LIVING LABELED:

HOW STUDENTS MAKE MEANING OF THEIR LABEL OF AUTISM

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Abstract

The purpose of this study is to examine how high school students labeled with autism make meaning of their label and how, for them, the label functions in their day-to-day lives. Being diagnosed with autism can have many implications for an individual and his or her family and how a label is understood is very much connected to the impact that it has. A label can be instrumental in accessing resources and supports that enable a person to thrive, but it can also conjure stereotypes which may categorize a person or limit them in particular ways.

Using critical theory and phenomenological analysis, short semi-structured interviews were conducted with high school aged participants prior to their attending a full day workshop. The workshop included half-day art creation and a half-day focus group which sought to understand participants’ experiences through their descriptions of their art and through collaborative discussion about their experience living labeled.

The findings suggest that while their experiences are as diverse as the individuals who have them, there are similarities in how the label functions which may be more universal. Participants in this study discussed how the label of autism assigns positive or (more often) negative value to a person; how their label linked them with certain resources (and not others), and how they experienced and understood these resources; and the way labels can both protect and confine a person. Consideration of how high school students understand of their label of autism can prompt us all to think more
critically about how labels, and the meanings we assign to them, affect and shape experience for those who live labeled.

**Key words**: Autism, Labeling, Accommodation, Expectation, Value/Undervalue, High school students, Critical Disability Studies
This thesis is dedicated to Rachel and her family in thanks for being the impetus to my career and inspiring me to help others see the potential that you have so beautifully shown to me. You have impacted and shaped me in ways you can never know and I will be eternally grateful for the opportunity to have known you all.

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The road to competing my MSW began in the summer of 2013 when I began a 1-year advanced HBSW program at Lakehead University, followed immediately by a 1-year MSW program at McMaster. Through two years of full time schooling, working and raising my family it has been an exhausting yet extraordinarily rewarding adventure and I have many people to thank for getting me to this point.

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# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>iii</td>
</tr>
<tr>
<td>Acknowledgments</td>
<td>v</td>
</tr>
<tr>
<td>Chapter 1: Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Chapter 2: Historical and Theoretical Context</td>
<td>6</td>
</tr>
<tr>
<td>Historical context</td>
<td>6</td>
</tr>
<tr>
<td>Medical Model of Disability</td>
<td>8</td>
</tr>
<tr>
<td>Social Model of Disability</td>
<td>11</td>
</tr>
<tr>
<td>Challenges with dominant perspectives</td>
<td>12</td>
</tr>
<tr>
<td>Critical Disability Theory</td>
<td>13</td>
</tr>
<tr>
<td>Situating myself in theory</td>
<td>14</td>
</tr>
<tr>
<td>Looking towards the literature</td>
<td>16</td>
</tr>
<tr>
<td>Chapter 3: Literature Review</td>
<td>18</td>
</tr>
<tr>
<td>Labels and Labeling</td>
<td>19</td>
</tr>
<tr>
<td>Expectations</td>
<td>22</td>
</tr>
<tr>
<td>Internalized Abelism</td>
<td>24</td>
</tr>
<tr>
<td>How the label functions at school</td>
<td>26</td>
</tr>
<tr>
<td>Participation in the creation of knowledge</td>
<td>30</td>
</tr>
<tr>
<td>Context of this research</td>
<td>31</td>
</tr>
<tr>
<td>Chapter 4: Methodology</td>
<td>32</td>
</tr>
<tr>
<td>Research Design</td>
<td>32</td>
</tr>
<tr>
<td>Participants</td>
<td>34</td>
</tr>
<tr>
<td>Methods</td>
<td>35</td>
</tr>
<tr>
<td>Semi-structured Interview</td>
<td>35</td>
</tr>
<tr>
<td>Art Creation</td>
<td>37</td>
</tr>
<tr>
<td>Focus Group</td>
<td>38</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>40</td>
</tr>
<tr>
<td>Transcribing</td>
<td>42</td>
</tr>
</tbody>
</table>
Chapter 5: Findings

Participant Art Explanations
  Jack’s Art Explanation 45
  Everett’s Art Explanation #1 46
  Everett’s Art Explanation #2 47
  Ben’s Art Explanation 48
  Emilia’s Art Explanation 49
  Tessa’s Art Explanation 50
Understanding ‘Labeling’ 52
Value and Undervaluing 53
  Undervalued People 54
  Valued People 57
    - Jack - 57
    - Everett - 58
    - Ben - 59
    - Emilia - 60
    - Tessa - 61
Distribution of resources and supports 62
Boundaries 67

Chapter 6: Discussion and Conclusions 71
  Value and Undervaluing 71
  Distribution of resources and supports 74
  Boundaries 77
  Reflections on methodology 79
  Limitations and implications for the future 82
  Conclusions 83

References 85

Appendices
  Appendix A – Email Recruitment Script 92
  Appendix B – Participant Screening Form 94
  Appendix C – Letter of Information and Consent of Parents / Guardians 96
  Appendix D – Letter of Information and Consent of Participants 99
  Appendix E – Assent for Minor to Participate in a Study 102
  Appendix F – Focus Group Interview Guide 104
Chapter 1: Introduction

This thesis involves an exploration of the social construction of disability. The ways disability is constructed socially, directly impacts the self-concepts and relationships of individuals labeled as disabled. This thesis looks specifically at the constructions of disability for high school students labeled with autism spectrum disorder (ASD).

At this point in history, the constructs surrounding ASD are heavily based on parent and professional perspectives. These accounts frequently focus on treating the presenting ‘challenges’ of autism and motivating the individuals who are ‘unfortunate’ enough to have this ‘disorder’ to behave like their ‘neuro-typical’ peers. This is done in kindness, and often with great love. Parents typically hope for the ‘best’ for their child, and in North America (and much of the Western world), this hope commonly includes academic success, circles of friends, athletic achievements, at some point a healthy intimate relationship, employment, home ownership and children. Common professional discourse at this time supports this desire for therapeutic efforts to normalize the behaviour of people labeled with ASD. Many of the ‘challenges’ of autism inhibit these milestones from being achieved in a traditional way and can therefore lay the groundwork for a focus on ‘fixing’ the child and getting him or her as much ‘on track’ with typical development as possible.

Autism, as the diagnostic label suggests, is experienced on a spectrum.
Individuals diagnosed on this spectrum can have vastly different presentations of their autism, making an understanding of the condition difficult. Consequently, many individuals draw together pieces of information and form stereotypical ideas of who someone with autism is. These generalizations often include some or all of the following notions; limited or no speech capacity, profoundly narrow interests that limit all other daily activity, extreme violence and aggression, perpetual rocking and hand flapping, exceptional savant-like abilities in subjects like mathematics, and the requirement for constant and continual care and support to function.

Notions such as these can inspire pre-judgment of a person labeled with autism and his or her capabilities and potential. As the voice of individuals on the autism spectrum grows louder, increasing acceptance of Dr. Stephen Shore’s\(^1\) well-known mantra, ‘if you’ve met one person with autism, you’ve met one person with autism’ is felt. Being labeled with ASD typically activates treatment programs, therapeutic interventions; parent-training and coaching; social skill training; education-based accommodations and more. These standardized reactions to a label fail to recognize the diversity among people with autism and are less focused on the individual person’s

\(^1\) Dr. Stephen Shore is diagnosed on the autism spectrum and was recommended for institutionalization due to his ‘limited skills’ as a child. Today he is a professor at Adelphi University, is married and is an internationally recognized speaker and author, focusing his work on adult issues pertinent to education, relationships, employment, advocacy and disclosure. His insider perspective from the spectrum has enlightened societal and professional understanding of living on the autism spectrum.
needs, but rather a chain reaction of interventions understood to be ‘good for (all) people with autism’.

At the age of 17, I had the privilege of working with a young woman who was diagnosed as non-verbal autistic. I was hired as her respite worker to take her into the community and do things that girlfriends would do. We went to the beach, shopping and hiking and had lots of laughs. On the surface, it appeared that her skills were poorly developed and her potential limited and once doctors identified her challenges were connected to autism, she was labeled as low functioning. Were I not able to look beyond the surface, I might have missed what an incredibly compassionate, intelligent, kind and beautiful person she is. This young woman set the tone for my professional attitudes and profoundly shifted my understanding of disabled people. She taught me that I must never pre-determine a person’s capabilities based on their diagnosis, presenting characteristics or what a file says about them. She taught me patience and to stay judgments, to allow people to set their own limits and that if you give time, space and understanding, the possibilities are limitless. She taught me to look beyond expert opinions and to let her show me who she is and what she is capable of.

Over the course of my career I have intentionally aligned myself with professionals and organizations who share these philosophies that I have adopted and taken ownership of. I have grown and developed both personally and professionally because of the hundreds of individuals labeled with autism who I have had the pleasure
of knowing.

I was inspired to conduct this thesis because for so long I have been a part of conversations about children, youth and adults labeled with autism and I wanted to take the opportunity to conduct research that really heard their voices and valued their perspectives. I believe that so much of what continues to construct disability, particularly autism as problematic and in need of a ‘fix’, is constructed by from outsiders who believe there is a right way to have a conversation, make a friend or be a ‘successful’ adult. I believe there are many, many ways to have conversations, make friends and be successful as a person and I feel strongly that conducting research with labeled individuals allows power to shift and can redefine what is considered expert opinion.

With self-advocacy growing exponentially within the disability community, recognition of individual and collective resistance to treatment focused interventions, problematizing outsider directions about who and how labeled people should be is possible and increasingly prevalent. This is especially relevant for young people labeled on the autism spectrum because these prominent and respected voices of people ‘like them’ (meaning labeled similarly) are resisting invisible barriers established and maintained by labels. Adolescents like those interviewed for this study are growing up in a community where they are increasingly empowered to push boundaries and surpass expectations traditionally held for people ‘like them’.
At this point in history, I believe asking individuals on the spectrum how they make meaning of the label that is applied to them is profoundly important and also timely. I have worked in the autism community for more than ten years and over the last couple, I have begun to see a shift in the research initiatives, where space, albeit small, is being created for perspectives from the spectrum. Continued focus on these conversations can only work to unleash the voice of a previously silenced population and I am elated with the possibility of things we may learn as a result.
Chapter 2: Historical and Theoretical Context

I think for most people, myself included, initial understandings of disability and difference begins from a place of ‘problem’; a dysfunction in need of correction and in many cases, worthy of pity. For as long as I can remember, this has felt uncomfortable to me. As I have consumed the literature for this thesis, I have also come to understand how deeply entwined the broader social perceptions of what disability is and is not, are embedded in my own understanding of it. This leaves me feeling all the more uncomfortable.

In an effort to grapple with my own understanding and construction of ‘disability’ and so I can fully explore and negotiate my research questions, I believe I must first understand the prevalent theories and contextualize some of the history surrounding disabled people and their movements. Through this, I believe it is possible to understand the literature reviewed and also articulate where my own theoretical positioning stands at the time of this thesis. Given the space and time limitations of an MSW thesis, the historical and theoretical context that follows is a high-level overview of the key points.

Historical context

As individuals seek to establish and develop their own sense of identity, naturally individuals look to the world around them as a way of positioning who and where they fit, beginning to categorize and differentiate the ways in which one is like and unlike
others (Boyle, 2013). Fook (2012) refers to this process as ‘othering’ wherein, an oppositional binary of ‘other’ is created in comparison to an individual or personal attribute, and this ‘other’ is typically viewed negatively or as holding less value. This process can result in bias, labeling, judgment and preconceived notions that in no way reflect who a person truly is (Damico, Buller & Ball, 2010; Fook, 2012).

During the eighteen hundreds and early nineteen hundreds, this process of identifying, categorizing and labeling difference – in particular, difference based on presumptions of (in)ability - began happening in North America where individuals presenting as disabled were categorized based on a presumption of their ability (Queens Printer for Ontario (A), 2014). Much of the language used to refer to people presume to have intellectual or developmental differences (including we would now understand as having ASD) stemmed from the eugenics movement and the prevalent medical, scientific and moral viewpoints of the time (Queens Printer for Ontario (A), 2014). Overtime, labels evolved to include ranking systems within a particular label. For example, within the category of ‘mental retardation’ (a term no longer used to refer to people with intellectual disability), early rankings such as moron, idiot and imbecile were replaced by the gradations of mild, moderate and severe and profound mental retardation during the nineteen sixties (Queens Printer for Ontario (B), 2014). These labels did more than just categorize people; they carried with them a definitive set of assumptions about and expectations of people so labeled.
Over the course of history, there have been societal shifts regarding expectations of people based on their assigned label. Language practices have also begun to shift with more respectful ways of identifying and labeling disabled people emerging (Boyle, 2013; Queens Printer for Ontario (C), 2014). Right up to our present day, debates continue about the best, right or most respectful language to be used by academics, disabled people and the systems which allocate and distribute funding and provide services and resources (Crow, 1996; Queens Printer for Ontario (D), 2014). It has become clear to me during the course of this research that the language one uses in speaking about people with disabilities is often an indicator of which ideology or theoretical position one holds and the associated assumptions. The medical model and social model are, I would argue, the most dominant voices in the study of disability however debates and shifts in both are occurring. Critical disability studies is a more decent development in disability theorizing that is gaining traction. Within disability studies, constructs of ‘impairment’ and ‘disability’ are critical to our understanding of each of the different models currently dominant in theorizing disability at this point in time and will be explored further throughout the following sections.

**Medical Model of Disability**

As the medical system and the diagnostic criteria for ‘psychiatric disorders’ and other cognitive impairments evolved and assessment tools were developed, the labeling of individuals increased and was used as a way of explaining their presenting ‘problem’
(Damico, Muller & Ball, 2010). Historically, the rise of science, industrialization and eugenics led to a common understanding of impairment as a ‘problem’, a difference that is found within the individual, their impairment is problematic and in need of treatment or correction (Mallett & Runswick-Cole, 2014; Boyle, 2013). Problematizing disabled people in this way works to pathologize individuals by rooting impairment and difference in how a body and mind work and function in comparison to others. By understanding people, and consequently difference in this regard, the body and mind are marked as ill, diseased, and/or broken – as a medical problem (Mallett & Runswick-Cole, 2014). Further to this way of thinking, any oppression or disadvantage the disabled person experiences is directly linked to their functional limitation and impairment, and can only be rectified through treatment of their symptom(s) (Crow, 1996). This ‘treatment’ is commonly dictated by ‘expert discourses’ constructed and enacted by the powerful medical professionals conducting and analyzing assessments (Hiranandani, 2005).

Power is ever present within the medical model discourse where ‘experts’ are positioned as knowledgeable about the ‘best’ options for disability treatment. During the era of eugenics and institutionalization these professionals claimed to best know how to raise children ‘like that’ and in many cases, influenced biological parents to such a degree that many signed guardianship over to the state, seldom seeing their children again (Pantich, 2008).
As conversations about language evolved, so too did ideas about who disabled people are and from that, emerged greater understanding for their capacity to influence and participate in society. This shift was largely aided by the disabled people’s movements, for example the Anti-Psychiatry movement in the nineteen sixties through which disabled people themselves rebelled against the overmedication of people labeled with mental health impairment and demanded greater emphasis on unique treatment plans (Boyle, 2013). Resistance to institutions as the ‘best’ and ‘only’ residential option and to their ‘best practices’ for treating difference began to surface (spurred in part by the rampant abuses of people with disabilities in intuitional care), eventually leading to the deinstitutionalization movement and the final closing of large institutions in Ontario by 2009 (Queens Printer for Ontario (A), 2014). While as a society, we are largely better informed about the potential of disabled people, the medical model ideas surrounding disability continues to receive less support than dominant understandings rooted in the medical models. Perceptions of disability as a ‘problem’ in need of treatment, and this notion continues to hold a significant place in the conversations surrounding disability today.

Recognition of the impact that labeling and categorizing of individuals has on a person and societies understanding of disability presupposed that there is an ideal way of being, one based on a presumed set of valued abilities – that is an ideological positon that privileges some bodies / minds over others (Boyle, 2013; Crow, 1996).
Social Model of Disability

By way of countering this dominant perspective, the social model of disability emerged in the 1970s “feisty” and ready to challenge the medicalization of disability (Shakespeare, 2006: 6). The social model reframed the ‘problem’ of disability as existing within a society that was inaccessible and was shaped by problematic reactions to disabled individuals and their difference. This model and much of the activism surrounding it was founded on the notion of disability as a social construct (Woodward, 2002). This social constructionist view requires that instead of focusing on the individual we must examine and then redefine how society looks at and understands the nature of what is actually ‘disabling’ individuals.

This shift away from the person as the problem came as a relief to individuals who had been struggling to negotiate their identities, allowing them to feel comfortable in their own bodies (Crow, 1996) and their own ways of being in the world. “The social model perspective was and continues to be hugely inspirational. It is not melodramatic to say that the social model of disability has saved and continues to save lives” (Goodley, 2014:7), and does so by challenging the disablism which can be so destructive for individuals, communities and society as a whole (Goodley, 2014).

The social model of disability has been instrumental in improving access to opportunities for disabled people, however much of this focus has been on reducing physical barriers. Those experiencing intellectual and social difference continue to meet
many barriers to participation and equal opportunity in their communities (Crow, 1996).

**Challenges with dominant perspectives**

The medical model and the social model are the loudest voices in most venues, however they are not without their faults, and many argue that they are insufficient to adequately negotiate the complexities of ‘disability’ independently. Of primary importance in this regard is how each model attends to and facilitates (or suppresses) the voice of disabled individuals, their ability to contribute and participate in their own care and in the movement that propels their participation and acceptance in society forward.

The medical model is shaped and founded upon expert opinion, which assess problems and direct treatments. This frequently negates individual perspective and problematizes people because the way they communicate, think, move and / or function happens outside of a narrow set of norms defined by a social construction of who citizens ought to be (Goodley, 2014; Hiranandani, 2005; Mallett & Runswick-Cole, 2014).

The social model, in spite of all its good, the progress and the liberation of disabled people, has been heavily criticized for what it fails to acknowledge (Crow, 1996; Mallett & Runswick-Cole, 2014; Oliver & Barnes, 2012). Discrepancy about the depth and reach of the model, lack of acknowledgment of impairment, pain, oppression and the body, the often narrow foci which excludes some disabled people and that is representative of a primarily white, male, middle class, Western world (Mallett &
Runswick-Cole, 2014) are among the most hotly contested constructs of this model. This model has been profoundly influential, primarily in the United Kingdom, but does hold a prominent place in disability conversations worldwide.

**Critical Disability Theory**

Academic conversations about disability theory and exploration of both the medical (with its almost exclusive focus on impairment) and social modes of disability (focusing much more on disability / disablement) have lead to the creation of binary distinctions between the two (Meekosha & Shuttleworth, 2009). This fails to acknowledge that neither impairment or disability is completely separate from the other, nor does it recognize what might be gained by reconsidering either approach. Critical disability studies acts in many ways, as a bridge between these different theoretical positioning, fueling movement away from conversations about ‘social versus medical models’ and ‘disability versus impairment’ (Goodley, 2014; Meekosha & Shuttleworth, 2009; Shakespeare, 2006) and toward thinking about people. The increasing presence of critical disability studies within theoretical positioning has allowed fresh perspectives and understandings of “lived experience of disabled people and the potential ways forward for social, political and economic change” (Meekosha & Shuttleworth, 2009:49). These conversations are rich with perspectives, frustrations and hopes of disabled people themselves who, if not leading these conversations are actively participating in them.
Critical disability studies does not operate in a vacuum and the social model was very present within the development of critical disability studies (Hosking, 2008 in Meekosha & Shuttleworth, 2009). At their core both theories are born out of critical theory (Meekosha & Shuttleworth, 2009). The ultimate goal for any critical theoretical positioning is “to smash myths and empower people to change society radically” (Neuman, 1997:83), questioning the current social climate and strategically shifting conditions more favorably for the oppressed and disempowered. Throughout this thesis, I attempt to challenge commonly held assumptions and knowledge rooted in exclusively medical model thinking with respect to individuals labeled on the Autism spectrum.

**Situating myself in the theory**

The way this thesis was constructed is very much entwined in the values and beliefs I hold personally. I believe it is important to acknowledge where, at this moment in time, my perspectives sit, not only to add efficacy to the tone in which it was written and the intention in its structure, but because over time things shift. What I believe and value today may change with time and the evolution in perspectives.

Theoretically, I fall most in line with critical disability perspectives, placing emphasis on the people within the flawed structures and abelist ideologies that perpetuate the oppression and devaluing of disabled people. I acknowledge the huge and valuable impact of the social model of disability, and the aim of removing barriers
for disabled people, which it seeks to achieve. Recognizing that social model has made a
significant impact for people who are physically impaired, there is still much work to be
done for those identified with intellectual and developmental disabilities. I believe that
there also is a place, small as it may be, for the medical model thinking with respect to
early identification and intervention and best practices with regards to treatment
protocols.

I do not believe that anyone should ruthlessly pursue therapeutic intervention
within the intention of ridding a person from his or her disability or difference. I
acknowledge we live in a socially complex, able-body / able-mind preferred society and
that for people to negotiate within this society, particular ways of being are desired.
Knowing the climate of our current society, it is necessary to provide people with every
opportunity to achieve their full potential. Providing every opportunity does not mean
forcing a child to attend a therapy that they hate, nor does it mean ridding a person of
their isocracies because they are ‘strange’; it means creating intentional opportunities
for skill growth and development in all areas, and allowing the individual to take the lead
and pursue the type, duration and intensity of therapy which feels right to them.

I believe that as a society we have socially constructed what defines a disability;
consequently it directly impacts an individual’s self-concept and shared identity within
their community and in a school system. I think this social construction works to
stereotype individuals and box their potential into predefined outcomes, which further
disables and disadvantages them. Individuals who are marginalized because of their
disability are not only victims of this ostracism, but of the social-degradation that the
label casts over them, allowing people to limit their potential before they even get to
know or understand them. In an academic system directed by documents which define
people, dictate program modifications and objectives, and hold reports on each struggle,
outburst and setback, I believing labeling can deeply impact the outcomes of these
students.

I come predominantly from a critical perspective where, my aim is to “smash
myths” (Neuman, 1997: 83) about the presumed limitations of disability and inspire
acceptance of people on an individual basis, looking beyond labels and progress reports,
creating space for different ways of being in the world. I do also acknowledge that much
of my formal training and professional experience is situated in a progressive medical
model environment and the language practices of these experiences do continue to
seep into my vocabulary from time to time in spite of my continued efforts to adjust my
words and reshape my thinking.

Looking towards the literature

Literature reviewed for this thesis will explore labeling and labeling theory, the
expectations of disabled people founded on a diagnostic label and the concept of
internalized abelism as well as the intersection between these concepts. The review will
focus on individuals diagnosed with Autism Spectrum Disorder (ASD) and will speak to
the current academic understanding of student experiences and opinions as well as their participation in creation of knowledge about their own lives. It is my hope that this review will position you as a reader as able to hear and learn from what I believe to be the authentic voice of the participants in this study; to better understand their experiences and if I am successful, to uncover some deeply held assumptions.

Following the literature review an overview of the research methodology and methods used in this thesis will be covered as further positioning for the findings and discussion sections of this thesis.
Chapter 3: Literature Review

“A neurological condition that can render standard forms of communication like tone of voice, facial expression and even spoken language unnatural and difficult to master, autism has traditionally been seen as a shell from which a normal child might one day emerge. But some advocates contend that autism is an integral part of their identities, much more like a skin than a shell, and not one they care to shed” (Harman, 2004:2).

For each person diagnosed with autism, the presentation and existence of ‘symptoms’ are different, simplifying and also complicating their life in a multitude of unique ways. The way society thinks and speaks about autism and the individuals diagnosed on its spectrum, profoundly impact and shape how people construct their understanding of themselves and the development of their identities (Woodward, 2002). The common understanding of a “shell” from which one can emerge has been generated by a historical pattern of disabled people, including individuals labeled with autism, being spoken for rather than included in the conversation, (Humphrey & Lewis, 2008). Expectations for an individual persons’ potential has also been reduced because of assumptions about a diagnosed label (Allday, et al., 2011; Boyle, 2013).

In this literature review, I draw from labeling theory and critical disability studies to discuss disability labels and how they function socially, considering both ‘negative’ and ‘positive’ social consequences of labels. I then focus specifically on labels as they relate to expectations of disabled people, particularly those diagnosed on the autism spectrum within the school setting. In the final sections I explore the necessity to include oppressed voices in conversations about their own lives, establishing space for
the co-creation of knowledge and new possibilities for who and what qualifies as expert opinion.

**Labels and Labeling**

The practice of labeling has a long history in the field of medicine, education and social and psychological sciences and is perpetuated by the “human propensity to generalize, stereotype, and construct meaning” (Damico, et al., 2010:18) based on observations from the world and individuals in it. The meaning people make from how others perceive and categorize them can be very influential in the construction of their own identity (Boyle, 2013). In an attempt to avoid undesirable categorization, people will often filter the outward presentation of themselves in an attempt to shape or control the external labels applied on them (Boyle, 2013; Woodward, 2002).

Canadian Sociologist Erving Goffman conducted several influential studies during the 1950s and 1960s (Boyle, 2013), perhaps, most famous is the “presentation of self in everyday life” conducted in 1959 (Treviño, 2003). Results from this study indicate that typically, when a person is in the company of others, he or she will attempt to guide and control the interaction through contriving the environment (setting, appearance, or their own mannerisms) to depict an idealized version of themselves which others will base impressions on (Treviño, 2003). At the same time, the other person or people in the interaction are using information gathered from their observations to formulate an opinion of the other; in formulating this opinion, often there is categorization of the
person and the characteristics or qualities he or she presents with (Treviño, 2003).

At present, the social construction of disability tends to focus on the more negative or problematic aspects of impairment, frequently suggesting that individuals labeled as disabled are incapable, incompetent and less likely to achieve, than their non-disabled peers (Damico, et al., 2010; Ho, 2004). It is important to understand labels in the context of the performance that seeks desirable impressions from others. External labels, particularly those with a negative connotation such as a disability, are often imposed on people before they can even begin the act of good impressions; this is a significant disadvantage (Boyle, 2013).

Labeling theory highlights a social process of identifying others as ‘different’ from oneself and predicts that persons who are labeled will perceive themselves, and even behave in ways that are in accordance with the negative stereotypes their particular label(s) elicit from society (Osterholm, et al., 2007; Shifrer, 2013). Research in labeling theory frequently demonstrates that the negative connotations of the label are applied to the individual regardless of personal characteristics, even those that present in contrary to the generalizations about their label (Damico, et al., 2010; Ho, 2004). “Treating labels as verification of intrinsic disability” (Damico, et al., 2010:15) can be damaging a persons’ own self-image and to the opinions and expectations that others draw about them.

When a person is viewed exclusively through the lens of their label, all of the
other parts of their personality and experience can seemingly fail to exist, and may be excluded from their identity. The practice of labeling is further entrenched by the ways systems of support for disabled individuals are constructed and maintained. Within the current system, money for support and care could not be provided without legitimizing the need through a label (Boyle, 2013), the same is true for accommodations and specialized opportunities based on need, which almost always require a diagnosis to access (Ho, 2004). This kind of labeling, however, can also have some benefits. A label can also be useful in helping people such as teachers and caregivers understand learning needs for a person and can also provide a place to begin support with more tailored interventions specific to particular needs (Ho 2004; Jackson Brewin, et al., 2008; Osterholm, et al., 2007). Categorized labels allow individuals to pull together challenges into a tidy package that are digestible and meaningful for others (Diamico, et al., 2010). It is common that “individuals displaying atypical behaviours... are more likely to be stigmatized and rejected when there is not a ready explanation for their difference” (Osterholm, et al., 2007:6).

While it is clear that there is some value, given the context of current support provisions, and established best practices for treatment planning, the negative consequences are very significant. “A review of the literature relevant to sociological labeling theory offers relatively strong support for the view that negative or deviant labels generate unfortunate expectations” (Osterholm, et al., 2007:5).
Expectations

During the late 1800s in Belgium there was an asylum that housed 270 children labeled as ‘epileptics’ and ‘idiots’, and as part of their treatment model, these children were divided into “improvables and nonimprovables” (Boyle, 2013:1). There is a long history of placing value on a person based on their perceived potential, and whether it is likely they may achieve ‘normal’ behaviour. This valuing process is reflective of the power and control exuded in the medical model clinical assessments of disabled people (Damico, et al., 2010) and may dramatically shift or reduce the opportunities for support, growth and development provided to a labeled individual.

When professionals observe ‘difference’ in their patients or clients, they commonly begin to build stereotypical categories and slot the individuals into widely recognized diagnoses that fit with the presenting symptomology (Shifrer, 2013). This process can be useful when considering a medical condition in need of specific or specialized treatment methods. There is great power allotted to health-care professionals or educators who define a person they support through a particular diagnostic category which can be transformative for individuals. A study exploring parental perspectives on the quality of life at school for their children diagnosed with Asperger’s Syndrome (a subcategory of ASD), found that when professionals were unaware of the meaning or existence of their child’s diagnosis, they were ill equipped to support them (Jackson Brewin, et al., 2008). They reported that when school staff had
an accurate understanding of their child’s needs, teachers were less likely to identify their child’s behaviour as ‘bad’ or as a result of poor parenting and were more understanding and accommodating to the student’s presenting needs and challenges (Jackson Berwin, et al., 2008).

What can be troubling about this process is that frequently labels are the means to access assessment and testing and these assessments are based largely on observations from other professionals (perhaps teachers or primary health care providers) and parent-report data (Allday, et al., 2011). In an effort towards efficiency, this data is frequently reviewed prior to in person observation or interaction with the individual being assessed and can create a labeling bias (Allday, et al., 2011). In my professional experience, I have also encountered several children who have reports written by professionals who have had extremely limited interaction with the child, and in some cases, have never met them. I believe this largely biases their report and fails to capture an accurate reflection of who the child is at this moment in time.

In the early 1960s Robert Rosenthal conducted a study involving lab rats and student experimenters. He randomly assigned the label of ‘intelligent’ and ‘less-intelligent’ rats and asked the experimenters to teach the rats to run through a maze. The rats labeled ‘intelligent’ had exceedingly better outcomes than those labeled ‘less-intelligent’ (Rosenthal & Jacobson, 1966). In 1966 Rosenthal and Jacobson published their study applying the same experimental design to teachers where they randomly
labeled students as more or less likely to achieve significant IQ gains in the classroom. Not surprisingly, “the children for whom the teachers had been led to expect greater intellectual gain showed a significantly greater gain in IQ score than did the control children” (Rosenthal & Jacobson, 1966:116). The researchers concluded that the dramatic gains were likely as a result of increased attention from the teacher, and teaching methods and curriculum more specifically tailored to the students expected to achieve greater gains (Rosenthal & Jacobson, 1966). Both the lab students and teachers expected more from those labeled more likely to succeed and not surprisingly, they did achieve greater success.

Subsequent research on the topic has indicated that disability or delay labels ascribed to individuals equates to lowered expectations for success, and a startling lower skill acquisition rate for these same individuals (Boyle, 2013; Damico, et al., 2010; Ho, 2004; Osterholm, et al., 2007; Shifrer, 2013).

**Internalized Abelism**

From the moment a child is born, he/she emerges into a world where he/she receives messages that to be disabled is to be less than, a world where disability may be tolerated but in the final instance, is inherently negative. We are all, regardless of our status, shaped and formed by the politics of abelism (Campbell, F.K., 2009:17).

As humans, we are shaped by these messages that directly influence how difference and disability are understood in our own lives. Societal structures and common practices establish “network of beliefs” (Campbell, 2009:5), the common ways
of doing, thinking, moving and behaving have become what is considered ‘normal’ (Campbell, 2009; Mallett & Runswick-A Cole, 2014). Through this common understanding those who are born with or acquire different ways of being in the world are “then cast as a diminished state of human being” (Campbell, 2009:5).

Our un/conscious everyday lives have been shaped and influenced by abelist ideologies. These discourses build on information gathered and stored through observation and experiences with one’s own body; relationships and interactions with others in society; and experiences of judgment from others (Campbell, 2009; Wolbring, 2007:1 in Goodley, 2014:22). For disabled individuals, abelism often translates into an internal process where they embrace the identity and strive for abilities which are not their own. Campbell (2009) identifies this as “internalized abelism” (7).

Rosenwasser (2000, in Campbell, 2009) identifies the internalizing of oppression occurs as an involuntary reaction to social constructions of what or who a person ought to be. This internalization of abelist ideologies would not exist without recurring oppression and ongoing negotiations of identity through competing responses to disability, which overtime becomes internalized, requiring little encouragement to remain ever present in the person’s mind (Campbell, 2009).

Internalized abelism instills self-doubt and an undervaluing of oneself, which can serve as a measure for how a person positions themselves “in the social hierarchy of ability, potential and acceptance” (Baines, 2012:547). This can shape how a person
accesses services and views their entitlement to equal opportunity and inclusion in their school, community and in the world.

**How the label functions at school**

Labels that are used in the school system are generated by a “medically based system of categorization” (Ho, 2004:89). These labels are taken up in school systems where they have particular functions, and essentially two main aims. The first is to provide appropriate access to support services for children identified as needing it, within the regular school system (Boyle, 2013; Kluth, 2003). The second is to link a “cohort of needs” (Boyle, 2013:6) with particular learning styles so that educators can strengthen their teaching methods and present information most appropriately for identified students (Boyle, 2013; Kluth, 2003). Parents also report value in labels at school due to increased understanding of student needs resulting in increased support and access to individualized instruction (Jackson Brewin, et al., 2008).

These intentions in labeling are perfectly reasonable, but the trouble is, the use of labels has been linked to negative outcomes for students, primarily because the label ignites the assumption that this student is less capable than the student without the label (Damico, et al., 2010; Ho, 2004). Shifrer (2013) reported study findings indicating that students with an intellectual or learning disability label were perceived by both their teachers and their parents are less likely to advance to post-secondary education than their similarly achieving, unlabeled peers. When students are expected to attain
less, they are more likely to be placed in “less rigorous, ‘special-ed’ classes that have lower attainment probabilities. Teachers also often have different expectations of and attitudes towards these students” (Ho, 2004:87; Shifrer, 2013).

Knowledge about living with disability labels - including the label of autism - has for a very long time been primarily defined and understood through the lenses and words of parents and professionals (Billington, 2006; Jackson Brewin, et al., 2008; Mallett & Runswick-Cole, 2014). Labeled people who experience diagnostic categories as part of their daily social lives, are rarely asked for their own options and perspectives. This contributes to the internalized ableism and construction of their identities.

“Perceptions of ability continuously emerge through social interactions, which in turn play[s] a central role in shaping how youth negotiate their identities as learners” (Baines, 2012: 547). Understanding the ways these identities are constructed and how the label of autism contributes to the construction is a powerful consideration (Baines, 2012).

Research conducted with youth diagnosed on the autism spectrum by Kelly (2005) indicated that children and youth make meaning of their label or diagnosis “in the context of their own lives and are able to articulate their own experiences and perceptions” (273). What it means to embody their place on the autism spectrum is influenced by reactions and interactions surrounding their label as well as their strengths and needs (Humphrey & Lewis 2008). Because the autism label can be such an
influential aspect of the education system, schools are a primary environment where these interactions can and do occur. Kelly’s (2005) study also found that youth diagnosed with autism were found to rely on their caregivers “to develop their understanding of learning difficulty labels” (263).

From these two primary environments of influence, Humphrey and Lewis (2008) identify a divergence between descriptions of student’s autism as “negatively valenced notations of their difference” (31), and “those for whom acceptance of [autism] was central” (31). For many students, association with the label of “autistic” or being identified as having “autism” brings negative connotations, particularly for those who are higher-functioning (Baines, 2012; Humphrey & Lewis, 2008; Kelly, 2005). Many of these students actively avoid a connection with this label by way of positioning themselves socially, and through rejection of academic and social support that may identify them as autistic (Baines, 2012).

“Awareness or lack of awareness of the child’s diagnosis affected how the child was treated at school by fellow students, and in particular, by teachers and other professional staff” (Jackson Brewin, et al., 2008:5). This awareness or lack of awareness is complex and multifaceted. Through conversations with parents, Jackson Brewin, et al. (2005) identified that not only is awareness of the label or diagnosis important, but also the educator or peers thorough understanding of that label and its meaning for the individual, that contributes to the positive or negative framing of the label. Students
must operate as “skillful social actors” (Kelly, 2005: 261) to negotiate between the various understandings of their needs and difference as a way of protecting themselves and creating acceptance where they are able.

Carrington and Graham (2001) identified that with respect to students on the autism spectrum, it is necessary to gain a more “in-depth exploration of the real-life experiences” (47) through research and academic conversations. Without the inclusion of their voice, readers are left with the suspicions and opinions of teachers and parents who may speak for students on the spectrum. This is essential because findings from Hughes & Patterson (1997, in Kelly, 2005) suggest adults routinely underestimate the skills and abilities of labeled children, as well as the breadth and depth of their experiences.

Students with autism “are on average 20 times more likely to be excluded from school than their peers” (Barnard et al., 2000 & NAS, 2003b, in Humphrey & Lewis, 2008:24) and without a thorough understanding of this experience, there can be limited change. Autistic students are frequently excluded because of their social difficulties, uncoordinated movements and restricted range of interests (Billington, 2006; Humphrey & Lewis, 2008; Jackson Brewer, et al, 2008). Extracurricular activities and social situations are structured in schools to meet the needs of the majority of the population; students on the autism spectrum fall outside of these boundaries and are consequently excluded (Jackson Brewer, et al., 2008). Increased emphasis on including the
perspectives and opinions of students labeled with autism would help to diminish this exclusion thus increasing opportunities and inclusion of different students.

**Participation in the creation of knowledge**

As the disability movement progresses and society’s understanding of what it means to be disabled shifts, there is recognition of the need to include the perspectives and experiences of disabled people in the work that so deeply affects them (Crow, 1996). Participatory techniques are increasingly being accepted as they actively include the ‘emic’ view within emerging literature, balancing out the dominant ‘etic’ voice (Pauwels, 2015). These “autistic insider accounts”, (2006:1) Billington tells us, are providing “insights into the inherently social contexts for the development of human feelings, thinking and meaning” (2006:1).

These insights give way to the notion of equal humanity among disabled people where, for so long, they have been perceived as less (Mallett & Runswick-Cole, 2014). As academics consuming literature who are able to read and connect with the words of people previously silenced, there is a realization that the words being utilized are not unlike the words that non-disabled readers use themselves to tell their own life stories (Billington, 2006). In choosing to read or listen and attempt to appreciate an individual’s experiences in their own words, Billington (2006) suggests that this process begins to break down the idea of ‘abnormality’ and creates space for individuals labeled as ‘other’ to establish new ways of knowing and understanding the world.
Context of this research

The research for this thesis will seek to understand how high-school students diagnosed on the autism spectrum make meaning of their label. Research questions will focus on their understanding of how labels and expectations shape their experiences at school by engaging arts-based research methods.

This research was prompted by my work with children and youth diagnosed on the autism spectrum over the last thirteen years. Much of my professional work supporting families has involved the complex relationships between a family and their child’s school. So often the internal debate has arisen for parents about whether or not they should tell their child’s school about their diagnosis for fear of the implications the label may have on how their child is treated. Through conversations I have had with autistic youth over the last number of years, I have begun to wonder what impact being labeled has on them. Do they find it useful to identify they are diagnosed with ASD and therefore need accommodations at school and understanding of their unique needs? Or do they find it harmful, being associated with a broad label of ASD, which can mean so many different things? I have long felt that individuals on the autism spectrum have been spoken for, instead of spoken with, and feel it is of utmost importance to include their voices and perspectives in the conversations that occur about their lives.
Chapter 4: Methodology

Research Design

The intent of this study was to create space where the thoughts, ideas and perspectives of a small group of high school students labeled on the autism spectrum were considered. By including the perspectives on individuals diagnosed on the autism spectrum, it is possible to gain an understanding of how they make meaning of their label. The study was designed and conducted in a way that was inclusive and safe for participants.

Individuals diagnosed on the autism spectrum can experience difficulty with both social communication$^2$ and restricted and repetitive patterns of behaviour$^3$ in varying degrees of severity, based on the level of support that is required (American Psychiatric Association, 2013). This can mean difficulties with new environments, new people, unfamiliar routines, processing oral communication and navigating unwritten social “rules”. In some individuals this may be experienced through anxiety, increased sensitivity to sensory information and an increase in self-regulatory behaviors as a way to cope. Considerations regarding anxiety, difficulty with new environments and people,

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$^2$ Social communication challenges refer to persistent challenges with social interaction across multiple contexts and include difficulty with social reciprocity, non-verbal communication and difficulty establishing and maintaining relationships.

$^3$ Restricted and repetitive patterns of behaviour, interests or activities can include motor movements, insistence on sameness and inflexibility, highly restricted passions frequently in an uncommon interest area and sensory sensitivity.
specialized sensory needs (such as type of lighting, background noise, and more) were considered and accounted for during the design of this research study.

This study was envisioned, designed and conducted using a critical framework (Kreuger & Neuman, 2006). Within this framework, research is used to challenge false beliefs that fail to recognize individuals who are marginalized as creative, adaptive and full of potential (Kreuger & Neuman, 2006). Individuals labeled with autism have been acknowledged as marginalized within social contexts, including high-school (Billington, 2006; Humphrey & Lewis, 2008), and as such they are, in some circumstances not included in conversations about their own lives or research about their label (Connors & Stalker, 2007; Humphrey & Lewis, 2008; Tangen, 2008).

The emphasis in this study on participant perspectives and gaining an understanding of lived experience aligns with the intentions of a phenomenological methodology (Groenewald, 2004). This methodology seeks to understand what it is like to experience a particular phenomena, such as living with a disability label, and does so through conversation with multiple perspectives, allowing a researcher to understand individually and more generally the lived experience of their participants (Groenewald, 2004; Giorgi & Giorgi, 2003 in Humphrey & Lewis, 2008).

Consistent with the approaches of critical and phenomenological methodology, the methods engaged in this study were structured to hear the participants’ stories and understand their perspectives. The methods (discussed in-depth later in this chapter) of
semi-structured short interviews, participant art creation and focus group were utilized to engage with and give power to the voice of the participants in this study.

**Participants**

Participants for the study were recruited through an Ontario based charitable advocacy organization named Autism Ontario (AO). Recruitment materials were distributed by a AO staff person (see Email Recruitment Script, Appendix A) who sent them through a monthly e-news letter and also posted them on social media such as Facebook and Twitter sites.

Interested participants and / or their parents were asked to contact me directly where I conducted a phone screening (see Participant Screening Form, Appendix B) to determine if the participants met eligibility to participate. The basic criterion for participation in the study was that participants be high school students with a diagnosis on the autism spectrum. Due to the time constraints of an MSW thesis and also a focus group methodology, I felt certain limits were necessary to ensure I could properly support the participants given the context. I required that participants be comfortable speaking about their diagnosis with functional verbal skills and that they received limited support in their academic setting. Safety for both the participants and the research team was also a consideration and I required participants have established self-regulation strategies and limited verbal and physical aggression. It was my intention to create situation where individuals could participate well with the relatively limited
support I could make available during the workshop. If at the end of the phone
screening, it was felt their child would like to and was appropriate to participate, a pre-
workshop meeting was scheduled.

In total, five youth participated in this study. No two youth attended the same
school and geographically, were spread throughout the recruitment area. Their ages
ranged from 14 years to 16.5 years and individuals had diverse experiences in terms of
their classroom placements and systems of support at school. Each participant signed
consent at the pre-study meeting and reaffirmed consent to participate several times
throughout the research study day.

Methods

Semi-structured Interview

Semi-structured interviews are among the most popular data-collection methods
(Bannister, 1994; Hopf, 2004 in Humphrey & Lewis, 2008) because they generate data
that is in-depth and personalized to the individual (Harrell, Bradley, et al., 2009).
Utilizing semi-structured interviews as a research method “involving individuals with
ASD provides a voice for participants and a window into their thoughts, feelings and
experiences in a field dominated by impersonal experimental studies” (Humphrey &
Parkinson 2006 in Humphrey & Lewis, 2008). ASD tends to challenge social interactions
in even those with the strongest oral and receptive language skills so, to effectively
engage meaningful data, researchers must thinking outside the box so to speak, to
create a research design which fits an individual’s complex needs. For my research study, semi-structured interviews was not the primary source of data, but was an important source regardless.

The semi-structured interview for this study was held during the later portion of a pre-study meeting held with participants. The purpose of this meeting was twofold. First, it was to provide the participants with an opportunity to see the location of the study, discuss the study directly with me, to receive an information package that included an agenda for the research day, a brief introduction to the Research Assistants (RAs), and a card with my direct contact information on it. This helped to reduce some of the more challenging aspects of working with participants on the autism spectrum by making them more comfortable with the environment, people and agenda prior to the day of the study.

If interested in participating in the study, the meeting provided an opportunity to sign appropriate consent or assent forms (discussed further below). After consents were signed, the semi-structured interview portion of the meeting began. Three preliminary research questions were asked to establish a baseline understanding of the participants perspectives prior to their participation in a focus group. These questions were; a) *What words do you use to identify your diagnosis of autism? For example, would you say I’m autistic, I have autism, or something else?*; b) *What does being labeled as having autism, autistic, or being on the autism spectrum mean to you?*; and c) *What
*does having autism mean for you at school?*. The responses to these questions were audio recorded, transcribed and included in the analysis of this study.

**Art Creation**

“The collection of ‘visual’ data is broadly considered to be a useful but neglected method in social science research” (Flick, 2002 in Humphrey & Lewis, 2008). As well, few research studies include the perspectives of children, particularly those labeled with a disability (Billington, 2006; Connors & Stalker, 2007; Humphrey & Lewis, 2008). By seeking to understand individual’s experiences, disability and participatory art challenge the more dominant ideas of what constitutes acceptable academic data (Haranandani, 2005). Utilizing art as a means of data creation offers insight into unsayable experiences felt by the participants and provides a conversation starter to further understand the participants’ thoughts, perspectives and insights (Humphrey & Lewis, 2008; Pauwels, 2015). It also ‘works’ to “get stuff out” (Sinding, Warren & Patton, 2012:4) and has “the potential to be educative, transformative, expressive, participative and liberating” (Barnes, as quoted in Haranandani, 2005:6). Art is able to connect and reveal things that words and conversation lack the depth to acknowledge.

Participants were given a little over two hours to complete a creative art project centered around their experiences at high school with the label of ASD. They were provided with artist canvas boards in a variety of sizes, acrylic paints, brushes and blending pallets to make colours. They were not limited to a single image, however,
only one participant chose to complete more than one painting. As is to be expected, some finished quicker than others so board games were provided along with snacks to those who were finished early to avoid the artists still completing their work feeling rushed.

Aside from acknowledgment in the pre-study meeting that the creation of an art piece was part of the study, and the general topic, no parameters or prompts were given from the research team about what to create. On the day of the art creation and focus group, participants were seated around a large table with all the supplies in the middle. Video and audio recordings occurred during the art making process to capture any relevant conversation during the art creation process. Hand written notes by members of the research team were also taken during this process and at the completion of each participant’s art, a photograph was taken (photos can be viewed at the beginning of the Findings section of this thesis) with consent.

Focus Group

For this thesis, the data generated through the focus group was the primary means of data creation and collection. Focus groups “are dynamic group discussions used to collect information” (Harrell, Bradley, et al., 2009:5) and can provide depth and collaborative understanding of experiences, ideas or feelings, through a group of participants meeting a particular set of criteria (Harrell, Bradley, et al., 2009). In the case of my research, a focus group was also useful to help participants trigger particular
pieces of their experience which are often common for adolescents on the autism spectrum, and may not have surfaced if not for others in the room.

The focus group took place in the same room as the art creation, and around the same large table. Participants were offered lunch between the art and focus group portions of the day. The organization of the focus group (for detailed account review (Interview Guide – Questions for Focus Group, Appendix F) was semi-structured, allowing participants to bring their own perspectives forward, while providing the research team with a loose structure to ensure relevant questions were asked and explored. This portion of the day was video and audio recorded, transcribed and analyzed.

The group began with the participants explaining their art. They determined the order and at times, there was discussion between explanations if a concept needed to be explored further, or conversation arose. Generally the conversation stuck to the presenters’ art and questions directly to that until everyone had had an opportunity to share.

Following the last participant sharing her art, questions to the group were asked to gain further insight. These questions were; a) Who can tell me what being labeled means?; b) What do you think it would be like for you at school, exactly as you are, with autistic characteristics or tendencies, but for you to not be labeled as autistic, or as having autism?. These questions drew together many of the concepts that has been
raised throughout the participant art discussion, both of which are discussed in the
Findings and Discussion sections of this thesis.

**Ethical Considerations**

This study was given ethical clearance by the McMaster Research Ethics Board
(MREB) prior to the start of the recruitment or data collection phases of the research.
Informed consent was obtained from participants at all steps of this research project
including several times throughout the art creation and focus group. It was made clear
to both parents and participants that at any point, consent could be withdrawn without
consequence (see Letter of Information and Parent Consent, Appendix C, Letter of
Information and Participant Consent, Appendix D, and Letter of Information and Assent,
Appendix E).

Special care was also taken during the recruitment phase of this study as I am
employed at Autism Ontario, the organization that I recruited through. To minimize
conflict of interest and ensure no participant felt pressured, I recruited in a geographic
area where I do not provide service. Recruitment was conducted through a colleague
local to Hamilton who reached out to families on my behalf. During the pre-screening
phone call with parents I disclosed my employment connection to Autism Ontario and
assured them that anything shared as part of the research study would remain
confidential and was not connected to their family file at Autism Ontario.

In all aspects of this study, the characteristics of ASD and how they may impact
an individual’s participation in this research were thoroughly considered. The location for the pre-study meetings, the art creation and the focus group at the Hamilton chapter Autism Ontario office was useful for a number of reasons. Participants local to Hamilton were familiar with the location thus reducing anxiety. The office was thoughtfully designed to consider the sensory challenges many individuals with ASD experience. The pre-study package was provided to meet transition needs and visual learning styles, this also supported individuals experiencing anxiety. The structure of all face-to-face portions of this study was open and at the participants own pace. The right to pass on a question or to participate was always available and participants were continually reminded of this. Additionally, an open and friendly environment was established and participants were encouraged to ask questions and their understanding of every step of the process was ensured through numerous check-ins.

As part of the consent process, potential psychological and social risks to participants of the research project were explained, as were the steps that I had taken to mitigate these risks. The participation of two RAs with experience working with youth with complex needs were included on the project to ensure both emotional and physical safety for all participants. Their participation also allowed for one-on-one debrief or direct support for participants if necessary throughout the art creation or focus group.

A secondary reason for the inclusion of RAs was to ensure that I was in no way biasing my responses or favoring the perspectives of one participant over another. The
RAs provided subtle cues to me during the focus group if I was getting off track and shared with me their observations of the group, which I recorded and referenced during analysis. I also provided them with a synopsis of my overall themes generated in my findings to ensure the key findings were an accurate reflection of the participants’ views and perspectives by their recollection.

Confidentiality was an additional major consideration in the structure of this research. Specific wording was carefully crafted to ensure participants were both aware of what I hoped they would share, but also what they should keep private (see Focus Group Interview Guide, Appendix F for script). Throughout the focus group, participant contributions were closely monitored and individuals were cautioned that this is not a place to tell secrets if they began to speak in a way that felt too private to any member of the research team. Participants were also encouraged to respect one another’s privacy and keep things shared in the group, within the group. It was also acknowledged to the participants that there is no guarantee that anything shared would be kept private because of the nature of a group, and this was additional reinforcement to refrain from secret sharing.

**Transcribing**

Transcription of pre-study, art creation and focus group data was completed by me. While I considered hiring someone to complete this, I felt I would gain a greater connection to the data, and more familiarity with it through my independent work in
this regard.

To ensure confidentiality of the participants through the transcript, pseudonyms were assigned to each participant. By publicizing the participants art in collaboration with their comments through the focus group, I knew the participants would be identifiable to themselves through my writing, and I felt it necessary to allow them some say in the creation of their pseudonym. At the start of the art creation, participants were provided with a list of male, female and gender-neutral names and asked to circle 3-5 that they would be comfortable being referred to in the research study and to also cross out any names that they absolutely did not want to be ‘named’. From this, I built their pseudonyms.

Once transcribing of data and saving of audio-video files began, all documents were secured in a password protected file of my computer, backed up on a password protected USB key that was kept in a locked desk drawer. The digital photographs of the participants’ artwork was kept in the same way. All participant consent forms and RA hand written notes were kept in a locked desk drawer with the USB key and all identifying information on the notes was covered with black ink. In every regard, steps were taken to protect the participants’ identities.

I now shift forward into the Findings section of the thesis, sharing the great insights provided by the participants and their lived experience on the autism spectrum.
Chapter 5: Findings

Participant Art Explanations

The following photographed art and descriptions of it are in the participants’ own words, and presented in the order that the art was shared at the workshop. Additional details about the art were provided by each participant in response to questions from the researcher, research assistants and other participants, however, the passages included under each piece of art are the unprompted, unquestioned descriptions of the meaning of the art and the experience it expresses. Further details of the art and experiences are discussed as part of both the findings and discussion sections of this thesis. The images and descriptions are provided for the reader to contextualize reference to them as part of the findings and discussion sections that follow.
Jack’s Art Explanation

“This is a comic strip about how school is going. ... As you can see here, I get special privileges for having autism. I have an IEP [Individual Education Plan] and don’t have to take notes in class, so life can be good. But sometimes whenever a pop quiz shows up or loud noises are blaring, I go ape-ship, and I cause sensory overload ... so I need medication.”
Everett’s Art Explanation #1

“This has to do with autism because... all of us here face a lot of challenges, just like Sonic the Hedgehog. He fought against them, and he always overcomes his challenges, just like all of us are trying to do also...”
**Everett’s Art Explanation #2**

“And then my second one ... a brain in the middle, surrounded by lots of colours, because of all the different colours represent all our emotions and the different perspectives, and personalities, ... all the different sensories that bug us, ... everything that can confuse us. And that is basically how everything can be messed up at once, and you can’t really understand. It is basically like what Jack was talking about with the sensory overload, how when stuff becomes too much, or too complicated, ... too much stuff at once, it's an overload, the brain.”
Ben’s Art Explanation

“Super Why – you may think he is only an ordinary PBS character, he is also confidant, fearless, and smart... and smart. I believe my creativity can match upon his confidence.”
Emilia’s Art Explanation

“I guess it represents me a little bit. … There is this fence, … at first the fence was made by people, but then along the way, you think maybe it would be safer behind it, so you help it be strong, but on the other side of the wall, it is like a weed, you can’t technically contain yourself completely, and I guess, some times, when time goes by, your wall won’t be able to hold you any more… and then it might break, and … that is what relates to everybody. Everybody is scared … to let people in, or let them understand, and I think that when people do that, … the more scared to their wall down. The more they try to make the wall stronger, the more it gets weaker, and when it finally breaks, it will just be, completely defenseless, to ourselves… (long pause). And to think about it, if someone just didn’t create the wall in the first place, we wouldn’t know the feeling of cagement, of being caged, or being behind a wall… and wanting to be shut away from everything else. IF we were just like, freed from the beginning, and we would already know what to do, … and not have fears of letting people know us, because they would already know us and not another person.”
Tessa’s Art Explanation

“Dun-du-na-na! Yah, so the painting I made is kind of, not even like at school, but anywhere... I feel like it represents autism. I just wrote on it “autism” and “the apple in the fruit bowl” because the bowl that I made is surrounded by blue, several blueberries and grapes, which I kind of paint to represent boys and girls. And then there is the apple, which I feel is autism. The odd one out, in other words. Because it is not the same as the blueberry or the grape, so it is considered one of its own. Which is both a good thing and bad thing.
The major research question informing this thesis project was *how do high school students labeled with ASD make meaning of their label?* Through the pre-workshop conversations, art-making and focus group portions of this research project, I have come to realize that this question was inadequate to capture the depth and breadth of the themes uncovered through the analysis of the participants contributions. More appropriately, the findings section of this paper, and subsequent discussion will seek to address the question *how does the label of ASD function for high school students?* And the additional query of *how do young people respond to their label of autism?* will be addressed.

There were three major themes that emerged from the focus group discussion; the ways the label of ASD assigns positive or (more often) negative value to a person; how their label linked them with certain resources (and not others), and how they experienced and understood these resources, and the ways labels can both protect and confine a person. In the sections that follow I consider both how the label – the social construction of autism – shapes participants’ lives, and also how they themselves (and their families) shape the meaning of the label.

I have structured this section of the thesis by first providing an explanation of the participants’ own understandings of ‘labeling’ and their experiences feeling undervalued as a result of being labeled. Having provided some context to their experience I will then introduce the participants so you as a reader may gain an appreciation for their
ability to find value in themselves in spite of the negative oppression injected through their label.

**Understanding ‘Labeling’**

Imperative to this thesis is for the reader is to gain an understanding of how the participants identify and understand the experience of being labeled. By virtue of different lived experience, their own home, school and community environments and their unique personalities, each of the participants in this study experienced labeling in slightly different ways. Generally, in the conversations of this focus group, the meaning of labeling took on a negative tone. Emilia identified labeling as “something [that is] put on you which equates to value”, meaning the usually negative value of an individual person to their society. Everett and Tessa felt that being labeled felt like having a “spotlight” placed on them, and resulted in their being the “center of attention”, constantly having their ‘difference’ recognized by those around them. Jack added that labeling is perceived as insulting and that when people are labeled, they are “not seen for who [they] are...”, rather what assumptions a label imposes upon people.

The participants identified that it was labeling itself which was problematic - the process of others applying a label, which is stereotyping, to them as a group of profoundly diverse people. Emilia identified that “if we weren’t even labeled ‘autistic’..., we wouldn’t feel ashamed of being autistic because we wouldn’t be called autistic in the first place” and collectively the group agreed. It seems this process of labeling feels to
be something imposed on them, and that for them, it is not comfortable to be
categorized in this particular way, Everett explained that “it is almost like everybody is
looking at you. Like an odd look, like why are you different? Why aren’t you like us? And
then everybody is staring at you”.

Tessa felt that prior to there being a diagnosis and label for “autism”, people
were only perceived as “quote unquote being weird”, but that they were not limited by
the same social constructs which the label seems to hold for people in her life. Emilia
felt that “it would have been a lot better if people just didn’t know, it would be more
healthier if people didn’t know a label for us”. Emilia says she likes who she is, but feels
it is the label that creates difficulty for her in her social world.

The participants, in relation to their label, seemed intent on disproving the myths
about autism and reinforced numerous times throughout the focus group that they are
unique individuals, in need of the opportunity to be recognized as individuals. The
uniqueness celebrated about themselves was countered throughout the discussion as
individually and collectively the participants resisted and in many cases resented being
labeled. This understanding is important to consider as the findings and discussion
unravel.

Value and Undervaluing

I will begin this section by exploring the participants’ experiences and
perceptions of being undervalued when others have imposed the label of ASD on them.
Then I will briefly move away from the research questions to more fully ‘introduce’ the participants and their art, exploring how individually and in their families, they have celebrated and acknowledged their unique skills and talents. I do this by uncovering the participants’ experiences of being valued and perceiving their own value, through a more narrative format and tone.

Undervalued People

The first question I asked of each participant during the pre-workshop interview was *what does being labeled on the autism spectrum mean to you?* Tessa identified that it meant being perceived as “different” from her peers and that in some ways she stood out. Ben associated the label of autism with the judgment that he has “having trouble doing stuff” and with the feeling that others occasionally thought he was “crazy” as a result of his label. During his art description, Jack also connected to the word “crazy” as part of his experience being labeled. To the initial question, Emilia simply responded that she felt “disrespected” being labeled on the autism spectrum. When probed further, she elaborated that being labeled feels like she is reduced to “a thing that is named. They are showing us that we are not worthy of being a person or being in the same group as them”.

Throughout the focus group, the participants spoke a lot about their interactions with medical professionals, interventionists and specialists. Participants relayed their own feelings of frustration around these appointments and articulated that attendance
with a professional who typically didn’t include them in conversations about their own
development was devaluing. They felt this exclusion was linked to the professionals’
perceptions of their usefulness and the contributions someone labeled with autism
might be able to make at such an appointment.

This same sense of being undervalued by those in “power” (Tessa, Emilia) around
them occurred within the context of school. Tessa compared the power enacted on
labeled people to the training of pets: “It is like having a pet. You feed it, you take care if
it and then you appreciate your work for doing it because it is like... they grow up and
become cute and obedient. But it is kind of sick when you think about humans doing
it...”. This enactment of power over labeled people was perceived by the group to
diminish their autonomy and have great implications for their lives.

Participants felt that, even though they bear a label which entitles them to
support and resources, they were not given individualized help which would enable
them achieve their full potential (Everett, Ben). They felt that the work provided to
them and the courses available at school were leaving them ill prepared for their future
careers and lives (Emilia, Everett, Tessa). Emilia voiced this frustration regarding work
completion: “If we tried, and went on our OWN to the library, and researched [our
projects] on our own, and figured out on our OWN how to figure stuff out and how to
put notes down and then at the end, we would know what to do”. This frustration is
also linked to the expectations held for individuals in relation to their label, which will be
discussed later in this chapter.

Throughout the conversation, there was also a sense that the impact of their disability (its severity) on their ability to function at school was undervalued - that because they are ‘high functioning’, less support was offered from teachers and paraprofessionals (Everett, Tessa). Tessa stated, “I feel like I’m especially underrated at my school” because of the lack of support she received for her needs in comparison to her similarly labeled peers (this comparison with peers will also be explored later in this chapter).

Alternatively, Emilia shared an experience where her label was linked to more visible characteristics of autism and she felt that she was excluded from her peer group because of their misunderstanding about who she is, because of what she is labeled.

Before, when I was in elementary school, the kids would come and see me first, they wouldn’t think that I was autistic. And if I told them that I was, they would think that what I’m acting is autistic, and they’d be more ok with it because I’d be more like them. I am like them. ... But when they see my brother [who is also diagnosed with ASD], they are like, what is ‘wrong with him?’ And I say ‘he is autistic too,’ and then they look at me like I’m a freak or something. They give you that look, that you know their perspective of you has totally flipped in a second, but they try really hard to hide it, but it’s the second that shows it on their face, it shows you everything.

Emilia told me this story in our pre-workshop meeting, and again shared it with the focus group. For her, this story illustrates the way difference is constructed, how stereotypes or devaluing linked to the way a label presents in a person, have the ability to creep and distort the perceptions of another who shares the same label, but for
whom the label holds entirely different meaning. Later in our discussion, Emilia added that after her label was disclosed and a correlation had been made with what others perceived about autism and her, that she was treated differently: “And just yesterday, [I] didn’t even say anything [about my label] and they were there asking me to come [play], and then all of a sudden they weren’t”.

The experiences the participants identified of being undervalued originated exclusively in the world around them. They themselves did not appear to undervalue their skills, talents and abilities and in small ways, actively resisted the undervaluing that occurred from those around them.

Valued People

I will step back a bit now from the research questions to be addressed in this section to focus on each participant’s experience individually.

- Jack -

Throughout our conversations, Jack presented unique perspectives and experiences, often in opposition to the rest of the group members. For him, the label of autism was not particularly impactful. He felt that those in his family, school and community accepted him as he was, and that while the label of ASD acted as a key to unlock particular tools of support, the label was not used in a way that minimized his personhood or devalued his characteristics. Jack identified that the challenges he experiences in relation to autism are part of the symptomology of ASD; sensory
challenges, anxiety and focus, rather than in relation to his label. “...I've got great people around me who recognize me as a person, but some of you guys don’t have that, and that is sad”. Through the conversations, Jack was able to see the difference between his experience and the others around the table.

Jack repeatedly made visible his self-confidence and awareness of self through his reactions and contributions to the group. When asked if you could go to school exactly as you are, but not be labeled with autism, what would be different? Jack responded, “I would totally be... hum, be essentially the same way that I am now”. Through his words, it was clear Jack felt proud of who he is as a person, and that this was in direct relation to the value placed on his individuality from those around him.

- Everett -

Everett is an advocate. This is clear through his art as he focuses on the ways that living on the autism spectrum impacts him, and as he perseveres through the challenges he encounters. He recognizes and values the difference, “we don’t process things the same way [as other people], ... our senses are different”, but “we have to fight against it and to try to lift ourselves up again”. By “it” I felt he was “fighting against” the label and / or the challenging aspects of his autism as Everett spoke a lot about working through the challenges that autism presents and actively disproving the stereotypes the label of autism can instill in those around him. He felt these stereotypes predominantly from educators and worked to disprove their more negative impressions of the
limitations autism presents for him, by showing them the brilliant, capable, articulate young man that he is.

Another way that Everett enacts self-advocacy is through a presentation about his autism to his peers. “Every year I explain to my class what it is and why I act differently”. He finds that his peers often question why he behaves in particular ways that are different from them and that through his explanation, “everybody understands and things are a lot better for me at school, I am more accepted”. For Everett, the label appears to increase understanding among peers, and seeks to acknowledge the value he holds as a member of the class. It is when his peers are unaware of his label, and attribute his autistic behaviours to him being “weird” rather than “different” or disabled that he feels most undervalued.

- Ben -

“One day, in the future, we will picture this [day and this art] in our minds to remember how smart we really are”. Ben, while probably the least talkative in the group, provided deep and powerful insights into the value he holds for himself as a person and for the unique contributions he is able to make through his experiences on the autism spectrum.

Through his art, Ben articulated his connection to the character he drew, “he is known as the spirit of my consciousness”, the person he aspires to be everyday. Ben engaged “Super Why” and his admirable characteristics of “positive, confident and
“smart” to represent the way he sees himself, the way he wishes the world understood him to be. This is demonstrated when questioned by a group member why Ben has “smashified” “Super Why” with other Super Mario Bros. characteristics and he questioned back, “why can’t I let him be epic for once?” Ben values and acknowledges the existence of these characteristics within himself, but also recognizes that because of his label, others do not view him in this way.

- Emilia -

Resilience was the central theme in Emilia’s narrative as she spoke through her art about the garden wall. She articulated the internal struggle between the fear of breaking free from protective barriers (to be discussed in depth later in this chapter), and the internal desire to be free and venture in this world on her own. She was able to see the value in learning from mistakes, trying and failing, and then trying again. She was also able to pull teachable moments from the times she had been limited and defined by her label of ASD, and that she used this to propel her forward.

Emilia identified being troubled by the ways in which the ASD label had attempted to categorize her, but in spite of this, she was able to know her true self and to grow through the adversity. She placed great value in her capabilities, her perseverance and her potential. Emilia identifies having consciously “forced myself to

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4 “Smashified” is a process where video gamers take the characteristics of a number of videogame characters and ‘smash’ them together to create a super character. This process recreates a classic character who by modern standards may be perceived as less able to defeat present-day game villains, by empowering him or her with advanced skills and abilities.
try to do active things”, all sorts of different things, “people told me when I was little, that to do everything in the world was impossible”, but she has not let this limit her, constantly trying new things, joining groups and learning new words to expand her vocabulary and knowledge.

Advocacy was also an undertone to her story as she shared instances when she had stood up against injustices and challenged the status quo. As part of her dialogue with her peers, she questioned existing practices in the special education system such as accommodation allocation and advocated for people to look beyond labels to see the true person inside. She provided a message for the readers of this thesis, encouraging you to “stop going down the path on which this whole society is built... stop focusing on the little things like hair and words... I feel like labeling is a thing you put on an item, and I feel like people should stop labeling everything, and that includes us”.

- Tessa -

Like Jack, Tessa felt less impacted by the label of autism than the others in the focus group. When asked what does being labeled as having autism or autistic mean to you? She responded, “It means that ... some people might look at me a different way, although that is usually not the case. Personally [the label] doesn’t really affect me as much as it might other people”. Tessa linked the label’s lack of effect on her to her experience of people not identifying she is on the autism spectrum from their initial impression of her.
Through her art, Tessa explored the idea of an apple as a person or people with autism, and it being the “odd one out” amongst groups of blueberries (boys) and grapes (girls), each with their own unique interests and traits. The apple was at the center of her image and stood out amongst all other fruit, she identified this was “both a good and a bad thing”. “Everyone knows that the apple doesn’t fit in just right, and it is kind of off the pattern of the grapes and the blueberries”, but the fact that the apple is unique makes it special. Tessa placed great value in not being “like the grapes and blueberries” and celebrated that she felt free to be who she wanted without having to conform.

Returning to the more thematic analysis of this study, I will now explore the participants understanding of the resources and supports they accessed as a result of being labeled on the spectrum.

**Distribution of resources and supports**

Academic resources or accommodations are modifications and an alternative presentation of tasks, assignments, or daily living activities, which are offered or provided for students with different learning needs in an effort to equalize their opportunity for success in a particular environment. Examples of accommodations identified by most of the participants were access to a laptop computer at school as an alternative method for note taking. Participants identified the ways their label linked them with certain resources (and not others), and how they experienced and
understood these resources.

As part of the pre-workshop meeting, I asked participants what having ASD meant for them at school and in each case, I offered the suggestion of accommodations that might be provided to them at school as a result of their identification and label on the spectrum. Each participant was able to identify ways their school provided accommodations for them to support and enhance their learning and success at school.

During either the pre-workshop interview/meeting, or during the workshop, each participant identified having access to their own school board-issued laptop in their classroom. Jack and Ben have access to quiet space for test writing and Jack was also provided with a note-taker in the classroom either through a peer, educational assistant or his teacher. Ben received a variety of direct supports through an Education Resource Worker (ERW) at his school. Everett spoke about “a special class that will help...organize everything” that he is enrolled in for next academic year which is a specialized class for students with different learning styles and who have an Individual Education Plan. He also has an accommodation to wear sunglasses in class when the lighting in the room is overwhelming for him. Each participant disclosed having an Individual Education Plan (IEP)\(^5\), which they articulated as the gateway to their accommodations at school.

In their conversation, participants noted both the benefits and the troubles associated with the resources linked to their label. Tessa identified that although “no

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\(^5\) An IEP is a working document which teachers, support teams, parents and students use to identify learning goals and to outline accommodations and modifications in curriculum presentation based on the student’s unique profile.
one says it out loud, I’m pretty sure that people who get accommodations are [perceived as] lesser on the knowledge scale than the normal people in class”. Ben and Jack felt the accommodations they received were beneficial, and experienced them as welcome and active support: “it feels pretty good to have someone help me” (Ben). Everett continued that items like laptops were a means to help students labeled with ASD “rise above some of our problems”, as a tool of enabling participation. Emilia found challenge with the process of accommodation allocation, wondering why individuals needed to make a point of formally asking for accommodations if a person’s need is obvious.

Interestingly, all of the participants spoke not only about what accommodations they had access to, but also the accommodations their peers received. The comparison seemed central to the story for many of the participants (Tessa, Everett, Emilia). These comparisons with peers were very revealing. They showed more about how participants understood the resources and arrangements linked with disabilities and disability labels.

Tessa, Jack and Everett were able to identify and list their “special privileges” in comparison to their peers. On several occasions they highlighted the inadequacy and “unfairness” of others getting “privileges” and they did not. Tessa’s observation here sparked great reaction from around the table;

Tessa: I feel like I’m especially underrated at my school because literally, ... I do get the laptop and the IEP, but that is about it. I don’t get help on notes, I don’t get extra math help which is a big thing in our school, and another big thing in our school is skipping French… and I know, like, every other kid I know that has a laptop gets to do all that and I don’t and I feel like it is
somewhat unfair.

Shona: What is unfair about it?

Tessa: They get more privileges than I do.

In this discussion, unfairness seemed to fall entirely on some people having ‘more’ resources than others. There is no suggestion that others might need more or less, and thus justifiably receive more or fewer accommodations. Everett described another kind of unfairness, echoed by Tessa;

Everett: And something that I’m frustrated with, just because I’m more high functioning it seems like I’m not as important as all the other kids with autism.

Tessa: I know, it is the worst feeling.

Tessa linked the inconsistencies between a persons’ access to accommodations and their status as “normal” to the concept of reputations. She spoke about two individuals in her school, a boy, who Tessa identified as not having a label “who is perceived as normal...has an IEP and a laptop and occasionally gets extra help” and a female friend of hers “who sometimes gets extra help and is perceived as not so normal”, and is also labeled on the autism spectrum. The difference between the two classifications of normalcy being the peer’s reputation, their label and the classmates’ understanding of their difference and access to resources at school.

Accommodation in relation to the label of autism also came in the form of less challenging academic work. Tessa, Jack and Emilia felt that their work was not as
challenging as their unlabeled peers, leaving them unprepared for their future academic and employment ventures. “I think school would prepare us more if it was harder” (Emilia). Emillia felt that being challenged to complete assignments unsupported would be beneficial to her. Overall, she suggested that an appropriate balance between supporting and disabling her with excess support needed to be met. Consensus emerged from the group that there are places where support is essential to success, such as at school, provided it is done in the right way, but that at home, the same intensity of support is not required and in many cases is unnecessary.

While Tessa and Everett appeared to be most frustrated by the inadequacies they perceived in their own accommodation in relation to others’, Jack shared;

The thing about [my town’s] education system is that it treats us autistic kids like actual people and not disabled people. It just treats us as people. Yah people who need help sometimes, but people. Everyone needs help some time.

In asserting that “everyone needs help some time” Jack offers a notion here of difference and need for help as a universal human trait, suggesting that the resources linked to any disability label are about enabling participation.

It is obvious that, when discussing their peers, classroom resources are sometimes described in ways disconnected from any ideas about ‘need’ or ‘creating a level playing field’. This speaks to the incredibly complex nature of the construction of meaning through disability labeling, and the supports and structures put in place to ‘help’. This will be explored further through the discussion chapter of this thesis.
Tessa also identified that she was hesitant to accept assistance at school: “I don’t really see that much of an advantage to it, yes it would make things easier and I would get a bit less homework, but it would also make me look a little bit, slightly, lesser in the knowledge”. It seems that the acceptance of help accessed through the label of ASD can also stigmatize students as less intelligent.

**Boundaries**

The third overarching theme highlighted by the participants was the effect the label of ASD had on the boundaries and expectations that were set by parents, teachers, and peers. In some cases these boundaries were identified as protective barriers that supported and protected them, in others these boundaries set invisible limitations on things the participants might achieve and were linked to lower expectations of their individual success. Interestingly, boundaries were also identified as constructions within family units that created safe and supportive spaces where individuals felt that they could be themselves.

The concept of boundaries was first introduced by Emilia as she explored her creative art piece. She spoke about a “fence” which later became the “garden wall” and how in the beginning it was made by people, often parents, who form a protective barrier around their child as they are growing and developing. This protection was felt to be supportive and encouraging. Emilia spoke about how over time, the wall can begin to “cage” a person in because they have been protected behind it for too long. From
this, participants related their own experiences, feeling like parents, teachers, medical professionals and at times, peers built protective barriers around them with rules and support systems that protected them, but also in some ways limited them because they were so protected. Some of these protections included shadowing during social activities, not being permitted out of the house alone, registration in programs designed to “help and fix” (Everett) as opposed to programs for pleasure.

Everett felt that “it is almost like they put us into a maze, and things that we want to do are blocked off, and some people are biased and say ‘no, you can’t do this’, and you can only pick certain paths, because we are autistic”. These experiences in many ways negatively impacted the participants’ view of their autistic label, and their own abilities as a direct result of the label. For most of the participants, the autistic label seemed to signify that others perceived their difference as problematic and that they were thought to be less capable than others.

Through discussion it was revealed that when parents checked in with the participants, in essence creating a safe space to explore their feelings about being labeled and attending appointments, groups and ‘treatment programs’. By constructing a space to ‘check-in’, the participants tended to feel more positive and they seemed to repel the more negative impacts of the ASD label.

On several occasions, participants identified feeling that because they are labeled with autism, people in their lives placed invisible limits or expectations on them,
believing because “I have autism, people think that I’m not as able to do things as some of the normal kids” (Everett). Both Emilia and Tessa shared that their schools implemented boundaries and supports that they felt were unhelpful for them later in their lives. “When you get past all of the schools and college, ... the whole time you’ve been surrounded by people who have been directing you because you are different” (Emilia). This feeling of being unprepared was expressed in a number of areas, that life skills such as budgeting and interpersonal relationships were not being taught, nor were the skills to be successful in a career or negotiate the challenges of their particular presentation of autism.

Most participants appeared to struggle between wanting additional support and protective barriers, yet at the same time, resisting the implications of their label that they needed more support than “the normal kids”. Emilia may have captured the essence of this collective struggle with her words; “it is kind of like you are fighting against yourself, like, you want to be out, but then part of you is scared” and wants to stay in the protective wall.

An alternative perspective was also offered which spoke to experiences of not being overly protected because of their label. There were some participants who felt that their label had a very minimal impact on their lives because they were treated as an equal to those around them. Their expected outcomes did not appear to be limited by their label, rather they were seen for the bright and capable young people they are.
These participants shared that protective barriers can still exist, that conversations and acknowledgement of the existence of their label was necessary, but that the label didn’t need to define them, rather was merely “a piece of the complex puzzle of who I am” (Jack).

It seems through the focus group discussion that the label of autism can function in a multitude of ways. The impact of the label, and what is done in relation to it tended to vary as well, depending on the person and their experience. What is important to consider, and will be picked up through the discussion chapter next, is the significance of how protectors, caregivers and significant others in the person’s life understand the label. Responses to the label from people in the person’s immediate social circle can deeply impact how that label functions for the person on the spectrum and also how they make meaning of that label.
Chapter 6: Discussion and Conclusions

The literature reviewed has emphasized an increasing need to include the perspectives of disabled people (Beauchamp-Pryor, 2011; Mallett & Runswick-Cole, 2014; Michalko, 2009; Crow, 1996) and suggests that the use of arts-based methods may engage their voices in a meaningful way (Sinding, Warren & Paton, 2012; Pauwels, 2015; McNiff, 2008). The findings from this research study validate these thoughts, and the methods used to engage the voice of these participants has revealed meaningful themes which I know will shift my practice and hopefully inspire change for readers. As I wrap up this thesis, I will pull together key themes and observations from the literature and study, reflect on the methodology, limitations and future implications before some final concluding thoughts.

Value and Undervaluing

Through exploration of the concepts of value and undervaluing of individuals in reaction to the label of autism, many perspectives were offered. Most prevalent in the literature was the notion of value of the ‘insider’ perspective offered by those who are labeled with autism (Brownlow; 2010; Connors & Stalker, 2006; Humphrey & Lewis, 2008; Kelly, 2005; Tangen, 2008). While limited literature focused on the value a label created for individuals outside of this, Humphrey & Lewis (2008) did report that when participants understand autism as part of who they are as opposed to autism being their only identity, they feel a greater acceptance and celebration of their differences.
This is not unlike the experiences of several of my participants who felt their label connected them to their unique abilities that set them apart from their peers in positive ways. For them, like the participants in Humphrey & Lewis’s (2008) study, this was deeply connected to the perception and acceptance of autism in the people around them such as teachers and parents, and this contributed to their more positive outlook and relationship to the label of ASD.

It was interesting for me to hear the conversations between participants during the workshop that identified how their labels function so differently for each of them, but at the same time, acted to unify them. During our research team debrief we discussed how quickly the participants came together while at the workshop, supporting one another and sharing their common experiences. It appeared to us as a research team that the label was of great value in connection and recognition of shared common experiences.

Perhaps because socially, the label has been constructed as significant, even though participants collectively opposed being categorized by it, their label and the label of others in the room held significance for them. One of the first questions that Everett asked to Ben was what his label was and both Tessa and Everett made a point of sharing that they are “high functioning”. In identifying this subcategory of the label they actively separated themselves from others (not in the study, but on the spectrum) who may have been identified as lower functioning. In this way, they affirmed the widespread
social and cultural devaluing of people on the spectrum who are identified as ‘low functioning’.

While each participant was able to articulate some positive connection to their label, connecting to the label in a problematic way was the more dominant voice at the table. This was not unique to these adolescents; much of the literature reviewed for this thesis that engaged the voices of young people on the spectrum found a consistent undervaluing of individual characteristics that are associated with ASD. Jackson Brewin, et al., (2008) also found through their study that “awareness or lack of awareness of the child’s diagnosis affected how the child was treated at school by fellow students and, in particular, by teachers and other professional staff” (5). In other words, the labeled child was not perceived to have the same potential as his or her peers and was consequently undervalued.

The study participants spoke a lot about this as well. They felt that very often when their label and its meaning for them was understood by those in their life, they felt empowered and understood. It then equated to their feeling valued and their ability to positively contribute in a classroom and their community was acknowledged. Emilia spoke passionately about not wanting to be reduced to having a “value”, that this was for things, not people. The consensus among the group was that there was a difference between being valued and having value. Being valued meant recognition of their personhood whereas the idea of ‘having value’ was disempowering and felt as though
they were reduced in some way because they are labeled with ASD.

Further research might pay particular attention to “the different ways of talking about and conceptualizing autism” (Brownlow, 2010:15) and how this is connected to individual self-esteem, acceptance, understanding from peers, educators and service providers and young peoples’ overall experience being labeled. This wider and enriched set of understandings of autism, over time, could act as an impetus for the greater social networks around an individual. I wonder if it is possible to shift towards greater acceptance and decrease the emphasis on the need to conform to socially constructed standards and norms of behaviour.

Additionally, research focused on the initial presentation of a label to the person (by both professionals and family members) and how this relates to self-esteem, self-advocacy skills and the connection to their label could be very useful. Understanding how and what contributes to more positive self-images in relation to a label may shift how disability and its subsequent labels are constructed within society and spoken about within families and schools.

**Distribution of resources and supports**

Regarding resource and support allocation, several studies have highlighted the positive correlation between receiving a label and the education systems’ provision of some form of accommodation to support academic achievements (Allday, et al., 2011; Baines, 2012; Connors & Stalker, 2008; Humphrey & Lewis, 2008; Kelly, 2010). Limited
literature also considered the resources provided were less about the unique needs of a particular student and more connected to the generalizations about what a person with a particular label usually needs (Baines, 2012; Kelly, 2010).

Participants in my research study spent a great deal of time speaking about “special privileges” and this was echoed in Humphrey & Lewis’s (2008) study where participants also equated their opportunity to attend their community school as a “privilege” they were granted access to. Some of our conversation about “privileging” may have been introduced by examples I offered to a pre-study question (discussed further in the methodology reflection section), however the concept was not new to the participants and it appeared from their stories that their schools had constructed the resources offered to equalize learning opportunities as ‘privileges’ rather than a right or educational necessity.

Recognition of accommodations being constructed in this way is essential to understanding how the label functions for individuals on the spectrum. Autism is commonly referred to as an ‘invisible disability’ because when you look at someone with autism, you may not know they have a disability. Understanding that schools construct (and/ or that labeled young people perceive) the resources supporting learning and accommodating needs as a ‘privilege’ is important. According to Oxford Dictionary a privilege is an “advantage or immunity; something regarded as a rare opportunity” (Allen, 1990:951). It would be shameful to indicate to a person who uses a wheel chair
that they are ‘advantaged’ because of it, or that their accommodation was a ‘rare opportunity’, yet as a society, we continually construct things that support individuals with intellectual and social challenges in this way.

Additionally, a salient concept throughout the focus group was that the participants felt that apart from the few accommodations they “got” as a direct result of having the label of ASD, their supports were insufficient because others got more. In the focus group it came down to the notion of ‘fairness’ on a topic which can never be ‘fair’ if fair is ‘equal’ because all people are not created equally. This further emphasizes why constructing a necessary resource as a privilege is disconnected from the premise that as unique individuals we need different support in order to thrive.

I found it interesting that the participants indicated for the most part that they would have liked to receive additional resources at school, particularly since the concept of reputation was introduced to the conversation. In my experience, students on the spectrum identified as ‘higher functioning’ tend to reject resources such as laptop computers and note takers because it does visibly identify them as different from their peers. This is also supported in the literature (Baines, 2012).

I believe future research focused on understanding why accommodations are constructed as privileges and how, through social work practice we might begin to break down this ideology is necessary. Emilia questioned why students need to make requests for accommodations and suggested that surely students who do not have disability
labels would benefit from alternative teaching and learning methods. Gaining perspective in this way might enable some shifts, resulting in students having access to the things they need to thrive simply because they have a need, label or not.

**Boundaries**

Boundaries in either the protective or restrictive ways identified by my participants was not explicitly mentioned in the literature I reviewed for this thesis. I wondered if part of the reason was the significant emphasis on parental and teacher perspectives in the literature, and the lack of parental or teacher participation in my study. It is possible that parents and teachers do not notice or problematize their creation of boundaries, or only view them as positive protections rather than also ‘encagements,’ as Emilia said. In this way my study can be seen to confirm the value of prioritizing labeled peoples’ own perspectives, as it brought forward an issue, boundaries, that is not obvious in the literature. It is also possible that due to the age of my participants this natural tension of wanting to pull away from protective parents and being apprehensive about venturing on their own was contributing to their experiences, thus being less about ASD and more about adolescence so not the focus of the literature reviewed.

Regardless of the reason for the silence in the literature, boundaries and their impact on the participants in this study were important. From my professional experience I have witnessed countless families who react to their child’s label by
establishing large protective boundaries, protecting them and instituting restrictive measures to ensure safety. Schools and community programs, including many in which I have been involved, function similarly.

Labels can instill expectations, and expectations can be understood as a kind of boundary. As Humphrey and Lewis note, “...once children have a label applied to them they tend to be ‘defined by their diagnosis’ (Molloy and Vasil, 2002, p.661) – leading to a loss of individuality and the limiting of people’s expectations” (2008: 31). These limited expectations can shape the way protective barriers are established and maintained for individuals. When a person perceives another to be more vulnerable, protective instincts kick in and this can blur perceptions about capabilities.

Labels seem to demand additional information about a student, participant or patient. Special forms that talk about their label and needs are filled out, prior to ever entering the school or program, and these forms prompt opinions and ideas about who the child is based on their label and the information presented by their parents. For parents who resist this process, resources are not offered and integration at school or in a program can be all the more difficult as a result.

Based on the conversations through the focus group, I felt the participants were requesting more nuanced conversations about what they are ready for now, and moving forward as an ongoing conversation. I sensed that it was necessary for them to find a balance between having support and protection from their teachers and families, but
also having space to try things independently. Additional research about how to support families and teachers to have these conversations and supportively launch their children or students would likely be welcomed by adolescents such as my participants who felt so caged.

**Reflections on methodology**

This research is structured methodologically as it is because I wanted to truly hear the participants’ voices through this study. Much of the literature I had reviewed, while including young peoples’ perspectives was balanced with parent contributions and analysis of their child’s experiences. I wanted this study to be free, as much as possible, from outside commentary, and open to hearing the participants’ narrative in their own words, from their perspectives.

As I reflect on both the literature and my own findings, there are noticeable differences between my study findings and the broader literature (explored previously in this section), and I wonder if the exclusion of the parental input is a contributing factor for this difference in some cases. As noted, most of my participants did not describe having trouble or being excluded at school. Schools may be problematized in the literature because parents who have been interviewed for those studies may have contradicted their child’s perceptions of their experience at school. During the phone screenings and pre-study meetings, parents made comments or gave looks that indicated to me that their own understanding of their child’s acceptance or exclusion at
school as a result of their label was different from their child’s perception (with almost every parent implying that their child was more excluded at school, than their child reported being). I wonder if I had included parent perspectives as part of my research, the findings may have been different.

There were times when I wondered if I were to observe the students at school, if my understanding of their experiences may have differed from what they reported in the focus group. As I reflected on this, it became even clearer to me that my understanding of social interactions at school are often based on a socially constructed notion of what a ‘real friend’ or ‘acceptance’ looks like. It would have been easy for me to impose my own value to their experience, rather than letting them define for themselves what is the nature and meaning of their experiences and relationships.

The biases I am describing here are very much embedded in professional practice. One of the tools I use professionally is the Quality of Friendship Scale, which is a theoretically grounded “measurement instrument [used] to assess the quality of children’s and early adolescents’ relationships with their best friends according to five conceptually meaningful aspects of the friendship relation” (Bukowski, Hoza & Boivin, 1994: 471). These understandings of friendship relation are based on expectations regarding typical peer relationship patterns and, in my opinion, are biased towards a norm of behaviour which exclude a-typical social relationships from scoring well on the assessment, and are organized in ways that often discredit the young person’s own
experience. For example, a young person might report that he has many friends. The scale then asks him to describe whether the person would share their lunch with him if he forgot. If the person probably would not share, then the young person is not considered to have ‘real’ friends. It was my intention to remove this external judgment on the participants’ experiences and to give space to their own understandings, apart from how the ‘rest of society’ may view them.

Try as I may, I was not able to remove all of the social constructions that I carry, from entering into the study. As mentioned previously, the concept of “special privileges” was a dominant theme as participants spoke about their resources and supports at school. I realized as I was reviewing the data from the pre-study meetings that for two participants, Tessa and Jack, I used the term “special privileges” when I asked them about the accommodations they received at school while I provided an example to expand on the question. I initially wondered if I had introduced the term to the participants and if this might have unduly influenced their contributions, however, on closer inspection of the transcript I recognize that each participant who used the term (and they all did) had their own understanding of it, based on their individual experiences. I feel assured that even though I was the first person to use this term in our interactions that it was not foreign to them, rather language they are exposed to routinely in their school settings.
Limitations and implications for the future

Part of the complexity of this study is that it is a challenge, if it is possible at all, to disentangle what is happening to the participants as a result of being labeled with autism versus what is happening in reaction to their presentation of autism. As I reviewed the data and developed the findings this question was continually present in my mind.

One of the things that I could have done to better understand and unravel this question would have been to schedule one-one-one interviews with the participants after the art creation and focus group to probe further into their meaning and understanding through particular statements they made and words they used. I believe this additional step would have provided me with greater clarity and insight into the participants meaning making of their label, and allowed me to better understand what was ‘about’ the label and what was about how they present in the world.

Another step I would have liked to take to ensure the accuracy of my understanding would have been to share it with the participants prior to the completion of this thesis. As part of Humphrey & Lewis’s (2008) study, participants were engaged in this way and their feedback provided unique insights and clarifications that would have been missed otherwise.

With respect to the criteria for participant inclusion in this study, I intentionally drew forward participants who demonstrated particular characteristics. This was done
for a number of reasons (explained in methodology), but I recognize that I missed out on what others might have contributed to the conversation because they were excluded. I wonder if I had had conversations with individuals who have low verbal skills but average to high cognitive functioning if they might have reported greater exclusion as a result of their label. I think any other set of criteria would have likely yielded unique elements to the findings. Many of the studies I reviewed which included these measures were multi-year team studies, which simply was not possible for me at this time.

If I were to engage in similar research studies in the future consideration, of these methodological factors would be a priority for me. While not possible within the time constraints of a one-year MSW thesis program, I believe these components would further the validity and quality of the findings.

Conclusions

Our pride comes not from ‘being disabled’ or ‘having an impairment’ but out of our response to that. We are proud of the way we have developed an understanding of the oppression we experience, of our work against discrimination and prejudice, of the way we live with our impairments (Crow, 1996:216).

This response to impairment or disability about which Crow (1996) writes can only come from individuals who, like her, understand first-hand what it feels like to be labeled. In my study, I was moved and inspired by the pride that the young people expressed in who they are, and learned so much from how they describe living with the label of autism. Inclusion of this perspective is essential to gaining an understanding of
how individuals make meaning of their label and how their label functions to shape their life, and the lives of those around them.

Understandings gained from this study can be useful for educators, parents and professionals in the autism community to more productively engage in meaningful conversations about labeled individuals’ experiences. The primary message reinforced for me throughout this study was how different each person’s experience is and how there is no one way of supporting, engaging or understanding a label or the person who has been labeled. Rather, as a society, there must be intentional conversations which seek to highlight their pride in themselves and their difference; providing support for challenges individually identified and embracing acceptance for who they are and who they aspire to be.
References


APPENDIX A

Email Recruitment Script
Sent on Behalf of the Researcher by the Holder of the Participant’s Contact Information

Shona Casola, B.A., B.S.W.
Masters Candidate in Social Work

Study Title: Redefining expert perspectives: understanding the meaning of identity and labels in high school students on the autism spectrum

Sample e-mail subject line: Seeking Participants for an arts based study about high school students and autism

Dear Chapter Members and Recipients of Autism Ontario E-News;

Shona Casola, a McMaster University student, is seeking participants for a study she is doing about high school aged students (15-20 years of age) who are diagnosed on the autism spectrum. This research is part of her Master of Social Work program. The following is a brief description of her study:

Parents spend a great deal of time and energy figuring out that their child is diagnosed with Autism Spectrum Disorder. This diagnosis opens doors for funding, services and understanding into the differences their child presents with. There is much literature that speaks about the challenges parents encounter when negotiating this diagnosis with their child, as well as the emotional implications, but little literature exists that tells of the experience of the children, youth and adults who are labeled as being on the autism spectrum.

This study will engage youth in a full day program. A morning session creative arts project will allows participants to explore their experiences of living on the autism spectrum at school. Lunch will be provided and then the afternoon will engage participants in a discussion with same-aged peers to share their experiences and tell their stories. Families will be invited to attend the last 30 minutes of the program to view the participant’s art before they take it home at the end of the day.

If you are interested in getting more information or your child participating in this study, you can contact Shona by e-mail at casolas@mcmaster.ca or by telephone at 289-200-1609.

Shona has worked at Autism Ontario in the Potential Programme in Simcoe, York, Durham, Peterborough and Toronto Regions since 2006. If you choose for your child to participate in this study, this will be completely separate from Shona’s role at Autism Ontario and will have no implications for the services you or your child receive from your local chapter or the Potential
Programme at Autism Ontario. All study data will remain confidential and your child can choose to withdraw from the study if he or she no longer wishes to participate.

A copy of her Letter of Information and Consent Form is attached to this e-mail, which can provide you with further details about her study.

In addition, this study has been reviewed and cleared by the McMaster Research Ethics Board. If you have any questions or concerns about your rights as a participant or about the way the study is being conducted, you may contact:

**McMaster Research Ethics Board Secretariat**

Telephone: 905-525-9140 x23142  
Gilmour Hall – Room 305 (ROADS)  
E-Mail: ethicsoffice@mcmaster.ca

Sincerely,

LB Brown  
Family Support Coordinator  
Hamilton & Niagara Regions  
Autism Ontario – Potential Programme
Appendix B

Participant Screening Form

Shona Casola, B.A., B.S.W.
Masters Candidate in Social Work

Study Title: Redefining expert perspectives: understanding the meaning of identity and labels in high school students on the autism spectrum

Thank you so much for your interest in my study. I’d like to ask you a few questions about your child to confirm their eligibility for participant and ensure this group will be the right fit for them. If you are uncomfortable answering any of these questions, please just let me know and I will happily move on to the next one. If, at the end of our conversation you are not interested in having your child participate, or don’t feel they would be interested in participating, that is not a problem.

1. Is your child between 15 and 20 years of age? ☐ Yes ☐ No
2. Does your child currently attend a publically funded high school in either Halton, Hamilton or Niagara Regions? ☐ Yes ☐ No
3. Is your child diagnosed on the Autism Spectrum? ☐ Yes ☐ No
4. Do you, or your child keep this diagnosis private from others? ☐ Yes ☐ No
5. Is your child aware of their diagnosis? ☐ Yes ☐ No
6. Is your child able to speak about his or her experiences having autism? ☐ Yes ☐ No
7. Is your child at least partially integrated into regular streamed courses (for credit) for half the day or more? ☐ Yes ☐ No
8. How much, if any, support does your child receive at school this year from either an Educational Assistant or a Special Education Resource Teacher?

9. Please tell me about your child’s verbal communication skills?

10. Is your child able to read and / or process verbal text at a grade 9 level or above?
11. Does your child have established self-regulation strategies and a consistent ability to manage their emotions independently?  □ Yes  □ No
12. Is this study something you have discussed with your child?  □ Yes  □ No
13. Is your child interested in participating in this study?  □ Yes  □ No

If appropriate for the study:
Thank you so much for answering my questions. Based on your responses, I think your son / daughter would be an excellent fit for my study and I would love to have them join us. The next step in this process, as you may recall from my Letter of Information, is to set up a Pre-Study meeting where you and your son / daughter can meet me with face-to-face and see the space where we will host the study. At this meeting, we will review the process for the study, you and / or your child will sign the consents necessary for participation in the study, and you will both be provided an opportunity to ask questions. I will also ask your son / daughter two baseline questions, that I will record, to learn a bit more about how they understand their diagnosis or label of autism and what this means for them at school. Are you interested in booking a Pre-Study meeting? [Proceed with booking, and provide location details if appropriate].

Thank you so much for your time and interest in my study. I really appreciate it and look forward to meeting you and your son / daughter at the Pre-Study Meeting. Do you have any other questions that I can answer for you today?

If not appropriate for the study:
Thank you so much for answering my questions. Based on your responses, I do not feel that your son / daughter is an ideal fit for this study. I appreciate your interest, and your time today. I would be more than happy to provide you with a brief summary of my study results when I have submitted my thesis, would this be of interest to you? [Proceed with getting contact information if they are interested]. Thanks again for your time and have a wonderful day.
Appendix C

Letter of Information and Consent of Parents / Guardians

Study Title: Redefining expert perspectives: understanding the meaning of identity and labels in high school students on the autism spectrum

Student Investigator: Shona Casola
Department of Social Work
McMaster University
Hamilton, Ontario, Canada
(289) 200-1609 / casolas@mcmaster.ca

Faculty Supervisor: Chris Sinding
Department of Social Work
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext.22740 / sinding@mcmaster.ca

Purpose of the Study:
This study explores what being labeled as a person with autism feels like in the context of high school routines and expectations. So much of the research I have reviewed for this project asks teachers and parents for their thoughts and opinions, but I really want to hear from individuals who experience life on the autism spectrum themselves. I believe it is so important to include their perspectives and to redefine who is thought of as an expert when thinking about experiences at school. So much of a young person’s life is spent at school and I know there are often challenges there, I’m hoping to understand their experiences at school a little bit better, so when I’m finished school, I can help other young people have an easier time.

Procedures Involved in the Research:
Your child is invited to take part in this study on autism and identity that uses creative arts as a conversation starter, an opportunity to share their knowledge. The study involves:
- A phone screening between parents / guardians and myself to ensure your child meets study criteria
- A Pre-Study meeting for 15-20 minutes at Autism Ontario – Hamilton Chapter office (533 Main Street East, Hamilton) to discuss the study and to gather basic information about your child, have you and your child sign consent forms and to better understand their needs while participating in the study. This meeting will also include an audio recording of three questions and responses from your child to establish a baseline of their awareness prior to the study. The date will be arranged after your phone screening.
- A workshop at Autism Ontario – Hamilton Chapter office (533 Main Street East, Hamilton) on Saturday, April 25, 2015 from 9:00 am – 3:00 pm with other high school aged students diagnosed on the autism spectrum. The workshop has three parts:
  1. Your child will be given about 2 hours and a variety of art materials to create on canvas a piece that helps me understand what attending high school with a diagnosis or label of autism feels like.
  2. Your child will join other participants in a focus group to speak about their art project and share their experiences. This discussion will last about 2 hours.
  3. During the last half hour of the day, from 2:30-3:00 pm, there is an opportunity for you to come in and view the art work your child, and others in the group, have created.
**Lunch and snacks will be provided for your child between the art and discussion portions of the day.

Potential Harms, Risks or Discomforts:
The risks that your child may encounter in this study are not different from the risks that people diagnosed with autism may experience while participating in any new program. If your child takes part in this study, they may experience the following:
- Discomfort with the new environment and new people they are working with
- Some discomfort with our topics of discussion
- Stress while explaining and discussing their personal art project and sharing their story with the research team and participants
- Worry about how others will react to what they say about their experiences and feelings with respect to their
In order to minimize these risks, I have taken the following steps:

You, your child and I will have a private meeting in this new space (Autism Ontario – Hamilton Chapter office) before April 25, 2015, for 15-20 minutes. On this day, I will provide a pre-study package that will include:

- an agenda for our program day, an introduction to the Research Assistants who will be at the study, the types of questions I’d like your child to be thinking about for their art project, my contact information, in case you or your child have any questions between the Pre-Study day and the day of the workshop.

- I will review with you and your child what I hope to learn from my research project at the Pre-Study day and I will review it again on the day of the study.

- The research team is highly trained and experienced and will be able to provide your child with support if needed throughout the day.

**Potential Benefits to Your Child:**

The research will benefit your child by giving them an opportunity to participate in a creative arts project. By participating, your child will explore their own experiences through art materials of their choice. This arts-based telling of their personal story will be theirs to keep at the end of the workshop.

**Confidentiality:**

Every effort will be made to protect your child’s confidentiality and privacy. I will not use their name or any information that would allow them to be easily identified. In my write up for my research, I will create a pseudonym for your child to further protect their identity. At any time during the study, your child can identify particular information as private and this information will not be included in my research analysis.

Because of the nature of the group, the other group participants will learn your child’s name (as they introduce themselves) and see them as part of the group. I will try to keep information shared in the group as confidential and private as possible. I will ask the other members of the focus group to keep what your child says confidential but I cannot guarantee that they will do so. We are often identifiable through the stories that we tell. Please remind your child of this as they consider what information to tell me.

The information / data you and your child provides will be kept in a locked desk where only I will have access to it. Information kept on a computer or on a portable storage device will be protected by a password, and the portable storage device will be kept in a locked desk drawer.

**Limit of Confidentiality:**

Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information (e.g. if your child tells me about being abused, harming themselves or someone else). At the start of the workshop, I will review confidentiality in more detail, including the circumstances in which I must share information with others.

**Participation and Withdrawal:**

Your child’s participation in this study is completely voluntary. If he or she decide to be part of the study, they can stop (withdraw), from the group for whatever reason before or during the workshop. After the workshop on April 25, 2015, only images your child’s art contribution can be withdrawn. There will be no consequences to you or your child and any data you have provided prior to April 25, 2015, will not be included in the study, unless you and your child agrees that it can.

**Information about the Study Results:**

I expect to have this study completed by early Fall 2015. If you would like a brief summary of the results, please let me know how you would like it sent to you. You can let me know at any time by contacting me by e-mail or phone.

**Questions about the Study**

If you have any questions or need more information about the study itself, please contact me at: casolas@mcmaster.ca or 289-200-1609

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you
have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:
McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
C/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

CONSENT
- I have read the information presented in the Letter of Information about this study being conducted by Shona Casola of McMaster University. □ YES □ NO
- I have had the opportunity to ask questions about my child’s involvement in this study and to receive additional details I requested. □ YES □ NO
- I understand that if I agree for my child to participate in this study, they may withdraw from the study at any time up until the date of the workshop, April 25, 2015, after which time, only the image of their artwork may be excluded from the study. □ YES □ NO
- I understand that if my child withdraws from the study after the workshop, their contributions to the focus group cannot be deleted. □ YES □ NO
- I have been given a copy of this form. □ YES □ NO
- I agree for my child to participate in the study. □ YES □ NO

I agree that the question period of the Pre-Study meeting and the workshop on April 25, 2015 can be audio and video recorded. I understand that this will be used to contextualize discussion, understand body language, and to transcribe and analyze responses to the discussion. I understand that this recording will be transcribed (written out word-for-word) and quotes will be used to illustrate themes from the discussion. I understand that my child’s real name will not be used in the transcript or in the replication of their quotations in the final thesis paper.
□ YES □ NO

I agree that the artwork my child creates can be photographed and published in the final thesis report, as well as any subsequent presentations or articles which may be given / published from this study.
□ YES □ NO

☐ Yes, I would like to receive a brief summary of the study’s results.
  Please send them to me at this email address ______________________________________
  Or to this mailing address: ____________________________________________________
  ______________________________________

☐ No, I do not want to receive a summary of the study’s results.

If participant is under the age of 18, or is unable to legally consent to participate in this study, a parent or guardian will be required to give consent. An assent form is provided in addition to this form to ensure consent from the participant is understood and agreed to.

Signature of Parent / Guardian: __________________________ Date: ________________

Name of Parent / Guardian: __________________________

98
Appendix D

Letter of Information and Consent of Participants

Study Title: Redefining expert perspectives: understanding the meaning of identity and labels in high school students on the autism spectrum

Student Investigator: Shona Casola
Faculty Supervisor: Chris Sinding
Department of Social Work
McMaster University
Hamilton, Ontario, Canada
(289) 200-1609 / casolas@mcmaster.ca

Purpose of the Study:
This study explores what being labeled as a person with autism feels like in the context of high school routines and expectations. So much of the research I have reviewed for this project asks teachers and parents for their thoughts and opinions, but I really want to hear from you. You experience life with autism and all that this entails and I feel very strongly that it is important to include your perspectives and ideas in the conversation. You spend a lot of your time every week at school and I know there are often challenges there, I’m hoping to understand your experiences at school a little bit better, so that when I’m finished school, I can help other young people have an easier time at school.

Procedures Involved in the Research:
You are invited to take part in this study on autism and identity that uses creative arts as a conversations starter, an opportunity to share your knowledge. The study involves:
- A phone screening between your parents / guardians and myself to ensure that you meet the study criteria
- A Pre-Study meeting for 15-20 minutes at Autism Ontario – Hamilton Chapter office (533 Main Street East, Hamilton) to discuss the study and to gather basic information about you, to have you sign the consent forms and to better understand your needs while participating in this study. This meeting will also include an audio recording of three questions and responses from you to establish a baseline of your awareness prior to the study. The date will be arranged with your parents / guardians after the phone screening.
- A workshop at Autism Ontario – Hamilton Chapter office (533 Main Street East, Hamilton) on Saturday, April 25, 2015 from 9:00 am – 3:00 pm with other high school aged students diagnosed on the autism spectrum.

The workshop has three parts:
4. You will be given about 2 hours and a variety of art materials to create on canvas a piece that helps me understand what attending high school with a diagnosis or label of autism feels like.
5. You will join other participants in a focus group to speak about your art project and share your experiences. This discussion will last about 2 hours.
6. During the last half hour of the day, from 2:30-3:00 pm, there is an opportunity for your parents / guardians to come in and view the art work you, and others in the group, have created.

**Lunch and snacks will be provided for you between the art and discussion portions of the day.

Potential Harms, Risks or Discomforts:
The risks that you may encounter in this study are not different from the risks that people diagnosed with autism may experience while participating in any new program. If you take part in this study, you may experience the following:
- Discomfort with the new environment and new people you are working with
- Some discomfort with our topics of discussion
- Stress while explaining and discussing you personal art project and sharing your story with the research team and participants
- Worry about how others will react to what you say about your experiences and feelings with respect to your personal story.
In order to minimize these risks, I have taken the following steps:

You, your parent / guardian and I will have a private meeting in this new space (Autism Ontario – Hamilton Chapter office) before April 25, 2015, for 15-20 minutes. On this day, I will provide a pre-study package that will include: an agenda for our program day, an introduction to the Research Assistants who will be at the study, the types of questions I’d like you to be thinking about for your art project, my contact information, in case you or your parents / guardians have any questions between the Pre-Study day and the day of the workshop.

- I will review with you what I hope to learn from my research project at the Pre-Study day and again on the day of the study.
- The research team is highly trained and experienced and will be able to provide you with support if needed throughout the day.

Potential Benefits to You:
The research will benefit you by giving you an opportunity to participate in a creative arts project. By participating, you will explore your own experiences through art materials of your choice. This arts-based telling of your personal story will be yours to keep at the end of the workshop.

Confidentiality:
Every effort will be made to protect you confidentiality and privacy. I will not use your name or any information that would allow you to be easily identified. In my write up for my research, I will create a pseudonym for you to further protect your identity. At any time during the study, you can identify particular information as private and this information will not be included in my research analysis.

Because of the nature of the group, the other group participants will learn your name (as you introduce yourself) and see you as part of the group. I will try to keep information shared in the group as confidential and private as possible. I will ask the other members of the focus group to keep what you say confidential but I cannot guarantee that they will do so. We are often identifiable through the stories that we tell. Please remember as you consider what to tell me.

The information / data you and your parent provides will be kept in a locked desk where only I will have access to it. Information kept on a computer or on a portable storage device will be protected by a password, and the portable storage device will be kept in a locked desk drawer.

Limit of Confidentiality:
Although I will protect your privacy as outlined above, if the law requires it, I will have to reveal certain personal information (e.g. if you tell me about being abused, harming yourself or someone else). At the start of the workshop, I will review confidentiality in more detail, including the circumstances in which I must share information with others.

Participation and Withdrawal:
Your participation in this study is completely voluntary. If you decide to be part of the study, you can stop (withdraw), from the group for whatever reason before or during the workshop. After the workshop on April 25, 2015, only images your art contribution can be withdrawn. There will be no consequences to you or your parents / guardians and any data you have provided prior to April 25, 2015, will not be included in the study, unless you agree that it can.

Information about the Study Results:
I expect to have this study completed by early Fall 2015. If you would like a brief summary of the results, please let me know how you would like it sent to you. You can let me know at any time by contacting me by e-mail or phone.

Questions about the Study
If you have any questions or need more information about the study itself, please contact me at: casolas@mcmaster.ca or 289-200-1609
This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat
Telephone: (905) 525-9140 ext. 23142
C/o Research Office for Administrative Development and Support
E-mail: ethicsoffice@mcmaster.ca

CONSENT

- I have read the information presented in the Letter of Information about this study being conducted by Shona Casola of McMaster University. ☐ YES ☐ NO
- I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested. ☐ YES ☐ NO
- I understand that if I agree to participate in this study, I may withdraw from the study at any time up until the date of the workshop, April 25, 2015, after which time, only the image of my artwork may be excluded from the study. ☐ YES ☐ NO
- I understand that if I withdraw from the study after the workshop, my contributions to the focus group cannot be deleted. ☐ YES ☐ NO
- I have been given a copy of this form. ☐ YES ☐ NO
- I agree to participate in the study. ☐ YES ☐ NO

I agree that the question period of the Pre-Study meeting and the workshop on April 25, 2015 can be audio and video recorded. I understand that this will be used to contextualize discussion, understand body language, and to transcribe and analyze responses to the discussion. I understand that this recording will be transcribed (written out word-for-word) and quotes will be used to illustrate themes from the discussion. I understand that my real name will not be used in the transcript or in the replication of their quotations in the final thesis paper.

☐ YES ☐ NO

I agree that the artwork I create can be photographed and published in the final thesis report, as well as any subsequent presentations or articles which may be given / published from this study.

☐ YES ☐ NO

☐ Yes, I would like to receive a brief summary of the study’s results.
   Please send them to me at this email address ________________________________
   Or to this mailing address: _____________________________________________
   _____________________________________________

☐ No, I do not want to receive a summary of the study’s results.

Signature: _____________________________ Date: _____________________________

Name of Participant (Printed) ________________________________
APPENDIX E

Assent for Minor to Participate in a Study

Shona Casola, B.A., B.S.W.
Masters Candidate in Social Work

Study Title: Redefining expert perspectives: understanding the meaning of identity and labels in high school students on the autism spectrum

Your parents / guardians have allowed me to talk to you about a project that I am working on with a couple of other people. In this project, I am researching how you feel about having a diagnosis of autism and how, if at all, this is important to you at school. I am going to spend a few minutes telling you about my project, and then I am going to ask you if you are interested in taking part in the project.

Who are we? My name is Shona Casola and I am a Master's Student at the McMaster University. I work in the Department of Social Work. I have also worked for Autism Ontario for 9 years and in that time have done lots of fun programs with individuals of all different ages diagnosed with autism, as well as with their families. I work in Durham, Toronto and Peterborough Regions of Ontario which are between 1 and 3 hours away from Hamilton. I will have two other people working with me on my project. Their names are Tracie and Quentin. They are both Social Workers, like me and have also worked with people with autism in the past.

Why are we meeting with you? I want to tell you a little bit more about my research project, and give you an opportunity to ask any questions you might have. I want to see if you would like to be in this study too.

Why are we doing this study? I want to do this study because much of the research I have read about autism asks parents and teachers for their opinions. I really want to hear from you. You experience life with autism and all that this entails and I feel very strongly that it is important to include your perspectives and ideas in the conversation. You spend a lot of your time every week at school and I know there are often challenges there. I'm hoping to understand your experiences at school a little bit better, so that when I'm finished school, I can help other youth during their time at school.

What will happen to you if you are in the study? If you decide to take part in this study there are some different things we will ask you to do. There is one thing I will ask of you today. If you sign consent to participate, I will ask you two questions that I would like to audio record, this will just take a few minutes. I will also ask you to come back to this office on Saturday, April 25 to participate in a day-long group with Tracie, Quentin, myself and between 5 and 8 other youth, also diagnosed with autism. On this day, there will be two main things I will ask you to do, the first is to create an art project that helps me understand what attending high school with a diagnosis of autism feels like. The second thing that I will ask you to do is to talk about your artwork with the group, and answer a couple of questions about it.

While doing these things all you have to do is try your best. If you have tried your best and do not know what to say or do next, you can guess or say ‘I do not know’. You can always ask me questions as well.
Are there good things and bad things about the study? What we find in this study will be used to help Social Workers like me learn to work better with youth at school, as well as in other settings like the community and at home. As far as I know, being in this study will not hurt you and it will not make you feel bad.

Will you have to answer all questions and do everything you are asked to do? If we ask you questions that you do not want to answer then tell us you do not want to answers those questions and that is OK. If we ask you to do things you do not want to do then tell us that you do not want to do them and that is OK too.

Who will know that you are in the study? The things you say and any information we write about you will not have your name with it, so no one will know they are your answers or your artwork. The researchers will not let anyone other than themselves and the other members of the group hear your answers or know any other information about you. Your teachers, principal, and parents will never see the answers you gave or the information we wrote about you. There will be a report completed at the end of our work together where I will use some of your words, as well as the other group members’ words, to share our important stories. I will only use a pretend name that I will pick for you, in this report.

Do you have to be in the study? You do not have to be in the study. No one will get angry or upset with you if you don’t want to do this. Just tell me if you don’t want to be in the study. And remember, if you decide to be in the study today, but later you change your mind, then you can tell me later you do not want to be in the study anymore. You can decide this until before you come to the workshop, or even during it, however, once you have started to participate in the focus group, I can’t take your contributions out.

Do you have any questions? You can ask questions at any time. You can ask now or you can ask later. You can talk to me at any time during the study. Here is the telephone number and e-mail address to reach me.

Shona Casola - School of Social Work - 289-200-1609 / casolas@mcmaster.ca

IF YOU WANT TO BE IN THE STUDY, SIGN YOUR NAME ON THE LINE BELOW:

Youth’s name, printed: __________________________________________

Date: ______________________________

Signature of the Doctor/Professor/Student: _____________________________

Date: _____________________________
APPENDIX F

FOCUS GROUP INTERVIEW GUIDE

Shona Casola, B.A., B.S.W.
Masters Candidate in Social Work

Study Title: Redefining expert perspectives: understanding the meaning of identity and labels in high school students on the autism spectrum

I) INSTRUCTIONS:
Thank you everyone for your amazing work this morning on your beautiful art projects. They all look amazing. I’m really looking forward to hearing all about them.

In a minute, everyone will have time to share their work of art and tell us about their experiences. But first, I would like to review with you confidentiality and how we will make sure all of our stories stay safe when we share them today.

Confidentiality: I want to spend a few moments talking about confidentiality and to go over some basic ground rules for our focus group discussion today:
- Everyone’s views are welcomed and important.
- I will put together what we hear and learn today in a report that I need to hand in at school.
- In that report, I will include everyone’s opinion in some way.
- I will not link your name with what you say. Instead I will write: one of the focus group participants said… OR I will use a made-up name, not your real name.
- Tracie, Quentin and I will protect your confidentiality and I am asking all of you here, to respect each other’s confidentiality. Anything heard in the room should stay in the room.
- Even though I will not use your real name, someone who reads the report might guess that it was you, because we are small community, just from the kinds of things you said,
- AND, I can’t guarantee that no one else in this room will tell others about what you have said
- So I am asking you to say things in this group that you are comfortable with others hearing or reading.
- This is not a place to tell secrets, and Tracie, Quentin or I may stop you to check in if we think you might be about to tell us one that doesn’t fit with the reason we are here today
- All voices are to be heard, so I will step in if too many people are speaking at once or to make sure that everyone has a chance to speak.
- I may also step in if I feel the conversation is straying off topic.
- You can expect this discussion group to last about 2 hours.
Use of Tape Recorder
• As you will recall, this focus group will be recorded to increase accuracy and to reduce the chance of me misinterpreting what anyone says. This [showing audio recorder] will be recording for our focus group only. I will turn it off when our discussion is finished. I might remind you to say your first name for the first few times you speak so that when I’m transcribing the tape I can get used to recognizing your voice.
• I’ll also ask that when using abbreviations or acronyms, you say the full name at least once to make it easier for me as I transcribe.
• When I type up the focus group discussion, I will remove your real name. Each of you will have a pseudonym (made up names) attached to your quotes which only I will know.
• All tapes and transcripts will be kept under lock and key.
• Only myself and the members of the research team, Tracie and Quentin will have access to transcripts (with real names removed) of this focus group.
• We will also use a “flip chart” to write down key points during the focus group and take notes.

Use of Video Recorder
• As you will recall, the art making and the focus group will be video recorded to increase accuracy and to reduce the chance of misinterpreting what anyone says.
• All video will be kept under lock and key by the researcher.
• The video recorder will record throughout the duration of the day, but will not be transcribed.
• The video recorder will be used to better understand body language, group dynamics, and a visual reminder of art, as you are describing it.
• The video camera will be stationary throughout the day and will not move.

Use of Digital Photographs
• As you will recall, the artwork that is the product of this study will be photographed digitally as a way of recording your images for the purpose of this study.
• No participants will be included in these photographs and they will therefore be non-identifying.

II. INTERVIEW
[Focus group discussion begins with me asking who would like to speak about their piece of art first]
• After a person has spoken about their artwork, they will be asked:
  o You know this project is about what life at school is like for you, with autism... how does your art work show that?
  o You said [word / phrase] – what does that mean to you?
  o [TO THE GROUP] Does anyone else relate to this [word / phrase]? Do you have things to add? Anyone with a different experience at school?
An opportunity for other group members to ask questions will be offered.
An opportunity to say any final things about their art will be offered

I will ask who would like to share their art next, and the process will repeat until each participant has had an opportunity to share

Once each person presents, I will say / ask:
So now I want to talk about being labeled with autism at school. Does everyone know what being 'labeled' means? Tell me about what it means…
I know some people who think it's really good and useful to have the label, and once you have the label, it can get you some support at school, accommodation to do your assignments differently or in a quiet space to write your tests maybe. It can also sometimes help people to understand you, and the things that you do a little better because they know you have autism. Other people I talk to think it is not good at all to have the label because in some cases, it puts ideas in people's heads about who a person is, based on their understanding of autism. Or they may tease a person because they have autism and are different. I want to know what your own experience is, how is the label or diagnosis of autism good or useful for you? How is it not good, or a problem for you?
What do you think it would be like for you to be in school as you are, but not to have the label 'autistic'? What would be different? How would your artwork change?
Is there anything we forgot or something important that we should know / talk about before we leave today?

I want to thank each of you for being so open and trusting me with your stories. I appreciate all of the insight into your lives and you sharing your talents with me today. I have learned so much from you and I think the information you have given me will be so helpful as I finish my big project for school.