

DIS/ABLING A LEARNER DIAGNOSED WITH AUTISM:
THE DIALECTICS OF LEARNING AND DEVELOPMENT IN HIGHER EDUCATION

by

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This manuscript has been read and accepted for the Graduate Faculty in Developmental Psychology in satisfaction of the dissertation requirement for the degree of Doctor of Philosophy.

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Abstract

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This dissertation examines the learning experiences of a young female student diagnosed with autism, referred to as Hannah, in the context of the community college from which she graduated with an associates' degree. The aim of this study is to examine the dialectical relationships between learning, identity development and autism as embedded and grounded in social practices. Drawing on Vygotsky's approach extended by the theory of Transformative Activist Stance (Stetsenko, 2008, 2010, 2012, 2013) and Disability Studies, processes of learning, self, and autism were approached in this study as intersecting social practices, that is, as culturally and historically produced and enacted in the activities in the context of community college. Conceptualizing learning as a leading force of development, as a collaborative activity of knowledge production, and as an instrument of identity making, I focused on Hannah's learning experiences to understand her development.

The emphasis of the analysis is on the dynamic negotiation of power as Hannah and the individuals who engage with other participants in learning activities position themselves and Hannah by employing various cultural tools (e.g. institutional and teaching practices, societal discourses on disability, autism and learning). In other words, my focus is on how Hannah's socially produced identity emerges in the context of community college, ranging from the

position of an agentic active learner with a purposeful life project to the position of a disempowered disabled person. Exploration of these trajectories reveals Hannah's identity and development as a dynamic, interrelated and transformative process, constructed and embedded in collaborative human activities. Hannah's engagement in learning activities and other social practices within the college embody both *individual* and *social* transformation, as she changed herself and community practices. Thus, my analysis reveals that Hannah not only changed and developed as a college student and human being, but did so by instigating changes in community practices of the college, including its participants. In a dialectical manner, positioning Hannah as an agentic student and transformative activist within organized learning activities, and full recognition of her equal contribution to community practice by some instructors, promoted Hannah's development and transformation.

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I thought many times of this moment when I would finally write “thank you” to my family and friends in Slovakia, New York and Brazil, of which Hannah and Ingrid are part, and trying to express in a foreign language how much I value and appreciate their support and love.

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is that I shall be capable of providing such freedom, understanding, support and love to my daughter Paula, who was my biggest inspiration and patient and loving supporter.

Lúbim Vás a ďakujem Vám.

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1. Introduction and rationale

This study grew out of a desire to apply my knowledge of learning and development, based on cultural-historical theory, to understand and support a college student diagnosed with autism, herein referred to as Hannah.

I can say that I fell in love with Hannah even before I met her, as I kept hearing about her from my husband, who was teaching her at a community college. He, and as I later found out, some of his colleagues, felt challenged to teach a student diagnosed with autism. This was a novel experience to them, all of whom had none or very limited knowledge of autism. Feeling challenged and compassionate about engaging Hannah, and making sure he was doing his best to teach her, my husband started to consult with me about how best to provide effective instructional support to Hannah. Thus, we developed this routine of talking about her after every class, discussing how well she did, and whether and how she was engaged or challenged. The more I learned about her, the more I wished to meet and get to know her. It soon became clear to us that Hannah would benefit from tutoring, as she was experiencing difficulties with some abstract concepts in his general psychology course. In one particular occasion, my husband had to tutor her, with the help of her guardian, for almost three hours to help her understand the concept of classical conditioning, which she failed to clearly explain in a written exam. Despite being informed by the Office for Students With Disabilities of her special needs, not much help was available to instructors other than offering special accommodations for tests. No support was available concerning pedagogy. As I later found, this deeply troubled some of the instructors teaching Hannah, as they perceived a need for special attention and tutoring, especially as they all recognized her vast potential to learn.

Early that semester, her former teacher, now friend and informal guardian, herein referred to as Ingrid, introduced herself to my husband. She told him about Hannah and her needs, and asked if she could be a liaison between Hannah and him, if necessary. He welcomed her request, as Hannah struggled with the fast pace of the course – not a unique problem, considering that general psychology is a “high-risk” course, failing more than 30% of the students. Out of this conversation, he came up with the idea that I might assist Hannah with some assignments and perhaps even tutor her. We all met to discuss this possibility and Hannah and Ingrid were pleased with that.

As I met Hannah and began tutoring her on a more regular basis, I also became interested in learning more about autism. I was hoping I would be able to understand her and her needs in order to tailor instructional support accordingly. As I began reading about this topic, I quickly became disappointed with the scientific literature, especially in psychology, as it presented a deficit model of autism. Most academic works consist of lists of impairments, descriptions of deficiencies, and failures in various tasks in psychological experiments found in persons diagnosed with autism, usually children. Reading this academic literature, one could form quite a gloomy image of a person diagnosed with autism as a dehumanized being, unable of developing many of the most fundamental human abilities. This focus on pervasive deficits was at odds with my impression of Hannah.

Even though Hannah clearly stood out from other people, to the point that her being diagnosed with autism was evident to her instructors and classmates, it was clear to me that she was not simply a collection of deficits. She was neither incapable of learning, nor of interacting with others. The way I saw her, and many others around her, was quite different. In Hannah, I got to know an intelligent and honest person, a diligent student, a young woman with impressive

memory, vocabulary, knowledge in biology, classical, rock and pop music, playing piano, and a wonderful baker and hostess. I got to know an active and interesting person, a pleasant companion, an honest friend, and a truly genuine person. In fact, being with and around her felt refreshing to me, as there was no pretense, and the usual politics that goes on even between the best of the best friends. I saw it as a great asset that Hannah could be brutally honest. At the same time I continued hearing about and witnessing Hannah's struggles in college, including difficulties comprehending assignments, as well as difficulties relating to some instructors. I learned about numerous rejections Hannah experienced throughout her life, and her worries about the future.

As I continued reflecting upon my fascination and interest in Hannah, I could not help but conclude that I felt a deep interest and admiration for her. However, I started to recognize many missing links between Hannah's exceptional abilities and qualities as a human being and the negative portrait of a person diagnosed with autism gleaned from the psychological literature. Moreover, there seemed to be disconnections between many of her abilities and qualities and the failures and rejections she experienced. The more I got to know Hannah, the more questions arose for me. Although she manifested and experienced some of the difficulties typical for a person diagnosed with autism as described in the literature, those were not consistent. Furthermore, her difficulties appeared to be context dependent and most importantly, did not prevent Hannah from enjoying life and somehow sharing that with the people around her.

Seven years passed since I met Hannah. During this time we got to know each other quite well as our relationship grew. I kept on learning about autism and disability from Hannah in the context of my relationship with her, including observing her interactions with others. I also

engaged in an extensive review of the literature on autism. In this process I continued learning about my own misconceptions and stereotypes about autism and disability and, importantly, I continued learning how to challenge them.

While I tutored Hannah, I realized that many of the difficulties she experienced with assignments, such as comprehending text, analyzing data, synthesizing findings, or employing critical thinking skills, were not out of ordinary. In fact, those are commonly reported by many students.

Importantly, when working with Hannah in close proximity in one-on-one tutoring sessions, I repeatedly questioned my abilities. For instance, I began examining how I posed questions, explained the material, my understanding of given assignment, and so on. Pondering about this type of a situation, I started to wonder who was really disabled. Was it Hannah because she could not grasp a given concept? Or was it me, because I was either not asking a question clearly, or simply not presenting a concept in an accessible way? Or could it be the assignment or the text that was unclear or too complex to comprehend? Clearly, Hannah could perform certain task, or manifest certain abilities and skills better in some contexts than others.

Thus, I realized that in addition to asking questions like “*What is disability?*” and “*What is autism?*” I had to also pose questions such as “*Where are disability and autism located?*” and “*Is autism always disabling?*”

As I continued inquiring about how best to tutor Hannah, I became increasingly aware of some of my own “disabilities.” This led me to reflect on my abilities as I have carried out a range of roles and activities. I then realized that all social roles or positions I took on, be it a foreigner, an ESL student, a woman, a mother, were at least at some point materialized as disabilities. Depending on contexts, they took on various forms, frequency, and intensity. For instance, as a

mother of an infant trying to move around New York City, especially when trying to use public transportation, I felt and *I was* disabled. I certainly began giving much more thought to the wheelchair users and their experiences with such a mundane task as taking the subway. Similarly, as an aspiring academic and student, part-time employee, and full-time mother, when updating my curricula vitae, I found myself trying to find the ways to hide the fact that I am a mother and cover up (and yet to be truthful) a gap in my professional achievements. My motherhood amounted to nothing else than a disability I was trying to hide in the context of my professional carrier and employment prospect. I realized how disabling motherhood could be in this society. Moreover, I also became aware of how differently various people and institutions perceive my “disabilities.”

All these personal reflections influenced my professional stance as a psychologist. I began to feel that I should be able to understand Hannah, and her experience better, in order to support and assist her in many of her struggles. The desire to construct such knowledge was the core motivation underlying this research project. Thus this study embodies both my deeply personal involvement with Hannah and my professional quest for answers about how to support learning and development of a person diagnosed with autism. This was the basis for my commitment to this research project.

As I started reviewing the existing literature in the area of autism, I learned that scholars attempting to conceptualize it work within a wide range of theoretical perspectives. As a result, a plethora of conceptualizations have been proposed, from impairment in social interactions and cognitive deficits to neurological and contextualized views. Despite a great deal of progress, much conceptual work needs to be done in order to coherently integrate the insights gained from these diverse approaches into a unified account.

My contention is that conceptual progress entails moving beyond the traditional study of autism based solely in terms of impairments and deficiencies. The rationale for such a conceptual move is based on the fact that the application of such deficit model to the study of autism in treatment and interventions, including the education of individuals diagnosed with autism, has led to a predominant focus on fixing their “differences” and modifying their behavior. I believe, among other critical voices, that this has distorted our view of persons diagnosed with autism. Thus, I propose that we need to ground our understanding of autism firmly on a solid developmental perspective. As I argue in this dissertation, failure to synthesize theoretical perspectives on autism is linked to the lack of a unified theory of development capable of bridging the gaps between theory and practice, genes and environment, psychopathology and development, cognition and emotion, social and individual, and so on. My work is an attempt to supersede such dichotomies by basing a developmental account of autism on Vygotsky’s cultural-historical theory of human development. Specifically, I draw on his theory of the development of disabled children (theory of defectology-disontogenesis), which I complement with further elaboration of Vygotsky’s approach, namely the recent conceptual advances by the Transformative Activist Stance (Stetsenko, 2008, 2010, 2012, 2013). Based on integrating TAS-extended Vygotsky’s approach with Disability Studies, I propose a different approach to understanding the development of disabled individuals, specifically individuals diagnosed with autism. My contention is that acknowledging transformative ontology (Stetsenko, 2008) as a guiding metatheory for studying human development. As such, I will focus on the dialectical unity of social and individual aspects of human development and dialectical relationship of learning and development.

This study draws also on the common ground between Vygotsky's approach extended by TAS and Dynamic Systems Theory (DST), as both seek to overcome common dichotomies in scientific approaches. Vygotsky's approach extended by TAS fully integrates DST as a compatible approach that provides broader and additional light to the issues central to this project. Specifically, both approaches claim that development is a thoroughly epigenetic process (Lickliter & Honeycutt's, 2003, 2007, 2010), where natural and environmental, individual and social dimensions are co-constructed in their interdependency in the process of "active transformative practice" (Stetsenko, 2009, p. 126). Such notion of development ultimately removes disability out of the individual's body and mind and requires a radically different approach to understanding and "curing" the disability. Using Vygotsky's notion of human activity as a source of and the core process of psychological and identity development, I argue that disability (and all the efforts to eliminate it) as traditionally understood, has to be "relocated" from the individual into collaborative culturally mediated purposeful activity. Such "relocation" is attempted in this research project by focusing on collaborative, mediated, goal oriented activity as a unit of analysis. Specifically, autism is approached as a sociocultural phenomenon, socially produced and practiced in everyday social interaction, as a dynamic process situated in specific and intersecting activities. In other words, this approach stands in contradistinction to traditional approaches based on reductionist assumptions about mental disability, and autism in particular, as a relatively fixed and individually bounded trait only minimally susceptible to sociocultural influences.

In consonance with Vygotsky's approach and Disability Studies, I aim to move beyond the individual as a "natural" unit of analysis. Drawing on Vygotsky's conceptualization of learning as a gateway through which development proceeds, my claim is that focusing on learning opens

up our understanding of individual's development. Learning is understood as a special type of human collaborative activity. Understanding learning as a profoundly social and dialogical activity challenges cognitive analyses that focus on decontextualized mental processes that serve to reinforce deficit views. Therefore, focus of the research and analysis are Hannah's past learning experiences in community college.

It is important to emphasize that a Vygotskian approach, particularly as further elaborated and articulated in the transformative ontological approach (Stetsenko, 2009) not only represents a different theoretical approach but is understood as a different worldview. In other words, the Vygotskian project (Stetsenko, 2009), as a metatheory, proposes a radical departure from any individualistic, preprogrammed and prespecified notion of development that either ignores the social and historical context (e.g. cognitive and information processing theory) or individual agency and active contribution to one's own development (e.g. behavioral theory). This worldview entails a relational ontology that approaches social and psychological phenomena as processes that "exist in *the realm of relations and interactions* – that is, as embedded, situated, distributed, and co-constructed within contexts" (Stetsenko, 2009, p. 132, emphasis in original).

However, Stetsenko's expansion of the Vygotskian project (2008) supersedes relational ontology by proposing collaborative transformations as the ground from which development proceeds as expanding individual contribution to sociocultural practices. As Stetsenko (2009, p. 126, emphasis in original) puts it, the central issue in this approach is "*active transformative practice as the source as well as the ultimate 'fabric' (the very matter) of psychological development.*"

Designing this research project as a case study allowed me to explore the dialectical and dynamic relationships between learning, self and autism in the process of Hannah's development

in close proximity, as she engaged in social practices across different activity contexts and settings. Furthermore, this research design promoted development of my intensive relationship with Hannah, and my position in the study as a personally involved researcher and a person actively participating in Hannah's development. Such close relationship between principal research participants and me as a researcher gradually developed into an *activist collaborative research methodology*, which capitalizes on collaboration and mutual partnership of participants and researcher.

Inspired by the recent advances in sociocultural theory, specifically by Holland's and her associates' concepts of positioning and positional identity (Holland, Lachicotte, Skinner & Cain, 1998), I analyzed negotiation of power between Hannah and other participants as they engaged in learning activities. I explored Hannah's positioning, mediated by various cultural tools (e.g. institutional and teaching practices, societal discourses on disability, autism and learning) employed by the participants, including herself. Hannah's positioning enabled me to explore how her socially produced identity emerges in the context of community college, ranging from the position of an agentic active learner with a purposeful life project to the position of a disempowered disabled person. Exploration of these trajectories reveals Hannah's identity and development as a dynamic, interrelated and transformative process, constructed and embedded in collaborative human activities.

In the process of writing this work I often struggled with expressing myself in appropriate language, that would adequately reflect my theoretical and personal stance and understanding of disability, autism, disabled person or a person diagnosed with autism. In the literature I reviewed I found various ways of writing about and referring to persons diagnosed with autism, as well as

to disabled persons in general, without a clear and unified terminology that would be satisfactory and dignifying to this population.

Pollack (2005, p. 5), who offers one of the most exhaustive discussions on this issue, concludes that “[i]n this field, there is virtually no vocabulary which has universal support, but there is agreement that under a social model, disability results from social organization, whether a person is a wheelchair user, partially sighted or dyspraxic.” In general, I relied on Pollack’s statement for guidance. I use the term “disabled students,” which I prefer over the frequently used person-first “student with disability,” to indicate that the disability does not reside in the person, rather in the context and activities a person engages in. For this reason, the term “student with disability” is used only when citing original source or referring to institutional terminology. For similar reasons, I opted to use a term “person diagnosed with autism,” or “person diagnosed as autistic,” instead of frequently used “autistic person,” or “person with autism.” In some cases, I use quotation marks to indicate my position and intention of subverting the meaning, for instance “autistic person,” “being autistic.”

However, I use term “autistic identity,” to refer to the social identity of a person diagnosed with autism identifying the membership of social group of persons diagnosed with autism. Frequently, this term is also used by the members of autistic community.

These general rules and conventions notwithstanding, I often found no matter which is the term of choice, its meaning, and the intention of the author employing it, can not be fully understood from the isolated term itself, but only becomes clear(er) when used in the overall context of the text. For instance, it has been advocated to use “difference” or “different” instead of “deficit”. However, if “difference” is used to label individual differences in order to categorize people, and label some individuals and groups as “developmentally different kind of people”, the

attempt of avoiding pathologizing people and using more dignifying label fails. Vygotsky's idea that there are not different kinds of people, only different path of development (including differentiated cultural tools) truly captures this point. I wish, and I hope, that this point of Vygotsky, which I consider as one of the central ones for this work, will come through in the following text.

2. Theoretical foundations

2.1. Vygotsky's cultural- historical approach to development

In this chapter I will briefly review how the Vygotskian project, early since its inception, approached the issue of disability from a cultural-historical developmental perspective. Notably, Vygotsky (1993) criticized then current medical views of disability based on reductionist developmental views. More than eighty decades ago, he criticized mechanistic views of disabled children and their development. He pointed out that psychological methods applied for working with such children are based “purely on quantitative conception of childhood development impeded by a defect, i.e. degree by which the intellect is lowered, without characterizing either the defect itself or the inner structure of the personality created by it” (Vygotsky (1993, p. 29). As I discuss in great detail below, such view is still prevalent in the medical model of disability in general, and autism in particular.

Vygotsky's critique is still highly relevant in that the current medical model conceptualizes human development as an individual and additive (or in the case of autism rather subtractive) process. According to this model, the disabled child equals the normal child minus the impairment causing the disability. Consequently, the focus of this approach is to “solve the equation,” meaning to “acquire” a normal child by negating the child's defect through curing, minimizing, or modifying it. Importantly, the medical model downplays the role of contextual factors in the manifestations of disability. Moreover, in the medical model the suspect of the source of defect and impairment is frequently viewed as genetic or biological in origin. This entails a predeterministic view of future development (see Gottlieb, 1998, 2006) that further complicates the equation, leaving it without solution insofar as the genetic or biological defect is unknown and unchangeable.

Such decontextualized model of development underpins many cognitive approaches to development that focus exclusively on defects and impairments of the individual child. For instance, Gavelek and Palincsar (1988) criticize the information-processing model applied by Lee Swanson (1987) to learning disabilities in which a “complex phenomena is reduced into manageable and understandable pieces of information” (1988, p 278). Glaringly, this view persistently eliminates the social milieu out of analysis for the purpose of analyzing individual functioning. As these authors claim, any “conceptions of development of the abled or disabled that ignore the social, cultural, and historical milieu are, at best, incomplete and, at worst, misleading” (1988, p. 280).

Practices guided by such decontextualized approaches, be it research, therapy, education, or any other type of intervention, locate the disability, defect, or impairment exclusively in the child’s body or mind. As a result, the focus is on how to “eliminate” and “cure the defect” in order to “normalize” the child. Furthermore, many approaches also narrowly focus only on some aspect of “defects“ on development, such as cognitive, behavioral or emotional aspect or its manifestation in one of these areas. For instance, behavioral therapy, which is considered one of the most successful interventions for children diagnosed with autism, focuses on eliminating unwanted behaviors without an effort at understanding the source of such behaviors or how symptoms emerge and become interrelated in the course of the development of the child. As is well known, behaviorists believe that behavior modification is of great help to the developing person diagnosed with autism. However, as many have pointed out, there are clear limitations to such program, as the goal is to control behavior, rather than to promote development by seeking to engage the person diagnosed with autism in meaningful sociocultural activities.

It is precisely this type of mechanistic understanding of development that Vygotsky (1993) radically rejects, when he argues that development cannot be understood as “merely quantitative growth, by a gradual strengthening and heightening of mental activity.” According to him, development is essentially about the “transition from one qualitative type to another, to a chain of metamorphoses” (p. 42). Thus, he claims that a child in every developmental stage, in each of its phases, “represents a qualitative uniqueness, i.e. a specific organic and psychological structure; in precisely the same way, a handicapped child represents a qualitatively different, unique type of development” (p. 30).

By focusing on participation and contribution to sociocultural practices as the ontological and epistemological grounding of development, a Vygotsky’s approach to understanding disability rejects any attempt to locate disability solely in individual minds or bodies. Importantly, this view also rejects a radical separation between “normal” and “abnormal” development, as all children develop only insofar as they have access to and opportunities to engage in sociocultural activities. Thus, one of the most important points of this project, which I refer throughout this work, is that studying development in disabled children means applying exactly the same kind of theoretical principles, concepts and methodology necessary to study typically developing children. Following TAS, this entails viewing development as the socially situated process of striving to participate in and contribute to social practices. Though this point may appear trivial, my contention is that not following this line of thought, explicitly or implicitly, leads to misconceptions of development with further implications resulting in misleading interventions. However, the idea must not be confused with the need for applying different research methods in studying and working with disabled children and adults that reflect their different developmental path and need for differentiated tools.

Before discussing Vygotsky's theory of defectology in greater detail, I will briefly present my understanding of development (based on Vygotsky's cultural-historical approach as further extended by TAS), including the key principles I utilized in this study. This will help me to present a proper understanding of Vygotsky's theory of defectology.

2.1.1. Dialectical view of development: Transformative ontology

Vygotsky's notion of dynamic development is fully compatible with Dynamic system theory's (DST) conceptualization of development. Specifically, both approaches converge on their relational ontology further extended by Stetsenko in the concept of transformative ontology (2008).

As Honeycutt and Lickliter (2007) point out, Neo-Darwinian theories treat development as a predominantly predetermined process. Chief among such contemporary approaches, evolutionary psychology champions a view of phenotypic development that separates elements into "genetically determined and environmentally acquired" (2007, p. 462). As these authors point out, these views have penetrated into many developmental theories and are present even in interactionist theories that attempt to distinguish themselves from dichotomized and dichotomizing theories by acknowledging the importance of the interaction between genetic and environmental factors. They strongly reject a gene-centered explanation of human development. Instead, they propose Dynamic Systems Theory and its "constructive interactionism" as an alternative. According to them (2003, p. 462-463):

[D]evelopment is seen as self-organizing , probabilistic process in which pattern and order emerge and change as a result of complex interactions and relations among developmentally relevant resources both internal (including genes, but also cells, hormones, organs) and external to the organism (and not from some set of prespecified substrate, independent of the activity, experience, or setting of the individual. This relational focus on the ontogenetic construction of phenotypes undermines any meaningful opposition between genetic and

environmental sources of information for development.

This view has direct implications for a critical examination of current research paradigms in autism that privilege genetics as the ultimate ontological grounding of this disability. As I contend, the hunt for “autistic genes” and for the “cure” of autism are often based on a predeterministic misconception of development that Lickliter and Honeycutt (2003, p. 463) call “old-school version of interactionism.” Despite acknowledging the interaction between genetic and environmental factors, in this view “ontological separation of causal components representing nature (genes) and those that represent nurture” is maintained. As these authors claim, traditionally, genes are attributed a primary or determinative role in phenotype expression, and overweight the role of environmental or non-genetic factors that are considered only as supportive or disruptive to the development. At most, environmental factors are understood as only “activating or triggering the instructions that are presumed to be encoded in the organism’s genome” (2003, p. 463). This misconception is even more prevalent, and rarely challenged, in conceptions of atypical development, in which the ontological separation of sources of development is further exacerbated. For instance, if the “source of a defect” is considered to be biological, the development of disabled children will appear to be dominated by nature to a much greater extent than in the case of typically developing children. If the “anomaly” is proven to be genetically caused or linked, then development becomes even more profoundly a matter of an unfolding, predetermined, pre-specified, gene-centered, and almost always tragic, developmental trajectory. Consequently, the weight and role of genes, or other biological factors, is even more pronounced as they are seen to dominate phenotypic expression even more significantly than in typical development. By the same token, the role of the environment is further downplayed as that of only “activating or triggering” the instructions already encoded in the genotype. In such

theoretical accounts of disability, social factors are relegated to a merely supportive apparatus that potentially might influence already predetermined development. Consequently, disabled children are often seen - and treated as a result of these conceptualizations- as victims of a given developmental “defect.”

Conversely, drawing on Vygotsky’s cultural-historical approach, atypical, just as typical development, is considered a dynamic and probabilistic epigenetic process in which all factors, biological and socio-cultural, *constitute its construction* on all levels. As Lickliter and Honeycutt (2003) put it, the phenotype is not simply “expressed,” but rather *generated* in individual development. They further argue that (2003, p. 463):

what is actually passed on or made available in reproduction is both a structured genome and a structured segment of the world. This perspective thus emphasizes the interdependent rather than co-relational nature of the link between genes and the organism’s developmental context. From this view, genes are part of the developmental system and do not act as independent causes. Thus, the mere passing on of a genome cannot serve as a sufficient explanation for the achievement of any phenotypic outcome, although it is certainly a necessary one. Traits or characters (be they behavioral, cognitive, or otherwise) must be *constructed* in individual ontogeny, whether or not they have an evolutionary history. Thus, DST stands in contrast to the widespread belief that ontogeny and phylogeny are alternative processes by which information is made available to developing individuals. A focus on the ontogenetic construction of phenotypes, in which the organism coactively constructs itself in each generation in relation to its internal and external environment, undermines any meaningful distinction between genetic and environmental or experiential causes of phenotypic development.

Stetsenko (2009) discusses relational ontology in terms of psychological development and develops it further into *transformative ontology* by emphasizing and bringing upfront human activity as a basic way of humans of relating to world which is “material, practical, and always by necessity social, collaborative processes aimed at transforming the world” (p. 137). This position further extends Vygotsky’s project and other post-Vygotskian concepts of development by emphasizing the very centrality of individuals’ *contribution* to the collaborative practices from an “authentic subject position as the grounding for human subjectivity” (2009, p. 138) and

the way individuals relate to the world through contributing to it and transforming themselves in the process. In Stetsenko's words (p. 138):

[I]t is the simultaneity, or in even stronger terms, the unity of human transformative practice on the one hand, and the process of becoming (and being human) and of knowing oneself and the world on the other, that is conveyed in this conception. Human beings come to be themselves and come to know their world and themselves *in the process and as the process* of collaboratively changing their world (while changing together with it)-in midst of this process and as one of its facets-rather than outside of or merely in connection with it. This conceptualization of human development moves beyond the dualistic designation of nature and culture and does so not by simply stating their bi-directional relation or hybridity. Instead, the collaborative human practice is posited as the new unified-and unique-ontological realm that takes over and dialectically supersedes (or supplants) both nature and culture, absorbing and negating them within its own, and radically new, transformative ontology.

The continuous overemphasis on biological or genetic factors, their determination of further development, and at the same time the view of social environment as only supportive and corrective in the development of disabled children, is quite striking. It completely undermines understanding social interactions and sociocultural tools as constitutive elements of development. In such views, the impairment multiplies the weight and dominance of the genetic and biological in the development and makes them more problematic, if not impossible, to change the course of development. However, the development of disabled children, and particularly mentally and cognitively disabled, is arguably even more dependent on the socio-cultural environment than that of typically developing children. This is due to the need to intensity social interactions and the demand of creating novel, nontraditional socio-cultural means of behavior based on finding and developing detours for development in general and, from a Vygotskian perspective, specifically for the development of higher mental functioning.

The argument that development in disabled children (especially in intellectually disabled children) is dominated by biological factors through the impairment/s that cause it, which in many instances entail viewing development as "doomed," is easily confirmed whenever a child

is left to develop on his or her own without the adequate socio-cultural means that are routinely available to a typically developing child. If this scenario is reversed, meaning a typically developing child would be left on such a “deserted island” of self-maturation, it is without a question that s/he would not, and could not, develop typical psychological functioning.

2.1.2. Vygotsky: General theory of development

The last point above brings me to the very essence of Vygotsky’s theory (1962, 1978), the notion that *social development precedes individual development*, which highlights the role of others in psychological development. Through this notion Vygotsky inverts and indeed resolves the social-versus-individual dichotomy common to traditional developmental accounts. He elaborated the primacy of social processes in human development in his famous “genetic law” of the emergence and development of psychological functions, in which he analyzes how higher mental functioning develops first in *interpsychological* process (between people) and only then it can be internalized to become an *intrapsychological* process (Vygotsky, 1978). In other words, first the child’s higher psychological functioning is conditioned by collective behavior in cooperation with other people, and only subsequently becomes internalized as the child’s own psychological functions. These higher psychological functions are developed in the process of mediation through *cultural tools and symbols* (Vygotsky, 1978).

Therefore, the role of *cultural tools and symbols* in human development is central to Vygotsky’s theory of cultural mediation of mental functioning. In his work, Vygotsky focused on language as a major tool through which children appropriate culture. In this view, culture is crystallized not only in language, which is the most distinct and elaborated form of crystallization of culture, but also in all kinds of material or symbolic artifacts such as musical

tones and geometrical forms, habits and rituals, values and norms, tools and instruments, material objects of everyday use with culturally fixed ways of handling them (Stetsenko, 1993). Elaborating on this point, Stetsenko (1993) further points out that culture not only provides the context in which development takes place, but it constitutes the very basis from which human development emerges. The immense importance attached to culture in human development lies exactly in its mediating role in the psychological development of humans and that is why one of the most challenging tasks of human development is to acquire the culture we are born into (Stetsenko, 1993). Simply put, without culture, its tools and symbols, no human being can develop.

In interpreting the role of cultural tools in human development, one has to be careful not to fall into the trap of exclusively concentrating on tools while neglecting the role of social interactions in mediation process (see Stetsenko, 1999 for further discussion of this issue). Focusing solely on tools and symbols in the process of social interaction do not enable us to really study their *use* and their meanings. Mediation as a social process does not come from the tools and symbols and they cannot be understood as objects. Their mediating role results from the social meaning of tools and symbols while interacting with, using, and acting upon them. Thus, it is other people, adults or other more competent partners, who essentially promote children's development in that they mediate the process of passing shared knowledge and experience using cultural tools and artifacts. Importantly, the origins of knowledge and mind are in social activity and not in tools and objects by themselves. Therefore, tools represent the embodiment of human activity (Stetsenko, 1999) and it is the meanings of symbols and tools that are passed through activity, not thoughts. For example, when a child acquires language, she or he acquires an activity, that means the ability to abstractly represent the word (Nelson, 1996).

In sum, as Stetsenko (1993, p. 40-41) explains, the child's psychological development is "a process of appropriation of socially and historically developed means and modes of psychological functions, means and modes which are transmitted to a child by people through cooperation, communication, social intercourse and shared activity". This process of "interiorization of cultural forms of psychological processes is the core of cognitive development and the development of personality" (Stetsenko, 1993, p. 42).

2.1.3. Transformative Activist Stance

However, as the same author emphasizes (e.g. Stetsenko & Arieviditch, 2004), the process of internalization, the very process of human development, entails more than socialization and participation in the world, as for example concept of community of practice (Lave & Wenger, 1991; Wenger, 1998) proposes. According to Stetsenko (2009) it is the *collaborative purposeful transformation* of the world that is "the core of human nature and the principled grounding for learning and development." (Stetsenko 2009, p. 139). Positioning a collaborative transformative practice as a source of development, as suggested in theory of Transformative Activist Stance (for detailed discussion see Stetsenko 2008, 2010, 2012, 2013), allows for dialectical understanding of learning and development that further embodies the interconnection between learning and identity development. According to this view:

[The] material, practical, and always social, collaborative process aimed at transforming the world can be posited as the core reality out of which both human development and learning unfold. This proposition is in line with the famous statement by Marx that "[t]he philosophers have only interpreted the world, in various ways; the point however, is to change it" (Marx, 1978, p. 145; emphasis in the original). The suggested expansion in TAS goes beyond the epistemological level by stating that while there is indeed no gap between changing one's world and knowing it (a point well understood by Piaget and Dewey), there is also no gap between changing one's world, knowing it, and being (or becoming) oneself; with *all three dimensions* emerging and developing together, with no

ontological gaps posited to separate them (Vianna & Stetsenko, 2011, p. 317-318, emphasis in original).

The goal of my dissertation research is to employ this dialectical relationship between learning and development as conceptualized in Vygotsky's cultural-historical approach as, and by TAS in particular, to understand the development of a young woman diagnosed with autism. Therefore, I will now briefly discuss the relationship between learning and development further, building upon already presented ideas.

2.1.4. Learning and development

Leontiev (1975/1983), one of the founders of cultural-historical tradition within psychology, shared the interest in human historical practice as the source of human subjectivity and development. Specifically, he focused on explicating the dynamics of various levels of activity that lead to the production of the self, which, according to him occur in “two-fold transition.” Namely “(a) the transition from the world (in all the complexity of its dimensions) into the process of practical goal-oriented activity, and (b) the transition from activity into subjective product – human mind and self” (Stetsenko & Arievitch, 2004, p. 484). Within activity, an individual connects and relates to the world, and at the same time human subjectivity is realized in this activity. Leontiev further claims that each activity is driven by certain motives and those are of social origin. This means that human activities are always driven by “something objectively existing in the world, rather than by some events and occurrences in the hidden realm of mental processes or human soul” (Stetsenko & Arievitch, 2004, p. 486.). Furthermore, Leontiev suggests that some activities become dominant - leading ways of child's relating to her environment, and certain activities (e.g. play, learning) are characteristic for stages of mental development in early ontogeny. Stetsenko & Arievitch (2004) expanded on Leontiev's

understanding of the dialectical relationship of social and individual dimensions in human development and the concept of leading activity by introducing the concept of *the self as leading activity*. In this view, the self is “a process of real-life activity that most explicitly positions individuals to meaningfully contribute to the ongoing social collaborative practices in the world” (2004, p. 493). As a *process*, the role of the self is to connect “individuals to the social world around them and serves the purposes of organizing these social connections and ties.” As such the self represents “a moment in ongoing social activities that is not stored somewhere in the depths of human soul, but it is constantly re-enacted and constructed by individuals anew in the ever-shifting balances of life” (2004, p. 493).

According to these authors, the self as leading activity further implies that (p. 493-494):

- 1) Self is realized through *transformative* practices, i.e. the self is an activity and instrument of transforming the world, an instrument of social change.
- 2) Self is not something that simply comes on top of an individual’s engagement with the social world, but *is the very engagement*.
- 3) Self as a value- and commitment-laden activity, is always produced from certain standpoint, with certain agenda and goals in regard to concrete socio-political and cultural-historical as well as personal circumstances of shared social life.
- 4) Self has a leading role in organizing and directing all other pursuits and activities of the person, as self is always connected to other activities that individuals conduct and engage in, and is inherent in the totality of a person’s life.
- 5) Self as produced in social and historical practices is also inherently social and historical product.

These tenets indicate that the self can be understood as a process, originating and being materialized in contributions to collective transformative practices, rather than a mental entity somehow arising inside of the head or body of the individual. The dialectical relationship between individual and social in the very process of producing the self, as proposed in the concept of self as leading activity, is embodied in the contribution to social practices, as the “contribution is something that individuals do, but only as members of their communities who are fully immersed in social collaborative practices” (Stetsenko, 2010, p. 9).

This conceptualization of the self allows for a radically different understanding and analysis of the development of disabled persons than traditional individualistic theories of self, or even some other social practice theories can offer. For instance, it suggests asking questions such as “Is the disabled person enabled by her communities to be fully immersed in social collaborative practices?” “What are the tools available that allow, support or prevent contributions and transformation of the world and oneself?” “How is disability as a social practice itself used as a social tool preventing already marginalized people from participating and engaging in social practices?”

Within Vygotsky’s cultural-historical approach, what connects learning and identity development is that both of these processes entail the collaborative participation in social practices, learning being a specific type of social practice. This is one of the ideas presented by Vygotsky (1978), who claimed that processes of child development and learning are interrelated, creating a unity, although they are not identical. According to this view, development does not proceed learning, as for instance in Piagetian constructivist theory. Instead, he claimed that learning, if properly organized, can result in mental development and set in motion a variety of developmental processes that would be impossible apart from learning (Vygotsky, 1978). Building on Vygotsky’s theory, Galperin (1985) devoted most of his research agenda to exploring the relationship between the quality of instructions and learning. He argued, and throughout his research career provided significant evidence, that the quality of cultural tools, such as scientific concepts, play a key role in children’s cognitive development.

Furthermore, according to the Vygotskian approach, development of affect and intellect represent a dynamic unity. Specifically, scholars working within Vygotskian tradition argue that the motivation, cognition and social development of the school child are connected through the

activities the child engages with other people, (Elkonin, 1971; Hedegaard & Chaiklin, 2000; Leontiev, 1978; Vygotsky, 1978). As Hedegaard (2002, p. 217) points out, the motivation, cognition and social development of the schoolchild are “connected through the activities the child practices in with other people – in daily family activities, leisure-time activities, as well as with study activities at school. The meaning of these activities for the child is the source of motivation.”

2.1.5. Vygotsky: Theory of defectology

Vygotsky’s theory of defectology/disontogenesis¹ (Vygotsky, 1983, 1987), which is less known in the west, specifically addresses the development of cognitively and physically disabled children. Before I explain this theory, it is important to note that both Vygotsky’s general theory of development and his disontogenesis theory are the results of his deep social commitment and engagement with the most disadvantaged members of society, such as homeless and disabled children. His involvement with his society, its old and emergent issues, together with his commitment to building a new, just society were materialized in this (till this day) revolutionary understanding and explanation of human development (for further discussion of socio-historical context of Vygotsky’s work see e.g. Knox & Stevens, 1993; Lompscher, 2006; Stetsenko 2004). It is no surprise that one of the most important assets of his theory, although often overlooked in

¹ The language used by Vygotsky to refer to disability, disabled children, and their development appears outdated. For a reader in the 21st century might seem to reflect a deficit model of disability. However, it is important to read his work within the historical context and keep in mind that Vygotsky wrote a theory of defectology in the early 20th century, when such terminology was a common (and the only available) practice. When I wrote about his theory, I made an effort to change and update the original language as much as possible, while maintaining the original meanings. I kept the original expressions (e.g. “mental retardation”) when directly quoting Vygotsky. I made an effort to change and update the original language as

many of its modern interpretations, is the commitment to social justice.

This point is extremely important, as it converges with the focus of disability studies on the inclusion of disabled persons, which is ultimately an issue of social justice. Regarding the development of disabled children, Vygotsky provides a theoretical explanation of why, for them, equal access to cultural tools that allow for participation in and contribution to collective activities is not only a matter of human rights, or merely an opportunity that *might* enhance development, but rather these are *necessary* and *constitutive* forces and conditions of development. In fact, Vygotsky (1993, p. 17) called for a modern defectology that would be liberated from “any trace of philanthropic, invalid-oriented, or religious atmosphere based on an interaction of pity and charity”. This point will be further elaborated throughout this chapter.

However, before continuing with my discussion of how Vygotsky’s theory of defectology can contribute to contemporary disability studies, it is important to present some historical aspects of the development of his thought. Vygotsky wrote his theory of defectology between 1924-1931 (Rieber, 1993), before autism was officially described by Leo Kanner in 1943 and by Hans Asperger in 1944. Therefore, he makes no specific reference to autism as a diagnosis as we know it today. Nevertheless, based on his description of the disabled children he worked with, their behaviors and psychological functions, it can be suggested that he encountered children who displayed autistic tendencies.

In his classification of children whose “behavior deviates from the norm and who therefore stand out from the general mass of children with respect to education” (p 173). Vygotsky, based on his notion of primary and secondary impairments (further discussed in detail on page 30), recognizes two types of disabled children, handicapped and difficult children (1983, p. 173):

much as possible, while maintaining the original meanings. I kept the original expressions (e.g.

a) the type of child whose behavior deviates from the norm as a result of some organic defect (physically handicapped children including blind, deaf, blind-deaf, and crippled children along with mentally retarded or feeble-minded children who suffer from some organic defect); and

b) the type of child whose behavior deviates from the norm as a result of some functional disorder (difficult children in the narrow and strict sense of the world, such as delinquents, children with character disorders, and psychopaths).

In an effort to conceptualize autism within Vygotsky's theory of disontogenesis, one key question relates to locating autism within his classification of types of children's disabilities (handicapped versus difficult children) and in terms of primary versus secondary impairments. In the case of autism, this is to a large extent a question of its etiology, which is still very far from being clearly determined. For instance, Piven and Folstein (1994), who focus on the possibility of genetic etiology autism, note that autism is a "behavioral syndrome" defined by clinical features, not by etiology (p. 31). They also claim that although validity at a syndromic level is well established, it can be claimed with almost certainty that autism is an etiologically heterogeneous disorder. They report that autism can develop in association with etiologies as diverse as "congenital rubella (Chess, 1971), tuberous sclerosis (Hunt and Dennis, 1987), and the fragile X anomaly (Brown et al, 1986), as well as in the absence of any identifiable, co-occurring, etiologically defined condition" (Piven & Folstein, 1994, p. 31). Some of the most recent findings from research in genetics that focuses on the search for genetic links of autism indicate that different types of autism need to be considered due to various types - and their strength- of genetic links as well as various ways and levels of interaction among genes and other contexts, such as biological, cultural and historical (Walsh, 2010). The results of one multinational study that looked at the genetic makeup of thousands of individuals diagnosed with autism around the world, whose goals was to find any patterns or genetic clusters that would indicate autistic

"mental retardation") when directly quoting Vygotsky.

symptoms, found out that each person diagnosed as autistic had a unique genetic makeup. Another study of almost 200 twins (Hallmayer, 2011), of which one twin was diagnosed as autistic, explored the possibility of the second twin being diagnosed as autistic too. The researcher found out that both fraternal and identical twins had the same probability of getting a diagnosis, which, according to this author suggests that twins common gestational or early childhood experience may have contributed to their similarity.

Thus, there seems to be a general consensus around possible multiple and diverse causes of autism and even that each case of autism might be a result of the confluence of several factors. The broad spectrum of symptoms and manifestations, as well as their intensity in individual children, support such view. Therefore, the clarification and clear identification of causes of autism, as well as identification of primary and secondary “impairments” in autism remain problematic and difficult. Thus, the results of the recent studies I reviewed, which looked at both genetic and environmental origins of autism, support the probabilistic view of development I discussed in the previous section of this chapter.

The issue of identifying and recognizing primary and secondary impairments of autism is very important. For many researchers it represents, in one form or another, the insurmountable reason for not applying, or even discrediting Vygotsky’s theory to approaching autism. However, I believe that such conviction, and the questioning of the theory and its application on this basis, only betrays a misunderstanding of disontogenesis theory and, more broadly, a misunderstanding of Vygotsky’s theory as a metatheory and worldview. I hope that the following more detailed presentation of disontogenesis will provide further elaboration of this point.

The distinction between primary and secondary impairments implies that although an “organic defect” (i.e. primary impairment) itself cannot be reversed or influenced by

psychological or educational intervention, its impact in terms of the overall system of symptoms and disability is *always* only limited. As the symptomatic character of autism (Piven and Folstein, 1994) indicates, and a growing body of research on autism corroborates, most of the symptoms related to autism are of secondary nature. Therefore, these secondary symptoms should be accessible to instructional support in the form of education, therapy, or other social practices.

As Vygotsky's theory instructs us, secondary impairments, often ascribed to and located within the individuals and their diagnosed disability, "disappear" altogether depending on socio-cultural and historical context of the activity (including the cultural tools) in which individual's development is situated and constructed.

In order to highlight the importance of Vygotsky's conception of disability, I present in the following section the key points of Vygotsky's Fundamentals of Defectology.

Positive differential approach: Disability as a different path of development

Vygotsky suggests viewing the development of a disabled child in terms of differences rather than deficiencies. Disability needs to be understood and approached as a different path of development and becoming, rather than deficiency of normalcy (1993, p. 96):

A child whose development is impeded by a (mental) handicap is not simply a child less developed than his peers; rather, he has developed differently. A child in each stage of his development, in each of his phases, represents a qualitative uniqueness, i.e. a specific organic and psychological structure; in precisely the same way handicapped child represents a qualitatively different, unique type of development.

Furthermore, he emphasized that in the upbringing and educating of a disabled child, as well as in understanding her development, we need to focus on the strengths of a child, rather than her weakness and impairments (1993, p. 123):

[I]t is impossible to explain mental retardation on the basis of a purely negative definition. It is impossible to be guided only by what a given child lacks, by what he is not. On the contrary, it is necessary to have some conception, even if the most vague understanding, of what his capabilities are and what he represents.

Employing such an approach to studying children's positive characteristics expands the purpose of studying disabled children. Specifically, it allows for "the purpose of finding the best form for practical action" (p. 123) to promote their development.

Importantly, Vygotsky's theory calls for a different meaning of the defect. Accordingly, the defect should not be understood only as a weakness but as strength, as a "*developmental force*" whose positive aspects have been mostly neglected in educating children. According to Vygotsky (1993, p. 34), the positive uniqueness of a disabled child lies in the new formations created by the impairment - a uniqueness not found in a typically developing child:

Whatever the anticipated outcome, always and in all circumstances, development, complicated by a defect, represents a creative (physical and psychological) process; the creation and re-creation of a child's personality based upon the restructuring of all the adaptive functions and upon the formation of new process-overarching, substituting, equalizing-generated by the handicap, and creating new, roundabout paths for development.

Therefore, the major goal in the study of intellectual disabilities is, according to Vygotsky, the creation of a *positive differential approach*, based on identifying and classifying children according to their various individual talents and potentials. According to him, it is the "wealth of each retarded child's reserves and strength that must be the determining factor in establishing a program for him or her" (1993, p. 20). Such education program focus on developing "special pedagogical techniques aimed at the positive uniqueness of these children, in order to create in them the necessary sociocultural superstructure which will shore up development at its point of physical or mental weakness," (1993, p.17).

Through the realization of child's Zone of Proximal Development (ZPD), teachers help the

child acquire the tools needed for this higher level of psychological activity, so to enable independent action in the performance of the aimed-for activity. The potential development of disabled children is usually wider, so their present level is more apparent than their potential. Therefore their potential must be forced by teaching through adequate tools including additional instructions.

Recognition of primary and secondary causes of impairments

Vygotsky proposes a dynamic conceptualization of disability based on distinguishing between *primary* and *secondary* causes and impairments of handicap. The primary impairment is an organic one, due to both endogenous and exogenous biological causes. The secondary impairment refers to a consequent distortion of higher psychological functions (e.g. abstract reasoning, logical memory, voluntary attention, etc.) as the result of the interaction of the primary impairment with the social environment of the disabled child. The primary organic impairment can prevent a child from mastering some social skills and knowledge, which usually leads to impaired development. However, many of the resulting symptoms are of a secondary nature, as they are acquired in the process of social interactions. As Vygotsky emphasizes, it is the child's social milieu, including social interactions and cultural tools available (or not) to the child, not the organic impairment per se, that alter the child's development and results in disontogenesis (defective development). Obviously, the quality and accessibility of social interactions and cultural tools mediating all the activities of the child are of utmost importance for her development.

As Vygotsky emphasizes, the distinction between primary and secondary causes of developmental impairments is not simply of theoretical interest, but has profound implications

for intervention because its secondary complications and delays are more responsive to therapeutic pedagogical activity- unlike organic conditions that cannot be eliminated.

The fundamental laws of development are the same for both typically and atypically developing children

Vygotsky (1993, p. 124) highlights that the basis for the scientific study of the development of intellectually disabled children is the notion of “unity of laws governing development in both normal and abnormal children.” Importantly, mediational means that are associated with “different intrapsychological tools” on which a child relies must be different insofar as disabled children are, as Vygotsky points out, “psychologically different from normal children and from each other” (1993, p. 15). The general pattern of development of children diagnosed with any kind of disability is essentially the same as that of typically developing children. Consequently, the educational content must be the same for both, typically and atypically developing children.

The education of disabled children should not lag behind regular education. Disabled children might take an atypical route on their development and learning as a result of using differentiated tools (e.g. different means of communication), and employing compensatory processes, but essentially they can and need to follow the line of development of the same higher psychological functions as typically developing children.

Vygotsky further claims that (1993, p. 124):

[t]his position does not negate the fact that the laws governing a mentally retarded child’s development acquire a qualitatively unique, specific expression and that the task is not limited to maintaining this unity. The task consists of showing how child development laws, united in essence and principle, find a concrete, special expression in the case of a retarded child.

Diversified and adequate cultural tools: special system of cultural signs and symbols adapted to the specific psychophysiological characteristics of an atypically developing child

As I already discussed above, Vygotsky explained in his theory the prominent role of cultural

tools. In his own words (1993, p. 15):

[I]n order that the child mediates, makes sense of, and interact in a meaningful way with the environment, he or she must have access to and acquire a multitude of psychological tools or artificial, historically developed, cultural signs available to shape and organize the world.

He further points out that because most of the psychological tools are designed for the typically developing person with all senses and mental functions theoretically intact, “special psychological tools must be developed for the abnormal child which focus on his or her other healthy functions and residual strength” (1993, p. 15). The implication here is that all children, both typically and atypically developing ones, follow the same principles and laws of development and education. Consequently, the psychological nature of instruction should be identical. However, the techniques for instructing a child must always differ depending on the nature of her impairment. The meaning of the tool and the goal of the psychological function to be developed by mastering the tool is the same for typically and atypically developing children. However, the technical shape and the actual type of tool is different and must be adapted to, and be in congruence with the impairment, so the mediation of a cultural and/or psychological meaning is possible. For instance, in the case of language, the leading and the most important tool for child development, it is not important what form it takes (e.g. sign language, Braille or other forms of language representation, or a special communication devise). What matters is that the child appropriates the tool through its meaning, as it is the meaning encoded in the tool that is important, not the tool itself. Therefore, it is the activity and its context, including the goals and motives in which the meaning of the tool is embedded and gives a rise to such meaning, that is crucial, not the type of the tool.

Vygotsky further stresses that the child has to have a variety of tools available that are ready-made, so that the child does not have to reinvent every tool needed. Lompscher (1999), who

continued in Vygotsky's tradition and further developed the concept of learning activity², emphasizes that although the tools should be presented to a child as ready-made, the goals of the tools have to be constructed in the process of learning activity occurring with the child's ZPD. Vygotsky (1993, p. 179) argues that diversified cultural tools (i.e., different symbols, methods, techniques, and formal skills) that are coupled with "identical content with normal schools in all the training and learning processes" should be the fundamental principle of special education.

Social origin of compensatory developmental processes

Vygotsky (1993, p. 147) maintains that, in order to understand the disabled child and her development we must never focus exclusively on her negative characteristics and impairments because they still say very little about the child. Rather, the characteristics of a disabled child must necessarily be "twofold". According to him, the positive uniqueness of the disabled child lies precisely in the "new formations created by the lapse- a uniqueness not found in a normal child." As he further explains (1993, p. 34):

Whatever the anticipated outcome, *always and in all circumstances*, development, complicated by a defect, represents a creative (physical and psychological) process. It represents the creation and re-creation of a child's personality based upon the restructuring of all the adaptive functions and upon the formation of new process-overarching, substituting, equalizing-generated by the handicap, and creating new, roundabout paths for development. The course created by a defect-that of compensation-is the major course of development for a child with physical or functional disability.

² His work based on Leontiev's (1979) notion that activity and the development of self presuppose appropriate motivation, all kinds of activities differ with respect to their motivation. Accordingly, learning activity, as a special kind of activity, aims at psychic transformations of the subject itself (Lompscher, 1999). As Lompscher further notes, other kinds of activity (e.g. play, labor, everyday communication, etc.) may have learning results too. However, they are not consciously aimed at by the subject. Moreover, he argues that learning activity, as any other kind of activity, is directed at goal formation by confronting the learners with phenomena, situations, and tasks going beyond their actual possibilities to such a degree that a problem situation can arise.

Vygotsky believed that in the analysis of the disabled child, the defect alone tells the psychologist nothing, unless she “determines the degree of compensation for the defect, until she shows what lines of counterbalancing behavior will form and what attempt the child will make to compensate for those difficulties which he encounters.” (1993, p. 148). For instance, Vygotsky provides the example of a patient with tuberculosis with indications of 1, 2, and 3 biological defects that show the gravity of the illness, while A, B, and C show compensations for the disease in the patient. He argues that only such combined data can provide a complete picture of the person’s illness and his or her state. It is the degree to which a patient can compensate for some symptoms of the illness that play an important role in the final result of how the illness plays out for the patient, such as the extent of the effect of the disease on the patient and how well the patient can work.

Furthermore, Vygotsky further pointed out that compensatory processes do not always occur successfully. This process depends on “reserves”, or the strength of the child, and her social milieu. According to him, it is the socio-psychological realization of the child’s strength that “decides the fate of personality, not the defect itself” (1993, p. 34).

However, in order to fully comprehend and appreciate compensatory developmental processes and their role in the development of atypically developing children, we need to pay attention to Vygotsky’s discussion of this issue in greater detail. In particular, one must note his precise and articulated explanation of the theoretical background of the compensatory process, its source and origin. He points out that the concept of compensation was usually not adapted to the development of intellectually disabled children because some theoreticians believe that “the single and exclusive basis of compensatory processes is the actual subjective reaction of the child’ personality to that situation which was created as a result of the defect” (1993, p. 125). In

other words, the compensatory process was typically understood in terms of stimulus –reaction reflex. The child’s developing compensatory process tended to be seen only as a reaction to one’s awareness of his or her condition in form of inferiority complex. As such, the impairment was seen as acting as a stimuli for compensatory process. The actual compensation for the impairment is only possible as the struggle to overcome one’s own inadequacy and raising to a higher level.

In contrast, Vygotsky argued that compensatory developmental processes can arise even if they are not linked to awareness of deficiency. Thus, he offers a dynamic proposition about the social origin of compensatory processes (1993, p. 126-127):

The source, or initial stimuli, for the emergence of compensatory processes are those objective difficulties with which a child struggles in the process of development. He struggles to get around these difficulties with which a child struggles in the process of development. He struggles to get around these difficulties or to overcome them with the help of a whole series of such formation not initially found in development. We have observed the fact that, when coping with difficulties, the child is forced to proceed along a roundabout path in order to overcome them. We have observed that the process of a child’s interaction with his environment gives rise to a situation in which the child is propelled along a path of compensation. The following serves as a most important argument for this: *The outcome of compensatory and developmental processes as a whole depends not only on the nature and severity of the defect, but also on the social reality of the defect, that is, on those difficulties which the effect causes from the viewpoint of the child’s social position.* For children with handicaps, compensation occurs in totally different circumstances depending on what the situation is, in what kind of environment the child is reared, and what difficulties arise for him as a result of his handicapped conditions.

Vygotsky connects the questions of compensatory development with compensatory reserves and questions what is the source and driving force of the compensatory process. He radically refuses the idea that the source of compensation is the “inner goal-directed nature of life’s developmental process itself and an inner integrity of personality” (1993, p. 127). He radically rejects such simplistic view that stands on a teleological position according to which (p. 127):

each child is endowed with certain purposefulness, a dynamic impulse or inner drive that draws the child in some indefinable way toward development, toward full self-assertion;

some instinctive life force pushes the child ahead and guarantees his development, no matter what.

Vygotsky refuses to base the source of compensatory processes in some “inner burst of forces.” Rather he suggests that “the reserve of compensatory forces is, to a large degree, to be found in *the social-collective life of the child*,” (1993, p. 127, emphasis added). According to Vygotsky, collective behavior represents the source whence a child finds “the material to build the inner functions which are realized during process of compensatory development.” (1993, p. 127).

Vygotsky notes that the extent of child’s “inner reserves” (e.g. the degree of intellectual disability) is the essential and primary factor in determining to what degree a child will be capable of using this material. Although Vygotsky admits that the extent of intellectual disability is a significant factor of the extent of the inner reserves of the child he also emphasizes that at the same time “it is not the determining factor at higher stages, and in many cases this discrepancy is eliminated in the process of the child’ development“ (1993, p. 127).

Natural and cultural lines of development

Applying the notion of fusion of natural and cultural lines of development to the atypically developing children, Vygotsky challenges traditional approaches that usually conceive organic defect in a child as reason of contracted development, that further limits and disables the cultural development of the child. He makes the opposite proposition: because of the limitations of natural line of development, the cultural line of development has to be reorganized, enhanced, and supported to substitute and compensate for the limitations or obscurity of natural development.

Following Vygotsky’s general theory of development, it can be understood that a typical

child's socialization is usually fused with the processes of her maturation and both lines of development-natural and cultural- coincide and merge one into the other. Consequently, as he states, "both series of change converge, mutually penetrating each other to form, in essence, a single series of formative socio-biological influence on the personality" (1993, p. 42). However, as he further explains, such fusion is not observed in disabled children and their natural and cultural lines of development do not merge. Rather these lines usually "diverge more sharply". The reason for such diversion is the fact that human culture, and everything the cultural line of development embodies, such as material tools, its sociopsychological apparatuses, institutions, are all "intended for a normal psychophysiological constitution". More specifically, Vygotsky's explains that (1993, p. 167, emphasis added):

The entire apparatus of human culture (the outer form of behavior) has been adapted to a human being's normal psychophysiological organization. Our entire culture is intended for man who possesses certain organs-a hand, an eye and ear-as well as certain functions of the brain. All our instruments, our technology, all our signs and symbols are intended for a normal human being. Hence, there arises an *illusion of convergence, of natural transition* from natural forms to cultural forms. Such a natural transition, by the very nature of things, *cannot occur*.

As Vygotsky argues, because culture and all its products are created by and for the use of typically developing individuals, the use and mastering of these tools, including psychological apparatuses, assume, as necessary prerequisites, "the presence of innate human intellect, organs, and functions" (1993, p. 42). As he pointedly explained, such view is based on the *illusion* of a smooth, naturally unfolding, contained developmental process. Because typically developing children are usually gradually introduced to tools that correspond with their psychophysiological structures, the process of socialization and mastering of those tools is seemingly natural and spontaneous. However, the true essence of the process and its "artificial" nature is revealed when an "atypical development (conditioned by defect) cannot be spontaneously and directly

conditioned by culture, as in the case of a normal child,” (1993, p. 42).

As Vygotsky further explains (1993, p. 167-168):

[a]s soon as we have before us a child deviating from the norm, a child afflicted by some psychophysiological deficit, then even a naive observer will see that convergence immediately gives way to a strong divergence, to discrepancy and disparity between the natural and the cultural lines of child development. Left to himself and to his own natural development, a deaf-mute child will never learn speech, and a blind person will never master writing.

Vygotsky illustrates this point with the example of a blind person who, unable to see, can never implicitly learn (as seeing persons do) that if it is dark outside and s/he is inside a lit up room without shades or pulled down blinds, then s/he can be seen from outside. The blind person has to be explicitly taught and become aware of such fact.

As Vygotsky identifies, the fundamental problem in the disabled child’s cultural development is “inadequacy, the incongruence between his psychological structure and the structure of cultural forms” (1993, p. 168). My contention is that this is also true in the case of autism. Even though development in persons diagnosed as autistic is characterized by social and communication impairments, these features tend nonetheless to be seen as a matter of unfolding natural development, as innate and evolutionary based behaviors. Glaringly, social and communicative processes, so obviously relational, interpersonal, and situational, are typically reduced to biological processes conceived as predetermined (i.e., innate or congenital) and thus their development is seen as a matter of fixed unfolding. However, research on autism, and in particular research on interventions (e.g. Potter, 1997; Whittaker & Reynolds, 2000; Yuill, Strieth, Roake, Aspden, & Todd, 2007; Wolfberg, 1995), provides evidence of children diagnosed as autistic acquiring certain types of behavior and knowledge by being explicitly taught, as well as through joint participation in organized activities that typically developing children appropriate through their everyday socialization. Again, the fact that typically

developing children implicitly learn and acquire many forms of social behavior, gives the impression that this occur as a matter of natural maturation.

The work of one of Vygotsky's successors, Alexander Meshcheryakov, with blind-deaf children clearly illustrates the social origin of behaviors that are traditionally considered as the most natural and fundamental biological functions, evolutionarily wired for survival, such as reflexes and basic responses of the organism to physiological needs (i.e., hunger, cold, thirst and discharge). The accounts of the initial conditions of blind-deaf children, either born as blind-deaf, or becoming blind-deaf in early childhood, prior to systematic instruction (1979), present them as "absolutely helpless and deprived of the capacities of human behavior and thought" (1979, p. 79, as cited in Bakhurst & Padden, 1991). From the description of blind-deaf children by Meshcheryakov (1979), his predecessor Yarmolenko³ (1961, as cited in Bakhurst & Padden, 1991), and his friend philosopher Ilyenkov⁴ (1977, as cited in Bakhurst & Padden, 1991), we learn that these children, if left alone, stay passive and immobile, absolutely irresponsive to their surrounding and physiological needs⁵. Bakhurst and Padden (1979, p. 204) note that according

³ Yarmolenko (1961, p 82, cited in Bakhurst & Padden, 1991, p. 203): "These "inert masses" or "frenzied animals," as they appear to the outside observer, are shut out from ordinary life by the absence of aural and visual impression. Passive and immobile, they would sit in the same spot for hours at a stretch, sometimes even in the same pose. They do not use the faculty of touch to investigate spatial relationships or to familiarize themselves with new objects: even the process of eating, dressing and undressing and the satisfaction of their most basic physiological needs are only carried out after external stimulus, without which the process concerned might be postponed in time until an extreme degree of need be reached, which in its turn would produce an outbreak of fury. They do not manifest even the most elementary urge for contact with other people."

⁴ Ilyenkov (1977(a), p. 23 cited in Bakhurst & Padden, 1991): "[The blind-deaf child] is a creature which, as a rule, is immobile and reminds one rather of a plant, of some kind of cactus or ficus, which lives only so long as it is in direct contact with food and water, and dies without uttering a sound if one forgets to feed, water and protect it from the cold. It makes no attempt to reach for food, even if that food is half a meter away from its mouth. It utters not a squeak when it is hungry, will not cover itself from the draught with a warm blanket, it is a human plant in the full sense of the term."

⁵ One of the extreme cases reported by Meshcheryakov (1979, p. 111, cited in Bakhurst &

Meshcheryakov these children “fail to exhibit many of the unconditional reflexes which on the Pavlovian or ‘reactological’ framework Meshcheryakov rejects, form the innate basis of animal behavior”. For instance, these children do not display a “search orientation” reflex. Namely, they do not attempt to find or manipulate objects, or orient themselves with respect to them. Based on Meshcheryakov’s observations, in spite of their total dependence on other people, blind-deaf children demonstrate no tendency to communicate, and fail to exhibit facial expressions that are considered the most “natural,” as “these are children who must even be taught to smile” (Meshcheryakov, 1970, p. 80, as cited in Bakhurst & Padden, p 204). As Bakhurst and Padden note (1991, p. 203) “the blind-deaf children do not engage in end-oriented activity.”

Fully recognizing the profoundly social nature of human development, and its reliance on cultural tools, Vygotsky proposes to develop “specially devised roundabout paths of cultural development” that are important in the history of cultural development from two perspectives.

First, he argues that “*the cultural forms of behavior do not depend upon a specific psychological apparatus*” (1993, p. 169). According to him, the divergence between natural and cultural development occurs in typically as well as atypically developing children. However, due to “disparity between cultural forms of behavior intended for the normal human psychophysiological make-up, and those behavioral forms available to the handicapped child” (p. 168), this disparity is greater, more obvious, and clearly observable in disabled children. Therefore, Vygotsky sees the solution, and the only way to achieve the desired congruence of the natural and cultural lines of development in disabled children, through education and by “creating artificial, cultural techniques, that is, a special system of cultural signs and symbols

Padden, 1991, p 204) is a girl, Lena, G. “who came into Meshcheryakov’s care at the age of two. Until this time, she had been carried around by adults to such a degree that she appeared to have lost the capacity to regulate her own body temperature”.

which are adapted to the specific psychophysiological characteristics of an abnormal child,”

(1993, p. 168). Vygotsky further argues that cultural forms of behavior serve as (1993, p. 168)

the only path of education for an abnormal child. This path means the creation of roundabout ways of development at that point where it proves to be impossible to proceed by direct paths. Braille for a blind and writing in the air for the deaf-mute are just such roundabout psychological means of cultural development.

Therefore, it is the second, cultural line of development we have to pay attention to, because it best serves the development of the higher mental processes. According to him, this requires a special pedagogue who provides instructions and creates learning opportunities that promote developing these roundabout paths of development for disabled children.

Vygotsky called for a “radical reevaluation” of the psychology of the atypically developing child that, which was based entirely upon methods “intended for the functions which lapsed from the psychology of typically developing children.” This was due to understanding handicap as only “a flaw, minus, a deficit, which limits and constricts the development of the child who is characterized first and foremost from the standpoint of the failure of one or another function” (1993, p. 169).

Instead, Vygotsky proposes a more dynamic approach to the development of the disabled child, based on the assumption that a defect has a twofold impact on a child’s development. Not only a defect creates impediments and difficulties in the child’s development, but it also functions as a developmental stimulus of “paths of adjustment, of substitute functions which build a superstructure and which strive to compensate for the deficit and bring the entire system of the disturbed equilibrium into a new order” (1993, p. 169).

Such an approach translates into considering not only the child’s “negative” characteristics, but also positive aspects of his personality, a picture of “complex developmental paths.”

Vygotsky further points out that (p. 169, emphasis added):

the development of higher psychological functions is possible only along paths of cultural development, whether or not this development processed along lines which master external cultural means (speech, writing, arithmetic), or along the line of an internal perfection of psychological functions (the development of voluntary attention, logical memory, abstract thought, concept formations, volition, and so forth). Investigations have shown that an abnormal child is usually delayed precisely in this respect. *Cultural development, then, does not depend upon the organic deficit.*

Thus, he suggests that “cultural development is the main area for compensation of deficiency when further organic development is impossible. In this respect, *the path of cultural development is unlimited*” (p. 169, emphasis added). What this means for the cultural development of inner behavioral functions, such as voluntary attention and abstract thinking, is that specific techniques must be developed for roundabout paths. Vygotsky proposes that if these two higher functions-attention and thought-are to develop in intellectually disabled children, a similar tool to Braille for the blind, or dactylogy for the deaf, has to be available. In other words, “a system of roundabout paths of cultural development must be proposed at that point where the defect has cut off direct routes” (1993, p. 170).

As I argue throughout this work, Vygotsky’s arguments are extremely useful in the case of autism. Specifically, based on current understanding of autism and its etiology, if autism is considered in terms of incomplete convergence of natural and cultural lines of development (and obviously the extent of convergence or divergence of lines representing a wide spectrum of the condition in individual children), the course of the development of natural and cultural lines of development remains unclear. In other words, we can not understand various possible developments, points, and extents of divergence of development. However, based on Vygotsky’s theory, whether the goal is to compensate for inhibited natural development or underdeveloped cultural forms of behavior, it is cultural development that has to be enhanced and be enabled through developing roundabout developmental routes by employing new tools specially

developed for children diagnosed with autism.

Role of collective and collaborative joint activity

Vygotsky's position on the social origins of human development is also reflected in his explication of the role of collective and collaborative joint activity in typical and atypical development. He sees the collective as a source of "the possibilities for the new development of personality" (1993, p.200). For instance, from the point of view of understanding the intellectually disabled children, the relationship between the impairments and their personality, and the changes that their personality undergo, "we would see that each of the children who made up the collective acquired a new quality and specialness by assimilating himself into some kind of [larger] entity" (1993, p. 200). He further claims that studying "unimpeded social life" among intellectually disabled children will uncover a whole new perspective to the biological "incompleteness" of such children's personality. "It will offer the opportunity to approach the problem of mental retardation from the perspective of social accommodation for the child" (1993, p. 200). According to him, this must be a focus in work with intellectually disabled children. As he further points out, when comparing education for typically and atypically developing children (p. 202):

We see the same pedagogical aims with distinctive ways of attaining those goals, goals which are unattainable by abnormal children using the direct path. Thus, the general formula for comparing the pedagogy of normal and abnormal children is entirely appropriate for the problem at hand: the pedagogy of the child collective.

Importantly, he emphasizes that the collective has to be heterogenous in regard to children's cognitive level because "the difference in intellectual level is an important condition of collective activity." Children who find themselves in homogenous groups are deprived of "dynamic source of development" (p. 201). Vygotsky points out that intellectual disability can be understood and

interpreted as isolation, and the source of the intellectual disability is then solitude. The role of upbringing and education for all children, typically and atypically developing, is an engagement of children into the process of appropriation of social forms of behaviors. This is particularly important for disabled children. It can only be realized through *collaborative activity* (p. 218, emphasis in original):

The developmental path for a severely mentally retarded child lies through *collaborative activity*, the social help of another human being, who from the first is his mind, his will, his activities. This proposition also corresponds entirely with the normal path of development for a child. *The developmental path for a severely mentally retarded child lies through relationships and collaborative activity, with other humans.*

As he also explains elsewhere, “that which is impossible on the level of individual development becomes possible on the level of social development“ (1993, p. 219). This is the very idea of Vygotsky’s “genetic law” of the emergence and development of psychological functions, mentioned earlier, that social development precedes individual development. In the case of disabled children, the *interpsychological* process in which psychological functions develop first might require more time during which special and more intensive instructions are employed and introduced by an adult. The independency of a (disabled) child results from initial (more intensive) social dependency. In other words, for a child to become independent she *must* first be socially dependent.

The work of Meshcheryakov (1979) with deaf-blind children illustrates this point. As it has been pointed out by both Vygotsky and Mescheryakov, the development of disabled children provides a “slow-motion like” view of human development. For instance, the initial fundamental behaviors and activities that some deaf-blind children were taught, such as eating, described by Mescheryakov illustrate in detail every step in the (a) social origin of every aspect of the activity of eating (including chewing, opening and closing mouth, (b) role and gradual mastery of tool

use (e.g. using spoon), (c) complexity of the activity (all actions involved and their relationship with tool), (d) role of joint action between adult and child, (e) internalization of the activity (child eating independently). In sum, joint collective activity is a necessary initial condition for appropriation of social form of behavior and source of human development and development of personality.

Studying the child's whole personality

Vygotsky repeatedly emphasizes that in order to truly understand the child's *complex* developmental path, the socio-cultural and historical contexts in which it occurs must be considered as constitutive forces, rather than additive factors. Furthermore, as I mentioned previously, Vygotsky calls for understanding the disabled child as a complete being, focusing on his or her entire personality, rather than on isolated defects. He warns that focusing on defects themselves does not produce understanding of neither the defect nor the child. Rather, we need to view development as context-dependent and focus on the dialectical relationship between the impairment and the child's personality, (i.e. the socio-psychological realization of disability). It is impossible to understand the impairment itself unless it is studied in connection to psychological structures and the child's personality, what for Vygotsky means the system of activities and hierarchy of motives in which the defect enters.

As he explains in more detail, a defect and a child's personality interact with each other (Vygotsky, 1993, p. 124-125):

In the development of any child burdened by a given handicap, there occur certain processes which stem from the reaction of both the child's organism and his personality to those difficulties encountered. Both the child's organism and his personality react to a particular deficiency precisely when in the process of developing. During active adaptation to the environment, the organism and the personality work out a series of functions, with the flop of which they compensate and equalize the deficits.

Then, as Vygotsky claims, in order to educate a disabled child, it is important to know how she develops. The focus needs to be on the reaction of a child, specifically how the child's personality develops in response to the encountered difficulties resulting from the handicap. As Vygotsky explains, "the mentally retarded child does not consist of gaps and defects alone; his organism as a whole is restructured. The personality as a whole is balanced out and compensated for by the child's developmental processes" (1993, p. 125).

2.2. Theorizing dis/ability

In the following section I discuss the contribution of both the Social Model of Disability (SMD) and Disability Studies (DS) to understanding and researching disability. My contention is that exploring the intersection of Disability Studies with a developmental perspective of Vygotsky's approach is central to critically examine, and ultimately overcome, many gaps in conceptualizations of disability in general, and in autism in particular. One key aspect that I will discuss in greater detail later concerns how conceptualizations of autism have been mostly based on cognitive and neuropsychological perspectives that largely ignore issues raised both above mentioned theoretical approaches. Thus, the emphasis here is on how developmental perspective and DS inform and complement one another in advancing a "meaningful" conceptualization of disability as a dynamic, developmental and dialectical process. In other words, I argue that a conceptualization of autism that goes beyond an exclusive focus on individual mental deficits, which ultimately is disempowering to person diagnosed with autism, needs to be firmly grounded in a non-reductionist theory of disability in general.

As indicated above in the title of this section, my attempt is to discuss how a fully dialectical view allows us to overcome common pitfalls in current accounts of disability that can have important practical consequences. The main point I will pursue here is that all the usual dichotomies in theorizing, and otherwise practicing disability, such as disability versus ability, normal versus abnormal, impairment versus disability, biological versus cultural, and social versus individual, must be overcome by integrating them into a dynamic system that brings to the fore the dialectical interrelationships among these categories as they clearly define and construct each other. Although these common dichotomies and artificial separations are the most obvious and present in the medical model approach to disability, the following brief discussion of how

disability has been theorized will reveal that such dichotomous views are also present in some critiques of the medical model, in the social model of disability itself, in some critiques of the social model of disability, and even some discussions within Disability Studies suffer from such dichotomies as they often lack a developmental perspective. Furthermore, much of disability theorizing also suffers from an almost exclusive focus on physical disabilities, or from its narrow applicability to specific conditions of disability and diversity within a condition, for instance autism and categories of high- and low-functioning autism. My claim is that we do not necessarily need a separate disability theory, but a theory that would integrate disability into human development in a way that would overcome dichotomized and ultimately reductionist views of disability. Such broad theoretical account would be equally *applicable* to and *inclusive of any disability*. Thus, a developmental, dynamic and dialectical approach to disability is proposed herein as such alternative.

2.2.1. Disability as a deficit

The Medical model approach to disability, as an individualistic and objectivist account of disability, has focused on explaining, diagnosing, treating, and curing disability as pathology (Gabel & Peters, 2004). In this approach, disability represents a physical or mental anomaly that manifests in “subnormal functioning in domains such as physical mobility and performance, sensory operations such as learning, and social or adaptive behaviors” (Danforth, 2008, p. 46). Consequently, the diagnosis of disability is considered as “an objective professional activity involving a mixture of clinical judgment and scientifically validated psychometric measures” (2008, p. 46). Psychology, applying individualistic accounts of development and positivistic

research practices, has significantly contributed to the notion of disability as an exclusively individual characteristic, encapsulated in human body and mind.

2.2.2. Disability as a social category

In the last decades of the 20th century in the UK and North America, the medicalized and individualized understanding and practicing of disability has been opposed by a growing movement of disability right activists and disability scholars. In the 80s this movement led, in the UK, to creating a Social Model of Disability formulated by the Union of the Physically Impaired Against Segregation (UPIAS) under leadership of Vic Finkelstein and Mike Oliver (Shakespeare & Watson, 1997). Although in North America this movement was originally organized around and framed as a minority-groups issue, based on Lewian minority-group analysis of the situation of disabled people (Fine & Asch, 1988; Hahn, 1988), the terminology of the “Social model” approach to disability has been broadly employed here too.

Most of disability theorizing has been centered on the original social model, its internal or external critiques, its central idea of disability as socially constructed the relationship between disability and impairment. By considering disability as a social construct, the social model takes a sharp position against the medical model that views disability as an individual deficit. For instance, according to one of the main organizations championing the SMD, UPIAS (1975), disability is defined as: “the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical... impairments and thus excludes them from participation in the mainstream of social activities” (as cited in Oliver, 1996, p. 22). As this definition indicates, the focus of this initiative and its followers was on the issues and lives of physically disabled people. Although major contributions and

developments have been made in theorizing and addressing intellectual disabilities, physical disability remains somewhat the dominant topic in Disability Studies.

The fundamental point of the SMD is to understand disability as a socially constructed oppression. This recognition has been acknowledged as its main strength and contribution. However, this model has been criticized for identifying the cause of disability exclusively within society and social organizations (e.g. Terzi, 2004). Some authors (e.g. Shakespeare, 2006) claim that such understanding of disability creates a new dichotomy by separating disability from impairment. Specifically, Shakespeare argues that the SMD considers impairment as an individual phenomenon, defined as separate from disability, which is seen as a structural and public phenomenon. According to those authors, the social model posits as its goal to accept impairment and to eliminate disability by removing social and environmental (external) barriers (Shakespeare, 2006) that prevent and deny access to participation in the society.

To resolve the issues of separating impairment from disability, Carol Thomas (1999) proposes considering “impairment effects” in order to consider the limitations caused by impairment and thus take into account the relationship between impairment and disability. She proposes a bio-social model of disability that would “allows us to think through, rather than around, the intersections and interactions of disability (social oppression) and impairment (bio-social functions of our bodies)” (Thomas, 2001, p. 57).

In a slightly different vein, Shakespeare & Watson (1997) see the solution of overcoming the dichotomy between impairment and disability created by the SMD in acknowledging that impairment plays some role in causing disability, that disability is caused by both impairment and social oppression. Medical sociologists (e.g. Burry, 1988, 2000; Williams, 1999) also call for

understanding disability as a bio-social product and persist on acknowledging that impairment and chronic illness cause disability (Thomas, 2004).

However, as Thomas (2004) further points out, these critics consequently see disability only as “*restricted activity*.” She states that the social model and his “founders” do not ignore and deny the existence of impairment and the limitations of activity it causes, but “these are not what is of interest in studying and combating disability” (2004, p. 581). Rather, their focus was on redefining disability as a social category with an “explicit commitment to assist disabled people in their fight for full equality and social inclusion” (2004, p. 571). As Finkelstein claims, “you see disability fundamentally as a personal tragedy or you see it as a form of social oppression” (2001a, p. 5) as something “imposed on top of impairment” (Finkelstein, 2001b, p. 1). For Finkelstein, (2001b, p. 2) “at personal level we may talk about acquiring an impairment as a personal tragedy, but at the social level we should talk about the restrictions that we face, and should be interpreted as, a crime.” For him disabled people should aim for making public “many social exclusions that constitute disability “ (Thomas, 2004, p. 578).

Thomas (2004) recognizes the misleading critique of the social model by Shakespeare, Watson, Bury, and Williams, and the value and main goals of the social model and the movement its founders initiated, as seen in this excerpt (p. 578-579):

[The] disability is not equated with, nor defined by, restrictions of activity per se, as it clearly is for Shakespeare, Watson, Bury, and Williams. Rather, the attempt is made to completely redefine the meaning of disability, laying a foundation for the concept disablism to come into being on a par with concepts like sexism, racism and homophobia. Put another way, once the term ‘disability’ is ring-fenced to mean forms of oppressive social reaction visited upon people with impairments, there is no need to deny that impairments and illness cause some restrictions of activity- in whole or in part. Shakespeare, Watson, Bury, and Williams’ understanding of disability does not involve such a radical redefinition. They stick with the commonplace meaning of disability in contemporary culture-as ‘not being able to do things’ and as ‘restricted activity’. It is this adherence to a commonplace understanding of disability that underpins their refusal to deny that impairment and illness have direct disabling effects by limiting activity.

As Thomas further states (p. 580, emphasis in original):

Writers such as Shakespeare, Watson, Bury and Williams utilize [restricted activity] understanding of disability themselves and make common cause in their opposition to the social model because it has become synonymous with the view that *impairment does not cause disability because all restrictions of activity [i.e. disability] are caused by social barriers*. What has been obscured by the shadows of the social model of disability is the pioneering social relational understanding of disability to be found in the original UPIAS formulations. That is, what has been lost is an understanding that disability *only* comes into play when the restrictions of activity experienced by people with impairment *are socially imposed*, that is, when they are wholly social in origin. Such a social relational view means that it is entirely possible to acknowledge that impairment and chronic illness directly cause *some* restrictions of activity. The point is that such non-socially imposed restrictions of activity do not constitute ‘disability’.

Although I agree with Thomas’ critique of restricted activity approach to disability, I would challenge her last point regarding “non-socially imposed” restrictions of activity. Even if a restriction of activity is caused by chronic pain (an example in Thomas’ analysis), that might seemingly appear as purely biological and occurring within the physical limits of the body of the individual, the ways how the pain is experienced, managed, or controlled, are also socio-culturally and historically constructed.

In sum, the founders of the SMD, in an effort to uncover the oppressive nature of living as disabled, do not focus on and are not interested in the interaction between an impairment (understood as personal, individual, biological and even seen as personal tragedy) and society. Rather, they focus on uncovering oppressive processes of socialization of impairment, specifically how this - what is considered as individual characteristic - is played out and materialized into disability by the society. Authors like Shakespeare and Watson try to overcome such “separation” of individual (impairment) and social (disability) through what I would call “individualized disability,” meaning that that disability is understood as an interaction between an individual characteristic (impairment) and society (social and environmental conditions that

might be oppressive), and as such disability takes a form of “restrictive activity.” Thomas urges for a return to a “social relational understanding of disability,” which she claims can be found in the very original UPIAS’s formulations out of which the SMD has arisen. While acknowledging and recognizing the socio-political importance of a social relational understanding and analysis of disability by SMD she pushes for recognizing and paying attention to interaction between the impairment, understood as bio-social functions of our bodies, and disability. In other words, these views of disability rely on identifying points of *interaction between the individual* (usually understood as a biological impairment) *and the social* within either impairment or disability. For SMD, the “meeting point” of interaction between the social (public social oppression) and the individual (private personal impairment) is exactly where impairment becomes the disability. For Shakespeare, the individual meets the social within the disability. Lastly, for Thomas, this interaction lies within impairment. These various “locations” of meeting points between the social and the individual have obvious implications as they allow authors to recognize and claim different levels and intensity of social oppression, “individual responsibility” for disability, and room for personal and individual experience of living with disability. Theorizing disability then becomes a matter of shifting points of interaction between the social and the individual, and the forms which disability takes, for instance for Thomas it is attitudes and relations of social oppressions, for Shakespeare disability takes upon a form of physical pain, illness and social relations. However, what remains consistent for all these various definitions and approaches is the *interactive nature of the social and the individual*, although SMD pays attention predominantly to the consequences and product of this interaction (social oppression) rather than the interaction itself. Before I further discuss this topic and present my own understanding of

disability, I will continue with discussion of SMD and DS and their contributions to theorizing disability.

Despite acknowledgement and recognition of the “non-theoretical” purpose of the SMD, it has been continuously scrutinized and subjected to changes, additions and alternations. For instance, since the early 90s several authors have proposed to make SMD more relevant to disabled people’s lives (e.g. Crow, 1996; French, 1993; Morris, 1991). Calls have been made to include both impairment and the personal experience of disabled people and their knowledge in the model (Corker & Shakespeare, 2002; Shakespeare & Watson, 1997). Furthermore, some authors propose to move beyond SMD altogether, for instance Gabel and Peters (2004, p. 588) suggesting to adopt an eclectic model of disability based on resistance theory, which as they propose would enable one to “connect paradigms and theories, specifically eclectic theorizing and connecting of postmodernism, historic materialism, interpretivism, and functionalism.” However, considering that different paradigms usually represent radically different epistemological approaches, the applicability of such eclectic theorizing might be limited and only go as far as the included paradigms and theories are compatible.

Despite the internal and external criticism of the social model, the role of the model and its impact on society and understanding disability as a socially constructed is undeniable. It is important to mention that, as Michael Oliver (2003, 2004), one of the founders of the Social model and movement around it emphasizes, SMD is not a social theory, rather an “organizing principle, a rallying cry, and a practical tool,” although it has been frequently treated and criticized as such. As Shakespeare, one of the opponents and critics of the British social model, admits, it (2006, p. 199) is arguably the “most powerful form, which social approaches to disability have taken.” Specifically as he points out, the social model facilitated societal changes.

Politically, it promoted social movement of disabled people; *instrumentally*, it enabled and empowered “liberation of disabled people” by “identifying social barrier to be removed” and; *psychologically*, contributed to the “self-esteem of disabled people and building a positive sense of collective identity” (2006, p. 199).

Furthermore, and probably most importantly, the SMD provides conceptualization of the disability as a socially constructed category. Although this was not a completely new idea in academia, SMD materialized a new socio-political movement. Based on the contribution and impact of the SMD on the society, including academic enterprise, I believe it is fair to say that its impact overgrew its original purpose and expectations of the human rights activists’ initiative. SMD as a momentum of human rights movement, its derivate efforts and activities clearly played a significant role, directly or indirectly, in forming and recognizing a new interdisciplinary field of Disability Studies, and in establishing *disability as a new social category*, just like race, class, and gender (Asch & Mc Carthy, 2003; Kudlick, 2003; Linton, 1998; Thomas, 2004).

Disability Studies continue in pursuing principal goals of SMD, for instance uncovering nuances of societal oppression of disabled people, making oppressive practices visible and transparent, and enhancing full inclusion of disabled individuals into society. DS as a field has challenged the concept of disability by shifting “‘problematic’ disabled bodies onto social structures and cultural practices” (Connor, 2008, p. 452). Furthermore, as the same author identifies (2008, p. 452), DS broadens the view and understanding of disability by concentrating on several issues, such as “celebration of disability beyond the framework of oppression, emphasizing the *value* of people with disabilities,” recognizing the “different ways of knowing and understanding particularized through the experience of disability,” portraying the disability

in positive rather than deficient terms, as advantages and something to be proud of, as integral part of their identity and way of being. Furthermore, the research practices within DS facilitated inversion of power and situated disabled people, be it disabled researchers or research participants, in a central position from which their issues, interests, and concerns can be addressed (Connor, 2006). Importantly, DS continues problematizing the very concept of disability by challenging the hegemony of normalcy (Davis, 1995), ability and ableness (Campbell, 2008; Linton, 2006). For instance, as Linton (2006) states, “nondisabled position and its privilege and power “ has to be recognized and theorized the same way as other dominant positions, such as the white, the male and the heterosexual because “[i]t is not neutral, universal position from which disabled people deviate, rather, it is a category of people whose power and cultural capital keep them at the center” (Linton, 2006, p. 171). Ableism is recognized not only as a form of discrimination, in favor of the able-bodied, but it “also includes the idea that a person’s abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to nondisabled people” (2006, p. 161). Moreover, as Linton (2006, p. 171) discusses, the *dis* in word disability is to represent the “semantic reincarnation of the split between disabled and nondisabled people,” the supposedly oppositional categories are always in dialectical relationship, for instance as Waltz (2005, p. 435) points out “the ‘othering’ of people constructed as disabled shores up the ultimately hollow construction of normalcy, a category that can be defined only by what it excludes.” Davis (1997, p. 3) notes that the “normalcy is constructed to create the ‘problem’ of the disabled person,” and Linton (2006, p. 168) points out that “[t]he absolute categories normal and abnormal depend on each other for their existence and depend on the maintenance of the opposition for their meaning.”

All of these issues that DS brought forward are important and relevant and must be incorporated in theory of disability, a theory of human development in which disability would be integral part of. However, I believe that DS in general, and a concept of disability in particular would benefit from building upon developmental perspective, which is frequently missing in current DS and disability theorizing. Authors often claim that disability is a socially constructed category, however, in their analyses frequently rely on traditional individualistic view of disabled persons and imply reductionistic view of human development.

As I mentioned earlier, one of the major achievements of SMD that is being further worked out within DS, is recognizing and establishing disability as a new *social category* just like race, class, and gender. However, this position can be further advanced by approaching disability not only as a socially constructed *category*, a “bearer” of personal identity that might be subjected to oppression in social interactions, and frequently leads to theorizing disability limited around the perspective of identity politics. In the following section I discuss such alternative, in which disability is conceptualized as a social practice.

2.2.3. Disability as a social practice

Marxist sociologist Paul Abberley (1987) proposed approaching disability as oppression. He bases his theory in understanding impairment as socially and historically produced rather than private, individual and biological, as usually understood. Thus he avoids the pitfalls of dichotomizing impairment and disability and instead proposes Marxist analysis of impairment and disability in the context of relationships of social production.

In his sociological analysis he illustrates his point on several examples of preventable or modifiable medical conditions and their social aspect. For instance, he points out to

Phenylketonuria (P.K.U.), a hereditary inability to metabolize the amino-acid phenylalanine that nowadays can be detected and, through dietary control, intellectual disability, otherwise a natural consequence of it may be prevented. Abberley claims that the example of P.K.U. “reveals the complex interconnection between congenital and social factors in the production of impairment“ (p. 12) and therefore as he continues (1987, p. 12):

impairment is to be understood as social in origin, and to distinguish it from the more usual sociological generalizations about the social origins of handicap... The latter position, at least in its more worked out forms, presents handicap as totally the product of social meanings, in other words as reducible to ‘attitudes’. It implies that a change in attitudes could abolish disability. Claims about the social origin of impairment, however, are direct at the explication of the social origin of what are material and biological phenomena. Thus such a view does not deny the significance of germs, genes and trauma, but rather points out that their effects are only ever apparent in real social and historical context, whose nature is determined by a complex interaction of material and non-material factors.

Abberley proposes a theory of disability as oppression, that (1987, p. 17):

- 1) recognizes and, in present context, emphasizes the social origins of impairment;
- 2) recognizes and opposes the social, financial, environmental and psychological disadvantages inflicted on impaired people;
- 3) sees both (1) and (2) as historical products, not as the results of nature, human or otherwise;
- 4) asserts the value of disabled modes of living, at the same time as it condemns the social production of impairment;
- 5) is inevitably a political perspective, in that it involves the defense and transformation, both material and ideological, of state health and welfare provision as an essential condition of transforming the lives of the vast majority of disabled people.

As Abberley (1987, p. 17) further claims, in order to fully apply a notion of oppression to impairment and disability we need a theory “which connects together the common features of economic, social and psychological disadvantage with an understanding of the material basis of these disadvantages and the ideologies which propagate and reproduce them.”

Obviously, the main contribution of Abberley is that he proposes a theory of disability that would analyze *real material and historical practices of disability*, not only their meanings

represented in attitudes towards, and discourses about disability, the point that is complementary with Vygotsky's socio-cultural theory, not by surprise given their common roots in marxism. However, he falls short of fully recognizing development as a dynamic, epigenetic process where all the factors (biological and socio-cultural) are *co-constructed* on all levels, for instance when he refers to the "effects" of germs, genes, and trauma.

Somewhat similar proposition is made by Mark Willis (1995/2009), by applying Freire's (Freire, 1990) concept of banking education to disability and conceptualize it as praxis, predominantly praxis of oppression, a cultural experience of everyday situations and actions, rather than ideological system.

Drawing on presented Vygotsky's approach, including his disotogenesis theory and TAS (Stetsenko, 2008, 2010, 2012, 2013), a further elaboration of concept of *disability as a social practice* is proposed, specifically as a social practice of oppression.

Locating disability in social practice means that disability is not to be found in the brain and body of the person, or even attitudes and discourses produced by society and culture. Sources of disability cannot be found exclusively in attitudes and meanings about disability represented in discourses of disability, although those undoubtedly are effective tools of disabling. I argue that locating disability exclusively in cultural discourse leads into incomplete understanding of disability. Although it is important to identify dominant cultural discourses of disability, only analysis of social practices can unveil how the dominant discourses of disability, together with other cultural tools, are employed to disable people. Specifically, we need to be able to understand the dynamics of the process and social practices from which dominant discourses arise, and/or become transformed into material tools and social practices. I believe, that paying

attention of what I would call *dominant cultural practices of disability* might provide better understanding of role of disability in the society and the process of disabling people.

The overarching idea of Vygotsky's disontogenesis can be summed up in a single statement that the child, even if born with impairment, only *becomes* disabled in the process of her development. Disability, just as the self, mind, as well as all psychological functions, originate and develop in human activity, always mediated through cultural tools. Vygotsky, in his theory explains that depending on organization of social practices in which a child (born with impairment) participates and engages in, and Stetsenko would add and emphasize "contributes to," and the cultural tools available to her, the child can achieve different levels of development. In a dialectical fashion, Vygotsky points out that intellectual disability can be understood and interpreted as isolation, and the source of intellectual disability is solitude. As Vygotsky explains, and as is discussed in greater detail earlier, such isolation can be a result of "inadequacy and, the incongruence between child's psychological structure and the structure of cultural forms" (1993, p. 168), including lack of special system of cultural signs and symbols that would be adapted to the specific psychophysiological characteristics of an atypically developing child. Vygotsky particularly emphasizes constitutive and therefore enormous role of *collective* human activity in development of disabled children. Based on transformative activist stance (Stetsenko, 2008, 2010, 2012) expanding Vygotsky's position it is a claim that the activity in which human engage and through which she relates to world is truly developmental if it is *transformative*, that means if an individual participate and even more importantly *contributes* to social practices, and thus, in and through the process of *transformative collective activity* individual transforms the self and the world. Stetsenko, (2010, p. 9) reminds that this notion of individual contribution "transcends the dichotomy of social and individual: contribution is

something that individuals do but only as members of their communities who are fully immersed in social collaborative practices.“

The view of an individual as a transformative activist and the role of contribution in development are of paramount importance in relation to disability as it brings a different spin to understanding disability as a social practice. It can be even better understood if juxtaposed to community of practice concept (Lave & Wenger, 1991; Wenger 1999). If human development would be a matter of socializing into human culture through participating in it, disability would represent practices disabling that participation. However, from the perspective of TAS, disability represents practices that excludes and prevents, and thus *disables contribution and transformation of the world and oneself*. Therefore disability can be overcome only if contribution to and transformation of the world and oneself is created and possible within transformative collaborative activities.

Learning and teaching, as specific social practices, play central role in development as explained by Vianna and Stetsenko (2011, p. 318):

[T]eaching and learning take the center stage because these processes constitute precisely the pathway for individuals to acquire the cultural tools that allow for participation in and contribution to social practices and, thus, the pathway to becoming unique individuals. In this view, education is not about acquiring knowledge for the sake of knowing, but an active project of becoming human through one's own activist pursuits. Learning is the pathway to creating one's identity because it provides learners with knowledge about social practices evolving in history and thus, the baseline from which a meaningful contribution to these practices can be made. This is the view that capitalizes on the unity of knowing, being/becoming, and doing as well as the unity of learning and identity— all merged on the grounds of viewing individuals collaboratively contributing to and changing their community practices as the core grounding for human development.

Vygotsky's conceptualization of an atypical development, formulated in his theory of disontogenesis, expanded by TAS, has enormous implications for research, as well as intervention, including education and inclusion of atypically developing children. If the goals of all these social practices, including research, education and intervention, would be organized in a

way that would facilitate and promote contribution to and transformation of the world, these social practices could also be transformed and practiced differently. The goals for education and inclusion of atypically developing children and adults could be formulated and organized in such a manner that would exceed being controlled, tolerated, accepted, and enabled to participate within their communities and society. The goals have to be set up much higher – all the way up to the level of a true human development – namely to have equal opportunities and conditions of contributing and changing the world.

2.3. Theorizing autism

Although autism was first defined by psychiatrist Eugen Bleuler in 1911, who used the term “autist” (Aylott, 2000), it was the independent research of two Austrians, Leo Kanner in 1943, and of Hans Asperger in 1944, that put autism on a map of psychiatry and psychology. In 1979 Wing and Gould proposed to use the term of “autistic spectrum disorder” as they noted that the individuals described by Kanner and Asperger had more in common than not, and therefore such term would be more appropriate (Aylott, 2000).

Autism, officially named as Autism Spectrum Disorder (ASD) and medically defined as neurodevelopmental disorder (APA, 2000), is usually described in terms of impairments in social interaction, communication, and occurrence of repetitive behaviors. Medically, according to APA, the scope of the disorder is determined by manifested indicators that are considered to be the consequences of the impairments in the three areas of development in an individual.

In parallel with dominant cognitive paradigm in the US psychology cognitive theories and explanations were the primary and dominant explanation of psychology of autism.

Since 80s, when several cognitive psychologists (e.g. Baron-Cohen, 1985; Leslie, 1987) suggested that observed “systematic failure” of individuals diagnosed with autism to explain behavior in terms of mental states (i.e., to mentalize) results from their inability to form second order representations. Thus, the Theory of Mind (ToM) became the dominant theoretical framework around which autism and their consequent impairments have been traditionally conceptualized.

ToM, as a single cause of autism, was challenged within a cognitive psychology community (Rajendran & Mitchell, 2007). Further cognitive research suggested that there are other cognitive

processes and functions that need to be considered in addressing autism, namely, executive dysfunctions (Ozonoff, South, & Provençal, 1981), and weak central coherence (Happé, 2006).

The idea of ToM as a primary and central concept of understanding autism was challenged also outside of cognitive psychology. The opponents of this approach criticize ToM for focusing squarely on cognitive processes, or at least on individual mental processes, neglecting important social and cultural aspects that enter the social construction and practice of autism as individuals diagnosed with autism engage in practical activities of life. Thus, in the last decade the idea that underdeveloped ToM is the core source of impairments related to autism has been repeatedly challenged for the conceptual shortcomings of the theory itself (e.g. Bruner & Feldman, 1994; Colombino, 2004, 2006; Costall, Leudar & Reddy, 2006; Hendriks-Jansen, 1997) as well as for misconceptualizing the mechanism and the role of ToM in autism (e.g. Williams, 2004). Several authors have called for a more contextualized and situated approach to the issue. For instance, Bruner and Feldman (1994) suggested taking into consideration how the cultural and social context contributes to how people experience and represent the intentional states of others as well as their own.

Research in the area of neural plasticity opened up opportunities of exploring autism outside exclusively cognitive processes. For instance, Mundy (2001) proposes the transactional social-orienting model of autism in which interactions between impairments in social orienting and joint attention further contribute to significant challenges of social information in children diagnosed with autism, which according to the author, further results in insufficient input for typical neurological development. Although this approach provides understanding of development in more contextual and dynamic view, it remains addressing autism within deficit-based framework.

It has been well established that disability is the product of social, political, economic, and cultural practices (e.g. Asch & Mc Carthy, 2003; Corker & Shakespeare, 2002; Danforth & Gabel, 2006; Fine & Asch, 1988; Hahn, 1988; Kudlick, 2003; Linton, 1998; McDermott, 1993; Thomas, 2004; Vygotsky, 1993). There has also been growing body of literature focusing specifically on autism and Asperger's syndrome as socially constructed (e.g. Broderick & Ne'eman, 2008; Molloy & Vasil, 2002). The first-hand (e.g. Mukhopadhyay, 2008) or mediated accounts of personal experience of individuals who are diagnosed as autistic or "Aspergers" (e.g. Bagatell 2004, 2007; Baines, 2012; Biklen, 2005; Ochs, 2002; Ochs & Solomon 2004, 2005; Rocque, 2007; Sterponi, 2004) deserves the special attention as they challenge the mainstream discourses of autism, or what Broderick & Ne'eman (2008) call "culturally dominant metaphor" in autism discourse. As such they represent autism outside of a "disease" and deficit framework. It was predominantly ethnographic research that started opposing a biomedical deficit model of autism and embracing and applying notion of autism as socially constructed, often using a concept of neurodiversity (to various degree and with different interpretation), emphasizing positive experiences of life and, strengths. Most importantly, these works provided accounts of meaningful lives of persons diagnosed with autism. This stream of research truly enriches our understanding of *autism*, and even more so understanding of *people* diagnosed as autistic. This shift in research focus entails providing windows into people's lives, identity and their development.

The concept of neurodiversity adapted and introduced by neurodiversity and Autistic Rights movements (Bumiller, 2008; Solomon, 2008) has undeniably played a pivotal role in forming a societal "counter-narrative" in the "process of cultural critique and resistance to ideological hegemony" (Broderick & Ne'eman, 2008, p. 459), and has inspired new type of research that

aims at alternative depicting of autism and individuals diagnosed with as autistic. I believe it is important to recognize significance of the neurodiversity concept, its role and contribution to the society as well as its limitations, especially when applied to research. Similarly, as in case of Social Model of Disability, neurodiversity concept has originally served as a guiding tool of social movement, and only gradually has been introduced into research and academia as a theoretical framework.

Neurodiversity, applied in research, has been predominantly used as an identity marker (Brownlow, 2010; Griffin & Pollack, 2009), positional identity (Bagatell, 2007), as a reference for counter-narrative of researchers participants (Brownlow, 2006), and more generally as a tool and reference of identity affirmation. The concept is frequently used without clear conceptualization and clarification, further followed by various interpretations. For instance, as it will be discussed later, when neurodiversity is applied in the context of higher education, it mostly results in a narrow understanding of neurological difference as individual characteristic.

One of the limitations of neurodiversity movement, that is usually not addressed in research applications, however critiqued by feminist scholars (Bumiller, 2008), is that autistic identity is an inheritable genetic variation that should be accepted and not pathologized. From the developmental perspective of Vygotsky's approach, including theory of disontogenesis, as it has been already explained, development is a complex, dynamic and probabilistic process. Phenotype is always generated and co-constructed in a synergistic interrelationships of genetic, other biological factors and socio-cultural processes and cannot be understood as a simple expression of genotype. In other words, no aspect of cognitive, socio-emotional or physical development is a direct result of individual's genetic makeup.

Furthermore, following Fraser's distinction between affirmative and transformative politics of recognition, one could argue that the neurodiversity perspective is akin to the former as a type of identity politics insofar as it seeks to revalue unjustly devalued disabled identities while leaving intact the content of those identities and its group differentiation (Fraser, 1998). For instance, Fraser contrasts gay identity politics with queer politics, as the former promotes homosexuality as a cultural positivity in and of itself whereas the latter treats homosexuality as and the "constructed and devalued correlate of heterosexuality thus rendering both as reifications of sexual ambiguity codefined only in virtue of each other" (p. 24). In this sense, queer politics aims not to solidify a gay identity but to deconstruct the homo-hetero dichotomy so as to destabilize all fixed sexual identities. As a caveat, the transformative (in this case queer politics) does aim at dissolving all sexual difference in a single, universal identity, but rather to promote a sexual field of multiple, non-dichotomous, fluid, ever-shifting differences. Similarly, it could be argued that neurodiversity, while rightfully promoting a politics of recognition aimed at revaluing misrecognition of autistic identities as "disabled" identities and changing cultural-valuational structures (symbolic and institutionalized), may fall short of promoting a more radical politics of recognition aimed at deconstructing the ability-disability dichotomy to destabilize all fixed disabled identities. Such radical reconceptualization of human ability is precisely what Vygotsky's theory of disontogenesis affords (and his general theory of human development) in that human ability, mental and physical, fundamentally depends on access to cultural tools (material and symbolic) for its development.

Fraser's in her analyses of recognition of difference further proposes that the struggle for a just "recognition of difference" (Fraser, 2000, p. 107) requires a *status* rather than an *identity model*. This can further be applied to neurodiversity movement and proposed as their future

objective. Fraser claims that it is not a group-specific identity but the “status of individuals as full partners in social interactions” (p. 119) that is necessary for recognition of difference. If neurodiversity as a social movement refocuses from identity politics to status recognition and “parity of participation in social interactions” for persons diagnosed as autistic, the movement might gain broader recognition and support from within autistic community as well as outside of it.

For some researchers working within qualitative and ethnographic tradition and social constructivism the underlying approach and theme is viewing autism in a more positive way, as a socially produced disability rather than disease with a loose reference to human neurodiversity, its acceptance, and celebration of differences resulting from this diversity.

For instance, Grinker (2010) calls for shifting the focus from autism as a “childhood disease” toward seeing autism as an adult condition, “more generally as a human, social, and cultural phenomenon” (p.172). He claims that the focus of researcher on autism viewed as childhood disease presents “the injured or damaged child, the child with deficits and impairments, the child who cannot speak or cannot interact, the recovered or cured child” (p. 172) and requests addressing autism as socially produced disability instead of as a disease. According to him, focusing on disability would highlight the “society’s deficits in accommodating the individual” (p. 172) instead of highlighting individual’s deficits as it is in disease model of autism. He claims that autism could “be reconfigured as possibility rather than limitations, as sociality rather than the selfism denoted by the term *autism*” (p. 175, emphasis in original).

Grinker (2010, p. 173) continues:

The old stereotypical image of the person with autism, male, nonverbal, mentally retarded, self-injurious, unaffectionate, and unable to engage in any social interaction has given way to an understanding that autism is a range of different conditions, strength, and weaknesses. Autism today is better defined in terms of its heterogeneity, as a group of autisms. There are,

to be sure, people who might fit a stereotype, but most of the people who comprise the current pool of children and adults with an autism diagnosis, counted in the current best estimate prevalence rate of 1 in 110, are active participants in society. Many resemble my own daughter. Isabel, a high school student who plays in her school orchestra, volunteers at our local zoo, and goes to summer camp.

Although, this approach and much of what Grinker has to say is very appealing, it only goes half way. It illustrates the point that applying social model of disability and positive view of disability might not be sufficient to understand lives of all individuals diagnosed as autistic, and for instance, does not overcome traditional dichotomy of low- and high-functioning autism diagnosis. Specifically, his point about “people who fit” a stereotype of autism that he so radically rejects is somewhat problematic. His new model of autism as possibility and sociality does not seem to apply to those “male, nonverbal, mentally retarded, self-injurious, unaffectionate, and unable to engage in any social interaction,” instead they “remain” within the traditional model of deficits and impairments. Then the question remains “Where do we draw the line between these two categories of autism, on the *spectrum* of autism?” Is a sub-diagnosis of autism, of a low- and a high-functioning autism, sufficient enough as a cutoff? Does a low-functioning autism represent a deficit view of autism, whereas high-functioning autism can be associated with a view of opportunities and possibilities? Traditionally, such a distinction in autism diagnosis represents the score of above or below 70 on IQ test. It seems that all that Grinker (and others who share this approach) does, is to push the line of definition of humanity, limits for meaningful opportunities to participate in the society, a little bit further than traditional medical model, but not quite far enough to include all on the spectrum. Such view of autism does not eradicate a deficit model of autism, only makes it less applicable to some on a higher end of the spectrum. Many researchers are unable to escape this “trap.” In their conceptualizations they claim applying a social view of disability and autism to present it as socio-cultural phenomenon,

however they connect it, although often only implicitly, with an individualistic view of human and human development. Consequently, the “more autistic” person appears to be, the more individualistic view of the person is employed, in another words, disability is viewed as an individual characteristic and deficit.

The researchers theorizing autism seem to belong into two opposing camps, with conflicting and irreconcilable views. The first camp, that I would call *interventionist*, seems to approach autism as deficit and therefore is in need of diagnosis, intervention and treatment. Some scholars point out to the source of disagreement around the issue of interventions, and argue to first question goals, purpose and ethics of intervention (Bagatell, 2007; Broderick & Ne’eman, 2008) and eliminate those that are focused on eradicating non-normative behaviors in order to fit socially. The second camp, of *acceptance*, claims that autism is a matter of human neurodiversity and it should be accepted and celebrated as such. Not surprisingly, they seemed to work well on the opposite ends of autistic spectrum.

I argue that TAS-extended Vygotsky’ theory of disontogenesis allows for theorizing autism as a difference enacted in activities and social practices individual engages in rather than as a deficit. Furthermore, this approach understands disability as socio-culturally and historically constructed social practice and yet, does not oppose intervention in the form of support, including instructional support. In this conceptualization individuals diagnosed with autism are respected and accepted, and they, their struggles, achievements, and contributions are valued, recognized and acknowledged as equal members of their communities and society.

Simultaneously, disabling and otherwise oppressive social practices and cultural tools that dehumanize, patronize, disadvantage, alienate, isolate, marginalize and disempower or otherwise prevent full participation and contribution are eliminated.

3. Methods and Analysis

3.1. Methods

3.1.1. Research goals and design

The goal of this research project, designed as a case study, is to explore the dialectical and dynamic relationships between learning, self and autism in the process of development of Hannah, a young woman diagnosed with high-functioning autism as she engages in social practices across different activity contexts and settings. Drawing on the Vygotsky's approach extended by TAS, including disontogenesis theory and self as leading activity (Stetsenko & Arievitch 2004), and Disability Studies, learning, self, and autism are approached in this study as processes, as social practices culturally and historically produced in intersecting contexts of learning. Conceptualizing learning as a leading force of development, as a collaborative activity of knowledge production, and as an instrument of identity making, I focus on Hannah's learning experiences to understand her development. Hannah's learning experiences will be explored in relation to both her development and autism, which will be described and analyzed within a context of community college. The context of college in which Hannah's learning experiences are embedded is not considered in this study simply as a background to her development, rather it is treated as constitutive of her development. This entails an emphasis on the dynamic emergence and negotiation of power, positions and identities (including the one of an "able" versus a "disabled learner") as Hannah and the individuals who participate in those activities position themselves and one another. In other words, my focus is on how Hannah's identity

emerges in learning activities, identifying various positioning⁶, ranging from the position of an agentic active learner with a purposeful life project to the position of a disempowered disabled person. Furthermore, broader contexts (e.g. higher education, more specifically community colleges in the US, and support system to disabled students provided within the US higher education, autism-related support and educational opportunities) of which community college is part of, the cultural tools produced by and utilized within these contexts are also included in the analysis.

Although the label of a “case study” has been used for different elements of research process, for example, as a method, a methodology, a strategy, or a design (Tight, 2010), I use a case study as an umbrella term for my overall research design, that includes multiple research methods (e.g. interviews, participant observations, field notes, written and other institutional documents, materials produced by participants) and theoretical perspective of TAS-extended Vygotsky’s approach and Disability Studies. The case study in this project serves as an indication of focusing on experiences of one person and focusing on a question about “what specially can be learned about the single case study” (Stake, 2008, p. 120). Moreover, as Yin (2006, p. 111) emphasizes, compared to other methods, the “strength of the case study method is its ability to examine in-depth, a “case” within its “real-life” context.” Case study enables, and by default requires, production of “context –dependent knowledge” that is particularly valuable in research on learning, and importantly part of any “study of human affairs” (Flyvbjerg, 2006, p. 221). Thus, zooming in on Hannah’s case revealed in great detail the intricate patterns connecting learning, identity, and learning and other institutional practices, including exploring gaps and contradictions as Hannah navigated college. The upshot is that an analysis of Hannah’s case with

⁶ The concept of positioning and its methodological and analytical use in this research is

its highly contextualized dynamics functioned, analytically, as a microcosm of the complex system revealing with great clarity conspicuous processes that otherwise remain hidden in less dramatic cases. Close partnership between principal research participants and me as a researcher that developed in the context of case study enabled and was the foundations of developing an *activist collaborative research methodology*, described in further detail later.

The conventional critique of the value of application of case study has been increasingly challenged (e.g. Flyvbjerg, 2006). The importance and relevance of case study approach is growing and increasingly more recognized as critical for making generalizations based not on population averages, but rather on in-depth understanding of individual cases (Fogel, Greenspan, King, Lickliter, Reygadas, & Shanker, 2008). The same authors further emphasize that “this sort of fine-tuned, case-based documentation of the real-life histories of change over time is critical for making informed policy decisions” (Fogel *et al*, 2008, p. 253).

3.1.2. Community college: learning activity as a research site

I met Hannah in fall 2005 while she was in college. Later on, I became her tutor assisting her with two of her courses. Besides working on her courses and assignments we also spent leisure time together, including my family and her close friend, a former teacher Ingrid who acts as her guardian. Based on Hannah’s and even more so on Ingrid’s reports, Hannah was undoubtedly exposed to various experiences throughout her courses, as she engaged with different curricula and interacted with several instructors with varying pedagogical styles.

On many occasions instructors initially expressed reservations about Hannah’s ability to fully participate in their courses when they found out she was diagnosed with autism or presented a

discussed in detail in chapter 3.2. Analysis.

letter from Office for Students With Disability indicating she was registered with the Office as a Student With Disability, without further specific diagnosis. As I mentioned earlier, I was also learning from my husband, that he as her instructor, and some of his colleagues teaching Hannah, felt unprepared to provide her with adequate instructions and questioned their competency to involve Hannah into course activities and learning. Many instructors, regardless their initial attitude, embraced her “as autistic” and were quickly able to recognize and appreciate her many qualities as a diligent student. She experienced various degrees of accommodation from her instructors, as well as assignments and instructions of various quality. Based on informal discussions with her and her friend Ingrid about her experiences, there seemed to be one reoccurring pattern in her college experiences. Her achievements in course work seemed to correspond with her instructors’ attitudes toward her autistic identity and opportunities of meaningful engagement in learning.

Furthermore, several instructors seemed to question and attribute her achievements and successes in coursework to the assistance and outside support she was receiving. At the same time, any difficulties in comprehending the course material and assignments were usually attributed to Hannah’s diagnosis of autism, although many of her struggles were not out of ordinary to other typically developing students. As Fine and Asch (1988, p. 9) put it, “when a disabled person faces a problem, it is assumed that the impairment causes them”. Many of Hannah’s experiences seemed to indicate her instructors’ individualistic view of her and her learning. Their position towards her, and their positioning of her resonated also with other common assumptions about disability (Fine & Asch, 1988), for instance that disabled person is always perceived, and positioned as a victim, and that disability usually located exclusively in biology is consequently considered “uncritically as an independent variable” and therefore,

“[d]isability is portrayed as the variable that predicts the outcome of social interaction when, in fact, social contexts shape the meaning of disability in a person’s life.” (p. 8-9).

It was becoming more obvious that many of Hannah’s learning experiences, and struggles in particular, were shaped by her instructors’ understanding of disability, autism and Hannah’s positioning within learning activity. Hannah’s experiences in college prompted me to explore her learning experience and “her disability” in context of activities they occurred.

3.1.3. Negotiating and transforming the roles: Roles of the participants in the research and role of the research in participants’ lives

I proposed to Hannah to be a participant in my dissertation research project and we started to discuss possible ways of her participation and our collaboration. I explained my interests and rationale for the research to her and to Ingrid. Collectively, we started identifying some of the potential participants I could contact.

The theoretical foundations of this research and my experience of interacting and working with Hannah were the constant reminders of the false and illusionary roles of researcher as a “disinterested” expert, a neutral and objective observant, and research participant as a subject as understood in a traditional research. I wished to surpass traditional mode of carrying research *about* Hannah, simply documenting her learning experiences and thus positioning her as a passive research subject, although providing room for her voice in the story. I was seeking to develop a research project that would facilitate more participatory, collaborative, agentic, and therefore more meaningful involvement of Hannah in a research project, in other words carrying out research *with* her, rather than *on* her. However, when I presented the possibilities of carrying out a project in the tradition of participatory action research, Hannah was not interested in

pursuing her own research agenda, and she was not interested in developing one. I was hoping that she might change her mind as we engage in actual research. She was very cooperative during interviews, helpful in identifying and contacting instructors and other participants, but that itself did not lead to changing her interest nor spurred any research questions she might have wished to explore. Nevertheless, we continued to spend time together, participating in various entertainment and educational activities and our relationship intensified.

Reflecting on the research process, I realized that from the very beginning my research was equally driven and guided by a strong theoretical position and by my personal relationship with principal research participants, Hannah and Ingrid, materialized in my overall stance and activist position towards research participants and research as a social practice. I further realized that not only I gained their trust to become part of their lives, represent their voices and standpoints, but they gained my trust too. This was fully materialized when I felt comfortable not only to discuss my work with them, but when I invited both of them to read, edit and contribute to my interpretations and thus open my standpoint for discussion. This move was not part of the original design and evolved organically from our mutually committed personal relationship. The nature of our relationship facilitated and transformed the nature of the research, whereby the “personal” became an integral and vital part of methodology and research practice. In a dialectical fashion, research facilitated the deepening personal relationship as we engaged in conversations about the research and my findings. The knowledge produced within research became increasingly employed as cultural tools of our everyday practices. Research developed into truly collaborative transformative social practice, as Hannah’s and Ingrid’s research roles gradually transformed from research participants to research collaborators and contributors, while all three of us acknowledging and recognizing the transformative process. Simultaneously,

my role as a friend, becoming increasingly informed by knowledge produced in research process, also transformed, as I was able to take a more activist stance and become an advocate *with* and *for* Hannah. My own role of a researcher was far from a mere observant. My roles of the researcher and friend infused within our collaborative transformative practice into an activist stance within, as well as outside of the research project. Hannah's, Ingrid's, and my role in the research, can also be understood in terms of positioning, as truly relational and dialectical, as we gradually experienced and acknowledged each other as agentic individuals engaged in our lives.

3.1.4. Research Questions

The main objective of this study is to explore Hannah's development in the context of her learning experiences within context of the community college asking the following questions:

- 1) How does Hannah position *herself* and engage in the given context of learning activity (i.e. ranging from the position of an agentic active learner with a purposeful life project to the position of a disempowered disabled person)?
- 2) How is Hannah positioned and engaged *by others* (i.e. college instructors, administrator, guardian/friend and peer) in various contexts of learning activities (i.e. ranging from the position of an agentic active learner with a purposeful life project to the position of a disempowered disabled person)?
- 3) What *cultural tools* and *conditions* of identity development, learning, and agency development are employed and constructed by participants that *mediate* specific ways of engagement and positioning of Hannah as an active learner or disabled person? Are the tools, conditions and mediation of an activity learning promoting agency and development or disempowerment and disabling of Hannah?

- 4) What is a relationship between Hannah's diagnosis of autism and "her disability?" What are the conditions that constrain Hannah's learning and engagement and, consequently, shape her diagnosis of autism as a disability? Conversely, what are the conditions, including the cultural tools available, that allow Hannah to learn successfully, and engage in activities in ways that her diagnosis of autism manifests as strengths or at least differences, rather than as a disability?

By studying different contexts of learning activities within community college as a context of development, I expected to be able to understand the space between Hannah positioning and engaging herself and being positioned by others as an active learner or disabled and "autistic person." It is important to emphasize that Hannah's positioning and engagement in learning is understood as a continuous or dialectical relationship rather than two separate dichotomous categories of ways of being and identity. The space and relationship created by tensions, negotiations, and contradictions between those two positions and ways of engagement can indicate and create opportunities for various levels and forms of Hannah's participation and contribution to social practices, as well as her agency. Exploring the dynamics between these two possible ways of Hannah's engagement with the world provided further understanding of the process of collaboratively and socially constructed agency within the given activities with particular goals and motives.

Through exploring the dynamic relationships between social practices of learning, self and autism, I described the identities that the community college as a developmental context produced. I focused on understanding and explaining processes and tools of disabling and dialectical relationship between social and individual aspects of identity and agency development.

3.1.5. Research Participants

The principal research participant and a focus of this case study is **Hannah**, a 31-years old woman diagnosed with high-functioning autism. As I already described, I met Hannah in fall 2005 when she was a college student at Metropolitan Community College pursuing her two years associates degree. She was in the second semester of her studies.

Shortly after we met, we have worked on several assignments as a part of Hannah's course work when I was tutoring her or simply going over the reading material or watching a movie together. We also enjoyed leisure activities, often including her friend guardian Ingrid and my family. However, it was not until the early spring of 2009 when we considered working on a research project that could potentially become my dissertation research. We officially started pilot research in March 2009.

Despite Hannah being diagnosed as autistic, the fact that usually evokes impressions or concerns about her communication skills, she is a very effective and articulated communicator and writer. Throughout our interactions we learned to communicate with each other effectively. For instance, during our study sessions we used drawings and diagrams and simplified language, or we simply made sure we understand each other. Hannah frequently helps me with a vocabulary and my grammar, and does not hesitate to correct my pronunciation. While spending time together, I have also learned to accommodate her needs, such as her requirements regarding the food preferences, or keeping a time schedule. I learned to monitor the signs of fatigue, overstimulation or anxiety and whenever we worked together or carried any kind of activity, I made sure I paid attention to those and assured she wishes to continue. I would also like to emphasize that Hannah is very straightforward and open, in her own words "brutally honest". She is usually very clear in expressing her needs and wishes, for instance when she does not wish

to participate in a certain activity or simply wishes to stop it. In return, she was always flexible and negotiable especially on our trips when my young daughter was with us too. Simply put, we learned about each other and we got to know and understand each other well enough, so we both feel comfortable expressing and respecting our needs and interests. This level of trust and mutual respect greatly facilitated access to and understanding of the intricate dynamics of Hannah's learning and identity development, including at its deeply personal and emotional levels that typically remain hidden in research from a more "objectivist" position that employs detached and supposedly "neutral" methodology.

Ingrid, Hannah's former school teacher, friend and guardian, who has known her since she was four quickly became an important participant of the study, and my informant. Hannah and Ingrid became very close friends throughout the years and currently they are roommates.⁷ Although Hannah is legally independent, and Ingrid has no legal relationship with Hannah, it could be said that she is practically her mother, often acts as her (unofficial) guardian and presents herself as such. Ingrid has played a significant role in Hannah's life, especially in her education as will be described in further detail. Ingrid has taught, supported and guided Hannah throughout the years, and has always been her advocate. Although she constantly encourages her independence and strives to support Hannah's agency, she continues to be an integral part of Hannah's life and is involved in all the important decisions of Hannah's life. Due to her role in Hannah's learning and life in general, Ingrid was interviewed not only about their relationship but also as an active participant of learning activities within community college.

Together with Hannah and Ingrid we identified fourteen former **instructors** that could potentially be interviewed as research participants. I encouraged Hannah to choose instructors

⁷ Hannah's and Ingrid relationship is described in more detail in chapter five.

with whom she had positive or negative experiences, and courses in which she did well or less so. I contacted all fourteen instructors we identified out of which eight responded and were interested in participating in the study. However, two of them were unable to meet for the interview. Although I had an opportunity to interview only six instructors, this group represented almost one third of instructors Hannah encountered during her studies. Specifically, Hannah studied at the MCC between Spring 2005 and Spring 2008. During that period, she was instructed by twenty instructors, while participating in twenty-four credit courses. Two of the interviewed instructors taught Hannah in two courses. All of them were senior full-time instructors. All courses she took with the interviewed instructors were 3-credit courses, except remedial math course. Other courses were on the topics in the area of social studies, humanities, communications and health. Although only six instructors participated in the study, given Hannah's various experiences with them (her grades in the eight courses taught by them ranged from A to +C), intensity of their interactions, nature of their relationship, and diverse subject matter of courses, participating instructors represented quite a heterogeneous group. Importantly, Hannah took these courses throughout her entire study at MCC and therefore instructors met Hannah at different point of her studies.

I also interviewed a **Director of Office of Students With Disabilities (OSWD)**, with whom Hannah came frequently in contact and who seemed to play an important role within studied learning context.

Through one of the interviewed instructors I was able to contact one of Hannah's former classmate who worked at the OSWD as a student tutor and interview him about both of his roles as a **student tutor at the OSWD** and as a **Hannah's former classmate**.

Another potential participant we identified with Hannah and Ingrid was Rob, Hannah's tutor and friend who was her classmate in two courses and tutored her privately in three courses. Although he initially agreed to participate, unfortunately, he was unable to be interviewed as he later relocated to a different city.

I was hoping to recruit other of Hannah's peers, whether a former classmate and/or any friend/s who she met in college for this study. Unfortunately, I was unable to contact any of the potential participants because Hannah lost touch with them and they had already graduated by the time I was ready to contact participants.

One of the disadvantages and shortcoming of the study was that it started after Hannah graduated from the college. Consequently, there was a considerable lapse of time between Hannah's participation in courses and the time of the interviews. Although occasionally participants had difficulties to recall the details of the particular event they remembered Hannah well and considered her as exceptional and memorable student. Moreover, if the research project had started during Hannah's studies, I would have attempted to observe and participate in classes and other activities in college.

3.1.6. Research methods and sources of data

In order to understand the complex dynamics of dialectical relationship between social processes and individual development, diverse range of data from multiple data sources were collected:

Interviews

I interviewed all research participants (i.e. Hannah, Ingrid, six of Hannah's former college instructors, director of the OSWD, and a peer/student tutor) using format of semi-structured

interviews. Interviews with instructors, director and peer/student tutor were all conducted at a community college, and all except one were tape-recorded.

Interviews with Hannah and Ingrid - I interviewed Hannah and Ingrid individually three times, each interview focusing on different area and periods of their lives, namely 1) their past focusing on Hannah's educational path, their relationship and Hannah's goals and motives to attend a college, 2) Hannah's learning experiences in college, and Ingrid role in the process, 3) Hannah's future and reflections about research. All of these six interviews were realized in their house and took between one to one and half hours and were tape-recorded. Our relationship developed in a way that many additional discussions, email exchanges and informal conversations occurred and added further richness to formally collected data. Some of them were tape-recorded, or recorded as my written notes, or typed text (e.g. emails). Whenever I wanted to use data from our informal communications I always asked for Hannah's and/or Ingrid's permission to include them into my analysis. As already explained, they also had an opportunity to read and approve or disapprove usage and interpretation of the data.

Instructors' interviews included questions about their and classmates students' interactions and experiences with Hannah, accommodations provided to Hannah, her interactions with other students, their course and teaching practices, understanding and views of autism and disability, institutional support, teaching experiences at MCC in general, lessons learned, recommendations for other students, instructors and institution. The interviews were conducted in summer of 2009 and took between 1 to 3 hours.

In the *interview with director of OSWD* I asked questions around his experience and interactions with Hannah and Ingrid, and as well other students registered with the office, accommodations and services provided by the Office, his views and understanding of autism and

students diagnosed with autism, his interaction and experiences with instructors, recommendations for students registered with the OSWD, instructors and institution. The interview took one and half hour.

Interview with peer/student tutor aimed at both of his roles, as a former classmate of Hannah and his more recent position of a student tutor and work at the OSWD and took about one hour.

“Member check” method

Hannah and Ingrid agreed to provide a “member check” (Kieffer, 1984), a method in which research participants read, edit text, provide feedback, may contribute to researcher’s interpretations, and most importantly approve or disapprove them. Hannah and Ingrid, both provided their individual feedback. This process involved numerous discussions and exchanges of the text. First, I provided Hannah and Ingrid with text and after editing it I reread their edited version. They typically added details and provided further clarifications to the story. According to their feedback, they genuinely enjoyed the process, although commented on demanding nature of it. Ingrid, as an avid reader, articulated writer and a poetic person tended to eliminate or change parts that included more conceptual language, as those parts seemed to be too technical to her. When I felt that important points were left out of my original text we discussed it. I explained the meaning of the terminology and applied concepts, and the importance of the point I was trying to make. Although this method turned out to be quite time consuming and lengthy process, it was important to learn that neither Hannah nor Ingrid objected to my interpretations of the events. To a great extent it was in the process of these conversations and negotiations that we learned about transformative potential of this research as well as depth of our relationship. We were able to recognize our own and each others’ activist stance.

Participant observations – Activist collaboration

Since I started to work on this research, my interactions with Hannah and Ingrid intensified and we spent considerable amount of time together in all kinds of occasions and across a variety of settings. I was included in different capacity in various activities and events, such as searching for job for Hannah, accompanying Hannah to Meet-up group of young people diagnosed as autistic, accompanying Ingrid to various events related to autism, disability or career opportunities (e.g. visiting Job Fair, Family and Professional Resource Fair for family and professionals supporting disabled children and adults, lectures, movies, etc.). Attending professional and/or disability or autism related events was always an opportunity for us to engage in conversations about issues related to this research, such as our (Hannah's, Ingrid's and mine) and others understanding of Hannah, autism and disability, practices and tools of disablement, oppression or empowerment.

Together with Hannah, we also spent more time informally, sharing our interests and hobbies (e.g. visiting museums, zoo, botanical garden, baking, going for walks, concerts and other type of performances, dinning out or in each others house with Ingrid and my family) and celebrating holidays and special events (e.g. family members' birthdays and holidays).

Through engaging in everyday activities with Hannah and Ingrid I gained a privilege of a (participating) observer and ethnographer, and unique opportunity to get to know Hannah in different contexts as all three of us created opportunities for nuanced understanding of each other, of our ways of relating to others and world. Moreover, "participant observations" became a catalyst for developing close and mutually committed relationship, which in turn facilitated more emancipatory research that became meaningful and relevant to Hannah and Ingrid. I believe we surpassed "participatory observation" method; as described above, through our

relationship and engagement in mutually relevant activities we transformed and created a research method that I would call *activist collaboration*.

Field notes

I took notes during all the interviews and wrote up my field notes after each interview, which for instance included my impressions, further questions and initial interpretations.

I also often took notes while or after spending time with Hannah and/or Ingrid. Writing and revising my field notes provided me with a systematic method of further articulating my questions and analysis, issues that required necessary clarifications with participants or consultations with literature.

Written material and work produced by participants

I asked Hannah for permission to use written materials produced by her in college, (e.g. papers and other written assignments), her study notes and written work produced during tutorials and discussions of the readings. To supplement interviews and data collected during participant observation I asked Hannah and Ingrid to answer some additional, usually clarifying questions. Finally, with their permission, I also used some of the written material produced within our email communication.

Institutional materials and documents

I collected a multitude of institutional documents that were rich source of data and illustrations of numerous institutional tools and practices employed by institution and individual participants. Collected documents included materials produced by the Office of Students With

Disabilities (e.g. OSWD website including Instructor's Manual, Instructions for students, OSWD letter to the instructor introducing Hannah as a student registered with Office), materials and documents produced by instructors (e.g. course materials including course descriptions, syllabi and course assignments instructions) and other institutional documents (e.g. Hannah's transcript, MCC website, MSS newsletter).

Although this research was not carried out as a participatory research project per se, theoretical conceptualization of the study, the case study design and engaging Hannah in an activist collaborative research methodology promoted her involvement and contribution to research as more emancipatory practice resonating with participatory research paradigm (Heron and Reason, 1997). Specifically, as Heron and Reason (1997, cited in Reason & Torbet, 2001, p. 6) note:

[T]he purpose of inquiry is not simply or even primarily to contribute to the fund of knowledge in a field, or even to develop emancipatory theory, but rather to forge a more direct link between intellectual knowledge and moment-to-moment personal and social action, so that inquiry contributes *directly* to the flourishing of human persons, their communities, and the ecosystems of which they are part.

In return, as already described, my continuously developing relationship outside and within research project with Hannah and Ingrid promoted my development and growth, my personal and professional transformation.

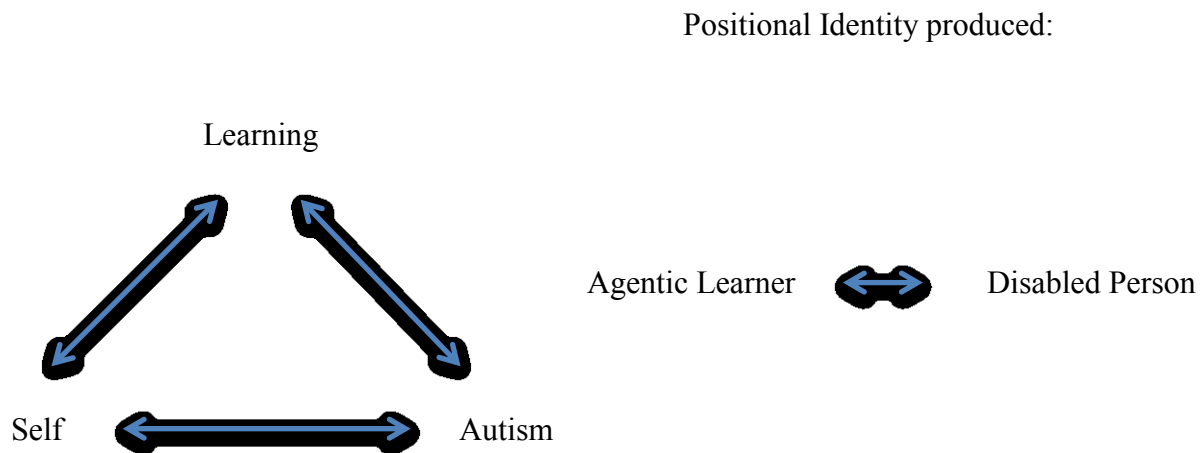
3.2. Analysis

In this study, my focus is on exploring the dialectical and dynamic relationships between learning, self and autism as a young woman diagnosed as autistic engages in the social practices of learning in a community college. Drawing on Vygotsky's approach extended by TAS and Disability Studies, I approach the intersecting processes of learning, self, and autism as social practices, understood as culturally and historically produced and practiced in the context of activities of a community college. Although designed as a case study, the *unit of analysis* in this study is not limited to Hannah as an individual, nor was this study concerned with identifying her stable individual characteristics or social roles. Following Vygotskian theory, my focus was on the dynamics of learning and development as Hannah engaged in a range of collaborative activities situated in particular institutional setting. Specifically, I focused on collaborative transformative practice as a source of development, with emphasis on the activities in which Hannah and other participants of the learning and other activities collaboratively engaged, specifically learning activities within the contexts of Community College (diagram 1).

Based on recent analytical advances in sociocultural theory, the focus of my analysis is on identifying patterns of engagement and forms of *positioning* as instantiated by community practices on the one hand, and enacted by Hannah and by other participants with whom she interacted within community college, on the other. I also focused on the kinds of cultural tools that afforded and made possible such positionings. This includes analyzing conditions and processes that supported Hannah's learning and enabled her to more fully engage in activities as an active and agentic learner, and, conversely, to identify processes and conditions that constrained her agency, and disempowered her by ascribing to her the position of a disabled person. The essential elements of activity are identified *cultural tools* (including social practices)

and their mediating role in Hannah’s engagement in (learning) activities and interactions among participants. The analysis of positions, cultural tools and practices that mediate processes of positioning allowed me to analyze meaningful patterns related to how Hannah, other participants and social practices co-evolve in dialectical relationship, dynamic processes of negotiation of power, and transformation of the participants and relationships among them. Moreover, my analysis also concentrates on whether and how, and under what circumstances, Hannah negotiated, resisted, and transformed her position as disabled or other disempowering positions.

Diagram 1: Learning Activity and potential produced positional identity.



In this study the context of the community college was analyzed as an open-ended system of activities both embedded within broader contexts and interrelated to other contexts of activities. Therefore, my analysis included the US system of higher education, specifically community colleges and their role in supporting and providing education to disabled students, as well as the current state of support available to students diagnosed with autism within the US higher education. Such analysis provided understanding of current dominant discourses and practices

employed in Metropolitan Community College as socio-culturally and historically produced and embedded in the context of the U.S. higher education.

Similarly, Hannah's personal story, told through her relationship with Ingrid, who was her teacher, friend, and guardian and ultimately became her "adoptive" mother and advocate, adds to an analysis and understanding of Hannah's initial motives and goals of becoming a college student. Importantly, the analysis of her identity development before she enrolled in college sheds light not only on her positioning and her stance as a learner contributing and transforming to socio-cultural practices of the college and its participants, but also the very significance of her stance in the later life.

Although positioning might illustrate a "moment" in person's identity and in the process of her engagement in social practices, it does not represent static identity or entity. Positioning refers to something a person *does* as engaged in social practice, rather than something she *has*. According to sociocultural authors who have used this notion for analytical purposes, social positions and positional identities (Holland, Lachicotte, Skinner & Cain, 1998) arise in the social relations and relational standing of participants they take vis-a-vis each other. As Rahm (2008, p. 98) argues, positioning as a relational concept affords:

[a] dialectic underlying the analysis of becoming, in that positioning is understood in relation to its socio-historical context, yet that context itself is also re-constituted through such making of identity and hence, continuously changing and re-made within that relational ontology.

Importantly, the concepts of positionality and positioning have been used widely to study identity construction with overlapping though different meanings. Both positioning theory as proposed by Harré (Harré & Gillet, 1994; Harré, Moghaddam, Carnie, Rothbart, & Sabat, 2009) and the positional identity concept developed by Holland (Holland et al., 1998) have capitalized on the social, relational, and dynamic nature of identity. However, whereas Harré focuses on

positioning of individuals within social discourses, Holland focuses on positional identity as a process of negotiating constantly shifting positions in the figured worlds of social practices. Harré's and Holland's concepts of positioning have been applied as analytical tools to study an identity of young people diagnosed as autistic as a process of negotiations of positions of "normalcy" and of being "autistic" or "neurodiverse," for instance of high school students diagnosed as autistic by Baines (2012), and young adult diagnosed as autistic by Bagatell (2007). Although both Baines' and Bagatell's analyses allow for understanding of identity, specifically autistic identity as socially constructed in discourses and/or other social practices, they also imply somewhat limiting understanding of identity development of person diagnosed with autism in terms of negotiations within dichotomizing positions of "normalcy" versus "being autistic/Aspie's."

Drawing on the premises of the Vygotsky's cultural-historical approach extended by TAS that source of development is a collaborative transformative practice "carried out through unique individual contributions to this practice" (Stetsenko, 2010, p. 6), and learning being a constitutive part of this process, I use positioning as an analytical tool to explore dialectical and dynamic relationship between learning, self and autism within learning activity and positions produced in this process. Focusing on how identity, learning and autism intersect as Hannah engaged in learning in community college provided me with an understanding of her identity development and her own self-understanding beyond dichotomy of "autistic" versus "normal," or neurotypical versus neurodiverse. Moreover, acknowledging the role of learning in identity formation yielded more nuanced understanding of identity, as a process of negotiation of multiple and ever-changing positions and ongoing process of dynamic negotiations. Although never static, always in flux of negotiations of multiple positions, identity is also understood as a

process directed towards potentially unified and integrated self-understanding of which autism and disability can be integral part.

Using multi-methods approach yielded wealth of data from various sources (see table 1). Initial phase of analysis included transcribing interviews in the order they were conducted. After each interview was transcribed, I listened to the whole interview, wrote a brief summary and looked for overall theme in the narrative of the interviewed participant.

The interviews with instructors were further organized into a matrix by topics of interview and emerging themes (e.g. Initial contact and meeting Hannah; Initial concerns; Hannah as a learner/student; Hannah's strengths; Hannah's difficulties/challenges; Hannah's interactions with instructor; Hannah's interactions with other students; Hannah's participation in class; Hannah's contributions; Experiences of teaching Hannah; Similar to/Different from other students; Changes in teaching after Hannah; teaching philosophy and practices, Institutional support; Interaction with OSWD; Transformations; Understanding of disability; Understanding of autism; Recommendations; etc.). Data organized into this matrix provided an opportunity to analyze data by a single instructor or by a theme or topic across all interviewed instructors.

Based on a close listening of the interviews and reading of the transcripts, I was able to make initial analysis and identify more specific topics, salient themes, patterns of positioning in social practices participants engaged in and were part of, identified cultural tools and practices of positioning, and contradictions resulting from the dynamics of relationship among participants, and vis-à-vis institution.

Table 1: Data collection and focus of analysis

Participants/ Setting	Method/Source of Data	Focus of Analysis
Hannah and Ingrid	<ul style="list-style-type: none"> • Semi-structured interviews • Participant observations/activist collaboration • Member- check method • Field notes • Written material and work produced at and for college (e.g. papers and other written assignments, study notes and written work produced during tutorials and discussions of the readings) • Other written material and work produced (e.g. written work produced to supplement interviews) 	<ul style="list-style-type: none"> • Identifying forms of enactment of positioning and engagement of Hannah and participants of learning activity • Identifying cultural tools and practices that mediate processes of learning, self and agency development, or disablement and disempowerment
Hannah's former Instructors	<ul style="list-style-type: none"> • Semi-structured interviews • Field notes • materials and documents produced by instructors (e.g. course materials including course descriptions, syllabi and course assignments instructions) 	<ul style="list-style-type: none"> • Identifying tensions and contradictions among positions and engagement of Hannah as an agentic learner, autistic person, and disabled learner
OSWD Director	<ul style="list-style-type: none"> • Semi-structured interview • Field notes 	
Hannah's peer/ Student/OSWD tutor	<ul style="list-style-type: none"> • Semi-structured interview • Field notes 	<ul style="list-style-type: none"> • Identifying Hannah's overall positioning and stance toward life and her future orientation
Institutional materials and documents	<ul style="list-style-type: none"> • materials produced by the OSWD (e.g. OSWD's website including Instructor's Manual, Instructions for students, letter to the instructor introducing Hannah as a student registered with Office) • other institutional documents (e.g. Hannah's transcript, MCC Newsletter, MCC website) 	

Methodological and continuous *triangulation* (Denzin, 2006) of diverse range of data yielded a systematic analysis of patterns of positioning, identifying cultural tools and processes of negotiation of power, vis-à-vis positioning of Hannah and instructors and other participants.

Finally, I concluded the analysis with identifying Hannah's overall positioning toward life, including her orientation and stance towards the future.

4. Disabled Students in Higher Education System

In this chapter I discuss the role of community colleges in the US higher education and their role in providing education to disabled students. Furthermore, I pay attention to currently dominating educational goals and expectations from disabled students that are rooted in contemporary individualized and autonomous notions of self and personhood and as such serve as the basis of legislation, policies, and teaching practices in postsecondary education institutions and propose TAS as a guiding principle for organizing education and life goals for all students.

This discussion thus provides an understanding of socio-cultural and historical context within which dominant discourses and practices utilized by Metropolitan Community College and its administrative and instructional staff is situated.

4.1. Role of Community Colleges in higher education system

Community colleges represent the fastest growing sector of public higher educational institution in the USA, with over 40% of all currently enrolled undergraduate students (Goodwin, 2011). The growing importance of community colleges in the US higher education and economy was evident in July 2009 when President Obama unveiled the American Graduation Initiative, “the first major federally funded community college project since the 1960s, that aims to bolster the effectiveness and impact of community colleges, raise graduation rates, modernize facilities, and create new online learning opportunities” (Tiernan, 2010). The president referred to community colleges as an “essential part of recovery in the present, and our prosperity in the future” (Goodwin, 2011), and characterized them as “promising incubators that can lift people out of poverty and into the workforce, strengthening the country as a whole” (Myers, 2012, p. 8).

Although he pledged \$12 billion to community colleges as part of his goal for the United States to lead the world in the proportion of college graduates by 2020, Congress only approved a small fraction of that funding (Goodwin, 2011). Despite unfulfilled governmental funding to community colleges, thus limiting their further improvement and growth, these institutions still represent the largest sector of the US higher education system. As a consequence of the current unstable and haltered economy, enrollment in community colleges began to increase to the point that many community colleges now turn down many applicants and struggle to serve enrolled students (Myers, 2012). The popularity of community colleges is mainly due to their affordability, and even though tuition is increasing, flexible class schedules that accommodate working students, open admissions policies or easier standards for admission, convenient locations, and their established relationships with local businesses, all contribute to the appeal and smaller expense compared to that of a four-year college (Tiernan, 2010). Importantly, as Myers (2012) notes, community colleges are of interest to a myriad of people with regards to their goals, for instance those who are interested in transitioning to four-year college and continuing in further education, obtaining specific job skills, further developing already established career, or testing a new field. In addition, Perner (2002, as cited in Andreon & Durocher, 2007) also reports that community colleges provide students with more individual attention.

4.2. Disabled students in Community Colleges

Community colleges play a particularly important role in providing postsecondary education to disabled students. Due to legal protections and the effects of inclusive reforms⁸ introduced in 70s and 90s, the number of disabled students entering college in this country has been increasing steadily (Barnett & Jeandron, 2009; Cook & Rumrill & Tankersley, 2009; Garrison-Wade & Lehmann, 2009; Hadley, 2006). Specifically, the National Educational Longitudinal Transition Study 2 (NLTS2) indicates that between 1987 and 2003 there has been a 17% increase in numbers of disabled students who enrolled in two-years colleges, and two-year institutions experienced the greatest growth (Wagner, Newman, Cameto, & Levine, 2005, as cited in Garrison-Wade & Lehmann, 2009). Barnett (1996) reported that community colleges serve the largest portion of disabled students, enrolling up to 71 % of all postsecondary disabled students. Despite this continuous growth, Garrison-Wade & Lehmann (2009) maintain that disabled students remain significantly underrepresented in community colleges student population. This is also due to the fact that disabled individuals attend postsecondary education at lower rates than the non-disabled population (Wehman, 2005) and they tend to drop out of higher education at a higher rate than non-disabled students (Murray, Goldstein, Nourse, & Edgar, 2000). However, data from the National Center for Education Statistics for 2004 and 2008 indicate a positive trend in completion rates for community college disabled students, which increased from 11% in 2003 to 16% in 2007 (Barnet & Jeandron, 2009). Disabled students who graduate from college have a greater chance of becoming financially independent (Quick, Lehmann, & Deniston, 2003) and

⁸ Federal laws such as Individuals with Disabilities Education Act (IDEA), 2004, Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA) of 1990 and 2004 were crucial in creating more opportunities for further the rights of disabled students to attend institutions of higher education (Cook *et al*, 2009; Garrison-Wade & Lehmann, 2009).

are three to five times more likely to be employed than a disabled person who never attended college (United States department of Labor, Employment, and Training Administration, 2004, as cited in Cook, Rumrill & Tankersley, 2009). Even completion of any type of postsecondary education (e.g. one college course or a certificate program) significantly improves the chance of an individual with disability to be employed (Zaff, Hart, & Zimrich, 2004). However, the rate of employment of disabled individuals aged 18-64 is only 32% compared with the rate of 81% for their non-disabled peers (National Organization on Disability, 2000, as cited in Hart, Pasternack, Mele-McCarthy, Zimbrich, & Parker, 2004).

4.3. Expectations, educational and life goals for disabled students

Garrison-Wade & Lehmann (2009) point out that the college success (or failure) of disabled students corresponds with low expectations, which further leads to these students being poorly prepared for college. According to the same authors this is a result of two issues, namely a) students not advised to take classes that meet college entrance requirements, and b) students' learning is compromised if they do not receive the types of support they need (Garrison-Wade & Lehmann, 2009, p 420). The findings from the Wave 2 NLTS2 study (Wagner, Newman, Cameto, & Levine, 2005, as cited in Garrison-Wade & Lehmann, 2009) show that 35 % of secondary students with learning disabilities received the standard general education curriculum, however only 52% of these students also received the necessary modifications that would help those students succeed in general education classes.

This finding clearly points to the gap created by not providing students with diversified and adequate cultural tools that are necessary for students to benefit from general education curriculum.

Furthermore, disabled students entering the college also face transitional challenges resulting from transition from high school to college as college impose different and new expectations from them. Those mostly originate in the legislative gap between the rights, available services and support provided to disabled students at high school and college.

While students during high school have a legal right for Individualized Educational Plans (IEP) that can be incorporated in general education curriculum, students in postsecondary education cannot legally demand any individualized plans. In addition, once the students become legally adults their parents (or legal guardians), who are often intensively involved in their education and provide ongoing support, cannot intervene and act on their behalf.

By entering college the students are expected to act independently, manifest their autonomy and self-advocate for themselves. This usually includes that the students self-identify themselves as “Student with Disability,” provide supporting documentation of their disability, request their support and services, identify the academic accommodations needed, self-advocate to their instructors to implement their support and participate in the services that meet their needs (Getzel & Thoma, 2008; Hadley, 2006). Commonly, disabled students enroll into the college unprepared to disclose their disability, lack the understanding of how to access disability support services on campus, or even postpone and wait to disclose their disability until they experience academic problems (Getzel & McManus, 2005). Thus, for disabled students the transition from high-school to college usually involves developing a whole range of *new* skills and abilities as they participate in the social practices that they did not necessarily participate in while in high school. Moreover, many of the skills and practices that disabled students are expected to manifest and engage in are not only new to them, but frequently they are *additional* ones to the repertoire of practices of the typically developing college student. In other words, in addition to navigating the

world of college students, disabled students have to appropriate a subculture of a “Students With Disabilities”.

The literature and research on transition and expectations by postsecondary education institutions focus predominantly on individual responsibility, autonomy, self-determination and self-advocacy skills of disabled students (e.g. Clark, Olympia, Jensen, Heathfield & Jenson, 2004; Getzel & Thoma, 2008; Halloran, 1993; Ryan & Deci, 2000; Skinner, 1998; Thoma & Wehmeyer, 2005). For instance, Halloran (1993) considered self-determination as the “ultimate goal” for disabled students. Clark and her colleagues (Clark et al, 2004) see in self-determination skills the means of preparing cognitively disabled students for this “universally agreed upon goal of education, being as autonomous as possible in making meaningful life choices” (2004, p. 151). Getzel and Thoma (2008), based on the claims of several other authors, state that developing self-determination and self-management skills along exploring technology and obtaining internship or other career-related experiences are the most essential to the retention of disabled students in postsecondary education.

Garrison-Wade and Lehmann (2009) are critical of the existing prevalent emphasis on individual responsibility and self-advocacy skills of disabled students within the literature and research on transition as well as expectations by postsecondary education institutions. They call it deficient for its ignorance of the “obligations of community colleges and policymakers to support those plans” (2009, p. 438). They further claim that besides teaching self-determination and self-advocacy skills in high school, “early and systematic planning” that starts in high school and involves communication among institutions, setting up the future educational goals for the high school students, and goals for their community college experience and for future career is

also necessary. Cobb and Alwell (2007) optimistically conclude that interagency and multiagency planning, including planning with postsecondary institutions is increasing.

I agree that for the transition of disabled students from high school to postsecondary education institutions collaboration on all levels, from individual to institutional, involving interpersonal and inter- and multi-institutional collaborations throughout the preparation and planning is clearly desirable and necessary. However, I argue that the very understanding and defining of the educational and life goals for disabled students entering college should also be reconsidered.

Traditionally, the life and educational goals for disabled people focus on increasing their independence and autonomy. This goal is predicated on two assumptions: a) that more autonomous a person is, the more likely he or she is to experience a higher quality of life (Brown, Branston & Hamre-Nietupski, 1979, as cited in Craig, 2001), including emotional and mental well-being (Clark et al, 2004), and b) on a conflicting logic that only autonomous and independent being can be a good citizen that is able to contribute to national economic prosperity (Philips, 2001, as cited in Robertson, 2001). Furthermore, self-determination, including autonomy, is considered to be an individual attribute originating and developed by and within a person, although with support from the social environment (e.g. parents and caretakers, school psychologist, teachers, etc.). For instance, self-determination is conceived as “an *innate* need that motivates an individual change in certain behaviors, in particular, behaviors considered “self-actualizing” (Ryan & Deci, 2000, as cited in Clark et al, 2004, p. 151, emphasis added).

The limitations of upholding independence and autonomy as life and educational goals, whether for disabled or non-disabled individuals, is also obvious in a narrow and dichotomized

understanding of independence as an individual characteristic, an individual trait and ability of a person acting alone, unrelated to others and to its surrounding. Clearly, being engaged in any activity, even in the most solitary act, human beings are always *related* and therefore *dependent* on others through using cultural tools that are inherently social. Independence in this limited view is usually understood in being independent *of others*. In the culture that praises individualism, being dependent socially and relying on interactions with others in daily activities is commonly perceived as a weakness, especially if it involves interaction deviating from a normative means of interactions, as it is often the case for disabled people. This limited view of in/dependence resonates with the notion that dependent person is somehow less human and *has less of the self*. However, what creates dependency is the hegemony of the dominant culture.

An alternative view, based in cultural-historical and other relational perspectives, is that we are always dependent on use of cultural tools, whether the ones that are internalized (e.g. using a concept of addition and substitution to carrying out simple mathematical operation) and therefore this seemingly mental operation appears to be carried out independently of anything and anybody as an internal activity “inside person’s head”. This example refers to Vygotsky’s point of mind conceived as an internalized social interaction as explained in his well know claim (Vygotsky, 1983, p. 145):

We can formulate the genetic law of cultural development in the following way... Every function in the child's cultural development appears twice, or on two planes. First it appears on the social plane and then on the psychological plane. First it appears between people as an inter-psychological category and then within the individual child as an intra-psychological category... but it goes without saying that internalization transforms the process itself and changes its structure and functions. Social relations or relations among people genetically underlie all higher functions and their relationships.

The same mathematical operation can be carried out more externally, by employing also “external” cultural tools (e.g. abacus, calculator, or pen and paper) to calculate a problem, or even with help of somebody else.

In/dependence are always in dialectical relationship, context bound, situated and embedded in activities, including the tools employed. Independence, in a traditional sense, is “measured” by the level of immediate reliance on the external environment, whether social or material. The more immediate reliance on the social environment the more dependent we appear to be.

Paradoxically, independence and autonomy are frequently achieved by *increased* dependence and reliance on technology, which is often considered as a desired outcome for disabled people.

We are inherently dependent on technologies of our bodies, other people and interactions with them, or other external technologies, be it cultural tools such as mathematical concepts, language, facilitated communication and computer, paper and pencil, or educational, legislative and welfare systems. Inevitably, with increasing globalization, the complexity of societies and the specialization of human activities we are becoming increasingly dependent.⁹

⁹ Martin Packer (2011) provides this eloquent description: “As an infant my needs were simple, and I was dependent on one or two people. As an adult, far from it being the case that this dependence has been replaced by autonomy, my dependence is in fact far greater. As a professor my work depends on the administration of a university and the good work of colleagues and support staff, not to mention the willing participation of my students. My ability to eat depends on the labors of those who grow, transport, and market the food, and sometimes on those who cook it. It also depends on the money I earn, which I keep in a bank where it is sustained and either gains or more frequently loses value at the hands of numerous others, whose task it is to guard it, tend it, spend it, invest it, report on it, and return what's left to me. My ability to communicate in this way with the recipients of this message depends on the technical innovations of numerous teams of people, combined with the labors of those who constructed, maintain, repair and improve the communication network. Am I more capable than I was as an infant? Hopefully. Am I more autonomous, less dependent on collaboration with others? Certainly not. I am tied up in an intimate and far-extended network, a system whose smooth functioning renders it transparent and invisible, but that is absolutely essential for my continued identity and existence. My 'individual' capacities remain dependent on this system. Drop me into

Rose (1998) and Danziger (1990, 1997) provide a radical analysis of the contemporary individualized and autonomous notion of self produced mostly by psychology and related disciplines and institutions in the cultures with liberal values of freedom, equality and self-governance. Martin and McLellan (Martin & McLellan, 2008; Mc Lellan & Martin, 2005) illustrate how such highly individualistic concepts of selfhood and personhood are applied in Western education and autonomous self-governing individual is celebrated at the expense of the socially dependent, committed citizen.

As the above-mentioned authors explain and demonstrate this is due to establishing educational goals and practices including interventions on the principles of theories of self that predominantly rely on individualism and psychologism despite the fact that “major, historical theories of selfhood come replete with social, moral and political considerations” (Martin & McLellan, 2008). As the same authors continue given that the (2008, p. 440-441, emphasis in original):

[e]ducational systems have a social, institutional mandate to prepare students as persons and citizens capable of functional levels of both self-sufficiency and civic participation [a]n overemphasis on the former does much more than risk endangering the latter...[A]n overly individualistic emphasis in education also jeopardizes students’ self-sufficiency by possibly providing too little in the way of exposure to the interests and perspectives of others with whom a reasonable level of civil co-existence is necessary for both personal and societal flourishing....[F]ailure to situate self-regulation within its appropriate and necessary sociocultural, historical, interpersonal, and moral context may inadvertently decouple *self-sufficiency* from *civic responsibility* in the minds of otherwise well-intentioned teachers and students.

The focus on independence and autonomy as life goals specifically for disabled persons have been widely criticized, whether as life goals for disabled people in general (e.g. Bogdan & Taylor, 1992; Brown & Smith, 1989; Carnaby, 1998; Condeluci, 1995; Contompasis &

a place where I don't speak the language and have not practiced the customs, and I am as an infant again, if not worse.”

Burchard, 2004; Fisher, 2007; Knox & Bigby, 2007; Lee, 2009; Olivier, 1990; Sevenhuijsen, 2000, 2003; Turnbull 1991; Ward 2011; Wendel, 2006; White, Simpson, Gonda, Ravesloot, & Coble, 2010), or as educational goals specifically (e.g. Gooden-Ledbetter, Cole, Maher & Condeluci, 2007; Linn 2011; Robertson, 2001). Although the authors come from various perspectives focusing on different aspects of disability and/or development, they commonly criticize the notion of independence as a result of an artificial and false dichotomy between in/dependence and propose focusing on *interdependence*, reciprocity, relationality, connectedness and collective agency. For instance, Olivier (1990, p. 184) criticizes the conception of independence for suggesting that:

the individual needs no assistance whatever from anyone else and this fits nicely with the current political rhetoric which stresses competitive individualism. In reality, of course, no one in a modern industrial society is completely independent: we live in a state of mutual interdependence. The dependence of disabled people therefore, is not a feature, which marks them out as different in kind from the rest of the population but different in degree.

Similarly, Kennedy (2001, p. 123) claims that the dependence of disabled people

is not qualitatively different from what other people experience. All people are dependent on others; it is part of social nature of human life. Indeed, people's dependence on each other is the basis for social interaction and the social relationships that emerge from those interactions.

Disability studies scholars, particularly the ones coming from the perspective of ethics of care, point out that disabled people have always been positioned as dependent, within the false dichotomy of carer and cared for, only as recipient of care and services (e.g. Carnaby 1998; Kennedy 2001; Williams 2001; Williams & Robinson, 2001; Ward 2011). As Ward (2011) further explains, the false dichotomy of carer and cared has its purpose as it enables producing and maintaining a status quo of vulnerable and dependent as well as “false believe in the independence of those who have not been labeled learning disabled” (p.173). Researchers Knox and Bigby (2007) in their study of families with intellectually disabled people found that the

families relied on interdependence, including disabled members, to maintain independence of the whole family. Similarly, Williams & Robinson (2001) found out that disabled people, including some intellectually disabled who had high support needs, were performing care tasks for their elderly parents, although the interdependent relationship was usually not fully recognized either by the parents or their adult children. The researchers note that mutual caring is indeed far more common than is acknowledged and recognized and it often includes people with severe learning disabilities.

Two examples from research projects of programs of integration of intellectually disabled people (Carnaby, 1998; Gooden-Ledbetter, Cole, Maher & Condeluci, 2007) illustrate that the positive self-esteem, self-efficacy and overall social integration can be achieved “easier” in programs that focus on *interdependence* rather than independence. Carnaby (1998) describes a support model in Milan, Italy, for intellectually disabled people in which interdependence is at the center of its approach, and self-esteem is viewed as “resulting from the social integration of service users as a peer group rather than as individuals, while encouraging independence for users in the form of paid employment” (Carnaby, 1998, p. 219). The program encourages intellectually disabled adults to integrate with the local community as a group, rather than as individuals. Furthermore, personal significant relationships developed within the group and community provide the context for positive psychological development. An important part of the program is a “sheltered employment scheme, which, in accordance with Italian legislation, pays a wage comparable to non-disabled colleagues, in turn enabling tenants to pay a standard rent and not to be reliant upon state benefits” (p. 225).

Similarly, Gooden-Ledbetter and her colleagues (Gooden-Ledbetter et al, 2007) found when comparing two different teaching goals of one Independent Living Program (ILP) in

Pennsylvania for disabled people, that self-efficacy (skills) and *interdependence* specifically were both significant, however *interdependence* was a more significant predictor of life satisfaction. The self-efficacy skills in this ILP are taught with the understanding that teaching interdependence allows the disabled person to “begin to make decisions about how to accomplish those tasks that he/she can or cannot do for him/herself“ (p. 157).

Further examples from other cultures in which *interdependence* is valued over independence, self-sufficiency, self-determination and autonomy also point to the illusionary dichotomy between in/dependence, prevalent individualism and overemphasis of independence that dominates US education and welfare system.

For instance, In Portugal the special education system promotes social integration of children with a main goal of inclusion of children reflecting a cultural emphasis of social interdependence over self-sufficiency (Linn, 2011). In contrast, the American system with its focus on independence, embedded in IDEA legislation, can create barriers to children’s social integration (Linn, 2011).

Similarly, Navajo family and disability literature indicates that although traditional and semi-traditional Navajo people value self-regulation and autonomy, these concepts are understood with emphasis on interdependence and group cohesion above independence and autonomy (Frankland, Turnbull & Wehmeyer, 2004).

The presented examples support the claim that a) life and educational goals based on individualized notion of selfhood, overtly promoting independence and other self-regulatory competencies are flawed, and do not necessarily yield a happier, more independent, and self-sufficient person, b) individual’s development, including agency and autonomy, does not occur

within the limits of individual's mind and body, instead it *originates* within interconnectedness with others, from the engagement within collective activity and engagement with the world.

In words of Martin & McLellan (2008, p. 442):

sources of consciousness, meaning, mind, and selfhood lie in interactivity with others within historically established sociocultural practices and ways of life... It is in our worldly interactivity with others, not in our underlying mental and neural functioning, that the meaning and significance required to fuel our goal-directed functioning might be located.

This already well elaborated point in socio-cultural theory literature (e.g. Vygotsky, Leontiev, Galperin, Mesheryakov) is further developed by Stetsenko (e.g. 2008, 2010, 2012, 2013) in previously discussed concept of transformative activist stance (TAS) and the idea that the “collaborative transformative practice, carried out through unique individual contributions to this practice...is the constitutive ontological grounding for human development“ (Vianna & Stetsenko, 2011, p. 317). And as Stetsenko states elsewhere (Stetsenko, 2009, p. 145):

[f]rom an activist transformative stance persons are agents not only for whom “things matter” but who themselves matter in history, culture, and society and, moreover, who come into Being as unique individuals through and to the extent that they matter in these processes and make a contribution to them.

Importantly, this collaborative transformative practice “aimed at changing the world and enacted by individual activist contributions [is] the grounding for both identity and learning” (Vianna & Stetsenko, 2011, p. 313).

4.4. Transformative Activist Stance as a guiding principle for organizing educational and life goals for disabled students

As it has been suggested when establishing life and educational goals for disabled students, including the research upon which the goals are based, intervention, curriculum, principles of inclusion, and other institutional policies, a paradigm shift is necessary.

The current predominant goal of education of “fostering the independence of individual learners” as critiqued by Robertson (2001, p. 122) needs to be redesigned and the focus on inner, mental and neurophysiological states and processes of self-contained learner has to shift to the “activity of persons in the biophysical and sociocultural world, a world of materials and practices shared with others“ (Martin & McLellan, 2008, p. 442).

After all, it is not the degree and extent of independence of our bodies and minds on/from technologies and other tools that makes us human. Consequently, the goal of human life and the point of human existence is not to become independent, adapt to the world as an individual and independently participate in the world. Rather, as previously presented in TAS approach (Stetsenko 2008, 2010, 2012), the point of our existence is to change the world, to contribute to its transformation, which is always simultaneously individual and collective process. Therefore the goal of education should not be fixed on increasing the independence of individuals (as solitary learners) but creating opportunities for and enabling all human beings including disabled students to meaningfully contribute to transformation of human lives and the society as suggested in Vygotsky’s approach and in TAS in particular.

In this effort we can rely on Vygotsky’s notion of unity development and teaching-learning and seeing them as processes “representing facets of one and the same continuous and unified historical Becoming of communities and individuals” (Stetsenko, 2010, p. 11). According to TAS one of the ways identity and development are connected to teaching-learning is the relevance not only of past, present but also of “future activities envisioned by learners” and therefore “cultural tools need to be revealed through instructions and active recreation by learners in their *potential application in possible future practices* envisioned by students“ (Stetsenko, 2010, p. 13). Students’ learning is understood as a prerequisite for their identity

development, as a transformative and an identity-making tool. Dialectically student's identity is a prerequisite for their learning, which is only possible if knowledge is revealed in its relevance to learner's identities.

Following tenets of TAS approach, education for *all* students can be organized on the principle that teaching/learning and development represent a dialectical unity of promoting “meaningful life project,” while learning represents introducing students to cultural tools of identity development. Such education would afford to create opportunities for students to engage in social practices *interdependently* while recognizing their unique and original contributions to those practices.

5. Students Diagnosed with Autism in Higher Education System

This chapter focuses on a current state, existing practices and policies within the context of higher education that are relevant to students diagnosed as “on autistic spectrum” (including those diagnosed with Asperger’s syndrome). Discussed practices and policies are undoubtedly informed and based on various theoretical approaches to development and learning, although, as it will be discussed, this is frequently not fully acknowledged.

The legislation, educational policy, institutional, educational as well as research practices position students diagnosed with autism as disabled, learning disabled or different. Frequently, a student’s positions shift and change depending on activity s/he is engaged in and its context in which it occurs. Integral part of learning and development for disabled students is to navigate the multiple positions available and sometimes forced on the students. Individual institutions, communities as well as individual instructors, staff, students’ families and the students themselves accept, challenge, resists, and often transform their roles and positions originally available and provided through legislation, institutional policies and practices. Presented analysis aids to understand the policies and practices as cultural tools available and used for such positioning of and by students, instructors, staff and other participants within the context of learning at college.

5.1. Growing population of students diagnosed with autism in higher education

In spite of some obvious issues community colleges play an important role in providing education to students diagnosed with learning and intellectual disabilities and increasingly to students diagnosed with autism and Asperger’s syndrome. Although there is no specific statistics

on the number of students diagnosed with autism attending colleges, whether four-years or community colleges, the 2006 survey of The American Association of Community Colleges reported that “Autism Spectrum Disorders” were among the least frequently reported categories of disability among disabled students attending community college (Barnet & Jeandron, 2009). However, according to Ne’eman and Robertson (2008) the anecdotal accounts of disability student service offices, college instructors and administrators indicate increasing attendance by college students diagnosed with autism over the last 15 years. Wolf and her colleagues (Wolf, Thierfeld Brown, & Bork, 2009) report that based on informal survey of 42 US colleges in 2006 there was an average of more than four (4.28) students diagnosed on autistic spectrum at four-year institutions and almost nine (8.9) students at community and technical colleges.

The growing population of students might be due to increasing number of young adults who have been diagnosed autistic in 1990’s (the period of increased occurrence of diagnosis due to changes in the diagnostic specification of Autism Spectrum Disorders, also often referred to as an “epidemic increase”)¹⁰, and the fact that 75% of the increase in autism diagnoses is occurring in the milder categories of Autistic Spectrum diagnosis (Grinker, 2007). Furthermore, reasons for increase in enrollment of students diagnosed with autism and Asperger’s syndrome might be also result of better academic preparation, improved transition planning, and increased federal funding for scholarships and model programs that are generally available to students diagnosed with learning disabilities (e.g. Brinckerhoff, McGuire & Shaw, 2002, as cited in Orr & Hammig,

¹⁰ According to Gilberg (2005), diagnoses of ASDs are currently estimated to be identified in 0.2% of the general population of children. The center for Disease Control estimates that 1 out of every 166 children in the United States is diagnosed.

2009).¹¹ The growing interest of students diagnosed with autism specifically in community colleges might be partially due to the earlier mentioned advantages of community colleges including an opportunity for students for more gradual transition from high school to college¹², continued living with their families while attending a college, and community college providing a possibility of more gradual transition to four-years college that are particularly relevant to disabled students, as well as other support available to disabled students and students diagnosed with autism specifically.

5.2. Providing support and enabling access to higher education for disabled students and students diagnosed with autism

Institutions of higher education are obliged under Section 504 of the Federal Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990 to provide *reasonable*

¹¹ According to Orr and Hammig, (2009, p. 181) despite increasing enrollment of disabled students in postsecondary programs, retention and degree completion rates of disabled students in higher education are not increasing as many students drop out in the first year. Paradoxically, mostly due to “inadequate academic preparation . . . , a lack of transition support between high school and college . . . , fragmentation and inconsistency in service provision . . . , and lack of faculty knowledge and use of appropriate accommodations and modifications.”

¹² The transition from high school to college is commonly facilitated by providing an opportunity of ‘double enrollment’ when students have additional year to graduate from high school during which they can enroll in college course, the option available to all disabled students between the age of 18-21. For instance, Columbus Community College in Ohio developed, and in academic year of 2008-2009 introduced, Autism College Transition program, which will supposedly serve as a model to other community colleges in the country. This program that specifically targets high-school students that can take college-level classes focuses on student independence, social competency and future planning, provides an opportunity for students to meet among themselves and provides an ongoing support (e.g. in time management, organizational skills and locating resources) through regular contact of counselor with students (communitycollegenews.com, CSCC Ohio, 2011). Although one of the goals of the program is to improve student-instructor interaction, the focus of services and support is aimed exclusively at students and does not involve instructors.

*accommodations*¹³, *academic adjustments*, and *equal access* for disabled individuals to all college programs and services. Initial implementation of this law was mostly concentrated on needs of physically disabled students, such as providing ramps for wheelchair users or books in Braille (Freedman, 2010). When the concept and the legislation were to be applied to students who are diagnosed with “invisible” (learning and intellectual) disabilities, the very understanding of what constitutes reasonable accommodations and academic adjustments became somewhat controversial issue. Literature consistently reports that the instructors who are mandated to provide reasonable accommodations, often without much of the guidance, understanding of specific disability and knowing individual students, express concerns about lowering academic standards and rigor (Cook, Rumrill, Becket-Camarata, Mitchell, Newman, Sebaly, & Steuernagel, 2006; Cook, Hennessey, Cook, & Rumrill, 2007; Freedman, 2010; Grigal & Hart, 2009) or that providing reasonable accommodations is too time consuming (Bourke, Strehorn & Silver, 2000).

The ways the policies and practices are interpreted and implemented in the context of providing education to students diagnosed with autism and Asperger’s syndrome in individual colleges vary greatly. Some of the biggest obstacles in enabling equal access commonly reported seem to be mentioned lack of understanding of what constitute reasonable accommodations and academic adjustments, especially for diagnosed students, unwillingness and ambiguity of instructors to implement them, and lack of resources, mostly funding.

The further important implication of this legislation, or the very basis of it, is that the services

¹³ A concept of reasonable accommodation, in other words “an adjustment made in a system to “accommodate” or make fair the same system for an individual based on a proven need” is usually mandate by law and has been applied to religion, academic, or employment (Wikipedia.org, 2012)

and support considered as any *additional* services and academic or nonacademic support to those commonly available to any student are provided on a basis of disclosed and documented disability. Consequently, a student diagnosed with autism or Asperger's syndrome can claim, demand and request additional support only as *disabled*, unless the institution provides autism related support and services outside of the Disability Student Services Office. However, in that case, the services are usually fee-based. Furthermore, if the institution does not offer any special autism related program or services within their services for disabled students, the most probably college approaches the student as having *learning disability* and might provide only academic accommodations and support (VanBergeijk, Klin, & Volkmar, 2008). Several authors discussing the needs of college students diagnosed with autism propose that they require modifications and support in organizational and social, including communicative areas (e.g. Andreon & Durocher 2007; Robertson & Ne'eman, 2008; VanBergeijk, Klin, & Volkmar, 2008).

5.3. Autism related services and support in higher education

Number of colleges respond to the increasing demand and provide services and specially designed transitional programs for students diagnosed autistic to help them make transition from high school and assimilate into college. Some programs focus on ongoing academic and nonacademic support. The colleges, that provide autism-specific support and services, are usually approached more intensively by students diagnosed with autism or Asperger's syndrome and their families than those that do not offer such services.

Specific autism related services and support within the higher education institutions are usually provided by:

- a) Offices for Students with Disabilities (OSWD)

b) transitional and training program for diagnosed students

c) degrees targeting specifically students diagnosed with autism and Asperger's syndrome.

Frequently, autism related services and programs come with additional cost to students, anywhere from \$2,500- 8,500 per semester.¹⁴ Provision of tuition-free support is exception rather

¹⁴ Many post-secondary institutions offer transitional programs, individualized and group support services (based on list posted at [Collegeautismspectrum.com](http://www.collegeautismspectrum.com), <http://www.collegeautismspectrum.com/collegeprograms.html>):

1) University of Tennessee Chattanooga

MoSAIC program - a yearlong course in which students develop executive functioning and social skills

Free of charge for UTC students

2) Boston University

Supported Education Services (part of ODS)

Individualized assistance with skills and support

Free of charge for BU students

3) Autism College Transition program

Columbus State Community College, Ohio

Transitional program for CSCC students

4) Community College of Baltimore County- Essex Campus

Individual student support

5) AIM (Asperger's Initiative at Mercyhurst), Pennsylvania

Program of support and mentoring educating college students living with ASD in a program that equally emphasizes academic and social competency

6) Midwestern State University (Wichita Texas)

Residential Program and mentoring support

7) Eastern Michigan University

Autism Collaborative Center

Individualized support services

\$4,400 - \$8,500 per semester

8) Marshall University, West Virginia

Autism Training Center at the College Program for Students with Asperger's Syndrome

West VA Autism Training Center

Positive behavior and academic support

\$3200 per semester

9) Fairleigh Dickinson University

COMPASS Program

College-based support for students with Asperger's syndrome

first two years of college \$3000 per semester

10) Rochester Institute of Technology

Provides individualized support to students on the Spectrum

than given. This usually is a case when the support is integral part of services provided and coordinated by Offices for Students with Disabilities.¹⁵

Special degrees for students diagnosed with autism and Asperger's syndrome

In addition to colleges providing support to students while enrolled in regular college courses some universities started to design college degrees that specifically target students diagnosed on autistic spectrum. For instance, Sage Colleges and Excelsior College in Albany, New York created an online program for students diagnosed on autistic spectrum with emphasis on computer science, that “can be customized to meet a student's particular disabilities, but it is as rigorous as any other degree” (Williams, 2011). Coursework is available by video, audio and text. However, this educational opportunity for students diagnosed on autistic spectrum come

Rutgers University Full support services and life coach
\$2500 per semester

11) Taft College, California

Transition to Independent Living Program

Post-secondary program focused on independent living skills

12) University of Alabama

Autism Spectrum Disorders College Transition and Support Program (UA-ACTS)

Comprehensive academic and behavioral supports

\$3000 per semester

13) University of Arkansas

Autism Support Program

Comprehensive services to the students in the areas of academics, social skills, and transitioning to independent adult roles.

\$5000 per semester

14) University of Connecticut

SEAD Program (Strategic Education for students with ASD)

Comprehensive academic and behavioral supports

\$3000 per semester

¹⁵ Boston University provides free of charge individualized assistance with skills and support and Strategic Education Services for their students as a part of services of Office of Disability

with a hefty price tag, the tuition for the first two years is about \$27,000, and in the third and fourth year, when the course load doubles the tuition increases to \$43,000. In relation to creating degrees specifically targeting students diagnosed on autistic spectrum in private colleges, the question arises whether this movement leads to segregation and production of *Special Education in the context of higher education*. Inclusion of students diagnosed on autistic spectrum in this educational context comes with price that excludes students from general population of students.

Fee-based out of college organizational support

In addition to higher education institutions, other for-profit and non-profit organizations provide mostly fee-based assistance and autism related support to students. For instance, AHEADD, a private community organization, originally developed in cooperation with Equal Opportunity Services of Carnegie Mellon University, provides support services not only to students diagnosed on autistic spectrum but also offers trainings for families, employers, and high school and university staff with the goal of addressing “students' inherent social, communication, and organizational issues, and helps students develop individualized strategies to manage their college careers independently” (AHEADD, 2011). The AHEADD currently charges a fee of \$4,200 - \$5,300 per student, per semester.

Clearly, some of the conditions (e.g. related fees) of services provided that are supposed to enable access of students diagnosed on autistic spectrum to the college programs and activities lead to exclusion rather than inclusion of the students. In other words, the very practices that are supposed to promote access and inclusion of students diagnosed on autistic spectrum might contribute to their exclusion, at least for the students who cannot afford to pay for the services

Services for students diagnosed with psychological disabilities, and University of Tennessee in

that could promote and facilitate their access and full participation in education the given institutions provide to students without disabilities.

Free autism related support

Significant and mostly free support for students diagnosed on autistic spectrum, as well as their parents and guardians, and to some extent to instructors and staff come from autistic community itself. For instance, ASAN (Autistic Self-Advocacy Network) posted this year on their website a publication *Navigating College: A Handbook on Self Advocacy* (ASAN, 2012) that was written by adults diagnosed with autism for students diagnosed on autistic spectrum.¹⁶

The OAR (Organization for Autism Research) produced a twelve minute video (available to watch online or as a DVD upon request) in cooperation with the Global and Regional Asperger's Syndrome Project (GRASP) *Understanding Asperger's Syndrome: A Professor's Guide* that focuses on informing professors, teaching assistants, and other instructional professionals on "what it means to be a college student on the spectrum and how they might best be able to help them succeed" (www.researchautism.org/resources/AspergerDVDSeries.asp, 2012). The video can also guide students in articulating their needs and request for accommodations in higher education institutions.

their yearlong MoSAIC program provides individual support to students diagnosed with autism.

¹⁶ The group is also working on developing a booklet on teaching college students diagnosed on autistic spectrum how to go about engaging in policy advocacy through on their college campuses. Specifically, the booklet will address "how to form effective student groups, will educate participants about disability history and disability laws, and will provide examples of strategies to bring about systems change in higher education" (ASAN, 2012, <http://autisticadvocacy.org/projects/>). Finally, the ASA also launched a new program *Autism Campus Inclusion Leadership Training* for college students diagnosed with autism in summer 2012. Twelve to eighteen college students would have an opportunity to learn the skills how to "effect systems change in their individual campuses and increase their own skills in self-advocacy and self-help" (ASAN, 2012, <http://autisticadvocacy.org/projects/>).

Number of other resources (e.g. online communities and other initiatives run by individual persons with autism or advocacy groups) are available online and mostly serve potential and enrolled college students (Robertson & Ne'eman, 2008).

Typically available and recommended autism related support in higher education institutions

Recently, the growing interest of the students diagnosed on autistic spectrum in obtaining higher education as well as demands of the instructors and administrators on how to best provide instructions and services to the students led to increasing number of publications on the topic. Some of the authors make suggestions in providing guidance for students, parents, instructors, counselors and other staff in postsecondary options for students diagnosed with autism or Asperger's syndrome (e.g. Adreon & Durocher, 2007; Hart, Grigal, & Wei, 2010), providing academic and other support to students diagnosed with autism (e.g. Robertson & Ne'eman, 2008; VanBergeijk, Klin & Volkmar, 2008), navigating college life with a special focus on stress that that is frequently associated and experienced by students diagnosed with Asperger's syndrome (Glennon, 2001), or specifically addressing teaching students diagnosed on autistic spectrum (Taylor, 2005). Martin (2009) offers a novel approach to providing guidance to the instructors and other college staff as she reverses locating the triad of impairments that are associated with Asperger's syndrome in the higher education institution itself. From this starting point she develops suggestions for ability of the institution to "deliver good communication, flexibility and socially appropriate experiences" (Taylor, 2001, p. 158) and thus ways of providing institutional support to students.

Freedman (2010) in her book offers systematic guidance for “developing college skills in autistic students and Asperger’s syndrome” that targets students, parents as well as instructors and other college staff.

The language used in some of these publications (e.g. comorbidity, deficits, treatment, etc.) clearly indicates deficit perspective of the authors to autism and consequently positioning of the students (e.g. Adreon & Durocher, 2007; Freedman, 2010; VanBergeijk, Klin, & Volkmar, 2008). This fact only emphasizes the importance and relevance of the voices of authors from autistic (including Asperger) community that is gaining attention and its own place within academic community. They offer their perspectives on support of college students (e.g. Robertson & Ne’eman, 2008), as well as personal accounts of college experiences of students (Shore, 2001; Willey, 2000) including teaching assistants and instructors diagnosed with autism and Asperger’s syndrome (Prince-Hughes, 2002, 2004). The work of researchers exploring and documenting students’ college experience from the neurodiversity approach significantly contributes to the complex picture of the issue (Griffin & Pollak, 2009; Madriaga & Goodley, 2010).

Regardless the theoretical perspective of the authors discussing the types of support, assistance and accommodations specifically for students diagnosed on autistic spectrum there seem to be a general agreement that it should address academic as well as nonacademic aspect of education and college experience (Adreon & Durocher, 2007; Freedman, 2010; Glennon, 2001; Robertson & Ne’eman, 2008; VanBergeijk, Klin & Volkmar, 2008). Researchers emphasize the importance of counseling and social support, including independent living skills and self-advocacy (Adreon & Durocher, 2007; Freedman, 2010; Glennon, 2001; Robertson & Ne’eman,

2008; VanBergeijk, Klin & Volkmar, 2008), pastoral care¹⁷ that the colleges should provide to students diagnosed on autistic spectrum (e.g. Griffin & Pollak, 2009; Taylor, 2005). MacLeod and Green (2009), based on their research in the UK even argue that Student Support Services need to see pastoral and non-academic support as the central to the support that they offer. Some emphasize that students diagnosed on autistic spectrum may benefit from the type of counseling “directive, explicit guidance and counseling” (VanBergeijk, Klin & Volkmar, 2008, p. 1364). As already mentioned, the individual needs of students diagnosed on autistic spectrum for support and assistance may vary greatly depending on “individual strength, challenges, preferences and needs because of large variants exists among autistic people” Robertson and Ne’eman (2008, p. 4). Therefore some diagnosed students may only need support in social interaction and nonacademic areas, which might not be readily and commonly available at the colleges that do not offer any autism related services and available support and accommodations relate to only physical, learning and intellectual disabilities. Table 2 provides an overview of typically available accommodations for disabled students at colleges.

In addition to the accommodation typically available to disabled students literature (Adreon & Durocher, 2007; Freedman, 2010; Hart et al, 2010; Robertson & Ne’eman, 2008; Taylor, 2005; VanBergeijk & Volkmar, 2008) also suggests further academic and classroom accommodations that students diagnosed on autistic spectrum may benefit from (see table 3).

¹⁷ Pastoral care is a term used predominantly in the UK and generally refers to social support.

Table 2: Accommodations typically available at the higher education institutions for disabled students (based on Hart et al, 2010, p. 138, and Freedman, 2010, p. 192).

<p>Instructional Accommodations</p> <ul style="list-style-type: none"> Peer note taker Tape-recorded lecture Laptop computer Outline or notes from professor Textbooks on tape (RFBD* or other) Spell checker and grammar checker Kurzweil Reader or e-reader TextHELP: Read and Write software Screen Reader (CCTV) Screen enlarger FM listening device Priority seating Advanced receipt of syllabus and course handouts Course materials available in alternative format Modified assignments
<p>Academic Accommodations:</p> <ul style="list-style-type: none"> Academic support, counseling referral, and special advising Tutoring Modified course load Priority registration Early registration Course substitute for “required” course Pass/fail or credit/no credit courses
<p>Test Accommodations:</p> <p><i>Setting Alterations</i></p> <ul style="list-style-type: none"> Separate room for test Minimal distractions Priority seating <p><i>Time/Schedule Changes</i></p> <ul style="list-style-type: none"> Extended time (50%, 100%, etc.) Breaks during testing Administer test in several sessions Specific time of day that is best for student <p><i>Test Format Changes</i></p> <ul style="list-style-type: none"> Reader to read directions and questions or oral test Dictate answers to scribe or tape recorder Allow student to mark responses on test rather than on Scantron answer sheet Increase size of answer sheet bubbles Larger type Use of word processor for written responses

Note: RFBD = Recording for the Blind and Dyslexic, CCTV = closed-circuit television.

Table 3: Additional academic and classroom accommodations potentially beneficial to students diagnosed on autistic spectrum (Adreon & Durocher, 2007; Freedman, 2010, Hart et al 2010; Robertson & Ne’eman, 2008; Taylor, 2005; VanBergeijk & Volkmar, 2008).

<p>Instructional Accommodations:</p> <ul style="list-style-type: none"> Access to class notes (including slides) preferably before class. All instructions and assignments available in written form. Explicit instructions on when to begin a research paper, write a draft, and final paper, length of paper, etc. Voice recognition software for dictation of papers.
<p>Academic Accommodations:</p> <ul style="list-style-type: none"> Other organizational support – organizing classroom and study material, due dates of the assignments, etc. Support and assistance with time management, including prioritizing, and dealing with procrastination. Breaking course loads down into smaller, more manageable units, turned in separately. Checking for understanding of instructions, and /or clarification of material, on a regular basis until it is clear that understanding is adequate. Specific guidance for working in groups
<p>Environmental Accommodations:</p> <ul style="list-style-type: none"> Allowing sensory breaks where student leaves the classroom for short periods of time, as needed, to deal with sensory issues. Use sensory-limiting devices to mitigate the distraction caused by fluorescent lights and noisy corridors, e.g. sunglasses, tinted glasses, headphones.

Although the presented account of existing and available, as well as recommended services and support to students diagnosed on autistic spectrum might not be complete and exhaustive, it documents that it can be quite comprehensive and at the same time fragmented, exclusionary or simply nonexistent in individual institutions of higher education. It also indicates that depending on by whom, how and what support is provided to a student s/he might be positioned within the higher education institution as different or disabled.

Importantly, it needs to be emphasized that despite the above discussed efforts in providing education to students diagnosed on autistic spectrum these refer to only teaching strategies and techniques at most. Currently, the only existing theorizing of pedagogy and learning of students

diagnosed on autistic spectrum in the context of higher education focuses on the concept of learning styles, discussed in the following section.

5.4. Autism in the context of higher education: Disability or Difference?

One could argue that if, in the context of the current legislation applicable to higher education institution, autism needs to be labeled as disability, as a prerequisite for obtaining support and enabling access to education, then by the same token the institutions need to recognize autism as a separate category among disabilities¹⁸, rather than simply identifying it with learning disability, especially given that diagnosed students may need modifications and support in nonacademic areas as already mentioned. Following the logic of the current situation, it could be argued that recognizing and acknowledging autism as a separate category could potentially lead to broader and more tailored support to students. Furthermore, recognizing autism a separate category could further help in obtaining necessary funds and providing support to instructors and staff, including professional development and increasing awareness about autism and neurodiversity at college. However, the reality for most college students diagnosed with autism is that they need a diagnosis and a disability label to receive the support in order to access the education. Paradoxically, even if a student receives a diagnosis, discloses and identifies herself as autistic *and* disabled, still she might not receive the necessary support and accommodations that have been recognized by the students themselves, and increasingly identified and recommended by researchers and educators. Until support to students will be legislatively tied to determining and identifying disability, the necessity of recognizing autism as

a disability, separate from other disabilities, will persist. Alternatively and optimally, the support to students could be provided regardless existing and documented disability.

There is a disagreement among scholars and educators on the very need of labeling students diagnosed with autism and regarding them as having “special needs” and “disability.”

Baron-Cohen (2002), one of the leading experts on autism within cognitive approach, claims that because Asperger’s syndrome and high-functioning autism (AS/HFA) “involves special needs and requires extra support ... (e.g. “they need to be recognized as different, may require different kinds of teaching methods or schooling or specific kinds of treatment”)” it is a disability (p. 188). However, as he further admits the actual function of the term disability is to “ensure[s] access to provision—it may be the legal system that needs revision so that a child whose autistic “difference” leads him or her to have special needs will still receive special support” (Baron-Cohen, 2002, p. 188). He claims that the second reason that reflects disability rather than the difference in individuals with AS/HFA is their “lack of social interest” or “lack of normal sociability or communication” (p. 188). He also believes that it is the “environmental expectations... world where individuals are all expected to be social” that makes people diagnosed on autistic spectrum to be perceived as disabled and “if individuals with AS were set down in a different environment, they would not be perceived as disabled” (p. 189). Despite recognizing contextual conditions of what creates disability out of AS/HFA (e.g. legal system, health and education economics, social policy and social conventions) and the fact that the label “disability” serves the existing systems, Baron-Cohen maintains that Asperger’s syndrome and high-function autism is a disability.

¹⁸ The revisions of IDEA in 1990 led to identifying autism as a “separate and distinct category” (Vari, p. 64, 2008) and autism, and Asperger syndrome are legally recognized as disability by Social Security Disability Services (<http://www.socialsecurity-disability.org>).

In contrast to Baron-Cohen's claims of necessity of maintaining the status of disability for individuals diagnosed with high-functioning autism and with Asperger's syndrome, Pollak (2009) argues that labeling students as such and regarding them as having "special needs" only leads to addressing them in compartmentalized way and it should not occur. Instead, he and several other scholars (Griffin & Pollak, 2009; Lawson 2001, 2006; Martin, 2009; Pollak, 2009; Symonds, 2009), drawing on concept of neurodiversity and social model of learning difference, suggest viewing students as different rather than disabled.

The disconnect between Baron-Cohen's and Pollak's argument is not so much about disagreement about disability versus difference, rather it is about referring to what the situation *is*, given the current legislation, and what it *should* and ideally *could* be. Although Pollak and other advocates of neurodiversity approach identify with social model of disability and thus rejecting individualistic view of disability and human being, in principle they rely on individualistic notion of human mind and learning.

Specifically, the central to their neurodiversity position of different rather than disabled learner is a different type of brain that results into different cognitive processing that consequently leads to different learning styles. Those, according to the discussed authors, can be accommodated through inclusive practices such as implementing principles of Universal Design for Instructions¹⁹. For instance, Pollak (2009, p. 1) introduces the book stating "this book is about variety of types of brain". Lawson (2001), who proposes to view autism as a "differing learning style," states that "[w]hen you consider how our differing cognitive processes inform

¹⁹ Universal Design for Instruction (UDI) - is an educational framework for applying universal design principles to learning environments with a goal toward greater accessibility for all students, including students with disabilities. UDI involves considering the potential needs of all learners when designing and delivering instruction by identifying and eliminating

our experiences, then it is quite apparent that even within our differing personalities we have distinctive learning styles” (p. 65). Symonds (2009) argues that different learning styles of diverse learners, who do not fit one model, require various models of assignments and assessment outside of traditional educational world, which offers “largely linear, text-led, exam-based, time-focused, standardized learning” (p. 243).

The efforts of applying a concept of neurodiversity in higher education by number of authors (Pollak, 2009) deserve recognition and attention as they contribute to a positive view of students diagnosed with autism and other neurodiverse learners by emphasizing a) as difference/s rather than disability or defect, b) value of diversity of neurodiverse students contributing to body of learners and teaching process, c) promoting implementation of rules and tools of Universal Design for Instruction and other nontraditional methods of instruction and assessment, and d) necessity of increasing awareness of neurodiversity and embracing it as a part of human diversity.

However, I argue that it is also necessary to recognize limitations of this approach and fully acknowledge its implications, especially for educational practices. Using neurodiversity to view students diagnosed with autism, or other neurotypical learners (dyslexia, dyspraxia, dyscalculia, etc.), as merely having different brains and consequently different learning styles that simply need to be adequately matched with variety of types of assignments and evaluation and assessment methods is oversimplified view of the learners and process of learning itself. This view is essentially relying on cognitivist view of autism that, despite their efforts of focusing on nondeficit aspects, sustains locating autism in the individual’s brain.

For instance, the very concept of autism as cognitive style rather than cognitive deficit was

unnecessary barriers to teaching and learning while maintaining academic rigor (Burgstahler,

proposed by Happe (1999, p. 216), a prominent scholar in cognitive approach to autism, who suggests that deficit accounts of autism cannot explain all the traits and characteristics of autistic person (e.g. “savant skills in math, music and drawing, and islets of ability in visuospatial tests and rote memory”). Instead she proposes an alternative account of a “cognitive style biased towards local rather than global information processing- termed ‘weak central coherence’” (p. 216).

Accordingly, Siegel (2010) suggests reconceptualizing the taxonomy for diagnosis of Autism Spectrum Disorder as Autism Learning Disabilities (ALDs) and Autism Learning Styles (ALSs), ALDs corresponding to specific “functional defects in perception, processing, storage, retrieval, or output of sensory, affective, or cognitive inputs” (p. 559), and ALSs defined as “characteristically stronger, intact functions (sometimes exceptional and seen as ‘splinter,’ ‘peak’ or ‘savant’ capacities) that individuals with autism spectrum disorders automatically deploy in compensations for their ALDs” (Siegel, 2010, p. 560).

The concept of learning styles, conceived as individual trait, fits concept of reasonable accommodations well and further “individualizes” a student, as a student is expected to understand her disability, identify her learning style and accommodations she might request. These expectations that become student’s individual responsibilities are commonly perceived as an opportunity for the students to develop their self-determination skills as the following excerpt illustrates (Hart et al, 2010, p. 137-138, emphasis added):

[I]f a student requires modifications, the responsibility falls to the student and to those providing assistance to ensure the course material is accessible and the student will be able to successfully participate. This may mean that students register for a course using an “audit” option instead of taking the course for credit in order to become more familiar with the course content. It also may mean for some students that courses available via continuing education departments might be better *matches* for their interest, *learning styles*, and

Burgstahler, & Cory, 2008).

academic abilities. It is important that we withhold our decisions about how students will participate in courses until they start attending classes. This is a rich opportunity to teach students self-determination skills where they are engaged and guided as to how they wish to participate in the course once they have attended several classes.

As Hart and her colleagues suggest it is predominantly student's "responsibility" to identify her personal learning style, "identify courses of [her] interest and match the student with instructor versed in alternative styles" (Hart et al, 2010, p. 141), shop around and if necessary, take a class for no credits. Unfortunately, not all students have an option and resources of trying out various classes and instructors, audit the course, or take it for no credit, due to financial and other restrictions. Commonly, financial aid is based on the amount of credits student takes per semester.

5.5. Reframing support and learning/teaching learners diagnosed with autism: From supporting individual learner to supporting learning activity

The application of the concept of learning styles in the context of providing education to students diagnosed with autism (or other learning and intellectual disabilities, or any other type of neurodiversity for that matter) lends to individualistic view of learners, whether originally positioned as disabled (e.g. by deficit/medical model) or different (e.g. by neurodiversity model or social model of learning difference). If a difference is located within an individual's brain, making it a "difference" rather than a "disability" will not significantly reposition student from being disabled and being individually "responsible" for their difference and learning.

Narrow understanding of neurological difference as individualistic trait leads to what Gutiérrez and Rogoff (2003, p. 19) recognize as:

strategy of locating characteristics separately in the person and in the "context," and "crossing" style and context as in the Aptitude X Treatment approach. In educational

settings, work on learning styles has often attempted to take context into account by seeking style matches between students and schooling experiences or between student and teacher (Banks, 1995).

Recognizing, acknowledging and valuing brain differences of diverse learners do not take us far enough. The efforts of accommodating different learning styles of diverse learners maintain the focus on individual as “the source and target of the intervention” (Gutierrez & Rogoff, 1997, p. 18). The same authors further critically point that individual’s learning style represents a trait that is “independent of tasks and contexts, ... is constant over time” and as such does not account for “change in the individual, the activity setting, or the community” (p. 19).

Based on Vygotsky’s approach, it can be suggested that the focus of analysis and of providing support and accommodations cannot be a “different” or “disabled *brain*”. Focusing on *individual* “different” or “disabled *learner*” is not satisfactory either. Taking into account dialectical and collaborative nature of learning/teaching process and production of knowledge, the attention needs to be paid to *learning* as a relational process situated in a student's meaningful engagement and contribution to social practices mediated by cultural tools. Therefore, services and support originally focused on exclusively or predominantly on students diagnosed with autism have to be conceptualized and organized in a way that support and promote *learning activity* of which not only diagnosed students are part of, but also instructors, service providers, institutional practices and other societal tools.

6. Hannah's path to education: Collaborative activist effort

In this section I attempt to reconstruct Hannah's educational path, based on Hannah's and Ingrid's accounts. Listening to their memories and anecdotes from the past, it became obvious that Hannah's story of her educational background is a story of her relationship with Ingrid. This story illustrates how Hannah, under Ingrid's guidance and support, developed appreciation for learning, her future goals and her agency as a learner and human being.

From their accounts, I learned of Hannah's development as a learner, her remarkable trajectory from an autistic child deemed incapable of learning to successfully graduating from a community college. This reconstruction of Hannah's developmental path based on their accounts affords the opportunity to analyze each participant's role and their positioning toward one another. Based on what I learned about Hannah's family from Ingrid, (Hannah's early childhood teacher,) the role Hannah's mother played, the schools Hannah attended, and the medical and social services institutions, all of which mediated their relationship and, consequently, shaped Hannah's development. In this analysis, I pay close attention to their discourses on (a) autism and disability, (b) learning and development, (c) family relations, which provides a rich perspective on the profound and complex meanings of their relationship. The data presented here and their interpretation is based on what Ingrid and Hannah told me in response to my questions about Hannah's education and childhood, and how they developed their relationship to the point that Ingrid became responsible for Hannah when she came to live with her. One important aspect I wanted to understand is how the responsibility to raise Hannah was transferred from her parents to Ingrid. It further needs to be emphasized that although I met Hannah's parents on several occasions, I never interviewed them or discussed any of the aspects of Hannah's life presented here. They were not participating in this research project. Obviously, roles and positions of

Hannah's parents in this story are also reconstructed based on my interpretation of Ingrid's and Hannah's narratives.

Hannah's formal education started in October of 1986 in a public school in the Special Education kindergarten class where she met Ingrid²⁰ who was going to become her teacher for the next three years.

²⁰ Ingrid is a white woman in her late 70s who arrived to the US in 1960 from Western Europe to study graphic design, as she explained "eager to leave my small landlocked country and expand my horizon". She was a Special Education teacher in Public School system in her home country.

Upon her arrival in the US, she found a job as a recreational worker in an institutional suburban setting for children with emotional problems. She worked there full time for three years and part-time in the fourth year while studying graphic design. Her first job was in an architectural firm. However, soon she realized that her passion was working with children. Although she enjoyed design work, became increasingly successful and well compensated she missed working with children and slowly started "The Children's Workshop," offering classes in her home, first on Saturdays mornings, and then adding classes after school. She taught baking, sewing, and knitting. The children enjoyed learning new skills and putting effort, imagination, creativity, and high standards for one's self into their projects to gift to one's family and friends. Meanwhile, she gave up her design job to devote the next 20 years to her "Children's Workshop".

Ready for a new challenge she went back to college to earn a Special Education license to teach in the public school system in the US. As a Special Ed teacher she could work with smaller groups of children of diverse backgrounds and abilities and be involved with each child intensively. As a true Deweyian, she liked the challenge of creating nurturing environment for every child based on their needs and interests and she felt that working with children in Special Education classes gave her more freedom to do so. She believes that it was her destiny to meet Hannah in my second year of teaching.

For Hannah's sake, Ingrid restarted a "Children's Workshop" on Saturday mornings to provide an opportunity for Hannah to be with a small group of mainstream children and to learn like everybody else to bake, knit, and sew. As she recalled: "I remember how she loved to pick colors for her projects, how peacefully and attentively she worked on them, and how proudly and joyfully she mailed her first completed item to her grandmother."

By the time Hannah left school for autistic children, Ingrid left teaching position so she could fully concentrate on homeschooling Hannah and prepare her for making transition to general education class.

From the very first moment Ingrid saw Hannah, the little girl sparked interest in her and Ingrid felt drawn to her. This is how Ingrid described how she first met Hannah:

I was starting a new class teaching at [school] ..., and I was getting my classroom ready, and looking forward for my job with young children, and I met Hannah in a hallway having a tantrum, screeeeeeeeaming, and she looked like very unhappy girl ... it was something about Hannah that just...asked me ... touched me, and ... when the children were going to be assigned to my classroom I asked my principal if I could have Hannah, and her regular teacher was actually very happy to get rid of her, that worked out well. Ahm..., she was very tiny and very...light, ...and I don't know I just ahm somehow fell in love with her...

Hannah continued to draw Ingrid's attention; she was the youngest and smallest child in the classroom and would not readily join the group:

[U]sually, in a classroom she sort of wanted to have things her own special way. When it was time for the children to sit at their desks she totally ignored the call and just stayed in the back of the classroom, and I never forced her, ... and somehow it seemed to me that she somehow even if she was not where she was supposed to be she was still paying attention.

At that point, neither of them had any idea how Hannah's transfer to Ingrid's class would change their lives. Hannah found in Ingrid a lifelong tutor and quasi guardian who was cognizant of her potential and has been guiding and supporting her ever since they met. At the same time Ingrid found in Hannah a daughter. Their relationship has many flavors and forms. It is a friendship, a teacher-student and a mother- daughter relationship. Noticeably, whatever position Ingrid takes on when talking about Hannah, it is often quite emotional, even poetic.

Undoubtedly, in addition to that "something about Hannah" that Ingrid talked about in my interview with her, it was also Ingrid's persistence, time, and financial resources available to her that enabled her to dedicate attention to Hannah beyond regular school hours and form a strong relationship with her.

An important aspect that calls attention to Ingrid's narrative is how she positions herself as someone who could see potentialities in Hannah, which, as I detail below, she contrasts with other professionals and with Hannah's family. For instance, Ingrid recalls that she did not really

see Hannah as very different; rather, as she puts it, “it just turned out that sometimes she just sort of had her own way about doing things, and I just gave her that freedom.” Ingrid continued:

She was not in any way a difficult child, and although she would often just attend from afar, ... I was always amazed, you know, it sort of seemed that maybe she was sort of doing her own stuff or not listening or whatever, but I soon realized that she pretty much knew what was going on up front by the blackboard.

Hannah and another of her classmates were Ingrid’s first pupils who were diagnosed as autistic. She did not know much about autism. It was not a topic discussed in society at the time as it is today. She started to seek information in books and at lectures and seminars presented by grass root organization.

She later saw a program on TV presenting an educational approach practiced in Japan that fully integrated children diagnosed with autism into mainstream education. Ingrid remembers that watching the program confirmed her personal believe that these children could learn from and together with typically developing children. This approach was in sync with Ingrid’s own way of raising and educating children in her Special Education class, and even more so in her own Workshop, an afterschool program she conducted in her home, where children of different ages and abilities interacted and participated in extracurricular activities, as she described:

I started the Workshop when I realized that skills like knitting, sewing, cooking and baking were not taught in the American school system. Learning these skills was an important part of family and my school life in Europe. They have enriched my life in many ways and by creating a Workshop for children I could pass them on.

She described a number of anecdotes about children, either from her class in school or in the Workshop, interacting among themselves within a collective activity, engaged and participating to various degrees, often supporting each other’s involvement. Ingrid, based on the description of these activities, emphasized not only the importance of mastering certain skills and knowledge, such as baking a cake, but emphasized the role of children engaging in collective

activity, and how it mediated interactions among children, their mutual support, and individual contributions of whatever degree in a joined effort. For instance, she mentioned one occasion when children made a gingerbread house and each child contributed according to their interest and capabilities to create a masterpiece. She also spoke of another example of children supporting a classmate, a nonverbal girl, whereby children on their own intuition were creating opportunities and situations for her to learn to say a word, as Ingrid described:

I remember Jack pulling Julia sitting in milk cart up and down the hallway, stopping and going to teach her “stop” and “go”. Other times they span around with her and in unison sang “spin,” or they jumped up and down trying to impress on the word and meaning of jump.

Every child had an important role in a collective, was integrated in activities and encouraged to participate (with special efforts paid to provide motivation for such participation and involvement), without insisting and forcing their participation. As I observed, this was an important aspect of not only Ingrid’s educational and upbringing philosophy but a characteristic of her overall relationship with Hannah as well as her general way of relating to people. However, the attitude of Hannah’s parents, and their vision for Hannah was quite different and in contrast to that of Ingrid.

Hannah was born a first child in a rural, small town hospital setting in 1981. Ingrid was told by Hannah’s mother that from the start Hannah was not an easy child. She cried a lot and was difficult to sooth. She rejected bodily togetherness, made no eye contact, and behaved best when left alone. In the early 80s when was little know about autism and even less about educating and providing support to children diagnosed with autism, Hannah’s parents received little support in bringing up “an autistic child,” and did not seem to actively explore and search for such support. The grandparents thought that Hannah was a spoiled child.

When Hannah reached pre-school age the family made a career move to a large urban city in another state. Here Hannah was bused three days a week to receive play therapy in a group of children diagnosed with autism, at local University hospitals. Based on how Ingrid and Hannah describe Hannah parents' attitudes, they seemed to accept most of the official suggestions, recommendations and opinions from institutions that tended to be rather pessimistic about their daughter's development. For instance, the parents were told that Hannah would not develop beyond the third grade level and they did not object to or chose to fight this prediction. When they were told that there was no "cure" for autism, they did not search for any alternatives or solutions.

When Hannah was eight and "aged out" of Ingrid's classroom, Hannah's mother opted to place her daughter into a private school that specialized in schooling children diagnosed with autism because her mother felt it would be a better place for her. Children could attend school up to the age of 21 at what point the state funding stops. Hence, by fall, Hannah was picked up every morning at her house and bused out of her neighborhood, Monday through Friday. Hannah recalled:

[M]y mom thought ...that I wouldn't be able to attend a mainstream school ... because my mom thought that [school for autistic children] was ok school for me because of small classes and that she thought that I was not ready to be in mainstream school, but it was not right...

Ingrid described that perhaps partially due to lack of knowledge and support Hannah's family related to her diagnosis, with shame and embarrassment infused with a feeling of personal guilt. According to Ingrid, Hannah's family adopted a very limited view of autism inculcated by health professionals with the attendant low expectations about Hannah's development. Based on Ingrid's account, their main focus was on controlling Hannah's behavior. Her critical reaction to

Hannah's parents' approach gave Ingrid an impetus to take the initiative in being centrally involved in Hannah's life because she believed that adopting a more optimistic perspective and proactive attitude could make a big difference in Hannah's development. According to Ingrid, Hannah's parents' attitudes were translated into them focusing their efforts on eliminating improper behavior, rather than seeking and creating opportunities to stimulate Hannah's development. For instance, Ingrid mentioned that she never managed to convince Hannah's mother to read books to her at home. Furthermore, on several occasions Hannah would be left to stay in her room alone while her birthday would be "celebrated" with family and friends. As Ingrid further describes, Hannah was given a walkman to listen to the music so she would be quiet in public, among similar examples. In order to prevent unwanted behavior and protect her either from embarrassment, teasing or overload, Hannah was frequently prevented from participating in many everyday activities and environments that typically developing children are ordinarily included. Perhaps because Hannah was not developing typically, her parents did not have high expectations for her, or as parents they did not feel adequate to participate in her atypical development. Perhaps it was both.

Ingrid's expectations for Hannah were always high. She believed in her ability of further learning and social maturation through participation in and integration into everyday family and life activities, and the benefits of the mainstream education. Ingrid admitted that she secretly dreamed of mainstreaming Hannah. She was convinced that education would change Hannah's life, to become what she was capable of becoming although it would require a great deal of work, effort, and the cooperation of many people. Ingrid feared discussing her vision with Hannah's mother, and suspected that she might even feel offended by the suggestion to mainstream Hannah. Therefore, Ingrid decided to move on her own. In contrast to Ingrid activist

stance, Hannah's parents who mostly accepted official, institutional medical position on Hannah's diagnosis and who were uncertain about how to go about Hannah's upbringing, took upon a role of protecting her. In terms of Zone of Proximal Development (ZPD), Ingrid was constantly pushing and expanding Hannah's ZPD, whereas Hannah's parents remained within her existing actual ZPD and hesitated to move beyond it in any way. Their own position of "uncertain parents" lead to sheltering Hannah, even if it meant further disabling her. Ingrid, in Hannah's parents' eyes was positioned as representing a professional authority, being an educator, and an expert in special education. By positioning Ingrid this way it was "natural" and perhaps also convenient for parents to let her take the initiative and leading role in Hannah's education and life. However, I believe that the most important difference between Hannah's parents and Ingrid was not the social roles they occupied, whether as a teacher/expert versus protective parent; rather, the difference resided in *how they positioned Hannah* and how they related to her. Hannah's parents related to Hannah as *a disabled child*, while Ingrid related to her as *a child*. Taking such a unique position, sharply different from all others in Hannah's life, and relating to her in that way allowed and enabled Ingrid to become Hannah's advocate who was continuously promoting her development. Positioning Hannah as a *child* rather than *disabled child* was agentic for Ingrid, who is always driven to take action also in her own life. In contrast to Ingrid's positioning of Hannah, her parents, who willingly adopted an official mainstream deficit model of autism and thus, the disability of their daughter, not only placed Hannah into a position of a disabled child but also disabled their own agency as parents.

Contrasting attitudes and expectations of Ingrid and Hannah's parents occasionally created some tension. The story about the birthday card remembered by Ingrid about the day when

Hannah turned 13, illustrates how radically different Hannah's mother expectations for Hannah were from the ones of Ingrid:

[S]o I wrote Hannah a birthday card, I can't not remember what present I gave her, but in the card I made a list of all the many wonderful; things she had learned to do, " swim like a fish, travel on the bus by herself, play the piano, knit, bake, do advanced math, write good stories...and than I said aloud "that some day she will go to, I may have said Harvard or something," and the mother was ..., she was so furious, she was almost ..., she called me later at home, she felt it was very, almost like making fun of her?... Or mocking, or something you know that was so out of range, what a nerve I had to say something like that.

Although such conflicting positions occasionally created tense situations between Ingrid and Hannah's mother, gradually, Hannah's parents let Ingrid take more and more initiative in Hannah's education and upbringing, the contrasting attitudes and beliefs about Hannah, her abilities and future seemed to be working in a more dialectical fashion rather than a conflicting one. Over time, Hannah's parents seemed to welcome Ingrid's growing interest and support in their daughter's education and overall development. Hannah's mother openly recognized and acknowledged Ingrid's success in relating to Hannah. Ingrid appears to be the first person in Hannah's life who entered and made significant impact on her emotional life. She managed to develop more intimate emotional relations, including physical contact (e.g. by carrying and "piggy bagging" her to the top floor of the school building where the classroom was or holding hands when walking on the street). Ingrid recalls how this was acknowledged by Hannah's mother:

"I remember that [the mother] told me at a parent/teacher conference, that I was the first teacher who would ask her to participate in Hannah's education and that she felt sort of ... left out, and she also told me at another time that I gave her Hannah back because Hannah apparently used to keep much more to herself and one could not easily touch her, but she said "it is different between two of us now."

While still Ingrid's pupil in Special Education class, Hannah started coming to Ingrid's home once a week after school joining another child, a (typically developing) boy of a similar age to

take recreational classes in Ingrid's Workshop. Both children would engaged in both individual and joint activities, such as cooking, sewing, knitting, and woodworking.

The additional time spent with Hannah outside of school provided further opportunity for the growth of their relationship. Ingrid's narrative and recollection of Hannah at this time obviously focuses on socio-emotional development of their relationship and Hannah's budding socio-emotional life, her increasing awareness and interest in others. For instance Ingrid recalls when Hannah started to use the pronoun "I" to refer to herself instead of referring to herself in the third person; when and how she started to initiate conversation, made comments, and started asking questions.

Ingrid's interest, care, love, and all the efforts that were materialized in the welcoming and accepting environment of her classroom and home were filled with meaningful activities that created opportunities for Hannah's cognitive development in conjunction with her socio-emotional development. The activities Ingrid created for Hannah and other children mediated their development as a dynamic unity, a process referred to in Vygotsky's approach, in which motivation, cognition and social development of children are connected through the activities the child practices in with other people (Elkonin, 1971; Leontiev, 1978; Vygotsky, 1978). As Hedegaard (2002) states, the meaning of activities in which children participate with other people, for instance daily family and leisure time activities, as well as the study activities at school constitute the source of motivation. Following Hannah's and Ingrid's story, this becomes very obvious, with the social source of Hannah's interest, motives and goals clearly tracing back to their construction in the activities Ingrid initiated and Hannah participated in.

Hannah started a third grade in September 1989 in another Special Education class in a new public school. However, in November she was placed in a private school for "children with

autism and Pervasive Developmental Disorder”. The school, still in existence, relies mostly on applied behavioral analysis as the key intervention approach. The main focus of the school is on life skills with focus on independence, and vocational preparation for adulthood rather than on preparing children to further their education. Although this is not an uncommon practice in special education, it is obviously a problematic one from the perspective of Vygotsky’s approach on development of disabled children. As discussed earlier, leading activity for children of school age is learning, more specifically learning of scientific concepts (Elkonin, 1971; Leontiev, 1978; Vygotsky, 1978). In addition, as also explained by Vygotsky in theory of disontogenesis, formal learning is a guiding force in children’s development, regardless their abilities (Vygotsky, 1983).

However, for disabled children, and children diagnosed with autism in particular, the goal of development and consequently, of a leading activity in their development is often redefined and organized by their parents, educators, service providers and/or other institutions involved, so as to “become normal”. As a result, the process of “normalization” competes, overshadows or completely eliminates meaningful learning from the development of disabled children and thus radically diverges their developmental trajectory in ways that radically differ from the experiences of typically developing children.

Ingrid never approved of this school for Hanna. Her goal for Hannah was integration and inclusion into society mediated through education and meaningful learning. She understood the dialectics of this process. Meaningful education and learning could only be achieved through integration and inclusion into societal practices.

Hannah spent six years in the “school for autistic children“ and although she has some keen memories of her classmates and some teachers, she always ends the conversation with

lamentable phrase, “this was a big waste of time. I did not learn a thing and I felt I was falling behind.”

On a different occasion, when we talked about the school Hannah mentioned that school did not have grades (she started school when she was supposed to be in the third grade) and it “did not go beyond third grade”. When I asked her what subjects she studied there, this is what she had to say:

Hannah: *I had occupational therapy*

Researcher: *Ok...*

Hannah: *... and speech therapy, ... and counseling...*

Researcher: *Mhm, and did you have reading, math?*

Hannah: *Yes, I did.*

Researcher: *You had all the subjects, right? Do you remember what subjects did you study?*

Hannah: *It was math, English, including reading and grammar and spelling, ... and a little science, ... and I had... occupational therapy, and speech therapy and I also had some prevocational occupations.*

Researcher: *Like what?*

Hannah: *You know like sorting out screws.*

Researcher: *What did you call it? Prevocational ...?*

Hannah: *Prevocational therapy.*

Researcher: *What did that include?*

Hannah: *I did sorting out screws.*

Researcher: *What else, do you remember?*

Hannah: *I do not remember what I did there. It was not very academic, it had very low academic expectations. ...They thought I was incapable to do work beyond third grade level.*

I assume her prevocational therapy probably did involve other activities than sorting out the screws; importantly, what stayed with Hannah was a memory of her carrying out a meaningless activity, with the therapy being pointless. Although she had some good time at the school, she clearly disapproves of its low academic standards and expectations. Every time she talks about this school she expresses the frustration about wasted time and not growing there academically as the following excerpt illustrates:

I remember that I was often chosen to deliver messages from the teacher to the principal's office. I also spent much time in occupational therapy where I bounced balls. We also learned about grooming our bodies, which I already knew about... We made cheese sandwiches for the staff and brought them to the office for lunch. I was thirteen years old then. I think it was a big waste of time. Also adding and subtracting became boring to me because I knew it so well. I was often student of the week or month. It depended on how hard the students worked and how well they behaved, like following the teacher's instructions, and paying attention, and stuff like that... Too bad the school did not teach me well. The people at the school thought that I was incapable of doing work above third grade level. They did not realize how smart I was because I was an autistic child.

She clearly resists and looks back at this institution critically. Not only it was not academically stimulating, the time spent there set her back in her education and although she caught up later on, she was “too old” for any high school to be accepted. The school not only lacked on providing her with education but in addition, as Hannah sees it, the lost time prevented her from attending high school because of her age, and thus was denied of the high school experience:

After I graduated from junior high at 8th grade no high school would accept me because they thought that I was too old, due to early childhood autism, and that I wasted so much time in school [for autistic children] doing work below 3rd grade level and having occupational therapy which I did not need.

During the period of attending the school for autistic children Hannah's parents agreed to let her spend Saturday afternoons and later the whole day at Ingrid's, engaging in all sorts of everyday activities of family life, for instance shopping at the market, baking, writing stories,

painting and drawing, as well as driving to nurseries and shopping for flowers and plants for the garden, or going for walks in the park, or visit a museum, often with Ingrid's husband joining in. Ingrid continued and enjoyed creating conditions for Hannah's developing interests and learning. Hannah was continuously exposed to and participated in activities that promoted her further growth and development, including a trip to Ingrid's hometown in Europe when she was 12 years old.

After spending six years in the school for autistic children, Ingrid, was finally able to convince Hannah's mother to take her out of school. Ingrid also believes that the mother was finally convinced when she witnessed some incident in school and did not like how Hannah or another child was treated.

The plan was for Ingrid to home school Hannah for one year. Ingrid had clearly earned by now the trust of Hannah's parents to let her take full responsibility of Hannah's education from here on in. Ingrid's goal was to bring her up to the sixth grade level. Ingrid not only instructed Hannah in math, English and other academic subjects. She also continued organizing educational and extracurricular activities for Hannah to provide her with the opportunity for a "well-rounded" development that created opportunities for Hannah to develop various skills, interests and hobbies, promote Hannah's socio-emotional development. Within the range of activities organized by Ingrid Hannah regularly interacted with peers. At this time, the relationship between Ingrid and Hannah, already grown beyond the relationship between a teacher and a student, has intensified even more.

Ingrid was well aware that in order for Hannah to be accepted into a mainstream school, Hannah would have to be qualified to prove that she was capable of following the required

academic curriculum, that she could apply the social skills necessary to be integrated, and that she could abide by the rules set forth by the school.

Ingrid asked for the sixth grade curriculum of a prestigious private school to guide Hannah's academic learning at home. In addition, she arranged for Hannah to be included into the sixth's grade weekly music and singing class at the well-known music school. And, to keep fit, Hannah was enrolled into a by-weekly gym class at the local Y in the neighborhood. Ingrid also planned several field trips. One that both remember fondly was a weekly stay in farm country where they read the book "The Red Pony" by John Steinbeck.

She was also aware that in order for Hannah to be accepted into mainstream school and be integrated Hannah had to prove her ableness and competency. To produce evidence of Hannah's learning and progress, Ingrid created a portfolio with work of each discipline studied over the year, including her skills in knitting, cooking, and music. Portfolio was one of the tools that mediated Hannah's acceptance into mainstream school and presented and documented her abilities in addition to the official documents. Hannah's portfolio illustrates one of many examples of Ingrid's resourcefulness in advocating for Hannah. Evidently, one of the most important ways of advocating for Hannah by Ingrid was her integration in all aspects of life, whether into general education, family life, or peers group.

By the time of school enrollment, Ingrid had found the ideal place for Hannah in her neighborhood. A Greek School founded 50 years ago. It admitted children of any race, color, religious belief, and national or ethnic origin from Kindergarten through Eighth grade. Enrollment of students was 100, the teacher-ratio 10:1 within an average class size of 10 students. Ingrid also liked that the school demanded a dress code for school and gym activities.

Making further inquiry, Ingrid learned the Head of the school was a woman with a masters of education from the prestigious university and pursuing her Doctoral degree. From the brochure also learned that she, like her hero John Dewey, believed that “children should always be treated with respect and kindness where limits are placed to create a learning environment that is safe, non-threatening and, above all Fun!!” (as cited from the School’s original flyer that Ingrid still keeps). Ingrid made an appointment with a director who, after viewing Hannah’s portfolio invited Hannah to spend two school days at the school. She was admitted in June 1995. The school was not opening a 7th grade in the following academic year. In addition, the school administrators also believed that starting in the 6th grade might be an easier transition into a mainstream school environment. Hannah started the 6th grade in September 1995 as fourteen year old.

Although Hannah was in disadvantaged position regarding the delay in her education, this was a tremendous success and acknowledgement of her and Ingrid’s effort, given that this was the first time in her life she was included into a general education class. In Hannah’s own words:

The [Greek] School is a Greek Orthodox school. This is where I started my academic life at the age of fourteen.

The students at the Cathedral School had to wear a uniform. It consisted of a navy blue pleated skirt, a white blouse, navy blue tights, a white polo shirt, navy blue socks, a white tee shirt, a navy blue blazer, a tie, a navy blue and white cardigan, a navy blue sweat suit, and navy blue shorts. I was proud to wear a school uniform so that I could be equal to the other students.

Being in a mainstreamed school made me feel proud. I got to catch up with academic learning after spending too many years at the [school for autistic children]. I was put into sixth grade so that I could get used to the academic standards.

Hannah’s parents felt happy. They agreed for Hannah to go to Ingrid’s home after school to do her homework. When the first parent-teacher conference was announced, Hannah’s mother expressed discomfort and accepted with relief the offer that Ingrid would represent her. A letter explaining Ingrid’s role in Hannah life was sent to the school and Ingrid was accepted to

advocate on Hannah's behalf in the future. This was the first time when Ingrid officially represented Hannah at an institution on behalf of her mother or father.

One day early in the 7th grade as Hannah was working on her assignment late, Ingrid called her parents asking for permission if Hannah could stay over night. Parents' agreement prompted Ingrid (who was widowed by that time) to ask if Hannah could move in with her. According to Ingrid, this was a "very welcomed" suggestion and the parents agreed. Hannah was sixteen when she moved in with Ingrid. She would leave Friday night to visit her parents, coming back on Saturday night to have Sunday to prepare for the next school week.

Parents' permission for Hannah to move in with Ingrid, and Ingrid's participation in the parent-teacher conferences were clearly momentums and indicative of parents openly admitting and handing over the full responsibility to Ingrid for their daughter's education as well as future life, although legally Hannah's parents remained her primary caregivers.

Hannah genuinely enjoyed learning at school, worked hard and academically did very well in all the subjects. This is how she remembers her years in Greek school²¹:

Science was one of my favorite subjects. I learned about invertebrates, botany, and vertebrates in biology. I also studied the phases of the moon, the solar system, volcanoes, earthquakes, rocks, and tsunamis in earth science.

I learned Greek with a teacher named Miss [Maria]. She also taught Greek history and mythology. Having a talent in languages, it was easy for me to learn the Greek language all by myself. I was an A student. I remember Miss [Maria] forming a zero with her fingers when one of her students did not do the homework. "Big fat zero!" she scolded.

Miss [Stitos] was my English and social studies teacher. I learned geography, World, and American history with her. We also read short stories in class and novels. The Scarlet Letter by Nathaniel Hawthorne was my favorite book. She also taught grammar and vocabulary. I hardly needed help in doing the grammar and vocabulary homework because I loved words and grammar. However, I needed some help with the reading assignments because some of the literature was on a higher level than the books that I read with Ingrid in

²¹ Presented excerpts are from Hannah's notes. After I interviewed her I asked her to write and expand on her experiences in Greek school.

homeschooling.

In math, I was fascinated with the formulas for the perimeter, circumference, and the areas of the shapes. The formulas for finding the volume of three-dimensional figures also intrigued me. I was also good with algebra, fractions, decimals, and percentages.

While Hannah enjoyed learning she admits that it was not always easy being part of a mainstream school, especially being different among children and subjected to teasing:

Being in a mainstreamed school was difficult for me at the beginning because my classmates did not treat me nicely. Some students slammed the door into my face. They teased me by calling me owl because I stared at them. Retaliating, I clutched my fists, growled like a beast, and hit my classmates. In order to cope with the teasing, [my science teacher] advised me to keep my hands to myself, and tell the teachers when the children were bothering me.

Although Hannah did not socialize with other children to the extent and ways most of the children did, she made several friends and spent time with some of them also outside of school, often inviting them with Ingrid to their home. Hannah remembers Russian boy Yuri who she used to play with and who told Ingrid that “he had great respect and admiration for me because I was smart and diligent”. Hannah indeed earned admiration of many children for her academic achievements. Studying hard and diligently under guidance and with Ingrid’s support, Hannah was passing with flying colors and her grades were well deserved. Although Hannah recognized her effort put into learning she felt proud of herself and confident academically.

In order to be an A student, I had to work harder than other students because I was academically behind when I first entered the Greek School... I was about eighteen years old when I graduated from eighth grade at the Greek School. When my name was called at the graduation in the church to come forward and pick up my diploma, I felt proud because I had earned good grades in every subject.

Learning clearly promoted Hannah’s agency and self-determination. She graduated from 8th grade in 1998. However, no high school would accept her because of her age. Hannah was 17 years old.

Hannah being denied of high school education did not discourage either Hannah or Ingrid. Hannah continued her education again at home with Ingrid, preparing for the GED test. Hannah once again demonstrated her diligence and Ingrid her resourcefulness as she continued to support Hannah in academic and extra-curricular activities, including opportunities of interacting with peers. In order for Hannah to have “outside-of-home experiences of learning” she found and signed up Hannah for classes or tutoring outside of home including the community college she later attended. As Hannah recalls, she studied “writing and grammar, science, social studies, reading, interpreting passages, and mathematics.”

Besides preparing for GED, she continued her active life in many areas. She took Spanish classes for four years. She joined the fitness center and exercised regularly. She also attended a chorus and took piano lessons once a week. She continued enjoying baking, knitting and crocheting, exploring the zoo and studying flora and fauna.

After five years of studying and preparation Hannah passed GED test in December 2004.

Hannah’s interest in culinary arts and baking in particular grew and with Ingrid’s ongoing support it became a goal of her professional carrier. Ingrid introduced an idea of Hannah pursuing higher education that would enable her to continue in studying culinary arts and eventually become a baker. Once they started to consider a college degree Hannah also realized that this would provide her with further opportunities for her personal development, as she put it, to become “a cultured person and to have the experience of what’s like to be in college”. From her schooling of eighteen years Hannah spent only three years in a mainstream school environment integrated into regular education in a collective of children. Compared to her contemporaries, she fell behind for about four years, but was able to fulfill all the conditions and in March 2005, as a twenty-three year old, she was enrolled in a Metropolitan Community

College²². She enrolled to college with goals of learning what it is like to be a college student, further her education to become a better human being, and fulfill her dream of becoming a baker.

In the above section, I attempted to describe Hannah's educational path and background. As illustrated, Hannah's education and personal growth is inherently connected to Ingrid and their relationship. Hannah's educational history and development could not be understood in isolation from Ingrid and their relationship, as Ingrid initiated and co-constructed that path together with Hannah.

As documented here, Ingrid, due to her love, intelligence, dedication, and resourcefulness, as well as lack of Hannah's parents initiative, began to expand her role in Hannah's life beyond being her tutor to increasingly taking on the role of providing parental guidance and assuming responsibility for Hannah's education and life in general. She carved the educational path that she believed was meaningful to Hannah and to her. She instilled and cultivated values familiar to her, those that reflected her white middle class Western European cultural background.

By introducing Hannah to a variety of educational activities and everyday life social practices, including her own cultural repertoire, Ingrid provided opportunities for cultivating and further developing Hannah's knowledge and interests. With Ingrid's ongoing support, Hannah's interests gradually evolved into well-defined hobbies, such as sustained self-initiated learning in botany and zoology leading to the accumulation of an impressive and detailed body of knowledge on flora and fauna, long-term piano playing leading to a pretty accomplished technique and the cultivation of musical knowledge in general, swimming, and nature photography. Increasingly, especially in the past few years, Hannah's love of baking grew into the future career goal of becoming a professional baker. Importantly, in addition to ascertaining

²² Name of the college was changed.

that Hannah would have a wide range of knowledge and intellectual skills (based on academic disciplines), Ingrid always nurtured ethical principles as part of Hannah's development, most notably caring for others and for her surrounding, including an appreciation for and commitment to the preservation of nature as well as an awareness of environmental issues. Moreover, she instilled in Hannah an interest for social issues by following the news and paying attention to current events and world affairs. As a result, Hannah grew up to be well informed and aware of social justice issues, such as environmental problems (e.g., advocating for endangered species) as well as happenings in her immediate community. Hannah developed a sense of community service and justice, and found her own way of contributing to socially relevant and activist endeavors. For instance, she is a member and supporter of World Wildlife Fund and the zoo. She also collects coins on the streets throughout the year, which she donates during Christmas to charity (a fund that brings Christmas present to poor children), and which has increased every year coming now to almost hundred dollars. She also volunteered to help what she refers to as the "less fortunate" on several occasions. For instance, one entire summer she volunteered in a Pantry preparing food for homeless. Hannah, as a skilled baker often shares some of her products with relatives, friends and people in her community. For example, as a frequent visitor of public swimming pool she often brings cookies or a cake to the guards.

As Ingrid combined the roles of Hannah's teacher, tutor, and guardian, she became the most important person and most significant influence in Hannah's life, essentially becoming a mother to Hannah. She was her teacher for most of Hannah's schooling, beginning with Hannah's first three years in school, one year of homeschooling before she went to mainstream school in 6th grade, and five years of preparation for GED. In the later years, Ingrid both directly instructed Hannah and organized her education, including tutoring and providing academic support

throughout the four years in community college. Importantly, all those different roles entailed and embodied an overarching role of being Hannah's full-time, long-term, unwavering advocate. Indeed, it was Ingrid's positioning as Hannah's advocate, as an instantiation of her taking an activist stance towards securing resources and creating opportunities for an equitable future for Hannah that grounded, unified and defined Ingrid's relationship with Hannah. Through this process Ingrid mediated the way Hannah relates to the world. Ingrid, as a transformative activist, brought up Hannah with the same values and approach to life, and activist stance towards her own future and place in the world. Hannah not only became knowledgeable and academically competent young woman, but through her relationship with Hannah and others, her engagements in sociocultural contexts she developed into an agentic person. She became a transformative activist herself.

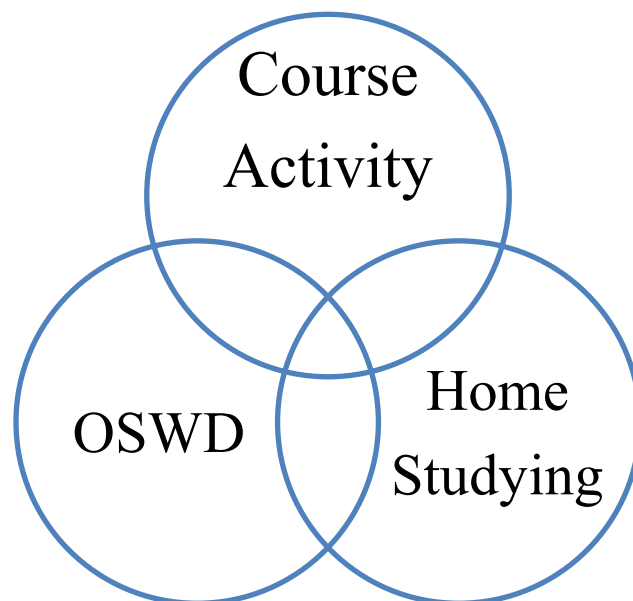
Given the overall theme of this study, the emphasis in this section has been on reconstructing Hannah's educational path and Ingrid's crucial role in it. However, I would like to emphasize, and thus remind the reader of the important overall theme of this research project, that the construction of a person and the self is always relational and dialectical. Therefore obviously, not only Hannah's life and identity, her education, her understanding of disability and autism, and her goals and motives and other important aspects of her life were constructed in and through this relationship *and* its broader context, but by the same account, so was Ingrid's life and identity. As her role in Hannah's life was growing, shifting and changing, so was Hannah's position and role in Ingrid's life. Hannah, her development and advocating for her became Ingrid's focal point of life, in other words, this pursuit became Ingrid's leading activity. In a dialectical fashion, as Ingrid transformed Hannah's life, so did Hannah transformed Ingrid's.

They produced this relationship and, simultaneously, they themselves became the product of this relationship.

7. FINDINGS

In the following sections I present my findings through describing Hannah’s learning in college as participation in social practices organized in three most significant subcontexts of learning activities, namely as engagement and participation in the Office for Students With Disabilities (OSWD), Course Activities, and Home Studying (see diagram 2).

Diagram 2: Three Subcontexts of Learning Activities



The subcontext of Course Activities represents Hannah’s participation in the course (in and outside of the classroom), her interactions with other participants (instructor and students) and the cultural tools utilized by the participants within this subcontext (e.g. syllabi, instructions and other teaching practices, institutional policies). Similarly, participation at the OSWD practices includes Hannah’s engagement with the office and interactions with the staff. Although Hannah’s participation in the Course Activities and interactions with instructors in and outside of the class represent the central component of Hannah’s learning, the other two subcontexts (OSWD and Home Studying) including their participants and the tools and practices produced

and utilized by the subcontexts, were constitutive of overall learning activity, and consequently Hannah's positioning and development.

Findings are broadly organized according to Hannah's engagements and participations in the context of learning activities represented as a college, its three subcontexts, and her positioning by participants within each subcontext as experienced by Hannah and Ingrid, and by other participants (e.g. instructors and OSWD director, and peer/OSWD student tutor). Importantly, presented subcontexts need to be understood as analytical tool to organize and describe the findings and they do not necessarily represent subcontexts separated and isolated from one another. In contrary, the subcontexts overlap as the activities and tools of individual subcontexts are shared, impact each other, and the participants of each subcontexts may enter multiple (sub)contexts. For instance, the policies and practices of the OSWD were introduced and were significant part of Course Activities and impacted interactions between Hannah and instructors and her participation in the course. Similarly, organization of learning activity in the individual courses (Course Activity) informed and determined Home Studying practices. For example, Hannah's study practices, type of support and Ingrid's involvement in individual courses depended on subject matter, course objectives, instructor's evaluation method and expectations and inclination to collaborate with Hannah outside of the classroom, as well as their openness to Ingrid's suggestion or possible participation in class.

First, I introduce the college as the context of learning activity and focus specifically on identity construction of disabled students by presenting relevant institutional practices made predominantly available through OSWD to the students and instructional staff. I describe the initial process of Hannah's enrolment in college as experienced by Hannah and Ingrid and their entering the OSWD activity subcontext. Through the accounts of Director of the OSWD, and

Hannah's and Ingrid's experiences of their engagement with the OSWD, I explore Hannah's positioning by the subcontext of OSWD.

I continue by describing Hannah's and Ingrid's establishing their positions within learning activity, focusing on the intersection of Course Activities and Home Studying subcontexts. I pay attention to Ingrid's experiences, her role in the learning activity and Ingrid's positioning of Hannah. Then I concentrate on Hannah's own accounts of her experiences and resulting positioning within the given learning activities.

Finally, I turn attention to instructors' account of engagement with Hannah in learning and their positioning of her.

Based on participants' accounts, I explore how disability as a social practice is enacted in their activities on various levels, such as institutional, classroom or interpersonal. Exploring the intersection of social processes of learning, autism and self allowed me to identify cultural tools and practices employed by all participants and the institution that mediated specific ways of engagement and positioning of Hannah within different subcontexts.

7.1. Metropolitan Community College

Hannah was acquainted with Metropolitan Community College (MCC)²³, a college of her choice located in tri-state metropolitan area, in 2003 when she had attended classes there preparing for her GED. As a prospective student, she visited the campus with Ingrid and together they inquired about the possibilities of majors, choice of courses and availability of financial aid. Hannah was accepted as a freshman to begin her studies in the Spring of 2005. The

²³ In order to protect anonymity of the participants the real name of the community college has been changed.

choice of Liberal Arts as a major suited her interests and goals.

According to the MCC's website, the college is proud of its quality of their faculty and the diversity of student population who come from over 160 countries and speak 127 languages natively. The student population of 18,000 consist of 43 % Hispanic students, 22% are Asian, 18% Black, 13 % White, and 4% describe themselves as Others. Many of the students are immigrants or children of immigrants and represent an underprivileged population. Because of their varied ethnic backgrounds, abilities, and exposure to diverse educational systems, most of the students have to take remedial courses to catch up in basic math and reading comprehension. Consequently, it is very common that it takes these students longer, up to three or four years, to graduate from the two-year program. In the recent MCC newsletter (2012)²⁴ the provost noted that only about 25% of the students complete the degree and almost 40 % of those who drop out of college leave after the first year. As the provost further mentioned, some of the conclusion of an intensive internal research indicated that fragmentation of the MCC wide services and programs are to blame for this situation. Currently, the college introduced an Alignment project that aims at improving the support that is provided to students. The college offers over 50 associate degrees and four certificate programs in arts, sciences, and applied sciences as well as continuing educations programs. In spite of its problems, MCC has a reputation as one of the best community colleges in the tri-state area.

²⁴ In order to protect anonymity of the participants the reference was withheld.

7.1.1. Enrolling in Metropolitan Community College: Becoming a Student With Disability

When Hannah started the admission process to MCC, neither she nor Ingrid was familiar with the culture and functioning of a community college. They learned that there are three criteria for admission at Metropolitan Community College (MCC). Applicants must have a high school diploma, a General Equivalency Diploma (GED), or foreign secondary education credentials that are equivalent to a US high school diploma. Hannah had a GED. Although Hannah followed the standard admission process, it was not an easy and straightforward journey as Ingrid recalled:

On the day when the admission process started, a mob of students filled the main floor. Everybody needed council. Students gathered information in bits and pieces from one another. One of the students pointed us to the queue by the wall. Hannah was wearing a red winter coat. The line moved slowly. I noticed a thirtyish year old woman walking down the queue, interacting with students here and there. When she got to us, she asked us to step out. I wondered why she singled us out. Was it Hannah's red coat that attracted her attention? Or was it my white hair? We followed the woman up a narrow corridor to the back entrance of the admission office. There, she assigned a young man to help us. Hannah showed her GED with scores attached. She was given an application form and returned it to him when she was finished filling it out. The young man registered Hannah on the computer and gave her a print out to bring to the Bursar. There were two long rows of students waiting to get to the window. Hannah picked one out at random. After submitting the application fee, she got in line to get her student ID with her picture on it.

The enrollment process included a placement test which Hannah took a next day. This exam, required of all students, evaluates students' competence in reading, writing, and mathematics. Hannah failed to reach the score for writing and mathematics. She would have to take zero credit remedial classes in those two disciplines.

Up to this point Hannah had taken the same route in the admission process that was demanded of every student who enrolled MCC as a freshman. However, when she could not obtain an academic advisor like the other students, Ingrid, as she described, started to become

quite anxious:

I had this uneasy feeling of Hannah being singled out from this point on. I dreaded people's response to her. It had always been a negative experience as far as I can remember. An autistic person is generally assumed to be mentally disabled and to be feared. As a consequence, most are rejected from childhood on and excluded in society. Imagine, without ever seeing or meeting Hannah, I had been told by the principal of a public high school that, "We are not equipped to handle her," and the director of another educational institution commented, "As soon as she opens her mouth, you know that she is retarded."

Although Hannah fulfilled all the requirements of prospective student and the fact that she had to take two remedial course were not out of ordinary for MCC freshmen, Ingrid and Hannah started to realize that Hannah being admitted to college was just a beginning of a struggle they were familiar with when dealing with authorities of other institutions.

Neither of them could remember when and how they learned about the OSWD:

I do not recall how I was directed to the "Office of Disabilities" and by whom. I think we approached various offices and people searching for a student adviser without luck, I remember becoming quite frustrated. We needed guidance with about just everything. How to sign up for classes, where, when, what could Hannah select, was there a book about it? I was totally in the dark. There was no orderly process.

Somehow they learned about the Office for Students With Disabilities and potential support Hannah might be eligible to obtain. Upon visiting a reportedly active OSWD at the MCC, they learned that Hannah would indeed be eligible candidate for receiving assistance provided and facilitated by the office if she provides necessary documentation proving her disability. Ingrid further recalls the first visit to the OSWD:

Inside the office, located on the main floor of MCC, behind an unmarked door, Hannah was asked to put her name on a list that had already many names above hers. Then, we were directed to take a seat by the secretary. Most were seats were taken and we could not sit together. I noticed that there were no windows to let in light and fresh air. Nobody talked nor smiled. The secretary was busy on the computer. I thought it took forever for Hannah's name to be called. Other than getting her registered for classes, I did not know why we were sitting there.

Hannah and Ingrid met the Director of the OSWD who as Ingrid remembered presented

himself as a man of knowledge, power, and great confidence. Hannah was happy to meet the director and excited about registering for college classes:

I was happy to meet him. He helped me to register for the two zero credit remedial classes that I was required to take. In addition, I also needed to take another zero credit class called New Student Seminar, a weekly course to help students adjust to college and choose majors. This schedule allowed me to only take one three credits course. I picked Introduction to Sociology because I was interested in learning about society.

At this brief and formal meeting Hannah and Ingrid also learned what documentation Hannah needed to provide in order to register with the Office and receive services and support from the Office. This included a letter from Hannah's psychiatrist to verify, as Ingrid recalled directors' formulation of the request, that her diagnosis would not "interfere with her intellect and ability of being in class with other students". In addition, the OSWD Director also requested a letter from Hannah's parents that explained Ingrid's role in Hannah's life and gave their permission to act on their behalf²⁵. They also learned that despite providing all the necessary documentation and Hannah' registration with the Office, the OSWD did not provide any specific services or support for students diagnosed with autism. Ingrid became fully aware that they would need to think about how Hannah would introduce herself to the instructors and if, how and when she would disclose the fact that she was diagnosed as autistic. As always she felt uneasy about it:

I am usually guarded about disclosing that Hannah is mildly autistic. When I do, I immediately counteract the negative thoughts that may come up, with letting the person know how smart and sweet she is.

After the first visit of the Office, experiencing its cramped space and overall atmosphere Ingrid also realized that this would not be a conducive environment for creating new educational ideas together with students and faculty. She opted to work with Hannah's instructors directly and sidestep the bureaucracy.

²⁵ After receiving all the documentation Ingrid presented herself in college as a guardian.

They both started to apprehend that Hannah not only became a “college student,” by registering with OSWD she also became a “Student With Disability”. They gradually became familiar with the policies of the OSWD that followed the standard practices based on legislation mandating college to provide specific disability support and services, most of them already described in previous chapters.

I argue that these practices represent some of the most potent institutional tools relevant to disabled students that significantly contribute to the constitution of learning context, specifically organization of learning activities of students diagnosed with disability and positioning of the student within the learning activity. As such they also represent *disabled student identity making tools*. I further suggest that some of these institutional tools employed by the OSWD result in discriminatory practices and lead to stigmatizing and marginalizing of students served by the OSWD.

7.2. Office for Students With Disabilities

7.2.1. MCC students: Claiming disability

Following is the discussion of specific policies and practices of the OSWD at MCC as cultural tools mediating initial positioning of the students registering with the office.

The OSWD at MCC provides information and references for potential and current disabled students, their parents and guardians, and for the instructors teaching disabled students. The information is disseminated via website and also internally within the college. As their mission statement declares their “responsibility [is] to ensure equal rights of the students with disabilities to its programs and services and that the rights of students with disabilities are not denied”. Furthermore, they provide “advocacy and access to all college programs, and facilitates the

transition to college life for students with disabilities” (MCC website).

As the OSWD website further states the office serves three main functions: a) mediates communication between students and instructors, b) provides services to students with disabilities to “insure accessibility to college programs,” including personal, academic, career and accommodation counseling, testing for learning disabilities and adaptive/assistive technology, and c) provides source of reference and referrals (e.g., evaluation referrals).

In order to receive services and assistance from the OSWD every student has to provide “current and comprehensive documentation of a diagnosed disability” so s/he can register at the OSWD. Therefore one of the first encounters at the MCC for any disabled student is to officially and institutionally *establish* an identity of a “Student With Disability”. Student needs to register with the office every semester. As a result, the identity of a Student with Disability as such has to be reestablished and confirmed every semester in order to maintain the access to services and accommodations by providing necessary documentation.

The OSWD encourages students to disclose their disability to the office in order to “assure proper services” with a claim that “disability information is NOT going to affect admission to the College” (MCC website). Furthermore, according to OSWD website “a student with a disability does not have to disclose his or her disability to [college]. Disclosure of a disability is on a voluntary basis. However, a student will not receive accommodations unless he or she discloses this information” (MCC website).

Once a student is registered and her eligibility for services is acknowledged, each disabled student is supposed to be assigned a Counselor with whom appropriate accommodations should be discussed and determined by a Counselor and student based on the “documented needs, previous accommodations, and functional limitations of the student” (MCC website). In this

meeting the accommodation letters for instructors are expected to be generated. A student is responsible for distributing the letters to all instructors. Students are encouraged to “meet with their instructors to discuss their testing and other accommodations and to answer any questions the instructors have” (MCC website) but are not required to disclose their disability to instructors rather the instructors are referred to OSWD. The OSWD office will not disclose student’s diagnosis of disability but can offer some suggestions and resources, most of them already available online.

Accommodations at MCC are provided on individual basis and may include extended testing time, interpreters, note taking, and other adaptive technology services.

Although college, as an institution of higher education is required to provide “any reasonable accommodation that may be necessary for equal access to education” and “to ensure that a student with disability is not discriminated against” (MCC website), at the same time college is not required to develop any special programs for disabled students or have Individualized Educational Plans (IEP's) as could had been a case for students in elementary or high school.

In addition, a disabled student as a young adult has a right to choose having information about his or her case discussed with his or her parent/s through signing a release. The release cannot be a “blanket release” throughout the student's entire college career. Because the college student is in charge of his or her educational planning, he or she decides what is to be disclosed to the parents or guardians. Although this policy positions the students as a self-advocate in relationship to his or her parent, in some situations this may disadvantage the student, especially if the student is not used to or able to apply self-advocacy fully by herself. In addition, the OSWD Office suggests and encourages disabled student to develop a set of self-advocacy skills and abilities, namely:

- a) **Understanding Your Disability:** A student should be able to articulate what his or her disability is.
- b) **Communicating Disability:** A student should also be able to describe how the disability limits him or her functionally. A student should also be able to express some ways that he or she could be accommodated.
- c) **Being Proactive:** A student should provide acceptable documentation to OSD and request accommodations. A student should learn to work collaboratively with professors to ensure his or her success with the accommodations. A student should also be able to determine if his or her accommodations are not being met.

The official policies of the MCC are based on a current legislation, reflecting the mainstream societal discourse of independent and autonomous human being as an ideal vision for disabled students in higher education as discussed in previous chapters. The student is expected to act independently, strive for further independence, and take responsibility for their education as a “Student With Disability” in a college while applying self-advocacy skills. As the above cited text from the website suggests this includes understanding of a) what is *student’s* disability, in another words what kind of disability she “has” and “owns,” suggesting that disability resides within herself and her body, instead of practices that could be or might be disabling her learning, and b) *limits* that *her* (very own) disability imposes on her.

Although the role of OSD is to enable equality, at least in terms of access to education and other activities in college for disabled students, the official discourse of the OSD positions student as the owner of the disability limiting her functioning (including learning) and thus establishes an unequal and marginalized position of the potentially disabled learner right from the start. Importantly, by registering in the OSD and engaging in other described practices of the OSD a student *claims* the identity of SWD. This is a starting position from which student engages in learning activity and is potentially incorporated in identity construction of the learner – a “learner with disability” which itself can be disabling to learning.

7.2.2. OSWD practices: Positioning of disabled students in relation to instructors

In this section I focus on practices and tools produced and presented by the OSWD and made available to the instructors, and consequently possible understanding and positioning of the students by these tools in relation to instructors.

The tools and practices related to disabled students available to instructors at the college consist of a) OSWD website at MCC informing instructors about the rights and responsibilities of a disabled student as well as their own rights and responsibilities as instructors working with disabled student, b) specific disability information and teaching disabled students, c) general strategies of teaching disabled students including some inclusive strategies for teaching students diagnosed with disabilities. The instructors are referred to legislation based on which reasonable accommodations are expected to be provided and made available to students. As these documents outline, it is the OSWD Counselor who determines appropriate accommodations “based upon the substantial limitations of the student and the essential elements of the course” (MCC website).

The accommodations are not supposed to lower standards of learning, rather enable students’ access to it. Instructors are not part of the accommodation selection process, they are only mandated to provide them or allow students to utilize them. They understand that the accommodations are determined based on specific disability that will not be disclosed to them.

It is important to mention that while the OSWD website and other materials produced by the OSWD for students and instructors do not provide any reference to autism whether specifically or in reference to neurodiversity, the Faculty Guide, the key source for instructors available on OSWD website, makes references to teaching disabled students in general, and teaching students diagnosed with specific disabilities. These include: a) learning disabilities (i.e. “any of diverse

group of conditions of presumed neurological origin” e.g., dyslexia, dysgraphia, dyscalculia, and ADHD as a condition potentially accompanying LD), b) visual disabilities, c) mobility and hand-function disabilities, d) hearing disabilities, e) psychological /psychiatric disabilities (e.g. depression and anxiety), f) speech disabilities, and g) other disabilities (e.g. AIDS, Cancer, Cerebral Palsy, Multiple Sclerosis, Muscular Dystrophy, Respiratory Problems, Seizure Disorders, Sickle Cell, Anemia, and Substance Abuse), (MCC website).

It is somewhat ambiguous how instructors are supposed to utilize the information on specific disabilities, especially in case of “invisible” and/or undisclosed disabilities, and in cases when a student chooses not to disclose her diagnosis of the disability and/or discuss her needs for accommodation with instructor. The information under each disability type usually includes a definition, a brief description of symptoms and possible manifestations of the disability and accommodations students might benefit from suggesting the selection of accommodation type based on disability type. It might be problematic for instructors to provide accommodations relevant to specific disability without trying to monitor, observe and identify students’ “symptoms” themselves. Such attempts can easily lead to the risk of overlooking, misinterpreting and neglecting to accommodate students’ actual needs as well as stigmatizing and ableism²⁶.

The main reasons for students not being obliged to disclose the disability to the instructor is to protect their privacy as well as prevent stigmatization. Barnard-Brak, Lechtenberger and Lan (2010, p. 421) note that the socio-cultural necessity of maintaining information regarding one’s disability as private and confidential, “this imperative for privacy in itself implies that there’s something wrong with being disabled.” I found out that in Hannah’s case certain behaviors

²⁶ Campbell (2008, p. 153) characterizes ableism as any practices, institutions, processes and relationships based on the idea that “person’s abilities or characteristics are determined by disability or that people with disabilities as a group are inferior to non-disabled people”.

putatively associated with autism (e.g. speaking loud, avoiding eye contact, occasionally interpreting things literally, etc.) and anything that made her and her behavior stand out as “different” and “out of norm,” was as stigmatizing as a label of diagnosis itself. For instance, Hannah asking the same question repetitively, or laughing loudly in class caused, at least initially, concern of instructors about her abilities and competence as a student.

The students, as well as instructor, might benefit more from incorporating principles of Universal Design for Instruction and other inclusive practices in teaching and thus accommodate and better meet the needs of all students regardless disclosed and/or identified disability (Orr & Bachman Hamming, 2009). However, employing inclusive practices in teaching in MCC is only suggested to instructors. In addition to applying inclusive practices, instructor may approach a disabled student individually and attempt to discuss if her needs are met, without necessity of disclosure of her diagnosis. Legally and institutionally, it is not instructor’s responsibility to approach a student and the instructor may be ambivalent to do so as it requires a great deal of sensitivity and personal engagement. Instructors’ approachability and empathy is individual and certainly cannot be mandated.

It can be suggested that the OSWD produces the “Student With Disability” identity by engaging in above described practices and as such this position is officially presented to the instructor in a form of the letter informing them about student’s existing undisclosed disability and relevant accommodations that instructor is legally bind to provide. Frequently, the letter is the only communication between the OSWD and an instructor that occurs during the whole semester. Moreover, accommodations are clearly determined by OWSD Counselor without any involvement of the instructor and input about the course goals and objectives, subject matter, assignments or instructors’ expectations. In short, accommodations are determined without

acknowledging any relevance to specific learning activity organized by given instructor. There is no official mechanism for reflecting and providing feedback and possible suggestions from the instructors to the OSW in regard to determined accommodations and their effectiveness for specific student and their course. Moreover, there is no professional development being offered to instructors in respect to teaching and supporting disabled students at the MCC.

Additional tool that contributes to positioning of disabled student in learning activity in relation to instructor represents the information addressed to instructors in the mentioned online Faculty Guide. Initially, the disabled students are presented by the Guide as bringing “a unique set of strengths and experiences to college” and pointing to the fact that “[w]hile many learn in different ways, students with disabilities differences do not imply inferior capacities” the instructors are also reminded that “[t]here is no need to dilute curriculum or to reduce course requirements for the students with disabilities” (Faculty Guide, MCC website). Although the MCCs OSWD discourse might occasionally to resonate with social model of disability (without any concrete reference to it) by acknowledging and appreciating the strength of diverse students and rejecting inferiority based on disability, on the other hand the description of learning disability (LD) as “marked discrepancy between intellectual capacity and achievement” and the process of its diagnosis at the college that “emerge[s] from a battery of aptitude and academic achievement tests” (Faculty Guide, MCC website) promotes understanding learning disability as an individual characteristic that can be observed and measured as such, situated within a student.

I will discuss later how the above identified policies and regulations, available support and guidance targeting instructors were applied, negotiated and resisted by interviewed instructors in their teaching practices, particularly in relation to Hannah.

7.2.3. Positioning of Hannah by OSWD: Disabled among Disabled

At the OSWD Hannah mostly interacted with the director who was interviewed for this project. In addition to the director of the OSWD, I also interviewed Juan, a student who worked at the OSWD as a tutor in a capacity of fifteen hours. Juan's account of his experiences working at the OSWD provided additional view of the OSWD and its practices. He also knew Hannah from a writing class they took together, however he neither tutored her nor interacted with her at the OSWD as he started working at this position only after Hannah graduated.

The director of the OSWD could not remember if Hannah was the very first student diagnosed with autism at MCC but in the interview he referred to her as an "extreme example of her particular condition" and as a student who had "one of the most pronounced social disabilities than anybody here," and therefore as somebody hard to forget. Although the OSWD does not provide any specific support or training to students diagnosed with autism, and had no plans of developing any in a close future at the time of the interview, the director felt confident in working with and supporting students diagnosed with autism, as the number of students at the MCC was reportedly increasing:

We had a number of students with Asperger's and we still do and we serve them. I guess informally or unofficially we got a good reputation in our department in a community for being able to work with and serve Asperger's students with sensitivity and understanding so we get continuously referrals, and we also had students that had been diagnosed with various degrees of traditional autism, so we had several and we continue have them, so that's nice, we did a good job if people continue making referrals to the office.

As the following excerpts from the interview illustrate, the director of OSWD saw Hannah as intellectually capable but socially immature with limiting repertoire of social skills, as someone with "one of the most pronounced social disabilities than anybody [at MCC]". He mostly described Hannah through the lens of deficits and ableism:

Hannah has a lot of... mmmm ...a lot of strength in her intellectual capacities but I think that her greatest challenge is in the social interactions, and so her voice is very loud, and she is unaware if it is loud and mmmm, she, you know, comes across in her interaction as supposed in her activity, she comes across somewhat childlike in her social interactions and her social affect is limited in terms of a palette of social expressions, and sometimes she'll repeat herself, she sort of gets stuck saying the same thing several times. Um, I remember Ingrid would sort of either touch her or verbally in some way 'kill' her to sort of free her from being stuck. Mmmm, Hannah answers tended to be rather singular, a sentence format was not easy for her to [give] a paragraph answer, um not that I don't think she had the ability on an ideal level but I don't think she had the skill set to be able to put the ideas into words and have a substantial utterance in a conversation. Mmmm, and you know, I came to the office and she was sitting in a waiting room, and she, you know, sort of would burst out with "Hi [John]" in a way that you could tell, even if you did not know who she was, you would say that this was not quite normal, you would not necessarily [know] why, but you would say this was not a typical social response. She was never inappropriate in terms of never menacing, or never expressing anger, she just obviously struggles in understanding the clues in her immediate environment, and that seems to be what I would call a hallmark characteristic of a lot of students that had Asperger's, that they just do not know the social clues, they cannot read them in others, and they don't know how to interpret themselves in the space, you know. I think Hannah was an extreme example because of her particular condition, you know the level of it, the nature of it.

The OSWD Director's accounts of Hannah consist mostly of comparing her performance, social interactions and behavior to states of normalcy. She is understood in terms of deviance from normal. Evidently, such practice of ableism yields marginalized positioning of Hannah. Director's deficit view of Hannah is even more obvious when describing the type of services she was receiving and the reasons of not being provided personal counseling and other mental health services:

I don't know if there was a lot of personal counseling going on because we felt that her ability to achieve insight was limited because of her Asperger's and the autism, so you know we didn't want it to be an uncomfortable thing for her in terms of an exchange, so I don't think we did a lot of personal counseling.

Later he added:

She did not use any [mental health services] and I am not really sure if she could have, because of her limited abilities to express herself. You know and in my mind limitations insights [she had], it was hard for her to hold a conversation, I don't know if you experienced, you know her ...but it was hit or miss with Hannah because you never knew on a given day how far you could go, you know.

The director clearly attributed her challenges in social interactions to her being diagnosed as autistic. Based on the normative understanding of social interactions and typical cultural representations of autism he saw Hannah so profoundly autistic that she was impermeable to any change or supportive mediation. Consequently, she was excluded from being provided assistance, probably one of the most relevant to her in regard to types of services OSWD provided. What appears to be his personal static view of disability, and a static view of a disabled person, informed his reasoning that led to exclusion of Hannah from services she was eligible for. Given that one of the primary responsibilities of the OWSD is to “ensure equal rights of the students with disabilities to its programs and services and that the rights of students with disabilities are not denied” (MCC website), director’s decision based on his personal beliefs evidently originating in medical/deficit and static model of disability led to disablism and discriminatory practice.

When I encouraged director to reflect on Hannah’s strength based on his own experience and reports from faculty, he praised her for her “academic strength and persistence”. However, even Hannah’s strength were noticeably juxtaposed with and put in the context of difficulties, limitations, and unpredictability, including the initial concerns and doubts about her performance in a classroom.

Researcher: *And what do you think were her strength, as you experienced her and maybe you also heard from other instructors?*

OSWD director: *I was very, very pleased with her academics. I think if anybody had concerns it was about how was she going to present herself in a classroom, in class participation, and there were some concerns about if she was going to be appropriate in the classroom. ...Academically, I think it was concern about her social presentation and we had some concerns because we did not know how she was going to behave in the classroom but ultimately she did quite well and she graduated. And people who taught her talked to us, faculty in their perception and impressions of her, her strength and that she actually participated, and participated well, so I think that was wonderful.*

Researcher: *And in your experience from interacting with you, did you see any strength?*

OSWD director: *Well, I think her strength was that she was always here, she took it very seriously, I think she had moods like everyone else, one day she was cheery, another day she was solid and sort of withdrawn but you know I was struck with her perseverance. You know and her ability to just sort of push forward, I think in one sense not being aware of what was going around helped her in a way, you know what I am saying, so she did not often come and said I need to talk to you about this and this and this, it just wasn't how she operated, so to speak, so those are the things that I noticed, you know her academic strength and her persistence, and her ability be here all the time, she did what she was told to do, you know and that's great.*

Given that the primary role of OSWD is to provide accommodations to facilitate students learning, it is striking that primary concerns of the OSWD focused on Hannah's fitting in and conforming to social norms of classroom behavior. Seeing Hannah's academic strength predominantly in her presence at college and doing "what she was told to do" is not particularly agentic view of her as a student. To large extent she was considered as a good and successful student based on her compliance with rules and social norms. Hannah was recognized only as capable of adaptation, but not necessarily as agentic person.

Directors' individualistic view of disability becomes also transparent in meritocratic view of disabled students in general, including their individual responsibility for "making up for their deficits":

[S]tudents with disabilities first have to find out how their disability shows itself and how it is going to interact with what college requires, it is different from the job, or living at home and taking care of oneself, but once you understand what the deficits and weakness are as well as your strength for academics, being given opportunity to learn and the best way possible. And to be given accommodations that allow you to show your output to the best of your abilities, and so a student with disability has to discover who they are, have to learn some techniques, have to understand that it may take them longer to do the test [compare] to kids next to them who have no disability. Getting one of these is a great thing (pointing to a tape recorder) because you can tape the class. And I tell them: "Honestly, yes, it is more work because at the end of the day you have to come home and you have to play it over and you have to take notes, and you will play and stop that tape hundred times so that the next day it is clean and you can tape another class, so no, it is not like you are going to get away with anything because you are going to put MORE time into what you are doing, because that's what is required if you really want to take this seriously and do well. And it is really up to you." And

I present it as a choice, you know students have to commit to it, I can't commit them, they have to commit themselves, and so we provide them with options and strategies, ultimately it is their decisions how serious they want to take them and use them, and so you know that's what I think students with disabilities have to confront and deal with.

Someone for the first time in their life explains to them why all these years of learning, that butterfly that you are chasing and never catch, and all of the sudden they have an explanation and a framework and they are 25, 35, 40, 50, so it is quite an event for them to first finally see a) there is a problem, b) what that problem is, and c) what options are there. And a lot of students get stuck in the "why me" phase, how come I did not get this news sooner? And I say, look I understand that, you have the right to be upset but, and I present it to them "you have a choice to make right now. You can spend your energy and time looking over your shoulder and into your past, or you can put your head forward and start in a present and work toward your future. It is ultimately your decision."

Director of the OSWD understood disability in terms of deficit that one has to compensate for by working harder than other non-disabled students. It is simply given by default of being a "Student With Disability" that one has to work more, longer and harder. Having the opportunity to "make up for the deficit" at the MCC is seen as an opportunity of a lifetime. If disabled students coming to MCC are not clear about who they are, it seems that the OSWD has a ready answer for them. For disabled students registering with the Office and learning at MCC seem to be understood as an opportunity to learn about their "flaws," to learn about available ways of compensating for them, and understand responsibility of committing oneself to normalization and rehabilitation. Directors sees himself in the role of enlightening disabled students to realize this opportunity, as he puts it, as a "facilitator helping students to achieve their goals and agenda," being in a position of dedicated advocate for students, holding a hard but rewarding job.

The position of the director of OSWD as an administrator and service provider obviously did not provide him with opportunities to engage in learning activity with Hannah. His knowledge of her as a student and learner was mostly based on Hannah's grades, informal and anecdotal reports of the instructors provided occasionally. The ways in which the director's relationship and interactions with Hannah took place within the subcontext of the OSWD, as well as his

static, individualistic and meritocratic understanding of disability, resulted in understanding her in a fragmented and disconnected way. As some of the excerpts from the interview illustrate, the director's account of Hannah consists of juxtaposing her cognitive and socio-emotional abilities. He described her self only in terms of ableism and separated in manner resulting in disconnected view of Hannah's self. The director positioned her as academically and cognitively competent, however not necessarily as an agentic student. Simultaneously, Hannah was positioned as a disabled person, socially and emotionally limited, incompetent, unsophisticated and deficient one, who stood out among other disabled students. When the OSWD director compared Hannah to other students registered with the OSWD, in regard to her social skills and interactions he positioned her not only as a "different" or "disabled" student, but he positioned her as *disabled among disabled*, as the following quote illustrates:

I would say that socially what made her stick out, that she was, she was, how to put it, she wasn't, she was not sophisticated in a social setting like other students, even with disabilities. They had more skill sets than Hannah did in her conversations and such, but academically she was right there with the best of them and academically was the key, that's' why she was here to get her degree.

The director does not conceptualize social and cognitive domains as intimately interrelated, as if learning and academic performance could be simply separated from students' social relationships and engagements in college. Such a sharp division is present not only in the director's understanding of students but also from the objectives of the OSWD and the way services are provided to students as the director explains:

I always tell students and I remind the staff we are a college, we are not a clinic, so this is not something we can do on open-ended extended basis, we are here to help them so they can succeed in their schooling, but if the issues are more rooted than we have an obligation to help them get help somewhere else, and we can still maintain our role as a counselor as related to school but they know they have a place on the outside to deal with those other issues.

The director explained the reasons why the OSWD provides only short term mental and health services to the students who otherwise are provided with referral to outside services hopefully covered by Medicaid, a private insurance or pay out of pocket. Although the director understood his professional role as a facilitator of students' agendas and goals, he repeatedly emphasized that the Office does not serve as a clinic and consequently is not responsible for addressing students' social, emotional or other aspects of their personal lives. A fragmented, incoherent and compartmentalized view of student's self, as it was in the case of Hannah, reflects fragmented and disconnected, often poorly coordinated services, as a result of institutional practices typically separating learning from student psychosocial development. Importantly, I would like to emphasize that although I provide quite critical perspective of director's understanding of disability, disabled students and Hannah, I argue that his positioning of Hannah, was not simply mediated by his personal narratives, cultural representations of autism and institutional policies he implemented. Hannah's positioning by the director needs to be considered in the context of the OSWD understood as subsystem of the larger system, as an institution on its own. Expressed in a different way, positioning of Hannah by the director and the OSWD as cognitively adept, however deficit in social interactions, needs to be understood also as a product of the structure and organization of institutional practices, as a subsystem acting and embedded within broader context of the college and higher education system. The organization of the OSWD practices results in fragmented nature of services provided by the Office, and consequently, in limited opportunities of the staff to engage personally with Hannah in learning activities and recognize her contributions as an agentic member of the learning community.

Juan, a student tutor who worked at the OSWD and I interviewed for this project, was quite

critical of the quality of services provided to students and instructors. He also criticized some of the practices of the Office, including a poor enforcement of legislation which resulted into inadequate knowledge of instructors and students of their rights and responsibilities:

There are some instructors who are ambivalent to how the [OSWD] works. On several occasions, there has been a lack of understanding and communication among the student, the instructor and the office. At times, the instructor is not aware of the rights that a student has because a) the professor does not know or is not aware of the rights that a disabled student has, and b) the student does not advise the instructor that they have rights as disabled students. What should be done to clear this misunderstanding is that the college should have a mandatory workshop for instructors and the staff of [OSWD] that informs and address the rights of disabled students.

Juan later added:

[OSWD] should spread more productive awareness to instructors, counselors and professors on how to interact and understand students with disabilities. I feel there is a sense of ambivalence in the way in which information is distributed in the office and shared with the institution.

Juan evidently calls for the OSWD to take action and proposes a mandatory professional development for instructors that would promote understanding and communication between instructors and students. Juan's criticism was also aimed at the OSWD coordinators for being often disorganized, which commonly resulted in limited and unreliable schedule in already not easily accessible tutoring. As he mentioned tutoring available via OSWD is limited to 45 minutes per session, often at inconvenient times, and is not available throughout the whole semester. According to Juan, the OSWD only offers tutoring in English, Math and Science and a student must request tutoring two months prior to the beginning of the semester. Juan further expressed concerns about the role of tutors in assisting students given their training, relevant practices and support of the institutions to the tutors:

The tutors at the OSDS do not receive any prior training in working with disabled students. The tutor must have prior experience with tutoring the subject they are applying for, as well as a resume and transcript that verifies the latter. The tutor is not aware of the student's disability although, he or she is advised by the tutor coordinator to provide their email

in case the student has any additional questions. The tutors at the OSDS vary: some leave after a semester while others remain on the staff.

Throughout his account of his experiences at OSWD Juan recognized that the lack of understanding and communication among the student, the instructor and the office usually resulted in disadvantaging of a student.

Recent internal research conducted at the MCC focusing on increasing students' success and higher graduation rate as a part of state initiative indeed recognized numerous issues related to students' failure and high drop out rate, including fragmentation of support services and resources, lack of communication between faculty and students, and "silos" college culture (Collective of authors²⁷, 2010). Participating MCC faculty of the internal research calls for transformation of college's culture as a potential "glue" that could change fragmentation into cohesion, including "a trusting, caring relationship between faculty and students—one that allows for interactions outside of the classroom" (p.6). In addition, faculty is critical of creating culture of educational "silos" however well intended, that frequently leaves students without adequate support in the critical situations and personal crisis. Although the report neither fully recognized the issues of separation of learning from the rest of students' lives and the relationship between students' learning and identity development, nor it addressed issues of disabled students specifically, the relevant issues were voiced by the faculty who call for a systemic approach to provide services and support to MCC students.

²⁷ Reference was withheld due to maintaining anonymity of college.

7.2.4. Understanding the role the Office for Students With Disabilities

I now turn to Hannah's and Ingrid's accounts of their engagements with the OSWD. This analysis explores their understanding of the Office's role in Hannah's learning and positioning her as a Student With Disability with limited agency.

Hannah remembers the OSWD and the staff there as "nice and helpful," mostly helping her with administrative and practical matters:

When it was time to sign up for new classes, [Director] helped me to choose the classes that would match up with my Liberal Arts Social Sciences and Humanities major. When I came to the office to take a test, the staff found a quiet empty room for me and I was given extra time on the tests as needed. They also helped me to register or to withdraw from a class when the one that I had chosen was too overwhelming.

However, she did not develop any sense of belonging to the OSWD or form any close relationship with any of the counselors or other students at the Office. She did not feel that OSWD was a significant part of her being at the college.

The OSWD director recalled providing somewhat more intensive attention to Hannah in comparison to other "typical" disabled students.

I think they came several times because Hannah isn't a typical student, so there were unusual scenarios and we had to take it one at the time and discuss them among ourselves as a staff and meet with Ingrid and Hannah so it was a process, perhaps a bit more intensive than with other students but it followed the same model, it wasn't anything outrageously different we did.

When I asked director how frequently he saw Hannah he mentioned that she would come to the OSWD very often for different purposes:

I would say almost daily, she spent a lot of time here, whether she took exams, or sometimes we encourage leisurely our students to sit in our waiting area what I refer to as a quiet space. Hannah could not handle a lot of stimuli, you know hanging out in the hallway of a college can be very stimulating and over stimulating, and I think that being able to come in, sitting in a awaiting area and sort of relax, although she probably did not realize that she was doing, it was very helpful to her, so we encourage that, so I'd say I've seen her several times a week. Sometimes she wanted to see me, sometimes she wanted to see another

colleague, sometimes she just sat there, sometimes she had an appointment but she was here a lot, she was here a lot.

Although director and Hannah recalled the same reasons of her visits to the Office nonetheless, their memories of her participation and involvement with the Office differed and were experienced quite differently by them. Hannah did not experience coming to the Office as socially and “environmentally” supportive and meaningful in a way that the director perceived and remembered it. Meeting new people, making friends and socializing in general was very important and cherished aspect of college life for Hannah (as I will discuss later), however the OSWD was not the most significant source of it. Her actual understanding and purpose of the Office was as a place to obtain information or service. It was a place of function. Perhaps her way of understanding and consequently somewhat restricted participation in socializing at the OSWD contributed to the director’s view of Hannah as very “limited” in social interactions and relating to others.

Although Ingrid confirmed that the counselors were indeed helpful with finding out about classes that would advance Hannah towards the needed credits for her major she also expressed strong feelings about how they and other students were treated:

I felt at times a certain disrespect towards the students in the office. It was always a very long wait to access assistance. I think many times students in there felt ignored or forgotten. I certainly did. One was not considered important. The secretary was often rude. Sometimes the wait was over an hour. Of the two counselors I often preferred to talk to William²⁸ rather than [director]. He was lighter in his temperament, more pleasant and responsive. He could be sharing in the joy that a student was doing well and had a word of encouragement when a professor gave us a hard time. On the other hand, he thought nothing of answering the phone and talking to his wife or a friend forever while meeting with him. There were times when I felt like walking out. In contrast, [director] was more courteous, but usually unsympathetic and sided with the instructor no matter what.

Ingrid evidenced that the OSWD staff often treated students disrespectfully. Even if the

²⁸ Counselor at the OSWD.

students' achievements were acknowledged, they were treated from the position of power, as subordinates dependent on the staff's service and availability. She felt that one could often leave feeling unimportant, unheard and unsupported.

Juan, as an insider of the OSD who worked there as student tutor, confirmed Ingrid's criticism of the staff and their attitudes towards students coming to the Office for support. For instance, he mentioned that students were often not provided with sufficient and appropriate attention, experienced long waiting hours, disrespectful attitude from the staff and poor coordination of tutoring services in general.

When I inquired about the process how the letter informing instructors about Hannah being registered with the Office was produced and the accommodations she was eligible for were discussed and decided upon, Hannah did not remember working on the letter. Ingrid confirmed that "it was produced by the Office." Given the OSD's emphasis on students' independence and advocacy skills it is surprising that the office did not involve Hannah in discussing neither the letter for the instructor nor the actual accommodations with her. Not only it contradicts their official policy, it also seemed as a missed opportunity to practice Hannah's agency and self-advocacy. Ingrid also questioned the purpose and effectiveness of the letters for instructors:

At the beginning of a new class letters were prepared in the office to the various professors that the students could pick up and present. I once opened one to see what it said. It was a formatted letter, quoting the disability act, and giving permission for special accommodations. I do not think that it was mandatory to present this letter if a student with a disability did not ask for accommodations. I believe there were students who did not "label" themselves. The letter did not specify the disability, which in Hannah's case I found odd. How can one help her if one does not know about autism and what support she needs to succeed in class.

With increasing experiences, Ingrid understood that in many cases the letter represented the only point of communication between the OSD and an instructor. Limited accommodations as well as practically zero information regarding Hannah's needs as a learner, and autism

specifically, seemed to Ingrid as inadequate support to Hannah as well as to the instructor. Although Ingrid admitted that she always considered what and how to disclose, whether and what to say to instructor about Hannah's diagnosis, she also felt that maintaining confidentiality would be irrelevant given that Hannah is "visibly different". Ingrid believed that the specific information about Hannah's differences and needs, as well as general information about autism would be beneficial to the instructor. The poor enclosed information about Hannah, her needs and autism further encouraged her either to discuss with Hannah what she could and would like to share with instructors, meet with the instructor in person, or send a note with some specific reminder or request including introducing herself as Hannah's guardian.

One of the interviewed instructors shared Hannah's letter that was sent by the OSWD with me (see appendix) that identified following accommodations to be provided to her:

1. Additional time for exams, in a quiet setting.
2. Use of tape recorder
3. A copy of the syllabus for planning assignments and studying.

The instructor was also referred to the "University Manual: Reasonable Accommodations: A Faculty Guide to teaching college students with disabilities" available online under title "Faculty Guide" and enclosed was a list of "Teaching strategies for assisting student with disabilities" (see appendix). In overall, the letter evoked impersonal attitude toward Hannah rather than provided any meaningful information in regard to providing support and instructions to her. At the bottom of the letter from OSWD Ingrid added a note: "Hannah is autistic. Please make sure that she is clear about the homework assignment. Thank you. Ingrid [last name] (Hannah's guardian)". Especially at the beginning of Hannah's studies, Ingrid often took it upon herself to introduce Hannah to the faculty at the beginning of the semester in person or in a written note as "a mildly

autistic, rather shy person, however, with great potential.” She would also add that Hannah is “smart, diligent, and has a great memory. She is eager to learn, is literal, and she plays the piano beautifully. You will love her.”

In Ingrid’s view, having to get accommodation from the OSWD did mark Hannah as a “person with a disability”. Given the scope and type of accommodations Hannah was eligible for and provided with, Ingrid saw that labeling Hannah as disabled was in fact a primary purpose of the letter. However, she also felt that it provided her with the opportunity to meet the professors and to get personally involved with Hannah’s success at MCC.

In general, Ingrid felt disappointed in limited support available and provided to Hannah as much as in the overall role of the OSWD played in Hannah’s education, and the general lack of individual advisement that was provided to students at the college:

I guess, if we could have had a student adviser with knowledge and experience in autism, one could build a more meaningful relationship than was possible from the people at the OSWD one that could last from the beginning to graduation and possibly beyond an adviser and mentor could also mediate with the professors on the student’s behalf. I guess advisers who are also psychologists could better benefit the diverse student population at MCC. Life, especially in a community college is so hard for many students.

As the above excerpt illustrates, drawing on their experiences with administrative and instructional staff Ingrid recognized fragmentation, lack and discontinuity of support and services provided to students in MCC. For instance, Hannah neither had a constant counselor at the OSWD nor an academic advisor, whether at the OSWD or at the academic department. Given the high number of students in every major and cohort, diverse pace of students’ progress throughout their studies, students rarely enroll into the same class with a former classmate. Therefore, it is practically impossible to form an academic community with other students beyond one semester. The only exception is the cluster courses in which the same class of students takes three thematically connected courses together over the semester. Despite an

emphasis on moving beyond the traditional curricular structure that organizes learning into courses as separate units, such as by promoting learning communities, (i.e., clusters), in practice students have little opportunities to develop mutual and continuous support among them.

Although the official channels did not always work out as Ingrid anticipated and wished for, she did not get discouraged and continued navigating the college with Hannah as her advocate, in academic as well as administrative and organizational matters. She felt that her efforts often paid off as they developed many personal relationships with supportive staff who went out their way to assist them. For instance she recalled:

We got acquainted with this lovely woman in the financial office, [Name] who helped us a lot. She often invited us to meet with her in her office where she had a wonderful elephant collection on the window sill. She was thrilled that Hannah did so well in her studies. Over times we became real friendly with [her], and she became indispensable to us, not being computer savvy or understanding the process. She saved us hours of time. In appreciation for her help, Hannah baked a boxful of elephant-shaped cookies for her.

However, it was clear to Ingrid that most of such positive experiences were the result of personal encounters with individual staff members rather than institutional policies. Ingrid believed that, in contrast to the OSWD view and understanding of Hannah as a Student With Disability, outside the OSWD Hannah was viewed by many as a charming young woman with a talent in baking, in addition to being studious. Seeing Hannah's name on the board for students on the Dean's List was just one of the proofs of Hannah's achievements as an agentic college student.

Hannah's, Ingrid's and Juan's reports provide an explanation why disabled students would not necessarily choose the OSWD as a place to look for informal support or just to hang out. The OSWD was neither perceived and experienced by Hannah and Ingrid as environment conducive to learning nor to socializing and positive identity development. In the midst of becoming familiar with policies and practices of the OSWD and available support, Ingrid understood that,

as so many times before, she remained Hannah's primary advocate and continued supporting Hannah with her usual resourcefulness and proactive approach. Although Hannah continued coming to the OSWD, it was mostly for assistance with either technical and administrative aspects of her studies, or to take an exam. Therefore, tutoring that Hannah identified as the key support in her academic activities, as well as other types of academic accommodations and support, were mostly initiated and organized privately and independently of the OSWD by Ingrid.

In addition to Ingrid's disappointment with limited services and support provided by the OSWD, she realized that Hannah was misrecognized by the OSWD as an agentic learner and person. Hannah enrolled in college with expectations of becoming empowered through participating in learning. The OSWD officially acts as an institutional system enabling and assuring equal access of disabled students to learning, to facilitate positioning of disabled students as equal participants in learning activity. However, Hannah and Ingrid understood that in addition to the OSWD failing repeatedly in providing students with adequate support and facilitating students' learning, the Office further disadvantaged Hannah's participation in learning activity when positioning her as a Student With Disability.

7.3. Establishing positions in learning activity

Ingrid proactively provided or sought out support for Hannah's transition into college and her participation in the courses. In the next section I describe how Ingrid and Hannah resisted and challenged Hannah's disadvantaged position as a Student With Disability and a deficient person in social interactions ascribed by the OSWD. I also examine how Ingrid took it upon herself to make up for insufficient or lacking services and accommodations provided by from the OSWD.

In taking on this active role, Ingrid constantly mediated Hannah's interactions with instructors. I further examine how Hannah and Ingrid developed a system of activities, including drawing on refashioning cultural tools in a constant struggle to recast learning as a collaborative activity while expanding Hannah's opportunity to take on an agentic position in the learning activities in which she engaged.

Initially, Ingrid was coming with Hannah to meet instructors either at the very first class or early in the semester and discussed some of the accommodations Hannah may benefit from (e.g. recording the lessons). She usually asked instructors to make sure that Hannah would be clear about homework assignment. Occasionally she asked instructors for permission to sit in classes and come to meetings with Hannah, especially at the beginning of her studies. Hannah did not hesitate to self-identify herself as a Student With Disability handing in a letter from OSWD, sometimes also referring to herself as "mildly-autistic," or as a "high-functioning autistic" person.

Although Ingrid often introduced Hannah to the instructor and even participated in classes (mostly as an observer), her involvement with instructors and participation in classes varied. In addition, when Ingrid did not feel she could provide sufficient support and keep up with requirements and content of the courses, or simply could not devote herself due to time constrains, she hired a tutor that would assist Hannah throughout the whole course. Occasionally, she asked a friend or acquaintance to consult an individual assignment or asked a specific question. Sometimes the support was needed in regard to using a word processor, blackboard or other computer related question.

As Hannah settled into the culture of college, Ingrid withdrew some of her involvement. Although Ingrid noted that "there truly was no class that Hannah did absolutely independently,"

there were several classes in which she worked mostly on her own successfully. For instance, in Liberal Arts Seminar that was organized around food, a topic of Hannah's personal interest, Hannah only occasionally discussed a specific issue or question with Ingrid. Hannah also worked quite independently on assignments, usually the ones that were structured in way that allowed for Hannah's genuine participation and spoke to her personal interest (including the assignments in Oral communication and English that instructors referred to and will be described later).

The table 4 illustrates the support Hannah obtained in classes she took with interviewed instructors, as reported by herself and Ingrid, including information on Ingrid's level of engagement in class and with instructors. The data fully correspond with instructors' reports. The data also indicate that support to Hannah in each class was negotiated individually and varied quite significantly depending on organization of the course, instructors' teaching practices and requirements, their approachability and availability, as well as Ingrid's availability and Hannah's needs.

Hannah quickly learned to articulate her needs to the instructors and manifested her agency as an active and involved student. For instance, the interviewed instructors mentioned how Hannah never hesitated to ask for written or oral instructions and clarifications on the assignments. Several of them also mentioned how she always sat in the front row, as Cultural Anthropology instructor put it "where the action is". The English professor described how Hannah positioned herself in the language lab right next to her desk so she could be in a close proximity to her, and always had an opportunity asking questions and discussing her work. On Ingrid's advice, Hannah approached a student almost in every class and asked for contact information in case of an illness.

Occasionally, she would also ask other students if they would share their notes because the professor talked too fast and she could not keep up. Hannah clearly developed several strategies that would assure her full participation in class.

All the interviewed instructors confirmed Hannah's high motivation and dedication to learning and class participation. They would all comment on her exemplary attendance and never being late for class. All the instructors were impressed by the quality of Hannah's homework assignments, always being prepared for class and having read assigned readings. They also noticed her focus and her attention in classes. They described her as an exemplary and even ideal student with admirable motivation and work ethic. As Ingrid said, the "[Math] professor loved her and he said that Hannah was an inspiration to himself and her classmates."

Undoubtedly, this was also an intensive, and as Ingrid said, at the times even anxious period of their lives. Hannah had to make sacrifices in order to keep up with her studies:

I had to give up a lot of things like baking and practicing the piano. I had to cancel a lot of piano lessons. At the end I decided not to attend the Music School for the time being, because it wasted the teacher's time and it was a waste of money. Baking and playing piano took a huge block of my studying time away.

Hannah indeed worked intensively, often long hours, quite possibly more than most of her classmates. Partially, this was due to her high work ethics, taking the studies very seriously, and the high expectations that were set up by herself and by Ingrid. Several instructors commented to me that unlike most of the students, Hannah always submitted all the homework and every assignment, including optional ones.

Table 4: Examples of support Hannah received in courses with interviewed instructors*.

Instructor/ Course/ Semester/Grade	Support received as described by Hannah	Ingrid's support and engagement in class and with instructor
<p>Math Instructor</p> <p>Math in Action II SPRING 2005 Grade: A- Credits: 0</p>	<p>I was tutored by a college student who helped students in math and science.</p>	<p>I do not remember telling him up front that Hannah is autistic but I must have done so. I helped Hannah with the homework and made sure she understood the concepts. A few weeks in, I found out from another student who I asked about the class when I was on college ground that they also had math assignments on the computer. I was horrified. Hannah never picked up this fact but instead did extra homework in the textbook that definitely helped her, but did not give her credit. I gave Hannah a note to give to [professor] asking to meet with him after class.</p> <p>I was early and peeked through the glass window in the door. He must have seen me as he came out to ask if I was Ingrid. He ushered me into the room and put a chair right next to Hannah's desk. "It's okay Hannah, say hello," he assured her. Then he turned around to continue with the math problem on the board. At one point he also asked Hannah to come to the board to solve the next step, which made me nervous, but she did well, hence I felt relieved and proud. I explained to him the computer debacle. He minimized the mishap, initiated Hannah's disc on his computer and explained to me how to access it at home. He told me that he loved Hannah and that she was an excellent student and very diligent. That same meeting he also invited me to attend his math class as a senior student, which I did ever so often. I also helped other students in Hannah's class occasionally.</p>
<p>Sociology Instructor</p> <p>Introduction to Sociology SPRING 2005 Grade: B Credits: 3</p>	<p>Discussing readings together with Ingrid. Going to the library together for research. Brainstorming and editing the drafts of my papers.</p>	<p>One of the special accommodations allowed was to tape the lectures. However, it was very time consuming for me to replay the tapes at home in order to discuss with Hannah the topic studied in class. Halfway through the term I abandoned this method. It had a rewarding side to it however, hearing Hannah's voice making contributions in class that were relevant and properly related. From then on I asked [professor] if I could sit in when he was showing a documentary. At the beginning I left quietly when the light was turned back on, but eventually I just stayed to the end of the class. I actually even raised my hand at one time and he graciously called on me to tell my point of view. On those days that I could not make it to class, [professor] would write in Hannah's note book the name of the film so that Hannah and I could watch it together at home on You-tube, or see it after school or on a weekend in the college film library.</p>
<p>Communications Instructor</p> <p>Oral Communication</p>	<p>Ingrid accompanied me to the zoo to take pictures and collect information for my presentation. Ingrid coached me for my oral presentation.</p>	<p>I met with her briefly before her first class to let her know that Hannah is autistic. I felt very secure with [her] that she would bring out the best in Hannah. She also made it clear to me that she was in command and that there was no need for me to be concerned. She was allowing me to attend a class at the beginning when she was explaining an individual project assignment. I was totally floored by her teaching style and her presentation of the homework.</p>

FALL 2005 Grade: A Credits: 3		I was at peace. Every single student in her class had an opportunity to do well in the course. Another time that [she] invited me to the classroom was during the time of oral presentations. Not just to be there when Hannah presented, but also to see and watch other students. At the end of the course, [she] was conferencing with each student about their final grade earned. She invited me to attend the meeting. While there with Hannah, she asked Hannah to read aloud the composition that she wrote on her final written exam. It was so beautifully written, I was near tears. Also all the questions on the test were correctly answered. Hannah got an A with barely any help from me. [Professor] was special, a great natural teacher, we were lucky to have her in our life.
English Instructor	I received extra guidance on a regular (weekly) basis in professor's office for the reading and writing assignments. She welcomed Ingrid to our meetings.	I can't remember attending classes. However, I did read with Hannah all the assigned books. Frankenstein was my favorite. I also remember Dracula, instructor's questions to the students of their readings were provocative and tested empathy and in the book of Frankenstein were actually coinciding with one of Hannah's personal issue (to be an outsider). I also helped Hannah with writing her papers. It was a wonderful opportunity to discuss social issues with Hannah. To help broaden her world. [Professor] was very helpful to me at our joint meetings in her office, and she took a personal interest by researching autism on her own. At the end of the term I presented her with a book about an autistic boy called, <i>The Curious Incident of the Dog at Night Time</i> by Mark Haddon. I learned that [professor] made it a reading assignment in a subsequent class.
Composition SPRING 2006 Grade: A Credits: 3		
Research Paper SPRING 2006 Grade: A Credits: 2		
Anthropology Instructor	Ingrid tutored me in taking down notes while watching the movie that was shown in class at home. She explained to me how to quote from movies in the term paper.	I met with him at the beginning and explained how autism manifested itself in Hannah's life. I guess he asked me. I probably did not do a very good job. He felt very uncomfortable and somehow imposed on. I met with him several times throughout the term and he was always concerned that he did not do right for Hannah, that he was not prepared for her or able to alter his teaching style. I remember he was talking very fast.
Cultural anthropology FALL 2006 Grade: B+ Credits: 3		
Health Science Instructor	I was tutored by Rob. He was a classmate in the biology class.	I talked him into meeting with Rob, Hannah's tutor. He finally consented. However, Rob told me that he had a very hard time to get hold of him. He constantly deferred the meeting for one reason or another. He was not very approachable. I was so overwhelmed with all the other classes that I dumped it on Rob for payment to take over and be Hannah's sole tutor.
Drugs & Behavior SPRING 2007 Grade: C+ Credits: 3		
Sociology Instructor	The professor allowed Ingrid to watch the movies that were shown in class to help me understand the films.	See above (Introduction to Sociology)
Urban Sociology SPRING 2008 Grade: A Credits: 3		
Instructor/ Course/ Semester/Grade	Support received as described by Hannah	Ingrid's support and engagement in class and with instructor

* Courses are listed in chronological order

When reflecting on the times at MCC, Ingrid mentioned that these were not easy times, often being in a “state of anxiety,” thinking of deadlines and projects to do, Hannah usually taking three classes at the time. Nevertheless, she also admitted that “she misses those times and it was all good for Hannah”. Hannah’s efforts indeed paid off and she established an excellent record. Her average GPA was 3.66 and she graduated with honors.

Most importantly, with Ingrid’s ongoing support and mediating learning as a collaborative practice, Hannah positioned herself as an agentic learner. The dynamics of this process will be discussed in further detail in the following chapters.

Despite the fact that Ingrid felt that the process of registering with the OSWD and other practices of the Office involved labeling, promoted stigmatizing and singling Hannah out, she also believed that what ultimately mattered most, was how the instructors responded to Hannah.

I think that they would have noticed that Hannah might interact differently in social situations. There was no way around it. Hannah is often unaware that she repeats herself, or she speaks in a monotone voice and speaks loudly. She also has a tendency to keep to herself and she does not socialize easily in a new setting. You know, if instructors were ignorant about Hannah’s autism, they would not experience what a great person she is. [Instructors of Oral Communication, Psychology, Sociology and English], and others treated her alike to the other students in their class. [Math instructor] went out his way for her, but [Drugs and Behavior instructor] and [Anthropology instructor] would have rather not have her in their classes.

Hannah being labeled, stigmatized, marginalized and excluded was not unfamiliar experiences to either of them. Ingrid was aware that Hannah often had to buy herself out of stigma by proving herself “over and over that she is intelligent and as good or better than the majority of her classmates”. Ingrid’s and Hannah’s way of resisting and fighting Hannah’s marginalization and exclusion was to continue finding ways in participating and being continuously engaged in activities and roles that might have been originally inaccessible or

denied. Undeniably, Ingrid had played a key role in initiating and mediating Hannah's participation in the classroom and continued throughout college. Whatever position was assigned to Hannah by the institution, be it a "Student With Disability" or a "disabled learner," Ingrid did not experience Hannah as such:

I think it is not so much that you are a disabled learner than that Hannah learns differently. Accommodations need to be offered if necessary, but the expectation of quality of work must be the same as for everybody else. The kind of work might need to be adjusted so that the quality of work can be met. Quality of work can never be compromised.

It is remarkable how Ingrid captures Hannah's position vis-à-vis her diagnosis when she says: "I think it is not so much that you are a disabled learner than that Hannah learns differently." These words capture well that Ingrid understood the role and purpose of the accommodations well. From the practice of teaching Hannah, engaging in learning with her throughout the years, she ultimately understood *accommodations as cultural tools* and the role of cultural tools in Hannah's development. She, as an educator herself, strove for a meaningful and transformative learning experience, to expand Hannah's ZPD. Positioning Hannah as a different but capable learner, she advocated for the means of accessing and enabling learning by mediating communication between instructors and Hannah assuring understanding of the expectations and goals of the instructors. Supporting Hannah by preparing her for classes, providing organizational help, assisting with time management and other support provided "accommodations" that were not offered by OSWD. Importantly, as will become evident from instructor's experiences discussed later, Ingrid's providing accommodations and support was a *relational* activity. As Ingrid entered the relationship between Hannah and her instructors by participating and engaging in the learning activity, whether directly or indirectly, provided accommodations to Hannah as well as to instructors.

Several of the instructors acknowledged and recognized help and support from Ingrid in

teaching Hannah. Ingrid not only provided support and accommodations to Hannah, she frequently mediated instructors' participation in learning activity as well. It can be said that Ingrid contributed to accommodating *learning activity* rather than provided accommodations to Hannah as an individual learner. Ingrid's own positioning in the learning activity as a tutor, advocate and mother for Hannah was an instantiation of her transformative activist stance. Hannah established for herself a role within a college (at least in some of the courses Hannah participated) as a provider of support to instructors and to learning activities in which Hannah participated.

7.4. Growing into a college student

As will be illustrated through the following section, mostly based on Hannah's experiences in college, she positioned herself within learning activities as an agentic learner with purposeful life project. Undoubtedly, understanding and positioning herself in such a way was a process of ongoing negotiations of discourses and positions in the context of college, ascribed by others and available to her as she engaged in learning activities and cultural practices in a college. College and its community practices and discourses produced the space where, if learning activities were organized in such ways that valued participation and contribution of diverse learners, Hannah's multiple social roles and identities were integrated into learning activities and the new ones were developed.

Hannah is a caring person, interested in others, who has many interests and hobbies. As the following passage illustrates, that is also how she sees herself:

Researcher: Before we start with more specific questions, what would you like to tell me about yourself?

Hannah: *That... I had made, I made some friends at [Metropolitan College], like Martin, a classmate of mine from oral communications who worked on project with me.*

Researcher: *And when you think of not only college, but in general, what do you think people should know about you, what do you want people to know about you?*

Hannah: *That I am smart, diligent, hard working, talented, like having a talent in baking, and that I have a passion for culinary arts, and being a nature lover, and loving photography, ... and me being attached to my grandparents and telling granny all about the exciting things that are happening in my life, ...getting to know somebody like you and Andrew, and professor [Math instructor] from Math 095.*

Researcher: *And what would you say, who are you?*

Hannah: *I am a person...who loves to bake and take pictures.*

Hannah describes herself as a person with multiple social roles to which she actively contributes and out of which she developed a particular sense of herself or identities, including being a granddaughter, friend, committed student, as well as a nature and photography lover, and a talented baker. Throughout this chapter I will describe how these identities and positions related to and became integrated into her learning and academic activities. Importantly, these positions and identities were negotiated with others with whom she interacted in the course of social-institutional practices (shared activities), such that Hannah being given opportunities of introducing and integrating these identities into her learning activities further led to empowering her position as an agentic, committed learner and a person in general. As it will be further illustrated, Hannah had opportunities to engage in such learning activities that allowed her to include other nonacademic identities (i.e., activities personally relevant to her) in a positive way in her learning activities, which spurred the development of new identities. Such learning and developmental opportunities and mediations were often created, in varying degrees, by her instructors, especially within the course assignments, in relationship with other student/s and tutors, by Hannah's own initiative or as a result of Ingrid's suggestion. In this process, Hannah's new identities, such as creative author, college and classroom community member, model

student, classmate, friend, and an expert on insider experience of being diagnosed with autism began to emerge in the context of college and learning activities.

On the other hand, administrative staff members and instructors also employed meditational tools that repeatedly positioned Hannah in marginalizing and inevitably disabling roles entailing identities curtailed in terms of agency and activism. Clearly, institutional policy implemented by the OSWD positioned Hannah as a Student With Disability. Furthermore, by drawing on deficit-oriented discourses on disability and autism, static notions of disability, and individualistic understandings of learning and human development those professionals positioned Hannah as a socially incompetent person or a cognitively impaired learner. However, those negatively charged identities that disempowered Hannah were negotiated, resisted and often rejected by Hannah as well as by other participants of the learning activity, including Ingrid, her tutor Rob, and some instructors. Whether individually or with support of others, Hannah often remade, reconstrued, and transformed initially disabling positions that were in conflict with her personal agenda and life project of becoming a baker and a better human being. I argue that Hannah introduced and gradually integrated her identities into learning and reciprocally into her selfhood and integrated identity. From this stance, she also resisted and rejected negatively charged and marginalizing identities. As Stetsenko (2010) claims, one way how identity development is connected to teaching–learning is the relevance of past, present but also “future activities envisioned by learner” (p.13). It was indeed Hannah’s clear future orientation that was a guiding force in integrating all existing and newly constructed identities into developing an integrated self. It is important to emphasize that this does not assume a static and monolithic self, rather a dynamic, fluid, and ever-developing socially and historically situated self. Her commitment to her personal growth as a learner, baker, person diagnosed with autism, community member, or

simply a human being were materialized in her activist stance as she engaged in learning. Furthermore, her activist stance was also materialized not only in her determination to learn and grow that would further enable her to contribute to sociocultural practices, for instance as a baker, but even more specifically and significantly, in her determination to realize the right to learn as an “autistic person,” resisting and rejecting oppressive positions she was frequently ascribed to claim and occupy, whether by the institution or individual instructors and college staff.

Although Hannah did not act and position herself openly as a political activist with agenda of transforming oppressive and discriminatory practices of social stratification based on putatively fixed abilities by the institution and its members, the way she engaged in the socio-cultural practices, including learning within a college, made it possible for her to be participating and actively contributing to *and* transforming not only herself but learning (and teaching) practices of other participants in her community, as several interviewed instructors acknowledged and recognized. Enrolling at the college as the first student diagnosed with autism was itself an act of *political activism*. From the point of becoming a MCC student Hannah continuously disturbed, challenged and transformed many existing social practices of the college, including commonly employed traditional discourses of disability and autism as well as those on learning/teaching and human development.

In this sense, a college and learning activities in which Hannah engaged, with undeniable support of others, served a role of not only learning activity context but as a crucial identity production site. Hannah was not merely negotiating her multiple identities, including an autistic one, and positioning herself or being positioned by others in a community practices of the college, she developed through her engagement a central position of her commitment to

changing those practices through her own vision and “goal-directed pursuits” (Stetsenko, 2010, p.13).

Turning now into Hannah’s accounts of her experiences in college will provide a window into Hannah’s understanding of herself, a process of emerging and negotiating multiple identities within social relations and practices of college. This will provide better understanding of her identity as a person diagnosed with autism and its integration into overall self-understanding.

I would like to emphasize that even while focusing on Hannah’s “autistic identity” this is not to be understood that being diagnosed with autism and “being autistic” is a Hannah’s dominant position from which she relates to the world, that is, not as her leading activity. Being diagnosed with autism or “being autistic” is not her defying identity. Neither her self can be understood in simple terms of dichotomy across the spectrum of being autistic or neurotypical, disabled or abled. This point will be fully elaborated at the end of this section.

Based on numerous accounts it was evident that Hannah truly enjoyed being a college student and she was proud of her new identity. She described her experiences as joyful and full of learning opportunities, as for instance in the following excerpts from the interview when talking about her experiences in college in general, and specifically about what she enjoyed while being in college:

Researcher: *Can you tell me about your experiences in college?*

Hannah: *My experiences were joyful because I learned a lot of new things.*

Researcher: *Could you give me an example?*

Hannah: *For example, in philosophy I learned about ethics, how to be an ethical person.*

Researcher: *Can you tell me more about it?*

Hannah: *Yes, to learn about racism. That people should not be separated by race.*

Researcher: *Anything else?*

Hannah: *Oral communication, how to communicate properly...and how to work in groups.*

At another occasion Hannah told me:

Researcher: *And can you tell me more about what did you enjoy about being a student at MCC?*

Hannah: *What I liked about being a student at MCC ...enjoy what I am learning, being tutored by a college student like Rob, studying hard for the exams and making new friends in class.*

Hannah enthusiastically expressed how her interest and commitment to learning, as well as interest in others and desire to make friends were met in college. Social aspect of being a college student was very important to Hannah and it was also evident when she talked about what kind of student she was. She took pride in being a college student, and referred to herself as diligent and smart, enjoying all aspects of studying and college life, including tutoring and developing new relationships:

Researcher: *Can you tell me more about what kind of student you are?*

Hannah: *I am smart, diligent...a hard working student, polite with others, ...showing interest in learning, ...enjoy the classes...getting good grades... by studying hard ...and attending classes, being on time.*

Researcher: *Anything else comes to your mind?*

Hannah: *And the tutoring I enjoyed, like my classmate Rob in biology who tutored me in science and philosophy.*

Hannah positioned herself as a competent and responsible student, diligent and hard working, obtaining good grades and taking pride in her achievements, fully immersed in and enjoying all the aspects of academic life including social one.

Spontaneously, she did not mention any negative experiences or referred to any difficulties she faced as a student although she was very open about the topic when I prompted her:

Researcher: *Was there anything difficult while being in a college? Is there anything difficult about being a student in college?*

Hannah: *Yes, some of the materials I did not grasp, and finding the material overwhelming, ...not having a very good professor, and having somebody who is disorganized and too much material on exam and in a semester.*

Researcher: *When you say you did grasp some of the material what do you mean by that?*

Hannah: *That some of the biology material and philosophy material I found difficult, so that Rob helped me to discuss it together.*

Researcher: *And when you say sometimes professor was not good...*

Hannah: *He was disorganized, cramped too much material into the exams, that's why I got C+ in Drugs and Behavior.*

Researcher: *Oh, that's what was happening, there was too much stuff?*

Hannah: *Yes.*

Researcher: *Do you know how other students felt in a class?*

Hannah: *Other students did not do well on the exams, because they found the material too difficult and overwhelming.*

Researcher: *You talked to them about it?*

Hannah: *I talked to Rob about it.*

Researcher: *Ok, Rob took that class too?*

Hannah: *He did not, he tutored me in it. I liked to have him as my classmate in biology and introduction in philosophy.*

Researcher: *Mhm, .. and was there anything else that was difficult while being a student besides difficult material, or too much material?*

Hannah: *I sometimes found the homework overwhelming. It was a little bit too much and I had to give up on a lot of things like baking and practicing piano.*

Researcher: *And was there anything difficult about dealing with other students or just navigating through the college?*

Hannah: *When I found a class too overwhelming and too difficult. I had to withdraw from history [of town neighborhood] because the work was too overwhelming and it was too much. And it was disorganized.*

Researcher: *Did you withdraw from any other classes?*

Hannah: *Yes, Short Stories I withdrew because I needed time to study for the [UWPE²⁹]. And Math 109 or something, when I attended a wrong math class when I was supposed to be attending Math 115. I decided to drop this class because Biology was a lot of material to cover.*

Hannah acknowledged occasional difficulties with comprehending some of the materials, especially when the amount of material to be covered in the course felt overwhelming. In addition, she attributed some of the difficulties she experienced to the teaching practices of the instructors, including presenting course material in disorganized and inaccessible manner. She clearly recognized how external conditions and the way learning activity was organized could disempower her learning and her as a learner. She was also well aware that other students, especially in so called “difficult” classes³⁰ also struggled and their performance suffered.

As Hannah admits, there were two occasions when she withdrew from the course, besides once when as she mentioned, was mistakenly registered for a Math class than she was not supposed to take. In other two cases the classes were simply too overwhelming. A Short Stories course was an intensive course that required reading and analyzing short stories for every class. In addition to the other two highly demanding courses she was taking that semester, Critical Thinking and Introduction to Philosophy, she was also preparing for UWPE, and thus studying became unproductive and anxiety producing and Hannah decided to drop the class. Later, she also withdrew from the History class that proved to be disorganized and disengaging. Hannah’s withdrawing from three classes is not unusual among the MCC students. Based on the

²⁹ UWPE – University Wide Proficiency Exam (name is changed), once a mandatory exam, no longer in effect at the university, that was commonly failed by many students. The workshop was introduced when university administration realized that students’ high rate of failure is partially due to lack of students’ comprehensions of the exam’s instructions.

³⁰ Biology course and most of the science courses were identified as so called ‘high-risk’ or difficult ones with a high rate of D or W (withdrawal) grades and high failure rate of 25% or more.

instructors' accounts, students frequently withdraw from classes during their studies, which in return contributes to slowing them down in graduating.

Hannah admitted that there at some point of her studies she felt so overwhelmed that she considered giving up:

Researcher: Hannah *did you ever feel discouraged in college by anything or anybody?*

Hannah: *There was a time when I found the work overwhelming. I told Ingrid that I wanted to drop out of college. Practicing the piano was more important to me than studying. Ingrid was upset. After we had a talk, she convinced me that it was crucial to have a college education for a bright future.*

Despite some difficulties Hannah experienced, she understood herself as a competent student who was able to face and overcome difficulties. Importantly, the struggles she experienced were not unusual to most of community college students. Available support coming from Ingrid and tutoring, as well as a possibility of reorganizing the schedule and adjusting the workload empowered Hannah's personal agency.

Most significant and varied support Hannah received from Ingrid who not only directly provided assistance with learning, but also organized tutoring and assisted Hannah in other administrative matters:

When I needed help in my studies in college, Ingrid hired tutors to work with me. When the professor showed a movie in class that I did not understand, Ingrid and I watched the film at home or in the college library so that we could discuss it together. I remember when I had to write a paper on [a historical event of the specific town neighborhood], Ingrid took me to a library in [that neighborhood] and helped me find information. We also attended workshops together for math and for preparing for the [UWPE] Exam. Ingrid also helped me get financial aid.

Tutoring was the most important kind of academic support Hannah received and she reported truly enjoying it. As already described, she was tutored by Ingrid and several other tutors, friends and acquaintances, or paid tutors formally hired by Ingrid. The extent of individual tutoring

varied, as well as its quality, mostly depending on course requirements and tutor's approach to teaching. Hannah equally enjoyed individual tutoring at home and group tutoring offered at college. For instance, she attended a workshop aimed at students' preparation for university wide proficiency exam (UWPE). This is how Hannah recalls this workshop:

Hannah: *I enjoyed attending the [UWPE] workshop.*

Researcher: *Why did you enjoyed it?*

Hannah: *So I could understand the material for [UWPE], and understand the material and interpret graphs and writing an essay on two readings, comparing and contrasting them, and relating my life experiences to the topic.*

Hannah took this workshop after failing the UWPE exam once. The workshop was offered to all college students aiming at practicing types of questions included in exam as much as clarifying the instructions and assuring students' understanding of the actual exam.

Individual tutoring provided an opportunity to review and discuss the study material, including readings, exam questions or a paper. Tutor often helped to "break" material in smaller chunks and make it less overwhelming and more accessible as Hannah explains:

Researcher: *So it seems like tutoring was important to you and was helping to you.*

Hannah: *It was.*

Researcher: *Can you tell me more what it was about tutoring that you preferred rather than studying alone?*

Hannah: *So I would not feel too overwhelmed so I can grasp the material better and understand it. And know how to solve the math problems properly.*

Researcher: *So the tutor helped you break things down into smaller task or understand the instructions better?*

Hannah: *The tutor helped me to understand the instructions better and break the topics into small steps.*

Researcher: *And anything else you can think of?*

Hannah: *So I can understand the material much better, and for instance how to start a good thesis for the paper.*

Importantly, tutoring sessions became a kind of social occasions that facilitated Hannah's engagement in dialogues, including questioning and reflecting on specific content topics. Based on her descriptions, it appears that she benefited from close, one-to-one interactions with another person that created opportunities for collaborative learning at her own pace. It is commonly assumed that students diagnosed with autism do not engage and even avoid group work. It has also been suggested (Breakey, 2006; Taylor, 2005) that to account for differences of students diagnosed on autistic spectrum in higher education they should not be assigned group work, which as Madriaga and Goodley (2010) argue only perpetuates marginalization. Although Hannah found participating in discussion groups of more than two other students challenging, working in dyad was often preferred way of studying and clearly benefited from collaborative way of engaging in learning.

She often talked about Rob, a middle-aged student from MCC who she met in Biology class and later also took a class in Philosophy together. He became her tutor and as Ingrid described, gradually a mutually meaningful friendship developed between them:

Actually, it was Hannah who approached him [in Biology class]. She didn't get the homework assignment, either it was delivered orally or she did not have enough time to copy it from the black board. So she asked one of the students in her class to write it in her notebook. At home she explained that he was older than the other students. I remember being quite impressed with Hannah's approach to solve her dilemma. After I met Rob, I was also pleased with her choice. I responded to him in Hannah's notebook, basically thanking him. I also informed him that Hannah is autistic and I asked him for this cell number in case we were unclear about an assignment. Hannah showed him the note and he put the number under it, and in the evening he called. His older brother had a boy with autism and he had a feeling that Hannah might be autistic. He was extremely interested in her and felt some affinity towards her. From then on he became an important figure in our life. Occasionally we invited him to have dinner with us. He took a keen interest in Hannah and it was important to him that Hannah did well. He invested much of his time to keep her abreast. But he also became a social friend. At times they would eat lunch together in the cafeteria and,

one weekend he accepted her proposal to spend a day together at the zoo. She proudly told him that she was a member and could bring a guest.

It seems that Hannah being guided by a stereotypical attitude– the oldest the most responsible- led her to making a wise move in approaching Rob and asking him among all other students for help in writing down the homework assignment. As Ingrid described, that incident gradually led to developing more than a usual tutor-student relationship that she herself welcomed and supported. Rob became involved in many other events and issues Hannah dealt with at college, as it is obvious from Hannah's account when they discussed the quality of instructions and assignments in relation to other students' learning and performance on exams. Hannah liked Rob as a person and admired him as a student:

I liked that Rob was my classmate. I thought that he looked handsome. He was smart and kind. Rob was an "A" student. He was a little older than my other classmates.

She enjoyed working with him as she appreciatively recalled:

Researcher: *What did you enjoy about tutoring?*

Hannah: *How I learned a lot of things about biology.*

Researcher: *You mentioned you liked tutoring with Rob. Why did you like tutoring with Rob?*

Hannah: *So I can get help and improve my tutoring habits in order to get good grades on the exams.*

Researcher: *Could you describe what was helpful working with him?*

Hannah: *Knowing the material for the tests and the lessons.*

Researcher: *Could you give me any example how he helped you to know the material?*

Hannah: *By taking notes from class.*

Researcher: *Ok, so he helped you to take notes?*

Hannah: *Yes.*

Researcher: *And when he was tutoring you, what did you do, how did he help you?*

Hannah: *By discussing the topics that were covered in biology. Rob checked my class notes and added information that I missed. He helped me understand the material that I did not grasp in class. He made diagrams on the cellular phases. He also prepared index cards with the questions on one side and the answer on the other side. We worked on answers together... This method helped me to get ready for the biology multiple choice test. He created all the questions from the study material in my notebook that was taught in class and Rob had helped me understand the concepts. He had great admiration for me because I was such a good learner.*

Rob got to know Hannah and her needs well, as her classmate in Biology and Philosophy courses as well as socializing with her in and outside of college. He also tutored her in Drugs and Behavior course that he himself never took. However, he met with instructor of the course and discussed the course expectations and Hannah's participation in class with him.

Rob was genuinely interested in Hannah and treated her with respect and as somebody who he could learn from and Hannah felt appreciated and recognized as such. Ingrid mentioned that Rob was an A student, spending many of his weekends studying in the library as he was working his way towards a medical degree. He was also helping other students from his Biology class leading a study group and preparing them for the exam. Ingrid recalled how Rob expressed his admiration for Hannah's persistence, hard work and intelligence. He would occasionally ask Ingrid for suggestions to help with his nephew, who was nonverbal and also diagnosed as autistic. Apparently, Rob was very involved with him often spending time together. Ingrid and Hannah were even invited to meet Rob's nephew and his family, and they enjoyed lunch and the afternoon on the beach together.

Ingrid recalled that Rob often went out of his way to find interesting and engaging ways to review course material with Hannah. For instance he often diagramed the ideas they were discussing. For instance, Ingrid described how once Rob and Hannah created a model representing the internal bodily processes.

However, Rob was fully aware of the course requirements and instructor's expectations in both, Biology and Drugs and Behavior classes, in which transmission model of learning was applied. He saw (and partially experienced himself) that students' learning in these classes mostly consisted of memorization of enormous amounts of facts that were to be examined in corresponding evaluation method – a multiple choice test. Therefore, in the times of test preparations Rob himself relied on memorization teaching strategies that matched instructors' transmission model of learning, as it was obvious from Hannah's account when talking about how Rob prepared her for the exams:

Hannah: *He dictated the material to me, write it down, and discuss it.*

Researcher: *So how did the dictation help you?*

Hannah: *To know what to write, find good studying techniques. With flash cards it worked for Biology and Drugs and Behavior [class]. He also gave me a written assignment to review for an exam, he was pleased when I knew the answers to the questions and would say, "You got it on the head."*

Ingrid confirmed that Rob indeed geared his tutoring toward memorization at the times of test preparation:

It was at testing time when he created a slew of questions for her that could possibly be on the test and she better spot the answer quickly and not be thrown by a variety of them.

However, Ingrid knowing Rob, and frequently witnessing their tutoring sessions and activities, had no doubt about his actual intentions and understanding of Hannah:

At testing time he just wanted her to do well because he knew from the work that she did with him and the answers that she gave in class that she deserved A. It mattered to him very much. ...Hannah was an inspiration to him and I sincerely believe that he treated Hannah as a smart person who was capable of understanding the material.

It appears that Rob made every effort to support Hannah in her learning. Based on Ingrid's accounts, without a hesitation he positioned her as an intelligent student capable of engaging in collaborative knowledge construction, as for instance in the case of creating a model of human

body and its processes. As somebody who got to know Hannah closely, as a tutor, classmate and a friend, he also took on a role of Hannah's advocate and was determined to prepare her for the tests that he knew might not reflect her actual knowledge and understanding of the subject.

Primary goal of tutoring was to provide support to Hannah in her learning, to supplement learning occurring in the class and continuously extend her ZPD in joint activity of learning. However, as it turned out to be in a case of Biology and Drugs and Behavior courses, tutoring frequently substituted teachers' instructions and compensated for inadequate evaluation practices.

Hannah passed Biology, one of the most feared and difficult classes in the college, with above the average grade B+. Hannah's and Rob's effort did not seem to fully pay off in Drugs and Behavior class in which she received C+.

As the above excerpts illustrate she enjoyed tutoring, as an engagement in social and intellectual activity. She recognized tutoring as an agentic practice that supported her learning and was empowering her as a student.

Whether in our formal interviews or informally in conversations Hannah admitted that part of her experiences in college was being treated differently, however not necessarily in a negative way, as she stated here:

Researcher: *Do you think you were treated differently than other students because you brought a letter from OSWD, or they knew that you were autistic?*

Hannah: *Yes! Other students don't need as much help as I do.*

Researcher: *And what do you think, how differently you were treated?*

Hannah: *Needing more help, explaining more things to me.*

Researcher: *And do you think you were treated differently by professors?*

Hannah: *I was treated kind, kindly, better than other students.*

When asked about differences, she acknowledged understanding herself as being different, especially in terms of requiring more support. Most of the time she felt she was supported and experienced these interactions as empowering, as it was in the case of tutoring. In addition, and I would argue that even more importantly so, Hannah was also aware and often complimented by instructors, that she stood out among students as a student of great work ethics, diligence, devotion to class, persistence and punctuality. Part of her being different and exceptional student had to do with making every effort to participate in learning. Most of the instructors acknowledged and reciprocated her determination with openness, providing support and being accommodating. Therefore positioned as being different, by herself and by others, was a dynamic and shifting phenomenon constructed in this dialectical process of socially interacting and engaging with others.

Although Hannah felt that most of the instructors treated her kindly, were responsive and supportive, even more so than with other students, she was also well aware of unfair treatment and attitudes that she occasionally experienced. For Hannah being different could mean that she finds herself anywhere on the continuum between feeling accepted and empowered versus feeling disabled and excluded. Her negative experiences had to do with either being excluded from participating in learning, or otherwise being subjected to practices and attitudes that disabled her as a learner, as it is evident from the following excerpt:

Researcher: And do you feel that some of the professors were not always kind, or nice? Do you have any negative experience?

Hannah: Yes, I felt that professor [in Writing through Literature class] wasn't very good. He did not explain to me...didn't explain the instructions of how to do the paper, if I should number the pages or not.

In a similar way, she was critical of Philosophy and Drugs and Behavior instructors, as some of it was already revealed. Frequently, the main reasons for her complaints were instructors being disorganized and the general lack of instructions that prevented her in understanding the homework and other assignments and thus disabling her learning.

Ingrid did not develop a very close relationship with any of these instructors either. She was not very impressed by them, their teaching practices and attitudes towards Hannah. For instance, as she explains, she was quite convinced that a Literature instructor was biased against Hannah because she was diagnosed as autistic:

After he learned from me that Hannah was autistic, he told me that there was a family member with autism in his family. I think it was a boy and I understood that this person was on the low end of the spectrum. Consequently, he was very skeptical about Hannah's abilities right from the start and suspected that I was doing most of her work. I was quite intimidated and never formed a helpful working relationship with this guy. He was also quite old and liked the pretty girls in class. Anyway, I think his own experience with autism could have influenced him.

Perhaps it was a combination of various factors, but Ingrid admits that she chose her battles. She could not support and advocate for Hannah with the same energy and involvement in every class. In a few cases she did not persist in trying to significantly impact and correct instructor's misunderstanding of Hannah as a disabled learner and she did not insist on resisting positioning Hannah as such. Especially in situations when she understood that her efforts of creating a dialogue with instructor were not met with either willingness or openness, she reoriented her efforts and energy elsewhere.

Occasions when instructors' misconception about autism apparently interfered with their teaching practices and eventually lead to positioning Hannah as disabled learner incapable of learning, at least initially, were not uncommon. In several cases, such initial attitude almost led to excluding Hannah from participating in class altogether. Hannah and Ingrid recalled that

several instructors expressed concerns about Hannah's ability to participate in their classes because she was diagnosed as autistic, even before getting to know her. Probably most openly this was a case with the Theatre and Anthropology instructors. When instructors explicitly expressed their hesitations about including Hannah in their classes, Ingrid assured them that Hannah would be capable of participation and learning.

Theatre instructor became convinced of Hannah's abilities when she impressed him with her knowing, as the only student in class, that the Dionysus was a God of wine in Greek mythology. It was a simple act of demonstrating a factual piece of knowledge, on a classic subject, and perhaps as such especially valued, that lead a Theatre instructor re-position Hannah from autistic disabled student to a student capable of participating and contributing to class learning.

Apparently, instructor became fond of Hannah and later encouraged her to take acting classes and work with photography as way of expressing herself. Hannah not only did very well in a Theatre class and received an A grade but enjoyed it and became attached to her class that was part of the cluster³¹.

Furthermore, Hannah learned that Anthropology instructor was also reluctant to have her in class and that he was doubtful whether she would be able to keep up with intensive 6-week course. Hannah remembers feeling not particularly welcomed in class:

Hannah: *And that I remember professor [Anthropology] felt uncomfortable about having me in his Anthropology class.*

Researcher: *Why do you think he was uncomfortable?*

Hannah: *Because ...I did not get all his stories and he was an actor.*

³¹ Cluster is a group of courses (usually three) connected by a common theme. Students are able to apply ideas and readings from one course to work in other courses. Activities and assignments are often linked as instructors plan the clusters together. The same group of students takes the courses together so a stronger community of learners is possible to form. Students in clusters often earn higher grades than students taking these courses separately.

Researcher: *And, but why do you think he was uncomfortable?*

Hannah: *Because... he felt that I was not ...well fit for his class.*

Researcher: *Why do you think so?*

Hannah: *Because I was supposed to be ... more knowledgeable about the stories and ...have them put in my head.*

Researcher: *And why do you think he was uncomfortable with you being in his class?*

Hannah: *Because he thinks that I am autistic, ...he felt that I did not belong in his class, because I was autistic compared to mainstream students...and that I was behind in the studies because I had to work harder because I was in the Special Ed school that had poor expectations and that was not so academic...and that I wasted a lot of time there, and that I had to make up for it by working harder than the other students and the high school would not accept me because they felt that I was too old due too early childhood autism.*

Researcher: *Uhm, and how did you feel about it?*

Hannah: *I felt disappointed that I could not attend ... and be accepted into the high school, which was public, because I was autistic, and felt excluded from the group. That I had to work harder than the others because I spent too many years in a special school that is for students who are diagnosed autistic.*

Hannah believed the instructor considered her as “unfit” for his class because she did not share his sense of humor, nor appreciated his way of teaching, somehow reciprocating his way of relating to students. Most importantly, she felt that he considered her as incapable of fully participating in class because she was diagnosed with autism and had to work harder to be able to keep up with other students. Hannah connected her current experience of feeling excluded with her past ones and the associated feeling of disappointment. She explained that she indeed needed to put more effort into learning because she was excluded from education and thus prevented from accessing cultural tools available to most of her contemporaries at the first place. She pointed out to exclusionary practices of special education and other regulations of educational system that set her behind and disabled her as a learner, not necessarily autism.

Hannah's intensive work was the compensation for earlier lack of education including inaccessibility to some cultural tools and exclusion rather than for "being autistic."

I encouraged Hannah to further explore how she felt about being subjected to ableism, including being judged as a student based on her diagnosis, and what she believed the instructor should know about her except being diagnosed as autistic:

Researcher: *How did you feel about it, that he knew that not all students were doing well but he felt uncomfortable about YOU, he was afraid that you would not do well because you were diagnosed autistic?*

Hannah: *Because he did not know that I was diligent, and hardworking, and smart.*

Researcher: *Do you think he changed his opinion, how do you feel about this?*

Hannah: *I felt I got a good grade, which is a B+. Because I studied so hard.*

Researcher: *I know you studied so hard, and I know you did well at the presentation. Don't you feel you should get a better grade?*

Hannah: *I felt that B+ was ok.*

Researcher: *Was it fair?*

Hannah: *Yes.*

Researcher: *What do you think it would help [the instructor] to know about you? What do you wish he would know about you from the beginning?*

Hannah: *That I am smart, diligent, and studious ... and that I can do well in school, ...and study hard. I am pleasant to be in his class, ...and that I can apply myself, ...do the homework, ...and make good study habits, that I can make new friends in class and work with them.*

Researcher: *So what do you think, if he had a student diagnosed as autistic again, what do you think he should know?*

Hannah: *He should know that he can do the homework, and study hard, and attend the classes on time, follow directions, and pay attention, and take responsibility in homework and put effort into the class.*

Researcher: *What a professor should do in class?*

Hannah: *He should allow students who are autistic to attend his class so they can have a chance to grasp the material, do the homework and make good study habits.*

Hannah felt that from the very beginning the instructor was not only unaware of *her* abilities and commitment, but also of the fact that *any* student diagnosed as autistic is capable of learning. She also felt that the instructor should focus on her abilities as a student rather than the fact that she was diagnosed as autistic. Although she felt she was unjustly discouraged to participate in class, she thought she was evaluated fairly despite working hard for this course. It is not characteristic of Hannah to simply complain and position herself as a victim. She was honest about her performance and was rather interested in being taken seriously and considered as a smart, diligent, responsible and committed student. Hannah was neither interested in receiving any special treatment nor in lowering expectations from her as a student. She was fully aware of her needs and challenges, support she needed and received either from instructors, Ingrid or other sources. Some instructors questioned and doubted the interdependent nature of Hannah's learning and the need for support was perceived simply as deficit, as Hannah's inadequacy as a learner and ultimately positioned her as a student lacking agency. However, Hannah recognized how the support she received in *interdependently* organized learning activities allowed her to access learning and knowledge and thus strengthen her agency and empowered her as a learner. Moreover, Hannah demonstrated her agency on a daily basis as she expected to be included and have an equal opportunity to participate in learning activities as any other student. This is one of the most important and reoccurring themes in Hannah's understanding and positioning of herself as an agentic student and person as illustrated in the following excerpt:

Researcher: *What do you think other people should know specifically about your life experiences as a person diagnosed with autism?*

Hannah: *Other people should give me a chance to find out how smart I am. I remember my grandfather saying, "My, Hannah is a schooler. I bet Hannah is going to become a professor*

some day." He was impressed how much I knew about nature and science. I am also a person who has a knack for learning languages, playing the piano, cooking, and baking.

In her request from others for “a chance to find out how smart I am” she calls for an inclusion and recognition by others as an equal participant of community of learners and the society in general.

I had an opportunity to interview Anthropology instructor. From his very candid accounts of Hannah and his own experience of teaching and interacting with her that will be discussed later, it was obvious that he indeed learned a great deal about Hannah, genuinely liked her and appreciated her presence and contribution to class. This experience not only changed his understanding of Hannah as an agentic student, but he himself was transformed through this experience. Unfortunately, this was never directly communicated to Hannah and Ingrid.

In our conversations we also discussed the difficulties and positive aspects of being diagnosed as autistic and explored what that meant to Hannah:

Researcher: *Do you think there is anything difficult in your life because you are diagnosed as autistic?*

Hannah: *Social conversations I find difficult to grasp. ...I sometimes feel uncomfortable around people whom I don't know well, often I don't grasp the topic other person is speaking...but I can learn how to make contributions to the conversation.*

Researcher: *And what do you do when you feel you are not grasping what other people are talking about?*

Hannah: *I have a tendency to drift off with my thoughts ...and not to show an interest what other people have to say.*

Researcher: *I think everybody does it, I mean people often do it because it is in a way easier...*

Hannah: *[jumped in] ...they often drift with their thoughts. Why do they do that? Could it be because they don't grasp the topic?*

Researcher: *Mhm. Why do you think you do that?*

Hannah: *I do that because I find the topic too difficult to understand.*

Researcher: *So what else could you do instead of drifting off, instead of 'leaving' the conversation? What else could you do?*

Hannah: *[quietly thinking] Look at person's eyes when he is talking, ...and ask questions.*

Researcher: *Yeah, that's seems to be a good idea. And how does it feel, what is that feeling when you don't understand?*

Hannah: *I feel I get lost in what the other person has to say.*

Hannah exhibits a varied and highly nuanced understanding and interpretation of what “being autistic” might imply. For her it might mean finding oneself lost in conversation and struggling with meaning of it, especially in interactions with strangers. Importantly, Hannah developed a whole array of strategies that might help to stay focused or reconnect during social interaction. She finds interacting in larger groups more challenging than conversing with only few people. Although she views autism as a source of some of her difficulties, she also acknowledged positive aspects of her “autistic identity:”

Researcher: *What do you think, what are the good things, are there any good things about “being autistic?” Are there any good aspects to it?*

Hannah: *Yes. Mildly autistic people can learn readily, ...work hard, ...be smart,... become good listeners, ... be attentive... attend school or work on time...not have too many absences or latenesses...follow directions...participate in what's going on...focus their minds on the topic that is being discussed...and...prepare themselves for college or trade school, and have a successful life and having a good job...and how to make a good life for themselves.*

Undeniably, Hannah attributes some of her difficulties to autism, especially navigating conversations and social interactions. She does not seem to experience being diagnosed with autism or “being autistic” as an advantage. Neither can I recall that she ever mentioned any specific skills, abilities or talents that she would ascribe to “being autistic.” Nevertheless, she understands that the difficulties associated with being diagnosed with autism do not preclude her

from learning and being an engaged student, from working towards her carrier aspirations and from leading a meaningful life, in overall engaging in activities from the activist stance. She experiences and positions herself both as autistic and agentic, developing and growing as a learner and human being. The positions of “being autistic” and agentic are not mutually exclusive, they are integral parts of her self. This is also evident when she explores her future or discusses if and what she would like to share with other students about autism and her experiences of being diagnosed as autistic:

Researcher: *And how do you, how do you see yourself in the future?*

Hannah: *As ... being a succesful baker...baking and cooking for ...other people, you know like baking and cooking in people’s houses... and a person paying me, ... this would be another possibility, since I love to give parties.*

....

Researcher: *Would you like other people, other students to learn about autism?*

Hannah: *Yes, I would for others students to learn about autism.*

Researcher: *Why?*

Hannah: *Because, there are famous autists, like Temple Grandin, and Donna Williams, who wrote good books and can achieve their carrier, and work hard for it, help themselves make better lives, and to have a productive adulthood.*

Researcher: *And if, let’s say you take another class in psychology and you learn about autism, would you like to share your experience with students and professor?*

Hannah: *Yes.*

Researcher: *What would you tell them?*

Hannah: *[I would] let them know how smart [autistic] students are and that they can do the homework, and study hard, ...and do well in school, ...be able to go to college, ...and achieve their carrier, to make better lives for themselves, ... find them a good job, I think mildly autistic people should be allowed to have a good job so that they can have a productive adulthood.*

Hannah is not inevitably proud of being diagnosed with autism or “being autistic” per se but she is certainly not reluctant to disclose and display it. She never attempted to construct her identity around being “normal” rather than “being autistic,” pretending or trying to pass as “normal,” as it often can be a case for young autistic people (e.g. Bagatell, 2007; Baines, 2012), and passing as nondisabled (e.g. Brueggeman, 2006; Garland-Thompson, 2006). However, she is certainly proud of her and other women diagnosed with autism, their achievements, the life they built and live. Hannah also participates in recreational activities of the group of young intellectually disabled people. Such relating and “locating oneself as part of the larger disability community can contribute to positive identity with disability” (Shakespeare, 1996, as cited in Bagatell, 2007, p. 414). While in college she also believed it was important to share her experiences as diagnosed with autism and “being autistic.” For instance, we discussed this issues several times and she expressed the desire and felt it would be important to discuss what it means to be diagnosed with autism and share her life experiences with class. Although Hannah does not hesitate to disclose her diagnosis and her autistic identity and occasionally participates in events organized by and around autistic community, she does not necessarily affirm autistic identity or seek cultural recognition as a member of autistic community.

In the context of college Hannah relied on her funds of knowledge (Moll, Amanti, Neff, & Gonzalez, 1992) to participate and thus contribute to the community of learners in every class it was possible. Instructors who organized learning activities in a way that promoted Hannah’s utilization of her experience and knowledge, also promoted understanding of the connection between personal and familiar on the one hand, and the subject matter on the other. This way, her personal knowledge, cultural resources and repertoires of practices became relevant to the academic content of the course. In the courses and assignments that were structured around

students' experiences, interests, and knowledge, it was possible for students to bring in their own cultural practices and discourses as valued contributions to a community of learners. Hannah evidently enjoyed and benefited from such opportunities. Although she approached all the course work with responsibility and commitment her favorite classes were the ones in which she was recognized as a valued member of the community of learners. This was well illustrated when she told me, and I must admit to my surprise, that Oral Communications was among her favorite subjects and classes in college:

Researcher: *Hannah what were your favorite subjects?*

Hannah: *Oral communication, ...psychology, ...introduction to music.*

Researcher: *And can you tell me why? Why oral communication?*

Hannah: *To help me become a better communicator and learn about steps in communicating.*

Researcher: *What else did you enjoy?*

Hannah: *Working on a bag project, like keeping things secret putting them in a bag³², so not to talk about them or show anybody, taping things on the outside of my bag that I am fascinated with and that I love.*

Researcher: *What do you mean taping... ?*

Hannah: *I would tape a picture from one of my zoo magazines, you know like gibbons swinging from a jungle world from zoo to show that I am a member, and also a picture of a granny and grandpa to show that I am attached to my grandparents, and a picture of me giving parties, being a host.*

Researcher: *Oh, so that was a presentation you prepared for a class?*

Hannah: *Yes. I also like presenting a presentation about the zoo.*

Researcher: *Oh, you made a poster for that right? I remember that poster.*

³² Visual BAG was an assignment in Oral Communications class in which students put pictures of things and people they like. For the presentation a student chose one symbol from the bag that best represented them and spoke for 1 to 1 ½ minutes about themselves in relation to the picture. One of the main goals of the assignment, besides practicing oral communication skills, was to introduce oneself to the class.

Hannah: *I made some boards of pictures of animals on a separate one.*

I further inquired if she had a favorite class in terms of her classmates rather than just a subject. The Oral Communication was again the winner:

Researcher: *And which class was the best that you enjoyed because of your classmates, because you liked your classmates. Which class did you enjoy the most from that point of view?*

Hannah: *Oral communication.*

Researcher: *Why?*

Hannah: *Because ...I got to discuss my own experiences and fascinations and give a presentation to the entire class.*

Hannah clearly enjoyed the class, including the assignments that one could have easily assumed she would have difficulties with and might not find interesting and enjoyable to work on. In this instance, I realized how quick I was to make assumptions about her (even while doing the work that is motivated by the desire to challenge the ways in which we all make assumptions about others. This was just one of many opportunities when I questioned my own thinking based on normative assumptions.) The assignments allowed her to express and share her interests, knowledge and experiences, private and personal, including, as she says, her “fascinations” with the rest of the class. The instructor developed series of in- and out-of-class individual or group assignments that allowed Hannah to connect and relate to the course content as well as a class community in a meaningful and personal way. Knowledge construction around the subject of Oral Communications was situated within a context of a community of learners of the class and became relevant to Hannah’s culture and personal values, her interests and experiences. The learning activities in this class were designed as practices that mediated presenting and applying cultural and personal resources and thus contribute to the individual and group knowledge

production (Gutierrez & Stone, 1997). Her identities of a nature and photography lover, a zoo fan, granddaughter, baker and a hostess that she introduced in class served as a source of expertise and knowledge. They were the positions from which she could engage with class as a valued expert while not being compared to and evaluated against standards of normalcy. Her uniqueness, her ways of engaging with others were not simply tolerated and accepted, they were respected ways of knowing and doing and as such, they became integral part of valuable collective knowledge and learning, and valuable contribution to diverse sources of knowledge.

Hannah also developed closer relationship with other two students from the class that was also acknowledged by Ingrid and the instructor who I had an opportunity to interview. Hannah was particularly fond of Martin, who Ingrid also met, and I got to know from Hannah's and Ingrid's accounts. Hannah would discuss their accomplishments in class, their assignments and simply enjoy conversing with him. They often rode a bus together from the college. As I already mentioned earlier, Hannah valued social aspect of college life, whether new relationships with individual students or being a member of a collective. Despite common assumptions about persons diagnosed with autism being seen as isolated individuals avoiding rather than seeking socialization especially with groups, Hannah cherished her experiences and opportunities of socializing, particularly the sense of belonging, collegiality among students and membership in the collective. It is important to remember that Hannah did not have such opportunities for socializing and being a member of collective on daily basis as most teenagers experience during their high school years as Hannah never attended high school. Her choosing the communication class also supports this conjecture. This could be best illustrated when I asked her about her friends as she mentioned several times that one of the enjoyable experiences being a college student was meeting new people and making friends.

Researcher: *Who were some of your friends?*

Hannah: *[List of names of ten students] from the Gothic Cluster with [English professor] and [Theatre professor] in acting, English 101 and 103. What is good about me being in a cluster is that I have an experience what it is like to be in a cluster.*

Researcher: *And what else is a good experience about cluster?*

Hannah: *That you do not have to loose each other, you can ...watch over each other...and have students' phone numbers just in case I need to know what the homework was.*

Researcher: *And do you keep in touch with any of your friends?*

Hannah: *Yes, Rob, I keep in touch with.*

Despite finding social interaction often challenging, including in-class group activities (especially with more than two other students), Hannah not only made an effort to understand social interactions and connect with others, she genuinely enjoyed, appreciated and sought to connect with others, often in her own ways. For instance, she baked cookies and brought them for her classmates, as I also learned from some of the instructors. Her multiple identities that she could bring into academic setting created important connections not only with subject matter but also promoted socio-emotional connections with the instructors and the rest of the class. In spite of common assumptions about person diagnosed with autism as emotionally detached and isolated, held also by some of the interviewed instructors and staff, for Hannah opportunities of emotionally and personally connecting with the subject matter and class community promoted and further motivated her learning and personal growth.

As stated earlier I was ultimately interested in Hannah's understanding of herself, more specifically, understanding her "autistic identity" in the context of her learning experiences in college. In other words, I aimed to understand Hannah through exploring intersectionality of development of the self, learning and disability.

Recent advances in theorizing self and identity from the social constructivist perspective and the growing interest in understanding identity development of children and young people diagnosed as autistic yielded new stream of research that focuses on autistic identity construction, for instance understanding and presenting lived experiences and identity construction of children diagnosed on autistic spectrum (Sirota, 2010), of high school students diagnosed with autism (Baines, 2012), and adults diagnosed with autism (Bagatell, 2004, 2007, Brownlow & O'Dell, 2006). Although the authors take various approaches to studying identity and its construction, including Harré's positioning theory (Harré, 2003; Harré and Gillet, 1994; Harré, Moghaddam, Carnie, Rothbart, & Sabat, 2009) and Holland's social practice theory of engagement in figured worlds (Holland, Lachicotte, Skinner & Cain, 1998), the researchers consistently refer, directly or indirectly, to two societal discourses of autism, the first one based on a medical deficit model of disability produced mostly by professionals, and the opposing one based on neurodiversity approach situated within social model of disability produced predominantly by autistic community as a reaction to the dominant discourse. Importantly, the identity construction of participants is predominantly understood as a struggle of identifying with one or the other discourse, and an effort of passing as "normal". For instance Baines (2012), in applying positioning theory (Harré, 2003), presented stories of two high school students who make deliberate effort to "promote positive perceptions of themselves" and using various identity positions and education as a tool to pass as normal (p. 548). Bagatell (2007, p. 414) using Holland's perspective of figured worlds and positional identity, describes identity construction of the young man diagnosed with Asperger's syndrome as a process of a struggle and complex negotiation of multiple identities, mostly between the figured worlds of normalcy and the "Aspies" world of neurological difference.

Comparing and juxtaposing stories of identity constructions of the young people in above mentioned research projects with that of Hannah's, provides more profound and clearer understanding of Hannah, her positioning and self-understanding, as well as the advances of conceptualization of this research.

All three young men from both research projects just mentioned, appear to put an enormous effort into passing as normal, whether as a result of their own desire and/or due to expectations from parents and close surrounding. For them, performing normalcy and passing as normal became the leading activity in their self construction. Fitting and passing the standards of normalcy became a leading activity that organized and directed all their pursuits and activities and engagement with the world (Stetsenko & Arievidtch, 2004).

For instance the two high school students from Baines research appear to purposefully construct multiple positions that mediate their passing as "normal" and all their future goals are organized around that goal. The main goal of education and successfully participating in learning becomes only a tool to achieve a status of normalcy. In the case of Ben, a young man diagnosed with Asperger's syndrome from Bagatell's research, it is especially strikingly evident that passing as "normal" was his leading activity. As this author reports, the process of the identity construction represented such a struggle of conflicting positions that he became repeatedly depressed and even suicidal. Discovering the Aspie's world and the act of coming out as a member of Aspie community provided him, at least temporarily with a positional identity that did not require to change himself. His differences were for once fitting normalcy of the Aspie's world. The two worlds, Aspie's and the "normal" one represented such conflicting positions that it was impossible for Ben to integrate them. Although a bright and successful student, college represented another part of a "normal" world that seemed to require Ben to act in certain ways

and engage in certain practices that did not appear to be overlapping with his Aspie's world, although this area was not discussed by the author extensively, except a brief note that Ben in the times of the peaking of his identity crisis seemed to be "more content, involved in his physics classes and excited about talking about the latest advances in space propulsion" (Bagatell, 2007, p. 424). It appears that the activities carried out in each of these separate figured worlds, "normal" and 'Aspie's," were impossible to carry across. Although I agree with the well established notion that disability does not constitute the most important aspect of a person's identity or social position (e.g. Connor, 2008; Linton, 1998; Wendell, 2006), based on Bagatell's account of Ben and his struggle I dare to speculate that for Ben the struggle for being and passing as "normal," fueled by the expectations of his surroundings, ultimately defined who he was, his identity.

Analysis of the above mentioned research projects, including analytical focus of researchers to understand identity development of their research participants and participants' understanding of themselves, helped me to deeper understand the advantage of my own analysis along with Hannah's own self-understanding and positioning. Precisely, I believe that conceptualization of this research, concretely exploring the intersections of identity development, learning and disability provided me with understanding of Hannah's identity construction and her own self-understanding beyond the two-dimensional polarities of abled/disabled versus autistic/neurotypical categories. For Hannah "being autistic" is an integral part of her identity. However at the same time, as already discussed, she did not appear to be consumed by performing "normalcy" and making effort to pass as "normal." Ingrid played a significant role in forming and supporting this perspective. For Hannah "being autistic," means she might relate to others and engage in activities in her own unique ways, but "being autistic" is not her leading

activity. While in college, her learning activity was learning with a goal of pursuing her career in culinary arts and becoming a better person. Although diagnosed as autistic, she is not defined by autism, or by disability; rather, she seems to be defined by her agency and activist stance towards her present and future engagement in the world. Hannah neither acts from (autistic) identity status rather from the “status for recognition” as full member of the society (Fraser, 2010). Importantly, she does not understand her personal agency solely in individualistic terms. Rather, she understands it as a collaborative process involving others and available resources, including cultural tools, while at the same time also understanding that she must take an active role in orchestrating her own goals and motives, her life pursuits.

7. 5. Instructors

The focus of this section is dynamic processes yielding unique patterns of positioning of Hannah as she participated in given learning activities organized by instructors participating in this research. The diversity of relationships and resulting positions that Hannah was to occupy were mediated by various discourses and social practices employed by instructors. The goals of this section are multifaceted; to identify instructors’ positioning of Hannah, identify the discourses and practices contributing to Hannah’s positional identity, and to reveal dynamic and dialectical nature of Hannah’s positioning.

Scholars working with teachers diagnosed with learning disability (Ferri, Connor, Solis, Valle, & Volpitta, 2005) identified multiple, however interrelated sources of knowledge about learning disability (LD) that teachers used to construct the meaning about LD, namely “media/cultural scripts, official (authoritative) discourse, personal narratives, and teaching experiences” (p. 68). I found out that the discourses and practices that participating instructors

employed in relating to Hannah and her positioning originated in similar sources of knowledge, and could be identified as cultural representations of autism and disability, institutional discourses, personal experience, and instructors' teaching practices and philosophies. However, as the conceptualization of this research suggests, and the findings indicate, in order to fully understand instructors' positioning of Hannah, it is imperative to take into account instructors' sources of knowledge and discourses (including their practices) of learning, teaching and human development. Instructors' understanding of disability and autism can be fully understood only if considered in relation to their theorizing of learning and development.

As explained in section on methods, I was able to interview six instructors who taught Hannah in eight different courses throughout three years of her studies between Spring 2005 and Spring 2008. Two of the instructors (Sociology and English instructors) taught Hannah in two courses (see table 5). All of the instructors were full time senior faculty, and all except one were tenured. The courses Hannah took with interviewed instructors were in the area of math, health science, social studies, and humanities, including communications. Most of the courses were 3 credit courses, except remedial math zero credit course. However, this course was graded. The range of Hannah's grades in the classes she took with participating instructors ranged from A to C+.

In overall, throughout her studies Hannah took twenty-four credit courses (ranging from 1 to 4 credits, majority 3 credit courses) in which she earned sixty-four credits. She was taught by twenty instructors, including six I interviewed. She also participated in additional five zero credit courses, such as New Student Seminar, Active Writing Preparation, and Internship. Her overall GPA was 3.660.

Table 5: Courses Hannah took with interviewed instructors

Instructor/ Course	Course description *	Course assignments and type of evaluation (based on Hannah's, Ingrid's and instructors' reports)
<p>Math Instructor</p> <hr/> <p>Math in Action II: Elementary Algebra</p> <p>SPRING 2005 Grade: A- Credits: 3 (Remedial course) 6 hours (5 lecture, 1 lab)</p>	<p>This course provides a careful treatment of elementary algebra, beginning with the line/linear equation, ending with the parabola /quadratic equation, and emphasizing the interplay between geometric and algebraic representation. Topics include graphing, systems of linear equations, functional concepts, rules of exponents, polynomial algebra, factoring, rational expressions, complex fractions, radical expressions, and the quadratic formula. Applications to linear and quadratic modeling are featured. <i>(Admission to the course is based on placement test scores.)</i></p>	<p>In-class activities: Lectures Whole class discussions (e.g. solving math problems collectively) Out-of-class activities and assignments Online homework assignments Hannah individually practiced math problems Evaluation: Mid-term (math problems) Final exam (math problems)</p>
<p>Sociology Instructor</p> <hr/> <p>Introduction to Sociology: Contemporary Society</p> <p>SPRING 2005 Grade: B Credits: 3 3 hours</p>	<p>This course offers students information and ideas with which to understand the social factors of human life. It places the study of social interaction, social processes, and social institutions in an historical context. It examines the human condition with particular reference to work, to culture, to personality, to ethnic, class, and gender relations, as well as to economic and political institutions.</p>	<p>In-class activities: Whole class discussions Students group work - discussions and writing Watching films Out-of-class activities and assignments Readings Watching films that were shown in class Evaluation Mid-term take home paper Final take home paper</p>
<p>Communications Instructor</p> <hr/> <p>Oral Communication Fundamentals of Speech Communication</p> <p>FALL 2005 Grade: A Credit: 3 3 hours</p>	<p>This course is designed to introduce the student to a broad understanding of human communication behaviors. Students will learn basic principles and concepts of interpersonal communication, small group communication, and public speaking. Topics include: What is communication? What are the types of communication? How does communication affect our perceptions and self-concept? What are verbal and nonverbal communication? What is active listening? How do we prepare and organize an effective presentation?</p>	<p>In-class activities: Group work in class- discussions Whole class discussions Low stakes writing Out-of-class activities and assignments Textbook readings Preparing for presentations Homework – (check the syllabus) Evaluation: Regular Exams- multiple choice and essay questions Individual presentations: 1) Who am I: Bag project 2) Favorite topic presentation - Poster presentation - 3) Poetry presentation Final In-class exam -</p>

Instructor/ Course	Course description *	Course assignments and type of evaluation (based on Hannah's, Ingrid's and instructors' reports)
<p>English Instructor</p> <p>Composition I: An Introduction to Expository</p> <p>SPRING 2006 Grade: A Credit: 3 (this class was part of a Gothic cluster) 4 hours</p>	<p>In this course students focus on writing as a process to create correct and effective expository essays in response to culturally diverse sources. Emphasis is placed on using various methods of organization appropriate to the writer's specific writing context. Students use a variety of rhetorical strategies, research methods, and documentation procedures in their essays.</p>	<p>In-class activities: Group work in class- discussions Whole class discussions Graded writings Watching films Field trip/ visit art museum and writing a gothic story</p> <p>Out-of-class activities and assignments Readings</p> <p>Evaluation: Gothic story – take home paper Final paper - on one of the readings</p>
<p>The Research Paper</p> <p>SPRING 2006 Grade: A Credits: 2 (this class was part of a Gothic cluster) 2 hours – computer lab</p>	<p>This course gives students intensive instruction and practice in library research and writing a staged, formal essay. Students will learn how to choose an appropriate research topic, pose a research question, and outline, organize, and integrate source material into their essays without plagiarizing. They will find and evaluate both print and on-line sources and practice taking notes, summarizing, paraphrasing, quoting, using in-text citations, and creating a Works Cited.</p>	<p>In-class activities: Writing short pieces focused on practising writing in genre of research paper</p> <p>Out-of-class activities and assignments Readings overlapped with Composition class</p> <p>Evaluation: Final in-class essay exam</p>
<p>Anthropology Instructor</p> <p>Cultural anthropology</p> <p>FALL 2006 Grade: B Credit: 3 3 hours</p>	<p>This course examines the similarities and differences found in the various types of human cultures and societies. It acquaints students with the basic concepts that help explain differences and similarities. The role of culture and language in determining human behavior is examined as is the interrelationship of aspects of behavior (economics, politics, family, and religion) in different types of societies. Patterns of cultural change will also be discussed.</p>	<p>In-class activities: Group work in class- discussion Whole class discussions Watching films</p> <p>Out-of-class activities and assignments Readings Group project – power point presentation</p> <p>Evaluation: Mid-term: Group presentation Final paper- take-home paper based on a film</p>

Instructor/ Course	Course description *	Course assignments and type of evaluation (based on Hannah's, Ingrid's and instructors' reports)
Health Science Instructor Drugs & Behavior SPRING 2007 Grade: C+ Credits: 3	This course is an overview of drug abuse and addiction. It encompasses issues related to alcohol and drug dependency. A variety of methods is used to explore such issues as the psychosocial aspects of drug taking; the dynamics of dependence; pharmacology; medical and non-medical use of drugs; preventive measures and alter-natives. Students will have the opportunity to develop a fundamental philosophy and understanding which can be used in more advanced study.	In-class activities: Whole class discussions Evaluation: Two short (3-5 pages) take-home papers Mid-term – multiple choice exam Final – multiple choice exam Out-of-class activities and assignments Textbook Readings Going to AA meeting in order to write paper
Sociology Instructor Urban Sociology SPRING 2008 Grade: A Credits: 3 3 hours	This course examines changing ideas about the city and the changing impact of the city on American lifestyles. With reference to New York City, the course explores the origins and the social structure of the city. It focuses on the relationship of class to family, gender, education, ethnicity, religion, politics, and economics. Visits to housing projects, community organizations, or service delivery agencies will familiarize the students with the issues of planning and change in the city.	In-class activities: Whole class discussions Students group work - discussions and writing Watching films Out-of-class activities and assignments Readings Watching films that were shown in class with Ingrid at home Evaluation Mid-term take home paper Final take home paper

* *Courses descriptions (taken from 2008 MCC catalog) provided by departments, not by individual instructors.*

As previously discussed, Hannah developed relationships of different intensity and quality with each of the instructors. Hannah also received support of various type and extent for each course. As was already described (and documented in table 4, page 194), Ingrid's involvement with instructors and type of her support to Hannah in these courses varied too.

Ferri and her colleagues (Ferri, Connor, Solis, Valle, & Volpitta, 2005) observed that teachers diagnosed with LD when constructing a meaning of LD engaged in a dialogue with all the discourses available to them, regardless which one was the most significant to them. Indeed,

the instructors interviewed for this study also employed multiple tools available to them when interacting with Hannah. For instance, they all did engage with “authoritative discourse” (Ferri *et al*, 2005, p. 62) of the institution, if at least initially. How they interpreted and negotiated it, and whether they adopted, resisted, or rejected it in relating to and positioning of Hannah, was individual and depended on other resources (including discourses and practices) available to them and their personal involvement with Hannah.

For example, all of the instructors were presented with an already familiar institutional policy of locating disabled student in a marginalized position of Student With Disability. Such understanding of Hannah was potentially even more fortified when instructors relied on stereotypical cultural representations of autism, and as a result positioned Hannah as an impaired person and learner with compromised competency. This general attitude of the instructors, points out to the need of providing instructors (and other staff) with non-deficit framework of disability, which would in Biklen’s words “presume competency” (Biklen, 2005), and, using Vygotsky’s (1983) terminology, rely on “positive differential approach” to disability. If the instructors maintained a deficit view of Hannah, consequently and dialectically, their teaching and instructional support in relation to her became limited and disabled too. However, some of the instructors resisted such limited and static understanding of Hannah. Applying different and additional tools (e.g. their teaching practices and learning/teaching philosophy, dynamic understanding of disability), relying on Ingrid’s support and knowledge of Hannah, and most importantly on Hannah’s engagement in learning, all contributed to repositioning Hannah as fully capable of participating and contributing to learning community. Given the plethora of existing and constructed discourses and practices utilized by each of the participating instructors contributed to a different story that reflected unique trajectory of patterns of Hannah’s

positioning. Exploration of these trajectories reveals Hannah's identity and development as a dynamic, interrelated and transformative process, constructed and embedded in collaborative human activities.

Getting to know Hannah

For all of the interviewed instructors Hannah was their first student diagnosed with autism and for most of them the first person diagnosed with autism they ever encountered. Their initial reactions to Hannah and having her in class varied and was a result of number of factors, such as instructors' general attitude and understanding of "Students With Disabilities," their understanding of disability and autism, when, how and by whom Hannah's diagnosis was disclosed, and Hannah's initial participation in class. Hannah either introduced herself and handed a letter from the Office for Students with Disabilities (OSWD), or was introduced to an instructor by Ingrid in person or in a note. In a case of Drug and Behavior class, in addition that Hannah provided a letter from the OSWD to the instructor, her tutor and friend Rob met with him, explained his relationship with Hannah, clarified some of Hannah's needs as well as discussed course expectations with him.

Almost by default instructors expressed concerns about Hannah's competency and ability to participate in class. Anthropology instructor reacted with uneasiness to Hannah's participation in his class even before meeting her. Others were taken by surprise by Hannah's unique and nonconforming behavior, for instance asking the questions Hannah was expected to know the answer if paying attention in class (Sociology instructor), or speaking loud and bursting into a laugh in class (Math instructor).

Sociology Instructor on meeting Hannah:

She was introduced by her companion who sat through the whole course. Hannah was introduced as a high functioning autistic. Originally, I was concerned because after the first sessions she asked fundamental questions that one should know the answers if you sat in class. But Ingrid assured me she was able to work quite successfully.

Ingrid's explanation and reassurance about Hannah and her abilities usually reduced instructors' anxiety. It appears that when Ingrid met with instructors in person, openly disclosed her diagnosis, and assured them that Hannah would be fine, was capable and diligent student, and they would like having her in their class, was the best way to introduce Hannah and transition her participation in class. Importantly, Ingrid's initial reassurance about Hannah's competency, and her presence and involvement, especially at the beginning of the course, not only allowed instructors to learn about Hannah and her needs, but also provided necessary support to the instructors as they learned to interact with Hannah and understand her. The following excerpt with Communication instructor illustrates this point. She talked about the first in-class assignment, a brief, introductory survey students responded to:

Communication Instructor: This was telling for me, her sentences, in staccato almost, very factual, and very not college like, not what I expect of adult. So when I first saw that, I was not sure about her because I knew she was not a second language speaker, so this kind of simplicity...but then Ingrid, wonderful Ingrid spoke to me and then I had a little bit more background at least for my observation.

Researcher: *When did you meet Ingrid?*

Communication Instructor: I 'm trying to remember and I'm not sure if it was the first day of classes or before, so it might have been the first day of classes, just waited for me, and introduced herself. She was very much in a role of helping to make that transition so that people would have that background information about Hannah. It was very helpful because I would not have understood so much.

What I believe some of the interviewed instructors described (and Hannah and Ingrid reported about other instructors who did not participate in this study), the initial concerns that instructors held and expressed represented their own fear of disability and, inadequate, fragmented knowledge and understanding of autism, predominantly based on cultural

representations of autism they anecdotally encountered in media. Fleischer (2005, as cited in Tyler, 2010, p. 8) argues, that it is this unacknowledged fear of disability that “ultimately engenders the hostility and bigotry that are the real barriers to equality for people with disabilities.” Gradually, the actual contact and interaction with Hannah, often mediated by Ingrid, and experiencing Hannah actively engaged in class, enabled instructors to focus on Hannah as a person and learner, rather than on the label of autism or disability. Once they got to know Hannah, their fear of disability and autism, their worries and uneasiness usually dissolved.

In addition and importantly, some instructors were anxious about their own competency to provide instructions and other support to Hannah. Anthropology instructor described and explained the reasons behind his concerns as he told me about how he met Hannah:

Well, I would like to start with saying that I was very upset that they would put a student in my class who was autistic, in a six weeks class, which is a very intense class. We are doing a double amount of work, in a course that is already difficult. You are doing a double amount of work in half the time, you know so it is a big challenge, and I was very upset. I thought that they should have consulted me first and ask my permission, you know, and then I would have said no, but I don't think it was fair to her, right. I wanted to let you know, I didn't show her that, I didn't tell them anything, but personally I was upset. I said that makes no sense, if you have somebody like this you want a twelve weeks course, you know, where they can gradually, not something so intense, all right. Having said, that later on I changed my point of view because two things, because I was assured by her guardian that she was only taking one course, all right, and that allowed her to focus on one thing, and that she was putting a lot of work into the class, you know, that made me feel a little better, you know, cause most of the students take two courses, you know and it is very difficult for them, that she took one and she was able to focus I was happy to hear that. Secondly, I have impression that her guardian worked with her a lot on her projects and so on, she attended the class, and we had meetings afterwards and I could clarify certain things, so I thought that the presence of the guardian was extremely helpful to me. The third thing I want to say is that I think Hannah was very fortunate, I don't know about other classes but I think she was very fortunate in this class, there was a group of students, older students, who appeared to be very maternal in their response to her, they took her, I don't want to say as a child but, under their wings, and they were very tolerant, they were very patient, they understood that, they learned how to adapt to her.

He clearly expressed uneasiness with Hannah's participation in his class as an "autistic student," but simultaneously he was concerned about his own role as an instructor and recognized Ingrid's and other students' roles in supporting Hannah *and* him.

Research conducted with college instructors suggests that it is not uncommon that instructors express initial confusions about "how to approach a disabled student on personal, curricular, and instructional level" (Cook, Rumrill, Becket-Camarata, Mitchell, Newman, Sebaly, Steuernagel, Cook, & Hennessey, 2006, p. 71).

The fact that some instructors openly expressed their hesitation about Hannah's abilities as a student to Ingrid, proved to be more constructive solution than hiding their biases and avoiding discussing it. Although somewhat uncomfortable situation, the fact that they engaged in openly discussing Hannah's participation, which in some occasions included Hannah, seemed to create an opportunity to reconsider instructors' understanding of Hannah, and focus on promoting her learning and their competency as teachers. Openly addressing the issue provided foundation for collaborative support of Hannah and instructors.

Almost all instructors, except the one from Drugs and Behavior class, mentioned that they independently researched about autism as they felt it could help them understand Hannah. Research conducted with faculty members suggest that in general they feel that it is important to access information about different types of disabilities, however they feel their institution does not provide sufficient disability-specific information (Houck, Assellin, Troutman, & Arrington, 1992; Cook, Rumrill & Tankersley, 2009), which proved to be the case in this study too. Anthropology, Math and Sociology instructors felt particularly unsupported by the institution, specifically by the OSWD, in teaching and supporting Hannah. In general, these instructors referred to the OSWD letter as meaningless and pointless, besides labeling Hannah. For instance,

Sociology instructor called for not only disability specific information, but also for possible suggestions for teaching strategies including evaluation:

Disability office simply sends a general letter that does not say anything except provide more time for exam if needed, nothing specific, with no identification of disability, no specific information, no support. I would find useful if they send feedback on very specific questions, for example on cognition. Should I know anything specific on specific intervention, instruction critical feedback, evaluation? They could provide some fact sheet, some specific information on condition and specific instructions.

Anthropology instructor lamented about lack of information provided by the OSWD not only in the case of Hannah, but in regard to all disabled students:

Researcher: *Do you wish you would have more information from the beginning?*

Anthropology Instructor: *Yes, definitely. Not only from Ingrid, but also from the department, what you call it again?*

Researcher: *Office of Students with Disabilities.*

Anthropology Instructor: *They should have sent information also to me about autism and you know even if it is just superficial. I had some other students, with hearing issues, they told me what to do, and I know the general thing, but the little.*

Math instructor's claimed that inadequate support of OSWD was even more amplified when compared to support he felt he obtained from Ingrid:

When Ingrid talked to me, and that is something that probably is not from the law that is protecting people with learning disability, because they are sent to our classrooms with a letter that is the same for everybody: this is a student from this program and this is bla bla bla bla. There is no difference in the letter, so you never know what is the condition of the student, there is confidentiality... Whatever I learned about Hannah is because of Ingrid, and let me tell you that made a WHOLE difference in my relationship with Hannah. Is not that I would have been different, it was, it was easier for me to relate to her knowing the condition... I am glad that Ingrid was there, because in the absence of Ingrid I would have been just working based on my own intuition.

Ingrid's involvement and contribution to facilitating learning activity was undeniably recognized and appreciated by all the instructors she met with. For the instructors who felt unsupported by the OSWD, Ingrid clearly substituted the role of the OSWD.

English instructor was the only one who felt supported by the OSWD adequately, particularly by the OSWD director with whom she seemed to have a good relationship, as she mentioned repeatedly during the interview and described here:

The Center for Disabilities, they tutor, they are specially equipped to do so, and they also give [students] extra time on exam and just structural reminders. And what I like about [the director], he is an advocate for you and for students, so if I say “I am a bit concerned about how I am helping her,” and he’ll say “don’t do that, she has to learn to do it,” you know so I like that he sets up the boundaries because that’s one thing that I am a little bit confused, how much I should be helping.

The English instructor did not mention any information, specific accommodation, or support that would be provided to Hannah or to her in addition to what other instructors listed. The only difference seems to be her personal relationship with the director. However, she felt the OSWD support was more than sufficient. The Communication instructor who also frequently discussed student’s needs with the OSW director provided probably the most realistic picture of the situation:

I know a director, as an individual and a leader, you know, I am so happy that place exist. It is obviously up to the student, trying to negotiate their own rights and [OSWD director] supports that, he also supports faculty, but as always too few resources, too few people working there, for volumes of students working, and it also helps to maybe talking more, at the beginning of the semester we get the rosters and the letter from OSWD are handed by students, and sometime is done the 1st day sometimes later, so maybe for an instructor some notice that particular student with particular need would be useful because I find myself scrabbling, because sometimes is about making syllabus larger to read if they have visual issues, or sometimes the student who is deaf is scrabbling to get interpreter, so all these things should be in place and lots of times they are not. So when an instructor feels negative, sometimes it is not about issue, you know the student and their needs, but about the services around that and I know as much can be done as given resources, they should be priorities.

In overall, the instructors’ and OSWD director’s reports indicate that for various reasons communication between instructors and the OSWD is more an exception rather than a regular practice, although such unofficial negotiations seem to be the most effective practice that leads to supporting instructors and students. In general, the instructors feel that they would benefit from

more significant support from the OSWD and the institution in general. Despite the official objective of the OSWD to support students *and* faculty, in reality the office predominantly operates as an administrative body managing students registered with the Office. The MCC is known for the intensive and ongoing professional development available to the faculty, however not on the issues of disability, whether on instructing disabled students or incorporating disability in curriculum. Despite the fact that diversity is heavily emphasized as an important topic in the college, disability is strikingly missing from the agenda. In addition, most of the interviewed faculty members were tenured senior instructors, holding positions of full professors. Frequently, other than their own personal initiative and interest as educators, there is no other incentive for reflecting on and investing in improving their teaching practices and pedagogy. Teaching practices and instructors' understanding of their own role in students' learning varied greatly among the interviewed instructors, as will be illustrated in the following sketches of interactions and patterns of positioning of Hannah by individual instructors.

Drugs and Behavior Instructor

Although he was a pleasant, patient and a courteous interviewee, his answers were mostly brief, carefully articulated, and I felt that he was trying to come up with socially desirable answers. His polite, but somewhat reserved manner of responding, was also present in his descriptions of Hannah. He claimed that it "was very nice to have her," he enjoyed her presence in class, and appreciated her spare but memorable interactions with him before the class, which he found quite entertaining:

Oh, I think it was a joy teaching her. I mean, she was actively involved in class, you could tell she was paying attention, which I wish I could say more about some, and just a way of speaking, very clear, and again that... "Good morning [full name]," that kind of thing, but she was a delight to teach.

He admitted that his teaching is not very participatory and does not “do that much sort of group work per se,” except that students have an opportunity to ask questions about material covered in previous class at the beginning of each class, and that Hannah took advantage of that opportunity regularly, which he appreciated:

I usually ask if anybody had any questions, comments or asking for clarification, and most people don't, and I think she had probably more than most, which is good, that's why I say it. I want people to say "I don't understand this, or what about that?" and she would usually had something to say, which again, it was on point, it was not tangential. And my guess is, there were more people who were wondering about it, but didn't say anything and she would just say it, which was good, and I think in some ways she was a good model for anybody else because she would say something, and I would interact with her, and I was hoping that it would catch with all the other people.

It appears that Hannah, because of her most intensive participation, was the student he knew the best from the class. He considered her as a model student for her active participation. The Drugs and Behavior instructor remembered her as a “quite good student, who did well,” he recognized and appreciated “her ability to concentrate, and her focus, and not being afraid to ask questions.” For the instructor, Hannah stood out among other students in a positive way:

Well, I think she was different that she paid more attention. Grade wise she is probably in the middle, a lot of people don't do well on the first test, but I think she probably did well just as anybody, maybe a little better.

However, according to him, Hannah faced challenge of articulating her ideas into written text. At least, that was his initial explanation why Hannah did not do well on his tests:

I think it might have been a problem with what she verbally understood, and talked about and then translating it into a text. So I think she probably knew more that what the test revealed. Mhm, I think if I had given her a verbal test, that she would do a lot better, mhm because she knew the concepts, and she knew certain facts that I've heard her say but when it came to the test, some people had problem with test, and I think that might have been her case, so maybe a different testing method might have been beneficial for her.

However, as the above excerpt illustrates, he at least entertained the possibility that the “problem” might not have been located in Hannah, rather in his testing method, admitting that

other students usually struggle with test too. At the time I interviewed him I already knew about some of Hannah's experiences in this class, including the fact that she received only C+, despite studying very hard for the course with her tutor Rob. Therefore, I was surprised to hear from professor how highly he talked about her, he experienced her very positively, as a good student, as he put it, as one "above average". In general, he referred to her as an active and capable learner. I was trying to understand this contradiction and the source of discrepancy between Hannah's reported performance in class and her grade. Eventually, I directly asked the instructor why Hannah did not receive better grade if he observed her as a good student, model to others, and he seemed to be quite confident about her knowledge and mastery of the course material:

Researcher: When you mentioned that in general, that she did well and even was a little bit above average, what would you say were her difficulties? Basically, why she didn't get an A? What was the difference between an A and her performance?

Drugs and Behavior instructor: Well, on the paper she did well, I think I gave her A, now the testing, you know, knowing it mentally and then putting it then on the paper, I think there might have been a little bit disconnect, but I think that is a problem for a lot of people. Because I know, there were certain things that she knew that we talked about but she missed on a test, it might have been wording of the test, I mean I am trying to pick up something [by test], as a test was essentially a multiple choice and true or false, and she might have had problem with that, and essay test might have been better, cause she can think more and use her own words rather than try to pick something up, mhm... but I am sure she knew more than what the test indicate, so again you might want to figure out different testing methods you know whatever that might be, breaking things down more, you know, because it was a lot of material, both midterm and final, and both had a lot of material she had to go through, it might have been breaking it down into a smaller chunks, might have helped.

Strikingly, the instructor was fully aware of students' difficulties of applying what they learned in class to his evaluation method – a multiple-choice test. As he talked, he shifted from what he saw as Hannah's internal and individual problem of relating abstract knowledge to his method of evaluation, to a more contextual understanding of the source of her difficulties, specifically his evaluation tool. He acknowledged that if she has had an opportunity to be

evaluated differently, she indeed might have obtained better results, that would correspond with her actual knowledge.

It was not clear, and I did not further interrogate, if he only reflected on the issue during the interview and realized it on a spot, or he was aware of Hannah's challenges and simply neglected an opportunity to accommodate her (*and* other students) in order to evaluate her fairly, or adjust her grade so it would reflect her actual knowledge. A multiple-choice test, his evaluation tool, seemed to disable all students, not only Hannah. Based on his other comments, he seemed to maintain an individualistic and mainly deficit view of community college students in general. This was also clear when I inquired about performance of other students:

Researcher: *But you are saying that she is not the only one who might have that kind of problem.*

Drugs and Behavior instructor: *Not the only one, I think, and some of the students here, they have a lot of deficiencies, you know whether that was in high school or further, there are behind academically, basically they are trying to play catch up, and that can be very difficult.*

In the context of the whole interview, the Drugs and Behavior instructor did not come across as particularly invested in his students' learning or engaging in critical reflections of his own pedagogy and teaching practices. Rather than taking an active role and responsibility in students' learning, he seemed to rely on a traditional model of teaching as transmission of knowledge, and blame students' individual "deficits" for challenges the students in his class faced.

Math Instructor

Math instructor quickly developed a friendly and warm relationship with Hannah and Ingrid, as was also described by Ingrid. He expressed his respect and admiration for Ingrid for her dedication and unconditional love for Hannah, and practically positioned Ingrid as her savior. He

also spoke very highly of Hannah as a math student, as “far best in a class,” and appreciated her motivation to learn:

Her interaction with me was a kind of interaction that I would like all students to have with me, it was based on respect, it was based on an incredible desire for learning which is something that you see rarely, she was a marvelous student. A marvelous student! Always trying to learn more, always doing her homework, this is a [student] who does not need to be told to do homework, she is going to do it because she wants to learn, but as I said, whatever conclusion we might get here, we have to [understand] and this is my opinion, through the existence of that angelic Ingrid. ... I honestly do not know where Hannah would be without that angel, because to me Ingrid is an angel.

He was shifting Hannah’s positions, from an excellent, exceptionally motivated and goal – oriented student, embodying his notion of an ideal student, to Hannah being completely dependent on Ingrid and denying her agency. Autism was understood as a disease, as a direct cause of any disablement Hannah might have experienced, and could easily be expressed in mathematical equation:

So making a subtraction of the case that you are dealing with the person with autism, she was a marvelous student and real pleasure to be with.

From his accounts of Hannah it was also apparent that to him she practically embodied the otherness:

I'd say that Hannah autistic condition is really strong, I have seen other people who are autistic and probably Hannah is one of the most who shows off signs more strong way than in other people, those aspects were reflected in class, in the email, in interactions with other students. I did not know that she was autistic when a class started so I was not prepared for the first time when she intervened. She intervened in class screaming, raising her voice, so everybody was like what's going on here, so immediately I understood that she was a special kind of student not like any other.... There was no interaction, I don't remember she interacted with anybody.

Hannah was to him what Ferri and her colleagues (Ferri *et al*, 2005) call “exotic spectacle of otherness,” whether understood in terms of deficit (for instance being socially isolated and emotionally detached), or abnormal, almost inhuman characteristics, including her ability to focus and learn:

Hannah never shows any emotions. It was like her feelings were totally disassociated with what was happening in the classroom and there was only one thing on her mind- to learn....She is highly analytical, and probably that is one of the reasons why she likes to work in mathematics, because [she] has time to think about the things, she [doesn't] spend time like all the other students thinking about other things. When she is in class she is really focused on what she is doing. Why is that? I don't know, but these are people who can concentrate on something for a long time. The classes that were two hours, and she was there for two hours doing just that, very, very strange in normal people.

Perhaps well-intentioned and impressed by Hannah's dedication and focus, however, armed with stereotypical views of autism and a deficit and individualistic view of disability, Math instructor was caught in understanding Hannah as a socially impaired and isolated person. He believed that being socially disconnected actually allowed Hannah to excel in math. He seemed to genuinely like her and even admire her, as the best student in class who could fulfill his expectations of a good student, working hard, and practicing math problems meticulously, because as he put it "she totally understood something that I hope all the student understand, that there is no mathematics without working hard, you need to practice, and she was practicing".

Perhaps the most striking was his understating of learning and teaching as isolated and detached processes, reoccurring theme in his narrative, evident in his response to my question whether he would make any changes in his teaching based on the experience with Hannah:

Mhm, ... no..., no, no, because Hannah reinforces my belief that the only thing you need to learn is to work hard, and that is what she did. She was working hard, overcoming all the problems her condition could impose on her.

Instructor's positioning of Hannah is best revealed as a dialectical relationship, when exploring his own positioning within learning activity and his role in Hannah and other students' learning. Interestingly, throughout the whole interview instructor's role in teaching Hannah was not spelled out and was clearly absent. Students are understood responsible for their learning, understood as mostly reproducing lectured material, learning math as a set of skills through

memorization and repetition, rather than system of cultural practices that entail conceptual development.

Math instructor recognized, admired, and even loved Hannah for her “otherness,” her exceptional diligence and working “against the odds of her predicament,” that according to him, she overcame thanks to Ingrid’s love. However, as a learner she was denied of agency and ability not only to *contribute* to collective learning, but even as being able to *participate* in learning as a collaborative practice:

Researcher: *Do you think she contributed to class?*

Math Instructor: *No she didn't contribute... well, her contribution to the class was passive contribution by example, unfortunately the students didn't take the example, ...because... her contribution was not in sense she came to board and explain the problem, or to explain a problem to other students, which is normally what I try to create in the classroom, there is no way of collaborative learning, she can not participate in collaborative learning. But I would say that she set a higher standards for herself and I would LOVE the other students to take the cue from that, but they didn't.*

The Drug and Behavior instructor expressed identical disappointment over students’ not “catching on” Hannah’s practice of participating in class and asking questions. Both instructors seemed to expect that students’ participation and learning has to be initiated by students and will happen somehow spontaneously, without acknowledging instructor’s own role in facilitating the process. Although Math instructor saw Hannah as capable of learning, this was understood in very individualistic terms, and experience with Hannah seemed to reassure this notion. The lesson Match instructor took from the experience of teaching Hannah was that one can learn, and even “overcome” her own deficit, if one only works hard enough. Such individualistic and meritocratic view of learning certainly does not leave much room for an active role of the teacher in student’s learning.

English Instructor

English Instructor met Hannah in a Gothic cluster that besides two English classes (Composition and Research Paper class that met in a computer lab) included also a theatre class taught by another faculty. English Instructor appeared as a dedicated and committed teacher who did not hesitate to work intensively with Hannah in classes, especially in Research lab, where she provided individual attention to Hannah. She also met regularly with Hannah and Ingrid outside of the class to discuss readings, assignments or clarify any necessary issues. They developed a routine where instructor would write assignments and other comments, including notes to Ingrid, to Hannah's notebook after every class to make sure Hannah would not miss anything. As all other faculty, the English instructor also liked Hannah, enjoyed her presence in class, and appreciated her diligence and motivation as a student:

As far of her participation in class she seem to enjoy participating, she ALWAYS did the work, she was ahead in the reading, she loved to read, in that course we read Frenkestein, Dracula, and several other things, sort of modern, and yeah, she seemed to enjoyed the readings. ... She had great motivation, yeah. She was the best reader in the class, she always did the work, she was right on point all the time, she was never late, you know she was never absent, she was never unprepared... I think she was pretty much an A student, I know that her final paper was quite good. Yeah, I am pretty sure she got As and everything. I don't think that was a problem at all.

Although instructor saw her as a committed, an A student, she mostly described her as emotionally and cognitively limited, and dependent on her support:

She was different in that she, she really did not connect with other students, she had very little affect, her tone was kind of a monotone, her voice was loud, she just looked straight ahead she focused on exactly what was going on, she did not tent to ask questions, except very factual questions about something, so again as I said in other context she was not very analytic... she had some of the features of that kind of linear, rigid way of being in a class. She needed step-by-step guidance on each of the projects that we did, she wanted very clear instructions.

In English classes in laboratory time and computer lab time students can write, and I remember that in Hannah's case, she is very good in completing assignments if she know exactly what to do, but she required o LOT of structure and guidance. ... When student is

doing a college level writing we expect that we can remove some of the scaffolding, meaning, do this in paragraph one, this in paragraph two, we expect that students can create a thesis, and can decide how to take charge of the essays, and have their voice, etc., and Hannah had really some limitations in that area so that she would execute a paragraph and we would discuss what that paragraph would be about, I would say this is an introduction and this is what you are going to do, and you have to have a thesis what you going to try to show, and that has to go throughout the whole essay so she would complete that paragraph and then she would come back to me and say ‘what do I do now?’ And she would need me to tell her exactly what to do next, so... from the point of view of working with a someone with high functioning autism, that was kind of you know, I felt a little bit on a fence about how much I should be guiding her.

She was very good in terms of factual learning, but I could not perceive that she was really going into any kind of depth, analytically, synthetically, comparing, doing those higher order thinking skills, mhm, emotionally ...she simply was not connected visibly even to things that had an emotional content and did relate to her.

Throughout the interview the English Instructor presented a well-constructed narrative about Hannah, full of many examples and detailed explanations of her deficits and limitations, openly attributing them to autism. I asked the instructor how she experienced other students and if she observed that they would struggle with similar issues as Hannah seemed to:

Researcher: When talking about Hannah’s difficulties in analytical thinking, synthesizing, etc. How do you see her in comparison to other students, is she unique in those difficulties, do you see any of that also in other students?

English Instructor: I do, for instance I can think of the student right now who’s been in my class for a couple of semesters, she is an older student, meaning she is a parent, she has kids, she is probably in her early 50s. I’ve had to work for two semesters to get her off the plot summary. The idea of analyzing a text is hard for her, so yes, I would say yes, I definitely sometimes see students, who have a lot of trouble getting away from a literal reading of something. I don’t know whether that’s a cognitive thing, or it also has to do with like a returning student who’s been out of school for a long time and just hadn’t had practice doing a certain kind of things. But it is a different than kind of student who might have cognitive limitations.

She further elaborated her point, about the difference between a disabled student with a fixed “cognitive limitation,” referring to Hannah, and “other” students. She told me about a science student from her class, who was not open to, and as she said, even “hostile” to carry out an emotional analysis of the text, yet became quite emotional in class as a

result of disclosing and dealing with some personal issues. Based on such emotional manifestation of the student, the instructor compared student's situation to that of Hannah:

It's funny you know what kinds of wall students put up, but there is a difference between a putting a wall up, and having a wall there, right, and not being able to pass it.

By "having a wall there" and "not being able to pass it," unmistakably, Hannah was positioned as a student limited by a constant cognitive impairment, impermeable to any change, including her intensive instructions. English instructor was evidently convinced that any challenges Hannah faced were the result of autism, which translated into being cognitively limited. The English instructor provided a very thorough explanation and systematic evidence for such understanding of Hannah. However, her persuasive narrative had some gaps, which she was not able to explain. Specifically, she mentioned that for a midterm paper she assigned students to write a creative Gothic story based on paintings that class saw in the art museum. (I remember Ingrid telling me about the assignment and how Hannah "sat in her room by herself and just wrote a really creative story.") The instructor recalled:

There was an exhibit of Edward Munch at the [art museum], so there were all these Dracula pictures, all these you know moody things like the Scream, so we took the class to see all of these pictures and I asked the class to write, to pick some pictures that they liked, either photograph them or buy a little postcard.... so I had them write a creative story, you know sort of ghostly story using the pictures... I was not quite sure what Hannah would do with that. I really could not have predicted that she would had enjoyed it but she loved it, she enjoyed it tremendously and it seemed to free her up. She understood that she didn't need kind of ask what she need to do next she could just do what she wanted, and Ingrid commented on that she never saw Hannah do something like that, and it was really quite interesting, you know a lot of detail and blood, and crazy things happening, so that was a little bit of surprise to me.

The instructors held a very static notion of intellectual disability, and consequently very fixed view of Hannah as a learner. Although she practically admitted that Hannah was capable of original and independent literary work, she maintained her view of Hannah as a limited learner. The instructor did not recognize that what might be disabling and limiting Hannah could be the

instructions, the very organization of learning activity, lack of opportunities for Hannah's active and creative engagement, or her very own positioning of Hannah as a limited and cognitively impaired learner. Whenever the instructor arrived to some instance of Hannah's ability in her narrative, she was not able to explain it and fit it into her deficit discourse of Hannah. She did not question or attempted to rework her deficit view and recognize Hannah's potential for development.

Anthropology Instructor

When Anthropology instructor learned about my research project he was eager to meet with me so he "could learn more about Hannah". He was very open and provided a candid interview. He repeatedly questioned his competency in providing adequate instructional support to Hannah. Anthropology instructor acknowledged his concerns about being "not prepared" to teach Hannah after he learned she would be in his class and not knowing anything about autism:

I didn't know anything about autistic student, I have not a clue, and I didn't know anything about autism, I've seen some movies about autistic children, but you know you just see a movie, but understand the characteristics of autistic students and how to respond I was completely ignorant. So I had create my ...and eventually I began to understand how she operated, her pattern of thinking and the kinds of questions she would ask and how she would take something and ask about it, so then I was able to adapt to that.

Despite the fact that he could only rely on his fragmented knowledge about autism, mostly based on popular cultural representations of mainstream discourse of autism, he felt supported by Ingrid and Hannah's classmates who he saw helped Hannah integrate in class and provided her with support. He made an effort to adapt and change his practices to accommodate Hannah's interaction and participation in class. According to him, Hannah actively sought out support from a classmate, and gradually developed a relationship with a group of female students who provided ongoing support to Hannah:

We didn't have group work in class, we had a group work outside of class, but in class at the begging she tried to negotiate with one of the students to take notes for her, and then he dropped the class, that was a disappointment, but then these women took his place. So any time she didn't know what was going on, they explained to her, they would write to her, so in that sense there was a constant interaction with her group, meaning a group around her. There was also a formal group that created a project and she worked with them, outside of class. So I think that in class she had constant support from the group, outside she worked formally with that group.

Although the instructor admits that his teaching itself did not lend itself for many opportunities for students to interact within the class, he observed that Hannah was integrated into class, formed relationships with other students, and evidently enjoyed and benefited from interacting with other students. I had an opportunity to meet the group of students with whom Hannah collaborated on a group presentation when they were finalizing their power point slides and Hannah rehearsed her part with me. I remember I was quite impressed with Hannah's colleagues, as they evidently liked her, were supportive of her, yet were able to interact with her as an equal member of the group without any patronizing or sense of sentiment.

The Anthropology instructor praised Hannah with regards to her commitment, participation in class and quality of submitted assignments:

So in terms of her performance, written performance was high standard, her participation in class, she was always very alert, asking questions, and got along quite well with the other students, I think she was pretty successful... Her strength I think were amazing, her ability to concentrate, her incredible memory and concentration, and her ability to discipline herself and commit herself to a task, she was never late with her project and so on.

He also appreciated Hannah's active presence in class, her contributions to class discussions and promoting students' participation in general. He saw in Hannah an example of extraordinary motivation and intellect with which she challenged others to become more responsible students:

I always think that students who do their work on time, students who are well prepared, who can answer questions and so on, they give the class certain quality, they rise the level of the class, so there is a critical mass of students that you need, to be doing the work, to be writing, to be asking a questions, and I think Hannah was among that group, so in that sense I think she helped to keep the learning ethos up to a certain level, I think that was her

contribution, keeping up the intellectual level of the class, and in challenging people to be more responsible and not take things for granted, I think she was very helpful.

In addition to Hannah being appreciated by the instructor for doing her class assignments well, he saw her as actively contributing to “learning ethos” of the class, motivating other students and consequently empowering him as a teacher. Yet, his view of Hannah, as an active and contributing student was contradicting his doubting of her independence and ability to produce high quality work on her own. To a great extent he attributed her performance to Ingrid’s supervision and support of which he became aware after meeting Ingrid:

I think that the fact that she had a guardian who was constantly working with her on her project was unique. Most students never had that. I don’t want to make a judgment, but I think that the quality of the work that she produced was due and large part to the fact that the guardian was there and explained and insisted that she produced, you know, not something sloppy... I think in terms of comparison with other students is difficult because they don’t have that, you see. Very often, they will get sloppy, very often it is superficial, and because they don’t have someone who can point out to them and tell them you can do more. I think her guardian did a lot with her, you know.

As it was already shown, Anthropology instructor was not the only one who questioned Hannah’s performance and understood agency in a relatively narrow individualistic way as being independent. The most probably, Hannah indeed received more support than most of the students. However, the support she received was also easily traceable to one source, to Ingrid, whereas the support of most of the students is usually more distributed and not so publicized. Anthropology instructor’s teaching practices and the organization of classroom activities did not allow him to engage Hannah in learning in a way he could experience her as an independent learner. Furthermore, despite commonly conceptualizing learning and mind as collaborative and *interdependent* activities, evaluation of students’ learning relies heavily on students’ independence, including evaluation activities being stripped of tools commonly available in everyday activities, the points well elaborated in Vygotsky’s concept of ZPD.

Sociology Instructor

Upon meeting Sociology instructor, it became clear that, in contrast to some other instructors (e.g. Math and Drug & Behavior), he positioned himself as an active participant in students' learning. Sociology instructor knew Hannah quite well as he had a unique opportunity to see how she grew as a college student within the span of her studies. She took her very first college course with him (Introduction to Sociology) and more advanced Urban Sociology class, almost at the end of her studies. Instructor compared Hannah at these two points of her studies: "In the first class, I did not know how much she did by herself, but in the second class Hannah was really independent." Without a hesitation he described Hannah as an active and agentic student:

She was very active in both classes, extremely attentive, always well prepared, she took notes, what I always encourage students to do, responded to my questions. My teaching is very participatory, it is engraved in participation, and I found that her comments reflected genuine ideas, she really brought her knowledge from outside, was able to apply the concepts we covered, and bring the examples. ...Hannah is very intelligent, extremely, and thoughtful. She is able to make connections, with abstractions, conceptualizations. She would make comments to our discussion on general topic. She was able to provide very concrete examples, for instance on sexuality that were to the point, on double standards of women on men. She often expressed her ability to connect general with abstract in class discussion, as she did in papers that were written at home.

The way his teaching was organized allowed him to experience Hannah as an actively engaged student. With confidence, he positioned Hannah as independent and contributing to collaborative learning, being able to apply the concepts covered in class, and relate them to specific examples. He understood Hannah as any other student with unlimited potential of development:

For Hannah there was no barrier to learning, infinite capacity to learn, no barrier to intellectual development, she is capable as any other student, as a very bright student. She was very successful in both classes I think she felt that way [too] because she took the second class [with me].

As he described at the beginning, at first Hannah was perceived as visibly different. The otherness perceived by instructor and students dissolved as they collaboratively participated in class activities. As other instructors, Sociology instructor was not familiar with autism and in the effort of trying to understand Hannah he researched the topic. As he recalls, what he learned through this informal research motivated him to adjust his own behavior and teaching practices:

I had to make some adjustment myself, had to do research [on autism], I learned about behavioral manifestations, for instance about repetition, that question was asked over and over, I understood why and replied with patience, she just needed repetition. By “normalizing” [this process] for myself and others, other students “normalized” their relationship with her and became quite fond of her, they did not really interact with her before and after class, but I think through my interaction with her they “normalized” their relationship with her and had warmer acceptance of her.

Sociology instructor made an effort to understand Hannah’s difference that could easily left her in a position of “other.” He adjusted his practices and introduced way of interacting with Hannah that became a “norm” in class and was adapted by other students, as he said he “normalized” his interactions instead of simply expecting Hannah conform to mainstream forms of participation in class. Through the small adjustments of mostly his practices, Hannah was repositioned from “strange” to “one of the students on class.” However, he felt he did not have to sacrifice his expectations or dilute the course content in order for Hannah to participate and succeed:

As for the course content, there are two levels or dimensions of preparation for writing in my classes and teaching: 1) reading and comprehension, and 2) speaking and articulating. They are connected to writing, conceptual thinking, taking sociological concepts and applying them. She could do as well as any other students. I did not reduce expectations for her at all.

In overall, sociology instructor positioned Hannah as a capable, agentic and ever developing student, equally contributing to class community of learners in class. Importantly, making adjustments, developing new forms of engagement, enabling and promoting Hannah’s

interaction facilitated not only Hannah's learning and contributions to class, but also of other students and his own:

Her diligence was exemplary, when you get a number of diligent students, then you can have a successful class. Her comment in participation in class often started and supported further discussion. [This experience] helped me to be more patient, helped me to understand tremendous range of abilities and behaviors and to be patient with students, that one cannot take anything for granted. I also learned that I had to make adjustments, not just her. I would always encourage instructors never be shy, or inhibited asking questions of any kind, whether substantive, methodological, mundane, because the questions are the bridge between the class and the individual [student], any information from student is useful. I would also emphasize the support that Ingrid provided to me and to Hannah.

For the Sociology instructor the experience of teaching Hannah turned out to be an opportunity to reflect on learning and teaching as truly transformative, collaborative and distributed processes to which all participants can contribute equally, regardless their diversity.

Communications Instructor

From my very first interaction with a Communications instructor when contacting her and inquiring about her possible participation in the research project, throughout the whole interview she proved to be a dedicated, committed and caring instructor, just as she was described by Hannah and Ingrid. Without being asked, she prepared for the interview, and presented me with her syllabi, course assignments and other materials, including her notes about Hannah's grades. One of the indicators of her commitment and interest in sharing her experiences with Hannah was the fact that our interview, originally planned for one hour, was extended to over three hours conversation. Before jumping to talk about Hannah, she explained her teaching philosophy and practices to me, including the course objectives and assignments and provided me with detailed understanding of the context of the course and class. Her understanding of learning and teaching as dialectical processes, and her dialogical and relational positioning of Hannah were the running

themes of her narrative. Importantly, she shared her experiences of teaching and interacting with Hannah as describing a process of her own development and growth as a teacher, reflecting on her practices, continuously reconsidering and adjusting them.

Communication instructor explained that while the course is heavily driven by theory, she made an effort to create learning environment where students would have opportunities to connect and apply theoretical concepts in several home assignments as well as class activities, carried out by students individually, in dyads, small groups, or as a whole class.

Although the instructor never worked with a students diagnosed as autistic, she felt that her background in speech pathology might have been helpful in understanding Hannah's and others students' diverse abilities.

She explained in detail Hannah's performance as it was materialized in her grades, reflecting Hannah's growth and earning increasingly higher grades, not missing a single assignment, commenting that "in the oral presentations she was just wonderful, she was really wonderful."

The instructor described that Hannah developed closer relationship with two classmates; Martin, who Hannah herself talked quite fondly of and did developed a friendship outside of the class, and as an instructor noted was "very much a wonderer, he was very open, very Californian I would say, and I think he and Hannah developed friendship. He was very tuned into helping her, and supporting her." She also befriended a female student, also called Hannah, as described by an instructor:

She was a tough little cookie, but she also took Hannah under her wings and she watched out for her. And when they were in small groups together, I noticed that she very much in particular was very tuned into Hannah.

Despite Hannah being perceived and experienced as socially isolated and impaired, not interested or capable of social interactions by some instructors and staff in the college, she

enjoyed friendships and socializing as described earlier. Communications and Anthropology instructors provided examples of Hannah's classmates not simply reciprocating Hannah's interest in them, but Hannah's peers being interested in and initiating relationships with her.

Similarly, as an Anthropology instructor, the Communications instructor admitted that she also repeatedly questioned her competency to support Hannah. Although she tried to act upon it, promptly look for the solutions, and negotiate ways of supporting and understanding Hannah, she acknowledged that it was not always easy. As most of the instructors, she found Ingrid's support indispensable in the process, although she negotiated Ingrid's role and presence in Hannah's learning too:

When I first met Hannah I thought that she was odd, because her behavior is right there, she doesn't hide anything, and it seems very deliberate, very patterned, almost scary, but I learned over the years that anybody can be sitting there, and anybody is different, so I just toned down my own apprehension, and you know I present what I have to present and let students ask questions and let it start with whatever it is. And then Ingrid presented herself as a way to bridge for Hannah and at that point I was not authoritative, I was happy for any help I could get, but I also was very clear, like for instance, asked when Ingrid was there I asked Hannah to be there too. I don't remember if she was there first or not, I think Ingrid was very, very ...mhm clear about her role, and she wanted Hannah to be there, but I also wanted to establish that we are not talking ABOUT Hannah, we are talking WITH Hannah, you know and I think it was very helpful to me, and Ingrid think was very much in tune, she was wonderful advocate for Hannah. She said to me, you know, that she will not always be in her life and she was concerned that Hannah came to college to get along with her life knowing that she would not always be there to advocate for her, so there was this very special affection, bond, you know it was wonderful, very admirable actually, and I think I learned from Ingrid try to also follow that, and sometimes it worked, and sometimes because of my own shortcomings, I was having trouble.

D: Do you remember any examples?

R: I think, when Hannah had something to say, she said it, so no raising of the hand, she just said it, and I felt very uncomfortable, I didn't know, because Hannah's behavior was stigmatizing to her, and I was struggling because I didn't think it was my role to say to the class, you know this is Hannah's situation and I must say when student comes to my class in a wheelchair or is deaf, has the interpreter, I feel I don't need to say anything, it is right there, ahm, and with Hannah, it is subtle and then not so subtle, so I struggled with negotiating that, and eventually what I did, and this is what I don't know if this is right, you know, even to this day, I didn't say anything overtly to the class, though I may have said

something specific to the other Hannah, like you know I see you are helping Hannah out, ahm I applaud you for that, because as you can see she needs little more, that kind of thing, but that was my struggle, you know, let Hannah to be herself and then negotiate, because sometimes, like at the beginning of the class when class has not started, people chit chat, Hannah sat in her seat, and she really did not chit chat, I observed that, so I felt that was her way to negotiate, it was painful to me but at the same time I felt it should not intervene because it was her.

As the instructor described, she did not always found the “right” solution or definite answers to her uncertainties and questions. However, she engaged in an ongoing dialogue and negotiations with Hannah, Ingrid, other students, and importantly with herself, and tried to understand, negotiate and often challenge discourses and practices they engaged in individually or collectively, and could either promote or impede Hannah’s participation in social interactions and learning.

At some point of our conversation I mentioned how we learned (and still do) to negotiate our needs and interest when on our outings, and I appreciated Hannah’s flexibility and willingness to renegotiate our plans, especially when my small daughter was with us. The instructor openly admitted, as did I, that it took some time to engage in such open conversations:

What was important that you were willing to have that conversation with rather than not, and just worry about that, that's exactly what I am talking about in a classroom, you know, there were times at the beginning when I was not willing to have that conversation, maybe because I was afraid, you know because she was unknown and her autism was unknown, so I was afraid to have that conversation.

Instructor provided numerous examples how she negotiated Hannah’s difference, including when fair grading of oral presentations that involved intonation and eye contact were in stake:

Communications instructor: *We try to work on the couple of things as an individual, and one thing was vocal variation, intonation, and the other one was eye contact. And I saw a definite increase in those behaviors, because again the dilemma for me is that I have a grading structure and somehow it was not always easy, I had to grade her fairly for herself, but I also had to grade her fairly in the context of everybody, and our rubric, and that was a struggle. The way I negotiated that for myself is to try to pin point specific behaviors that she needed to improve, and then look for improvement across that for her, so you know to say that she got an A is fair, another student in that class might say "Wait a minute!," you know, but my*

thinking was that “you started here and you got to here, but Hannah started here and got to here.”

Researcher: *You looked at her development, her progress.*

Communications instructor: *Yeah, because otherwise, quite frankly I would have been stuck. And I am not saying that what I did was totally correct, but I negotiated within context of that course and her, you know.*

Communications Instructor understood Hannah’s difference as part of human diversity and looked for ways to accept and accommodate it in a similar way as working with other students, for instance with a deaf student who presented her presentation in sign language with an interpreter, or a Muslim student presenting with veiled face. To her, so called “Student With Disability” was not an “issue,” rather as she put it “quote, unquote, a normal student who does not want to be there is a bigger challenge.” Her understanding of disability was contextual and situated, among many experiences based also on her early experiences of teaching Native Americans, labeled as students who had “problems” and labeled as “developmental students,” or experiences of the current students (and instructors) at college often scrambling for timely services and support. Although in general the instructor was appreciative of opportunities community college provided to students, she did not hesitate to openly challenge and criticize institutional practices that potentially disabled students and instructors, and point out to contradictions between the official discourse of college and actual daily practices that constituted students’ learning:

[Y]ou do want [disabled students] to be able to be independent, and you do want them to be able to do the things they have to and need to do, you know go to the bookstore, go to the registration tadadadada, so if any of those task present a problem, it would be kind of nice that there would be a support system for that, and I imagine what [the OSWD] is able to offer some sort of support system, I just I do not know where to draw a line in term so of, should they be able to do that without any support at all? Well, we all need help doing things, so whatever those possibilities are, they should be WELL in place, WELL funded, IF as our mission, education is available to all at community college, and if you want to think of

students as consumers, and we are deliver education as a product, I hate that analogy because it a business analogy, but OK, so you know it is contract, they should access it.

Moreover, the instructor pointed out to many other practices that potentially can disadvantage all students and instructors. For instance, the evening students do not have equal access to services that the day students have, or untenured instructors being cautious about engaging in open consultation with departmental chairs or other colleagues about any issues they might face in their teaching practices.

Communications class frequently involved working in groups, the practice that the instructor considered an effective way to engage students in practicing communications skills, decentralize her own authority as a teacher, and provide opportunity for students “to see that there is expertise among themselves, that they tend to ignore, or devalue.”

Being aware of students’ usual fear of public speaking, she developed several assignments that allowed students to focus on their interests, personal experience and knowledge, and thus build on who they are. First project, so fondly remembered by Hannah, was a “Bag Project,” where students were supposed to place on a bag pictures or writings about who they are, what they like, and they would like to (or would not mind to) share. They were also asked to place at least one item inside of the bag, something they can keep private. For the second project students were asked to choose one of their items from the bag and prepare a formal presentation.

Instructor explained the purpose of the projects:

Students are scared to death of public speaking, as am I, it is threatening to them. When they are sharing their bag, it is all about them. Many students resist the bag, because they feel they are adults in college and the first thing I ask them to do is ‘arts and crafts’. Later on they are asked to make a formative presentations about a topic. I want them to understand that when I ask you to think and pick a topic, if I ask you about something that is interest to YOU, if you look at that topic, something that you are really interest in, that you really want to share and teach somebody about, if you really look at that topic very carefully you will see yourself in the topic.

When they feel engaged, all of the sudden that terror, is still terror, but there is at least some connection, it is not so foreign, and different from who they are. So every presentation is really about you, it is aspect that is not threatening to you, it is conforming your existence rather than trying to kill you.

Instructor confirmed that Hannah's formal presentation she choose to do on zoo was exceptional not only by the content, but as she described Hannah's "enthusiasm [was] contagious, and I cannot tell you how I appreciated the zoo so very much just from her deep appreciation." Teaching practices and assignments that afforded Hannah's creative and active participation did not lead to "overcoming her disability," as her academic successes were often referred to, rather these assignments allowed for, as the instructor put it, "confirming her existence" as a valued and equal member of community of learners.

The analysis of Hannah's positioning by the instructors illustrates dialectical nature of constructing positional identities. For instance, it became evident that Hannah could not be positioned as an active learner in learning activity, unless an instructor understood and positioned herself or himself as an active participant within learning activity. Moreover, an instructor's positioning of Hannah as deficient, whether socially or cognitively, consequently disabled instructor's agency as a teacher.

Hannah's and instructors' accounts suggest that Hannah was relatively frequently allowed and encouraged to *participate* by sharing and applying her individually unique ways of being-knowing-doing in the learning activity. Although her participation was appreciated by all instructors and through this involvement she also regularly *contributed* to collaborative knowledge production, Hannah's participation often was not recognized beyond representing a token of diversity. Her contribution and her unique ways of being-knowing-doing were not

always acknowledged and *recognized as contribution* or as transformative to students, instructors and their teaching practices.

Instructors who understood learning as a collaborative practice (for instance Sociology and Communications instructors) and organized learning as such, acknowledged Hannah's uniqueness. Her ways of engaging with others were not simply tolerated and accepted, they were respected ways of knowing and doing and as such, they became integral part of collective knowledge and communal practices. These instructors did not hesitate to acknowledge challenges Hannah and they often faced in class without idealizing Hannah and her performance, however they did not simply attribute those difficulties to disability or to autism as Hannah's individualistic characteristics. They recognized their own roles in either potentially disabling or promoting Hannah's learning, as well as roles of Ingrid and other students. Although, due to lack of Hannah's peers participating in the study, their role in learning activity cannot be fully acknowledged and presented in detail, some anecdotal accounts of instructors indeed indicate how students within learning as a collaborative activity provided support to Hannah and to the instructor.

It was those learning contexts in which instructors afforded, promoted and recognized Hannah's contribution as that of an equal, able, and agentic, though unique *knower* and *doer* that learning was practiced as an "*active project of creating one's identity*" (Stetsenko, 2010, p.12). In other words, when Hannah's unique ways of *knowing-doing* were fully recognized as valid and equal to those of other community members, her unique way of *being* and *becoming* were recognized and validated too.

From Hannah's, Ingrid's and my own encounters with instructors I would say that it took instructor's open heart, open mind and an open office to recognize Hannah as fully capable of learning and contributing to other students' and their own transformation.

8. CONCLUSION

In this concluding chapter I summarize the most important themes of this study and reflect on their significance for both the participants and the theories applied in this study. In the light of the theoretical approach used in this work, namely Vygotsky's approach extended by TAS and Disability Studies, I also reflect on what I learned as a researcher and human being.

The purpose of this research was to interrogate, and possibly expand, current models of autism by closely examining the complex interplay of personal and social processes in the case of a young woman diagnosed with autism, referred to as Hannah, as she engaged in educational practices in a community college. Building from Vygotsky's approach extended by TAS (including Vygotsky's disontogenesis theory) and Disability Studies, this work aimed at conceptualizing autism in a way that radically moves beyond deficit, cognitivist, and predominantly reductionist understandings of autism and disability more generally. Instead, I sought to develop an understanding of autism firmly grounded on a dialectical, sociocultural, relational, dynamic, and transformative developmental perspective.

The TAS-extended Vygotskian approach provides such guiding metatheory for studying human development, including the dialectical unity of social and individual aspects of human development and dialectical relationship of learning and development. Employing this theoretical perspective provided me with a dialectical, dynamic and developmental understanding of individuals diagnosed with autism that stands in sharp contrast with prevailing perspectives. Following Vygotsky's central theses of the dialectical unity of learning and development, which posits that learning is a leading force of development, and a process of identity making, Hannah's learning and her engagement in learning activity was central to this research in understanding her development.

Specifically, I paid close attention to the dialectical and dynamic relationships between learning, self, disability and autism in the context of Hannah's engagement in learning activities in college. As I discussed earlier, learning, self, disability and autism were approached in this research not as individual characteristics or separate thing-like entities that a person possesses or that somehow reside in individual's mind and body. Rather, these processes were considered in this research as social practices, namely as historically and culturally produced activities enacted by individuals in their communities and mediated by cultural tools. In order to examine such dynamic relations, I explored how Hannah positioned herself and how she was positioned by the college, including by instructional and administrative staff in teaching practices, personal narratives, cultural representations, and other institutional practices in interacting with Hannah. Thus I paid particular attention to the cultural tools employed in learning activities and daily interactions with Hannah and their role in disabling or empowering Hannah's emerging identity, reflected in a range of positions she took, on a continuum from an agentic learner acting from an activist stance to disempowered disabled person with little agency.

On another level, analysis of the current state of community colleges in the USA, and their role in providing disabled students with access to postsecondary education, revealed that existing policies and practices are mostly based on deeply individualistic notions of disability, human development and learning. This is reflected in educational and life goals for students of diverse abilities as discussed earlier. Examining the conditions and opportunities available to students diagnosed with autism for participation in higher education reveals how policies and practices commonly result in exclusion, denial, or limited access to education. Consequently, students diagnosed with autism might end up feeling oppressed. Even when students diagnosed with autism are able to enroll and participate in higher education, some of the institutional practices

often disadvantage, marginalize, and disable them as learners and members of the college community. For instance, unless an institution provides autism related support and services outside of the Office of Students with Disabilities (OSWD), students diagnosed with autism can only receive additional support if they claim disability and identify as disabled. However, even if students follow this practice, they might not receive the necessary academic, and especially nonacademic support, if this is not part of the repertoire of services provided to students registered with the office. Advocates and members of the autistic community, as well as research findings, clearly suggest that nonacademic support is crucial in enabling full participation in learning process of the students diagnosed with autism. As a result, most institutions fail to provide and assure access to education, which is one of the fundamental rights stipulated by the law.

Although a growing number of studies and publications on the needs of students diagnosed with autism in higher education indicates increased interest and efforts of researchers, policy makers and practitioners, many still employ, if even only implicitly, a medical model of autism and individualistic view of human development and learning. Furthermore, those studies addressing the issues of teaching and learning of students diagnosed as autistic are predominantly concerned with teaching strategies and techniques, rather than with providing any systematic recommendations on pedagogy based on a rigorous learning theory in which learning and teaching are viewed as a collaborative process.

Currently, the leading theorizing of learning and teaching of students diagnosed with autism in the context of higher education applies the concept of neurodiversity in relation to different cognitive styles and consequently different learning styles. However, no matter how appealing the emphasis of a neurological difference over the notions of deficit or disability of the

individual might be, the current narrow understanding of neurological difference as an individual characteristic that simply needs to be matched with specific learning style, arguably essentializes it, thus further reinforcing an individualistic understating of students diagnosed with autism as well as of the learning and teaching processes.

My analysis also focused on how the institutional policies employed by instructors and administrative staff contribute to constructing learning contexts in the college. Thus these policies serve as powerful tools for students' positioning within the learning activity and as such represent tools of students' identity making. As researchers have argued, and my findings confirmed, some of these institutional tools employed by the Office of Students with Disabilities and by instructors mediate the processes of disablement, ableism and other discriminatory practices and lead to stigmatizing and further marginalizing of already marginalized students.

In order to better understand how institutional policies shape learning in the college, I also analysed the current state of education for diverse learners, especially the educational opportunities available for students diagnosed with autism. This analysis shed light on how the educational system that constitutes a broader context in which Metropolitan Community College, their instructional and administrative staff and students, including Hannah, were situated and operated within. It is important to emphasize that unequal distribution of resources at MCC, directly leading to disablement and exclusion of diverse students, also affects those serving and supporting them, including instructors, Office of Students with Disabilities and its staff. Offices providing services for disabled students are notoriously understaffed and lack resources to expand and intensify services and support to students and instructors. Glaringly, there is a dire lack of professional development for staff and instructors in the area of supporting diverse learners, especially students diagnosed on autistic spectrum. My findings corroborated this point.

As I observed in Hannah's case, she and other disabled students were indeed subjected to marginalization as a result of institutional practices. For instance, in order to benefit from the support and accommodations to which they are entitled, students have to claim disability. Thus, they already enter their learning communities from this initially marginalized position.

Some of the negative cultural representations of autism and personal narratives of the administrative staff that implied normative understanding of social interactions led to understanding Hannah predominantly in terms of deficit, particularly in regard to her social and communication skills. As a result, she was typically positioned as cognitively adept, yet as inadequate in social interactions, capable of social adaptation at most. Consequently, Hannah's agency and her contributions to the social practices of learning communities were not recognized by the staff of the Office of Students with Disabilities. I argue that this is partially due to the organization of institutional practices resulting in fragmented nature of services provided by OSWD. Consequently, the staff has limited opportunities to observe students' engagement in learning activities and (recognize) their contributions as agentic members of the learning communities. In analyzing Hannah's case, it was clear that her positioning needed to be understood not only as mediated through cultural tools in the processes of social interactions, but also as a process embedded within the institutional organization of activities which Hannah and the staff were part of.

Despite of the constrains imposed by institutional policies and practices most of the interviewed instructors responded to Hannah's and Ingrid's openness about Hannah's needs and unique ways of interacting. They were open to go beyond both the limits of normative interactions with students and their routine way of organizing learning activity. To varying degree, the instructors I interviewed were open to explore and negotiate new possibilities of

engagement in learning activity with Hannah. In each relationship between an instructor and Hannah entailed different dynamics. As a result, in each relationship Hannah expressed unique patterns of abilities or disabilities, including different positionings, such as agentic or disabled learner, and different degrees of social competency and cognitive impairment. My analysis reveals how Hannah was positioned in different learning contexts, as a result of the interplay of multiple components and actors of learning activity, including its organization, interactions with instructors and other students, and cultural tools (e.g., instructors' personal narratives, cultural scripts and representations of autism and of person diagnosed with autism, teaching and institutional practices) that mediated interactions within the system of learning activity. Some of these positions did not merely *label* Hannah as disabled. Rather, they *made* her disabled by maintaining the status quo of disabled learner, which entails being denied access to cultural tools by being prevented from participation in knowledge production and contribution to social practices of learning as a competent learner. As a result, Hannah was often denied the "status of a full partner in social interaction" (Fraser, 2000, p. 114).

In order to analyze these findings, Fraser's notion of "parity of participation" (p. 115) offered an important conceptual tool. Extending it from the TAS perspective, I argue that Hannah's "struggle with disability" is not a struggle with some internal deficit or neurological difference. Instead, it is a struggle for "*parity of contribution.*" In other words, from this perspective Hannah's struggles can be characterized as a struggle for status recognition as an equal contributor to social practices, a struggle for recognition as a learner within a community of learners, a struggle to be recognized as an activist in her own right and as an agentic human being.

One important aspect of my analysis was Hannah's sense of identity regarding being diagnosed and positioned as autistic. Although she is open and quite positive about "being autistic," Hannah does not necessarily affirm an autistic identity or seeks cultural recognition as a member of the autistic culture and community. Nor does she readily accept and affirm the position of disabled person which is so frequently attributed to her. Rather than acting from the identity status of "autistic" or "disabled" person, Hannah positions herself as an agentic learner with a purposeful life project and acts from the stance of a transformative activist. This is evidenced by her active demands, often mediated by Ingrid, to access tools that enable parity of participation and contribution.

I found out Hannah was the first student diagnosed with autism at MCC. As such, she challenged, resisted, interrogated, destabilized and transformed institutional practices, according to which she was supposed to claim disability and the position of a Student With Disability from the very first day in college. Instead, counting on Ingrid's ongoing support, Hannah claimed recognition as a nontraditional yet *agentic* student. In fact, Hannah claimed on an everyday basis her right to education and access to cultural tools that allow for contribution to social practices- instead of merely adapting to them. Through her everyday participation in classes, Hannah interrogated institutional practices established in her classes, including the teaching practices of her instructors, their and students' personal narratives and cultural representations of autism, as well as normative ways of learning and knowledge production, social interaction and understanding of disability and humanity. Importantly, Hannah contributed to the collective knowledge production in her courses with her intellect, dedication, and her unique ways of interaction. My analysis revealed that, when learning was organized in a way that Hannah could introduce and integrate her funds of knowledge (Moll, Amanti, Neff, & Gonzalez, 1992) as well

as her multiple positions and social roles (e.g., for instance as a granddaughter, friend, committed student, as well as a nature and photography lover, and a talented baker), within her learning activities, she was empowered to take the position of an agentic, committed learner and a person in general. In such instances, the developmental context of collaborative learning activities new identities began to emerge, including those of a creative author, critical thinker, college and classroom community member, as well as expert on autism. It is crucial to emphasize that Hannah was often allowed and encouraged to *participate* by sharing and applying her individually unique ways of being-knowing-doing in the learning activity. Through this involvement, she also regularly *contributed* to collaborative knowledge production. However, her contribution and her unique ways of being-knowing-doing were not always acknowledged and *recognized as contribution*. Her uniqueness, including her ways of engaging with others, were not simply tolerated and accepted, they were respected as ways of knowing and doing and as such, they became integral part of collective knowledge and communal practices.

These findings corroborate the important conceptual point of understanding identity as an activist project. As I demonstrated it was those learning contexts in which instructors afforded, promoted and recognized Hannah's contribution as that of an equal, able, and agentic, though unique *knower* and *doer*, that learning was practiced as an "*active project of creating one's identity*" (Stetsenko, 2010, p. 12). In other words, when Hannah's unique ways of *knowing-doing* were fully recognized as valid and equal to those of other community members, her unique way of *being* and *becoming* were recognized and validated too.

Therefore, I argue that some of Hannah's most significant contributions and transformative moments as a college student and human being were those when she destabilized "institutionalized patterns of cultural value that impede parity of participation" (Fraser, 2000, p.

115). From the TAS perspective, it could be extended and emphasized that she destabilized practices that impede “*parity of contribution.*” Finally, and perhaps most importantly, it should be noted that she was recognized for this contribution by some of the instructors, by Ingrid, and above all by herself.

This notion helps one see how Hannah’s engagement in learning activities, as well as in other social practices, within the college embody both *individual* and *social* transformation, exemplified through reciprocal processes of changing herself and her community practices. In other words, not only Hannah changed as part of her individual development as a college student and human being, but she also instigated changes in the community practices of the college. In a dialectical manner, positioning Hannah as an agentic student and transformative activist within organized learning activities, and fully recognizing her equal contributions to her community practices, as some instructors did, promoted Hannah’s development and transformation. As Vianna and Stetsenko (in press) emphasize, the dialectical transformative processes of social change and individual development are directly connected to social praxis, the central point of TAS approach. In their own words (Vianna and Stetsenko, in press, p. 23):

[TAS perspective] affords ways to reconcile emphasis on personal and collaborative dimensions of transformation at the intersection of individual and collective agency, thus, overcoming the outdated dichotomy of agency versus structure. The individual and the social dimensions are understood to exist in a mutually determining relationship as conveyed by the notion of “collectividual” (Stetsenko, 2012).

Dialectically, when instructors and others who interacted with Hannah recognized and acknowledged her as different, yet agentic, unique but equal, they simultaneously engaged in potentially developmental and transformative dialogue about themselves, about the meaning and norms of being human. This was described by several of the instructors, though to various degree. Importantly, this point applies to this research endeavor as well. As such, this research

project does not only *reflect* on such transformative processes of engaging in dialogue and actions, as they occurred in the context of college. Rather, this research *is* and *embodies a transformative practice* for Hannah and Ingrid, and even other participants, if only marginally. It certainly is and will continue to be transformative force for me as a researcher and, above all, as a human being.

Indeed, while reflecting on the research and writing process, I can clearly see how my theoretical understanding developed and changed in the process. Though I started with naïve questions and perspectives, I felt confident being well “equipped and armed” with powerful theoretical tools from Vygotsky’s approach extended by TAS. I also hope that my understanding and learning will continue developing as I will carry on asking questions and challenge not only other perspectives, but my very own too. The very practice of critically engaging in interrogating and reevaluating my own perspectives, including my normative thinking and acting, is probably the number one lesson I can take from this research. What I learned *from* and *with* Hannah about what it means to be human is one important reason why I deeply appreciate my friendship with her. (I must admit, sharing her marvelous cookies and other goodies with my whole family certainly makes the list too!) I feel incredibly lucky to choose this topic for my dissertation research. Throughout this process, our relationship grew and developed, and continued far beyond collection of data for this research project. In fact, our relationship deepened throughout this research as it shaped (and continues to do so) our everyday lives and vice versa, as our everyday interactions informed this research. In a dialectical fashion, the events and issues in our lives continued to be discussed in the context of the findings from this research. Thus, both theoretical concepts and research findings became frequent references used to understand, question and explore our everyday experiences and lives, such as our mutual relationships, our

futures, Hannah's and my professional carriers, and so on. In other words, we introduced the scientific concepts and research findings as cultural tools into understanding of our individual agencies, current positionings, crafting our everyday participation and contributions in our communities, everyday practices of disablement, oppressions and misrecognitions, and our own transformative stance. It was through continuously developing and deepening our relationship that the course of the research, including Hannah's and Ingrid's participation in the research processes, was transformed. With the increasing intensity of our relationship, solidarity and mutual care for one another, our mutual trust grew as well. One illustration of this was Hannah's and Ingrid's contribution to editing this text. Despite Hannah's initial decision of not wishing to actively participate in the research process. I invited her to examine my account of her learning experiences, as I realized that both Hannah and Ingrid might gain important insights by participating in editing my findings. As they later expressed to me, they both gained the comfort to edit the text and contribute directly to my interpretations of their experiences, presenting their voices and representing their standpoints. This was indeed an exciting process of negotiations, acknowledgement, and full recognition of Hannah and Ingrid as transformative activists.

All this was such an expansion of the starting point of this research, which was to learn *about* and *from* Hannah's learning experience and understand her development in the context of college. In the process of familiarizing myself with available theoretical constructs and instruments, I developed my appreciation for psychology, both as science and practice, in both positive and negative ways. Reviewing the literature in the area of autism, I realized the power of psychology, and science in general as an incredibly potent tool for either dehumanizing or empowering children and adults diagnosed as autistic. On a personal level, this power of psychology was a constant reminder of my role as a researcher and my responsibilities resulting

from it, positioning research participants and myself within research. I gained a better understanding of the dialectical relationship and unity between research and practice, and how they guide each other. I became increasingly committed to research as a social practice aimed at and guided by social justice. In other words, I learned to engage in *research as a practice of and for social justice*. Throughout this process, I made every effort to review my objectives and practices from this perspective, including recognizing the role and contribution of research participants to research practice as any other activity they engage in. I learned to value and strive for conducting research “as a critical activist practice aimed at creating more equitable futures premised on ideals of social justice and equality” (Vianna and Stetsenko, in press, p. 1).

Conducting this research, I further learned to appreciate the cliché of how much is at stake in asking the right question. Obviously, questions reflect a certain theoretical (and political) position from which they are asked. In a related way, as it is discussed in this work, different theoretical perspectives yield different answers to “What is autism?” (e.g., cognitive or neurological deficit, or neurological difference), or “Where does it originate?” (e.g., genes or environment). Despite a plethora of research investigations in this topic, as well as diversity of theoretical approaches, I found out that the existing literature does not offer a satisfactory model and theory of autism that could explain Hannah’s learning experience and provide an understanding of her as a human being. If I venture a “grand” generalization, I would argue that the literature overwhelmingly focuses on understanding autism, and persons diagnosed as autistic, either in terms of a *deficit* that needs to be cured, or a *difference* that needs to be merely accepted and tolerated. However, the most profound thing I probably learned about Hannah is how much more “similar” to any other (“regular,” neurotypical, “normal” or whatever normative category we might use) human being she in fact is, compared to how she might appear and be

considered, especially when she is judged against superficialities of normative behavior. I truly believe this seemingly trivial statement encapsulates some of the most profound ideas of Vygotsky's theory of disontogenesis. First, it reflects his claim that the fundamental laws of development are the same for both typically and atypically developing children and adults. Second, this conclusion also reflects Vygotsky's notion that the intellectual disability can be understood as a result of social isolation. Thus, as Vygotsky's theory implies, Hannah's case illustrates that there are no different "kinds" of human beings, as it is often implied in depicting individuals diagnosed with autism by media and cultural discourses, including the academic literature (e.g. Sacks, 1995) as if a person diagnosed with autism was coming from a different world or a planet. Instead, what Vygotsky suggests, and Hannah's case demonstrates, is that individuals might follow different paths of becoming human, including using different cultural tools that afford and mediate access to cultural practices as the source of human development. It is then the absence or lack of cultural tools that consequently results in isolation, materialized as inability to access, participate in and contribute to cultural practices, the very source of development. In this vein, the intention of this research was not to simply identify and document Hannah's identity, and, perhaps, with some "objective" accuracy, prove to what extent she is or not autistic, different or disabled. Neither was it to tell a success story of an "autistic college student." Instead, the point was to reveal Hannah's identity and development as dynamic, interrelated and transformative processes, situated and embedded in human activities. Furthermore, my goal was to illustrate that a person diagnosed with autism, just like all other human beings, depends on cultural tools to participate and contribute to sociocultural practices. Thus, I intended to show that autism is not merely individual, intrinsic characteristic, whether defined as deficit, disability or neurological difference, being instead a process enacted in

activities in which a person engages. The results of my study indeed demonstrate that Hannah's identity is a process continuously shaped by powerful social forces such as social discourses and community practices that are enacted in social interactions (including how she is positioned, what fields of possibilities and tools she is afforded in terms of what she is expected or able to do). Participating in these practices often entails a process of disablement, misrecognition and social exclusion. Importantly, her identity is not simply "handed down" to or conferred on her, as it were, by outside forces. Instead, she is actively negotiating, interpreting (including resisting) the social forces acting on her and thus constructs her own identity with the tools available to her in ways of an active process that is an amalgamation of these social forces and her own ability to constitute her own self, identity, and subjectivity.

Drawing on Vygotsky's approach extended by TAS this dissertation is an attempt to tell a story that would provide a plausible explanation and understanding of Hannah's development at the period of her life as a college student and her future. I propose that Vygotsky's approach extended by TAS, including Vygotsky's original theory of disontogenesis, allows for such expanded understanding of development of persons diagnosed with autism. This approach is characterized by the following:

- Developmental dynamics apply equally to the development of all individuals diagnosed with autism, including all the "manifestations" of neurological difference regardless of its extent.
- Neurological difference is understood as an integral part of human diversity.
- Disability is conceptualized as always enacted in activities rather than simply reflecting individual characteristic or deficit. Therefore the focus of research

- (including unit of analysis), educational and other support must be an *activity* rather than individual person,
- Phenotype is understood as *generated* and *constructed* in individual ontogeny within interdependent relationship between genes and environment rather than an expression and result of genotype.
 - The dichotomy of ability versus disability is destabilized by conceptualizing human ability, mental and physical, as fundamentally dependent on access to cultural tools (material and symbolic) for its development,
 - Traditional dichotomies, such as social versus individual, agency versus structure, and intervention versus acceptance, are overcome by understanding dialectical relationship of social change and individual development as parts of transformative collaborative practice, as for instance represented in the notion of “collectividual” (Stetsenko, 2012).
 - Developmental, including educational goals for disabled persons are based on principles of social justice, specifically “*parity of contribution.*”

Finally, my study reveals that the TAS’s focus on transformative collaborative practice as the source of development, including the notion of “collectividual,” has significant implication for how to address *and* answer the question that divides most of the research in the field of autism, praxis, and autism rights movements, namely, the question of intervention. Commonly, in relation to autism, the term “intervention” has negative connotations as it is understood as being about finding the cure for autism which implies normalizing persons diagnosed with autism to fit in with the conventions of social interactions and behavior, and entails a top-down societal imposition on marginalized individuals. Such an approach is, understandably, radically opposed

by many members of autistic community, their supporters, and increasingly by scholars, especially within disability studies. The way out of this conundrum does not only lie in semiotics, the need of changing the terminology, or reconsidering the goals of intervention. I believe that TAS's answer lies in changing our ways of conceptualizing human development. While understanding development as a unique work of being-doing-knowing by each individual, this process is also understood as profoundly social, in the fully dialectical sense of dynamics between the social and individual –as a “collectividual” process (Stetsenko, 2012). Consequently, all human beings are amalgamations of unique efforts in development, yet these efforts do not occur in a vacuum but necessarily encompass supports and affordances provided by others. In this case, there is no connotation of a top-down imposition but instead, the implied meaning is that of collaboration, solidarity and mutuality in development as distributed among the individual, the cultural tools, and the others.

Finally, I would like to conclude that I understand TAS approach not only as a theoretical approach, but also as an embodiment of social practice that can simultaneously provide guidance to praxis, including teaching and pedagogy, supporting students diagnosed with autism, advocacy and human rights movements, or any everyday activity individuals diagnosed with autism engage in.

Epilogue

After we finished working on editing of the text I asked both Hannah and Ingrid to reflect on working on the text, participating in this project and possibly learning throughout the whole process.

This is what they wrote:

Hannah:

Dear Dusana,

These are my answers to your questions.

I admire you for your diligence, intelligence, and kindness. What you wrote in your paper was interesting. Helping you with this project was a way to nurture my friendship with you.

When reading what you wrote in the text, all the events were stated accurately. The information about me was true. I enjoyed helping you by reading and editing the text. There was nothing that I disliked or disagreed in your interpretations. What you said was helpful because it made me proud to be who I am.

I learned that I had to work harder than most students. I had to learn to make sacrifices over pleasurable activities such as baking and taking piano lessons. Being a good student was my priority. Unlike most people, I have a fantastic memory and it helped me to recall mathematical formulas and factual information.

You and I developed a friendship that will last for a life time. I learned that you are a graduate student at Baruch College and that you are from Slovakia. At MCC, there were also students who came from other countries from around the world and from different backgrounds. Some were poor and others were rich. Some students had physical or mental disabilities. People who have those disabilities can be as smart, diligent, and talented as people who do not have a disability. They can also be kind, caring, and polite. It was wrong to assume that I was not smart or hard working even so I needed tutoring in some courses.

I hope that you like my answers to my questions.

Love,

[Hannah]

Ingrid:

Dear Dusana,

I am appreciative that you invited me to take a part in your research of Hannah's experience at MCC. Reading and editing your text was engaging and often made me add a fitting anecdote that came to my mind, because of your spirited descriptions of incidents. I enjoyed reading and editing your work in progress. The insight that you brought to your study actually freed me from a lot of stress and anxiety.

When Hannah was applying to the Cathedral School, she was accepted on her merits. In contrast, I felt that at MCC, she was viewed as separate entity, feared at the OWDS as a liability. Hence, reading your analyses and interpretations of Hannah's struggles and accomplishments brought welcome peace to my mind. It also emboldened my advocacy and my need to present Hannah to the faculty as a unique person with qualities of admirable strengths, before she was pointed out by the OWDS as a student with a mental disability.

I also value greatly how this research has affected a loving closeness among the three of us and, how over time, you included your child and husband to our bond of friendship.

Thank you for your holistic approach in getting to know and describe Hannah. Your kindness, warmth, and sincerity has not only benefited Hannah, but also me.

Congratulations!

With love,

[Ingrid]

Looking ahead

Hannah's dream of becoming a professional baker/recipe tester did not alter while she was a student at MCC. Therefore, several weeks before graduating, Hannah applied and was accepted for the two year Baking program at the Art Institute in her town. A new class was beginning in October 2008. Ingrid told me that it was a "well known school, operating for the past 75 years. It had an excellent reputation, but--- it was not meant to be." In late September Hannah, received an official letter stating that the Culinary program in her city would be phased out, due to the economic depression. Hannah and Ingrid felt distraught.

Hannah, immediately, applied through MCC for a grant at FEDCAP, a federally supported Career Design School where she was accepted into their cooking program in January 2009. Five months later, on May 29, 2009, Hannah was awarded a diploma of study in the Culinary Arts where as she recalled basic skills of preparing appetizers, salads, entrees, bake cookies from ready-made dough and washed dishes. She also learned about food safety and how to store food at safe temperatures in the refrigerator and freezer. Hannah felt that it was a helpful experience for her.

In the following two months Hannah took recreational baking classes at a prominent Culinary Arts Institution, and with Ingrid's help, Hannah updated her resume. To make it more personal, Hannah added a few pictures of baked goods that she had baked at home, and in the various classes that she had taken, including a photograph of herself baking.

With a fresh resume in hand, Ingrid set out advocating for Hannah at several local bakeries in the neighborhood. It was not easy process. It turned out that some workplaces did not want to take on a beginner. Others were hesitant or afraid of taking on a person with autism, or accept an outsider to a family business, protecting family recipes. At this point Ingrid felt quite dispirited, but she forced herself to approach one last store on her way home. It was a small deli that specialized in Egyptian dishes and other gourmet foods. The owners also tempted customers with a variety of daily freshly baked cookies and little cakes. Ingrid remembered shopping in the store occasionally and even taking Hannah there when she was still a child. Nevertheless, under the given circumstances it took courage to enter. Hannah found there a familiar salesman who knew Hannah since she was a little girl. Ingrid told him about Hannah's situation and begged to give Hannah a chance. He said he would have to talk to the chef. When Ingrid returned to the deli one week later, the same salesman told her that he did not have an opportunity to speak to the chef. It took Ingrid about five weeks of persistent begging, until Hannah was finally given a chance to meet the chef and to be on try-out on the following Sunday afternoon. Later in the afternoon Ingrid received a call from a chef that Hannah was on her way home. It was a female voice and only at this point did Ingrid learn that the chef was salesman's wife called Anta. "I love Hannah," she told Ingrid. Hannah started an apprenticeship with Anta at deli in August 2009. They all agreed that Hannah would not be financially rewarded during her first year. The second year she received a \$20 tip in cash weekly, and in the third year she was supposed to receive \$100 a week. The goal that was set for Hannah was to master all the kitchen skills, so that she would be fully employable, not only in Anta's kitchen, but in any kitchen. Periodically over the three year period, Anta, Hannah, and Ingrid would meet after work to reflect on Hannah's strengths and weaknesses. One big concern to Anta was Hannah's slowness. Anta suggested to practice at home with a timer at her side, and she provided Hannah with bags of carrots, onions, and other vegetables that needed to be cut. When Hannah was in her third year, she was now often left working on her own or with another team member. Ingrid

remembers that Anta would put up a list in the kitchen with all the work that had to be done by a specific time of the day, and made Hannah accountable. Unfortunately, the store was sold and was closed suddenly on May 31, 2012. Like many other small businesses in the area it was caught up in the economic crisis.

I had an opportunity to meet with Anta in Ingrid and Hannah's home. She spoke very highly of Hannah as one of her best employees. Anta said if she would start a new food related business, Hannah would be the first one to call. However, disappointed and shaken Anta decided to look for a job in a different, less stressful field. As for Hannah, she needed to find a new job.

Although Hannah lost her job and prospect of working at the deli as a full-time employee, it was an opportunity to reflect and time for much needed rest. Hannah and Ingrid started to search again for jobs.

Hannah and Ingrid also started focusing on other issues in Hannah's life, such as looking for apartment and exploring other possibilities of future living arrangements for Hannah. Hannah registered with social service agency that facilitated joining a group of young disabled people. Agency services include weekly therapy sessions. Although she liked her therapist she asked to change for a female therapist as she felt that she might relate easier to a woman, especially when discussing her childhood. Ingrid joined the sessions and currently, each of them meets with a therapist biweekly.

In effort to find a job for Hannah Ingrid approached the assemblyman in her district where they live. She had met him once before, at a meeting, together with other parents who had autistic children. It was thru him, that Ingrid found Hannah's present job at the bakery department in a very popular supermarket in the area. Her employment started in September 2012. Hannah and Ingrid feel that it is an excellent fit. Hannah is eager to learn new skills and, to serve customers is a new experience for her. She is well liked by her boss and her coworkers. She works part time, five hours five times a week. This is Hannah's first paid position and she is happy to earn a weekly pay check of \$179. When she comes home, Hannah uses the rest of her day to unwind by doing the crossword puzzle in the local paper, practicing the piano and baking. She also started to take Spanish lessons again. She wants to improve her Spanish, as she would like to be able to communicate with Spanish speaking customers coming to the store where she works. She often brings tastings of her baked goods to her boss, coworkers, and supervisor. Although Hannah's dream is to become a baker is still very much alive, Ingrid is convinced that it will reveal itself when the time is right for Hannah to move on.

We developed friendship and remained close. As I already explained earlier, Hannah and Ingrid became increasingly involved in this research project. Although there were times when my research and writing were the main focus of our conversations and activities, our relationship was never dominated by data collection or other research related activities. Our relationship grew beyond research. Research became part of our lives and relationship, as did other issues and events, such as holidays and family celebrations, searching for job, dealing with illnesses, all everyday life ups and downs, as they are shared with friends and among family members.

When I asked Hannah for additional clarifications, either for a mini-interview or put something into writing, she would usually respond that she would be happy to do that to "help me and nurture our friendship". Especially at the times of final and intensive writing of my dissertation, on several occasions I was unable to meet her and we had to postpone our plans. We would make a joke that I could not be with her because I had to write about her. We were talking about our plans, what we would do when 'it is over'.

I am grateful that I had an opportunity to work with Hannah and Ingrid, to work through this story about and with them. I am also very grateful that they both feel this *is* their story. I look forward to continuing making our story.

What was left out ...

In the spirit of reflecting on this research, partially inspired by my dissertation committee, as well as by article by Granek (2012), I thought of the list of issues and questions that were left out of my analysis, that were either not included or erased from it. Granek (2012) argues that despite the obvious effort of qualitative researchers to “value emotion and relationships as central to *both* the purpose of the research and the conduct of it,” (p. 38, emphasis in original) most of qualitative researchers engage in such erasures.

I think that one of the topics that I left out (not as much a matter of erasure as an act of avoidance) was a discussion of how I was confronted by my own “positivistic objectivism that organize the quantitative research world“ (Granek, p. 43). This is despite consciously knowing and valuing the role and significance of emotions and relationships in qualitative research. I think my own doubts about my personal involvement with research participants and validity of my research originated in being frequently questioned and interrogated about validity of this project, including my choice of a case study as a method for a dissertation research. As a case study, my research project was usually understood as a “single subject” research project. As such, validity of my research was often questioned, uncommonly, to my surprise, by the faculty and other colleagues working within a qualitative research tradition. Frequently, I found myself explaining to other psychologists that a case study is a legitimate and conventional psychological research method. In addition, I repeatedly engaged in explaining the significance of my research, as well as describing other aspects of my research project (e.g., actual number of participants, depth and scope of data collection, intensity and level of my data analysis, etc.).

At the same time, on several occasions my work was well accepted and recognized at professional meetings, receiving positive feedback from scholars as well as educators and other practitioners. However, I gained the full confidence in validity of my work when realizing the meaning and relevance of it for Hannah and Ingrid, and most importantly, when they acknowledged it.

I continue to reflect upon what a close relationship and emotions do for a qualitative research. This project was a wonderful opportunity to practice the kind of psychology that I would like to continue pursuing, which is the kind of work that *requires* a researcher to exist within the phenomena under inquiry, value emotions and relations with participants, and “assume meaningful interaction between the researcher and the subject“ (Granek, 2012, p. 40).

Appendix

Community College

COMMUNITY COLLEGE •
To: Instructor for
From: Director, Office for Students with Disabilities
Coordinator of Services for Students with Disabilities
Date: September 06, 2005

The above named student is registered for your class. She is also registered with this office.

In order that Ms. may have an equitable chance of success in school without being unduly penalized because of a disability, certain accommodations or modifications of standard classroom practices may be required. For this student the accommodations are:

1. *Additional time for exams, in a quiet setting.*
2. *Use of a tape recorder*
3. *A copy of the syllabus for planning assignments and studying*

Ms. understands that she is expected to complete all assignments and meet the standards for passing the course. What is required is an equitable chance to do so.

We would also request that you refer to the Manual: **Reasonable Accommodations: A Faculty Guide To Teaching College Students With Disabilities**. If you do not have a copy of the manual please contact us.

If there is a need for extra time or special testing accommodations, it is the student's responsibility to make the proper arrangements with OSD. Proctors are available to monitor exams in

The information about the condition of this student has been officially documented and is confidential. The accommodations as listed above are among those identified in Section 504 of the National Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA), which deal with the non-discrimination of the disabled student in post-secondary settings. You and the student may want to negotiate the options that will be best for both of you in meeting these accommodations. Please deliver exams which are to be proctored to prior to the time they are scheduled to be administered. **Special arrangements can be made for those students who need to be accommodated in our office.**

Please do not hesitate to call us at Ext. if you have questions regarding this student. Thank you for your consideration. Please read the attached document.

is autistic. Please make sure that she is clear about the homework assignment. Thank you. (quadim

TEACHING STRATEGIES FOR ASSISTING STUDENT WITH DISABILITIES

Primarily from: *Dr. Jay Segal of Philadelphia Community College*

1. Provide a course outline, i.e. syllabus with dates of required assignments, chapters to be read, test dates, and your method of evaluation.
2. Provide a time line for long-term assignments.
3. Explain each assignment's purpose and objective.
4. Schedule individual conferences.
5. Reduce the amount and speed of oral material when speaking to the student.
6. Write key words and phrases on the board.
7. For students who state they require:
 - a. taped lectures
 - b. use of a note taker
 - c. taped handouts, enlarged handouts and tests
 - d. use of taped texts
 - e. extended time up to double time on tests
 - f. tests in a quiet location

Please believe them and assist them in acquiring what they request, they are entitled to these rights by law. (Please refer to OSD letter).

8. Provide handouts that are neat and clear.
9. Allow extra time to copy assignments, take notes and complete in-class assignments.
10. In **MATH**, please check if reversals account for the pattern of the student's errors. For example: Have they reversed a formula by using a (+) as opposed to a (-) and vice versa? Is the student improving their computing skills, yet still having trouble grasping certain concepts?
11. Permit oral tests when a student is blind, visually impaired or has a reading disability.
12. Please be **PATIENT**. Students do not choose to have a disability. They have probably been criticized more often than not. Please accentuate the positive. Everybody has strengths and weaknesses.

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