HF autistic people.

Weak Central Coherence Theory

Central coherence [CC] refers to information-processing and the integration of contextual information in the creation of meaning. According to Rajendran and Mitchell (2007), one of the theory's strengths is its capability to explain differing levels of conceptual abilities. Studies that focused on the verbal aspects of CC found that the ability to process and understand ambiguous meaning is related to other core linguistic impairments that may accompany CC problems among autistic persons, but there is no claim that they are universal among people with autism (ibid). For example, the ability 'to read between the lines' is important to the understanding of communicational intention beyond the surface of language processing.

According to this theory, while NTs process information through extracting structure and main ideas, autistic people who suffer from weak CC are highly detail oriented and have problems with organizing information into higher orders of meaning through utilizing contextual information in order to understand their environment (Beaumont and Newcombe, 2006; Booth, Charlton, Hughes and Happe, 2003; Hill and Frith, 2003; Plaisted, Saksida, Alcantara and Weisblatt, 2003; Rajendran and Mitchell, 2007; Solomon, 2010). Although later accounts of CC theory shifted from defining the perception of detail-oriented information processing as deficit to perceiving it as processing style, proponents continue to assume that individuals with

weak CC will always focus on details and will have difficulties using contextual information.

Overall, weak coherence explains why persons with autism have impaired visual perception, visual stimuli processing (attention), reduced generalization and verbal-semantic coherence.

In summary, these four main cognitive theories on autism aim to explain the origins and the nature of impairments in socio-communicative skills among people on the autistic spectrum. Each theory is related to different aspects and sets of skills. Accordingly, intervention treatments based on and applying these theories aim to provide persons with autism with skills needed for social interaction, social understanding and appropriate communicative performance (Rajendran and Mitchell, 2007). These aspects include the ability to understand other's feelings, thoughts and beliefs; the ability to do 'mindreading' through non-verbal cues (visual and auditory); the ability to extract higher levels of meaning in understanding one's environment; the acquisition of pragmatic skills that enable people to understand what is 'between the lines' (in higher level creatures of language like irony and metaphors); the ability to create discourse and participate in conversations; etc.

In my view, all these theories are capable of explaining some deficits, but fail to explain the universality or causes of these impairments. Or, stated another way, the existence of multiple cognitive theories, on the one hand, and their super specificity, on the other hand, fail even collectively to provide an overarching, inclusive explanation. This is due, I submit, first, to the still exploratory nature of these investigations; and, second, more fundamentally to the limitations of the positivist and experimental approach of the bio-medical paradigm they employ to study autism. For example, they study autism mostly in controlled situations, rarely in natural settings. Thus, overall, they are incapable of explaining how autistic people function, interact and communicate in wide range of aspects of everyday life, in a variety of settings.

Furthermore, it seems fair to conclude that questions about autistic identity are irrelevant to the biomedical perspective. In contrast, the importance of studying

autistic identity emerges as relevant and central if we shift the focus from questions about *deficiencies* to questions of *difference*. Our discussion, thus, proceeds with initial overviews of two approaches that deal in depth with questions of difference.

2.2. The Anthropological Approach to Autism Theories and Research

The anthropological approach provides a holistic, largely socio-cultural perspective for investigations and interpretations of autism. In doing so, investigators explore, broadly, how autistic people, and those close to them, experience autism; social interactions and discourse among autistic people; and aspects related to autistic communities and autistic culture.

A fundamental assumption of the anthropological approach is that autistic people are social actors. Thus, it aims, among other things, to conceptualize autistic sociality, probes everyday interactions including communicative acts and documents the evolution of autistic communities, including the emergence of self-advocacy organizations that label autism as neurodiversity and promote social change (Grinker, 2015).

Methodologically, anthropological studies use open-ended, relatively unobtrusive methods that involve studying contextual constructions, such as: everyday lives of autistic people and multiple trajectories in family life and the social world (Lawlor, 2010); autistic parents (Prince, 2010); personal life narratives (Sirota, 2010); inter-subjectivity and communication of children (Sterponi and Fasulo, 2010; Kellman, 1999); and autistic sociality (Ochs and Solomon, 2010).

Several scholars, cited below, shared observations that frame, build the rationale for and cite contributions of the anthropological approach in autism studies:

Solomon (2010) claims the contributions of anthropology to autism research include conceptualizing inter-subjectivity through careful and attentive observation; focusing on lived experiences of autistic people; and using a meaning-centered interpretive approach to study everyday practices. She also shared two instructive comparative analyses that distinguish the bio-medical from anthropological approaches: First, Solomon claimed that these studies cluster around or move

between two poles: while biomedical research focuses ON autism as a neuro-developmental disorder, the anthropological approach undertakes studies OF autism in which attempts are undertaken to understand the experience of being autistic in everyday life settings and contexts. Studies within the former framework focus on developmental impairments or delays that lead to communication and social deficits. Studies within the latter framework focus on social interactions, narrative accounts and observing (participating in) everyday life activities in different contexts. These two perspectives differ not only with what they focus on but on the way they perceive autism and approach research investigations.

Solomon's second useful distinction claims that while the biomedical paradigm focus is on "*experience [from a]far*" of autism, ethnographic research offers an "*experience near*" approach, providing insights about autism coming from the people and the families themselves and with their own words. In doing so, ethnographers seek to learn through the "native's eyes" and to understand the "experience-near" of the participant. Thus, "experience near" proceeds through careful, attentive observation without assuming that the anthropologist can think like the people they study (Solomon, 2010).

Clifford Geertz, among the most well-known anthropologists who advanced the use of the anthropological approach in a wide range of social science disciplines, argued that *experience-near* is what "an individual... might himself naturally and effortlessly use to define what he or his fellows see, feel, think, imagine, and so on" (Geertz, 1974, p.28).

Collectively, then, the findings from anthropological studies enable us to gain insights into the autistic community "as a personal, family and community/social group experience as evidenced through the analysis of social interactions, narrative accounts, and participation and engagement in activities at home and educational, clinical, and other institutional settings." (Solomon, 2010, p. 242)

Focusing on autistic communication, researchers noted that anthropological research explores communication styles and how autistic persons address communication difficulties; how they function in social interactions; and how they

express their emotions. In comparison with the bio-medical approach, this shifts the focus in research in several key ways: (1) from the interpersonal to the socio-cultural, without neglecting aspects of sociality and social actors (Bagatell, 2007; Ochs., Kremer-Sadlik, Gainer Sirota, and Solomon, 2004; Seidmann and Pang, 2014; Solomon, 2010); (2) from studying *autism* to exploring *autistic people* (Ochs., Kremer-Sadlik, Gainer Sirota, and Solomon, 2004; Raymaker and Nicolaidis, 2013; Seidmann and Pang, 2013; Seidmann and Pang, 2014; Solomon, 2010); (3) emphasizing the *active* dimension (participation and sociality) versus the *passive* (deficit driven) dimension of the medical model; and (4) from *developmental deficits* to *difference*.

Furthermore, we should note that autism studies that apply the anthropological approach focus on facets that are hard to explain through the biomedical paradigm; for example, autistic sociality (Ochs and Solomon, 2010); and, how autistic persons establish and maintain their autistic community in either the physical environment (Bagatell, 2010), the virtual one (Sinclair, 2010) or both (Bagatell, 2010; Sinclair, 2010).

Finally, as noted in previous chapters, the concept of culture is important in understanding the lives of autistic people. The anthropological approach is very important in this regard as it enables us to understand the systems of meanings developed by the community and the construction processes of meanings (Grinker, 2015). Additionally, we understand that narratives of autism are constructed within a complex construction of cultural codes, norms and identities (Danforth and Navarro 2001, p.167; cited by Glinker, 2015, p.348).

Finally, the value of the anthropology approach is “to unmask the foundations of scientific representations, and to comprehend both the social life of autism, as a construct, and autistic sociality” (Ibid, p. 347).

2.3. Disability Studies: The Social and Affirmation Models

The third approach is a derivative of the disability movement, and includes two semi-theoretical and semi-ideological models of disability: the social and affirmation models. The *social* model shifts the focus from the individual to the

social. The *affirmation* model is affected by the social model but shifts the focus again to the individual.

Both models differ significantly from the biomedical approach in moving away from the ‘impaired’ individual to focus on the roles of environment and society in defining the difference between *dis-abled* and *abled* bodies (Anastasiou and Kauffman, 2013; Beckett and Campbell, 2015; Oliver, 2013; Shakespeare and Watson, 1997; Shakespeare, 2010).

These models had impact on the emerging concept of neurodiversity and the evolution of the autistic activist thought.

The Disability Movement

The disability movement started in the 1970s as an organized, ground-up civil rights movement of disabled people, who sought to advance their own changes instead of professionally dominated top-down solutions afforded disabled people (Oliver, 1996). In doing so, the disability movement marked a political change among people with disabilities from focusing on impairment and autism as a medical condition to identifying themselves as a marginal, oppressed group in society. As Shakespeare (1993, p. 250) said: “It is about ‘the victim’ refusing that label, and instead focusing attention on the structural causes of victimization. It is about the subversion of stigma: taking a negative appellation and converting it into a badge of pride”.

Overall, the disability movement aimed to break the link between the body and the social situation of disabled people by enabling autistic persons to focus on the social structure as the disabling factor, and specifically, prejudice and discrimination. Accordingly, the movement pushed for political change based on promoting full citizenship rights and facilitating independence through legislative change and implementation of programs that aimed to promote personal assistance schemes (Oliver, 1996).

2.3.1. *Social Model of Disability*

While the biomedical emphasizes impairments that led in turn to focus on prevention and cure, the social model relies on attributing the disability to the social structure and redefines the problematic focus on impairments and on the individual. In doing so, the social model focuses, first, on describing the representations of the main structural features of the disablement process, as opposed to providing theoretical explanations (Beckett and Campbell, 2015). Second, the social model emphasizes civil rights and demands social and structural solutions that confront marginalization, oppression and social barriers.

In terms of contributions, the model provided new ways of, first, framing disability and the disabled body. Second, it offered a new way to constitute a sense of community as an alternative “to disciplining ‘psycho-medical’ categories, which acted to individualize responsibility for disablement” (Beckett and Campbell, 2015, p. 278). In doing so, it contributed to the emergence of collective consciousness and positive collective identity among disabled people through shifting the responsibility to the social barriers (Shakespeare, 2010). The positioning of society as disabling provided a frame of reference for people that could recognise each other as members of the same struggle, share values and work together for social change (Beckett and Campbell, 2015).

Beckett and Campbell also position the social model as an “oppositional device”. As such, they claim, it provides “a framework for describing practices of invention, collaboration and resistance deployed by people against disciplining practices of subjectivation, to make themselves anew” (ibid, p. 272). In their theoretical discussion of oppositional devices, the authors analyse them while relying on Foucault’s typology of technologies (technologies of: production, sign systems, power and self). The authors claim that the social model as an oppositional device allows people to transform themselves; provides oppositional framework for activists; transforms subjectivities in bio-power relations; allows activists to reject

existing definitions and perceptions and define themselves as an oppressed group (disabled people).

Critics of the social model claim that it relies heavily on the social structure as the disabling cause and neglects to acknowledge the potential needs that result from the biological difference between them and abled people.

2.3.2. *The Affirmative Model of Disabilities*

The affirmative model advances positive and empowering perceptions of disabilities. These perceptions rely on positive social identities, both communal and individual. Swain and French (2000) formulated the model in response to the *social model* and the *tragedy model of disabilities*.

While the *affirmative* model acknowledges the contributions of the social model to social change and to the emergence of disability communities, it shifts the discussion from identifying the problem to affirming and emphasizing disability as positive identity. Thus, while both the affirmative and social models reject biomedical assumptions about normalcy and the focus on ‘curing’ disabled people, the affirmative model claims that people who perceive their disability as important part of their identity don’t seek to ‘adjust’ or to be ‘normal’.

Similar to the social model, Swain and French (2000) also reject what they define as the tragedy model. This model portrays disabilities as individual tragedy that results from the individual bodily impairments and not from the societal failure to address the needs of disabled people through inclusion and appropriate services.

The collective identity that emerged with the disability movement contributed to the development of the affirmative model. The model emphasizes the positive identity that is shaped by the disability. Swain and French (2000) claim that, by looking at impairment positively, the model disputes the dominant status of normalcy and strengthens the social model. Collectively, both project a symbiotic inter-relationship: Individual identities are shaped through and parallel to the emergence of collective identity; and, as well, the affirmation of positive identity reassures collective and individual identities.

Summary

This chapter presented three different approaches to autism: the biomedical approach, the anthropological approach and two models that emerged from the disabilities movement. The biomedical approach and its emphasis on deficits led to perceiving autism as disorder and by some, as disease. The perception of autism as such is at the heart of the debate between members in the autistic community and the biomedical approach. Autistic activists such as Sinclair (1993) claim that the definition of autism as disorder and the derived meaning of autism as disease lead to the assumption that autism can be cured. This definition of autism is based on perceiving human behaviour and development as divided between normative/non-normative functioning.

The anthropological approach asks different questions from the medical model and uses different research tools. Thus, such researchers investigate fundamental aspects of autistic lives by focusing on autistic people through an ‘experience near’ approach.

The difference between the biomedical and the ethnographic approaches in studying aspects of social communication is an instructive example. While the medical model focuses on identifying the mechanisms that cause communication deficits, ethnographers and linguists may approach social communication differently and reach different conclusions about social communication of autistic people. Ochs and Solomon (2010), for example, studied autistic sociality through studying everyday interactions and defined a model that explains autistic sociality. Davidson (2008) refers to autistic communication styles as ‘language games’ and claims that autistic people find how to communicate in ways that are more natural to them and the ways to interact with others.

The social model and the affirmation model of disabilities shift the focus from the individual to the social environment and the social construction of disabilities. Of the two models, the social model of disabilities had profound impact

on the evolution of autistic activism and the emergence of the neurodiversity movement and the autistic culture.

The research reported here uses anthropological methods of ethnography as the main approach to studying autistic identity construction among autistic bloggers. We will see in future chapters that the process of individual autistic identity construction involves negotiation with the perception of autism as reflected in the autistic culture and the neurodiversity movement.

The next chapter continues this discussion by focusing on the evolution of the neurodiversity movement, neurodiversity and autistic culture and the role of the internet in the evolution of autistic culture.

CHAPTER THREE

EVOLUTION OF AUTISTIC IDENTITY VIA AUTISTIC CULTURE, NEURODIVERSITY MOVEMENT AND ONLINE AUTISTIC COMMUNITIES

This chapter addresses social contributions toward autistic identity development which emerged with rise of autistic culture and the neurodiversity movement, enabled by use of the Internet by autistic persons.

3.1. Autistic Culture

Identity is constructed through self-narratives as well as interactions and negotiations with the social world (Bagatell, 2003; 2010). Culture, too, is constructed through webs of meanings (Geertz, 1974) and analyzing it, therefore, requires contextualizing identity negotiation with the social world. Sinclair (2010), for example, describes at length the emergence of the autistic community and evolution of the autistic culture. In doing so, he connects autistic ideology and the specific needs of members in the community and their role in the formation of the autistic culture. Thus, autistic culture is understood as an ever-emerging aspect of social life that evolves through shared experiences, values, and identity development through communication styles and autistic persons' own ways of interrelating with others (Jaarsma and Welin, 2012). The discussion in this first part of the chapter focuses on three of the key social ways autistic culture has evolved to date: socio-cultural context and culture development, community development and communication styles.

Socio-cultural contexts and culture development

Cascio (2015) claims that autism should be viewed in a larger, socio-cultural context that considers autism both in the localized context as well as the broader

cultural perception of autism as manifest in the international autistic community. Socio-cultural context may refer to the local cultures autistic people come from but also to the context of autistic culture and the interaction with localized cultures.¹³ Gil, Shoham and Shelli, (2016) talk about the interaction between the autistic culture, autistic community and the local dominant cultures to which autistic people belong and claim that the influence of local cultures on autistic people lead to differences between autistic communities that are affected by the local culture. Thus, local or national cultures affect the local communities and make them sub-cultures of the international autistic culture, with which local autistic communities share values and cultural practices with autistic people around the world.

For example, in defining normalcy as a main NT cultural value, Gil, Shoham and Shelli (2016) claim the NT culture assumes that disabled people strive for normalcy. The adoption of disability as part of the autistic identity rejects the main assumption of disability as tragedy. The collective identity of the disability culture enables positive self-perception and promotes sense of belonging and pride to the individuals in the community while co-existing with the dominant local cultures as well. An example to it can be found in the Israeli autistic community. While adopting the autistic self and the narrative of difference as central to the autistic culture, members of the Israeli autistic community embrace core values of the Israeli culture such as Zionism.

Community Development

Some of the communities of disabled people can be referred to as a ‘counter-culture’, especially those who reject selected cultural values while accepting other values of the dominant culture. Autistic culture is an example of such counter-

¹³ Although beyond the scope of the current research, it will be interesting to explore interconnections between the autistic community as counter-culture and local communities. In this sense, cross-cultural study of autism could focus on how autism is being perceived or framed by local cultures and how local cultures could potentially affect local autistic culture or interaction between autistic culture and NT culture in specific settings.

cultures, as rejecting ‘normalcy’ as a main value of the dominant NT culture is one of the central tenants of community members.

For example, returning to the critique of the dominant bio-medical paradigm, Gil, Shoham and Shelli (2016) claim that shifting the disability discourse from ‘deficiency’ to ‘difference’ moves the discussion from the biomedical discourse to the socio-cultural context. While the *social model* of disabilities moves the disability away from the individual to the physical, social and cultural contexts, the model of *affirmation* shifts the focus back to the individual while rejecting the tragic model of disability (Gil, Shoham and Shelli, 2016, p. 164). The authors arrive at their conclusions through examining the concepts of ‘culture’, ‘sub-culture’ and ‘counter-culture’ in a commentary; perhaps as a means to understand and/or rationalize the affirmative model through comparisons between the deaf versus autistic culture.

Roles of Communication Styles

As noted above, self-advocates from the autistic community often compare the autistic culture to Deaf culture, with a focus on the obvious parallel in the distinctive communication styles that characterize both cultures, and which contributed to their evolution as distinctive cultures. While the sign language used by deaf people is clearly distinctive and functional to the outsider, the differences in communication styles of autistic people are subtler to the NT outsider as observer (Dekker, 1999). For example, autistic communication differs from NT communication in rhythm, use of non-verbal cues, directness and tendency to focus on literal interpretation (problems of reading between the lines; Dekker, 1999).

Davidson (2008) finds Wittgenstein’s concept ‘language games’ and the idea of ‘form of life’ to be relevant to analyses of the evolution of autistic culture. Autistic communication styles are best defined as ‘language games’ which the author claims emerge from shared experiences as well as identification of the individual’s place on the spectrum. According to Wittgenstein, ‘language games’ connect between language uses and actions, which are infinite in nature.

For example, language uses are less dependent on the definitions and the meanings of terms and more on the context and the mutual understanding of the term used by a community of language users (Davidson, 2008, p.794). Thus, use of terms like neurotypical to describe the non-autistic typical people or ‘Curebie’ to describe (and criticise) people who are pro-cure [of autism] are examples of such language games.

Hacking (2009) suggests that the role of the narratives internal to individuals on the spectrum contribute to the evolution of a new language game that extends their way of being. The idea behind ‘form of life’ refers to the shared cultural meanings between autistic people, not as universal sharing but more on the level of understanding each other as a result of related experiences (Davidson, 2008, p. 794). Davidson connects autistic language games and ‘form of life’ when she says:

That is to say, autistic differences in perception and ‘processing’ tend to involve other ways of being-in-the-world, separate senses of selves and space that give rise to distinctive cultural experience, and so also, cultural expression. (Davidson, 200, p. 793)

By way of a final example, the development of the unique terminology of autistic self-advocates is reflected through the evolution of the term ‘neurotypical’. The early autistic self-advocates needed to find a term to distinguish themselves from non-autistic persons while avoiding the use of ‘normal’ people to describe them. The term neurotypical or NT describes the ‘neurologically typical’ and reflects the advocates’ rejection of ‘normalcy’ as a main cultural value and the emphasis on neurological difference. AC, is an inclusive acronym to refer to ‘Autistic’ and ‘Cousins’ [Ed. cousins are people who share some of the same symptoms with autistic persons]. Whereas terms like neurotypical and AC help foster the sense of community (Dekker, 1999). “Autie” [for autistic], “Aspie” [for Asperger], or “Curebie” [term used to criticize people who aim to cure autism] emphasize pride in autistic identity while distinguishing autistic activists from the NT world [i.e., ‘us’ and ‘them’ identifications] (Bagatell, 2007; Gil, Shoham and Shelli, 2016; Ortega, 2009; Runswick-Cole, 2014).

3.2. Neurodiversity and the Rise of the Neurodiversity Movement

Overall, neurodiversity calls for “recognition and acceptance of (valuable) difference” (Runswick-Cole, 2014, pp. 1120-1121) and strives for neuro-equality based on the understanding that neurodiverse or neurotypical are both human variations and ways of existing. Neurological difference is as significant as one’s skin color, gender, or sexual orientation and the autistic community is another example of marginalized groups in society like the queer, deaf and black (Bumiller, 2008; Jaarsma and Welin, 2012; Krcek, 2013; Runswick-Cole, 2014).

In his book *NeuroTribes*, Silberman (2015) describes the essence of neurodiversity as shifting the focus from diagnostic labels to “human operating systems”. This view of autism and other neurological differences is based on perceiving the brain as an adaptive organism and abilities maximization instead of focusing on limitations. Gannon (2007) added that a mixture of neurological abilities and disabilities coexist in many cases, noting that the different ways these combinations are generated and sustained depends on wiring of the brain.

In discussing the essence of neurodiversity as autistic culture, Runswick-Cole (ibid) describes the neurodiversity movement as aiming to provide spaces in which autistic people can feel pride in their identity, support each other and advocate as a community. Fein (2015), who studied the ‘work of culture’ in a role-playing games camp for youth on the spectrum, describes how the camp’s space was designed to provide conditions in which difference was appreciated and not stigmatized, reinforcing the “overall ethos of mutual acceptance and support” (Fein, 2015, p. 312). According to Fein (2015), it is the interaction between neurocognition and cultural practices where interplay between neurodiversity and cultural materials build and maintains the autistic culture.

Gil, Shoham and Shelli, (2016) agree with Fein’s observation and claim that the autistic neurodiversity affects any aspect of their being: way of thinking, sensory processing, emotional processing and communication style. This difference is reflected in the autistic community customs starting with mutual interests, structured

activities, and tolerance to physical behaviours considered unacceptable in the neurotypical world and ending with terminology that reflects their ideology, self-advocacy and autistic identity.

The neurodiversity movement was originally established by online groups of autistic people and later expanded to include other neurological and neurodevelopmental conditions (Brownlow, 2010; Fenton and Krahn, 2007; Jaarsma and Welin, 2011; Kapp, Gillespie-Lynch, Sherman and Hutman, 2013; Kras, 2010; Runswick-Cole, 2014). Proponents of neurodiversity challenge the medical model by providing an alternative representation of autism through making, at least, two fundamental inter-related claims: First, autism is a natural human variation and therefore focus should be on neurological differences rather than brain pathologies (Brownlow, 2010; Dekker, 1997; Fenton and Krahn, 2007; Glannon, 2007; Ortega, 2009; 2013; Sinclair, 1993; 2010). Second, the rights of autistic people derive from their specific needs and demands for acceptance and inclusion (Brownlow, 2010; Jaarsma and Welin, 2011; Orsini and Smith, 2013; Runswick-Cole, 2014). As we can see from the following description, this claim of ‘neuro-equality’ involves repositioning autistic persons from the medical model’s deficiency-centred approach to recognition as a legitimate but marginalized minority group in society.

Overall, then, the neurodiversity movement forced us to acknowledge the existence and versatility of neurological differences, and consequently, that the ‘normal’/‘abnormal’ (or pathological) dichotomy needs to be re-examined. Gannon challenges existing diagnostic labels of ‘pathologies’ and ‘mental disorders’, claiming that instead of focusing on the pathologies, researchers need to ask what counts as mental disorder and when the deviation from the general population becomes ‘neurological difference’ rather than ‘disability’.

Baron-Cohen (2015), one of the leading autism scholars working via the biomedical paradigm, acknowledges the logic behind the term ‘neurodiversity’, and consequently, agrees with the argument that there is more than one way to be ‘normal’. Further, he accepts the reasoning behind the neurodiversity movement’s

emphasis on autism as differential development rather than inferior development. According to Baron-Cohen, the benefit of this approach:

[is] in terms of inclusion and acceptance. Instead of those with a diagnosis feeling in some way inferior or excluded, the notion of neurodiversity breaks down divisions between those with and without a diagnosis by acknowledging that people are simply “differently wired” and that it is misplaced to think of some people’s wiring as ‘normal’. (2015, p. 1761-1762)

We can find echoes of resistance to ‘neuro-normalcy’ in parallel claims made by Davidson (2008) in her analysis of arguments advanced in the gay rights movement against seeing homosexuality as ‘illness’ or ‘disorder’. Similarly, Thomas and Boellstorff (2017) examine the classification of normal/abnormal through the evolution of the ‘spectrum’ metaphor in regards to autism by comparing it to a similar evolution of the spectrum metaphor for sexuality. The authors claim that the use of spectrum as a dominant metaphor implies “fundamental consequences for notions of disability, diversity, and normality”. Indeed, the search for a ‘cure’ for autism is at the core of the *autism as a disorder* versus *neurodiversity* debate.

The potential implications of neurodiversity arguments are deep and broad. and can be distinguished as three sets of arguments: neurological, diagnostic and moral.

First, following our earlier presentation of the bio-medical approach, we understand that the neurological argument claims that autism is a natural phenomenon of the human brain. In contrast, rather than view autism as a ‘deviation’ from the ‘normal’, autistic self-advocates claim that autism needs no cure, nor do autistic people need interventions that aim to ‘normalise’ them (Baron-Cohen, 2015; Fenton and Krahn, 2007; Jaarsma and Welin, 2012; Kapp, Gillespie-Lynch, Sherman, and Hutman, 2013; Orsini and Smith, 2013; Ortega, 2009; Seidmann and Pang, 2013).

The binary distinction between ‘normal’ and ‘abnormal’ (or pathological) reflects the medical hierarchy and the social attitudes and prejudices towards autistic people. The focus on deficiencies and the social structure that accommodates typical

people places and continues to support use of disabling barriers that result from lack of accommodation and discrimination in employment, housing and other civil rights (Kras, 2010).

Second, according to the diagnostic argument, there is a need to re-examine concepts such as ‘natural variety’, ‘normalcy’, ‘functionality’ and ‘autonomy’. One of the facets of functionality, for example, is assessed through ways of living independently. Success in independent living is defined as functional and implies personal autonomy. Fenton and Krahn (2007) examine these concepts and claim that we need to understand independent living as inter-dependent and autonomy as relational (2007, p. 4).

A third argument, the moral, too, needs to be acknowledged from a fundamental claim of the neurodiversity perspective that, from a rights perspective, autistic people *should* have more control over their lives as well as involvement in decisions about treatments or interventions (Brownlow, 2010; Fenton and Krahn, 2007; Kapp, Gillespie-Lynch, Sherman, and Hutman, 2012; Runswick-Cole, 2014). Three associative claims drive this rights perspective: (a) we must recognize there are different ‘ways of being’ (Jaarsma and Welin, 2012; Runswick-Cole, 2014); (b) differences in socializing, communicating and sensing should be advanced as manifestations of the fundamental neurodiversity argument; and (c) autistic people can provide valuable insights in therapeutic exchanges.

Returning to the general nature of this debate, we share the following summary positions: Krcek (2013) sees there are three sides to the debate: those who blame the environment as a cause of autism; those who see autism as genetic, in need of study through finding the relevant genes that cause autism (the medical model); and those who claim that autism is genetic but part of normal human variation (neurodiversity).

From a conciliatory point of view, each of these arguments while necessary is not sufficient and each requires much further investigation.

Finally, we might want to add consideration of the consequences of these points of view. For example, although accepting the reasoning behind the

conceptualization of autism as neurodiversity, Baron-Cohen (2015) expresses concerns about the potential moral implications of abandoning the ‘pro-cure’ model. Clearly more work needs to be done to clarify these important, yet early expressions of concern and analysis. Especially in consideration of the significant policy implications as we see from the following discussions.

Finally, Orsini and Smith (2013) point us to future positive consequences of advancing such investigations by discussing the implications of autism activism on public policy. The authors claim that the struggle over the definition of autism raises some significant questions within the realm of public policy. How, for example, should state resources be used to support individuals on the spectrum? Who are the experts? What assumptions will guide the definitions of the worlds of autism? (Orsini and Smith, 2013, p. 41). The answer to these questions lies in interactive policy styles that include what the authors refer to as ‘embodied knowledge’ that is applied in discussions of services and education for autistic people (Orsini and Smith, 2013: 51). The advocacy of neurodiversity as promoting acceptance and inclusion in the societal level yielded some practical implications such as the use of universal design principles in creating more inclusive environments (Kreck, 2013; Silberman, 2015) and cooperating with individuals on the spectrum as can be seen in projects such as AASPIRE¹⁴ (Silberman, 2015).

3.3. Neurodiversity and Autistic Identity

What connects the implications of neurodiversity for individuals with the social implications of recognition, acceptance and neuro-equality? I submit that it is the role played in the evolution of autistic identity on the individual level and as part of autistic culture. For neurodiversity advocates, autism is perceived as an essential part of their identity and activism is just one dimension in the struggle with the biomedical paradigm and the biosocial identity of the autistic person (Orsini and Smith, 2013). Accordingly, activists reject any conceptualization of autism as a

¹⁴ <http://aaspire.org/?p=projects>

‘disease’, ‘pathology’, ‘disorder’ and medicalization that leads to attempts to ‘cure’ autism. Indeed, they argue that such language and attempts are equivalent to trying to ‘cure’ black people from being black or forcing left-handed to become right-handed (Fenton and Krahn, 2007; Ortega, 2009).

Gannon (2007) claims that the mental traits of neurological conditions, such as autism, are essential parts of an autistic person’s makeup, as individuals. Moreover, autistic advocates also see these traits as what defines them, collectively, as members of a distinctive culture.

Ortega (2009; 2013) finds neurology and the concept of the ‘autistic brain’ to be central to the neurodiverse sense of identity and to the distinction between neurodiverse and neurotypicals.

The ‘cerebralistic identity politics of neurodiversity provided “the basis for identity formation along with social and community networks.” (Ortega, 2009, p. 442). Such use of neurological vocabulary and brain-related metaphors contributes to the constitution of new and non-apologetic positive identities. In doing so, Ortega argues there is a risk that this will lead them to leave discussion of what it means to be ‘human’ and lead to reductionist forms of identity politics (Ortega, 2013).

Some neurodiversity advocates reject the distinction between high and low functioning autistic people claiming that these differences represent variations of autism rather than fundamental neurological differences. However, the realities of diverse neurologies can often lead to a discourse that demonise concepts such as normalcy, on the one hand; but, as well, lead discourse towards discussion of bio-citizenship (see Brownlow and O’Dell, 2013).

Taking the presentation here in a different direction, neurodiversity as identity can be inclusive or exclusive. *Inclusive* neurodiversity conceptualizes it as part of diversity that includes everyone, including NTs. Furthermore, it promotes more inclusive citizenship and affects how we understand ourselves and each other (Bumiller, 2008: 982). The *exclusive* manifestation of neurodiversity emphasizes, indeed celebrates, the unique qualities of the neurodiverse that affect the formation of neurologically-based culture and autistic identity. Ortega (2013) explains this

process through what he associates with the more commonly used concept of ‘identity politics’ and claims that it leads to more separation between the neurodiverse and the NT mainstream on the expense of identifying individual differences across the spectrum.

Building on the identity politics argument, we can say that neurodiversity promoted a different presentation of autism, ‘neurological self-awareness’ and the emergence of autistic culture (Ortega, 2009). Indeed, the claim that neurological difference is a defining characteristic of identity plays a significant role in the emergence of autistic culture. Celebration of difference and the pride accompanying autistic identity are manifest through terminology developed among autistic advocates to mark culturally accepted vocabulary that reflects the autistic experience. For example, use of “identity-first” language as a cultural identifier is common among autistic advocates, as it exemplifies the neurodiverse claim that autism is an integral part of the individual identity of autistic person. Thus, reframing the social construct of disability (autism) from ‘person-first’ to ‘identity-first’ language is a cultural manifestation indicator of neurodiversity and contribution to formations of communities of autistic people with a shared identity (Ortega, 2009).

Neurodiversity activists advocate for recognition of autistic culture, perceive it to be a minority culture and refer to the marginalization, discrimination and exclusion of autistic people (Davidson, 2008; Jaarsma and Welin, 2012; Orsini and Smith, 2013; Runswick-Cole, 2014). As a minority group, the neurodiversity movement can claim group rights, proclaim themselves as belonging to a culture at risk that needs protection (Orsini and Smith, 2013). On the practical level, similar to the social model of disabilities, neurodiversity as a movement thrives to create a more inclusive environment and society, one that must attend to and accommodate for autistic needs in areas as health care and education, instead of focusing on normalization.

Seen broadly and historically, neurodiversity was highly influenced by the ideas behind the social model of disabilities - philosophically, ideologically and

politically (Kapp, Gillespie-Lynch, Sherman, and Hutman, 2013; Orsini and Smith, 2013). Similar to the social model, neurodiversity distinguished between the biological nature of the condition and the social barriers that continue to exclude autistic persons socially, economically and politically (Runswick-Cole, 2014). Furthermore, neurodiversity offered a new representation of autism; one that shifts away from, first, the biological impairment to the divide between identity and inclusion (Kreck, 2013); and, second, the lack of social accommodations to their needs as the disabling factors. However, unlike the social model that puts the environment in the spotlight and moves far away from the intrinsic features of the medical perception of disability, neurodiversity affirms neurological difference (intrinsic) as integral part of the bio-social identity of the autistic person (Kapp, Gillespie-Lynch, Sherman, and Hutman, 2013; Runswick-Cole, 2014; Orsini and Smith, 2013; Ortega, 2009; 2013).

3.4. Internet and Autism

The evolution of the Internet was a turning point for the emergence of autistic communities, autistic culture and the formation of distinctive autistic identity. The ability to communicate effectively and interact socially through the accommodating features of the virtual space (n.b., the utopian social ‘no place’ as Davidson [2008] framed it) challenged common conceptions and stereotypes regarding communicative and social competencies of autistic people (Brownlow and O’Dell, 2006; Davidson, 2008).

The autistic presence on the Internet as an independent grouping started as early as 1992 when Donna Williams, Xenia Grant and Jim Sinclair left a pen-pal list maintained by parents of autistic people and established their own community known as the Autism Network International [ANI] (Sinclair, 2005¹⁵; 2010). Initially, ANI included a newsletter and pen-pal list. In 1994, following cases of harassment of

¹⁵ http://www.autreat.com/History_of_ANI.html

several of the members by an online stalker, they created their first online discussion forum – ANI-L - that is closed to NT participants and has clear discussion and participation rules (Sinclair, 2010).

Throughout, self-advocates as well as researchers demonstrated the significant role of the Internet in sustaining and shaping the development of autistic communities (e.g., Bagatell, 2010; Davidson, 2008; Davidson and Parr, 2012; Dekker, 1999; Durkin, 2010; Goodman, 2006; Grinker, 2015; Sinclair, 2010). Similar to the accessibility to information enabled by braille to blind people, the Internet provides access to rich sources of information, alternative explanations about autism as well as mutual support through websites maintained by and for autistic people; for example, the Autistic Self Advocacy Network [ASAN]¹⁶. Furthermore, the Internet helps a user find people who share similar experiences and difficulties, via, for example, ANI¹⁷, Wrong Planet¹⁸, or ACI¹⁹. In doing so, it provides tools, and educates to enable communication in ways that accommodate their communication style (Bagatell, 2010; Davidson, 2008; Davidson and Parr, 2012; Dekker, 1999; Durkin, 2010; Goodman, 2006; Grinker, 2015; Sinclair, 2010). Thus, the Internet allows individuals on the spectrum to participate in social interactions in virtual space when, with whom, and even whether or not they choose to do so with others (Bagatell, 2010; Sinclair, 2010).

Through its technological features, the Internet has enabled community formation for self-help and self-advocacy to individuals on the spectrum across the world (Orsini and Smith, 2013; Ortega, 2009; Runswick-Cole, 2014); facilitated voicing and became an arena where autistic activists could promote personal and social agendas (Blume, 1997; Ortega, 2009; Seidmann and Pang, 2013).

Bumiller (2008) describes the contributions of the Internet to the neurodiversity movement as follows:

¹⁶ <http://autisticadvocacy.org/>

¹⁷ <http://www.autismnetworkinternational.org/intro.html>

¹⁸ <http://www.wrongplanet.net/>

¹⁹ <http://www.acisrael.org/>

The neurodiversity movement considers itself a new form of cosmopolitan interest group, one that signifies a worldwide community of interconnected individuals who aspire to be comfortable as atypicals. This new kind of interconnectedness is seen in how neurodiversity activists have utilized virtual communication channels that allow for easy self-expression, immediate exchange of information, and freedom from some of the intrusiveness of face-to-face interactions (Bowker and Tuffin 2002, cited by Bumiller, 2008, p. 981)

Over the years, autistic presence grew in numbers as well as type of online activities. Today one can find autistic persons active in: online communities maintained by and for autistic people; open or closed Facebook groups formed around a topic, goal or specific agenda; personal websites, blogs or personal Facebook pages. Individuals on the spectrum participate in forums to discuss topics relevant to their lives, to solicit advice, attempt to raise awareness, participate in activist organizations as ASAN and promote awareness of the nature of the autistic experience through expressing their own voices with little or no mediation.

Historically, ANI was the first online autistic community. It was established as a result of criticism about the emphasis on treatment and cure to autism (Ortega, 2009; Sinclair, 2010). ANI included forums for autistic people only, with very specific rules regarding who could join, and appropriate behavioral codes within the forum were developed and monitored.

In addition to the forums, ANI initiated and organized AUTREAT²⁰, a yearly conference maintained by autistic and targeting people. AUTREAT was an opportunity for autistic people to meet each other in their own retreat space and solely their own physical environment; to present or attend presentations that focus on topics relevant to autistic experiences; as well as to meet each other face-to-face. Both ANI-L as a virtual online space and AUTREAT were safe places where autistic people could find meet other people with similar neurology, communicate and consult with them, form friendships and find relevant information.

²⁰ <http://www.autismnetworkinternational.org/autreat.html#INTRO>

AUTREAT was the first extension of the autistic virtual space to the physical environment. Clear rules and codes of behaviours emerged from organizers' ideological perceptions of an autistic community as well as their practical knowledge regarding the variety of needs that need to be addressed. Thus, AUTREAT provides a space for individuals on the spectrum designed to accommodate their needs. It enables them to meet other people in one physical space and to be themselves without judgment about their behaviors, social skills or areas of interest.

Following ANI's formation and initial development, autistic communities emerged in other countries outside the US. ACI, for example, is an Israeli autistic community, established by four activists.²¹ The most dedicated ACI members consider themselves to be part of the local as well as the international community. I concluded from my interviews that the values embodied in this initiative reflect international autistic community values. Although small, ACI hosts forums and blogs and initiates activities for the community members in the physical environment, mostly hosting the yearly Autistic Pride Day celebration.

3.5. Internet and Autistic Culture

Scholarly papers and empirical works that focus on autism in the cyber-world refer to the Internet's dominant role in the rise of neurodiversity (Jaarsma and Welin, 2012; Kapp, Gillespie-Lynch, Sherman, and Hutman, 2013); the emergence of autistic social movements (Kras, 2010; Orsini and Smith, 2013; Ortega, 2009); the role of the Internet in shaping an autistic community and culture (Davidson, 2008; Jaarsma and Welin, 2012); and the Internet's role in autistic identity construction (Bagatell, 2007; 2010; Brownlow, 2010; Brownlow and O'Dell, 2006; Davidson, 2008; Ortega, 2009).

²¹ ACI founders: Sola Shelli, Ronen Gil, Chen Gershuni and Amit Felice <http://www.acisrael.org/> (Hebrew)

These researchers' overall conclusion seems to be that technological development and the growth of social media provided new means and new opportunities to communicate and to socialize. The Internet provided tools that facilitated communication and created opportunities for social interactions and sociality among individuals on the autism spectrum and between them and the non-autistic world. Furthermore, the Internet enabled the evolution of different forms of communities that created spaces for self-exploration and communal exploration that expanded the conceptualization of geographical boundaries (Davidson, 2008; 2010) to social geographies (Bertilsson Rosqvist, Brownlow, and O'Dell, 2013) and opened possibilities for marginal groups in society to form communities and to express their own voice.

The existing research focuses on collective autistic identity, autistic culture and neurodiversity. This noted, I concluded following completion of my review of the literature, that individual autistic identity development is understudied and, therefore, the role of the internet in an individual's identity construction deserves more attention. Accordingly, the investigations reported in this research report explored individual autistic identity construction through focusing on the personal blog space created and managed by those studied.

Identity construction process involves an exploration of the self through negotiating with the social world. Since negotiating with the social world is central to individual identity construction, the first step should be to explain the possible technological developments that affected the social processes and enabled the evolution of autistic identity. Such an explanation will be provided in the following chapter along with discussion of the communication approaches that contextualize these processes, evolution of autistic space and the blog as arena for individual autistic identity construction.

CHAPTER FOUR

COMMUNICATION APPROACHES, AUTISTIC IDENTITY AND BLOGS

Autistic communication styles are at the core of the evolution of neurodiversity, autistic communities and autistic culture. In the previous chapter we discussed the rise of neurodiversity and autistic culture, as well as roles of autistic communication styles in the evolution of the distinctive autistic identity. There we learned that Internet technology provided the tools and platforms that enabled the emergence of autistic community and autistic culture. Although discussed by several autistic scholars, the connection between technological developments of the Internet, specifically social media, and cultural processes that lead to the evolution of autistic identity deserve more attention. Indeed, identity construction involves complex processes of self-exploration and negotiation with the social world. An excellent and important example, especially for this research study, are the ways in which social media led to the evolution of ‘networked autism’ and the autistic spaces in which identity – individual as well as communal – could be constructed.

In order to explain the intersections between social, technological developments and identity construction, the discussion in the current chapter begins with presentations of three key communication approaches. This will be followed by presentation of other social processes and productions that contributed ‘affordances’ to the evolution of autistic space, including: the characteristics of the autistic space and its importance to the evolution of autistic identity; and the centrality of the personal space of the blog in identity construction. Blogs, studied in this research project, provide such autistic spaces. Of particular research interest are the ways in which technological features enable blog owners to maintain relative control to shape the blog’s space and to manage their digital self. The chapter ends

with summarizing the focus on blogs should be undertaken in studying of autistic identity and the need to probe more deeply into the bloggers' techno-identity.

4.1. Three Approaches to Study of Autism Communication

The anthropological approach to autism, as explained in the previous chapter, adopted in this study, largely investigates the socio-cultural dimension of autism. Among the phenomena focused upon are aspects related to the “transmission and maintenance of cultural knowledge and the construction of membership in social groups and activities” (Solomon, 2010, p. 242). Studies conducted to date explore multiple levels of this issue: individual (see Kellman, 1999; Bagatell, 2007; Sirota, 2010); interpersonal, using discourse analysis (Ochs, Kremer-Sadlik, Gainer, Sirota and Solomon, 2004; Ochs and Solomon, 2010); and communities (Bagatell, 2010). Yet, while valuing these contributions, it is important to note that investigations of communication methods and processes have been largely overlooked in macro-analyses of autism research.

Thus, the aim of this initial section is to present three communication approaches that taken together add a layer of understanding missing in autism research, especially in exploring the social processes facilitated and mediated by the Internet, creation and maintenance of online communities and contributions of the Internet to the construction of sociality and autistic identity – all phenomena at the center of the research presented in this treatise. These approaches investigate communication as a cultural process, convergence and participatory cultures as well as the evolution of ‘networked sociality’.

4.1.1. Cultural Approach to Communication

Carey (1989) offers a cultural approach to communication as a conceptual framework for investigating the connections between the mass media, media texts and social processes. Although his discussion and his examples focus on traditional media, his ideas are very relevant to questions related to the consequences of network communication for identity and social processes and, for groups and individuals. For

example, one of the foundations of this cultural perspective is the assumption it makes in regard to the dynamic role communication processes play in society as well as in how individuals come to understand reality:

Our minds and lives are shaped by our total experience – or, better, by representations of experience ... If one tries to examine society as a form of communication, one sees it as a process whereby reality is created, shared, modified, and preserved. (Carey, 1989, p. 33)

This view stands in dramatic contrast to the dominant transmission perspective applied in dominant paradigms applied to communication research.

In contrast, Carey emphasizes reproduction of culture through symbols, myths and cultural patterns and processes, such as rituals (see also Petersen, 1979). In fact, his conceptualization of the roles of rituals redefines communication as ritualistic. Instead of “sender and receiver,” “encoding and decoding,” “noise and mediation” (the channel, the medium), Carey proposes that we look at communication as “sharing”, “participation”, “association”, “fellowship” and “the possession of the common faith” (Carey, 1989, p. 18).

Thus, in terms of this research project’s focus, following Carey, blogs can be defined as both a type of communication and as a cultural product. As such, blogs emphasize the individual while enabling the blogger to share his thoughts with readers, invite others to participate in a dialogue or to take part in constructing collective consciousness that is equivalent to Carey’s “common faith.”

Viewed in regard to our interest in the Internet, Carey’s approach emphasizes *meaning* over transmission and symbolic construction of social order through codes, rituals and other symbolic forms. In doing so, he conceptualizes the communication process in a way that opens it up to multiple types of communication. More specifically related to the research project reported here, his approach contributes in helping to explain the phenomena of the autistic presence on the Internet in a shape of personal websites, personal blogs, online communities and a hybrid of online community and conferences run by and for autistic people.

More specifically, Carey’s view of communication as “symbolic process whereby reality is produced, maintained, repaired and transformed” (Carey, 1989, p.

23) can be related to two associative concepts: ‘figured worlds’ and ‘autistic space’. *Figured world* refers to social processes of co-producing activities, where practices are reproduced and developed through individuals and groups (Bagatell, 2007; 2010). *Autistic space* refers to a physical or virtual space where autistic people create their own identities, their own conventions and their own ‘togetherness’ (Sinclair, 2010). Thus, *autistic space* is appropriate when used to discuss the role of the Internet in the creation of autistic identity and communal lives of autistic communities, as will be explained later in this chapter.

Furthermore, according to Carey, studying communication involves the exploration of the social processes whereby the symbolic forms are created, including the technological developments that have significant roles in these processes. Within this framework, Carey claims that the significance of relations between technology, communication and social processes extends beyond changes in social institutions or as their being an extension of our senses, as some of the communication scholars suggested. When he asks - “how do changes in communication technology influence what we can concretely create and apprehend?” (Carey, 1989, p. 31), he rephrases the perception of the creation, construction and functionality of the symbolic forms in cultural production and reproduction. Thus, his fundamental approach assumes there are reciprocal relationships between technology, culture and social processes that affect reality construction and representations of self, groups and social phenomena.

While Carey wrote his book about communication and culture before mass use of the Internet, my research demonstrates that his perspective is essential in our understanding the evolution, pervasiveness and influence of social media on both the macro (cultural and social) and micro levels. Furthermore, as the next section, too, demonstrates, his perception of communication, culture and social processes can be, indeed, needs to be, developed further by including the concepts of ‘participatory culture’ and the ‘network society’, both highly relevant to the structural and social attributes of the Internet and social media, discussed over the following pages.

4.1.2. *Convergence and Participatory Cultures*

Convergence culture emerges with technological changes that influence media circulation and content circulation which, in turn, lead to cultural and social changes (Jenkins, 2006). Like Gutenberg's invention of the printing press, such technological changes provide tools for reshaping the production and distribution of content that lead to the cultural change through the active participation of nonprofessional users in media and content circulation.

Participatory culture intertwines with convergence culture but extends beyond specific contributions of meanings, production of cultural products and the distinction between producer and receiver (audience). It is no longer about active audiences that can actively process media content. Instead of audience, we talk about participants; and instead of one-way media production, we talk about nonprofessional participants actively participating in creating and (re)shaping culture (Jenkins, Ford, and Green, 2013).

Indeed, a new set of rules evolve in participatory culture that characterize and define the nature of interactions between participants in culture (Jenkins, 2006). As we see evolving with the social media revolution, users are shaping, reframing and remixing media contents shared within larger communities and networks that influence the circulation of content (Jenkins, Ford, and Green, 2013, p. 2).

The technology of the Internet provides tools that accommodate the needs of autistic persons. These *affordances* enable individuals on the spectrum to actively participate in generating cultural texts that contribute to the evolution of a distinctive autistic culture and autistic identity. This continues, first, because the Internet functions as a space in which autistic experiences and expression are *legitimized* (Davidson, 2008; Davidson, Edward and Hemsworth, 2013). Second, since autistic identity is shaped and constructed within a cultural context and through constant dialogue with the social world, this space *enables* identity exploration and construction to advance, if sought.

Autistic Speaking Day is an example of a cultural product that reflects both participatory culture and cultural approach to communication, as it invites

individuals on the spectrum to upload any type of text or art work to a webpage dedicated to this specific celebration.²²

Thus, the concept of participatory culture together with the cultural view of communication offer a solid conceptual basis for explaining the evolution of blogs as cultural texts and as arena for the evolution of cultural identities of autistic individuals through the use of the Internet.

These two theoretical approaches lay the foundation for the explanation of evolving cultures that extend beyond geographical borders. Without the Internet and social media, communities like the autistic community would likely have experienced great difficulties in their emergence.

4.1.3. *Network Society and Sociality*

Foundations: Network society is an excellent example of *participatory culture* as it induces new forms of social change and introduces different types of social processes, communication and communities. In *The Power of Identity* (2010), Castells describes the key features of the network society: Network society is defined as a networking organization and “by a culture of real virtuality and... by the transformation of the material foundations of life, space and time, through the constitution of a space of flows and of timeless time” (p.1).

Accordingly, the great *accessibility* to information and knowledge as well as to other people leads to processes of change in all levels: the individual, communal and societal. In this process, network society is influenced by social groups and shapes them through the information that spreads within and between groups.

The identity of groups in society, according to Castells, is a result of a cultural process of meaning that gives priority to cultural attributes over other sources of meanings. Identity is a source of meaning and experience for people. While identities organize meanings, social roles organize functions. Identity is meaning and meanings are defined by social actors through cultural attributes.

²² For more, please read the description that appears in the prologue of this research presentation.

Thus, to study identity, social processes and communication in the network society involves investigation of ‘webs of meaning’ (Geertz, 1973, 1974). Note that Geertz’s call for analysis of culture as a search for webs of meaning, including use of social discourse analysis, long before the Internet and network society. Thus we are adopting what has become a well-established and dependable research approach.

Identity & Meaning Making: Carey (1989) referred to these meaning making and identity processes when asking about the struggle of groups in society over the definition of what is real (p. 31), as a basis for his cultural view of communication. The struggle over definition of what is real refers to the struggle for identity and Carey’s approach connects communication with the variety of possible constructions of reality through communication. His cultural view of communication provides a conceptual framework for the examination of WHAT is the nature of the identity and HOW it is constructed both on the individual level as well as on the communal level (what Carey refers to as ‘groups in society’).

Castells (2010), for his part, distinguishes between three different forms and origins of identity construction among groups in society:

- *Legitimizing identity* focuses on the dominant institutions in society and the processes of legitimizing, extending and rationalizing their cultural dominance.
- *Resistance identity* originates in marginalized groups in society, such as the autistic community. Their narrative is one of struggle and resistance, and their identity is “generated by those actors who are in positions/conditions devalued and/or stigmatized by the logic of domination, thus building trenches of resistance and survival on the basis of principles different from, or opposed to, those permeating the institutions of society...” (Ibid, p. 8-9).

- *Project identity* refers to a redefinition of identity that impacts the positioning a group in society. Redefinition is created from and based on cultural materials available to social actors. This form of identity seeks both redefinition and transformation of the overall social structure.

By way of an appropriate illustration, resistance identity leads to the creation of new forms of collective individualism that introduce what Castells refers to as a “holistic philosophy of life” (Ibid, p. 66), also referred to as “cultural communes”. These communities are defensive in that they are created as reactions to social trends and norms, and protect members from a hostile outside world. They are characterized by being organized around specific sets of values that are related to self-identification through their meanings and codes. Accordingly, the Internet’s spatial, non-hierarchical organization as a redundant network provided a model that organizes “a new kind of human society compatible with the autistic way of being” (Dekker, 1997). Thus, the neurodiversity movement provided the ‘holistic way of life’ through the counter-narrative that redefined autism and the cultural norms that evolved around the idea of neurodiversity.

Networked Autism: The autistic communities, especially the ones created by and for autistic people, seem to follow Castells’s conceptualization, in general, and his conceptualization of resistance identity, in particular. For example, Sinclair (2010) describes the need for autistic space and the origins for the evolving autistic communities as rooted in experiences of alienation and hostility, as you can see in his description of the experiences of autistic people in NT spaces:

Being autistic among neurotypical people is likely to consist of not understanding what other people are doing, or why they’re doing it, or what they expect us to do; not being understood when we ask questions or try to join in; being misunderstood and misinterpreted in hurtful ways (such as being accused of dishonesty or hostility based on lack of eye contact or “flat affect”, or being perceived to be drunk, drugged, delusional or even dangerous). (Sinclair, 2010, p. 32)

Autistic communities that evolved as a result of these types of experiences, as described by Sinclair, follow similar features defined by Castell (2010). These communities, especially ones run by autistic people, are created in order to provide a safe space where people who share similar neurological conditions can express their voice with no external mediation, meet others, communicate and live with pride and feel a sense of belonging. They are organized by and through specific set of values and clear sets of codes of behaviors, and they allow very limited access to outsiders, at least in designated spaces within the virtual domain of the community.²³

Beckett and Campbell (2015) describe the ideological basis and practical tools provided by the social model of disabilities for the evolution of resistance identity. The social model of disabilities, enabled resistance practices that refuse socially mediated identities and the formation of communities of people with shared experiences of a disabling society. Applied to autism, we can cite the following three main oppositions/contributions by the neurodiversity movement

First, the neurodiversity movement offered individuals on the spectrum a counter-narrative to the dominant medical model and redefined autism to focus on neurological difference rather than disorder. Indeed, the underlying ideology of neurodiversity is based on the social model of disabilities in that it opposes the concept of normalcy, which is a main value in the mainstream culture, and finds social structure as the disabling cause.

Second, neurodiversity as a movement aims to promote autistic rights and prevent discrimination (Runswick-Cole, 2014). As discussed in the previous chapter, neurodiversity as an idea enabled the emergence of distinctive autistic identity through the developing community and culture based on neurological difference and shared experiences. Similar to Castells' definition of *resistance identity*, autistic communities are very protective and are organized around set of rules and norms that derive from neurodiversity principles and answer to the specific needs of the

²³ See ANI's set of values in <http://www.autreat.com/intro.html> and rules of behavior in <http://www.autreat.com/ani-1.html>.

community members. While *resistance identity* relies on the struggle of stigmatized marginalized groups, *project identity* redefines identity through cultural products that corresponds with some of the ideas behind the affirmative model of disabilities, discussed above. Both *resistance identity* and *project identity* are relevant to the exploration and the construction of the autistic self, autistic communities and autistic culture. Identities are shaped through an active process of dialogue between the individual, the community and the culture. This process involves engaging in social practices including the narration of the self (Bagatell, 2003).

Third, the Internet provides the tools and the ‘geography’²⁴ that suits the abilities of autistic people and their communication styles, as follows: The Internet changed the levels of their accessibility to information and knowledge, and affected involvement in shaping the culture through the production of cultural products. *Technological features* of the Internet enable evolution of communal or personal spaces. *Control features* affect degree to which a group will be open to non-members (who can be part of a group or a community; accessibility of the space to non-members to read or participate). *Design features* affect accessibility (adapting to individual needs of community members or potential followers); accommodation to different types of communication styles; or creation of clear codes of behaviors for either blog visitors or in community websites.

In summary, the three communication approaches presented in this section enable us to apply these conceptualizations to achieve deeper understandings of the foundations and evolution of the identity of a marginalized group in society. Carey (1989) provides the basis to connect between multiple types of communication and the social processes that led to the evolution of autistic culture and autistic identity. Jenkins (2006) explains how the technological environment enables creation of cultural texts through the rise of participatory culture. Castells (2010) explains processes through which network society led to creation of collective individualism

²⁴ Davidson (2008) uses the conceptual framing of critical geographers that expands beyond places in the material worlds to selves, spaces, individuals and communities.

and construction of group distinctive identity in society. Next, the role of the Internet in the identity construction process will be discussed, followed by examining the meaning of collective individualism and its role in the identity negotiation process of the bloggers.

4.2. Contributions of the Internet to Autistic Culture & Identity Development

4.2.1. *Affordances, Autism and Identity*

The rise of neurodiversity and the autistic culture can be explained through a body of research that focused on the connections between technology and the user, particularly as conceptualized in their term of reference - *affordances*. For example, Bucher and Helmond (2017) claim that the concept of *affordance* is essential for understanding social media and the connection between technology and the user. Different communication scholars studied the affordances of the Internet, in general, and social media, specifically, in order to learn how they affect Computer Mediated Communication [CMC] (Nowak, Watt and Walther, 2005); self-presentation and self-disclosure (Gibbs, Ellison and Heino, 2006); and identity management (Morioka, Ellison and Brown, 2016).

Early notions of affordances focused on the perceived properties of technology and their actual use. In their review, Bucher and Helmond (2017) describe two types of affordances - technological and communication - that can explain the practices of identity management in social media and the role of the Internet in providing the platform and tools for the evolution of distinctive autistic identity. 'Technological affordance' focuses on user actions and interactions with the media. It explains the rise of 'networked publics', such as the neurodiversity movement and the autistic community. 'Communication affordances' refer to the "possibilities for action that emerge from technological forms" (Hutchby, 2001a, p. 30, cited by Bucher and Helmond, 2017, p. 10).

Davidson (2008) explored the roles of virtual communication in the emergence of cultural expressions among individuals on the autism spectrum. She

claimed that the Internet promoted new ways of self-identification through shared ‘language games’, referenced in earlier chapters of this treatise. This enabled development of a collective cohesive voice and led to the emergence of a distinctive autistic cultural identity.

Other researchers reached the conclusion that text-based Internet communication plays a significant role in the emergence of the autistic community and culture (Brownlow, 2010; Brownlow and O’Dell, 2013; Davidson, 2008; Davidson and Henderson, 2010; Dekker, 1999; Kras, 2010; Kreck, 2013; Ortega, 2009). The Internet is more accommodating to autistic ‘language games’ and written communication helps clarify thoughts and facilitates turn-taking in social interaction. Furthermore, such asynchronous systems free users from temporal constraints that exist in synchronous communication (Nowak, Watt and Walther, 2005). For example, the environment of the text-based CMC is lean with non-verbal cues and provides the user with more control over the communication process (Walther, 1996).

In a 2007 study that focused on one person with Asperger’s and his quest for identity, Bagatelle found that the Internet was a turning point for the participant in his journey for self-exploration. Through the Internet he met people who shared his condition and they helped him shape his identity as an Aspie.²⁵ The online presence and the interactions with people who shared similar neurology and similar experiences helped him find his voice and express himself in a safe, non-judgmental environment.

In another study, Bagatell (2010) explained the centrality of the Internet in identity construction through defining the virtual space as a ‘figured world’ in which activities produce narratives and identities. This medium freed autistic people from NT discourse and interactional conventions, and offered them a more adaptive way

²⁵ Aspie is a nickname referring to people with Asperger Syndrome. The term Aspie is used by people from the autistic community.

of asynchronous text-based communication, free of non-verbal social cues that exist in face-to-face interactions.

The *figured world* of the Internet became an arena where people can meet, share stories, receive support and create their own terminology that distinguishes the autistic way from other ways of living, experiencing the world, communicating or interacting (Bagatell, 2010). As Bagatell reports (2010), the community she studied developed a distinctive identity through: redefining autism; labelling individuals on the spectrum differently from the NT labelling of autism; and developing their own terminology that reflected their view of autism through referring to people with Asperger as Aspie and to autistic people as Autie (e.g., Brownlow, 2010; Brownsberger, 2015; Kreck, 2013; Ortega, 2009). For example, the debate about use of key terms of reference between ‘people with autism’ vs. ‘autistic people’ has significant meaning in autistic discourse about identity and inclusion, as reflected in the following statement from an autistic blog:

In the autism community, many self-advocates and their allies prefer terminology such as “Autistic,” “Autistic person,” or “Autistic individual” because we understand autism as an inherent part of an individual’s identity — the same way one refers to “Muslims,” “African-Americans,” “Lesbian/Gay/Bisexual/Transgender/Queer,” “Chinese,” “gifted,” “athletic,” or “Jewish.”²⁶

In other words, the claim made is that the connotation - ‘person with autism’ - detaches the individual from the neurology and reflects the tragic model of autism. In contrast, addressing themselves as ‘autistic persons’, and expecting others to do so, emphasizes autism as part of the identity of a person, not a disease (Bagatell, 2007; Seidmann and Pang, 2013). In this manner they use cultural symbols to convey a wider perception of autism as part of the emerging autistic identity, on both individual and collective levels.

²⁶ <http://autisticadvocacy.org/identity-first-language/>

Based on her research studies, Anneke (2003) claims that identity is contextual as a concept and reflects relative saliency of shared and/or distinctive characteristics of social actors. Types of identities reflect unique criteria that distinguish an individual or a group, and are based on social, cultural or ideological similarities. Disability is an example of the use of such criteria, in general, while as a sub-group, autism is considered to be part of what members in the autistic community refer to as ‘invisible disabilities’.

Morioka, Ellison and Brown (2016) claim that social media platform affordances enable users to upload selective information related to their identity, in particular that affects their self-perception. In doing so, the authors distinguish between ‘identity play’ and ‘identity work’. While ‘identity play’ refers to the exploration of identity, ‘identity work’ refers to reaffirmation of identity.

In summary, the research surveyed here is in agreement that, first, identities are constructed through ongoing processes of self-exploration, discourse, interactions with others and participation in communal activities. Identity can be personal or collective. The Internet as a ‘figured world’ is where “activities [are] not constrained by the conventions of the discourse of normalcy” (Bagatell, 2007, p. 421). Second, social change can be induced in the shape of constructing and promoting an identity of new groups in society; through developing and accepting different types of communication; and through redefining social interactions and social networks.

4.3. Collective Individualism: Bloggers and Community

The most successful and famous instance of a non-hierarchical organisation today is the Internet (indeed a “society” in which many autistic people thrive). The Internet is effective and unlimited in its growth precisely because of its lack of hierarchy: it is a distributed, redundant network. Even though the Internet is an organisation of computers, not of humans, this could well serve as a model to organise a new kind of human society compatible with the autistic way of being. (Dekker, 1999)

The concept of ‘collective individualism’ (Castells, 2010) explains not only the distinctive social structure of the autistic community, but also autistic sociality

and cultural values that are at the core of communal autistic identity. Instead of conceptualizing autism as social impairment and deficit in communication, collective individualism conceptualizes the autistic way of being driving the identity construction process and evolution of distinctive knowledge of the self on the individual level.

Thus, the social world of autistic community and the evolution of communal autistic identity are important both contextually as well as individually in negotiating autistic identity on the personal level. Identities, claims Bagatell (2003; 2007), are created through a constant dialogue between the self and the community, through discourse, other voices and actions:

Identities and self-understandings are actively constructed in shifting networks of social relationships. People represent themselves through the voices or the words of others, the discourses both of specific individuals and communities. (Bagatell, 2007, p. 418)

Bagatell (2003; 2007; 2010) emphasizes the role of social worlds in identity construction. Sense of self is created through an ongoing process and knowledge of the self is constructed through experiences in the social worlds (Bagatell, 2003, p.13). In the new definition of autism, advanced by the neurodiversity movement, the focus on difference, inclusion and the centrality of the autistic experience are all part of autistic identity, on both the individual level and as a cultural commune. Accordingly, sociality and communication styles are important elements in the identity negotiation process, in general, and especially in the case of autism. Hence, we understand that the Internet plays a significant role in the process of identity development through its technological feature and the network organization that is compatible with autistic sociality and the autistic way of life (Dekker, 1999).

The Internet hosts and affords access to a great variety of virtual spaces, such as social networks (like Twitter and Facebook), forums and chat rooms, blogs, vlogs, personal websites and personal videos where people can among other things: practice narrative expressions and creativity, share thoughts, consult with other people, promote social change. Thus, the Internet provides platforms for people to share, and

others to read, their personal stories, thoughts, opinions and everyday experiences. These virtual spaces enable the evolution of communal autistic identity through community websites and individual autistic identity through communities that evolve around individual spaces such as blogs. Collectively, then, the evolution of autistic community around the individual reflects autistic sociality, as Dekker describes an autistic society:

Organised around individual. One main feature that sets autistic people apart from the rest of humanity is that an autistic person is not necessarily a 'social animal' and has trouble functioning in groups of people. The individual, not the group, would thus have to be the centre around which an autistic society is organised. (Dekker, 1999)

While chat rooms and forums emphasize the social aspects of identity negotiation and the community, blogs emphasize the *self* and the identity negotiation with the social is reflected through the writings, direct dialogue with blog followers and through the evolution of a community of bloggers. The blogger can negotiate the autistic identity through explaining autism to others or explore aspects of the collective autistic identity.

A community can be formed around one blog, through inter-connections between bloggers, or through a community that host blogs as part of their activities. It will be useful to discuss, briefly, how individual texts such as blogs can become part of both self and communal identity construction, while keeping the emphasis on personal narrative written by an individual. A community can be formed around a blog (and tracked down) through the dialogue that is created between the blogger and the readers or with other bloggers. One blog can be connected to another blog that is connected to a third blog or to a community of bloggers (Serfati, 2004).

Interestingly, Kenix (2009) describes a circuitous process in which a blog becomes the blogger, and a self-referential spiral can potentially become a group or a community of bloggers that evolved around a topic, an interest or goals (see also Sun, 2010). Boniel-Nissim and Barak (2008) pointed out that blog rings are part of what creates a virtual community, together with the comments posted on the personal blog and the links to similar blogs. Collectively, the blog rings serve as an important

component of the blogger's virtual as well as "real" worlds. Thus, blog rings are strong indicators of the existence of a dialogue with other bloggers, whether it is through the writings, direct dialogue through comments, hosting other bloggers or through links to related blogs.

Seidmann, Pang and Jingyuan (2016) conducted a network analysis of blogs written by individuals on the spectrum and found clear evidence for the existence of a community of autistic bloggers that was formed through referring to other recommended blogs written by people on the spectrum. Although the results confirmed the formation of a community, the community formation patterns were somewhat different from other studies that used network analysis. Instead of a community that is formed around one dominant blogger or around a topic, the community of the autistic bloggers was characterized with high-betweenness that can be best explained through the conceptualization of the autistic bloggers community as a 'collective individualism'. As noted above, *collective individualism* connects between the social world and the individual and can explain not only the autistic sociality but also the identity negotiation between the self, the community and the culture.

The empirical portions of this research study, presented in the following chapters, focuses on the individual expressions of bloggers and blogs as sites of self-exploration and identity negotiation with the social world. The next sections elaborate on the concept of 'autistic space' that is central to the exploration of the individual identity construction process in the personal space of the blogs.

4.4. The Autistic Space

Autistic people live and function in NT dominated spaces for a large portion of their lives. In contrast, *autistic space* is any space - virtual or physical - *designed* to accommodate the needs of autistic persons and maintained by them. Sinclair (2010) refers to such a 'space' as existing on several levels – *physical, virtual* and *symbolic*.

Therefore, autistic spaces can be homes, online forums, online communities or large gatherings like the autistic conferences and other public events.²⁷


The ability to control the environment and the distinctive features of the autistic space provides a refuge from the NT space. In the autistic space, one can organize the environment as it suits the autistic person/s, in order to engage in activities as s/he chooses, and to control over access to her/his space. Note that what makes a place an autistic space is not the number of autistic people compared to the number of NT people there or the elimination of NT people, it is the fact that it is *run by and for* autistic people: they run the space, identify needs and decide how to meet the needs of people participating.

In terms of needs, autistic persons differ not only in their autism level (i.e., across the spectrum from LF to HF and Asperger's), they also vary in sensory reception, sensitivity (i.e., type of senses involved) and social orientation. For example, some prefer to be alone, others would like to be with people but have difficulties initiating social contact and others need constant social stimulation (Sinclair, 2010).

With these needs in mind, as well as the fact that autistic persons live amidst NT persons, any creation of autistic space needs to address and accommodate social variability. As an aid to facilitation of social interaction in a physical space, the following color badge system was first designed for AUTREAT and since has been adopted for other autistic community events held around the world.²⁸

²⁷ AUTREAT in the US, AUTSCAPE in the UK, and other conferences in Finland and Germany

²⁸ See AUTSCAPE website <http://www.autscape.org/experience/autisticneeds>. AUTSCAPE is a yearly conference taking place each year in a different location in the UK.

No initiation	Red	Please do not initiate any interaction with me.
Prior Permission	Yellow	Please do not initiate unless I have already given you permission to approach me on a yellow badge.
Please initiate	Green	I would like to socialise, but I have difficulty initiating. Please initiate with me.
Neutral	White (or no badge)	I am able to regulate my own interaction.
	Black	Do not include me in photographs or video.

KEY: The color system seeks to facilitate communication and social interaction. It signifies the amount of sociality desired at any particular point in time. Any participant can signal to others if s/he is open to social interaction or not and if others can take pictures of her/him or not. The ‘communication mode’ varies within and between participants, and the system signals to others whether one needs help with initiating interaction; if one is open for a social interaction or needs to be left alone. Sensory stimulation, physical appearance and behavioural codes are also adapted to autistic needs in order to create a comfortable and safe space for them to socialize with other people who share their neurological conditions.

History

The evolution of ‘autistic space’ played a significant role in the formation of the autistic community and emergence of autistic culture. In line with Castells’s description of ‘cultural communes’, autistic space evolved from the need to create an accommodating space, organized through specific sets of values that evolved from the distinctive characteristics of autistic people. ‘Autistic space’ is a safe space where culture is evolving and autistic identity is negotiated and structured (Blume, 1997; Dekker, 1999; Sinclair, 2010).

It is through the reciprocal dynamics between, on the one hand, the identity of self and group identity, and, on the other hand, the autistic space where culture

is evolving. As addressed in the following discussions, autistic spaces can be *communal* spaces or *personal* spaces, such as blogs.

Communal Spaces

Previous studies that focused on the meanings of ‘safe spaces’ for individuals on the spectrum described them as providing adaptive spaces that enabled participants to create alternative social spaces, distinct from mainstream NT spaces. These ‘safe spaces’ were found to enable inclusive experiences through accommodating the variety of interactions to occur between individuals on the spectrum (Bertilsdotter Rosqvist, Brownlow and O’Dell, 2013; Ryan and Räisänen, 2008).

For example, Bertilsdotter Rosqvist, Brownlow, and O’Dell, (2013) distinguish between ‘neuro-separate’ and ‘neuro-shared spaces’. ‘Neuro separate spaces’ are dominated by autistic people and ‘neuro-shared spaces’ are safe spaces shared by NT and individuals on the spectrum. The authors report that autistic-only, separate spaces empowered the participants and raised their quality of life, provided opportunities to discuss topics relevant to them and also create “collective resistance to the dominating NT world” (Bertilsdotter Rosqvist, Brownlow, and O’Dell, 2013, p.373).

Safe spaces played a significant role in community formation and identity construction among participants in the studies conducted by Bertilsdotter, Brownlow, and O’Dell (2013) as well as Ryan and Räisänen (2008). Similarly, Sinclair, cited earlier as one of the founders and leaders of ANI, describes in his 2010 paper *Cultural Commentary: Being Autistic Together* the development of autistic culture when autistic people met, initially, face-to-face in private homes and formed the autistic community. *Autistic space* was one of the main constructs of autistic culture that evolved through these meetings and then later through ANI-sponsored retreats [AUTREAT] (Sinclair, 2010).

Personal Spaces

Blogs are one type of a *personal autistic space* that an individual can use in the autistic identity construction process in the quest for self-definition while negotiating an emerging identity engaged in interaction with community and cultural values.

It is not surprising that the concept of ‘autistic space’ originated from use of the Internet (Sinclair, 2010). The technological features of the Internet and the ability to choose asynchronous communication make the virtual space more accommodating to the communication style and autistic sociality, with little or no need for adaptation to make it accessible to autistic people (Bertilsson Rosqvist, Brownlow and O’Dell, 2013).

Accordingly, virtual autistic spaces are designed to provide the best and safest space for self-expression, communication and social interactions. ANI’s website and the ANI-L (the website that hosts the forums and mailing lists)²⁹ rely heavily on written language, include very specific rules and codes of behaviors and limit participation to autistic people in forums created for them in order to communicate safely with each other, without NT interference. AUTSCAPE emphasizes accessibility through their webpage as well, designing it to make the website as user friendly as possible in choosing the color scheme of the homepage (or any page) and through very user-friendly instructions on how to adapt the website’s accessibility to individual needs and disabilities.³⁰

The virtual environment provides safety by removing non-verbal cues from communication exchanges, thus reducing the stress autistic persons can feel when involved in face-to-face interactions. In these situations, acceptance and understanding from people with shared experiences was found to be a definitive dimension of safe spaces that could be applied in both online and face-to-face social

²⁹ <http://www.autreat.com/ani-l.html>

³⁰ <http://www.autscape.org/accessibility>

interactions (Bertilsson Rosqvist, Brownlow, and O'Dell, 2013; Ryan and Räisänen, 2008).

Blogs, Identity and the Symbolic Space in Summary

Sharing an autistic space for the first time, be it physical or virtual, is an intense and empowering experience for autistic people (Ryan and Räisänen, 2008). Both Bagatell (2007, 2010) and Sinclair (2010) report on people who found that the autistic space opened a new world for them; one where they are not 'weird' or 'unique'; where they feel they are with people from 'the same planet' or from 'the same tribe' (Sinclair, 2010).

Autistic space provides a sense of belonging but also a space where people can negotiate their identity. Autistic space can be individual or communal, physical or virtual. Autistic space can be a blog, a vlog, a virtual community, a closed group on Facebook, a room at home or an AUTREAT conference. Autistic space is where autistic identity can be explored and developed safely, with support from other community members or as a product of communal dialogue.

The symbolic dimension of the autistic space is implied in Sinclair's (2010) commentary cited previously. Carey refers to space as part of his cultural view of communication:

space can be mapped... in different modes – utilizing lines on a page, sounds in the air, movements in a dance. All three are symbolic forms, though the symbols differ, be they visual, oral, and kinesthetic" (Carey, 1989:27).

In line with Cary's definition of space, symbolic forms can be written language, images used in community websites, personal webpages or blogs, video recorded personal diaries through vlogs, or other YouTube videos that aim to visually illustrate different aspects of the autistic experience. The autistic space can be mapped and studied as a space where rituals are created and practiced; norms are being created and practiced through the use of variety of symbolic forms; and codes are being created in order to facilitate social interactions for people who have

difficulties with initiating social interaction and reinforce the sense of being accepted as they are.

Autistic space as a concept and as a cultural product provides better control over the environment to the individual on the spectrum or to members of the community. This relative control is achieved through codes of behaviors' clear rules and adaptation of the environment to the autistic needs.

In order to understand the potential role of the blog as autistic space in the personal identity construction process, and community values, the next section will discuss in more detail blogs as an arena for personal identity construction and will lay out the questions that guided the research.

4.5. Blogging the Autistic Self: On Voice, Exploration and Identity

A forbidden tongue that cannot tell its tale to thee
A tongue torn between time that was and time that is to be
The Other tongue, prohibited to its speaker and lord
Permitted to God and only to God
Because He, who listens to the world
Can hear silence becoming words.

Eyal Shahal
(non-speaking autistic person)

Early studies of autism and identity in scholarly work described individuals on the spectrum as lacking a sense of self or as a struggle (Bagatelle, 2003). For example, Sacks (1995) identified the need for identity among the autistic people with whom he met in therapy and Donna Williams described her personal journey in search for identity as a struggle (Bagatell, 2003). Later studies that explored aspects related to autistic community, autistic culture or autistic identity investigated a much wider range of contexts in which autistic persons engage in developing their autistic identity: individual stories through published autobiographies (Davidson, 2008); observations and interviews with individuals on the spectrum through traditional

ethnographic research (Bagatell, 2003; 2010); observations of identity negotiation and neurodiversity in role-playing game camp (Fein, 2015); and, identity construction in community websites (Brownsberger, 2015; Sarrett, 2016), chat rooms (Brownlow and O'Dell, 2006), online discussion groups (Bertilsdotter Rosqvist, Brownlow and O'Dell, 2013) and online forums (Spillers, Sensui and Linton, 2014).

Voice

Social media and new technologies can be effective in empowering users through the use of personal domains or simply by providing useful ways to communicate with others and enhance a sense of identity and community. Chat rooms and forums for example, provide additional means for helping a community of people with autism to find their own voice and advocate about autism to the wider community of the NT world (Bagatell, 2010:39; Brownlow and O'Dell, 2006).

Community websites host chat rooms and forums to communicate an opinion or post on personal blogs hosted by the community. While dialogical communication is expected in chat rooms and forums, they defer in their definition as 'separate spaces' (open for autistic people only, Bertilsdotter Rosqvist, Brownlow and O'Dell, 2013) or 'Neuro-shared' (NT and autistic people share the space, Bertilsdotter Rosqvist, Brownlow, and O'Dell, 2013). The nature of the communication and the negotiation is affected by the definition of the space as 'separated' or 'neuro-shared'. Chat rooms and forums that are 'Neuro-shared' (Bertilsdotter Rosqvist, Brownlow and O'Dell, 2013) focus more on negotiating meanings knowing they are open to the 'NT eye' and their narratives may be affected by it.

Researchers who investigated social media and autistic identity construction have studied community websites (Brownsberger, 2015; Sarrett, 2016), forums and chatrooms (Brownlow and O'Dell, 2006; Spillers, Sensui and Linton, 2014). Community websites, too, can host blogs, forums, chatrooms, or publish relevant articles. Forums and chatrooms can be part of a community website or form

communities themselves that evolve around the forum and are hosted by a portal that provides the technical means to create and manage a forum. Both community websites and forums emphasize dialogue between members, but only website or forum administrators can control some of the technological features that allow them to delete posts or block members who do not follow written or unwritten codes of behavior.

Previous studies on personal accounts of autistic people (Jones, Zahl and Huws, 2001; Jones, Quigney and Huws, 2003) focused on analyzing personal websites. These studies found that the autistic people focused on emotional and perceptual experiences. They talk about - emotional distress, frustrations and their sense of alienation, sensory experiences and coping mechanisms.

The importance of narratives as a tool of expression has been identified by researchers in cases in which it has been used with people with illnesses (McGeehin-Heilferty, 2009) but also in studying hard-to-reach populations (Harvey, 2011). However, the literature on autism reveals that researchers focused less on narratives as a source of identity construction and more on narrative abilities, narrative representations and narrative as intervention for and of autistic people. For example, studies have used the narrative as intervention technique (Jones, Zahl and Huw, 2001); as part of learning about the world of an autistic child (Kellman, 1999); or focused on the narrative abilities in HF children with autism (Losh and Capps, 2003).

Exploration

Within these contexts, the personal spaces of the blogs offer an opportunity for individuals on the autism spectrum to negotiate their identity in a relatively controlled environment. The identity construction process that takes place in blogs involves self-exploration and constant negotiation between personal and cultural aspects of identity. The negotiation process occurs through the writing process and dialogue with potential and actual followers.

Self-exploration through personal expression, too, is a powerful source for identity construction. People make sense of experiences they have and use narratives

to communicate these experiences to others. Narrative is, therefore, one of the main means to construct self-identity, alongside negotiation of identity with the social world (Bagatell, 2003). Indeed, Hacking (2009), who analyzed autistic persons' stories, observed:

A role for autism narratives internal to autism itself... it is developing a language, or, if you will, a new language game, one that is being created before our eyes and ears. This speech is, in turn, creating or extending a way for very unusual people namely, autistic ones – to be, to exist, to live. (p. 501)

These new 'language games' (Davidson, 2008; Hacking, 2009) are important in empowering the autistic self or in creating a sense of collective autistic pride (Davidson, 2008; Hacking, 2009).

Ortega (2013) considers the blogosphere as a major setting for identity construction for people with disabilities but claims that although scholars and self-advocates refer to the Internet as "an essential space of debate and identity development for autistic persons" (Ortega, 2013, p. 436), blogs have received inadequate attention in the study of autistic identity construction.

Blogs are located in virtual spaces designed to be individual oriented and emphasize more self-exploration and self-expression. The identity construction process in the personal space of the blog can be reflected through potential dialogue between the 'thinking self' and the 'social self'.³¹ It is up to the blog owner to decide how much the blog will be open to direct dialogue with others.

A preliminary analysis of blogs written by autistic people conducted prior to initiation of the research presented in this treatise revealed that the bloggers explore questions of identity and thrive to promote awareness to autism through their writings (Seidmann and Pang, 2013). The bloggers investigated explore private

³¹ Bagatell (2003) discusses the role of the dialogical process with the social world in identity construction using Mead's definition of the 'thinking self' and the 'social self' (1934, cited by Bagatell, 2003). According to Bagatell, Mead was referring to the interconnectedness between the two selves.

issues, describe inner processes, discuss topics relevant to autistic people in general and promote the neurodiversity agenda.

Similar to other studies that raised questions regarding the meaning of autism to autistic people and the neurodiversity claims, the researchers found that autistic bloggers tend to go against the common perception of autism as deficiency and the tendency to seek a ‘cure’ for people on the autism spectrum. For their part, these bloggers thrive to gain acceptance for themselves for who they are as persons, and to advance their desire that society will focus on their uniqueness instead of their disability. According to some bloggers, ‘playing’ according to NT rules in the NT world is at one and the same time ‘pretending’ while accepting the dominant NT value of ‘normality’ (Bagatell, 2010; Browlow, 2010). In contrast, in ‘their’ safe space, they talk openly about social experiences and social interactions; they distinguish between loneliness, the common stereotype of autistic people, and aloneness, which is a place of choice and comfort; they talk about empathy; and they talk about the need for neurodiversity and inclusion of autistic people in society.

Thus, the personal accounts of the blogs revealed that identity is very central to the definition of their selves and is closely related to their meaning of personhood.

Identity

Identity in the current research is defined as “thoughts and feelings about the self, or self-views” (Swann and Bosson, 2008, p. 448). Identity can be constructed through narrative and through dialogue with the social world. Bloggers who use more personal writing may rely more on the narrative as a source for identity construction. Bloggers who use their blogs to advance social change and identify themselves as self-advocates may rely less on narratives and the social world may be more dominant in their quest for the autistic self. The blog is the blogger’s online identity, according to Boyd (2006), and it is both a digital representation of the blogger and “a space for the embodied digital individual”. Although some bloggers may see the blog as means to reach a greater goal, other may very well see blogging as part of their identity.

Seeing blogging as possible part of the blogger's identity was reflected by one of the interviewees in the current study when he said that "blog is around the blogger while forums are around topics; the interaction [with the readers] is around the blogger even if the content is not personal". The blogger is therefore at the center of the blog and the content or the dialogue evolve around the blogger. If the blog is the blogger's identity and it functions as the blogger's digital representation and a space for the embodied digital individual (Boyd, 2006), its role in the identity construction process is far greater than providing simply a space for self-exploration. Therefore, there is a need to investigate more deeply the characteristics of the blogger's techno-identity.

Davidson, Edward and Hemsworth, (2012) who studied the role of the Internet in the lives of individuals on the spectrum found that the Internet is perceived as a safer place for them due to their ability to reveal their autism without revealing their true identity. In this sense, bloggers can explore their identity in the 'figured world' (Bagatell, 2010) of the Internet while controlling and shaping their "embodied digital"- self (Boyd, 2006). The virtual environment and the space of the blogs provide the autistic bloggers the platform to negotiate their identity. Regardless of the self-definition of the blogger, the digital representation may take part in the identity negotiation process.

Why Blogs? A Research Rationale

The choice to study autistic identity in this research project through blogs was based on their following distinctive features: The personal space of the blogs allows the blogger to write relatively long narratives and, therefore, provides the researcher potential access to the meaning-making process; the blog is a space that is updated by the blogger with additional posts, which emphasizes the importance and nature of identity construction as a process; and the virtual dimension of the blog provides the blogger with possibilities to negotiate his/her identity with the social world through the writings or through direct dialogue with blog followers.

Scholars differ in their definition of the blog. One of the most common blog definitions frames it as an *online diary* that is updated frequently or on a regular basis, published in reversed chronological order and often includes archives where earlier postings are preserved (Boniel-Nissim and Barak, 2008; Fullwood et al., 2009; McGeehin-Heilferty, 2009; Subrahmanyam et al., 2009;). Hookway (2008), for example, defines blogs as ‘self-narratives’ that allow the writer to post his/her private, even intimate, content on a daily basis or as frequent as desired by the blogger. The blog serves as an on-line diary that focuses on the ‘drama’ of everyday lives, interactions and events and allows the writer to share with others his/her thoughts about the self (Hookway, 2008).

Sonja (2015) refers to blogs as one form of online *digital storytelling*, relying heavily but not exclusively on the written text. Framed as digital storytelling (one type of a cultural product) and as a channel, the blog space provides an arena for identity construction through self-exploration and negotiation with the social world. In the process of identity exploration, bloggers do not necessarily need to commit to one writing style and can include essays, autobiographical memories, hosting of guest bloggers or interviews with persons they find relevant to their blog.

Boyd (2006) rejects the blog as online diary perspective claiming that it “depletes blogs of any agency as a concept”. In contrast, she defines blogging as cultural practice “producing digital content with the intention of sharing it asynchronously with a conceptualized audience” (Boyd, 2006). The blog’s features, derived from this definition, include: ongoing expressions; content captured locally; and although there are common values across blogs, the blogger is not bounded to shared set of rules, meaning the blog owner can set her/his own set of rules.

Boyd also talks about the blog as ‘extension of man’³² and refers to blogging performance as blurring of textuality and orality, Thus, according to Boyd, blogs are

³² Boyd (2006) uses McLuhan’s definition for ‘the medium as extension of man’

at one and the same time, a medium, a bi-product of expression and form of social practice.

The blog's features add other features that explain the functionality of the blog in the identity construction process. The social dimension of identity negotiation is manifest through Boyd's definition of the blogs as a culture-driven medium and blogging practice as blurring between textuality and orality. Audience presence is manifest through the comments or "other communicated references to the blog material" (Boyd, 2006) and the blurring between textuality and orality is compatible with the definition of the autistic communication style as "language games" (Davidson, 2008; Hacking, 2009).

Although Boyd's definition refers to blogs specifically and not to the Internet in general, these features are consistent with scholarly works about the role of the Internet in the evolution of autistic community and autistic culture as discussed above and provides a theoretical framework that reinforces some of the autistic activists' perception of the Internet as "shaping a new kind of human society" (Dekker, 1997).

Boyd's conceptualization of the duality of the blog as a channel and at the same time as a cultural product provides a good framework for this research project's working definition of the blog as, simply, autistic space and cultural practice.

Thoughts Toward the Empirical Study

Autistic blogs are an interesting combination of personal diary, manifesto and text open to the public. Some bloggers use personal writing and focus on their own experiences; others use personal writing to get support but also to discuss the 'bigger picture' and topics that are related to autism in general; and still others emphasize activism and their writing is less of a diary and more of a means to promote awareness and social change. The definition of the blog as online diary can only partially explain the functionality of the personal space of the blog to the identity construction of the autistic blogger and the blogger's meaning-making, or the quest for the autistic self. As such, the study of blogs must extend beyond content

to the practice of blogging and examine intentions and goals as well as the diverse styles within the blogs.

More specifically, the blog plays a significant role as a space for autistic identity construction. The blog as a medium and as cultural product provides the space in which the individual identity construction occurs. The formal features of the blogs provide the opportunity to explore the blogger's techno-identity and identity management (Schmidt, 2007) as well as the identity construction process. Therefore, the research questions that guided the present research are related both to the identity construction process and to the personal space of the blog:

How do autistic people structure their identity as bloggers and how do they negotiate their identity through their blogs?

What is autistic identity to the bloggers?

What are the constructs of autistic identity?

CHAPTER FIVE

METHODOLOGY

This study's primary aim was to explore autistic identity as manifest in blogs maintained by individuals on the autism spectrum. The underlying research assumptions were: blogs could be a space for autistic identity construction; blogging could advance the identity construction process through self-exploration; identity negotiation with readers, within and outside the autistic community, is manifest in the personal space of blogs.

The complexity of this project, as identified and analyzed in this and previous chapters, is due to the inter-relationship of the research goals, the nature of identity development and the characteristics of the specific social group investigated. The nature of this complexity, as revealed in both the review of the literature and the pilot study (Seidmann and Pang, 2013), created a formative situation that required extensive consideration and formative decision-making about the research approach and methodology.

Thus, this chapter on the research methodology selected and implemented opens with presentation of two key hubs of complexity: ethical dilemmas involved in studying autism online as well as the complexities of investigating identity development, in general, and with autistic persons. This discussion will be followed by the methodological challenges that emerged in organizing and implementing the research process. The remainder of the chapter presents methodological strategies: the blog sampling procedure; interviewee recruitment and consent; methods used for the data collection and the data analysis.

5.1. Formative Ethical Dilemmas in Studying Autistic Bloggers

The discussion below examines several of the main dilemmas involved in investigating autism online through the lens of main ethical principles of any public health or health communication research study³³. More specifically, many of the ethical dilemmas involved in online autism research are similar to other studies of online social media such as: questions of data validity, data ownership, anonymity, informed consent and confidentiality (Bronlow and O’Dell, 2002; Walther, 2002). This noted, one needs to be aware of additional ethical considerations in studying autism online that affect the research process and procedures as well as the ethical responsibility of the researcher in the data collection process. As noted, gaining a formative understanding of these challenges was essential in selecting and then applying the research approach and tools in this study.

The core difference between the ethical discussion of online research in general and conducting autism research is related to the perspective that can be, and all too often is, applied to individuals on the autism spectrum as ‘vulnerable’; and therefore, seemingly, ‘less autonomous’, ‘in need’ of special protections in the research process. This assumption is reflected clearly in formal regulations and the institutional expectations from the researcher. For example, greater demands for more rigorous ethical procedure are required in order to receive approval to conduct research when research involves individuals on the autism spectrum. Thus, labelling a certain group of potential research participants as ‘vulnerable’ embodies assumptions about the participants’ ability to provide informed consent (or withdrawal from the research after providing consent); greater vulnerability to power relations and exploitation; and susceptibility to risk and harm (Murray, Pushor, and Renihan, 2012).

³³ Guttman (2000) and Flicker, Haans and Skinner (2004) provide the relevant framework to identify and handle ethical challenges that researchers face in studying online communities and refer to autonomy; protecting participants from risk and harm; and linking private and public data.

The dominant biomedical approach in autism research defines autism as a neurological and developmental disorder, and focuses on social and communication deficits. The focus on deficits and on interventions that aim to ‘normalize’ autistic people imply the perception that autistic people are less capable, less autonomous and, therefore, in need of protection in the research process.

More specifically, bioethics is based on the ‘physician-patient’ model in which power relations between the researcher and the participant are very clear, and the decisions about the research procedure are made by the researcher alone. According to Atkinson (2007), the ethical issues involved in studying patients with mental illness, in general, and that characterize power relations between researcher and participant/s, in particular, are: sense of coercion; protectiveness and paternalism; stigma and discrimination. Each of these issues will be discussed here, briefly, in relation to autistic research.

Protectiveness and *paternalism* refer to the perception of the need to protect the participants from themselves, including their decision to participate in the study; presumably, to protect them from disclosing too much information in the research process. The demand in this approach is for the researcher to protect the patient through confidentiality, anonymity and the ability to withdraw from the interview process if it becomes too stressful.

The philosophical assumptions of the biomedical approach to ethics in research originate from the liberal tradition that puts the individual in the center, emphasizing the importance of autonomy, independence and freedom from exploitation. As a result, vulnerable populations are defined as less autonomous, more dependent and susceptible to exploitation.

Therefore, persons with disabilities, in general, and autistic people, specifically, are defined as ‘less able’ and ‘in need’ of special protection because of physical disability or neurological difference. In comparison, social research, while it does not ignore the values mentioned, emphasizes the dynamics and importance of contextual factors such as culture or social environment in contributing to the definition of different groups as vulnerable. Thus, while bioethics will assume

vulnerability as a result of physical/ developmental/ neurological deficiencies and places all the responsibility on the researcher, a social approach can open the door to negotiating vulnerability and research procedures with the community, and the possibility that different environments may impact issues such as vulnerability.

Vulnerability

The ethical dilemmas involving online research of sensitive topics needs to be discussed in light of the changing perception of vulnerability, in general, and, in particular, the unique characteristics of the participants in this research project. An important debate continues between scholars about formal definitions of ‘vulnerability’ and the research practices derived from various positions. Sinclair (1993) provides the basis for these discussions by demonstrating the need to reconceptualize vulnerability by calling to leave aside assumptions about shared meaning and normalcy in dealing with autism.

Aldridge (2014) claims that vulnerability is *context dependent* and needs to be examined carefully. Witham, Beddow and Haigh (2013) claim that the conceptualization of the protection of vulnerable participants can be debated and the focus should move from emphasizing weakness and fragility to openness and receptiveness.

Seidmann and Pang (2015) discuss potential problems with universal conceptualizations of vulnerability, claim that it could be affected by contextual and environmental factors, and therefore propose application of the social model.

The social model of disabilities emphasizes the role of the environment in defining disabilities. This model sets the epistemological basis to view autism as a social and cultural phenomenon as well as neurological, and leads to a possible reconceptualization of vulnerability as an ongoing negotiation of meaning and practical applications. The perception of vulnerability as an ongoing negotiation and the positioning of the qualitative approach in studying autistic identity affect researcher-participant relations and ethical demands from the researcher in the research process.

In conclusion, online autism research that enables autistic people to speak directly, with their own voices, not through caregivers or professionals, challenges the common perception of vulnerability and involves, in many cases, individuals on the spectrum capable of communicating verbally through the Internet.

Autonomy

The technological features of the Internet provide accessibility to communicative and self-expression tools that challenge traditional perceptions of autistic people as social actors and capable communicative individuals and, as a result, as a vulnerable population. It allows them to choose how to communicate (through written texts, paintings, poems, photos, videos), with whom and at what pace. For non-speaking individuals on the spectrum, the Internet provides independence in communicating with the world. Yet, those communicating through the Internet are not necessarily those who have been or will be officially diagnosed as HF autistic people. Indeed, the blogosphere hosts several non-speaking but highly articulate bloggers, some of whom are known beyond the autistic community, such as Carly Fleischman and Amanda Baggs.

In general, *autonomy* in health research refers to the ability of a potential research participant to understand the research goals, procedures and potential risks involved in participating, as well as the means taken to minimize possible risks and harms to the participants in the research process. In order to do so, the researcher needs to go through a very clear process of obtaining informed consent. The dialogue through which this takes place must inform potential participants of the research goals, confidentiality protocols as well as possible harms and benefits of their participation.

Blogging: The focus of this research project on autistic bloggers and characteristics of data collection conducted in the field, both in virtual and physical spaces, raises several ethical dilemmas involving the nature of blogs and use of such texts as a non-obtrusive research practice.

The first issue is related to possible uses of virtual texts posted online in the public virtual sphere. Many autistic bloggers use their blogs to explain autism to the NT world as well as to explore as well as debate issues related to their lives as autistic persons on the spectrum. Yet, in practice, many of these bloggers vary in their personal working definition of the purpose of their blog and their sensitivities regarding potential unauthorized use of their texts: Some bloggers promote autism acceptance through their texts and open their blog space to the public; others want people to know what it means to be autistic; still others prefer controlling those with whom they share their blogs through control of access.

On one hand, as a researcher studying blogs posted in the public space and open to all to read, watch or comment, one can adopt a naturalistic approach and intend that such study can be a non-obtrusive or invasive method to explore questions of identity construction, persona construction and the like. On the other hand, some of the bloggers may be sensitive to an unauthorized use of their texts for the purpose of study, let alone, autism research.

Researchers continue to debate whether there is a need to obtain informed consent in a non-obtrusive study of public texts. Some researchers argue that obtaining formal consent is not required since public texts are open to everyone and, therefore, they are open to academic research and analysis (Flicker, Haans and Skinner, 2004; Hookway, 2008).

I, on the other hand, felt that it was important to seek bloggers' informed consent, for the following reasons: sensitivities of the specific group due to previous experiences with the NT world, personal attitudes toward traditional autism research and the methodological need to interview them during the research process. The process of obtaining their informed consent through virtual means required adaptation to their preferred communication channel as well as providing them with the following information: a detailed description of the study's goals; the nature of data to be collected; steps to be taken to protect participants' identity; and researcher's contact information for further questions.

Non-maleficence

Following Flicker, Haans and Skinner (2004), I, too, accepted the view that it is the researcher's responsibility to minimize any risk of unintended harm to the participants during the course of the research. Unintended harm in Internet research can be caused by breaching privacy and confidentiality, but also can be related to other dimensions that derive from the specific characteristics of the participants.

In the case of the present study, the principle of unintended harm was affected by the focus on participants considered the most vulnerable and the need to collect data *beyond* the online published text (blog posts). My core assumption in doing so was that conventional methodological solutions to protecting the privacy and confidentiality of research participants may be insufficient since we are dealing with a sensitive topic and group of people who think, feel and communicate in ways that differ from NT persons. If so, a particularly sensitive ethical approach that is attentive to participants' sensitivities was needed. Flicker, Haans, and Skinner, (2004) addressed these concerns in studying online network of youth by establishing clear codes based on community values. However, I concluded that learning the codes, alone, was insufficient when studying bloggers and autistic identity. Rather, one needed to consider participants' prior experiences and cumulative attitudes towards traditional autism research as well as potential sensitivity, in general, to participant-researcher power relations.

Nicolaidis, et. al. (2011) and Nicolaidis, et. al. (2013) posed and solved such concerns through use of a *participatory* tool in researching autism-related topics with participants that involved members of the community as *equal members of the research team*³⁴. For example, although the participants were not equal members of the research team in the current study, I consulted with some of the participants throughout the research process regarding the research procedure and some potential solutions to methodological challenges I faced during the data collection.

³⁴ See also Raymaker and Nicolaidis (2013).

In the current case, I learned about participants' codes and values through the informants and later on while observing two autistic community-sponsored events. Non-formal observation at the autistic events provided useful insights about communication codes and preferences, cultural codes and expectations of researchers that could well affect my interactions with the bloggers. This process demanded continuous self-examination of my role as a researcher and my duties in handling their texts; including continuous learning of the most efficient and respectful interactions with the participants based on their sensitivities and communication patterns.

Linking public and private data

Flicker, Haans, and Skinner (2004) pose two ethical dilemmas derived from anonymity. The first dilemma is whether or not to use the bloggers' real identity, as some bloggers prefer to use a pseudonym in blogging, without disclosing their identity. Often times such an act is taken in order to make a statement. Others disclose their real identity and even post photos of themselves. Viewed from a researcher perspective, I concluded that there were two options to dealing with this dilemma: either employ universal anonymity when referencing bloggers and paraphrase their words; or, cite them openly when a quotation is employed since the blogs are already in public domain. Following requests made by some of the bloggers regarding the second option, direct citations, I added an amendment to be my application to the Institutional Review Board [IRB] stating that I will only cite bloggers interested in formal citation. Following receiving IRB approval, an email was sent to each of the participants describing the IRB approval and emphasizing that the citation procedure applies only to direct quotations from their blogs, so that confidentiality and anonymity of the interview transcripts will be maintained throughout the research and presentation process.

A basic question related to diagnosis is the second public-private dilemma: Is it self or professional diagnosis? Sarrett (2016) found that self-diagnosis among members of the autistic community is a fairly unique phenomenon compared to

people with other neurological conditions. Although debated in the community, the author describes the practice of self-diagnosis as embedding questions of identity, expertise, (mis)trust in the medical institutions and the values of the neurodiversity movement.

Here, the ethical dilemma of a researcher studying autism online is intertwined with a methodological dilemma about potential consequences of the sampling process. On the one hand, one way to insure there is a professionally determined diagnosis as autistic is to request access to their medical data in order to decide whether or not to include them in the sample. However, even if we receive consent, we risk breaching a very basic right (or privilege) to respect anonymity and loss of trust in following their blogs. Another way is to use their own definition or introduction as autistic as a reference point. It was my impression that many potential participants refer to their diagnosis and often specifically mentioned their official diagnosis as well as if they were diagnosed in childhood or as adults.

The dilemma of whether to ask for documents has in and of itself deep roots given the tendency to include self-diagnosed individuals as part of the autistic community. This aspect will be discussed further in upcoming discussion of sampling ethical and methodological considerations.

Ethical Approach Adopted to Research Procedure

Larkin, Dierckx de Casterlé and Schotsmans (2008) propose a ‘relational ethics’ that shifts the focus from discourse of rights and responsibilities to the relational commitment between people, in this case, between the researcher and the participant or the researcher and the community under study. The authors identify the following preferences, and challenges, in developing a dialogue between the researcher and participants: (1) acknowledge differences and possible influences of culture, language and systems; (2) emphasize the need for meaningful connections between people; and (3) seek to understand the interconnections needed for self-exploration. For example, employing a dynamic definition of vulnerability in such a relational approach can shift the focus from the individual to the interconnections

with the researcher in the research process. Such an approach embeds the necessary flexibility that is needed in the emerging nature of qualitative research in general and especially in a study on sensitive topics such as autistic identity.

5.2. Selection of Grounded Theory [GT]

Investigations to explore autistic identity require a methodological approach that provides a conceptual framework and very appropriate, rigorous tools to capture the role of the blog as a personal space; its involvement in the identity construction process; as well as a process that is sufficiently rich and robust to facilitate attaining understandings of the complexity of the identity negotiation process. In short, a process that enables the researcher to elaborate on the “complex nature of phenomena in terms of their various dimensional attributes” (Lal, Suto and Ungar, 2012, p. 4).

Within these broad aims, the following key considerations were identified that need to be taken into account in selection of an appropriate research approach: nature of the research topic and focus on online personal spaces; characteristics of individuals on the spectrum; and autistic community as reference point for negotiating identity with the social world. Furthermore, the different communication styles, uniqueness of the population and differences between myself, the researcher, as an NT person, and the participants added to the complexity of data collection and analysis processes.

The ground-up research process and its methodologies, too, seemed appropriate and capable of facilitating the elicitation of concepts and meanings in the identity construction process that I sought. According to Schou and Hewison (1998), GT emphasizes the process while exploring the interplay between particularization and categorization as well as the negotiation between the personal and the social in the creation of meanings (Schou and Hewison, 1998). The construction of personal identity as a dialectical interaction between the individual, social reality and social group, too, are at the heart of GT (Charmaz, 2006; Schou and Hewison, 1998). So, I concluded they would enable me to achieve the study’s

research goals as well as appropriate data collection and analysis processes. This was my mindset as I approached a range of issues, detailed below, involved in applying GT in this research project.

GT Investigations of Complex Phenomena

Similar to other studies that focused on identity construction of people with disabilities or people with chronic illnesses (e.g., Charmaz, 2006; Schou and Hewison, 1998; Stone, 2008), I too adopted GT. First, I felt that a bottom-up approach would enable me to focus on the bloggers as experts and their blogs as a rich source of information. Furthermore, GT provided the conceptual framework, research process and set of empirical principles and tools that I felt would allow me to collect rich data on perceptions, emotions, intentions as well as elicit contextual explanations to the personal or social processes under study (Charmaz, 2006; Lingard., Albert, and Levinson, 2008).

In particular, GT principles and procedures facilitate development of insights into the social and psychological aspects of the experience among people with chronic diseases that the biomedical approach was unable to explain or explore (Schou and Hewison, 1998). For example, in a study of women who went through stroke and used the GT approach, Stone (2008) justified the need for the use of GT, claiming that the self-understanding of “stroke survivors”³⁵ is important and authoritative in order to understand the self-perception of disability:

Biomedicine, which so far seems uninterested in the self-understandings of these young women, regards them objectively as ‘stroke victims’ or ‘stroke sufferers.’ The concepts of suffering or victimhood, however, do not resonate with the stories that these stroke survivors had to tell me. Clearly, there is a need to appreciate the importance of lived bodily experience as a source of authoritative expertise. (Stone, 2008, p. 202)

Accordingly, the methodology of GT moves the focus of the research from the researcher to the participant, and perceives the participant as an authority and

³⁵ As defined in biomedicine.

expert in her/his world. This approach is necessary as the self-understanding of disabilities and the lived experiences of people on the autism spectrum should be portrayed through their own words, as these texts open opportunities to understand the nature and evolution of the autistic identity.

Selection of GT Options

First, in probing more deeply into GT, I realized that a decision needed to be made between the *objectivist* (Glaser and Strauss, 1967) and *constructivist* GT approaches (Charmaz, 2006). Again, this decision, too, was influenced by the nature of the studied phenomenon, the unique characteristics of the group under study and the research goals. Whereas the *objectivist* GT approach stresses the researcher's neutrality and his/her role to *expose objective* facts, the *constructivist* approach emphasizes the *how* and sometimes *why* meanings are constructed in given context, culture or time, and acknowledges the possible existence of multiple realities. Furthermore, this interpretive approach embraces the complexities of the explored worlds and provides plausible explanations to the processes under study. I adopted the *constructivist* approach as I concluded that it was more suitable to studying the development of autistic identity. The process it provided sets out both a conceptual and methodological framework for exploring the different aspects of the research questions.

Second, the availability of *abductive reasoning*, a subset of the GT approach, seemed suited to the nature of the envisioned research process, in general, and data analysis, in particular. Abductive analysis does not assign generic identity categories and “arises from actors' social and intellectual positions” (Timmermans and Tavory, 2012, p. 167). This type of reasoning provides tools to explore identity construction through the identification of codes and norms and continuing with the construction of autistic space and the negotiation of autistic identity within and between personal writings.

In practice, the process of constant comparison and verification of hypotheses created the flexibility needed in this type of research. The data collection process

was guided by Charmaz's (2006) principles while referring to the guiding questions proposed by the author and focused on identifying the points of view of the identity construction process; aiming to identify how these processes emerge and how they are constructed by the participants; who controls these processes; and what are the meanings the participants attribute to the process and how do they talk about it (Charmaz, 2006: 20). These questions turned out to be very useful to data collection and analysis, as elaborated on in the remaining discussions in this chapter.

5.3. Methodological Challenges

The data collection process itself involved methodological and ethical challenges that may well have affected my relationship with blogger-participants as well as the quality of data collected. As described below, some of these challenges resulted from their past experiences with NT researchers as well as difficulties in social interaction with NT people in general. Other challenges were related to the neurological differences between the participants and myself as well as their pre-conceptions about communication and social interaction.

Attitudes towards Autism Research

By way of introduction to methodological challenges, we begin with noting that members of the autistic community are highly critical of the goals and procedures of autism research, and claim that autism research misrepresents them and does not reflect their lives. Nicolaidis, et. al. (2011) describe the development of a participatory research partnership with members of the autistic community developed in order to address some of the criticisms raised by individuals from the autistic community regarding the traditional autism research and methodological problems that result from the way autistic people are perceived and are often portrayed. Criticisms cited by the authors include arguments about problems in autism research, including the "...use of demeaning or derogatory language and concepts; threats to study validity derived from miscommunication between

researchers and participants; and the use of findings to advance agendas that opposed community values” (Ibid, p. 2).

Such sensitivities were reflected in comments by some interviewees in this research project. For example, the following statement reflects other community member sensitivities, stimulated by an interviewee in response to a description of the research approval procedures required of researchers in order to conduct their research in community events:

... the organizing committee needs to approve that the study comes from a positive perception of autism, does not use us as guinea pigs and that its’ goals will help improve the quality of our life or improve the understanding of people on the spectrum. [The committee must try] to prevent [a study that focuses on] deficiencies or fits us into an existing [academic] template.

Nicolaidis, et, al. solved this methodological challenge by integrating prominent autistic activists into the research team. This research project employed *member check*³⁶ during the data analysis in order to validate the analysis and to prevent unnecessary situations of unintentional harm.

Being Neurotypical in Autistic Space and Trust Building

Rather than attempt to place the experience of others within the framework of such a conception, which is what the extolled "empathy" in fact usually comes down to, we must, if we are to achieve understanding, set that conception aside and view their experiences within the framework of their own idea of what selfhood is. (Geertz, 1974, p. 31)

Trust between the researcher and participants is crucial in the qualitative research process, especially in a study that focuses on populations such as people on the autism spectrum. Trust can be built through social interactions with the participants, through learning community norms and codes of behaviors, as well as

³⁶ ‘Member Check’ is a technique used in ethnographic research for exploring the credibility of the results. In the current research, member check was used through returning to informants and exploring validity of the results.

through actions that adapt to the community culture. Yet, one of the inherent challenges involved in such relationships is that one of the defining characteristics of autism in the literature is related to difficulties autistic persons have in communication and social interaction. In turn, these difficulties affect the nature of their future social interactions, communication and willingness to interact with new people. We see this challenge in the following participant response to my request for advice of how to communicate with the participants:

A: You need to take into account that autistic people [...] have a problem interacting with people they haven't met before because there is a communication problem.

Q: They also have bad experiences from the past?

A: They are vulnerable because of too many miscommunications in the past.

Q: Ok.

A: Ok? And that's why they hesitate!

Thus, the first challenge I faced was related to the question of if and how do I approach the bloggers during the recruitment process, as well as later work with them during the interview process? I knew that I needed to find ways to interact with them that will lead to trust and not cause any stress. Blumer (1969, see Charmaz, 2006, p. 19) emphasizes the necessity to make an effort to focus on the participants' perspectives and gain their trust through developing rapport with them. This requires researchers to set aside their assumptions about the world and make an effort to learn how participants experience their world. In doing so, I knew that in order to learn about their communication styles, I needed to 'de-automize' my own communication style and de-familiarize any assumptions about social interaction. Later, during the data collection process and analysis of unsolicited blog narratives, my interactions with individuals on the autism spectrum forced me to reflect on my preconceptions about autism, the communication process, level of language I used while interacting with each participant as well as how to approach them, in general. The need for such action is reflected in the following exchange with one of the research participants with whom I spent many hours learning about autistic people and the autistic community:

- V *I somehow feel that if I want to learn how autistic people think and about the autistic culture, I need to put aside different assumptions. [I need] first to identify the most fundamental assumptions and then put them aside.*
- A *When I give a lecture to professionals that work with autistic people I always ask them: “Please take the basket you have with all the basic assumptions about communication and put it aside”. These assumptions are irrelevant when the communication style is different.*

Being a NT researcher studying autistic identity added to the methodological complexities that go beyond the challenges involved in studying foreign cultures (see for example the earlier discussion of ‘experience near’ vs. ‘experience far’ by Geertz, 1974) and are unique to studying autistic people.

5.3.1. Data Richness

Bloggers selected to participate in the study reported here write about autism. Some do it in order to raise awareness through their own story; others clearly aim to advance social change. Their blogs are open to the public and they are very much aware that they write for people on the autism spectrum as well as NTs, be they professionals, parents of autistic children or other family members and people simply interested in reading what they wrote. These bloggers are aware of their mixed audience, as their discourse style in these blogs is different from the discourse among autistic people in a safe space, and seems to be appropriate to both NTs as well as autistic persons. According to my informants, the former discourse style only takes place in closed forums, open only to individuals on the spectrum and individuals labelled as Cousins³⁷ in the community.³⁸

³⁷ ‘Cousins’ are people who share some of the autistic symptoms but are not diagnosed as autistic.

³⁸ Autistic communities around the world provide access to tests that help people learn about their symptoms and find out if they are part of the autistic spectrum. Self-diagnosed individuals can be part of the community and have access to the closed forum. The type of discourse that is accessible to the neurotypical researcher is affected by past experiences and the tendency to treat them as resource material rather than a whole person (Sinclair, 2005).

This limited access is at the core of the insider/outsider debate in ethnography in general and in discussing ethics in online research that focuses on sensitive topics such as life changes or around mental or physical illness (Paechter, 2012).

Practically, I knew that the strategy to be applied needed to be in line with the relational ethics approach³⁹ and the relativistic perception of vulnerability, explained above. The two strategies that I determined would be the most appropriate research procedures were “engaged listening” (Forsey, 2010, Paechter, 2012, p. 73) and finding the best ways to ask questions rather than focus on protectiveness. In practice, it was the use of intensive in-depth interviews that both helped overcome this challenge as well as add to data richness through validating the data conducted through the blog posts and elaborating on some aspects relevant to autistic identity that provided the means to go beyond adopting their points of view.

5.3.2. Neurological Difference is More than Just a Difference

An additional challenge for the data collection process comes from the following implications of neurological differences between the participants and myself as researcher. The first issue is related to the ideological dimension of the term ‘neurotypical’; the second is the need to find ways to go beyond our neurological differences in order to be able to establish better rapport and understand participants’ communication styles.

In terms of ideology, participants tend to define autism differently from the dominant bio-medical paradigm, and indeed celebrate neurological differences while acknowledging the difficulties they face. The term ‘neurotypical’ was first coined by Singer, together with Aspie (for Asperger) and Autie (for autistic) (Singer, 1999; Krcek, 2013) and has been adopted and used since by many members of the autistic community and by some researchers. Indeed, in many cases, use of these terms while indicative of the user’s general approach to autism continues to be in-determinative

³⁹ Larkin, Dierckx de Casterlé and Schotsmans, 2008.

as there continue to be a spectrum of meanings and uses: from simple acknowledgement of neurological diversity; continuing on with activist use as part of the diversity movement; to even ridicule (e.g., use of “curebie”⁴⁰ with reference to NTs who uphold the bio-medical approaches). Will Rogers, for example, describes neurotypicalism as

[...] a life-long disorder. People who are neurotypicalistic are capable of learning independently, fending for themselves, and developing peer relationships; however, these capabilities often result in apparent insensitivity to the strengths and needs of the non-neurotypicalistic population, as well as poor communication skills (which this group refers to as good communication skills). People who are neurotypicalistic refer to this disability as “normally functioning”.⁴¹

I learned about the term ‘neurotypical’ very early in the study. The ideological dimension of the term and the fact that I am a NT researcher were evident during in-depth interviews of bloggers. The main issue for me during data collection was to be aware that some people will be more suspicious or less comfortable with my presence or during interactions with the participants. I needed to learn how to interact with them and behaviors that could be perceived as offensive without compromising the research process, in general, and data collection, in particular. As noted by Sinclair (2010), I too found that the intensive type of interviews conducted revealed that autistic people had difficult experiences with the NT world. Furthermore, interviewees emphasized the need to approach people from the community with great sensitivity, either directly in the interviews or indirectly through interpreting their texts.

Neurological differences between participants and myself affected rapport development during the data collection process and forced me, continually, to identify and de-familiarize my preconceptions - some automatic, others unconscious

⁴⁰ “curistic” refers to approaching autism as disease and the possibility that cure from autism can be found.

⁴¹ Will Rogers on Asperger’s & Autism: living Asperger culture in a neurotypical world - <http://www.thestonkingsteps.com/thoughts-on-autism/neurotypical-syndrome-a-live-long-disorder/>

- about social interaction, communication patterns or information processing.⁴² For example, I became aware that use of *non-verbal cues* in social interaction is one of the central constructs in developing rapport with these participants. Based on information I gathered from my informants and through my initial blogs analysis I learned that the non-verbal cues I use automatically in interactions will not add to a conversation and can cause distractions. Therefore, I realized that I needed to find other ways to create rapport.

Reading between the lines is another component of NT communication that proved to be unreliable in building rapport with participants. I needed to learn how to be in more direct communication with the participants, to show respect for their perspectives and to be vigilant in applying a non-judgmental approach to narratives they shared with me.

Sensory processing was a third major factor I needed to take into consideration every time I interacted with the participants; in particular, during FTF, in-depth interviews, both in-person and virtually.

During preparations for data collection, I read accounts by the interviewees, autistic bloggers, that described their sensory sensitivities. I learned that sensitivity to sensory stimuli varies and can include sensitivity to noise, smells, textures and colors. I also learned that some autistic persons are sensitive to touch and will not shake hands, while others will be happy to hug. The fact that I was aware of these potential sensitivities helped me gain the participants' trust and to build rapport with them. Since I was not fully aware of each individual's sensitivities before we met, I made sure to wear clothing with neutral colors, to avoid a perfume fragrance or to

⁴² The concept of de-familiarization or de-automatization is used both in literary criticism and in psychology. *De-familiarization* is referred to in art to enhance the familiar and force the observer to remove automatism from perception. In psychology, the term '*de-automatization*' is related to mindfulness. Kang et al. (2013) discuss de-automatization as one of the functions of mindfulness that enables processes that lead to adaptive and self-regulatory strategies. The direct interaction with the autistic bloggers and their unsolicited texts made me question myself about those preconceptions I took for granted.

offer to shake hands with participants. I learned not to assume anything, and I learned to ask directly what will make them feel comfortable.

The following example demonstrates how I applied this reflective mindset and how this helped me develop rapport with one of the participants. This participant became a very important source of information and taught me a lot about the autistic community and their culture. I asked her to choose the setting where we first met. I did not shake hands with her at our first meeting. I also made sure not to stand too close or walk too close to her. In fact, I let her choose the best physical space for the interview within the setting. Retrospectively it was the right decision. When, after our first meeting, I shared with her that I was very much aware not to shake hands because I didn't know her sensitivities, she was a little surprised. She then shared with me that one of the difficulties she faces in the NT world is exactly that expectation, to shake hands, and she finds herself continually in unpleasant situations when she needs to explain that she does not shake hands.

Attentive listening is another example of not only a very good way of conducting everyday relations, but also a research strategy I employed to learn how to approach each of the participants and how to maximize my communication with them. Using this method efficiently provided me with better access to information and served as a learning tool that helped me perceive some of the deeper meanings of gestures, codes or norms employed by autistic people.

5.4. Data Collection

This section includes a discussion of the sampling process, methodological tools used to address methodological challenges relevant to the specific data gathering methods and sampling considerations.

5.4.1. Blogs

Hookway (2008) discussed three formal characteristics of blogs: blogger's goals, writing style and amount of accessibility to readers.

Autistic bloggers vary in *writing styles* and *aims* (e.g., on activism, personal growth, community support and autism awareness). Some blogs could be defined as more political, while other bloggers emphasize more their personal journey. Thus, some blogs look more like online diaries and contain personal writing about experiences, thoughts, struggles, etc.

In terms of *accessibility*, blogs can be: public and open to all for viewing or comment; posted in a closed community with access allowed only to authorized persons; published within an open community website.

Ethical and Methodological Considerations: One ethical issue associated with research methodology relates to data ownership. Some argue that open blogs are public material, accessible by all, and there is no ethical barrier to use of blogs as research data, and no need to obtain author consent. Others claim that bloggers own the copyrights to their texts and any use that goes beyond reading, or following, needs to be authorized by the blogger-author.

In addition, the focus on autism blogs written by individuals on the spectrum needs to consider the potential sensitivities of the autistic bloggers that result from their perception of autism research or prior experiences with the NT world. In order to solve this ethical challenge, together with the importance of gaining their trust, only blogs by bloggers who signed the informed consent were included in the final sample.

In their study of online forums of autism, Brownlow and O'Dell (2002) claim that researchers should not communicate any data published online without receiving clear consent, directly, from the data owners. 'Data' in online forums is considered to include any content produced by discussants. The practical approach they proposed in regard to the consent issue was that bloggers should post publicly in the forums that the author's prior consent for use of data must be solicited and obtained from the bloggers.

Based on Bronlow and O'Dell's proposal, the research reported here excluded posts' comments from the data analysis since it was impossible to track

down all the followers who commented on posts, either because they were no longer active or comments to the blog were posted anonymously.

An additional issue is what personal information about the blogger-author can be shared in this research project? All of the blogs included in the final sample included specific blogger information, including citing that their identification as *on the spectrum* was stated in their blog. Blogger details were collected for the most part from the blog's "About" section.

Two related decisions about inclusion in the research relate to this discussion of personal matters: First, 'functioning level' was not part of the selection criteria in order to open the list to people across the spectrum who write their own blogs.

Second, the decision to include *self-diagnosed bloggers* had methodological justifications beyond considerations mentioned in the ethical discussion. One primary reason is that I learned from my informants, at a very early stage of the interviews, that it is part of autistic community's values to accept self-diagnosed individuals as members.⁴³ According to Sarrett (2016), self-diagnosis is closely related to the concepts of *biocertification* and *biocitizenship* that link the biological features to personal and social identity. Further, one might argue from the perspective of autistic culture that a study applying a holistic perspective to investigate autistic identity must include cultural aspects related to the neurology of the individuals on the spectrum. Thus, one can argue that self-diagnosis could be an important part of the identity construction process and therefore the inclusion of self-diagnosed bloggers had methodological advantages that went beyond the need for formal diagnosis as declared by the bloggers in their self-description.

The Sampling Process: As is commonplace in qualitative research, 'purposive sampling' was used to recruit bloggers to the current research, both for

⁴³ Self-tests can be found in autism related websites, including some autistic communities' websites. Aside from self-testing, these postings can educate readers about symptoms, in general, as well as difficulties or differences common with other people on the spectrum.

analyzing blogs and in-depth interviews. It is not uncommon in a variety of disciplines to use purposive sampling methods to study marginalized and stigmatized groups, sensitive topics as well as to enable voices of hard to reach group members to be heard (McCoy and Kerson, 2006).

The choice of purposive sampling in this research project was due to the exploratory nature of the study, the characteristics of participants and the number of blogs available on the Internet. Regarding the latter consideration, while there are a relatively large number of autism-related blogs, authored mostly by parents or professionals, the number of blogs written by individuals on the spectrum is relatively small and not all of them are accessible to the public. The sensitivities of the autistic bloggers as discussed in the ethical section and the methodological challenges reinforced the need to use the purposive sampling method.

More specifically, the sample of blogs drew from a list of 90 blogs written by individuals on the spectrum, tracked down through the ‘snowballing’ method. Accordingly, the initial list was created through blogs recommended in autism related community websites (like the “Top 25 Autism Spectrum Blogs” or the “Autism Hub”). These blogs led to other blogs through the recommendations of the bloggers already on the list as appeared in their blogrolls. Each of the blogs found through the links in other blogrolls were checked in order to verify if they met the selection criteria and only bloggers that identified as being on the spectrum were included in the list.

The following sampling criteria for selecting blogs were applied:

1. Blogs written by autistic people.
2. Bloggers with official diagnosis or self-diagnosed.
3. Blogs that focus on autism-related topics.
4. Blogs open to the public and accessible without the need to register on a special portal.

All the public blogs were scanned for contact information. Some bloggers had clear contact information, either through posting contact information or a contact

page.⁴⁴ Bloggers who did not provide contact information were contacted through a message posted by me in their “About” section. My note included a general description of the research and contact information in case they are interested in participating or want to know more about the research. Consent forms were sent to the bloggers only after receiving a positive response to this request.

Blog Profile: All posts from the participating blogs posted until the end of 2014 were included in the sample, including archival posts dated to the blogger’s first post. Altogether the sample included 17 bloggers, 2,873 posts, 10,000+ pages, written in English and Hebrew, from bloggers residing in the Australia, Israel, Singapore, United States, and the United Kingdom.

Although self-diagnosis was included as one of the sampling criteria, all the bloggers that agreed to participate identified as officially diagnosed, mostly in adulthood. Eleven bloggers were diagnosed as adults, three were diagnosed as children or teenagers and three did not disclose if they were diagnosed as adults or as children. The late diagnosis of most of the bloggers in the study could have provided answers to the bloggers that affected their self-perception, as is discussed in the next chapter with presentation of the findings. In this sense, the bloggers did not become disabled through an illness or accident, and their identity construction may be different from participants in than studies that focused on people that became disabled.

5.4.2. *In-Depth Interviews*

Following the principles of GT, the interviewing process started during preparation of the research proposal and continued throughout data collection. Interviews were employed to achieve the following goals: First, to learn from

⁴⁴ Note that at the time of the actual recruitment, some of the blogs that were initially public changed their status to private and required the blogger’s invitation or the use of password to access to the blog posts. These blogs were not included in the recruitment process.

informants and bloggers about the main methodological issues relevant to the data collection process; second, to learn about bloggers' perceptions of different aspects of autistic identity and the blog's role in autistic identity construction; and third, to contextualize data collected from blogs to provide deeper understanding of theoretical conceptualizations emerging from the data analysis.

The intensive interviews with informants and bloggers provided priceless contextual information that exposed some of the ethical and methodological challenges involved in autism investigations as well as the main issues challenging autistic persons. Collectively, I learned how to approach people from the community, their potential sensitivities and how to communicate with them efficiently, in a non-offensive manner. I also learned from them about the history of the autistic community, autistic activism and their personal perceptions of autism (living with autism).

Recall from earlier discussion that biomedical autism research defines difficulties in communication and social interaction as some of the defining characteristics of individuals across the autism spectrum (Boucher, 2012; Blinkoff, 2010; Capps, Kehres and Sigman, 1998; Delincolas and Young, 2007; Murray, Lesser and Lawson, 2005; Rajendran and Mitchell, 2007; Sacks, 1995). According to the DSM 5 "People with ASD tend to have communication deficits, such as responding inappropriately in conversations, misreading nonverbal interactions, or having difficulty building friendships appropriate to their age."

Challenges presented in interviewing: Differing communication styles between participants presented challenges to the interviewing process on multiple levels. The first level refers to the interviewing method where there was a potential conflict between the benefits of using one interviewing medium for all versus need to adapt the interviewing method to the interviewee's preferred communication medium. The second level relates to the quality of the relationship between the researcher and participants during the interviewing process (n.b., such as: rapport, trust and other matters discussed previously) and the possible implications for the

quality of data collected during the interview. Here it is important to recall previous discussions about researcher awareness that neurological differences between the participants and researchers could well affect the data collection process. The interview setting was a third level of challenge as the choice of the appropriate settings for the interviews was crucial to data richness. Operatively this meant I had to find appropriate spaces to accommodate as many of the interviewees' needs as possible, both on the sensory level and in communication style. The following sections elaborate on these main challenges and methodological decisions made in guiding the interviewing process.

Selection of Interviewing Method: The interviewing method directly affects data richness. The intensive interview, selected for use in this study, is an interpretive method that, according to Charmaz (2006), locates the interviewee at the center of the process. Accordingly, the interviewee is to be enabled to share experiences and his or her narrative with the interviewer, and indeed to teach the interviewer how to interpret these experiences (Charmaz, 2006). The focus of the research reported here on autistic identity and adoption of the bottom-up approach led to adoption of the open interview method that employs a semi-structured process when conducting in-depth interviews. Both served as the framework that facilitated focusing on participants' narratives. With hindsight, I can say that, on the one hand, the open questions employed in semi-structured interviews provided the flexibility needed in order to focus on the participants' perspectives and to expose or elaborate on aspects that evolved during the interviewing process. On the other hand, the interview was structured enough to provide a solid basis for the cross-interview analysis conducted later in the research process.

The need to produce rich information through the interviews required dealing with two key issues: First, recognition that there are individual differences in participants' communication styles. This requires weighing potential strengths and weaknesses of two options: the strategy, as well as principle, of working with each interviewee's strengths versus implementation of a universal one-method-for-all

strategy. Second, the study needed to address potential problems that derive from different dynamics of immediate, synchronous FTF interviews,⁴⁵ video chats through Skype or online synchronous interaction versus asynchronous interview.

Consultation via the research literature revealed the options and complications involved in these two issues. In regard to the first issue, Sinclair (2010) and Bagatell (2010) emphasize the benefits of written language and asynchronous communication available on the Internet for autistic people (also Benford; 2011; Blume, 1997; Davidson, Edward and Hemsworth, 2012). They argue that asynchronous online interviewing has numerous advantages for autistic persons: it is a more adaptive environment in which participants can control the pace of communication, revise or rephrase their thoughts before sending the answers and practice more self-reflection resulting from the elimination of non-verbal cues during the interaction with the interviewer (Benford and Standen, 2011).

On the other hand, the immediate nature of participating in synchronous, FTF interviews provides more flexibility in the interview process and more opportunities for autistic persons to elaborate on their perspectives or raise new questions that derive from their narrative. Furthermore, the ability to develop rapport and trust through the interactions between the interviewer and the interviewee is greater in the synchronous communication of FTF interviews.

On the other hand, the less immediate nature of asynchronous communication of online interviews poses challenges for building trust between researcher and participant. Benford and Standen (2011) acknowledge this obstacle and claim that the non-immediate nature of the researcher-participant interaction in an email facilitated interview process can be addressed in the research design through immediate response to emails from participants or inquiries in case of hesitation or response delay but admit that the process is especially lengthy.

⁴⁵ FTF= face-to-face

The second issue - use of a single, universal mode of data collection or different modes per individual differences – required taking into account the importance of building trust, differences in comfort levels and proficiencies with certain modes of communication. I recognized that some members of the community prefer FTF interviews, others feel comfortable being interviewed via Skype, while others prefer an online interview via e-mail exchange. Although the use of a single universal method of data collection is recognized for advantages in terms of comparability, in this case communication differences could well affect the quality and the richness of the data more than adapting different interviewing channels such as FTF or email interviewing to the interviewees. In making my decision, I determined that the benefits of communicating with the participants in a channel that gives them more control over the environment or the social interaction with the researcher are far greater than possible loss of information as a result of non-unified interview channels or settings.

While Skype and FTF interviews provided rich data, e-mail interviews were limited in terms of data richness. In order to overcome the differences in the interviewing channels, the interviewing process was adapted to the participants' needs and was divided between intensive interviewing that lasted throughout the data collection process and e-mail interviews conducted at a later stage as part of the theoretical sampling.

The interview guide was developed in the research proposal stage along with the main concepts that emerged from the blogs in the preliminary analysis (n.b., for interview guide, see appendix A).

Based on these considerations, the informed consent form sent to participants included a detailed description of interviewing possibilities, and emphasized that each one participant was free to choose the channel best suited to through which we would engage in the interview (n.b., see exemplar informed consent form in appendix B).

Blogger Recruitment for Interviews: As noted previously, recruitment of bloggers to participate in interviews was based on their preliminary approval to participate in the study. Thus, recruitment for the intensive FTF interviews started in parallel with compiling the blog list, through use of the snowballing method.⁴⁶

More specifically, my first contact with a blogger was created through the mother of the youngest participant, whom I had known for many years. She provided several names of bloggers and recommended that I talk to another mother who is highly involved in the autistic community in Israel who she thought could be a good source of information.

While this first contact recommended bloggers already on my list, her mediation was helpful in assisting me gain entrée with these bloggers. An additional blogger she recommended, an adolescent, was approached via email. Although he agreed to participate he stopped responding once I told him that I would need his parents' approval. Therefore, this blogger was not part of the final sample.

Recruitment for interviews conducted via e-mail took place at a later point in data collection, as part of the theoretical sampling phase in the GT approach [n. b., see discussion below]. Contacted later, my email to these bloggers reminded them of their initial approval and asked their permission for me to send them my interview questions. Only after I received a positive response were my questions sent to them.

⁴⁶ Snowballing method, has been termed also as 'network', 'chain referral', or 'reputational sampling' (Stehlik, 2004, p. 39). This method is used in naturalistic, non-obtrusive research in which structures are not defined by the researcher, but rather defined through the interconnectedness between the links. The use of this sampling method was necessary (and the most suitable) in this study for three main reasons: the number of autistic blogs; the interconnectedness between the blogs; and trust building. Snowballing was used either through blogrolls (mostly for tracking down blogs) or through oral recommendations that helped with trust building (in the Israeli community only).

Attaining Interviewee Consent: In describing a variety of methodological dilemmas facing online interviewing, James and Busher (2006) claim that email interviewing raises issues of *consent, confidentiality and credibility*.⁴⁷

Consent and Credibility: The process of obtaining consent in FTF meeting provides better opportunities for the interviewee to ask questions, and for the interviewer to clarify aims and procedures as well as to verify the identity of the interviewer. However, since most of the participants in this research project lived in different parts of the world (Australia, Israel, Singapore, U.S.A., UK), most consents were achieved online through use of an email sent to the bloggers who expressed interest in participating in an interview and agreed to allow me to analyze their blogs. The email was followed by automated messages sent by Qualtrics that included the consent form and a short questionnaire that asked for some demographic details as well as their diagnosis.

Consent for the FTF interviews was achieved in the first meeting with the interviewees for the purpose of arranging the interviews. FTF interviewees received a copy of the consent form via email prior to the meeting so they had an opportunity to review the form and approve their participation when we met.

Another methodological issue raised by James and Busher (2006) is related to the *identity* of the person who actually provides the answers to the questions in the interview. Any online interviewer has a need to identify who really is behind the answers, particularly but not-exclusively in the case of the respondent's identity when it comes to non-speaking autistic people. The Internet gives them a voice, as it did with Carly Fleischmann, but may raise controversy around the authenticity of the voice.

Several bloggers in the initial blog list were non-speaking. All are known within the autistic community (either the international or the local autistic community) and maintained their own blogs, as was confirmed through other

⁴⁷ Confidentiality was discussed under 'linking public and private data'. Consent is discussed throughout the chapter.

bloggers' references or comments. In the final sample, only one non-speaking blogger responded to me, preferring a FTF interview over an online, as will be discussed below. Problems with identification and falsification can occur in any interview, FTF or online but they are much more salient in online interviewing.

Credibility challenges⁴⁸ were solved through the sample recruiting procedure: contacts with interviewees were initiated by the researcher either through their personal blogs or through personal contacts and snowballing methods.

Interviewee Profile: Recruitment produced 14 interviewees with autistic bloggers, and four informants. Eight participants chose FTF interviews, one participant preferred Skype interview and nine were interviewed via email. All FTF interviews were *intensive* conducted in Hebrew. The Skype interview was conducted in English and all e-mail interviews were conducted in English.

The blogger sample included eleven females⁴⁹ (one of whom was transsexual and her blog focused on being an autistic Trans), genderqueer/non-binary and five males ranging in age from 15-75 (n. b., the 75-year-old interviewee was a NT grandmother of the non-speaking 15-year-old male participant).

All blogger-interviewees were officially diagnosed except for one who had started the official diagnosis process but stopped when he was told he is autistic. Three of the bloggers were diagnosed as children or adolescents, eleven were diagnosed as adults, three talked about their diagnosis but did not disclose the age of their diagnosis, and two informants were NTs (the mother and grandmother of the youngest participant).

⁴⁸ Another dimension to the credibility challenge goes beyond the interviewing method (FTF, Skype or email) interviewing and was discussed as part of the sampling considerations and methods discussion.

⁴⁹ Not all define themselves as male/female. One or more used terms as asexual-spectrum, genderqueer/non-binary. Gender and identity among individuals on the spectrum are topics that I heard autistic people discuss. However, it is beyond the scope of the current research and therefore the sample is described through the traditional distinction between male and female with the exception of one Trans blogger.

Informants: Additional in-depth interviews were conducted with six non-blogger informants. Three informants were individuals on the spectrum; the other three were a blogger's spouse (n.b., herself a mother of two daughters on the spectrum) and the mother and grandmother of the youngest participant – a non-speaking highly articulate blogger who was 13 years old when I first met him and when we started the intensive interview process. Non-blogger informants provided important contextual information that complimented the information provided by the bloggers (three of whom were asked questions and provided important contextual information).

Interview Setting: The interview setting plays such a significant role in interviewing as to affect both the data quality and richness. Furthermore, the interview setting can affect trust building between participant and researcher as well as interviewees' willingness to open up and share information. For autistic participants, the characteristics of the virtual or the physical space needs to include adaptations to their needs in order to enable them to feel more comfortable. Bertilsdotter Rosqvist, Brownlow and O'Dell (2013) studied the difference between autistic-only spaces and neuro-shared spaces both in online communities and in community activities in the physical space. They found that the nature of the space, as separate or neuro-shared, affects the types of topics discussed, and in the case of the in-depth interview, it affects the narration of the interviewee's perspectives shared. With these understandings in mind, my main goal was to create a 'safe space' for the interviewing process via implementation of the following strategies: select a sensory-friendly environment adaptable to interviewees' needs; create a non-judgmental environment; and adapt to the individual communication patterns of the interviewees.

A sensory-friendly environment was very relevant in FTF and Skype interviews, in particular with reference to addressing such potential sensory stimuli as: visual, noise (both FTF and Skype) and smell (FTF only). Based on the sensitivities of the participants, individual differences and need to establish rapport with them, each interview setting was selected by the interviewees. Some preferred

to be interviewed at home, others in public settings, such as a quiet area in a café or in a relatively isolated part of a cafeteria at the academic institute attended by the interviewee.

Interviewing Process and 'Guide': In-depth, intensive interviews were used in order to reveal participants' perceptions on autism, what is autistic identity for them, the blogging experience, autistic space and the autistic community. All of the interviewees were involved in promoting autism awareness and were highly articulate in explaining autism to NT people.

The intensive FTF interviews were conducted in Israel over three summers with informants as well as Israeli bloggers, and these discussions continued over multiple meetings with interviewees. Unlike shorter in-depth interviews, the intensive interview process requires more time for: in-depth exploration; return to discuss aspects that appear to be significant at a later stage of the interview; opportunities for unanticipated data to emerge; or serve as dynamic part of theoretical sampling and the theory building phases.

Charmaz (2006) encourages GT researchers to use intensive interviewing in exploratory studies. According to the author, intensive interviews should be conducted in a non-judgmental environment by a researcher who facilitates being guided by the participant through their experiences as well as in the interpretation of those experiences. Thus, the GT researchers position the participants as experts and intensive interviewing provides the interpretive method that gives the participants tools for self-reflection and framing life experiences through egalitarian interactions with the researcher.

Glaser (1998) argues against GT investigations that employ preconceived interview guides or units for data collection. Charmaz (2006) reinforces Glaser's view on use of preconceived interview guide and recommends open ended, very general questions aimed to help elicit participants share their perspectives. These guidelines were used in the research reported here.

Thus, the interviewing process began with exploratory interviews conducted at a very early stage of the research. The process started with discussion of broad

concepts of autistic identity and autistic space. With the transition into the early stage of intensive interviewing, we discussed general questions about the blogging experience and reasons to maintain a blog, what autism means to them and how they perceive their personal identity. The intensity of the interviews allowed me to slowly and carefully gain the participants' trust, to access the meaning of autistic identity for them and the role of their blogs' space in self-exploration and autistic identity construction.

The information collected during the intensive interviews provided the basis for mapping the main aspects that proved to be relevant in the study of autistic identity and led eventually to the more focused and less open-ended interview guide that was sent to the bloggers in the online interviewing process. Online interviews were conducted during the theoretical sampling phase and included more focused questions on aspects that were related to the blog as autistic space and their perception of autistic identity.

5.5. Data Analysis

I have been concerned, among other things, with attempting to determine how the people ... define themselves as persons, what enters into the idea they have (but, as I say, only half-realize they have) of what a self... is... I have tried to arrive at this most intimate of notions [of the self] not by imagining my- self as someone else - a rice peasant or a tribal sheikh, and then seeing what I thought - but by searching out and analysing the symbolic forms - words, images, institutions, behaviours - in terms of which, in each place, people actually represent themselves to themselves and to one another (Geertz 1974, p. 30).

Geertz (1974) described the challenges to ethnographers in studying other cultures and specifically in exploring the notions of self. In a lecture presented and published in 1974, he claimed that the anthropological understanding of the 'native's' point of view does not go through adopting the participant's point of view but through the analysis of the culture's symbolic forms. This type of methodological approach provides flexibility in studying the meaning creation process and at the same time demands constant self-reflection from the researcher during data analysis

in order to be able to identify and analyze meaning creation through use of symbolic forms of participants' self-representation.

Charmaz's (2006) constructivist GT approach defines the data collection process and the researcher's role in the data analysis in ways similar to Geertz. Because her working assumption is that all meanings are products of social construction embedded in certain contexts, eras, places, cultures and specific situations, Charmaz's approach comes from the interpretive perspective that emphasizes the crucial role of researcher reflexivity during the data analysis. Further, in contrast to the objectivist approach to GT, which seeks researcher neutrality and assumes that data reflect objective facts about the world (Charmaz, 2006: p. 131-132; Glaser and Strauss, 1967), the constructivist GT approach acknowledges the existence of multiple realities and explores the dialectical process of meaning-making between the self, community and culture. Again, the assumption is that identity construction is a dynamic, complex process of self-exploration, dialogue, negotiation and actions between the self and other people within and outside the community.

The constructivist GT approach offered by Charmaz (2006) provides the necessary flexibility needed in exploring the autistic identity construction process. Blogs and in-depth interviews are sources of symbolic forms that can help expose the way autistic people explore, negotiate and define their identity. Ground up analysis of the blogs and in-depth interviews bring to the forefront structural features (the 'how' and the 'space'), self-exploration (the 'what') and dialogical aspects (the 'what' and the 'how') that are all involved in the construction of autistic identity.

5.5.1. *Use of Abductive Analysis*

This study's focus on autistic identity and early exposure to the blogger's narratives challenged my pre-conceptions about autism, autistic people, social order, social interactions, communication, community and culture. Therefore, I found the abductive reasoning method offered by Charmaz (2006) useful throughout the research process. Charmaz (2006) claims that the reasoning used throughout the GT

process makes it an abductive method. *Abductive reasoning* starts with examining plausible theoretical explanations to the raw data and formulates hypotheses about possible connections between the emerging concepts. Employing this method led to my raising questions about the meanings of the alternative social order, the place of the autistic person in general and the autistic blogger specifically in the autistic social order and the connections between autistic identity and social order.

Following GT principles, data analysis started early-on in the research process, including guidance of the data collection process (Charmaz, 2006; Glaser and Strauss, 1967). Glaser and Strauss (1967) emphasize the need for inductive data analysis in order to avoid the situation in which possible preconceptions are influenced by existing concepts and theories. Timmermans and Tavory (2012), on the other hand, claim that the existing knowledge need not affect the researcher developing a ‘fresh look’ during the data collection process. I, too, found that co-existence of theories is possible in the abductive analysis method and enables the emergence of new insights from the data while conversing with the existing literature. Thus, during my investigations, the simultaneous data collection and the analysis guided the data analysis through examining hypotheses and conceptualizations as they emerged throughout the coding process and guided the theoretical sampling process.

5.5.2. Coding

Charmaz (2006) talks about two stages of analyses: initially, coding identifies names key words, sentences or paragraphs in the text. The next stage is more focused and includes organizing the existing codes into higher level or more inclusive categories.

From the beginning of its evolution, coding has been central to GT. GT’s procedural ‘rules’ have long held that emergent coding from raw data should be developed without ‘leaning’ on preliminary conceptualizations based on existing theories.

Blog posts and the interviews were the units of analysis in this research project. The analyses coded smaller units within the posts and interviews. This process enabled constant comparisons between contents in blog posts and interviews. The initial coding process used *NVivo 11*⁵⁰ to identify the focus in the texts and how meanings were delivered. This stage included elements relevant to traditional autism research and theories, perceptions of autism in the NT world and elements that could be relevant to autistic identity, identity construction, autistic space and autistic culture.

The coding process involved constant comparisons between interviews, within interviews, between interviews and blog posts, between bloggers and within posts. On the basis of the initial coding and constant comparisons between the sources, the data was organized under higher level themes that are meant to be inclusive of different aspects of the topic analyzed. Here theoretical coding was employed in order to identify possible dimensions that emerged from the previous stage and connections between subcategories within each category.

Next, the analysis tried to conceptualize potential connections between the themes while developing further the different aspects that were emerging. This coding method was sufficiently flexible to enable the emergence of theoretical concepts not identified in early stages of the research and which appeared to have explanatory power of central elements of autistic identity, the construction process and the role of the perception of autistic people by the neurotypical world on the identity construction process.

During the coding process, I paid special attention to the language used by the participants, assuming the terminology may reflect autistic culture and autistic community. Coding the language and the terminology helped contextualize new concepts coined by the autistic bloggers, identify concepts that cross cultures (American, Australian, Israeli, etc.), explore the meanings they capture and through

⁵⁰ **NVivo 11** is qualitative research analysis software (Windows).

that, learn about the potential connections between language and autistic identity. NVivo 11 was used in order to explore where and how the bloggers use the terminology: contextualizing the terms' uses and organizing the data starting with the basic coding and later on with the evolving conceptual categories.

5.5.3. *Theoretical Sampling*

GT uses theoretical sampling in order to identify possible conceptual gaps, develop conceptual categories that emerged in earlier stages of data analysis and guide a more focused data collection. The goals of theoretical sampling result from the theoretical explanations that evolve from the data analysis that enables to further develop the conceptual categories through exploring the possible connections within and between the categories (Charmaz, 2006).

Strauss and Corbin (1998) claim that theoretical sampling needs to start early in the research process, following the identification of core variables (McCreadle and Payne, 2010; Newman, 2008; Simmons, 2010). Charmaz (2006), on the other hand, claims that theoretical sampling should not start too early in the research process, as too early a start can lead to imposing theoretical density on the data instead of letting them emerge (McCreadle and Payne, 2010).

In order to develop data properties, theoretical sampling can involve recruiting new participants, return to existing participants or use additional data forms and sources (Hense, Skewes McFerran, and McGorry, 2014; Lal, Suto, and Ungar, 2012). The theoretical sampling in the current study followed the principles of the constructivist GT according to Charmaz (2006). The constant comparative analysis of the data collected through the intensive interviews, early stages of textual blog analysis and interviews and contextual information collected through participant observations led to the emergence of categories that needed further development.

The theoretical sampling that guided development of the interview guide was used both for online interviews with bloggers not included in the intensive interview as well as in FTF intensive interviews. The theoretical sampling process involved

elaborating on specific aspects of autistic identity and the personal space of the blog as an arena for autistic identity construction. In addition to the principles used during the theoretical sampling process, a member check was used with two of the participants and one informant in order to ensure and validate the results and the conclusions. The member check process was conducted both via email and in FTF meetings.

5.5.4. *Theoretical Coding*

The results of theoretical coding are descriptions of how the codes, which may relate to each other, were found to be compatible with the conceptual framework of the research and explorations of the identity construction process. For example, exploration of autistic identity constructs and the identity negotiation process intertwines with evolution of cultural codes and values that define autistic space. The GT approach includes tools that facilitate study of complex processes and their interconnections. The method goes through “theoretical coding [that] results in descriptions of how the substantive codes may relate to each other as hypotheses to be tested. The testing consists in constant comparison of data with emerging conceptual framework” (Schou and Hewison, 1998, p. 299).

The process of theoretical coding in the current study was affected by the underlying assumptions of the interpretive constructivist approach that guided both data collection and data analysis. Charmaz (2006) explains that the emphasis in the interpretive GT approach is not on the explanation of a phenomenon but on its meaning. This approach assumes the existence of multiple realities that intertwine with facts and values. Theoretical coding and theory building in this approach goes through asking WHAT reality is for the participants and HOW they construct their reality.

The current research used theoretical type coding identified by Strauss & Glazer (1967, see Charmaz [2006] on theoretical coding, p. 63). These coding types included identity-self, cultural as well as theoretical coding that refer to processes such as situations and the social world (as part of exploring the identity negotiation

with the NT world). An integration of theoretical codes was used in order to avoid monolithic and unidimensional explanations of the autistic social world and the NT social world. The data analysis used this method in order to identify the identity construction process among individuals on the spectrum.

5.5.5. *Structural Analysis*

The written texts of the blogs provided non-obtrusive access to the naturalistic documentation of the autistic voice, but the study needed to go beyond the written texts of the bloggers in order to contextualize the explanations that evolve from the texts and provide richer data on the role of the blogs in the identity construction process. Autistic identity construction occurs within the individual space and through a dialogical process with the readers and with a collective identity at the communal level.

Blogs are individual spaces, by definition, that allow the blogger to define codes of behavior, interact with followers, block intruders, make the blog private in order to control who can have access to the blog contents, etc. In order to explore the role of the personal space of the blog, a structural analysis was used in addition to the GT principles. The structural analysis will be discussed in the data analysis section.

Analysis of bloggers' techno-identity followed structural features of blogs identified by Serfaty (2004) as having the following main features: accumulation, closure vs. open-endedness, self-reflexivity and co-production.

Accumulation refers to the cumulative use of different media available to the user, including: pictures, drawings, audio and video files, ads as well as hyperlinks to other websites or blogs. Since the blogger is the one to choose the form of representation for their blog in general and blog content specifically, the collective accumulation of information from *all the media involved* help create what the author refers to as the blogger's "rounded character" or "persona".

Closure vs. open-endedness refers to the difference between autobiography and diary writing. Autobiographies are blogs that are limited to a pre-defined set of

time and is characterized by its circularity and closure. Diaries are open-ended blogs that are defined through their linearity and the form of self-expression and self-definition that is different than the autobiographical writing.

Self-reflexivity according to Serfaty, takes two forms: commentary about the Internet and commentary about the diary-writing itself (2004, p. 463).

Co-production refers to the dialogical feature of blogs and the potential for community creation. Bloggers explicitly search for an audience and this alone turns the blog into a collaborative project. Writing and reading are both processes of meaning creation and the identification of the dialogical features with readers or other bloggers help identify the identity negotiation process and blogger's self-identity exploration.

In general, the structural features' analysis provided the basis for the exploration of the dialogical nature of those personal narratives and the way that the bloggers 'organize' their private autistic space. This analysis provided the dialogical and the structural features of the 'how'.

In Summary ...

This chapter reviewed the ethical considerations and some methodological challenges faced during the research. Some of these ethical dilemmas were similar to those reported in other studies, and involved issues of autonomy, non-maleficence and linking public and private data.

The definition of autistic bloggers as vulnerable participants led to a necessary discussion about the definition of 'vulnerability' and the potential methodological implications of adopting a 'relational ethics' and shifting the discourse from rights and responsibilities to relational commitment between the researcher and the participants.

The main methodological challenges I faced were related to the perception of autism research among autistic people. In addition, there were neurological

differences as well as different communication styles that differentiated the participants from myself, as researcher.

The study adopted GT approach as the most appropriate in studying identity construction among autistic bloggers. Within GT, I found abductive reasoning to be very useful in the data analysis process as it provided the tool I found to be most useful to examine alternative plausible explanations and formulate hypotheses about possible connections between the emerging concepts.

The next chapter presents the main findings that emerged from analyses of the blogs and the interviews. The chapter opens with examining the techno-identity of the bloggers through structural analysis of the blogs. This is followed by the meaning of autistic identity for the bloggers and key constructs in autistic identity construction.

CHAPTER SIX

RESULTS AND DISCUSSION

This chapter is organized in three sections, following the questions that guided the research. The first section explores the techno-identities of the bloggers through structural features of the blogs in the study and how they serve as personal spaces for identity negotiation. These findings are explained through describing how the blogs reflect conventions and preferences within the autistic community. The second section explores what autistic identity means to the bloggers through discussing: perceptions of autistic identity; autistic identity and the NT world; and multiple identities. The final section deals with the main constructs of *autistic identity* construction that emerged from the blogs and interviews: autism diagnosis, autistic agency and normality.

6.1. Blog, Space and Techno-Identity

Schmidt (2007) claims that the blog is a sheltered space for the blogger due to the relative control the blogger has over content, communication and identity management. For example, blogs in this study were designed as text based, lean cue environments.⁵¹ Walther (1996) claims that users have greater control over content in lean cues environments. Furthermore, in a text based environment with no or lean non-verbal cues, people have more control over the information and they tend to engage in ‘hyperpersonal’ communication.⁵² Computer-mediated-communication is hyperpersonal when:

⁵¹ Lean cues environment in CMC refers to non-verbal cues. See also the discussion of affordances in chapter 4 of this treatise.

⁵² The Hyperpersonal Model of computer-mediated-communication defines hyperpersonal communication as exceeding face-to-face communication by affording the sender communicative advantages over the traditional face-to-face sender-receiver communication (through strategic

[...] users experience commonality and are self-aware, physically separated, and communicating via a limited-cues channel that allows them to selectively self-present and edit; to construct and reciprocate representations of their partners and relations without the interference of environmental reality (Ibid: p. 33).

Nowak, Watt and Walther (2005) refer to affordances that serve asynchronous lean cue environments. In the first sub-section below, we learn that users of asynch-ronous systems have opportunities to edit their content and their environment is free of temporal constraint. Such environments emphasize the more controllable verbal and linguistic cues and this leads to self-presentation that is more manageable, selective and self-censored (Gibbs, Ellison and Heino, 2005, p. 153).

Thus, an initial characterization of the blogs in the current research is that they are, for the most part, text based, lean in non-verbal cues and free from temporal constraints. This allows bloggers full control of identity management and, thus, this selective self-presentation can be viewed as the bloggers' *techno-identities*.

Continuing with an overview, the examination that follows bloggers' techno-identity construction employs several conceptualizations: Serfaty's (2004) conceptual-ization of the blog's structural features enables us to identify the means employed by bloggers to construct their blogger 'persona'. Such an analysis considers aspects relevant to the connection between the techno-identity and the use of the blog's space for identity negotiation and identity exploration. In doing so, the analysis examines how bloggers perceive the blog's space, their writing (in terms of writing styles and perceived target audience and their perceptions of the act of blogging (e.g., their goals and how they characterize their blog).

Accordingly, we apply Serfaty's framework to analyse four structural features of blogs that autistic persons use to create and negotiate their autistic and

identity management and optimizing self presentation). The model is based on the assumption that "users exploit the technological aspects of CMC in order to enhance the messages they construct to manage impressions and facilitate desired relationships" (Walther, 2007, p. 2538).

techno-identity: accumulation, closure vs. open-endedness, self-reflexivity and co-production.

6.1.1. *Accumulation*

Accumulation refers to design of the blog space and features chosen by the blogger as the form of representation within the blog. According to Serfaty, accumulation helps create the ‘rounded character’ of the blogger through media selections, such as inclusion of specific ads, drawings, pictures, audio, video and hyperlinks to other blogs or websites. In analyzing this structural feature, special attention was directed to the bloggers’ communication styles and sensitivities they employed in their blog’s digital presentation.

Overall, the blogs were heavily text-based, and in doing so bloggers employed mostly black fonts on white backgrounds, with relatively limited inclusion of other media files (e.g. videos or drawings).

The choice to rely heavily on texts resonates with the affordances⁵³ of lean communication and minimal non-verbal cues, and seems to be consistent with the role of text-based communication in autistic sociality on the Internet (Brownlow, 2010; Brownlow and O’Dell, 2013; Davidson, 2008; Davidson and Henderson, 2010; Dekker, 1999; Kras, 2010; Kreck, 2013; Ortega, 2009).

Asynchronistic communication that characterizes blogs and reliance on low cue communication are consistent with the hyperpersonal model (Walther, 1996). Nowak, Watt, and Walther (2005) claim that mediating systems provide affordances that face-to-face communication cannot provide. These affordances include the ability to edit the text before publishing it, archiving and releasing the user from temporal and geographical constraints. Thus, similar to findings in other studies, bloggers in this study talked in the interview about the benefits of text-based communication and its role in enabling a more accommodating, less stressful form

⁵³ See chapter 4 for discussion on affordances.

of communication with others on the Internet and with the world. Indeed, text-based mediated communication enables more comfortable social interaction and frees the reader to rely on the meaning of the communicative message instead of “*what we do or how we look when we say it*”,⁵⁴ as one of the bloggers said in the interview. It allows the bloggers to emphasize their strengths and show “*the real me*”, as another blogger explains. Learning a new social medium is compared by a third blogger to learning a new social skill but without the judgement or stigmatization that accompanies face-to-face interactions.

Ruppel (2015) offers an affordance model of communication and identity management. Based on her model, there is a reason to assume that bloggers who utilize self-disclosure will develop stronger relationships with their readers and commenters, and less association with technology affordance. Hence self-disclosure affects the identity management of the blogger through the blog.

Self-disclosure, selective presentation and sensory processing

The non-verbal aspects of the blog’s design, such as colors selected as well as the display of photos and posters, are another aspect of structural construction and transmission of meaning in communication. For example, the selection of colors to use in the blog’s background or whether to post photos in the blog go beyond identity management of blogging practices described by Schmidt. Indeed, I found that decisions about the colors of photos or posters posted are related to standard identity management as well as to aspects relevant to the blog’s envisioned audience. Indeed, bloggers personalize their blogs spaces with the choice of background colors and photos they add even to specific posts. They include posters and ads that promote the autistic community’s causes and events in the body of specific posts, in the homepage or even in the margins of the permanent display of the blog.

⁵⁴ Quotes from interviewee’s blogs and interviews are italicized to distinguish them from quotes from academic research citations.

Colors: Some bloggers related that they took into consideration readers' potential sensory sensitivity in choosing the blog's color scheme. Similarly, the choice of photos and posters is related to self-disclosure as autistic, timing to "come out" as autistic and possible statements by blogger-authors about their identifying with autistic identity or involvement in autistic activism.

First, in terms of color selection, many bloggers selected colors such as light blue, light purple or light red for the background and neutral white for the text area. A few others chose stronger colors, such as purple and black, for the background. Some bloggers cited that background colors were chosen because of personal preference or could be related to attention of the blogger to potential sensory sensitivities of the readers as well. One blogger referred to this difficulty in designing accessibility on the Internet in one of his blog posts:

*It is possible that a certain design of the content that is needed as an accessibility accommodation for one person will be inaccessible for another person. For example: Font sizes. For some people a certain font size would be too small and for others certain fonts will be inaccessible because they are too large. Too many colours, too much graphical design and/or animations surrounding the content may be inaccessible to those that cannot focus on the content when the background is too colourful while others need the background colour and/or sophisticated graphic design and/or animations to be able to focus on the content.*⁵⁵

In order to make his blog more accessible, this blogger used his technical skills to add options of more neutral background colors for the readers to choose from.

Another blogger focused on structural decisions related to general accessibility on the Internet. This included citing the importance of using text labels for graphics and making it possible for users to activate all website functions through the keyboard. Although many bloggers were aware of the varieties of potential reader sensory sensitivity, not all could provide solutions for the users to be able to accommodate the blog's environment to their specific needs. To do so, the blogger

⁵⁵ Gil, R. (2007). Accessibility – A Look at Standards and Beyond. *Asparagus Soup Without Recipe*, March 20, 2007.

would need access to specific tools when designing the blog's space or have relevant technical skills to create the tools. For example, two bloggers applied tools, available as technical software mechanisms, that enable readers to manage the visual presentation in order to make it more accessible. One blogger provides the readers with the ability to control the contrast style of the page through choosing between 'normal contrast', 'high contrast' and 'high visibility'. Another blogger provides more elaborate tools to adjust the blog's visual presentation so that the reader can control font size, contrast (high or low) and background color.

Schmidt (2007) argues that the use of codes is a structural feature through which bloggers engage in identity management, selective self-management and self-exposure. He describes two types of coding software that allow bloggers to facilitate audience member interactivity with their blogs. Most of the bloggers in this study employed Wordpress, as it enables them greater control over the design of their own web server and contents. Such platforms provide the technical means for bloggers to design the visual environment of their blog as well as upload photos, change the blog layout or engage in information management.

Publishing pictures is another way bloggers personalize their blog (Serfaty, 2004). Beyond their decorative function, pictures enable the blogger to share moments, experiences, mood or recommendations. Bloggers in this study vary in their use of pictures in the blog posts across a spectrum from use of relatively few pictures to featuring them in a more dominant role. Generally, many personal pictures of the bloggers or of events discussed in specific entries were published on the blogs examined.

The choice to post personal pictures in the blogs may indicate the approach taken by the bloggers to disclose their autism to the world and, therefore, their willingness to expose their real identity. One of the bloggers talks about the hardship of hiding autism in a post in which she share her reasons for blogging:

I have been writing a lot here about disclosure and visibility and the importance of these in negotiating societal change... I find that I must now go a step further in making myself heard, even when you have shown me that you are not ready to listen. It isn't any secret that I hate personal conflict and will go to great lengths to avoid it.

*I can't do that anymore. Not without becoming a liar. And then I would hate myself again. Coming out to family, to those who have the most invested in their images of who their loved one is, is always hardest. It's never just a one-shot deal, free from obligation to repeat. This is who I am. This is always who I am. Please accept this invitation to what goes on in my head. Welcome to my blog.*⁵⁶

The use of the personal photos or videos together with disclosing their real names may indicate blogger willingness to openly discuss their autistic identity and other autism related issues. Davidson and Henderson (2010), who study strategies used by Asperger Syndrome [AS] people to disclose their identity online, claim that coming out as autistic involves resisting common stereotypical portrayals of autistic people. In their analysis of autobiographies published by AS authors, they identify four categories of 'coming out' strategies: 'keeping safe', 'qualified deception', 'like/as resistance', and 'education'. For example, the 'keeping safe' repertoire draws on past experiences of disclosure and, potentially, can have profound consequences. People who use this strategy will decide how and to whom to disclose. Similar to the choice between using a nickname or the real name of the blogger, the choice to publish the blogger's pictures, pictures that don't include the bloggers or other people or not to use pictures at all are all indicative of the blogger's stance in regard use of the 'keeping safe' repertoire. This observation is observable in the bloggers' written accounts and interviews with them about 'coming out' or challenges of the NT world.

6.1.2. Closure or Open-Endedness

Similar to other marginalized groups or groups of people with different health or physical conditions, blogs provide opportunities for autistic people to share their thoughts and process their experiences. Several studies explored use of blogs and benefits bloggers gain by writing blogs and sharing their thoughts and experiences with others (e.g., Clarke and Van Ameron, 2008; Guardiola-Wanden-Berghe, Sanz-Valero

⁵⁶ Bev (2007). To Whom it may Concern: A Confession. *Square 8*, May 3rd, 2007.

and Wanden-Berghe, 2010). For example, Serfaty (2004) argues that an important distinction can be made in analyzing a blog between its closure versus open-endedness, as in the distinction between writing an autobiography and a diary: Whereas a diary is open-ended and linear, autobiography is limited to a predefined set of time, and characterized by circularity and closure. Interestingly, the blogs studied in this research project cannot be characterized, in this respect, as purely autobiographical or diary writing.

Furthermore, bloggers' writing styles vary within and across the blogs to reflect the blog's goals, in general, or intentions of specific postings. For example, bloggers in this study differ in terms of their writing styles: Some emphasize personal writing while others focus more on activist writing. Many of the bloggers entwine autobiographical writing of their personal experiences and essay writing in order to talk about wider issues that are relevant to different aspects of their lives as well as to other individuals on the spectrum or the autistic community in general. Furthermore, these bloggers do not necessarily commit to a single writing style and, at times, they seem to move consciously from one writing style to another depending on their specific goal in a certain post. Thus, one blogger who uses her blog to talk about her experiences as an individual on the spectrum and a mother of children, also on the spectrum, describes her blogging as follows:

Sometimes, it's nice to blog in a more structured form where there is a clear beginning, middle and end to the whole piece. Those kinds are like essays, and they have their place in the blogging world, but then there's something to be said for the freestyle of writing that flows naturally from the writer as if you were having a conversation with them. It's a really authentic way to write, because readers can really feel they know you, and are a part of your everyday life, whereas essay type writing, while passionate, can be a bit colder.⁵⁷

Sonja (2015) claims that any type of first-person storytelling involves enactment of identity and, therefore, autobiographical stories play a role in shaping

⁵⁷ Shawna (2013). New Places & Trying New Things. *Thoughts of an Introverted Matriarch (Inner Aspie)*. April 1, 2013.

cultural meanings. Thus, blogs can challenge mainstream values whether postings are diary-like, personal reflections or manifestos. In all such cases, the bloggers can challenge NT world values, and vocalize alternative values through their use of the public sphere of an open blog.

Furthermore, writing style can vary according to the goals of the specific post or the writing style of the bloggers. The use of the blog space for their personal writings is reflected in their choices to share their personal experience, their choice of topics, and the dialogue with the readers and the followers, as one of the bloggers describes in the interview:

Sometimes I just share a story, but a lot of times I start with a story/experience and then use it to lead into a bigger topic, something I believe in or want to speak against. I like to make new connections that I haven't seen anyone suggest before. I also like to break down stereotypes.

Bloggers vary, too, in the amount of personal experiences they are willing to share with the readers, in focusing more on their personal lives or using more formal writing in an essay.

This fine line between the private and the public in their writings reveals a very interesting interplay: On one hand, the use of personal experiences can serve as a trigger to talk about wider issues with which many in the autistic community can relate; such as, discussion of the existence of multiple autisms. Avoidance of generalizations, too, is discussed. This is particularly important, as many persons in the autistic community oppose use of the tragedy model⁵⁸ and/or the biomedical approach both of which lead use of generalizations, and would rather emphasize the need to focus on the individual.

On the other hand, when they do write about their personal experiences, bloggers in this study tend to avoid exposing too many details; rather they share

⁵⁸ See discussion later in this chapter.

personal experiences as launching points to discuss an important topic. We see this finding reflected in one of the blogger's response to my question about writing style:

In the sense that I am sometimes writing about my life and things that happen in my life. I am sometimes writing about myself, in the sense that I am sometimes writing about the barriers I face. I am writing about society using myself as a lens, which is sort of like writing about myself. I use my own experiences as a launching point for broader theoretical issues more than I write only about myself. That is, I write about myself, but I generally do so in order to illustrate issues and points that are broader than myself. I'm mixing memoir and theory, in a sense, because ignoring genre rules I don't like is fun!

The tendency not to share too much personal experience may well be rooted in what Sinclair (2005) coined the “self-narrating zoo exhibit”. Here, his specific reference is to the role autistic participants are expected to play in NT-centered autism forums and conferences. For example, individuals on the spectrum who participated in an early forum of parents perceived that they were expected to provide information for use by other participants, but at the same time they were underappreciated (Sinclair, 2005). Shelli (2007)⁵⁹ describes an incident in which a father offered to collect and publish autobiographies written by autistic people in order to help parents understand their children. In response, Sinclair felt that autistic people are underappreciated and expected to participate in conversations only when they are invited by the parents and only in regard to matters that reflect their personal experiences. More directly, Sinclair argued that autistic people are not expected to initiate discussions or communicate with each other in the listserv. Rather, for the parents, their role is to respond and provide information upon request like a ‘self-narrating zoo exhibit’.

Similarly, another blogger referred to her own experience with a parent group in her blog as follows:

⁵⁹ Shelli, S. (2007). Snore, Pizza, and One Moment of Insanity. *Somewhere Over the Rainbow*, October 3, 2007.

*We are Universal Translators - they assume that what we think might be going on is now exactly what is going on, even if it really isn't. This falls under "walking zoo exhibit", which is the one where people think our sole purpose is explaining our strangeness to the world, often to help translate their children's strangeness. We do have lives, and we are not the same people as your children. We have similar problems.*⁶⁰

In summary, although some of the bloggers talk about their blogs and the act of writing as important for them, in order to process experiences or identity related issues, they do not see the blog as their personal diary. The choice of topics for the blog posts can be derived from personal experiences, issues for which they are passionate and desire to inform the public, special events or even news stories that triggered their writing. The bloggers write about their families, about growing up undiagnosed (for those who were diagnosed late), about their neurology, how they experience the world and more social change driven topics as autism acceptance and autism rights.

6.1.3. Self-Reflexivity

The personal space of the blog, which puts the blogger and the act of blogging in the center itself, reveals the bloggers' perception of the structural features of virtual space, and are especially relevant to understanding the important phenomenon of self-reflexivity. Blogs present relatively new forms of self-reflexive digital storytelling and share some common features to other forms of digital autobiographies (Sonja, 2015). The main distinction between blogs and other forms of self-reflexive narratives is "their episodic, organically unfolding nature, affording representation of fluid and complex identities" (Sonja, 2015, p. 35). Thus, these structural features foster self-reflexivity and facilitate the identity construction process. This is evident in blogger comments about the Internet or on writing itself (Serfaty, 2004). Thus, the opportunity and capability to choose to communicate

⁶⁰ Hillary, A. (2013). Politics of Parent-Run Autism Groups. *Yes, That Too*. Retrieved from <http://yesthattoo.blogspot.sg/search/label/Autistic%20Space>

through the blog, as perhaps their most convenient communication channel, is important for and manifest by individuals on the spectrum in numerous important ways (Brownlow, 2010; Brownlow and O'Dell, 2013; Davidson, 2008; Davidson and Henderson, 2010; Dekker, 1999; Kras, 2010; Kreck, 2013; Ortega, 2009).

Blogging and Autistic Space

As stated above, blogs provide a space for self-presentation and self-exploration. Bloggers can focus on their personal memories and use digital storytelling to explore their own personal autistic identity or promote autism acceptance. The blog can be open to the public or accessed only through invitations. Furthermore, the blogger can invite dialogue with followers or block intruders.

Schmidt (2007) claims that although bloggers encourage interpersonal communication with the readers, they “do not necessarily entail instantaneous replies” (p. 1412). Indeed, bloggers can control content and communicative settings. As such, bloggers can act as if the blog is a “protected space” (Ibid).

The perception of ‘space’ and of the blog as a ‘safe (personal) space’ is multifaceted, as revealed in the interviews, and so too the steps bloggers take to make the blog a safer space. Autistic space prioritizes and adapts the blog environment according to the variety of autistic needs. A blogger can propose and define codes of behavior that are presented to the blog readers/followers and/or use technical features embedded in blog software to control the space. The decision of whether or not to use these features or to announce about the right bloggers have to do so is left to the blogger.

For example, in addition to the previously discussed formal features, such as blog design and content, some platforms provide tools that can affect the potential dialogue with the readers. These features give the blogger various options, as s/he can choose whether or not to allow comments to be published automatically, to block them until they receive blogger approval or to be deleted if s/he deems content or the tone of the comment to be offensive or irrelevant. Indeed, through the interviews I learned that bloggers do utilize these tools to secure a safe space. Thus, the number

of comments visible to the reader does not necessarily reflect the full set of comments / questions / requests sent to the blogger.

In addition to technical features, the blogger can explicitly define codes of behavior that are expected from the commenter in order to provide the appropriate space for discussions. Schmidt (2007) refers to these codes as informal rules that constitute ‘blog etiquette’ that are often not stated explicitly but may be used in cases of conflicts. The bloggers in this research study are frequently more explicit in expressing such rules. As noted above, such actions are related to the perception of the blog as a safe space or as autistic space. For example, though bloggers invite people to comment and often welcome the dialogue, many maintain their right to delete a comment or not publish it because it is offensive or disrespectful.

Some bloggers emphasized their expectations for civilized discussion, inviting people to comment on the posts and even encouraging arguing as long as the discussion is respectful to the blogger, the topic, to autistic people as well to any other readers. In comments to readers, other participants emphasized that the blog is their personal space and they [the bloggers] are the ones to choose what and when to discuss specific topics. They also assert that they retain their right to decide if a comment is disrespectful, includes ableism⁶¹ or a threat of violence, and act upon it either by responding to the commenter or deleting the comment. Indeed, the importance of being in an inclusive space is a recurring theme cited by the bloggers; and, for some it seemed to be used as interchangeable with “autistic space”.

Returning to the theme of safety, as one of the interviewees commented, a space is considered safe if it is *“where you can be who you are without the expectations of society holding you back”*. In her blog, the blogger shares her personal journey as an Aspie and the struggle of people in her surroundings to deal with her official diagnosis. The blogger describes how autism is not a term used

⁶¹ Ableism is very central for some of the autistic activists and will be discussed later in the results section. According to the Merriam-Webster dictionary, ableism is defined as “discrimination or prejudice against individuals with disabilities”.

publicly in her immediate surrounding. It seems that what makes her blog safe, for her, is the fact that her family is unaware of her blog and it is the only place in which she can talk about autism and about her personal experiences as a young autistic woman. The autistic bloggers she met through the Internet add the sense of support for the blogger that, apparently, she needs and she describes the autistic bloggers she met virtually as her friends. The other bloggers come from around the world and she considers her blog as part of a community “*that is trying to help others understand us and also try and bring acceptance into the society*”.

The ability to be who you are without being judged by others in the social environment as well as the sense of belonging to a community of autistic bloggers is reflected in another blogger’s account of what makes her blog a safe space. According to the blogger, community support gave her the confidence to be open with what she writes. She says:

I have come to feel that my blog is a safe space because of the mutually supportive community of autistic bloggers that I have become a member of. There is a tangible sense of acceptance that instils confidence.

The ability to be who you are and receive support from other members of the community is very central to people in the autistic community; is closely related to ‘autistic space’, as defined by Sinclair (2010); and, more broadly, is fundamental to the evolution of the autistic culture. In essence, autistic space is run by and for autistic people.

Based on their personal experiences and those of other community members, autistic space is designed to accommodate as many needs as possible. A major part of these accommodations are the behavioral norms that help create supportive, non-threatening environments in self-maintained spaces, both in the virtual and physical environments. Thus, in blogs, the blog owner can express core values and set behavioral norms. These can be set out in clear, well-defined rules. As one blogger claimed in the interview, the intention in doing so is make a blog a safer space than other environments, especially since it articulates the blogger-creator-facilitator’s

expectations from the readers. According to this blogger, clear rules can refer to any aspect; from conversational norms to language used in discussions between the blogger and commenters.

Noteably, making the blog a safe space goes both ways – for the blogger and the readers. One of the bloggers implemented a method of ‘trigger warning’ in order to make the blog a safer space. Posted right under the post’s title, trigger warnings are applied to any content that might trigger retraumatization for some readers . But although a trigger warning can help foster the blog a safer space, it cannot cover all potential experiences, as one blogger wrote:

No matter how much work so-called radical folks might put into creating "safe" space, such as through avoiding scents/fragrances, banning flash photography, giving content notes and trigger warnings for a variety of commonly triggering content, intentionally not engaging in body or diet talk, avoiding microaggressions of any kind, and so forth, there is always a very real possibility (and it frequently happens) that someone will still experience a trigger or retraumatization because others simply didn't know and couldn't possibly have guessed (without knowing that person very well personally, which they might happen to not) that something specific would be triggering and retraumatizing.⁶²

Some bloggers interviewed do not consider the blog to be a safe space because it is open to the public. Regardless of their perception of the blog as unsafe space, they “*take risks in order to connect with others,*” as one of the bloggers articulated. A good example comes from a blogger who devoted his life to advocate for autistic and other disability rights. This blogger described, in the interview, how he decided that most aspects of his personal life will be open to the public, as part of his activism. He self-identifies in the blog through use of his real name; published the official document stating his diagnosis on the Internet; and, many of his blog posts include personal stories about him or his daughters (who, too, are on the

⁶² Brown, L. (2016). Disability Justice & Conference Space: Notes on Radical Access & Radical Inclusion. *Autistic Hoya*, October 25, 2016.

spectrum) in order to seek to advance a wider discussion regarding autism or human rights.

Notably, while this blogger discusses many sensitive topics in his blog posts and clearly defines his expectations regarding the codes of behavior in his personal space of the blog, he does not see his blog as a safe space. A safe space for him is detached from any other system and is one in which he can totally control the environment. Although (and maybe because) he knows programming and he manages an autistic community portal, the nature of social media and the Internet makes them unsafe for him. The question of closing the blog to the public is irrelevant to him since a closed blog will not make the blog a safer space for him, but it does not prevent him from sharing his personal experiences for the greater cause.

Dekker (1999) referred to the Internet's technological features and the non-hierarchically networked connections between nodes as a model for a society compatible with the autistic way of being. Although this same blogger agrees with the essence of what Dekker is saying about the autistic way of life and the contribution of the Internet to the autistic community, he defines the Internet as unsafe exactly because of the interconnectedness nature of the Internet. The more important factor for him is not that the space is objectively safe, but rather the *perception* of the space as safe. In his view, as the blog owner, his role is to provide a safe space in his blog. This requires that people know *who* is participating in the discussion, and that participants are people who self-identify themselves as autistic, ask themselves if they have connections to autism or come with compatible set of values.

Being a person-centered platform comes with the ability to control the environment. This is what makes blogs a safer space; as one where autistic bloggers can write, communicate, form cultural practices or create mutual links with other bloggers on the spectrum. Thus, what makes a place autistic is not the number of autistic people compared to NT people around or the elimination of NT people, it is

the fact that it is *run by and for autistic people*: they are running the space, they are identifying the needs and deciding how to meet the needs of the participating people.

Thus, notably, public blogs, such as those in the current study, are by nature ‘neuro-shared’ spaces (Bertilsson Rosqvist, Brownlow and O’Dell, 2013). The difference between neuro-shared spaces and neuro-separated spaces affects the discourse and the nature of the interaction with readers.

Bloggers in this study are very aware of the variance among their readers, citing that some are autistic, others could be NTs, yet others could be readers who wonder if they are on the spectrum. Furthermore, they realize that their blogs may help the latter in their quest for the autistic self, just as it may have helped them. Such an intermediate space, between the private and the public, is defined as ‘civic’ by Sonja (2015) who claims that the blog genre represents one type of “private in public” space. Use of autobiographical digital storytelling elements together with essays that discuss topics that are important to the bloggers embodies this type of tension between the private and the public. This tension is reflected in the bloggers’ emphasis on their blog as their personal space and the invitation to readers to visit and discuss while respecting the blog’s rules of behavior.

*On Blogging – “Blogs are Merely Windows on those Minds and Souls”*⁶³

*I may make it ‘identity and voice’ rather than just ‘voice’. I’m not sure. But voice is important.... if my voice is not used, it is all too easy to erase me from my own stories, and if no one admits we have voices, we might not use them. I have a voice. I will use it to tell my story, and I will use it to make sure the stories of those like me are heard.*⁶⁴

Here Hillary emphasizes the need to enable her and other autistic bloggers’ voices to be heard loud and clear. For her, the act of blogging is one important way

⁶³ Donna Williams blog, in response to a comment to one of her posts. March 31, 2008.

⁶⁴ Hillary, E. (2016) *Queer Autistic Voice. Yes, that Too*, August 26, 2013.

to do so. In the realm of the technological features and the possibilities provided in social media, blogs provide an arena in which the blogger is at the center of the stage, and so facilitates the self over social interaction.

Talking about the blogging process or the importance of blogging to the blogger is part of what Serfaty (2004) defines as self-reflexivity. Blogging is, for some bloggers, important as a means through which they can send a message to the world about autism. For others, blogging is a means to fulfil a need, as it helps them in their personal quest for the autistic self. Thus, blogging serves different functions for bloggers and this is reflected in their definitions of their blog's goals and through their writing about blogging in the posts. Thus, as a type of digital storytelling, blogging can serve to empower the blogger, process experiences or explore the self through the need to verbalize thoughts or phrase arguments about different topics related to autism.

The nature of autism and consequent focus on satisfaction of individual needs through blogging should not lead us to omit sociality. Rather, it is interesting and significant to see the consistency with which social interaction is adapted by autistic bloggers. For example, some bloggers related that finding other bloggers who share and describe similar experiences empowered them and provided them with a sense of belonging. Others shared that their initial motivation to open the blog was to help others learn about themselves and about autism through reading about the bloggers own experiences. Similarly, one blogger described her motivation to start blogging, in response to a question about her blogging goals:

My blog began as an online personal journey of sorts and quickly transformed to a place where I could help others understand what is FEELS like to be autistic. I still revert back to journaling type entries and just share my life with others, but there are over a 100 articles dedicated to answering questions about autism.

Most bloggers describe their blog as a space for them to explore and share their personal journey with their readers. The focus on personal journey was the initial motivation for most bloggers but their writing shifted and evolved to involve their addressing additional topics relevant to others as well.

The role writing plays is evident in some of the bloggers' responses. One blogger emphasizes writing as her need and blog writing as therapy. She says:

*I need to write, completely outside of anything medical. I thought about starting another blog, leaving this one, but the aspect of my identity that is tied up in autism, well, I don't believe that part is unhealthy, and I intend to use this platform to explore my life.*⁶⁵

The act of writing in and of itself can serve multiple functions and this blogger describes how writing helped her produce new ideas and process information. Other bloggers referred to writing as helping them understand themselves better through verbalizing emotions, describing difficult situations or reflecting on what would be the best thing to do in moments of meltdown or shutdown.

Although bloggers vary in their writing styles, all shared personal stories in their blogs. One blogger uses personal writing to write about different topics important to her. She discusses her emotions and analyses difficult situations. I found her writing to be very insightful. In describing her blogging process, she says:

I really find writing to be the way I best express myself, so I really like to just sit down with a certain subject on my mind, and let it flow out, and see where it takes me. I am quite passionate about disability rights, for example. The way my personal style might approach this subject is by telling my readers a personal story about my experiences with this topic, instead of listing facts, or writing open letters. The most important topics are the ones that I walk away from writing feeling like I know myself a little bit better, and perhaps gave my readers some points to think about.

The importance of writing is very evident for the youngest participant in the study, a 15-years old non-speaking individual on the spectrum, who maintains a blog, writes poetry and is very active in social media. Written language is very important to him as evident when he says: “*words establish worlds. Words help me in*

⁶⁵ Wayman, L. (2013). Is This Thing On? *Autistic Speaks*, May 12, 2013.

explaining my own world to myself". He learned the power and impact that words have on the environment when he was in pre-school, when he started to use Augmentative and Alternative Communication [AAC] to communicate independently with the environment. He started blogging when he was 9 years old. His blog was hosted in a portal dedicated to people with disabilities. The portal's administrator who saw his writings invited him to write in the portal about himself. The blogging experience was not easy for him, he says, because of the responsibility he felt towards the readers. But the act of writing the posts served an important role in his personal quest for the autistic self.

Siles (2011) talks about the importance of articulation as connecting between values, feelings, beliefs, practices and structures. Processes of articulation contribute to the 'sense of power' and as validation of the legitimacy of certain ways of thinking, being and acting in the world.

In describing her own quest for the autistic self after she was diagnosed in adulthood, Limburg (2016) distinguishes between the act of 'talking about' and the act of 'talking'. While 'talking about' is the separation from the selfhood, *'talking' "actually calls our narrative identities into being"* (Limburg, 2016, p. 149). The blogging process and experience combines 'talking about' and 'talking'. The act of talking is important in and of itself, but talking about ourselves separates the selfhood from the act of expressing it (Limburg, 2016). Here Limburg talks about the interplay between who we are and who we say we are in the identity construction process.

'Talking about' refers more to the public aspect of the open blogs. Similar to what Bertilsdotter-Rosqvist, Brownlow, and O'Dell (2013) say about neuro-shared spaces, the bloggers are very aware that the blog posts are open to non-autistic followers and their writing reflects their efforts to communicate their experiences to people off the spectrum comprehensibly. Thus, I found that 'talking about' is very evident in the tendency of bloggers in this study to use personal stories in order to discuss wider issues related to autism. Thus, they describe how they experience the world and the types of accommodations they need to feel less excluded. In doing so, these bloggers want people to know more about autism from autistic people.

They want people to learn about their needs and what needs to be addressed directly from them.

6.1.4. Co-Production: Negotiating Identity in the Blog's Space

Co-production is reflected in the dialogical nature and the potential for community creation (Serfaty, 2004). Community and interaction are not the first characteristics that come to mind with blogs. However, studies have shown that communities are formed around blogs or topics as well as between bloggers and followers (See Chin and Chignell, 2006; 2006a; 2007; Schmidt, 2007; Sun, 2010). On their own, blogs are not defined as virtual communities, like other platforms, though they can exhibit indicators of community through followers, mutual reference, linking patterns, etc. (Chin and Chignell, 2006a). Rather, the structural features of the blog, selected by the blogger, provide him/her with tools that can enable dialogue with followers or with fellow bloggers. Indications of co-production can be reflected in: use of hyperlinks in body of the posts, hosting guest bloggers and recommending other bloggers through the blogrolls.

One interviewee explicitly reflected on the aims of her own blog as part of a community that focuses on promoting awareness to the nature of autism, rather than the blog serving as a private space where she focuses on her experience and personal growth. She said:

A: I would say that it is part of a community. A community that is trying to help others understand us and also try and bring acceptance into the society.

Q: Can you please describe the community? Do you feel part of the international autistic community?

A: The online community has been very nice and receptive of my blog, and even make me feel that I have in some way contributed to advocating for us autistics. Since it is online, I do very much feel part of the international autistic community and some of my best friends in this community are from halfway around the globe.

All of the bloggers who participated in this research project maintain dialogue with the social world and seek to realize the potential to create a community around the blog or between bloggers. The technical means they use vary according

to bloggers' personal styles and tools provided by the hosting portal. Most of the bloggers use hyperlinks in posts in order to refer to specific texts, other bloggers as well as websites in their blogrolls.

The dialogical process with fellow bloggers takes place either directly through hosting other bloggers or indirectly through hyperlinks to the bloggers' sites or discussing a topic raised by another blogger. The dialogue with the readers mostly takes place through the comments. The bloggers vary in their involvement and some are more active than others in responding to comments.

Co-production can be reflected in the body of the text through the writing process or by hosting guests in posts through the use of interviews. The use of interview is an interesting feature of the dialogue; and though only three of the bloggers used interviews in their blogs, it is important to discuss, briefly, their contribution to the dialogical process. First, the interview is in itself a direct dialogue between the interviewer and the interviewee. Publishing the interview in the body of a single post, as dedicated to the interviewee's position, highlights the dialogue between interviewer and interviewee in dialogue with followers. Second, the blogger chooses whom to interview and topics discussed. The blogger's choices, too, reflect on the blogger's dialogue with the social world and with the readers.

One of the bloggers described the interviews as the most important of what she publishes in her blog, and an opportunity to inform non-autistic people about autism. She says:

My interviews are extremely important. People who know little about autism need to know that we're not all the same and can be very different from each other. There are also parents and professionals who are often around autistic people who do not realize how different we can be (they get stuck and very narrow-minded in the textbook definitions and DSM definitions they've bonded with).

Conceptually, Schmidt (2007) claims that the existence of the readers affects blogger identity management. The dialogical features of the blogs, noted above, are reflected in the bloggers' writing as well.

Boyd (2011) discusses the role of the audience in the evolution of networked publics. Audience is critical to context and an invisible audience can affect the adjustment, based on audience reaction/response. Turning to an imagined audience is a solution that helps assess potential reactions. Sonja (2015) talks about an “internalized imaginary public that storytellers consider themselves to be a part of or apart from” (Sonja, 2015, p.135). With an imaginary audience, the author refers to a mixture of “unknown, intimate and familiar [...] virtual publics” (ibid). This imaginary public can be an alternative ‘counter public’ or an ‘intimate public’ in which the first is a public composed of marginalized group that opposes the mainstream social world, and the second is characterized through shared experiences and worldviews (ibid).

Autistic identity negotiation with the social world is reflected in the dialogical elements of the bloggers’ writing varies according to the bloggers’ goals and the specific blog content. Bloggers that focus more on social change and activism may address a combination of the ‘counter public’ and the ‘intimate public’ while others may aim their content to the non-autistic mainstream world as well.

By way of summary, this structural analysis of the blogs examined the ways bloggers design the personal space of the blog as an inclusive space that enables them to explore their autistic self. These blogs are characterized by heavy reliance on text and lean non-verbal cues. Gibbs, Ellison and Heino (2006) claim that reduced communication clues and asynchronous communication enable users to engage in “selective self-presentation”. This conclusion is also supported by Walther (2007).

Overall, then, the blogging practices analyzed enable bloggers to negotiate their autistic identity through sharing their experiences and using relational practices (Schmidt, 2007), such as the use of hyperlinks, hosting guest bloggers and through the interplay between the private and the public as reflected in their writing styles.

The next section examines the main constructs of the autistic identity that emerged from the blogs and interviews.

6.2. Autistic Identity

Autistic identity, as evolved from the blogs and the interviews with the bloggers, involves exploring the autistic self through asking questions about autism; about the role of autism in how bloggers experience the world; and about autistic identity as meaning creation.

An important part of self-reflection is related to the way the bloggers perceive the meaning of autism and of autistic identity to them. All the bloggers who participated in this study perceive autism as very central to their identity, as it affects who they are, how they experience the world and interact with others within it.

Unlike other health related conditions, the bloggers see autism as integral to their personhood and inseparable from the self. Indeed, their perception of autism as inherent to their identity was evident in the bloggers' responses in the interviews to questions regarding their self-perception. One blogger said: *“autism colors every exchange an autistic person has. There is no other person. There is just an autistic person viewing life through autistic eyes.”*

Another blogger said: *“I am autistic, it is a part of my body chemistry, what makes me ME and as such cannot be separated from self.”*

Similar to these responses, a third blogger emphasized autism as core part of her identity:

Autism is such a core part of who I am; it influences how I perceive the world through my senses and affects how I interact with people. There is no way I could separate the autistic part of my identity from everything else because then I would no longer be me.

Thus, we see that their autism always existed; regardless of their being officially or self-diagnosed. Autism colors their experiences, their information processing, their sensory processing, their communication and the way they interact with others.

The contribution of the blogs in exploring the autistic self is evident in the bloggers' writings and in their references to other blogger's writings. Such a discursive process allows them to process what autism means for them, their

experiences and their difficulties and the way they perceive the autistic self in a non-autistic world.

Not all of the bloggers talk directly about the discursive process in the quest for better understanding of their autistic selves and their experiences. Those who do refer to it, explicitly, point to the significant role it played in their personal quest. For example, one blogger described the important role the label of autism played in her personal journey:

Early on, I needed the word “autism” to give me access to readings that taught me about myself. I had such a lack of knowing who I was that I had to read external accounts to realize that, why, yes, I do have major sensory issues. I didn’t know until I read about common behavior that clued me in to the fact that I do those things and thus have a root cause of sensory dysregulation. Autism was a word that opened up the knowledge of who I had been and who I will be.⁶⁶

We can conceptualize the role of the discursive practice in identity construction through social theory. Giddens (1991) and Hall (1996) explained that the identity construction process can involve rearticulating the self and maintaining a coherent sense of self. Giddens (1991) claims that self-identity, as a coherent phenomenon and integrated sense of the self, can be maintained through autobiography and journal writing. Hall (1996) describes identification as a discursive practice through rearticulating the relationship between the subject and the discursive practices. Indeed, empirical studies to date confirm such theorizing, ground our understanding and illustrate that identity construction is a complex, dynamic process that involves ongoing self-reflection and negotiation with the social world (Bagatell, 2003, 2007, 2010; Brownlow, 2010; Charmaz, 1995).

Bagatell (2003; 2007; 2010) conducted one of the earliest sets of studies that explored the social construction of autistic identity. She defined identity as “the way a person understands and view himself, and is often viewed by others” (Holland et

⁶⁶ Wayman, L. (2014). Whoopsy-Daisy; I Forgot a Title. *Autistic Speaks*, September 7, 2014.

al., 1998, p. 68, cited by Bagatell, 2003, p. 6). Charmaz (1995) defines personal identity as “the way an individual defines, locates, and differentiates self from others” (Charmaz, 1995, p. 659). Both Charmaz and Bagatell use definitions that emphasize the ongoing nature of the process and identity construction as meaning-making. While Bagatell’s definition emphasizes identity as involving self-reflexivity and negotiation with the social world, Charmaz focuses on identity construction as separated from the environment.

Autistic identity, as revealed in analyses of the blogs and explained in the interviews with the bloggers, involves exploring the autistic self through asking questions about autism; about the role of autism in how they experience the world; and about autistic identity as creation of meaning. An important part of self-reflection is related to the way the bloggers perceive the meanings of autism, in general, and autistic identity to them. The following discussion of this process takes place via three key constructs: autism as difference, autistic identity & the NT World and-multiple identities.

6.2.1. *Autism as Difference*

The centrality of autism as difference to the autistic self is apparent in the bloggers’ responses to the question of what autistic identity means to them. For example, one interviewee defined autistic identity, saying: “*[It] is first and foremost an identity of difference. It is an identity of peculiarity. An identity of a different sense of existence.*”

Another interviewee defined autism as: “*[...] difference [...] sensory difference, perceptual difference, motoric difference and these result with different ways of expression. Now, the social skills issue that most professionals consider as fundamental are actually a result of all four components I mentioned earlier...*”

While these bloggers emphasize *difference* as central to their perception of autism, a third blogger defines autism as infrastructure in analysing the *difference* between what being autistic means and what autistic identity means to her:

[...] *there are two things: The first is the way I perceive what it is to be autistic; and the second is what is autistic identity. These are not the same things. Autistic identity is how I approach it, how I think about it, [how I] want to belong to... etc. and this is equivalent to feminine identity or Israeli identity or any cultural identity. Views and beliefs are also parts of the identity. It's like...you know... when you have a profile and [you need to write what is] your opinion about religion. So you can be atheistic, you can be part of a specific religion, you can be agnostic and so on. So all these are types of things that are 'think of' or 'think about'. Similarly, I can 'think of' or 'think about' the meaning of being autistic. But the infrastructure is the mechanisms through which we do these things! And this is autistic! That's why I said it is infrastructure: the way I perceive things, the way I think about them...*"

Identity-First Language: Case of Autism-Less: The integral part of autism in their personhood is reflected in the discursive practices the bloggers use and their choice of language to describe their autistic identity. One blogger uses a cake metaphor to describe her autistic self:

I always say it's like the flour in a cake. Once you've baked it, you can't go back and take the flour out. Even if you could magically do that, you wouldn't be left with a flourless cake. It wouldn't be a cake at all, and me with the autism removed would not be me. It would be someone else. You can bake a flourless cake, and there are autism-less people, but you've got to plan it that way from the very start.

This blogger's decision to use the term 'autism-less people' is no coincidence. In her blog, the blogger goes against the tendency to separate autism and personhood and emphasizes the cultural meaning of autism-first language. Like her, most of the bloggers in this study emphasize the significance of identity-first language (autistic person) in contrast with the use of person-first language (person with autism). One of the bloggers explains:

*Saying a person has autism may imply that the person is defective or that there is an inherent problem or sickness within the person. It also implies that autism can somehow be separated from the person".*⁶⁷

⁶⁷ Aspitude, (2009). *Autism-First Language*, March 9, 2009.

The cultural meanings attributed to the connection between language and identity as well as the ways they affect personal autistic identity are reflected in another blogger's discussions about the topic, in which she says:

In the same breath, I scoff at what I call "semantic battles".

Words are my connection to this world. They are so much more than just descriptors of what is... they actually shape what will be.

Yet, I care little whether you refer to me using person-first language (person with autism) or identity-first language (autistic person), because the choice of lexicon has no bearing on who I am.

Which is it, kid? How do I reconcile this?

I don't, yet, in theory. In practice, it is through words, through writing this, that I begin the process of reconciliation.

Perhaps therein lies my answer."⁶⁸

The cultural meaning of identity-first language has been discussed and debated within the autistic community (Sinclair, 2007)⁶⁹ and the Identity-First Autistic campaign website.⁷⁰ However, in the following citation, a blogger explains in insightful ways that this debate includes but extends far beyond the autistic community:

Using the term "differently abled" to refer to disabled people actually reinforces the idea that there is one normal way to be human -- that there is one normal way to move, one normal way to communicate, one normal way to sense, one normal way to feel, one normal way to learn, and one normal way to think. It does not perform its intended purpose of suggesting that all people are different and that this is okay. It suggests that only disabled people, who must now be called "differently abled" instead, are deviant or defective from this normal human model, and it suggests that there is in fact a correct or right way to be "able." It supports the false idea of the normal body/mind, which is what "differently abled" is supposed to undermine, and thus it fails in its supposed purpose."⁷¹

⁶⁸ Wayman, L. (2013). The Paradox of Words. *Autistic Speaks*, October 13, 2013.

⁶⁹ Sinclair, J. (2007). *Why I Dislike "Person First" Language*. Downloaded from <http://www.cafemom.com/journals/read/436505/>

⁷⁰ <http://www.identityfirstautistic.org/>

⁷¹ Brown, L. (2013). How "Differently Abled" Marginalizes Disabled People. *Autistic Hoya*, August 29, 2013.

Similar to claims raised by the bloggers regarding the place of neurological difference in their identity and the central place of the person-first versus identity-first debate within the autistic community, Charmaz (1995) argues that identity is inseparable from the body. However, Charmaz argument is different-in-kind, because she focuses on chronic illnesses and the different ways people handle the change from one type of self-perception prior to the illness and their post diagnosis self-perception.

The autistic identity construction process differs on two inherent levels: First, autism is a neurological condition. A person is born autistic and autism is perceived as inherent part of the blogger's identity. Ortega (2009; 2013) points out the centrality of the *cerebration* metaphor and uses the term 'neurological self-awareness' to identity issues and to describe the emergence of autistic culture. Second, and related to the first dimension, the connection between body and self is at the core of the ideological (and practical) difference between the tragic model of autism and the neurodiversity movement. Regardless of the difference, the definition of identity offered by Charmaz (1995) is open enough to help theorizing the autistic identity construction given the need to emphasize the autistic self with reference to the NT world and the emphasis on the great versatility among and within autistic people.

6.2.2. *Autistic Identity and the NT World*

The bloggers in this study refer to the NT world and to neurotypicality in various ways. Some bloggers describe their coping through learning NT behaviors or cues in order to adjust better. Bloggers who talk about adapting to the 'neurotypical ways' describe it as coming with great costs. In a dialogue with a commenter, a blogger describes how although she will never navigate the NT world the same way as a NT, she learned through experiences and memorization what is acceptable after she stopped trying to figure out the 'why's'.

Another way bloggers refer to the NT world was through discussing the autistic experience in comparison to NT privilege. An interesting example comes from a document entitled “Checklist of Neurotypical Privilege”⁷² initiated by one of the bloggers. This document was created in collaboration with followers of her blog. Inspired by a book published in 1988 that analyzed white privilege,⁷³ the blogger invited her followers to contribute their inputs to the document through commenting or adding to the checklist in the comments section. Each draft was posted in the blog and was based on earlier comments.⁷⁴ The blogger explains in the introduction that the reason the document was created comes from autistic persons’ experiences of exclusion, silencing and violence. She emphasizes that their document celebrates human diversity, where neurodiversity is not limited to autistic people and their use of neurotypicality acknowledges and celebrates “*that every individual is complex and unique*”.⁷⁵

However, another blogger challenges the NT perception of autistic personhood in our interview when discussing her autistic identity:

Autism is not detachable from me. Because so much of the dehumanization Autistic people face is grounded in the idea. It's a rejection of the idea that autism is negative – folks only seem to ever insist that we not let negative things define us, and insist that we use person-first language on negative things to distance ourselves from them. If autism isn't negative, no need to do that!

An interesting approach is taken by another blogger who refers to her autistic self through analysing the NT self, as defined through social roles. In opposing this

⁷² Bev (2009). Checklist of Neurotypical Privilege: New Draft. *Square 8*, August 8, 2009.

⁷³ In her post from August 8, 2009, Bev explains the genesis of the document: “Since its publication in 1988, Peggy McIntosh’s essay, *White Privilege: Unpacking the Invisible Knapsack*, has come to be seen as a standard tool for examining the often unacknowledged advantages conferred on the white majority. The article has since been adapted to reflect the advantages of many other majority groups, spawning lists of straight, thin, cisgender, class, (temporarily) able-bodied and other forms of privilege. As far as I know, the advantages of being neurotypical (having a neurology that roughly corresponds to societal expectations) have not previously been listed in a systematic way, with the goal of encouraging a similar analysis.”

⁷⁴ An earlier draft included a list of 275 privileges. The cited list is a later draft and included 50 items and more elaborated introduction to the document.

⁷⁵ Bev (2009). Checklist of Neurotypical Privilege: New Draft. *Square 8*, August 8, 2009.

idea, she claims that her *self* is not defined through her social roles - as a mother, married woman or professional - since her *self* was always there, long before she was married, became a mother and had a career. Rather, the self is defined through her actions. It is, therefore, dynamic, not static. Her self is the sum of her values, her goals and how she chooses to fit them into her life.

Another blogger approaches her autistic self as part of a wider journey towards self-acceptance, presented in one of her blog posts:

*Another part of liking ourselves is accepting parts of our autism that we might not like, but accepting that they're there, and not going away. Things like sensory issues, misunderstandings, and emotional regulation issues... When I stopped fighting some of my demons, and started learning to accommodate them, my life became so much smoother. I quit trying to change myself to fit into what I thought was 'normal' and what I thought had to. I learned that there was option B, which was accommodating my sensory issues, and realizing that I am okay, even with my differences. I am always going to hate loud parties, and hate my routine messed up. Those things are always going to drive to the edge, and possibly over of a meltdown. My emotions are not the enemy.*⁷⁶

The identity construction process in reference to the NT world is part of autistic persons negotiation with the social world, and involves two simultaneous processes: one, a '*looking inward*' *self-exploration* which involves relating to questions, such as: what do I do, what do I experience, how do I experience, how do I process. The other, '*looking outward*' to explore the autistic self through the NT world, via the question: How does the mainstream NT world perceive me?

In regard to these negotiation processes, Morioka, Ellison, and Brown, (2016) distinguish 'identity play', which refers to the exploration of the self, from 'identity work' which refers to identity reaffirmation process. Based on these authors claim, we can say that the reaffirmation process includes negotiations with the NT

⁷⁶ Shawna (2013). #Autism & Self-Acceptance. *Thoughts of an Introverted Matriarch*, May 1st, 2013.

social world, as well as with, autistic community values, perceptions and shared terminology.

Charmaz (1995) defines the concept of “identity goals” to describe the preferred identity. This concept “assumes that human beings create meanings and act purposefully as they interpret their experience and interact within the world” (Charmaz, 1995: p. 659).

Bertilsdotter Rosqvist, Brownlow and O’Dell (2013) argue that there is no such thing as one autistic identity. Instead, they claim that “identity is multiple and that identities are related to the spaces that we inhabit at any particular time” (p. 369).

Bagatelle (2003; 2007; 2010), as well, rejects the idea of one unified autistic identity that interconnects identities and ‘figured worlds’ in which meanings are developed as well as co-produced, and practices reproduced.

Bloggers interviewed referred to their multiple identities both explicitly and implicitly, both in their writings and the interviews. In discussing the importance of identity-first language to autistic identity, many explain how autism is integral to their identity through referring to other identities as - - gender identity, ethnic identity, or religion related identity. In response to a question about the identity-first vs. person-first debate, one blogger explains her view:

Autistic people have an invisible disability—it is not physical and readily seen. Yet autism colors every exchange an autistic person has. There is no other person. There is just an autistic person viewing life through autistic eyes. The way of thinking and interpreting is so different, yet person-first language largely ignores that. Person-first language almost suggests that an autistic person should be like everyone else as much as possible before being autistic: impossible.

Now, let’s say an autistic person who identifies with neurodiversity is a painter or a singer. Maybe they want to be known as a painter or a singer and not an autistic painter or an autistic singer. Painting and singing might be their entire life and focus, even if they’re autistic. And they want to hold their own against other painters and singers. So perhaps they might just want to be noted as a painter or a singer in those instances. But when it comes to identity, they’ll identify as an autistic person and not a person with autism. Overall, there can be times when language orientation switches around a bit, even for an autistic person.

Sinclair (2007) explains his dislike of person-first language through analyzing the use of language and equating autism with other defining characteristics of personal identities:

We talk about "male" and "female" people, and even about "men" and "women" and "boys" and "girls," not about "people with maleness" and "people with femaleness." We describe people's cultural and religious identifications in terms such as "Russian" or "Catholic," not as "person with Russianity" or "person with Catholicism."⁷⁷

Culture as a web of meanings (Geertz, 1974) and the cultural context, too, play significant roles in the identification process. For example, one of the interviewees explained the role played by autistic culture in the individual autistic identity construction process:

Culture is a tool that enables the individual to adapt to changes in the environment or to adapt to different environments.... Culture is meaning. It is meaning that differs from other types of meaning in the sense that it distinguishes between those who are part of the culture and those who aren't... I was born to the Israeli culture as someone who was born to an Israeli family. I was born to the autistic culture as a person that was born with autistic neurology.

Gil, Shoham, and Shelly, (2016) discuss the connection between cultural affiliation and individual identity as well as possible affiliation with multiple cultures. The authors emphasize the significant role of cultural affiliation to the autistic identity construction and claim that their cultural affiliation is context-dependent: in the context of the international autistic community they will be affiliated as a sub-culture of Israeli autistic individuals; and in Israel the autistic community is a subculture of the Israeli culture.

Although autism is dominant in bloggers' identities, some bloggers mention other aspects of their identities related to gender, religious affiliation, ethnicity,

⁷⁷ http://web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm

marital status, parenthood, self-advocacy or occupation that are no less dominant. Bagatell (2003, 2007) claims that people find themselves in multiple worlds in which multiple identities are constructed. However, identities are sometimes compatible and other times incompatible (Bagatell, 2003). An example of compatible identities comes from a blogger, who reflects on her quest for the autistic selfhood throughout the blog and explains her decision to expand the blog beyond the sole focus on autism:

I have been moving away from the term 'Aspie' for awhile, and am wanting to incorporate a broader theme to my writing. You might have noticed that I am blogging about recipes, and other topics in addition to autism lately.

I still want to be an autism blogger, but I am feeling a little stale only writing about autism related topics. I want to branch out, and pursue my other interests, and thoughts about life in general. I toyed with the idea of opening up another blog directed to my other interests, but I simply don't feel like I can keep up with more than one at this time. I am having trouble keeping up with just one, to be honest! As with most of us, my life is about more than just autism. My blog exists to be a sort of electronic journal that I share with thousands of people. :) I am sharing with all of you what it is like to be me, and what I think about life, and most of all what I create. When I post a recipe that might capture a different demographic those people get a little glimpse of the life of an autistic woman when they visit my blog. I see it as a win-win.”⁷⁸

Another blogger, who identifies herself as an autistic activist, and whose blog is dedicated to promoting social change, uses her blog to explain autism to others through her experiences; to present important aspects of the autistic experience; and share different autistic persons experiences through posting interviews with other individuals on the spectrum. She explains in my interview her decision to move away from autism activism:

⁷⁸ Shawna (2014). Inner Aspie is No More! *Thoughts of an Introverted Matriarch*, January 16, 2014.

Autism played a HUGE part in my identity for about 6 years. I had to do this so I could know myself inside and out. But here I am now in 2015 and though autism will always be the lens through which I see, I am fully capable of understanding how non-autistic people think and approach the world. Matter of fact, I can emulate it. I can run an inner program of “Non-Autistic” and navigate the world while overwriting my own “Autistic” approaches. Neither approach is right or wrong, but on this earth, I think I will have much more success running a “Non-Autistic” program to navigate and communicate with others in daily life.

Both bloggers cited here consider autism to be a major part of their identities, and describe how they embrace their autistic identity. The incompatibility described by the second blogger is situational. She moves on beyond autism because of the circumstances that make it difficult to fulfill other identity needs if she ‘comes out’ as autistic in certain situations. Davidson and Henderson (2010) define a strategy like hers as the ‘keeping safe’ repertoire. In this blogger’s case, she refrains from disclosing her autistic identity in the professional setting through a rationale that emphasizes the possible profound consequences it could have on her professional life.

Three main constructs of the identity construction process and autistic identity emerged from the analysis conducted in this study: autism diagnosis, normality and autistic agency. Both autistic diagnosis and normality are central to the process, and function as formative to the autistic identity. Autistic agency emerged in the study to be at the core of autistic identity. The discussion that follows examines each of these constructs.

6.3. Autism Diagnosis

Most of the bloggers in this study were diagnosed as adults, and many cited that receiving their diagnosis was a formative event as it provided an official title to

different aspects of their life experiences and had a positive influence on their self-perception.⁷⁹

*Having a name for this, seeing that it might all fit together, rather than being a large collection of independently weird traits, helped me make sense of my life and stop blaming myself and get on with the business of living.*⁸⁰

Many of the bloggers describe how they always knew they were different but did not know how and why. The diagnosis played a dual role in their quest for the autistic self: giving them a title that explains their experiences and at the same time it provided them with a sense of belonging, as one of the bloggers described saying diagnosis helped “*finding my tribe*”.

One of the interviewees describes at length his quest for the autistic self. He describes how he started with self-diagnosis and later went on through an official diagnosis procedure which, eventually, he did not feel the need to complete. The blogger describes how he always knew he is different from others but didn’t know why and looked for years for answers. The turning point for him was the autobiographical book written by Donna Williams,⁸¹ where she describes what she went through until she was officially diagnosed as autistic. In her book, Williams provided a list of autistic characteristics and the interviewee found her description to fit what he experienced. The book led him to look more for any material written by autistic people on the Internet and to start his own blog.

The role of autism diagnosis is significant in the quest for self-acceptance. Most of the bloggers in the study were diagnosed as adults, and some use part of the blog to process the meaning of their diagnosis and its’ impact on their lives. These

⁷⁹ It is important to emphasize again that the this study focuses on the identity construction process as reflected in the blogs and in-depth interviews. Not all the interviewees experienced diagnosis as a positive experience.

⁸⁰ Bev (2007). Giving Up. *Square 8*, September 1st, 2007.

⁸¹ Williams, D. (1992). *Nobody Nowhere: The Extraordinary Autobiography of an Autistic Girl*. Doubleday, London.

bloggers do not consider autism a disease and many of them declared that receiving the diagnosis was a ‘defining moment’ in their quest for identity and self-acceptance. The bloggers are aware of the fact that their perception of the autistic-self and the discovery as a “*big step towards understanding myself*” is very different from the common perceptions of autism and it plays a significant role in their identity construction.

In writing about the diagnosis day celebration in her blog, one of the bloggers says:

*I’ve been lucky: No one’s used the information about how my brain works to enforce tragedy on me. This does happen to autistic people (and other disabled people, let’s be real) but remember: autism isn’t actually to blame for that. The people enforcing tragedy are.*⁸²

Autism diagnosis, official or not, provides labelling and explanations of different behaviors and helps bloggers construct a more positive self-perception. The diagnosis is described, both, in some of the blogs as well as in some of the interviews as labelling something they always knew and leading eventually to some kind of sense of self-acceptance. Here a blogger describes diagnosis day as her second birthday:

*I have seen some autistic adults who were diagnosed as adults celebrating their diagnosis day as a sort of a second birthday. Well, this is my diagnosis day. One year ago, I got confirmation, officially, from a licensed professional, that what I’ve known/suspected for a long time really is the case. I actually am autistic.*⁸³

Hillary is not the only blogger that talks about diagnosis as a milestone in the quest for the autistic self. Other bloggers described diagnosis as some type of closure, an end of a quest to explain symptoms and behaviors that made them feel different from others or, in more extreme cases, a sequence of misdiagnoses. For these

⁸² Hillary, A. (2014). Diagnosis Day. Yes, that Too, April 26, 2014.

⁸³ Hillary A. (2013). Diagnosis Day. Yes, that Too. April 26, 2013.

bloggers, this closure led to the ‘birth of a new identity’ or a step towards self-acceptance.

Diagnosis as part of the social negotiation in autistic identity construction reflects core values of the autistic community through the debate about the validity of self-diagnosis and the potential consequences to the autistic community (Giles and Newbold, 2011). The autistic community evolved around people that were officially diagnosed as autistic together with people that were either self-diagnosed and others that are defined as cousins in the autistic community.⁸⁴

Brownlow (2010) studied negotiation of the label of autism among online discussion groups of parents and professionals, and other discussion groups of AS people. Her findings reveal that whereas AS people reject cure or normalizing, the label leads to an emphasis on ‘normalizing’ through therapy for parents and professionals. This study found diagnosis to play a formative role in identity construction in addition to the rejection of normalcy.

6.4. Autistic Agency

*A big part of what was going on was that nobody knew me. I’ve always defined myself mostly as my thoughts, which I’ve never found a way to express very well or accurately, except through writing. I’m still not sure how other people define the thing called “self” or if most people think about it much. Maybe it’s one of those things like eye contact and small talk, assumed not to need thinking about, I don’t know.*⁸⁵

Agency emerged from the blogs as the core construct of autistic identity as meaning and practice; central both in exploration of the autistic self and identity negotiation with the social world. Throughout the blogs, blogger-authors discuss conflicting perceptions of agency, many of which are embodied in social definitions

⁸⁴ A cousin could be a person with ADHD, a person that was diagnosed with Tourette syndrome or simply have ‘autistic traits’.

⁸⁵ Bev (2008). The Meaning of the Word. *Square 8*. February 21, 2008.

of normalcy and behavioral expectations that derive from the normal/abnormal dichotomy.

Although the bloggers discuss different aspects of agency in their blogs, very few refer to it as agency. Thus Brown is one of the extraordinary bloggers who defines agency on a page she dedicates in her blog to definitions of terms she uses frequently in her writing.⁸⁶ Agency, she explains, is for her “*the ability to make independent decisions and act in one’s own best interests.*” Brown’s definition of agency reflects the motto of autistic activists around the world and emphasizes autonomy and capability of individuals on the spectrum to make informed decision.

The motto “nothing about us without us” encapsulates the claim that individuals on the spectrum are capable of independent thought and should be an active, integral participant on any level of decisions relevant to their lives. The main argument behind this demand is that many autistic people can express their needs and their experiences and if they are less capable, one needs to try to listen to the people involved or learn from other autistic people about their experiences and their needs. Furthermore, many activists argue that inclusion of autistic people in decision-making will lead to better accommodation and better inclusion of autistic people in all aspects of social life.⁸⁷

Autistic activists claim that any decision made about individuals on the spectrum needs to evolve from partnership with the autistic people themselves and should be practiced at any level - be it in designing policy, intervention plans or at the individual level. These deeper meanings of this motto is rooted in the

⁸⁶ Autistic Hoya

⁸⁷ Activist movements, such as ASAN (Autistic Self-Advocacy Network), claim that participation of individuals from the community should be empowered to control their lives. Activists from the organization emphasize the importance of self-representation. They claim that professionals and policy makers should learn from their experiences about rights, accommodations and inclusion.

conceptualization of agency and related to autistic identity both on the individual level and on the communal level.

Ahearn (2001) claims that any definition of the term ‘agency’ affects the perception of concepts like personhood, causality, actions and intentions. According to the author, agency needs to be examined within social, cultural and political contexts. One of the approaches to agency refers to this position as an expression of “free will” (Ahearn, 2001).

Scholars and philosophers that define agency as free will assume that it involves mental states of intentions, presence of the self, intentional control, motivations and responsibility (Ahearn, 2011). Gomm (2009) defines agency as the perception that “someone is the origin of his or her own actions because he or she is able to make genuine choices” (Gomm, 2009, p. 8).

Similar to other neurological conditions, the medical model of autism separates the self from the neurological condition (Weiner, 2011). In contrast, the bloggers who participated in this study emphasize the connection between them.

Nolan and McBride (2015) refer to the normative ideal of the ‘lived body’ as a semiotic site of struggle between the deficit-driven of the *tragedy model* and the counter-narratives of neurodiversity (Nolan and McBride, 2015, p. 1069). The *tragedy model* tends to separate the neurological condition from personhood, to perceive patients as blameless for their condition and therefore not in a position to take an active role in interventions and treatments. This stands in contrast to the bloggers in this study who argue against such a perspective, and embrace their neurology. In fact, they claim that the separation between the neurology and the self in the *tragedy model* leads to abandonment of any ascription of self-conscious or intentional behavior to individuals on the spectrum.

One blogger articulates this position clearly in her blog in response to a journalist who wrote the following about autism in her column:

[...] any person, autistic or not, is a world of its’ own. But because of difficulties in communication and because of fundamental differences in the innate experiences, it is very difficult to penetrate to the [personal] world of an autistic person. It is hard for people that assume the existence of this inner world and try very hard to learn and to

*listen; it is impossible to do if to begin with one does not assume the existence of this inner world or ignore it based on pseudo-scientific arguments.*⁸⁸

If this is the case, then the question is not about the existence of agency among autistic people but, rather, what is the meaning of agency for the bloggers and what is its' role in their self-perception and their autistic identity?

Another mental state the 'free will' approach assumes regarding agency is 'presence of self'. This mental state is very dominant in the blogs and manifest implicitly or explicitly in discussions about self-awareness, mindfulness and communication styles. Similar to Ahearn (2001), who criticizes the 'free will' approach for neglecting the sociocultural aspects of agency, the bloggers interviewed refer to various aspects that connect individual and social aspects of agency.

One blogger, for example, analyzes the connection between self-awareness and social-awareness within his autistic self. Self-awareness is an ongoing evolving process that is related to the recognition of one's own limitations. Social awareness is related to the position of an individual in the social structure, the social roles that result from it and interactions with surrounding people. This blogger opposes the assumption held by many autism researchers, who act through the biomedical approach, that the lack of social awareness among individuals on the spectrum indicates their self-awareness is also deficient. In his case, he claims, social awareness is low and disconnected from his self-awareness. On the other hand, because he lacks the intuitive mechanism of social awareness, his self-awareness is highly developed and his actions are characterized with 'intentional control'.

'Intentional control' is another state mentioned by Ahearn (2001) as part of the 'free will' approach to agency. Giddens (1991) claims that reflexivity to the self includes "observation of bodily experience" (Giddens, 1991, p. 77). Such reflexivity

⁸⁸ Shelly (2007). Associations on a Parrot: A comment to Neri Livne's Column in Ha'aretz Newspaper.

Somewhere Over the Rainbow, July 26 2007.

includes, according to Giddens, awareness to bodily actions like breathing, as in “how am I breathing?” (p. 77). The blogger’s description of his self-awareness refers to what Giddens described, as his self-awareness includes reflexivity of any bodily actions like taking a cup off the table or walking.

Awareness of the body also includes conscious monitoring of sensory input from the environment. Many of the bloggers talk about their sensory processing and the difficulties they face. One interviewee describes his tremendous sensory sensitivity⁸⁹ and how it affects the way he experiences the world:

A: Autism is a particle in my cosmic definition.

.....

Q: Tell me about the autistic particle.

A: The autistic particle is my sensitivity particle.

Q: Does the autistic particle affect the way you perceive the world?

A: Off course! I feel sensory and emotional pain!

Q: Do you mean that the emphasis is on the physiological aspect?

A: It is the origin. I totally live on a knife-edge⁹⁰.

Q: What do you mean by that?

A: As I live my life, I am the lamb, the sacrificial offering, I am Isaac, I am Abraham.

Another misconception about the ‘presence of self’ among individuals on the spectrum is manifest in the gap between the perception of the self as present (or absent) and communication styles. Autistic people are characterized by communication difficulties or different communication styles, as many in the autistic community refer to it. This view can be attributed, too, to the dominant biomedical approach which characterizes communication deficiencies as one of the two defiant

⁸⁹ In the long hours we spent talking, I witnessed his sensory sensitivities. One incident was especially insightful into his great sensitivity: We were at a café, with his mother and grandmother, conducting the interview. Suddenly the interviewee started rocking and covering his ears, and only few seconds later the rest of us were able to hear an alarm siren from a nearby motorbike. The ability to hear the alarm before the rest of us and the degree of his sensitivity to the noise were evident from his responses. Every sensory stimulation, such as the bike alarm, is very intense for the interviewee and accompanied by physical pain.

⁹⁰ The interviewee used a connotation taken from the bible. When I asked him to explain the term ‘knife-edge’ and for his help in translating it from Hebrew into English, he responded: on the edge of Ma’akhélet, knife for sacrificial slaughtering, mentioned in the story of The Sacrifice of Isaac in the Bible’s book of Genesis Chapter 22.

problems autistic people face across the spectrum. Common stereotypes of autistic people refer to them as ‘trapped in their own world’ or describe them as living in a ‘bubble’.

In contrast, the bloggers in this study oppose such misconceptions, claiming that a variety of types of communication exist that extend beyond the spoken/written language as communication tools (also Seidmann and Pang, 2013). One blogger explains the misconceptions about autistic communication as follows:

Every. Single. Person... can communicate. There are absolutely no prerequisites a person must meet to be ready to communicate with those around him.

This comes down to presuming competence. I have met too many autistic adults to keep count who were assumed to lack intelligence and have no ability to communicate for years, and sometimes decades. Their minds are fully intact, and they yearn for a way to show what they know.

For some, autism is not so much a difference in cognitive experience as it is a motor impairment. For these individuals, their brilliant minds take everything in... but their bodies do not obey their minds, so they do not have a means of showing us what they know.⁹¹

This blogger’s explanation emphasizes the versatility among autistic people and the need to observe and be open, not to the question of WHY a person communicates differently (or assume non-communication), but rather to focus on the possible ways an individual DOES communicate. For example, Baggs (2007), in her highly viewed YouTube video *In My Language*,⁹² exposes the viewer to different ways to communicate with the environment. Her natural way to communicate, she claims, is considered as non-language by the NT mainstream world, and non-language leads to the definition of non-personhood for individuals like her.

Sonja (2015), in discussing digital storytelling, focuses on the connection between subjectivity and agency, and use of these notions. She asks: “Who, for

⁹¹ Wayman, 2014. Buts and Rebutts. *Autistic Speaks*, June, 19, 2014

⁹² <https://www.youtube.com/watch?v=JnylM1hl2jc>

example, gets to become subjects, and what becomes of those excluded from such constructions?” (Nicholson, 1995: p. 5, cited by Sonja, 2015: p. 48).

Returning to Baggs’s arguments, the perception of ‘non-language’ as ‘non-communication’ excludes people like her from the mainstream NT world and denies the existence of autistic agency. Mead (1938) differentiates between the “Me” and the “I” in his analysis of the self and claims that the “I” is the internal experience of the self “and exists prior to language” (Hitlin and Elder, 2007, p. 178). Mead’s definition of the “I” makes the ‘non-language’ described by Baggs and different types of communication as valid parts of the self.

These bloggers’ arguments reflect different constructs of autistic agency and the challenges that NT perceptions pose to their understanding of personhood, autistic self-awareness and the autistic self. These arguments lead to the socio-cultural dimension of agency that reflects the negotiation of the autistic self with the social world. Giddens (1991) connects between the socio-cultural processes of agency and between the bodily presentations of the individual.

Stimming: An Insightful Case Study: The concept of ‘stimming’ emerged from the data as central to the blogger’s perception of autistic agency, as it challenges NT behavioral norms. Forshaw (2013) captured the essence of this claim in the title of her essay “I Stim, Therefore I am”,⁹³ as does Hillary (2014) in the following statement:

*When I stim openly, in public (as I will also do, this Autistic Pride Day), that is an expression of my pride, that I am proud of who I am.*⁹⁴

The term ‘stimming’ refers to repetitive self-stimulation behaviors that are perceived to be uncontrolled and abnormal by professionals and NT viewers. Indeed, the diagnostic criteria for autism as published in the latest version of DSM-5 include

⁹³ Forshaw, A. (2013). I Stim, Therefore I Am”. Married, with Asperger’s. October 14, 2013.

⁹⁴-Hillary, A. (2014). Failure. *Yes, that Too*, June 18, 2014.

repetitive patterns of behavior as part of what characterizes individuals on the spectrum. According to the DSM-5, frequent appearance of the repetitive behavior interferes with functioning in variety of contexts and should be taken into account in classification of a person as high or low functioning.

The connection between the body and the sense of self is discussed pervasively by the bloggers. They explain their sensory processing and talk about physical difficulties in different situations. Social theorists argue that conceptualizations of agency reflect assumptions about “personhood, causality, action and intention” (Ahearn, 2001, p. 112).

Giddens (1991) positions agency at the intersection of the self and others claiming that agency is at one and the same time dependent on personal control over the body and others’ perceptions of the individual as a competent agent. Furthermore, control over the body is central to agentive self-perception as one is expected to have bodily control, as Giddens (1991: p. 56) observed:

Routine control of the body is integral to the very nature both of agency and of being accepted (trusted) by others as competent.” (Giddens, 1991, 57). “Lapses in bodily control” should be avoided or “... signal to others by gestures or exclamations that there is nothing ‘wrong’ if such events should occur” (ibid, p. 56).

The deficit driven language of the medical model affects the perception of agency among individuals on the spectrum, and many of the bloggers describe how attempts to normalize them include interventions aimed to eliminate behaviors considered lapses of bodily control. ‘Stimming’ is an example of behaviors that may be interpreted as “lapses” that affect the perception of autistic people as agents. Treatments originated from the biomedical approach that aim to normalize autistic behaviors strongly discourage stimming-related behaviors.

Many of the bloggers claim that these social expectations of normative behavior are embedded in cultural assumptions about normality and they challenge these expectations:

Society judges your actions. It needn’t even be a majority verdict to cause shame. But if it is so negative — harmful in some cases — to the individual what purpose does it serve? Presumably there is some benefit to society, to the population as a

*whole. A way to coerce, a punishment to force members of that society to conform. I know: I've felt ashamed of my differences at times, of the way I failed to fit in. Of flapping and other obvious stims. Hmm. That's a pretty big downside: making someone ashamed of harmless, natural behaviors just because it makes other people feel uncomfortable or embarrassed. Because shame doesn't care whether the act is deliberate or accidental, helpful or harmful, right or wrong.*⁹⁵

Although it may seem dysfunctional and uncontrolled to outsiders, and while many in the autistic community learned ways to hide them so as to 'appear normal', they advocate against treatments that aim to eliminate stimming. Stimming, one blogger claims, is not unique to individuals on the spectrum and can be observed among NT people. In a post about stimming she describes:

*Chirping, rocking, tapping, facial contortions, growling, pacing, odd finger movements. These are so much worse than the things "normal" people do like throat clearing, jangling keys and that lovely sound some people like to make with chewing gum.*⁹⁶

Researchers have concluded that self-stimulating behaviors serve important functions of self-regulation for autistic people, and any attempt to eliminate these behaviors will cause more harm than good (Amundson, 2000; Seidmann and Pang, 2013; Sinclair, 1993; Sinclair, 2010). The bloggers talk about stimming. They talk about the type of behaviors they practice when they stim, about the different functions of stimming, and about the reactions of NT's to stimming behaviors. While, on the one hand, what the NT deficit-driven language refers to as rigid repetitive behaviors, which they try to eliminate, bloggers describe as functional. In the bloggers' view, self-stimulation behaviors help regulate emotions, sensory stimulations, social situations and even aid concentration, at school for example. Attempts like these reflects the NT tendency to see stimming as rigid and random, claims one of the bloggers, as she says:

⁹⁵ Forshaw, A. (2013). Why I Feel Ashamed? *Married, with Asperger's*. September, 17, 2013.

⁹⁶ Bev (2007). Eight Things I Do that are Getting on Some Peoples Nerves. *Square 8*, May 17, 2007.

Oh yah, comments so far including folks saying "huh, never realized that" kinds of stuff about the sitting still and not stimming taking the energy we could use for learning. And needing to learn to understand our body language rather than assuming we have none or assuming it'll be like neurotypical body language.⁹⁷

Nolan and McBride (2015) claim that the dominance of the medical and institutional in the discursive process that construct the deficit-driven language is a semiotic process. Semiosis is defined as “the process of signification in language and literature”⁹⁸ or as “a process in which something functions as a sign to an organism”.⁹⁹ Within this framework, the bodily and sensory utterances of stimming can be treated as texts and each stim can function as cultural practice or a language. Thus, according to one of the bloggers, stimming is a type of language that differs from the familiar word-based communication. In a post dedicated to languages, the blogger explains:

Anyhow, the language with which I interact with my environment, mostly when alone, is yet another means of interpreting the world. You might know this language as “stimming.” I flap, I tap, I spin, I flick, I hum, I repeat, and I watch. This language is a means of communication (aha! Once again, communication = two way street, in which I perform an action to elicit a response from my environment and adjust my reaction accordingly) with my environment.¹⁰⁰

In focusing on sensory processing among autistic people, Nolan and McBride claim that social and institutional mechanisms affect the interpretation of sensory information and detach the person from the direct sensory experience as a source of knowledge. The tendency to pathologize direct sensory experience is according to the authors the “theft of embodied sensory experience represents a denial of their very being” (Nolan and McBride, 2015, p. 1073). The authors conceptualize stimming as “nonverbal complex semiosis that constitute sensory utterances of

⁹⁷ Hillary, A. (2014). "Live" Blog of My Presentation to the Five Project. *Yes, that Too*, November 23, 2014.

⁹⁸ Oxford Dictionary (<https://en.oxforddictionaries.com/definition/semiosis>)

⁹⁹ Merriam-Webster (<https://www.merriam-webster.com/dictionary/semiosis>)

¹⁰⁰ Wayman (2011). Midnight Musings: Language. *Autistic Speaks*, September 15, 2011.

autism” and claim that the body and the bodily sensory apparatus function simultaneously as the index and the sign system (Nolan and McBride, 2015, p. 1075).

Nolan and McBride do indeed take it a step further and talk about stimming as the ”language of autism”. NT discourse separates sensory knowledge from common practices used to express feelings, emotions and communicative utterances. In doing so, NT discourse does not acknowledge that utterances such as stimming are natural and normative to autistic people.

In comparison, Davidson (2008) uses the term ‘language games’ to describe the uses and activities around language that connect “communication with actual social and spatial project and circumstances.” (Davidson, 2008, p. 794). Such ”language games” play a significant role in the construction of the autistic cultural identity as well as the individual autistic identity. Whether one agrees with the meaning of the terms or debates them, *language games* do seem to play a role in the autistic self-identification. Furthermore, the concept shifts the focus from normative and deficit-driven discourse about communication to a more open view of communication that can include less traditional utterances.

Parallel to claiming that the NT approach to stimming is rooted in socio-cultural assumptions about normality, some bloggers talk about stimming as a cultural expression of the autistic culture. The cultural meaning of stimming emerges in bloggers discussions of NT assumptions about normal function and the expectation to eliminate behaviors that are considered to be abnormal or uncontrolled. One blogger dedicated a post to the value and functionality of stimming. In her post, she describes stimming as an expression of culture. She says:

It is always an occasion of joy to see another autistic person behaving autistically. It's like finding a long-lost family member in a foreign country, the instant sense of recognition and fellowship. More than that, it's a powerful affirmation of survival in a world determined to extinguish any hint of difference. I've had meaningful and

*wordless conversations in unexpected places which are among my happiest memories.*¹⁰¹

In summary, *stimming* challenges NT behavioral norms (Nolan and McBride, 2015). As accepted behavior, *stimming* is part of autistic culture and some bloggers encourage their followers to tell others about their *stimming* behaviors or to engage in collaborative projects to create separate blogs or websites dedicated to *stimming*. For example, a blogger wrote about a collaborative project initiated by another blogger and encouraged the followers from the spectrum to contribute examples from their experiences. This call produced 1721 comments, all dedicated to the list. In another project, one of the bloggers in this research project created a collaborative blog dedicated to *stimming* and invited people on the spectrum to submit their definitions of *stimming*. In addition to defining *stimming*, followers are invited to ask questions about *stimming*, ask advice about exchanging different types of *stimming* behaviors; to post music or lyrics they enjoy as they *stim*.

Discussion about the cultural meaning of *stimming* for the bloggers, which is also central to their perception of autistic agency, leads us to present third main construct that emerged from the blogs and interview: the concept of normality.

6.5. Normality

*...it was really a time for reflection on all that had happened and giving myself permission to drop my fierce determination to mimic the so called 'normality' of others. I realised it was ok for me to be open about the challenges I had, to talk about them, that it wasn't something shameful or dirty.*¹⁰²

Bloggers' stances in regard to *stimming* are deeply rooted in claims raised by the neurodiversity movement regarding NT assumptions about normality and cure. Fundamentally, autistic identity is constructed partly through challenging the NT

¹⁰¹ Bev (2007). The Stimming Life. *Square 8*, July 14, 2007.

¹⁰² Williams, D. (2007). The Dietary Wheelchair; Autism and Dietary Interventions. Donna Williams Blog, July 26 2007.

perception of normalcy, and adopting a proud, non-apologetic identity. In principle, the neurodiversity movement rejects the concept of normalcy as it reflects mainstream assumptions of right and wrong, normal versus pathological (Fenton and Krahn, 2007; Gannon 2007; Jaarsma and Welin 2012; Kapp, Gillespie-Lynch, Sherman and Hutman 2013; Orsini and Smith 2013; Ortega, 2009; Seidmann and Pang, 2013).

The biomedical approach defines autism as a disorder and the different interventions that originate from this approach put “normalizing” the autistic person as their main goal. As one of the bloggers said in one of his posts about these intervention methods:

*The bottom line is that [all treatment approaches] share the same goal: to maximize the autistic person’s potential, meaning bringing him to be as close as possible to the ‘normative person’.*¹⁰³

Although normality is discussed by some bloggers as part of their individual quest, while others focus more on activist writing and aim for a wider social change, normality emerges as one of the center pieces in identity negotiation, on both the individual and social levels. The bloggers talk about the social assumptions and expectations to follow the rules about ‘right’ and ‘wrong’ ‘appearances’ that are embedded in information as well as sensory processing, communication styles and codes of behaviors.

*I don’t think we realise how we replaced moralism with freedom then with the glass prison of voyeurism as normality. One is no longer allowed to be solitary or dislike attention without being pathologised for it, needing a kind of ‘doctor’s note’ to justify one’s DIFFERENTNESS in a world with an ever narrower bunch of accepted guidelines on what’s ‘normal’ which are the greatest social myth of our time.*¹⁰⁴

¹⁰³ Gil, R. (2008). The Social Approach to Treating Autism or the Social Approach to autism – A Dissonance? *Asparagus Soup Without Recipe*, July 4, 2008.

¹⁰⁴ Williams, D. (2007). Answering to a commenter to blog post: A New Refrigerator Mother? Mom, What’s in the Fridge? *Donna Williams blog*, January 19, 2007.

These bloggers perceive the expectations to adopt NT sets of skills as contradicting autistic nature and, accordingly, any attempt to ‘train’ them to adapt so-called normalized behavior damages them. Indeed, in discussing the ‘normalization’ process through skills training for autistic people, one blogger explained that doing so is like forcing cats to become dogs through the right training.

Another blogger posted a story told by his wife who defines herself as a ‘cousin’. In the posting, she presents similar experiences to the ones described by the blogger and makes a clear connection to the identity construction process. This narrative describes the life story of difference and normalization, “of a ‘square’ trying for years to become a ‘circle’”. The discovery of other ‘squares’ in the world helped the storyteller understand that the same characteristics that make her a ‘square’, in which she tried to hide, were exactly the ones that make her unique. By the time she arrived at this realization, many pieces from the square were ‘cut off’ and she could no longer be the square she used to be. The revelation of other ‘squares’ led the storyteller to go back to some of those characteristics she put aside in the past with the hope to one day re-discover her identity and belong to a world that accept everybody, regardless of their shape.

The normalization process discussed by the bloggers comes from the outside world through social pressure and intervention techniques, but also comes from within due to socialization. Many of the bloggers discuss the damage caused by the ‘normalization’ process and by the emphasis on “non-autistic appearance”. Wayman describes what eye contact and socializing ‘the normal way’ is experienced by her:

Why are those traits so sought-after that we destroy our kids to attain them? We tell them to force themselves to make eye contact, even if it means they can’t listen at the same time, and even if it’s painful. We tell them to “love what you love... just love it less,” quashing their passions and possibly their futures, since passions often lead to work for autistic people. We force them to socialize the “normal” way... no matter how grossly twisted normal socialization is in our society. We tell them that it’s better

*to fit in than with everyone else and wonder about your identity than it is to be who you are and love yourself for it.*¹⁰⁵

Normalcy is very central to the bloggers' perception of the self and as part of the social aspects of the autistic identity construction. From these perspectives, 'normal' is about rejection and acceptance, conflicting expectations and appearance versus 'the real me'. Expressions such as "acting normal", "appear normal" recurring bloggers' discussions about the social meaning of normality and the heavy price they need to pay for appearing "non-autistic". "Passing normal" means adopting some of NT mannerisms and hiding the autistic self.

Some bloggers learned how to hide their autistic traits but they all claim it's exhausting and comes with a great price, as one blogger wrote:

*Some people do, however, claim that it is possible to "recover" from Autism; these people are usually professionals who work with Autistic children and adults. Other people prefer to discuss "passing," in which an Autistic person has learned how to appear more non-Autistic, thus "passing" for normal. The concept of "recovery" generates more controversy than the concept of "passing".*¹⁰⁶

"Looking normal" means finding a way to look at someone's face so are to appear that they maintain eye contact. So, it's about avoiding movement that may appear unusual or uncontrolled to NT mainstream eyes. The expectation to "look normal" reflects the fear of 'otherness', as explained one of the interviewees:

[They] try to train me because they are afraid of the stereotype. That's the reason. [They] are simply afraid of the stereotype. [They are] afraid that the difference will show. Because once you see the difference, it leads to a stereotype and to a negative reaction.... Stereotype is the only thing I keep an eye contact with. Whenever I see a stereotype I look at it in the eyes and say: 'go away!'

¹⁰⁵ Wayman, L. (2014). Buts and Rebuts. *Autistic Speaks*, June 19, 2014.

¹⁰⁶ Brown L., Autism FAQ, *Autistic Hoya* .

Normativity v. normalcy: In discussing, further, the meaning of normality in autistic identity construction we need to distinguish between two related concepts: normalcy and normativity. *Normativity* refers to social codes of behavior; while *normalcy* refers to assumptions of what is considered to be normal behavior (i.e. what is normal communication; what is normal social interaction). The process of identity construction among the bloggers goes through observing and reflecting on what is right ('normal') for them as autistic individuals. Negotiation with the social world goes through negotiating with the NT world in parallel with negotiating with the social world of the autistic community. Some bloggers do it explicitly, others do it more implicitly.

One blogger who self-identifies as an autistic activist, in which she views blog openly as an arena for her activism and self-advocacy, clearly expresses her view about NT expectations regarding what is “the right behavior” and about “normality” as follows:

*You see, I'm one of those Bad Autistics who doesn't sit down and shut up when the non-autistic parents and "experts" and researchers are talking. I don't go along with what you're saying because you're asking me to be good and play nice. I won't be your token so you get to say you included "self-advocate perspectives" when what you really mean is having me there for photo-ops or a good, long self-narrating zoo exhibit session. I'll say what needs to be said and I'll do what needs to be done, and I'll do it on my own terms, thank you very much. Because when what you want is compliance and normalcy and passing all the time just so you won't have to stare my autism in the face, to hell with that.*¹⁰⁷

Another blogger who cares dearly about autistic activism and autistic people's rights, uses more personal writing styles and shares with the bloggers the process she went through in her quest for the autistic self. She writes about different aspects of autism through her experiences as an autistic adult and through the experiences of her children, two of whom are on the spectrum as well. She writes:

¹⁰⁷ Brown, L. (2013). Annoying. *Autistic Hoya*, January 25, 2013.

*I talk about these things like they're really not all that special, because in my life, they're not. In my eyes, my boys, and I are who we are. We are normal for us. We're not awesome. We're just us. I view autism, and other 'disabilities' ... as just another part of the human existence. We are just another person. Different is just another way of being... There is a certain quiet comfort with my family that others notice when they're around us. I think it's a cool confidence in owning who we are.*¹⁰⁸

Towards Conceptualizing Autistic Identity Processes

The main constructs of autistic identity that emerged from the blogs and which are central to the construction process are their diagnosis as autistic, the concept of agency and their complex relationships with the perception of normalcy. Swann and Bosson (2008) claim that identity guides actions and behaviors, and identity negotiation aims to achieve and maintain a stable sense of self. The authors identified three identity-related needs that may play in the identity negotiation process: agency (feelings of autonomy and competence); communication (feelings of belonging and interpersonal connectedness) and psychological coherence (feeling of regularity, predictability and control) (Swann and Bosson, 2008, p. 452). The constructs that emerged from the blogs and interviews embed these needs and play a significant role in the identity construction process.

Agency is central to autistic identity through embedding assumptions about normality, self-perceptions of agentic capacity (or self-efficacy) and the negotiation of identity with the social world. Self-efficacy includes the ability to estimate operative capabilities and affects behaviors, thought patterns and emotional reactions (Bandura, 1982). Psychological theories emphasize agency as competency and see the individual as the source of one's actions. Sociology sees agency as affected by social structures, social forces or culture (Gomm, 2009).

¹⁰⁸ Shawna, (2013). Inner #Aspie Celebrates '1000 Ausome Things' #Autismpositivity2013. *Thoughts of an Introverted Matriarch (Inner Aspie)*, April 30, 2013.

Hitlin and Elder (2007) reject the use of “agency” when there is a vague sense of human freedom and under-emphasis of the connection between agency and the “self”. Instead, the authors differentiate between four types of agency: existential, pragmatic, identity and life course. *Existential agency* emphasizes elements of free will as self-efficacy (belief in one’s capacity), which involves defying social dictates; *pragmatic agency* focuses on the ability to innovate in routines breakdown; *identity agency* refers to the personal autonomy and the ability to act according to social expectations; and *life course agency* is the ability to perform retrospective analysis of decisions made in the past (Hitlin and Elder, 2007, p. 171-176).

This typology of agencies offered by Hitlin and Elder (2007) can help explain important aspects of autistic agency and construction of the autistic self. For example, *existential agency* can explain the process of rejecting NT discourse based on assumptions of normality, as well as the alternative they adopt of “agency of difference”. “Identity agency” can explain bloggers’ discussions about the need to focus more on strengths and their perception of autonomy and autistic voice.

Communication as a category of needs that play a role in identity construction is reflected through two dimensions. Swan and Bosson (2008) refer to communication as a sense of belonging and interpersonal connectedness. The diagnosis emerged as playing the role that leads beyond labelling to the sense of belonging. Bloggers refer to this in terms of “finding their tribe”. The second dimension of *communication* is reflected in the relational practice of blogging (Schmidt, 2007) as reflected in the blog space and the use of codes to actively create that sense of belonging.

Complex relationships with normalcy embed in *psychological coherence* the need that plays a role in the identity construction process (Swan and Bosson, 2008). The bloggers talk about the need for regularity and control and challenge the NT perceptions of regularity and control through debating NT normalcy and reaffirming autistic difference.

CHAPTER 7

CONCLUSION

The need to adapt to the NT world involves emotional difficulties that result from perceiving the autistic self as wrong. I felt I needed to delete my autistic part and to suppress myself. This brings you to very difficult places of self-hatred. And then when I found out about ACI and the autistic community that created self-maintained environment that accommodates autistic needs, [only] then I understood that it is good and it's legitimate to be autistic... one can nurture and enrich this special place and I can develop myself ... understand myself and read what other autistic people wrote. I understand myself much better and it makes it easier for me (Markowitz, 2016).¹⁰⁹

The goal of this research project was to explore autistic identity among bloggers on the spectrum. The guiding research questions dealt with the following topics: the blog as personal space and use of the blog for identity construction; meaning of autistic identity for bloggers; and, the main constructs of autistic identity among individuals on the spectrum. The first part of this concluding chapter will discuss the key research findings, followed by citing limitations of this research project and potential future studies.

Prior to this discussion, we begin here by reminding ourselves of two key operative assumptions. First, our working assumption is that the identity construction process occurs simultaneously through an exploration of the self and negotiation with the social world. Anneke (2003) distinguishes between identity, identification and negotiation. While 'identity', she claims, refers to the natural development of identity (e.g., gender identity), 'identification' is the outcome of the identity construction process. The process part of this assumption is critical in the research reported here. For example, most of the bloggers were diagnosed as adults, following their living with undiagnosed autism conditions for a substantial period of time. Furthermore, among those diagnosed earlier, only one knew he was autistic since he was diagnosed

¹⁰⁹ Assaf Markowitz, radio show interview, December 2, 2016.

at age five. If we look at Anneke's definitions, those who were diagnosed late did not have the opportunity to go through the 'identity construction' process at an early stage.

Second, the label 'autistic' is for the bloggers part of the identification construction process. Here, too, Anneke's research (2003) is illuminating as her claims serve to explain a deeper process in identification that occurs as bloggers reject 'autism-as-disorder' (person-first language - person with autism) and embrace 'autism-as-difference'. Blogs, we learned in this study, play an important part in this process, as we see the bloggers explore their autistic self and negotiate meanings with the social worlds - both inwardly within the autistic community and outwardly with the NT world.

7.1. Key Findings

Identification Process

This study found that blogging practices facilitate identity management and self-presentation.¹¹⁰ The self-presentation of the bloggers (e.g., I am autistic), their beliefs and values (autism as difference, autism as inseparable from their identity and the way they view the world) and their personal history (writing about experiences or memories) are all part of the meaning-making process of identification.

The act of blogging as a communicative act allows the bloggers to process experiences and different aspects of their reality on the personal level as well as the social and cultural levels. Bloggers are very aware that their blogs are public, as reflected in their blog's goal and writings.

The bloggers talk about autism through their own experiences and use them as a platform to share their understanding of 'the bigger picture'. Their selective self-presentation is reflected in their choice of the amount of exposure. They do not try to generalize about all autistic people, and the way they write about their personal

¹¹⁰ See also Schmidt (2007).

experiences is affected by a wider shared value of individuals in the autistic community to avoid being a 'self-narrating zoo exhibit'. Indeed, the blog is a personal autistic space that allows the bloggers to construct their personal identity and the sense of belonging.

Blog Technologies Facilitate Identification

Key findings that emerged from the structural analysis of the blogs provided us with a view into the autistic space as well as the ways bloggers manage their identity and practice self-presentation.

Generally, we know that the Internet provides both tools and platforms that enable users to express themselves and create cultural texts (Jenkins, 2006; Jenkins, Ford and Green, 2013). The bloggers who participated in this study decided to rely, for the most part, on text-based communication. This can be explained by their specific communication styles and sociality, as the technological environment of the blog provides the bloggers with affordances of reduced cues and asynchronous communication that enable them to have more control over the communication process as well as the identification process.

Like Morioka, Ellison and Brown (2016), this study found that social media affordances play an important role in 'identity work' among individuals with disabilities. In particular, the research found that social affordances and a reduced cues environment facilitate communication of messages. The asynchronous communicative environment of the blog, the ability to edit their texts - without distractions of conversational flow and reduced non-verbal cues accommodate these autistic bloggers' communicative needs.

The bloggers use of shared terminologies and forms of self-identification is identifiable through acceptance or rejection of key terms related, for example, to identity-first language. Their use of idiosyncratic expressions is conveyed through the use of blogging practices that utilize social media affordances to create symbols and to use them for the creation of distinctive language (like Aspie, Autie or

stimming), shared values and ideas (such as, identity first language and ideas behind neurodiversity).

The role of the Internet in the evolution of autistic identity can be explained through the connection between technology and the user, which has potential implications for social change and emergence of social groups that have proven, in this study, to be capable of expressing their voice through the Internet.

While this research project focuses on individual autistic identity, this cannot be examined without referring to the broader socio-cultural processes in which autistic identity is embedded. Due to our specific focus on the use of blogs, we turn to the work of two communication theorists to gain a glimpse into the inter-relations between personal communication and social - cultural change.

Castells (2010) work is insightful for understanding how identities and the identification process evolve in networked society as sources of meaning and experiences for people. Castells claims that networked society is characterized by greater accessibility to information and other people. This accessibility leads to changes at individual, communal and societal levels. Autistic culture emphasizes the individual, yet cherishes the value of collective individualism, inclusion, celebration of neurodiversity and acceptance of all human beings. Autistic identity is a result of constructing positive perception of the self. Autistic identity is a result of an ongoing, dynamic and complex construction which involves, indeed is a product of, communicating with others, or what Jenkins refers to as *participatory culture*.

Participatory culture is the result of the connection between the technology of the Internet and the end-users. In participatory culture, users such as bloggers can produce content and take part in publicly negotiating their identity through creating and reaffirming shared values of the autistic 'speech community' (Carey, 1997). Carey provides the theoretical foundation to understand the connections between media technology and between social and cultural processes:

Such communities can be identified with the following characteristics: a body of acceptable utterances; a common terminology of motives, explanations, and accounts; a distinct if not idiosyncratic expressive style in speech, writing, and other modes of

communication; a special vocabulary including an argot; and a specific social focus. In each community there are norms of conduct, values, prestige ladders, and a common outlook toward life. Shared perspectives, in other words, arise through common communication channels [...]" (ibid, p. 135).

Carey's view can explain the connection between technology and the rise of the distinctive identity of autistic people. The blogs provide autistic bloggers with spaces to express themselves and to take an active role in the communication process through which they explore their autistic selves and negotiate their identity with the social world. Carey claims that media technologies are used in the creation of distinctive cultures for marginalized groups in society with shared ideology. Specialized media promote the distinctive identity through use of collective symbols that transcend space, time and culture. His definition of speech communities and the role of technology in their evolution provides the theoretical framework to explain the personal space of the blogs ("common communication channels") as cultural texts that contribute to the evolution of the autistic community as a speech community of a marginalized group. Such technological developments provided the infrastructure for the emergence of distinctive autistic identity.

Autistic Identity Construction

Three key findings emerged from textual analysis of the blogs and interviews that provide us with insight into the identity construction process. The bloggers construct their autistic self through exploring the autistic experience and identifying the main constructs of their identity. The constructs which emerged from the data analysis were diagnosis as a formative event, normalcy and agency.

Diagnosis

Diagnosis was identified as a formative event for most of the bloggers. Receiving the diagnosis played dual roles: it provided a title and explanations to their life experiences; and at the same time a sense of belonging. Many of the bloggers described diagnosis as a defining moment that for some bloggers initiated

quest for the autistic self and for others it labeled what they always knew and allowed them to gain self-acceptance.

Diagnosis plays big part in social negotiation and reflects core values of the autistic community. This is reflected in acceptance of self-diagnosed people to be community members together with others who share some of the symptoms (Cousins) who, too, are to be welcomed to the community.

Normalcy

Normalcy is central to negotiation of autistic identity in the social world, particularly as an expression of resistance as bloggers claim that the assumptions of normalcy reflect the deficiency-driven approach towards autism (n. b., see end of discussion of agency below). We recall that the attempt of the NT world to try to ‘normalize’ individuals on the spectrum, through teaching them how to imitate presumed normative behaviors, socialize their self-perception and send a message that normalcy is a goal in and of itself.

Sinclair (1993) talks about giving up shared meanings about normalcy and opening the door to new meanings that evolve. Morioka, Ellison and Brown (2016) distinguish between ‘identity play’ (identity exploration) and ‘identity work’ (identity reaffirmation). In the process of *identity work*, people use affordances of social networks that enable selective self-presentation and asynchronistic communication. The dialectic process in their negotiation with normalcy reflects both concepts: their discussions about autism as integral part of their identity is part of the process of ‘identity play’. Their rejection of the NT perception of normalcy, as reflected in their celebration of stimming as an important mechanism, is part of reaffirming the autistic identity (‘identity work’). Thus, blogging provides users the opportunity to refer to aspects of their identity through describing their experiences. In this way blogging enables individuals to negotiate and construct identities.

Agency

Agency was found to be fundamental to both autistic identity and its development. The concept of agency is a key factor in negotiating with the social world that leads to self-acceptance. Although very few of the bloggers refer directly to the concept of agency, they describe situations and needs that are relevant to the creation of the appropriate conditions that enable them to exercise their agency.

The results of the analysis conducted demonstrate that in order to enable autistic people to practice agency, some *necessary* conditions need to be fulfilled:

1. Acknowledging the possible existence of multiple agencies leads to change in perception of agency;
2. Creating appropriate accommodations that will enable them to exercise their agency;
3. Using technology to facilitate communication and enable self-expression.

Fulfillment of necessary conditions and creation of *sufficient* conditions may lead to a more flexible perception of normalcy, and change from perceiving autistic agency as non-existent or deficient to a valid type of ‘agency of difference’. An autistic culture that celebrates difference and neurodiversity will foster cultural norms and rituals that accommodate the specific needs of the individuals in the culture. In this process, the social worlds, both NT and non-NT, are central to the construction of a positive autistic identity, development of a sense of belonging as well as the confirmation bloggers receive from other individuals on the spectrum. This confirmation is achieved through reading other individuals’ accounts about their own experiences, difficulties and emotions, as well as through direct dialogue with their readers.

Agency Leading to Resistance: Branscombe, Shmitt and Harvey (1999) proposed the ‘rejection-identification model’ that can be used to explain the identity construction process of autistic identity as an identity of resistance. In their model, sense of rejection affects self-perception and can lead individuals to identify with specific groups that are stigmatized and marginalized.

The results of the study reported here indicate that individual autistic identities are constructed through a dialectical process that goes through rejection of fundamental assumptions about normalcy and agency, adoption of the perception of ‘autism as difference’ and acceptance of the autistic self. Self-acceptance involves adopting autism as an integral part of their autistic selves and involvement in cultural discourse among members in the autistic community.

Castells (2010) talks about identities as organizing meanings and presents a typology of three different communal identities that characterize the networked society. The data analysis reveals clear indications that autistic identity on the communal level is a type of Identity of Resistance, defined and explained by Castells as follows: *Identity of resistance* leads to the evolution of collective individualism that introduces a new ‘holistic philosophy of life’ (Castells, 2010). The very demand to shift NT discourse from ‘autism-as-disease’ to ‘autism-as-difference’, together with the characteristics of the networked society and the autistic communication styles, collectively, touch the core of the origins of the autistic identity.

7.2. Study Contributions

The study offers several contributions. First, as one of the initial research projects focusing on autistic bloggers, the study demonstrates that the blogosphere is underutilized as an arena for investigating autistic identity. Second, the use of communication theories is important in the study of autism as they offer explanations not provided by other disciplines. The main contribution of communication theories is in conceptualizing the role of the Internet in providing different forms of communication and specifically the role of blogs in shaping the autistic identity. Third, the concept of autistic space is central to members of the autistic communities around the world and the study of blogs as an example of a personal autistic space is understudied as well.

7.3. Limitations

The current study focused on blogs written by English and Hebrew speaking bloggers. The sample available was determined, and limited, by the extant number of blogs existing on the Internet, accessibilities and ethical considerations that derive from studying the specific population. The selection of 16 blogs as the research sample out of a list of 90 potential blogs found on the Internet was due to the following considerations.

The blogs included in the sample were public, and written by bloggers who identify as autistic, whose blog focuses on autism, and those who provided informed consent to participate in the study. The decision to include only formally approved blogs by owners was based on the participants' characteristics and need to address the sensitivities of the participants.

Since the blogs included in the study were public, it is possible to claim that I was not exposed to other voices of individuals on the spectrum who neither identify as autistic nor identify with the autistic community and culture. In addition, a second limitation is that the content available to me was limited in that it is accessible to NT readers. In contrast, I learned in the intensive interviews with the bloggers that community websites include forums and chatrooms that are only open to individuals on the spectrum. Furthermore, the topics and types of discourse in those spaces will not necessarily be discussed in a neuro-shared space such as an open public blog.

Third, though I recognize that dialogue with blog commenters is significant in identity negotiation with the social world, comments were not included in the sample and analysis. The decision to do so was based on the following ethical considerations, contributed by Brownlow and O'Dell (2002). These authors argue that there is an ethical need to achieve informed consent in studying messages published in forums of individuals on the spectrum. Such a process seemed to be methodologically difficult in my investigations as it would require tracking down commenters, some of whom are anonymous, while others participated in dialogue with the blogger in posts that are few years old.

7.4. Future Studies

Following up on the previous points, there are a number of other potential sources involved autistic bloggers identity negotiation with the social world worthy of future investigations. These include: direct dialogue between bloggers and commenters; use of hyperlinks to other bloggers, hosting guest bloggers and posting interviews with individuals on the spectrum in the blogs. For example, Seidmann, Pang and Jingyuan (2016) conducted a small-scale network analysis study that aimed to explore the creation of a community of autistic bloggers through blogrolls. In addition, future research studies will need to develop methodological tools capable of quantitative analyses of all the parameters discussed above in order to study further the negotiation process, for example.

The importance of autism diagnosis (formal or informal) to the construction of autistic identity, too, deserves more attention. Though some were diagnosed as children, most of the bloggers in the current study were diagnosed as adults. Late diagnosis may well have provided answers to bloggers that affected their self-perception. The impact of growing up knowing you are autistic versus discovering it in adulthood is a topic that occupies members of the autistic community and was discussed in one of the workshops I observed in one of the autistic conferences. Although the negotiation of autism label was studied by Brownlow (2010), the meaning of diagnosis in adulthood in comparison to early diagnosis, too, deserves further exploration.

REFERENCES

- Ahearn, L. M. (2001). Language and agency. *E-J Annual Review of Anthropology* 30, 109-137. Retrieved from <http://web.b.ebscohost.com.ezlibproxy1.ntu.edu.sg/ehost/pdfviewer/pdfviewer?vid=2&sid=ee09ad7a-890d-4807-8925-f3a1c863e94%40sessionmgr104&hid=129>
- Amichai-Hamburger, Y., & Barak, A. (2009). Internet and psychological well-being. In: Y. Amichai-Hamburger (Ed.), *Technology and Well-being* (pp. 34-76). Cambridge University Press.
- Amundson, R. (2000). Against normal function. *E-J Studies in History and Philosophy of Biological and Biomedical Sciences*, 31(1), 33–53. Retrieved from www.elsevier.com/locate/shpsc .
- Anastasiou D. & Kauffman, J. (2013). The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine and Philosophy*, 38, 441–459. doi:10.1093/jmp/jht026
- Anneke, J. (2003). Conceptualising identity and diversity: Overlaps, intersections, and processes. *Canadian Ethnic Studies Journal*, 35(3), 10-25. Retrieved from <http://eds.b.ebscohost.com/eds/>.
- Bagatell, N. (2003). *Constructing identities in social worlds: Stories of four adults with autism* (doctoral dissertation), University of Southern California, retrieved from ProQuest Dissertations Publishing, 3116662.
- Bagatell, N. (2007). Orchestrating voices: autism, identity and the power of discourse. *Disability & Society*, 22(4), 413-426. doi: 10.1080/09687590701337967
- Bagatell, N. (2010). From cure to community: transforming notions of autism. *Ethos*, 38(1), 33-55. doi: 10.1111/j.1548-1352.2009.01080.x.
- Bandura A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, 37(2), 122-147.
- Baron-Cohen, S. (2015). Neuroethics of neurodiversity. In: J. Clausen, & N. Levy (Eds.), *Handbook of neuroethics*. 1757-1763. doi: 10.1007/978-94-007-4707-4_150.
- Baron-Cohen, S., Ashwin, E. Ashwin, C., Tavassoli, T. & Bishmadev, C. (2009). Talent in autism: hyper-systemizing, hyper-attention to detail and sensory

- hypersensitivity. *Philosophical Transactions: Biological Sciences*, 364(1522), 1377-1383. Retrieved from <http://www.jstor.org/stable/40485909> .
- Bargh, J. A., & McKenna, Y.A. (2004). The internet and social life. *Annual Review of Psychology*, 55, 573-590. doi: 10.1146/annurev.psych.55.090902.141922.
- Beaumont, R., & Newcombe, P. (2006). Theory of mind and central coherence in adults with high-functioning autism or Asperger syndrome. *Autism*, 10(4), 365-382. doi: 10.1177/1362361306064416.
- Beckett, A.E. & Campbell, T. (2015). The social model of disability as an oppositional device, *Disability & Society*, 30:2, 270-283, doi: 10.1080/09687599.2014.999912.
- Benford, P., & Standen P.J., (2009). The internet: a comfortable communication medium for people with Asperger syndrome (AS) and high functioning autism (HFA)? *Journal of Assistive Technologies*, 3(2), 44 – 53. Permanent link to this document: <http://dx.doi.org/10.1108/17549450200900015>.
- Benford, P., & Standen P.J., (2011). The use of email-facilitated interviewing with higher functioning autistic people participating in a grounded theory study. *International Journal of Social Research Methodology*, 14(5), 353-368, doi: 10.1080/13645579.2010.534654.
- Benham, J.L. (2015). *Proud to be Autistic: Metaphorical Construction and Salience of Cultural and Personal Identity in #StopCombatingMe*. Minnesota State University, Mankato, retrieved from ProQuest Dissertations Publishing, 2015. 1594434.
- Berger, J. (2014). Dys-/disarticulation and disability. In: *The Disarticulate: Language, Disability and the Narrative of Modernity* (pp. 141-181). NYU Press. Retrieved from: <http://www.jstor.org/stable/j.ctt9qg6xh.8>.
- Bertilsdotter Rosqvist, H., Brownlow, C. & O'Dell, L. (2013). Mapping the social geographies of autism – online and off-line narratives of neuro-shared and separate spaces. *Disability & Society*, 28(3), 367-379, doi: 10.1080/09687599.2012.714257.
- Beuving, J. & de Vries, G. (2015). Theorizing society: grounded theory in naturalistic inquiry. In: *Doing Qualitative Research: The Craft of Naturalistic Inquiry* (47-63). Amsterdam University Press. Retrieved from: <http://www.jstor.org/stable/j.ctt130h8g7.8>.

- Bieger, R.S. (2006). *Autobiographical accounts of autism: Implications for instructional leaders*. The University of Alabama, ProQuest Dissertations Publishing, 2006. 3236796.
- Block, P. (2015). The emergent landscape of autistic communities and autistic studies. *Culture, Medicine and Psychiatry*, 39, 352-355. DOI 10.1007/s11013-015-9453-8
- Blume, H. (1997). "Autism & the Internet" or "it's the wiring, stupid". Retrieved from http://web.mit.edu/m-i-t/articles/index_blume.html.
- Boler, J.F. (1968). Agency. *Philosophy and Phenomenological Research*, 29(2), 165-181. Retrieved from: <http://www.jstor.org/stable/2105850> .
- Bonieli-Nissim, M., & Barak, A. (2008). The blog: a personal online diary in the service of counsellors and therapists. *Haye'utz Hachinuchi*, 15, 123-143.
- Bonieli-Nissim, M., & Barak, A. (2012). The Internet to the aid of lonely adolescents: The therapeutic value of blog writing. *Mifgash Le'Avoda Socialit Chinuchit*, 34, 9-30.
- Booth, R., Charlton, R., Hughes, C. & Happe, F. (2003). Disentangling weak coherence and executive dysfunction: planning drawing in autism and attention-deficit disorder. *Philosophical Transactions: Biological Sciences*, 358(1430), 387-392. Retrieved from: <http://www.jstor.org/stable/3558150?origin=JSTOR-pdf> .
- Boucher, J. (2012). Putting theory of mind in its place: psychological explanations of the socio-emotional-communicative impairments in autistic spectrum disorder. *Autism*, 16(3), 226-246. doi: 10.1177/1362361311430403.
- Bowker N. & Tuffin K. (2002). Disability discourses for online identities. *Disability & Society*, 17(3): 327-344, doi: 10.1080/09687590220139883
- Boyd, D. (2011). Social network sites as networked publics: affordances, dynamics and implications. In: Z. Papacharissi, (Ed.). *Networked Self: Identity, Community, and Culture on Social Network Sites* (pp. 39-58). New-York: Routledge.
- Boyd, d. (2006). A blogger's blog: exploring the definition of a medium. *Reconstruction* 6(4). Retrieved from: <http://reconstruction.eserver.org/064/boyd.shtml>
- Branscombe, N. R., Schmitt, M. T. & Harvey, R. D. (1999). Perceiving pervasive discrimination among African Americans: implications for group

- identification and well-being. *Journal of Personality and Social Psychology*, 77(1), 135-149.
- Broderick, A.A. & Ne'eman, A. (2008) Autism as metaphor: narrative and counter-narrative, *International Journal of Inclusive Education*, 12(5-6), 459-476, doi: 10.1080/13603110802377490
- Brownlow, C., Bertilsdotter Rosqvist H. & O'Dell, L. (2015). Exploring the potential for social networking among people with autism: challenging dominant ideas of 'friendship'. *Scandinavian Journal of Disability Research*, 17(2), 188-193. doi: 10.1080/15017419.2013.859174.
- Brownlow, C. & O'Dell, L. (2013). Autism as a form of biological citizenship. In: Davidson J. & Orsini, M. (Eds.). *Worlds of Autism: Across the Spectrum of Neurological Difference* (pp. 97-116). University of Minnesota Press.
- Brownlow, C. (2010). Presenting the self: negotiating a label of autism. *Journal of Intellectual & Developmental Disability*, 35(1):14-21. doi: 10.3109/13668250903496336
- Brownlow, C. (2010) Re-presenting autism: the construction of 'NT syndrome'. *Journal of Medical Humanities*, 31(3), 243-256. doi: 10.1007/s10912-010-9114-4
- Brownlow, c. & O'Dell, L. (2006). Constructing autistic identity: AS voices online. *Journal of Mental Retardation* 4(5), 315-321.
- Brownsberger, D. (2015). *The ethos and identity formation of autistic writers: a rhetorical analysis of online advocacy narratives* (doctoral dissertation), Texas A&M University-Commerce. Retrieved from ProQuest Dissertations Publishing, 3724657.
- Bucher, T. & Helmond, A. (2017). The affordances of social media platforms. In: J. Burgess, T. Poell & A. Marwick (Eds.). *SAGE Handbook of Social Media*. London and New York: SAGE Publications Ltd.
- Bumiller, K. (2008). Quirky citizens: autism, gender, and reimagining disability. *Signs* 33(4), 967-991. doi: 10.1086/528848
- Capps, L., Kehres, J. & Sigman, M. (1998). Conversational abilities among children with autism and children with developmental delays. *Autism*, 2(4), 325-344. doi: 10.1177/1362361398024002
- Carey, A.C. (2013). The sociopolitical contexts of passing and intellectual disability. In: *Disability and Passing: Blurring the Lines of Identity* (pp. 142-166). Temple University Press.

- Carey, A. C. (1997). The communications revolution and the professional communicator. In: E., Stryker Munson & C. A. Warren (Eds.). *James Carey: A Critical Reader*, (128-143). University of Minnesota Press.
- Carey J. W. (1989). A cultural approach to communication. In: *Communication as Culture* (pp. 13-36). Boston: Unwin Hyman.
- Cascio, M.A. (2015). Cross-cultural autism studies, neurodiversity and conceptualizations of autism. *Culture, Medicine and Psychiatry*, 39, 207-212. doi: 10.1007/s11013-015-9450-y
- Castells, M. (2010). *The Information Age: Economy, Society, and Culture. Vol. II: The Power of Identity* (pp. 5-70). Wiley-Blackwell Publishing. ISBN 9781444319514.
- Charman, T. (2003). Why joint attention a pivotal skill in autism? *Philosophical Transactions: Biological Sciences*, 358(1430), 315-324. Retrieved from Jstore: <http://www.jstor.org/stable/3558144>
- Charmaz, K. (2006). *Constructing Grounded Theory*. London: Sage Publications. ISBN ISBN-10 0-7619-7352-4.
- Charmaz, K. (1995). The body, identity and self: adapting to impairment. *The sociological Quarterly* 36(4), 657-680. Retrieved from Jstore: <http://www.jstor.org/stable/4121346>
- Chin, A. and Chignell, M. (2006). *Finding evidence of community from blogging co-citations: a social network analytic approach*. Paper presented at Web Based Communities Conference (WBC), San Sebastian, Spain, 191–200.
- Chin, A. and Chignell, M.H. (2006). A social hypertext model for finding community in blogs. In *Proceedings of ACM Hypertext (Odense, Denmark)*. HYPERTEXT '06. ACM Press, New York, NY, 11-22, 2006.
- Chin, A. and Chignell, M.H. (2007). Identifying communities in blogs: roles for social network analysis and survey instruments. *International Journal of Web Based Communities*, 3(3), 345-363. doi: 10.1504/IJWBC.2007.014243
- Christensen DL, Baio J, Braun KV, et al. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *Surveillance Summaries* 65(3), 1–23. doi: <http://dx.doi.org/10.15585/mmwr.ss6503a1>

- Clarke, J. & Van Ameron, G. (2008). A comparison of blogs by depressed men and women. *Issues in Mental Health Nursing*, 29(3), 243-264. doi: 10.1080/01612840701869403
- Cole, M. (2013). Differences and deficits in psychological research in historical perspective - a commentary on the special section. *Developmental Psychology*, 49(1), 84-91. doi: 10.1037/a002962
- Corbin, J. & Strauss, A. (2008). *Basics of Qualitative Research* (3rd Edition). Los Angeles, California: Sage Publications.
- Davidson, J. & Parr, H. (2012). Enabling cultures of dis/order online. In: R., Wilton, E., Hall, V., Chouinard, S., Elliot, & A. Williams (Eds.): *Towards Enabling Geographies: 'Disabled' Bodies and Minds in Society and Space* (pp. 63-83). Ashgate's Geographies of Health Series, Ashgate Publishing Ltd.
- Davidson, J., Edwards, S. & Hemsworth, K. (2012). *Autism Online: The Role of the Internet in the Daily Lives of People on the Autism Spectrum*. Research Project Report.
- Davidson, J. & Henderson, V. L. (2010). 'Coming out' on the spectrum: autism, identity and disclosure. *Social & Cultural Geography*, 11(2), 155-170. doi: 10.1080/14649360903525240
- Davidson, J. & Henderson, V. L. (2010). 'Travel in parallel with us for a while': sensory geographies of autism. *The Canadian Geographer*, 54(4), 462-475. doi: 10.1111/j.1541-0064.2010.00309.
- Davidson, J. (2008). Autistic culture online: virtual communication and cultural expression on the spectrum. *Social & Cultural Geography*, 9(7), 791-806. doi: 10.1080/14649360802382586
- Dawson, G., Munson, J., Estes, A., Osterling, J., McPartland, J., Toth, K., Carver, L & Abbot, R. (2002). Neurocognitive function and joint attention ability in young children with autism spectrum disorder versus developmental delay. *Child Development*, 73(2), 345-358. Retrieved from Jstore <http://www.jstor.org/stable/3696362> .
- DePape, A.M., and Lindsay, S. (2016). Lived experiences from the perspective of individuals with autism spectrum disorder: a qualitative meta-synthesis. *Focus on Autism and Other Developmental Disabilities*, 31(1), 60-71. doi: 10.1177/1088357615587504

- Dekker, M. (1999) *On Our Own Terms: Emerging Autistic Culture*. Retrieved from <http://www.autscape.org/2015/programme/handouts/Autistic-Culture-07-Oct-1999.pdf> .
- Delincolas, E.K. & Young, R.L. (2007). Joint attention, language, social relating, and stereotypical behaviours in children with autistic disorder. *Autism*, 11(5), 425-436. doi: 10.1177/1362361307079595
- Dominguez, D., J.F. (2014). Toward a neuroanthropology of ethics: introduction. In: J. Clausen, & N. Levy (Eds.): *Handbook of Neuroethics*, (289-298). Springer Reference. doi: 10.1007/978-94-007-4707-4
- Dorozenko, K.P., Roberts, L.D. & Bishop B. (2015). The identities and social roles of people with an intellectual disability: challenging dominant cultural worldviews, values and mythologies. *Disability & Society*, 30(9), 1345-1364, doi: 10.1080/09687599.2015.1093461
- Draaisma, D. (2009). Stereotypes of autism. *Philosophical Transactions of the Royal Society*, 364, 1475-1480. doi: 10.1098/rstb.2008.0324
- Dunn, D.S. & Andrews, Erin E. (2015). Person-first and identity-first language: developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264. Retrieved from <http://dx.doi.org/10.1037/a0038636> .
- Durkin, K. (2010). Videogames and young people with developmental disorders. *Review of General Psychology*, 14(2), 122-140. doi: 10.1037/a0019438
- Eyal, G., Fitzgerald, D., Gillis-Buck, E., Hart, B. & Lappe, M.D. (2014). New modes of understanding and acting on human difference in autism research, advocacy and care: introduction to a special issue of BioSocieties. *BioSocieties* 9(3), 233-240. www.palgrave-journals.com/biosoc/
- Fein, E. (2015). Making meaningful worlds: role-playing subcultures and the autism spectrum. *Culture, Medicine and Psychiatry*, 39, 299-321. doi 10.1007/s11013-015-9443-x
- Fenton, A. & Krahn, T. (2007). Autism, neurodiversity and equality beyond the 'normal'. *Journal of Ethics in Mental Health* 2(2), 1-6. Retrieved from http://www.jemh.ca/issues/v2n2/documents/JEMH_V2N2_Theme_Article2_Neurodiversity_Autism.pdf .
- Fernandez, W.D. (2005). The grounded theory method and case study data in IS research: issues and design. In: D.N. Hart & S.D. Gregor, (Eds.). *Information Systems Foundations: Constructing and Criticising* (pp. 43-59). ANU (Australian National University) Press.

- Fernandez, W.D., Martin, M.A., Gregor, S., Stern, S.E. & Vitale, M. (2007). A multi-paradigm approach to grounded theory. In: D.N. Hart & S.D. Gregor, (Eds.). *Information Systems Foundations: Theory, Representation and Reality* (pp. 231-246). ANU (Australian National University) Press.
- Fleischmann, A. (2005). The hero's story and autism: grounded theory study of websites for parents of children with autism. *Autism*, 9(3), 299-316. doi: 10.1177/1362361305054410
- Flicker, S., Haans, D. & Skinner, H. (2004). Ethical dilemmas in research on internet communities. *Qualitative Health Research*, 14, 124-134. doi: 10.1177/1049732303259842
- Fullwood, C., Sheehan, N. & Nicholls, W. (2009). Blog function revisited: a content analysis of MySpace blogs. *CyberPsychology & Behaviour*, 12, 685-689. doi: 10.1089=cpb.2009.0138
- Geertz, C. (1973). Thick description: toward an interpretive theory of culture. In: C. Geertz (Ed.) *The Interpretation of Cultures* (pp. 3-30). New-York, Basic Books.
- Geertz, C. (1973). The growth of culture and the evolution of mind. In: C. Geertz (Ed.) *The Interpretation of Cultures* (pp. 55-83). New-York, Basic Books.
- Geertz, C. (2005). Deep play: notes on the Balinese cockfight. *Daedalus*, 134(4), 56-86. Retrieved from Jstore <http://www.jstor.org/stable/20028014> .
- Geertz, C. (1974). "From the native's point of view": on the nature of anthropological understanding. *Bulletin of the American Academy of Arts and Sciences*, 28(1), 26-45. doi: 10.2307/3822971
- Gibbs, J. L., Ellison, N. B. & Heino, R. D. (2006). Self-presentation in online personals: the role of anticipated future interaction, self-disclosure, and perceived success in internet dating. *Communication Research*, 33(2), 152-177, doi: 10.1177/0093650205285368.
- Giddens, A. (1991). *Modernity and Self-Identity*. California: Stanford University Press.
- Gil, R., Shoham, S. & Shelly, S. (2016). Constructing positive cultural identity in communities of people with disabilities. In: S., Mor, N., Ziv, A., Kanter, A., Eichengreen, & N., Mizrachi (Eds.). *Disability Studies: The Reader* (pp. 164-172) Tel-Aviv, Hakibbutz Hameuchad Publishing House.

- Giles, D. C. (2014). 'DSM-V is taking away our identity': the reaction of the online community to the proposed changes in the diagnosis of Asperger's disorder. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 18(2), 179-195. doi: 10.1177/1363459313488006
- Giles, D. C. & Newbold, J. (2011). Self- and other-diagnosis in user-led mental health online communities. *Qualitative Health Research* 21(3),419-428. doi: 10.1177/1049732310381388
- Glaser, B.G. (1998). *Doing Grounded Theory: Issues and Discussion*. Mill Valley, California: The Sociology Press.
- Glaser, B.G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New-York: Aldine De Gruyter.
- Glaser, B.G. & Hon (2010). The future of grounded theory 1. *The Grounded Theory Review* 9(2): 1-14. Retrieved from <http://groundedtheoryreview.com/2010/06/30/the-future-of-grounded-theory1/>
- Glaser, B.G. (2002). Constructivist Grounded Theory? *Forum: Qualitative Social Research* 3(3). <http://www.qualitative-research.net/index.php/fqs/article/view/825/1793>. Downloaded 3/10/2016.
- Glannon, W. (2007). Neurodiversity. *Journal of Ethics in Mental Health*, 2(2), 1-5. Retrieved from http://www.jemh.ca/issues/v2n2/documents/JEMH_V2N2_Theme_Article1_Neurodiversity.pdf
- Glover, J. (2014). The sense of self. In: *Alien Landscapes? Interpreting Disordered Minds* (309-312). Harvard University Press.
- Goffman, E. (2003). On face-work: an analysis of ritual elements in social interaction *Reflections*, 4(3), 7-13. doi: 10.1162/15241730360580159
- Gomm, R. (2009). *Key Concepts in Social Research Methods*. Basingstoke: Palgrave Macmillan.
- Grinker, R.R. (2015). Reframing the science and anthropology of autism. *Culture, Medicine and Psychiatry*, 39:345-350. doi: 10.1007/s11013-015-9444-9
- Grinker, R.R. (2010). Commentary: On being autistic, and social. *Ethos*, 38(1), 172-178. doi: 10.1111/j.1548-1352.2010.01087.x

- Grönvik L. (2007). The fuzzy buzz word: conceptualisations of disability in disability research classics. *Sociology of Health & Illness*, 29(5), 750–766. doi: 10.1111/j.1467-9566.2007.01014.x
- Guardiola-Wanden-Berghe, R., Sanz-Valero, J. & Wanden-Berghe, C. (2010). Eating disorders blogs: testing the quality of information on the Internet. *Eating Disorders*, 18, 148-152. doi: 10.1080/10640260903585565
- Hacking, I. (2009). How we have been learning to talk about autism: a role for stories. *Metaphilosophy*, 40 (3-4), 499-516. doi: 10.1111/j.1467-9973.2009.01607.x
- Hale, C. M. & Tager-Flusberg, H. (2005). Social communication in children with autism. *Autism*, 9(2), 157-178. doi: 10.1177/1362361305051395
- Hall, S. (1996). Introduction: who needs ‘identity’? In: S. Hall, & P. Du Gay (Eds.): *Questions of Cultural Identity* (pp. 1-17). Sage Publications Ltd.
- Happe, F. & Frith, U. (2009). The beautiful otherness of the autistic mind. *Philosophical Transactions: Biological Sciences*. Vol. 364(1522), pp. 1345-1350. Retrieved from Jstore <http://www.jstor.org/stable/40485905>
- Hardey, M. (2002). Life beyond the screen: embodiment and identity through the Internet. *The Sociological Review*, 50(4), 570-585. doi: 10.1111/1467-954X.00399
- Harvey, L. (2011). Intimate reflections: private diaries in qualitative research. *Qualitative Research*, 11(6), 664-682. doi: 10.1177/1468794111415959
- Hense C., Skewes McFerran, K. & McGorry P. (2014). Constructing a grounded theory of young people’s recovery of musical identity in mental illness. *The Arts in Psychotherapy*, 41, 594–603. Retrieved from <http://dx.doi.org/10.1016/j.aip.2014.10.010> .
- Henderson, V., Davidson, J., Hemsworth, K. & Edwards, S. (2014). Hacking the master code: cyborg stories and the boundaries of autism. *Social & Cultural Geography*, 15(5), 504-524. Retrieved from <http://dx.doi.org/10.1080/14649365.2014.898781> .
- Hill, L. & Frith, U. (2003). Understanding autism: insights from mind and brain. *Philosophical Transactions: Biological Sciences*. Vol. 358(1430), pp. 281-289. Retrieved from <http://www.jstor.org/stable/3558141> .
- Hitlin, S., Elder, G.H. & Jr. (2007). Time, self, and the curiously abstract concept of agency. *Sociological Theory*, 25(2):170-191. Retrieved from

<http://journals.sagepub.com.ezlibproxy1.ntu.edu.sg/doi/pdf/10.1111/j.1467-9558.2007.00303.x>

- Hookway, N. (2008). Entering the blogosphere: some strategies for using blogs in social research. *Qualitative Research*, 8(1), 91-113. Retrieved from <http://journals.sagepub.com.ezlibproxy1.ntu.edu.sg/doi/pdf/10.1177/1468794107085298>
- Jaarsma, P. & Welin, S. (2012). Autism as a natural human variation: reflections on the claims of the neurodiversity movement. *Health Care Analysis*, 20, 20-30. doi: 10.1007/s10728-011-0169-9
- James, N. & Busher, H. (2006). Credibility, authenticity and voice: dilemmas in online interviewing. *Qualitative Research*, 6(3), 403-420. doi: 10.1177/1468794106065010
- Jenkins, H. (2006). *Convergence Culture: Where Old and New Media Collide*. New York University Press.
- Jenkins, H., Ford, S. & Green, J. (2013). *Spreadable Media: Creating Value and Meaning in a Networked Culture*. New York University Press.
- Jeon, Y. (2004). The application of grounded theory and symbolic interactionism. *Scandinavian Journal of Caring Sciences*, 18, 249–256. doi: 10.1111/j.1471-6712.2004.00287.x
- Jones, R.S.P., Zahl, A. & Huws, J.C. (2001). First-hand accounts of emotional experiences in autism: a qualitative analysis. *Disability & Society*, 16(3), 393-401. Retrieved from <http://dx.doi.org/10.1080/09687590120045950> .
- Jones, R.S.P., Quigney, C. & Huws, J.C. (2003). First-hand accounts of sensory perceptual experiences in autism: a qualitative analysis. *Journal of Intellectual & Developmental Disability*, 28(2), 112-121. doi: 10.1080/1366825031000147058
- Jordan, C.J. & Caldwell-Harris (2012). Understanding differences in neurotypical and autism spectrum special interests through Internet forums. *Journal of Intellectual and Developmental Disabilities*, 50(5), 391-402. doi: 10.1352/1934-9556-50.5.391
- Jurecic, A. (2012). Illness narratives and the challenge to criticism. In: *Illness as Narrative* (pp. 1-17). University of Pittsburgh Press.

- Kam lager, C. (2014). *Identity making process of individuals with mild intellectual disabilities*. University of Kentucky, ProQuest Dissertations Publishing, 2014. 3582850.
- Kang, Y., Gruber, J. & Gray, J.R. (2013). Mindfulness and de-automatization. *Emotion Review*, 5(2), 192 –201. doi: 10.1177/1754073912451629
- Kapp, S.K., Gillespie-Lynch, K., Sherman, L. E. & Hutman, T. (2013). Deficit, difference, or both? Autism and neurodiversity. *Developmental Psychology* 49(1), 59-71. doi: 10.1037/a0028353
- Keith, H. & Keith, K. (2013). Defining the person: The moral and social consequences of philosophies of selfhood. In: *Intellectual Disability: Ethics, Dehumanization, and a New Moral Community* (pp. 77-94). John Wiley & Sons, Inc. doi: 10.1002/9781118606957
- Kellman, J. (1999). Drawing with Peter: autobiography, narrative, and the art of a child with autism. *Studies in Art Education*, 40(3) ,258-274. Retrieved from <http://dx.doi.org/10.1080/00393541.1999.11650061> .
- Kenix, L.J. (2009). Blogs as alternative. *Journal of Mediated Communication*, 14, 790-822. doi:10.1111/j.1083-6101.2009.01471.x
- Kenway, I.M. (2009). Blessing or curse? Autism and the rise of the Internet. *Journal of Religion, Disability & Health*, 13(2), 94-103, doi: 10.1080/15228960802581495
- Ko, H.C. & Kuo, F.Y. (2009). Can blogging enhance subjective well-being through self-disclosure? *CyberPsychology & Behavior*, 12(1), 75-79, doi: 10.1089/cpb.2008.0163
- Korsgaard, C.M. (2009). *Self-Constitution: Agency, Identity and Integrity*. Oxford Scholarship Online.
- Krahn, T. & Fenton, A. (2009). Autism, empathy and questions of moral agency. *Journal for the Theory of Social Behaviour*, 39(2), 145-166, doi: 10.1111/j.1468-5914.2009.00402.x
- Kras, J.F. (2010). The "ransom notes" affair: when the neurodiversity movement came of age. *Disability Studies Quarterly*, 10415718, 30(1), 1-22.
- Krcek T. E. (2013) Deconstructing disability and neurodiversity: controversial issues for autism and implications for social work, *Journal of Progressive Human Services*, 24:1, 4-22, doi: 10.1080/10428232.2013.740406

- Lacava, P. G., Rankin, A., Mahlios, E., Cook, K., & Simpson, R. L., (2010). A single case design evaluation of a software and tutor intervention addressing emotion recognition and social interaction in four boys with ASD. *Autism*, 14(3), 161-178, doi: 10.1177/1362361310362085.
- Lal, S., Suto, M. & Ungar, M. (2012). Examining the potential of combining the methods of grounded theory and narrative inquiry: a comparative analysis. *The Qualitative Report*, 17, 1-22. Retrieved from <http://www.nova.edu/ssss/QR/QR17/lal.pdf> .
- Larkin, P.J., Dierckx de Casterlé B. & Schotsmans, P. (2008). A relational ethical dialogue with research ethics committees. *Nursing Ethics*, 15, 234-242, doi: 10.1177/0969733007086021
- Limburg, J. (2016). 'But that's just what you can't do': personal reflections on the construction and management of identity following a late diagnosis of Asperger syndrome. *Life Writing*, 13(1), 141-150, doi: 10.1080/14484528.2016.1120639
- Lingard, L., Albert, M. & Levinson, W. (2008). Qualitative research: grounded theory, mixed methods, and action research. *British Medical Journal*, 337(7667), 459-461, doi: 10.1136/bmj.39602.690162.47
- Litt, E. & Hargittai, E. (2016). The imagined audience on social network sites. *Journal of Social Media + Society*, 2(1), 1-12, doi: 10.1177/2056305116633482
- Lomicky, C. S. & Hogg, N. M. (2010). Computer-mediated communication and protest. *Information, Communication & Society*, 13(5), 674-695, doi: 10.1080/13691180903214515.
- Losh, M. & Capps, L. (2003). Narrative ability in high-functioning children with autism or Asperger's syndrome. *Journal of Autism and Developmental Disorders*, 33(3), 239-251. Retrieved from <https://link-springer-com.ezlibproxy1.ntu.edu.sg/journal/10803/33/3> .
- Magnotto Neff, J. (1998). Grounded theory: a critical research methodology. In: C. Farris, & C.M. Anson (Eds.). *Under Construction* (pp. 124-135). University Press of Colorado, Utah State University Press.
- Markham, A. N. (2011). Internet Research. In Silverman, D. (Ed.). *Qualitative Research: Theory, Method, and Practices*, 3rd Edition. London: Sage.

- Marvin, C. (1997). Introduction: famed psychic's head explodes: James Carey on the technology of journalism. In: E. S. Munson & C. A. Warren (Eds.). *James Carey: A Critical Reader* (p. 119-127). University of Minnesota Press.
- Mazurek, M.O. (2013). Social media use among adults with autism spectrum disorders. *Computers in Human Behaviour* 29, 1709-1714. Retrieved from <http://dx.doi.org/10.1016/j.chb.2013.02.004> .
- Mazurek, M.O., Shattuck, P.T., Wagner, M. & Cooper, B.P. (2012). Prevalence and correlates of screen-based media use among youths with autism syndrome disorder. *Journal of Autism and Developmental Disorder*, 42(8), pp. 1757-1767, doi: 10.1007/s10803-011-1413-8
- McCoyd, J.L.M. & Schwaber Kerson, T. (2006). Conducting intensive interviews using email. *Qualitative Social Work*, 5(3):389-406, doi:10.1177/1473325006067367
- McCreadie M., & Payne, S. (2010). Evolving grounded theory methodology: towards a discursive approach. *International Journal of Nursing Studies*, 47, 781–793, doi:10.1016/j.ijnurstu.2009.11.006
- Mcgeehin-Heilferty, C. (2009). Toward a theory of online communication in illness: concept analysis of illness blogs. *Journal of Advanced Nursing*, 65(7), 1539-1547, doi: 10.1111/j.1365-2648.2009.04996.x
- McLuhan M. & McLuhan, E. (1988). *Laws of Media: The New Science*. University of Toronto Press.
- Mead, G. H. (1934). *Mind, Self, and Society: From a Standpoint of a Social Behaviorist*. W.C. Morris (Ed.). The University of Chicago Press.
- Mineo, B.A., Ziegler, W., Gill, S. & Salkin, D. (2009). Engagement with electronic screen media among students with autism syndrome disorder. *Journal of Autism and Developmental Disorders*, 39, 172-187, doi: 10.1007/s10803-008-0616-0
- Mogensen, L. & Mason, J. (2015). The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Sociology of Health & Illness*, 37(2), 255-269, doi: 10.1111/1467-9566.12260
- Morioka, T., Ellison, N. B., & Brown, M. (2016). *Identity Work on Social Network Sites: Disadvantaged Students' College Transition Processes*. CSCW '16: Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing, doi: <http://dx.doi.org/10.1145/2818048.2819959>.

- Molloy, H. & Vasil, L. (2010). The social construction of Asperger syndrome: the pathologising of difference? *Disability & Society*, 17(6), 659-669, doi: 10.1080/0968759022000010434
- Moss, P. & Teghtsoonian, K. (2008). Power and illness: authority, bodies, and context. In: P., Moss & K., Teghtsoonian (Eds.): *Contesting Illness* (pp. 3-27). University of Toronto Press.
- Murray, S. (2008). Presences: autistic difference. In: *Representing Autism: Culture, Narrative, Fascination* (pp. 27-64). Liverpool University Press.
- Murray, D., Lesser, M. & Lawson, W. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism*, 9(2), 139-156, doi: 10.1177/1362361305051398
- Murray, L., Pushor, D. & Renihan, P. (2012). Reflections on the ethic-approval process. *Qualitative Inquiry*, 18(1), 43-54, doi: 10.1177/1077800411427845
- Newman, B. (2008). Challenging convention: symbolic interactionism and grounded theory. *Collegian*, 15, 103—107, doi:10.1016/j.colegn.2007.12.002
- Nicolaidis, C., Raymaker, D. McDonald, K., Dem, S., Ashkenazy, E., Boisclair, C., Robertson, S. & Baggs, A. (2011). Collaboration strategies in nontraditional community-based participatory research partnerships: lessons from an academic–community partnership with autistic self-advocates. *Progress in Community Health Partnerships: Research, Education, and Action*, 5(2), 143-150, doi:10.1353/cpr.2011.0022
- Nicolaidis, C., Raymaker, D., McDonald, K, Dern, S., Boisclair, W.C., Ashkenazy, E., Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. *Journal of General Internal Medicine*. 28(6): 761-769.
- Nolan, J. & McBride, M. (2015). Embodied semiosis: autistic ‘stimming’ as sensory praxis. In: *International Handbook of Semiotics*, Chapt. 48, 1069-1078.
- Nowak, K.L., Watt, J. & Walther J. B. (2005). The influence of synchrony and sensory modality on the person perception process in computer-mediated groups. *Journal of Computer-Mediated Communication*, 10(3), doi: 10.1111/j.1083-6101.2005.tb00251.x.
- O’Neil, S. (2008). The meaning of autism: beyond disorder. *Disability & Society*, 23(7): 787-799.

- Ochs E., Kremer-Sadlik, T., Gainer Sirota, K. & Solomon, O. (2004). Autism and the social world: an anthropological perspective. *Discourse Studies*. 6(2), 147-183.
- Ochs, E. & Solomon, O. (2010). autistic sociality. *Ethos*, 38(1), 69-92.
- Olinger, C. (2010). *Working toward agency among the autism community: A participatory action research study*. Alliant International University, San Diego, ProQuest Dissertations Publishing, 2010. 3451908.
- Oliver, M. (2013). The social model of disability: thirty years on. *Disability & Society* 28(7), 1024-1026.
- Oliver, M. (1996). *Understanding Disability: From Theory to Practice*. Macmillan Education: St. Martin's Press.
- Orsini, M. & Davidson, J. (2013). Critical autism studies: notes on an emerging field. In: Davidson J. & Orsini, M. (Eds.). *Worlds of Autism: Across the Spectrum of Neurological Difference*. University of Minnesota Press, 1-28.
- Orsini, M. & Smith, M. (2013). Social movements, knowledge and public policy: the case of autism activism in Canada and the US. *Critical Policy Studies* 4(1), 38-57.
- Ortega, F. (2013). Cerebralizing autism within the neurodiversity movement. In: Davidson J. & Orsini, M. (Eds.). *Worlds of Autism: Across the Spectrum of Neurological Difference*. University of Minnesota Press, 73-97.
- Ortega, F. (2009). The cerebral subject and the challenge of neurodiversity. *BioSocieties* 4(3), 425-445.
- Peterson, R. A. (1979). Revitalizing the culture concept. *Annual Review Of Sociology*, 5, 137-166.
- Plaisted, K., Saksida, L., Alcantara, J. & Weisblatt, E. (2003). Towards an understanding of the mechanisms of weak central coherence effects: experiments in visual configural learning and auditory perception. *Philosophical Transactions: Biological Sciences*, 358(1430), 375-386.
- Prior, L. (2011). Using documents in social research. In Silverman (ed), *Qualitative Research*, Thousand Oaks: Sage Publications.
- Prince, D. E. (2010). An exceptional path: an ethnographic narrative reflecting on autistic parenthood from evolutionary, cultural, and spiritual perspectives. *Ethos*, 38(1), 56-68.

- Rajendran, G. & Mitchell, P. (2007). Cognitive theories of autism. *Developmental Review*, 27, 224-260.
- Raymaker, D. & Nicolaidis, C. (2013). Participatory research with autistic communities: shifting the system. In: Davidson J. & Orsini, M. (Eds.) (2013). *Worlds of Autism*. University of Minnesota Press, 169-187.
- Rose, N. & Abi-Rached, J.M. (2013). Personhood in a neurobiological age. In: *Neuro: The New Brain Sciences and the Management of the Mind* (199-224). Princeton University Press.
- Rose, N. & Novas, C. (2003). Biological citizenship. In: Ong, A. & Collier, S. (Eds.): *Global Anthropology*, Blackwell.
- Rose, N. (2009). Normality and pathology in a biomedical age. *The Sociological Review* 57(2), 66-83.
- Rovane, C. (1998). Preview of the normative analysis of personal identity. In: *Bounds of Agency: An Essay in Revisionary Metaphysics* (13-34). Princeton University Press.
- Runswick-Cole, K. (2014) 'Us' and 'Them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times, *Disability & Society*, 29(7), 1117-1129, doi: 10.1080/09687599.2014.910107
- Ruppel, E. K. (2015). The affordance utilization model: communication technology use as relationships develop. *Marriage & Family Review*, 51(8), 669-686, doi: 10.1080/01494929.2015.1061628.
- Ryan, S. & Räisänen, U. (2008). "It's like you are just a spectator in this thing": experiencing social life the Aspie' Way. *Emotion, Space and Society*, 1, 135-143
- Sacks, O. (1995). *An anthropologist on mars*. New-York: Vintage Books, a division of Random House.
- Sarret, J.C. (2016). Biocertification and neurodiversity: the role and implications of self-diagnosis in autistic communities. *Neuroethics*, 9, 23-36.
- Schietecatte, I., Roeyers, H. & Warreyn P. (2012). Exploring the nature of joint attention impairments in young children with autism spectrum disorder: associated social and cognitive skills. *Journal of Autism Developmental Disorders*, 42, 1-12.

- Schmidt, J. (2007). Blogging practices: an analytical framework. *Journal of Computer-Mediated Communication*, 12, 1409-1427, doi: 10.1111/j.1083-6101.2007.00379.x .S
- Schou, K. C. & Hewison, J. (1998). Health psychology and discourse: personal accounts as social texts in grounded theory. *Journal of Health Psychology*, 3(3), 297-311.
- Seidmann, V. & Pang, N. (2013). *Blogging the Self to Others: The Voice of Autism through Personal Blogs*. Conference Paper, presented at the IAMCR conference, Dublin, June 2012.
- Seidmann, V. & Pang, N. (2014). *Autism and Online Ethnography*. Conference paper, presented at the International Communication Association (ICA) Annual Conference. Seattle, May 2014.
- Seidmann, V. & Pang, N. (2015). *Autism Online: Vulnerability and Ethical Dilemmas in Ethnographical Research of Autism and Social Media*. Conference paper, presented at IAMCR, Montreal 2015.
- Seidmann, V., Pang, N. & Jingyuan S. (2016). *Autistic Bloggers and Community – A Network Analysis of Blog Rings*. Conference paper, presented at “Speaking Autism” conference, Tel-Aviv 2016.
- Serfaty, V. (2004). Online diaries: towards a structural approach. *Journal of American Studies*, 38(3), 457-471.
- Seyfarth, R.M. & Cheney, D.L. (2015). The evolution of concepts about agents: what do animals recognize when they recognize an individual? In: Margolis, E. & Laurence, S. (Eds.): *The Conceptual Mind: New Directions in the Study of Concepts*, 57-75. MIT Press.
- Shakespeare, T. (2010). The social model of disability. In: Davis, L. (ed.), *Disability Studies Reader* (3rd ed.), New York: Routledge, 2010.
- Shakespeare, T. & Watson, N. (1997). Defending the social model. *Disability & Society* 12(2), 293-300.
- Shakespeare, T. (1993). Disabled people's self-organisation: a new social movement? *Disability, Handicap & Society*, 8(3), 249-264, doi: 10.1080/02674649366780261
- Sherry, M. (2004). Overlaps and contradictions between queer theory and disability studies. *Disability & Society*, 18(7), 769-783, doi: 10.1080/0968759042000284231.

- Showden, C.R. (2011). Conceiving agency autonomy, freedom and the creation of the embodied subject. In: *Choices Women Make: Agency in Domestic Violence, Assisted Reproduction, and Sex Work* (1-35). University of Minnesota Press.
- Silberman, S. (2015). *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. New York: Penguin Random House LLC.
- Siles, I. (2012). Web technologies of the self: the arising of the “Blogger” identity. *Journal of Computer-Mediated Communication*, 17, 408-421, doi: 10.1111/j.1083-6101.2012.01581.x.
- Silverman, C. (2008). Fieldwork on another planet: social science perspectives on the autism spectrum. *Biosocieties*, 3(3), 325-341.
- Simmons, O.E. (2010). Is that a real theory or did you just make it up? teaching classic grounded theory. *The Grounded Theory Review*, 9(2), 15-38.
- Sinclair, J. (2010). Cultural commentary: being autistic together. *Disability Studies Quarterly*, 30(1).
- Sinclair, J. (2005). *Autism Network International: The Development of a Community and Its Culture*. Retrieved from http://www.autismnetworkinternational.org/History_of_ANI.html
- Sinclair, J. (1993). Don't mourn for us. *Autism Network International Newsletter, Our Voice 1*. Retrieved from http://www.autreat.com/dont_mourn.html on October 2014.
- Singh, J.S. (2016). Living with autism: perspectives of adults on the spectrum. In: *Multiple Autism: Spectrums of Advocacy and Genomic Science* (153-173). University of Minnesota Press.
- Sirota, K.G. (2010). Narratives of distinction: personal life narrative as a technology of the self in the everyday lives and relational worlds of children with autism. *Ethos*, 38(1), 93-115.
- Solomon, O. (2015). “But-he’ll fall!”: children with autism, interspecies, intersubjectivity, and the problem of ‘being social’. *Culture, Medicine, and Psychiatry* 39, 207–212.
- Solomon, O. (2010). sense and the senses: anthropology and the study of autism. *Annual Review of Anthropology*, 39, 241-159.

- Sonja, V. (2015). *Digital identity and everyday activism: sharing private stories with networked public*. Basingstoke: Palgrave Macmillan.
- Soulliere, D., Britt, D.W. & Maines, D.R. (2001). Conceptual modelling as a toolbox for grounded theorists. *The Sociological Quarterly*, 42(2), 253-269.
- Spillers, L.H., Sensui, L.M. & Linton, K.F. (2014). Concerns about identity and services among people with autism and Asperger's regarding DSM-5 changes. *Journal of Social Work in Disability & Rehabilitation*, 13(3), 247-260.
- Stone, S.D. (2008). Resisting an illness label: disability, impairment, and illness. In: Moss, . & Teghtsoonian, K. (Eds.): *Contesting Illness: Process and Practices*. University of Toronto Press, pp. 201-217. Stable URL: <http://www.jstor.org/stable/10.3138/9781442687738.15>
- Subrahmanyam, K., Garcia, E.C.M., Harsonon, L.S. & Lipana, L. (2009). In their words: connecting online weblogs to developmental processes. *British Journal of Developmental Psychology*, 27, 219-245.
- Sun, Y.C. (2010). Developing reflective cyber communities in the blogosphere: a case study in Taiwan higher education. *Teaching in Higher Education*, 15(4), 369-381.
- Swain, J. & French, S. (2000). Towards an affirmation model of disability. *Disability & Society*, 15(4), 569-582, doi: 10.1080/09687590050058189.
- Swann, W.B. Jr. & Bosson, J. K. (2008). Identity negotiation: a theory of self and social interaction. In: John, O. P., Robins, R. W. & Pervin, L. A. (Eds): *Handbook of personality: Theory and Research* (3rd edition), New York, NY, US: Guilford Press, 448-471.
- Tan, L. (2008). Psychotherapy 2.0: MySpace blogging as self-therapy. *American Journal of Psychotherapy*, 62(2), 143-163.
- Thoits, P.A. (2011). Resisting the stigma of mental illness. *Social Psychology Quarterly*, 74(1), 6-28.
- Thomas, G. & James, D. (2006). Reinventing grounded theory: some questions about theory, ground and discovery. *British Educational Research Journal*, 32(6), 767-795.
- Thomas, H. & Boellstorff, T. (2017). Beyond the spectrum: rethinking autism. *Disability Studies Quarterly*, 37(1), 1. Education Source, EBSCOhost (accessed June 19, 2017).

- Timmermans, S. & Tavory, I. (2012). Theory construction in qualitative research: from grounded theory to abductive analysis. *Sociological Theory*, 30(3), 167-186.
- Tynan, A. (2012). The identity of the critical and the clinical. In: *Deleuze's Literary Clinic: Criticism and the Politics of Symptoms* (120-151). Edinburgh University Press.
- Van Dijck, J. (2013). Engineering sociality in a culture of connectivity. In: Van Dijck, J., *The Culture of Connectivity: A Critical History of Social Media*, 1-22. Published in Oxford Scholarship Online: January 2013 doi: 10.1093/acprof:oso/9780199970773.001.0001
- Van Nijnatten, C. (2010). Social agency and social context. In: *Children's Agency, Children's Welfare: A Dialogical Approach to Child Development, Policy and Practice* (51-70). Policy Press at the University of Bristol.
- Van Nijnatten, C. (2010). The development of individual agency. In: *Children's Agency, Children's Welfare: A Dialogical Approach to Child Development, Policy and Practice* (17-32). Policy Press at the University of Bristol.
- Vivienne, S. (2016). *Digital Identity and Everyday Activism: Sharing Private Stories with Networked Publics*. Palgrave Macmillan, UK.
- Walther, J.B. (2007). Selective self-presentation in computer-mediated communication: Hyperpersonal dimensions of technology, language, and cognition. *Computers in Human Behavior*, 23, 2538–2557, doi:10.1016/j.chb.2006.05.002.
- Walther, J. B. (1996). Computer-mediated communication: impersonal, interpersonal, and hyperpersonal interaction. *Communication research*, 23, 3-43, doi: 10.1177/00936509602300101.
- Ward, M.J., & Meyer, R. N. (1999). Self-determination for people with developmental disabilities and autism: two self-advocates' perspectives. *Focus on Autism and Other Developmental Disabilities*, 14(3), 133-140.
- Watemeyer, B. & Swartz, L. (2016). Disablism, identity and self: discrimination as a traumatic assault on subjectivity. *Journal of Community & Applied Social Psychology*, 26, 268-276.
- Wehmeyer, M.L. (1999). A functional model of self-determination: describing development and implementing instruction. *Focus on Autism and Other Developmental Disabilities*, 14(1), 53-61.

- Weiner, T. (2011). The (un)managed self: paradoxical forms of agency in self-management of bipolar disorder. *Culture, Medicine, and Psychiatry* 35, 448-483.
- Witham, G., Beddow, A. & Haigh, C. (2013). Reflections on access: too vulnerable to research? *Journal of Research in Nursing*, 0(0), 1-10.
- Yirmiya, N., Sigman, M. D., Kasari, C. & Mundy, P. (1992). Empathy and cognition in high-functioning children with autism. *Child Development*, 63(1), 150-160.
- Zolkowska, T. & Kaliszewska, K. (2014). The social construction of social identity of people with intellectual disability. *International Journal of Developmental Disabilities*, 60(1), 3-12.

APPENDICES

Appendix A: Online in-depth Interview Guide

On Voice and Identity: Autism, Space and Identity Construction

Online in-depth interview

DATE:

NAME:

BLOG'S TITLE:

1. *Person with autism or autistic person?* Can you please explain what it means to you?
2. How do you write in your blog?
 - a. Do you write to yourself? Can you please explain?
 - b. Do you write about yourself? Can you please explain?
 - c. To you, what are the most important topics you wrote about?
3. Some bloggers write a blog to raise awareness; others want people to understand what autistic people face and what needs to be done; other bloggers will focus more on their personal journey and will treat the blogs more as a journal or an online diary. What is the purpose of your writing? Is your blog more on your personal journey/thoughts/events or to communicate autism to others?
4. People can say that they have more than one identity or that their identity is multi-layered. I, for example, am a woman, I am Jewish and I consider myself to be atheistic (and the list is longer). Each of what I described plays a role in my identity and I have more than one. What part does autism play in your identity?
5. How would you define your blog? Your private space? Part of a community?
6. Do you find your blog a 'safe space'? What makes it a safe space? How would you characterize the features?

7. I see blogs that are public and become private (by invitation only) and then become public again. Can you explain it to me?
8. Communicating with followers:
 - a. When will you respond to a comment?
 - b. When will you delete a comment?
 - c. When will you stop accepting comments to a single post?
 - d. Can you please provide examples of unwanted readers?

Appendix B: Citation Inquiry Letter to Participants Following IRB Approval

Dear ...,

As you may recall, you have agreed to participate in my research that is conducted for my PhD degree. The research focuses on autistic identity and autistic space through and you allowed me to analyse your blog and participated in an in-depth interview.

Following some requests from participants, I made a special request from the IRB committee (the ethics in research committee) in my university (Nanyang Technological University) to cite the source if I use quotes from **blogs** that were part of the research with the proper citation of the blog. My request was based on the claim that the blogs are public and I wanted to be able to offer the participants the ability to be properly cited if it is important to them.

The IRB committee has approved my request. However, it is important for me to emphasize that **the in-depth interviews will remain anonymous and confidential** and any quotes from the interviews will **not** include anything that may lead to a specific participant.

Based on the approval, I am writing to you and ask if you want to be cited in any publication that will use quotes from your blog. **If you don't want** me to cite you, please let me know and I will not use quotes and I will rephrase examples from your blog.

If **you do want** to be cited, please write to me and let me know:

- a. That you want to be cited
- b. How do you want to be cited (with your real name? just the blog name?)

Thank you so much,

Vered Seidmann

PhD Candidate

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