Mediated Action, Narratives of Risk-taking, and Identity Formation in Adolescents with a Visual Impairment

Jessica Rathwell, B.A. Hons.

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Faculty of Social Science, Brock University
St. Catharines, Ontario

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Abstract

The purpose of this project was to discern the inherent tension present in narratives told by adolescents with a visual impairment as they attempted to make sense of their experiences, specifically those surrounding risk. Mediated action, based on the foundational work of Vygotsky and Bakhtin, was used as both a theoretical and methodological approach; it is the theory that there are two components that constitute any human action: the "agent," or the person who is doing the acting, and the "mediational means" that he or she is using to accomplish the action in question. Tension ensues as neither is able to fully explain human behaviour. Ten adolescents with a visual impairment participated in a narrative interview, revealing numerous counter-narratives surrounding risk-taking, including "experimentation undertaken using good judgment." Participants offered examples of how they engaged, appropriated, resisted and transformed the dominant narratives of disability and adolescence in their identity formation.
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CHAPTER ONE: INTRODUCTION

According to the cultural-historical approach deriving from the writings of L. S. Vygotsky, individual action can only be understood by acknowledging the social origins and nature of putatively individual behaviour. Mediated action is a theoretical framework that takes this foundational notion as a point of departure in offering a pragmatic way to analyze human behaviour in terms of the irreducible and inescapable tension between an agent who is engaging in the action at hand (whether that action be participating in a discussion or reflecting silently on one’s self-understanding), and the cultural resources or “tools” (e.g., socially prescribed narratives, discursively embodied ideologies) that are at his or her disposal and which mediate the action in question.

In the present work, I use the mediated action framework to examine the narratives of young people with a visual impairment, with a view to foregrounding the features and contours of the tensile relationship between the agent and cultural tool. My research is motivated by the assumption that dominant, hegemonic discourses or stories and narrative templates available for consumption by individuals do not accommodate the experiences of many groups of people.

Adolescents with a visual impairment are an example of a marginalized group whose narratives and experiences have been silenced by the absence of narrative resources that speak to their day-to-day lives and aspirations. In this connection, research has shown that narratives around risk-taking play an especially important role in defining the experiences and identities of youth in today’s society. How do visually impaired adolescents appropriate and engage these narratives? Are cultural discourses surrounding risk-taking perceived as alien to the experiences of these young people because of the
physical limitations they face or because of societal expectations regarding risk-taking and the forms it takes?

In what follows, I will examine various disability narratives through the lens of the mediated action framework. I begin by discussing mediated action and its historical foundations in the work of Vygotsky. Subsequently, I consider various types of dominant narratives available for consumption by youth, including counter-narratives that function as forms of resistance. Finally, I apply these concepts to the question of identity formation of adolescents with a visual impairment, with a focus on the role of risk-taking behaviours and narratives in identity construction. The overarching goal of this thesis is to highlight the cultural tools that are available to adolescents with a visual impairment in the negotiation of their identities, and the ways in which these young people actively appropriate, resist, or transform these tools or create counter-narratives around their unique experiences.

**Mediated Action**

*Social Origins of Individual Functioning: Vygotskian Foundations*

Emerging out of the Vygotskian, cultural-historical tradition, mediated action is a theoretical framework that offers an alternative to viewing human action as influenced either entirely by the individual or entirely by societal forces. Vygotsky was a strong proponent of the view that sociocultural influences affect human functioning. He believed that individuals can only be studied to the extent that they are acting using mediational means, as these means are so influential in shaping, empowering, constraining and transforming human action (Penuel & Wertsch, 1995).
For Vygotsky, the social nature of individual behaviour is best illustrated by his
“general genetic law of cultural development”:

Any function in the child's cultural development appears twice, or on two planes.
First it appears on the social plane, and then on the psychological plane. First it
appears between people as an interpsychological category, and then within the
child as an intrapsychological category. This is equally true with regard to
voluntary attention, logical memory, the formation of concepts, and the
development of volition...[I]t goes without saying that internalization transforms
the process itself and changes its structure and functions. Social relations or
relations among people genetically underlie all higher functions and their
relationships. (Vygotsky, 1981, p. 163)

According to this formulation, mental functioning need not occur solely within the
individual; it need not, in other words, be bound by the skin, so to speak. In the
Vygotskian view, it is equally possible to speak about mental functioning occurring
between people or, in his idiom, intermentally. Mental functioning is an activity that can
be engaged in by individuals, dyads or larger groups (Wertsch & Tulviste, 1992).
Moreover, intramental or putatively individual functioning retains this social dimension:
the “composition, genetic structure, and means of action [of individual mental
functions]—in a word, their whole nature—is social. Even when we turn to mental
processes, their nature remains quasi-social. In their own private sphere, human beings
retain the functions of social interaction.” (Vygotsky, 1981, p. 164). As the general
genetic law suggests, development proceeds from the social to the individual, through the
mastery and internalization of various social processes (Wertsch & Tulviste, 1992).
Agent and Cultural Tool: A Productive Tension

Wertsch (1998) uses these foundational ideas in his articulation of the mediated action framework. According to this approach, there are two components that constitute any human action: the “agent,” or the person who is doing the acting, and the “mediational means,” also referred to as the cultural tool that he or she is using to accomplish the action in question. It is precisely the inability for either the social or the individualist views to completely describe behaviour that has called for the acknowledgment of this third alternative, or as Wertsch calls it, a way to “live in the middle” (Tappan, 2006, p. 5).

The interaction between the agent and the cultural tool, however, is not as seamless as it may appear. Due to the constant pull from both of these forces, the individual lives with the “irreducible tension” that is brought about by exerting his/her own agency, and the power inherent in the cultural tool to shape his or her action (Wertsch, 1997). This tension arises through various circumstances in which the cultural tool either dominates the situation and the agent feels as though variations are not possible, or situations in which the agent perceives a wide range of possibilities for improvisation, possibilities that stem in part from the form of the cultural tool itself.

The telling of historical events, for example, tends to impose constraints on individual and collective remembering, constraints which restrict autonomy and potential for improvisation (Wertsch, 1997). In his analysis of collective memories of Russian history, Wertsch (2008) describes various schematic narrative templates that help organize past events, thus structuring how they are remembered. The most notable in this case is the “expulsion of foreign enemies” template. Using this narrative template ensures
that the story's events are told in a certain manner, thus limiting the individual's opportunity to improvise:

[T]hey start in a setting where Russian people are living peacefully in their own land, minding their own business. A great threat then appears in the form of a foreign enemy. This threat is massive and may come close to destroying Russian civilization, but in the end the Russian people rise up and, through great effort and sacrifice, manage to expel the foreign enemy (Roediger & Wersch, 2008, p. 13).

Cultural tools can either be concrete objects, such as texts, technological devices or historical references or they can be psychological or semiotic tools such as words, language or discourse. Regardless of the form that these tools take, they play a large role in mediating or influencing human action. This mediation happens due to the inherently social, historical and institutional nature of human action (Wertsch, 2002). In other words, humans “think, speak and otherwise act by using the cultural tools such as textual resources that are made available by their particular sociocultural settings” (Wertsch, 2002, p. 18). Accordingly, cultural tools are the mediating link between active agents and their social settings.

Tappan (2000) offers an example of the powerful effect of cultural tools on the moral identity formation of Ingo Hasselbach, the founder of the National Alternative neo-Nazi party in East Germany. In his description, Tappan explains how the cultural resources (i.e., ideologies) available at different points in Hasselbach’s life affected his subsequent moral development more so than any inner, core sense of individual moral identity. In the following quotation, Tappan describes how moral identity formation for
Hasselbach was not a gradual process of elaborating a purely individual sense of morality, but rather a series of interactions with mediational means in the social world. [Hasselbach] does not tell the story of the gradual development of his own inner sense of himself as a moral person. Rather, he tells the story of his adoption of a series of ideologically-mediated identities—identities, that is, shaped by specific cultural tools and resources (i.e., the ideologies of the hippies, the punks, the skinheads, and the neo-Nazis), and embedded in a particular historical time and place (East Germany before and after 1989). Moreover, these various “moral” identities were not generated by self-reflection, or by the construction of an inner sense of self-coherence. Rather, they were generated by action (and interaction)—often aggressive, violent, and hate-filled—in the world. (Tappan, 2000, p. 102)

It is crucial to note that these interactions between the active agent and the cultural tool are not mechanistically determined. Wertsch (2002) highlights the role self-determination plays in the appropriation of cultural tools when he discusses the process through which cultural tools are consumed, or how individuals take these cultural tools and make them their “own.” Moreover, as I elaborate in the subsequent section, there are different ways we can conceptualize this process of taking the cultural tool and individualizing or “internalizing” it.

**Mastery versus Appropriation**

Wertsch (1997) argues against using the widely contested term “internalization”, due to numerous notions generally associated with the term in the human sciences, specifically the implication that an individual who has “internalized” a cultural tool has accepted it as “legitimate and reasonable.” Instead, he argues that a distinction has to be
made between the “mastery” of a cultural tool and the appropriation of that tool. Mastery in this regard has been taken to mean the cognitive capacity one has to use the tool, but not necessarily the acceptance of the tool as one’s own (Wertsch, 1998). An example of this would be a student who can recite the answers to questions on an examination verbatim from the textbook, but who is not able to re-tell the information in his or her own words because the discourse in question is not felt to be personally meaningful. The student in this case has mastered the facts of the course, but has not made these details his or her own to the extent that he or she could apply them creatively to understanding novel situations or problems.

To further the example of the student writing an examination, Wertsch (1997) has advocated for the Bakhtinian expression “appropriation” to denote the process by which one makes a discourse “one’s own.” A student who can retell a discourse in his or her own words in a way that is personally meaningful may be said to have appropriated that discourse. Appropriation is, accordingly, compatible but not synonymous with the term “mastery.” Wertsch (1997) clarifies that making a narrative one’s own may be quite distinct from mastering it, as, again, mastery does not imply that one has accepted the cultural tool. Indeed, mastery of a tool is not mutually exclusive with criticism of or resistance to a cultural tool. Moreover, it can be argued that appropriation is perhaps most evident in individuals’ responses to narratives they do not agree with: resistance, criticism or the creation of a counter-narrative presuppose that a creative process of appropriation has taken place. Somewhat paradoxically, then, it is precisely because a discourse is made one’s own and experienced as “internally persuasive” (Bakhtin, 1981)
that it is subject to transformation in light of and through dialogical engagement with competing discourses and experiences.

Wertsch (2002) describes the possible implications of being forced to master a narrative that one does not agree with, using as an example the collective memories of Russians in transition between Soviet and post-Soviet control. He found that while these individuals were able to “master” the historical facts that they were required to learn pertaining to the official state-sponsored history, many did not agree with the narrative, and therefore reacted by distancing themselves from their collective history by creating alternative narratives (Wertsch, 1997).

The Narrative Turn

*Narrative as a Cultural Tool*

The previous examples of individuals’ reliance on storytelling to recount aspects of their identity highlights the importance of narratives, and more explicitly, language as a cultural tool. In fact, Vygotsky argued that language is the most important tool at our disposal (Tappan, 2006). Our use of “linguistic mediation” forms an important part of the “toolkit of human cognition” because it allows individuals to represent the past through history and memory (Wertsch, 2009). In addition to its representational functionality, linguistic mediation is what allows for the creation of a cultural narrative, or a collective identity. Bruner (cited in Wertsch, 2009) describes that what makes history and memory collective are the shared narrative resources employed by members of that culture. Thus, the group acts as a sort of “textual community” in which the collective memory of the group is tied to the individual identities of its members.
Berntsen and Bohn (2009) describe the process of creating a life story using the cultural tool called a “life script,” or a culturally sanctioned prototype for describing a typical life story. According to the authors, individuals attempt to create coherent life stories that provide personal meaning, while using a few stable cultural norms for guidance. Thus they are able to take the cultural tools that are available to them, namely narrative and culturally relevant life scripts, in order to structure a personal identity and narrative. This research highlights how identities are formed when people choose to use certain cultural tools at their disposal on various occasions to accomplish an action. This use of cultural tools allows for a wide variety of possible identities and improvisation depending on the social context in which individuals finds themselves (Tappan, 2000).

In fact, Berntsen and Bohn (2009) argue that it is necessary for one to internalize the cultural concept of “biography” before a cultural self can emerge. The authors describe how life scripts both constrain and enhance narratives by helping individuals choose which events are important and which are not. These scripts are universally relevant to people within a particular culture, are passed down from one generation to the next, and are determined by the past behaviour of members of the same culture. Therefore, the cultural scripts that are available in one culture are, by definition, not the same tools available in another culture. These life scripts are so normalizing and prevalent that Berntsen and Bohn (2009) found significant agreement among participants when they were asked what the seven most important events in one’s life would be if you had to tell a new friend.

In fact, cultural tools are not only relevant to a certain culture; I would argue that cultural tools vary depending on the period of time one lives in, the cohort of individuals
one is growing up with, and the political and social climate of the time. This can be seen in the identities of Russian citizens since the transition from Soviet to post-Soviet times. During World War II, Russia transitioned from a state of “strict, centralized control over collective memory to open, if not chaotic public debate and disagreement” (Wertsch, 2008, p. 124). Through interviewing individuals aged 22-78, Wertsch (2008) found that there was a large discrepancy between the kinds of narratives that were told by younger respondents compared to older respondents. Older participants tended to tell stories inspired by growing up in a time when teaching of the Russian identity was very much controlled by the central state powers; this was shown in their narratives through the ever-present voice of the state (Wertsch, 2008). Younger participants, on the other hand, told stories that reflected a loss of state control over collective memory, and their stories were much less constrained and rigid. Therefore, it is possible that different generations growing up in the same “culture” can be influenced by very different cultural tools that produce very different kinds of narratives.

The preceding illustrations suggest that the presence of cultural tools that mediate human action work in diverse ways to constrain and enable the telling of stories and ultimately the construction of identity. The very language people use to describe their existence is determined by cultural forces. However, as my discussion of the different ways of internalizing these tools suggests, the outcomes of these interactions between agent and tool are not mechanistically determined, allowing for varying degrees of improvisation. People have a great amount of autonomy in relation to the practical consumption of a cultural tool. No two people will take a cultural tool and use it in exactly the same way. Thus, while their behaviour may be based on the foundation
provided by the tool, the act of mediating the tool to make it one’s own necessarily entails a sort of individuality of outcomes. Wertsch (1998) may have outlined this tension best when he responded to the question “Who is carrying out the action?” with the answer “individuals-acting-with-mediational-means” (p. 26).

Narratives are a very powerful cultural tool in the tool-kit of human cognition. Bruner (1991) maintains that narratives are the way in which social individuals organize their experiences, and the memories of what has occurred over their life. He also argues that narratives are socially constructed and depend on the “cultural conventions and language usage” (Bruner, 2004, p. 694) of a particular civilization. Thus, every culture is replete with a ready-stock of narratives available to be consumed and appropriated by its members in a unique process that involves mediation between an active agent and the available cultural tools—although, as I argue more fully below, not all groups find sufficient templates with which to describe and interpret their experiences.

**Dominant Narratives**

As claimed by Vygotsky, language is among the most important cultural tools we have at our disposal. Narratives are one important way that language is maintained and disseminated to individuals within a culture. Somers (cited in Smith & Sparkes, 2008a) notes that there are certain master narratives that are embedded in contemporary culture—for example narratives of progress, decadence, industrialization and enlightenment. Smith and Sparkes (2002) illustrate how these dominant narratives, as well as the current social structure, constrain and reconstruct our individual sense of self. They assert that these structures not only control the types of narratives that individuals have access to, but also how they get told, and in what circumstances.
Smith and Sparkes (2008a) argue that the term “narrative” itself implies a relational world, and there is a general consensus in the field that identities and selves are created in a larger socio-cultural environment by individuals realizing what it means to be in the world. Barton (2007) highlights the dialogical nature of narratives when she describes how narratives are rarely interrupted or truncated in interaction by others; rather, they are re-interpreted through interaction with one’s partner.

This dialogicality is described further by Kelly (2005) as she highlights the potential of narrative to create a dialogic self that allows for the separation between the self and other, while still acknowledging the meaning making that happens between two people. She foregrounds the dialogical nature of narratives when she states that “narrative is a form of social action that embodies the relationship between a particular life experience and the social and cultural world the narrator shares with others” (p.185). Thus the dialogical nature of narrative makes it possible for one’s identity to be formed directly through interaction with real or imagined others; in the case of the research conducted by Kelly (2005), the identities of parents of children with disabilities were formed in both the intimate and public contexts.

This sense of dialogicality is so engrained in our consciousnesses that the individual cannot be understood outside of the complexities of cultural and relational processes (Smith & Sparkes, 2008a). Individualism by this token is nothing more than a socially and relationally constructed concept. Individuals draw upon and resist narrative resources at their disposal, and these actions, while personal, are still very much culturally situated. Atkinson, Coffey and Delamont (2003) highlight this irreducible
tension between individuality and the social world when they discuss the functions and influences of narratives:

People do things with words, and they do things with narratives. They use biographical accounts to perform social actions. Through them they construct their own lives and those of others ... Such accounts are certainly not private, and they do not yield accounts of unmediated personal experience. If we collect spoken (and indeed written) accounts of “events” or “experiences,” then we need to analyse them in terms of the cultural resources people use to construct them, the kinds of interpersonal or organisational functions they fulfil, and the socially distributed forms that they take. (p. 117)

**Disability as an Individual Problem**

Smith and Sparkes (2008b) expand the notion of society’s impact on identity formation further by stating that it is essential to study the body when studying narratives, as it is through the body that narratives are projected. They argue that the body is not knowable in unmediated ways, and therefore it is important to study and understand narratives through the bodies that tell them. For this reason, they advocate for the necessity of studying the unique narratives of people with disabilities or those who experience impairments of any sort, as their experiences are written through their corporeal experience. Similarly, Kelly (2005) acknowledges the need to study the lives of people who have disabilities in an attempt to re-examine the complexities of the disabled body as it is experienced, as it is “simultaneously produced by structural conditions and cultural narrative” (p. 182).
Accordingly, Goodley and Tregaskis (2006) note that impairment, as a social phenomenon, is "storied, negotiated and constructed in different ways" (p. 644). Therefore, the authors believe that a better understanding of impairment may arise through the study of the personal and social narratives of people with disabilities. Finally, Harter, Scott, Novak, Leeman and Morris (2006) concur that disability is best understood through narratives, as individuals with disabilities face numerous complexities of experience unique to their population, including the way in which their identity is constructed and how their experiences are embodied.

Upon examining the narratives of disability that are available for consumption, it appears that their variety and overall tone are inadequate. Disability narratives with themes such as tragedy, frustration, failure and surrender are commonplace in disability literature and throughout society as a whole (Emens, 2007). These disability narratives, rooted as they are in the notion of disability as deficit, fail to acknowledge the social impact of an impairment and focus solely on attempting to cure the individual "defect" (Kama, 2004).

Kama (2004) argues that this view comes directly from the medical model of disability that focuses on ameliorating an individual's impairment or functioning rather than changing the social environment to fit the individual. Accordingly, these individuals are seen as responsible for personally ensuring their impairment is resolved, thus emphasizing the [false] belief that interpersonal alienation is faced by all people with disabilities. He argues that by making this distinction between individuals who are impaired and society as a whole, cultural storytellers are able to negate the social context of disabled people's experiences.
Similarly, by viewing disability as an individual problem, society is freed from the responsibility of acknowledging its role in creating the barriers experienced by this group of people (Kama, 2004). Dominant societal discourses impose these disability narratives on individuals in an attempt to keep them in a subordinate position, believing their identity and their impairment is caused solely by them and their lack of ability to cure the defect they possess. While this subjugation may not be intentional and cannot be attributed to any one source, the construction of “disability narratives” likely came out of decades of hegemonic struggle where the most dominant were able to succeed. Harter et al. (2006) argue that the world is ideally structured to cater to the physically and intellectually gifted. All others are relegated to the private sphere, where they are expected to deal with their challenges individually.

Consequently, the narrative of disability is constructed in a way that takes negative societal reactions to disability, such as “interpersonal alienation, inaccessibility, job and housing discrimination [and] stigmatization” (Kama, 2004, p. 448) and places it on the individual, making it a personal tragedy, thus dissociating the negative results from any social context.

Harter and colleagues (2006) also note that this power differential between the dominant group and the subordinate group is a historically situated phenomenon. According to the authors, various identities throughout history have been formed through “power-laden discourses with differential representation of human interests” (p. 18). In the same way, societal practices typically position people with disabilities on the outskirts of social life, disconnecting them from acquiring cultural capital and taking part in interactions with larger networks of people with varied experiences (Harter et al., 2006).
would argue that it is through the culturally sanctioned use of the “disability narrative” that society is able to place itself in a position of power over people with disabilities who are often marginalized and subjugated in dominant discourse.

In many cases, disability advocates and people with disabilities themselves attempt to bolster the positive image of people with disabilities and affirmatively deny the “disability narrative.” These individuals reject the disability narrative by accepting only narratives of advocacy and agency as legitimate, and paradoxically undermining the possible narrative multiplicity of people with disabilities (Barton, 2007). This narrow focus on a single disability narrative tends to harm individuals with disabilities as much as stigmatizing dominant narratives, as neither of these templates are likely to speak to the diverse lived experience of these individuals.

Goodley and Tregaskis (2006) highlight the importance of allowing for and accepting the multiple identities of people with disabilities, just as one would accept the multiple identities of individuals who are not disabled. The authors highlight the fact that while most people with disabilities experience situations in which they are oppressed, they also experience circumstances where they are able to demonstrate equal competence alongside non-disabled people. Allowing for multiple identities within one individual is crucial if these individuals are to be seen as fully human and capable of taking on numerous roles and identities within society (Goodley & Tregaskis, 2006). Therefore, the fixed category of “disability narrative” that only allows for one way of being is harmful, as it negates real-world experiences and attempts to force people with disabilities to take on an identity or role that may be foreign or contrary to their experience.
Barton (as cited in Emens, 2007) describes how these common narratives of disability (frustration, failure and surrender) are often “suppressed by the triumphant narrative of successful empowerment” (p. 126). She studied the narrative identities and narratives of parents who have children with special needs in a support group setting. She found that more often than not, parents wanted to express narratives of frustration and failure in relation to their children’s success, specifically the frustration of everyday parenting, narratives of giving up, and narratives of failed parent advocacy. The group facilitators, however, discouraged parents from telling these kinds of stories and attempted to move them towards more preferred counter-narratives, such as stories of affirmation. When some parents refused to take part in the dominant group narrative of affirmation, it was seen by the group facilitators as a reflection of political naiveté. Ultimately, the majority of parents shifted the tone of their narratives within group discussions, not because they experienced an epiphany, but because they were literally stopped from telling the stories they wanted to.

Barton’s (2007) research highlights the dangers of imposing a specific, all-encompassing identity on a heterogeneous group of people. Garland-Thompson (cited in Barton, 2007) highlights this truism of individuality when she states that individuals with disabilities “don’t all necessarily […] ally with the group […] work[ing] together toward the goal of making the world a more receptive and equitable place for people with disabilities” (p. 96). Like Goodley and Tregaskis (2006), Garland-Thompson is illustrating that the disability identity that is formed as a reaction to the negative stereotypes of people with disabilities may not be relevant to the experiences of everyone with a disability. Thus, it is crucial to resist imposing an identity or a narrative, such as
ones based on advocacy and agency, on individuals who do not necessarily identify with it.

**Counter-Narratives of Disability**

In an attempt to challenge both the dominant mainstream narratives and the dominant disability narratives, counter-narratives of disability have been identified. A counter-narrative, or “counterstory” as Nelson (2001) coins it, describes “a story that resists an oppressive identity and attempts to replace it with one that commands respect” (p. 6). Harter et al. (2006) describe this type of story as one that disrupts stories of domination by collecting other histories and anecdotes and creating a new narrative that is different from the dominant one. Finally, Andrews (cited in Barton, 2007) understands counter-narratives as “the stories which people tell and live which offer resistance, either implicitly or explicitly, to dominant cultural narratives” (p.109).

Smith and Sparkes (2008b) describe various counter-narratives that are relevant to the experiences of people with disabilities that reject the common, dominant account of disability as tragedy. Counter-narratives of disability with themes such as affirmation, quest and collectiveness “challenge and resist social oppression and ... allow different body-self relationships to occur” (Smith & Sparkes, 2008b, p. 19). These narratives work against the “dominant biomedical, sociocultural and political narratives of disability” (Barton, 2007, p. 95).

The affirmative model of disability is particularly noteworthy. Proponents of the affirmative narrative describe that it works to directly oppose dominant discourses of disability by building on the social model, which places the responsibility on society for creating disabling barriers, rather than on the individual for possessing an impairment.
By opposing dominant ideas, this narrative allows for positive social identities for both the individual and the collective by acknowledging the benefits and unique experiences of being "disabled."

Kelly (2005) offers an example of how one is able to actively construct a counter-narrative of disability, by recounting the story of a mother coming to terms with her daughter’s illness and disability. She describes a mother who actively resists the dominant narrative of profound impairment as tragedy and failure, instead choosing a counter-narrative centred on aggressively working for her daughter’s benefit. She describes how as the dominant narratives surrounding her daughter began to break down, she devoted herself as a mother to “sustaining and reproducing personhood within profound impairment through her daughter as a social being endowed with rights” (p. 188).

However, not all scholars are satisfied with these counter-narratives of disability. Barton (2007), for example, highlights the fact that these narratives stand only as a contrast in their resistance to dominant, stereotyped disability identities, but will never be legitimized as dominant in their own right. She sees these narratives merely as contributions to discourse: narratives that rely on the dominant discourse by problematizing it.

**The Disability Identity**

The controversial counter-narratives described in the previous section are created because the experiences of people with disabilities are largely absent from mainstream dominant narratives. According to Harter and colleagues (2006), there is an absence of people with disabilities within certain mainstream narratives, in terms of plots, narrators
or even as characters. And when they are included, their clichéd presence serves only to reinforce stereotypes of the identities of people with disabilities, for example the “supercrip” depicted as a musical prodigy or gifted athlete. This lack of representation (or misrepresentation) tends to reinforce the status of people with disabilities as outsiders and this belief penetrates their embodied identities. While tempting as an alternative to more stereotypical disability narratives, these counter-narratives still call for a form of homogeneity and uniformity that is rejected by some individuals with disabilities.

Additionally, it appears that as soon as a counter-narrative has been created, there will be a counter-narrative that replaces that counter-narrative. Disability stories and identities are a dynamic and quickly-changing phenomenon. Current research highlights some of the themes that are present in the present conception of a disability identity. Some of these themes seem to have come full-circle from the advocacy and agency narratives of the past. As I describe in more detail below, ideals such as incoherence, interconnectedness or interrelatedness, and expressivity are reflective of this movement.

In the dominant view of narratives, coherence is typically seen as a positive or necessary feature. McAdams (2001) describes how narratives, or life stories, have the capacity to create a more complete and coherent life story. He illustrates that in late adolescence through young adulthood, individuals tend to be actively involved in the process of constructing an identity. Life stories help to bring together the past, present, and anticipated future in a way that allows for individuals to possess an evolving self-story that is internalized and helps to create psychosocial unity and purpose. McAdams (2001) goes on to describe how individuals appropriate different aspects of their personal experience and construct narratives that make sense to both them and their audience. In
this way, children are constantly collecting culturally relevant pieces of information about themselves that will eventually make up the coherent stories they tell about their life in the future. He deems these integrative, coherent life stories to be so significant that “a person’s identity is not to be found in behaviour, nor—important though this is—in the reactions of others, but in the capacity to keep a particular narrative going” (McAdams, 2001, p. 112).

In stark contrast to this view is the research put forth by Smith and Sparkes (2002), who advocate for accepting incoherence in one’s narrative and consequently in one’s identity. Through the process of getting to know various men who experienced spinal cord injury, the authors realized the value of listening to and accepting stories that may not fit into culturally accepted narrative categories. For example, they found that if they listened to narratives expecting to hear stories about restitution, they may be complicit in further reifying dominant disability narratives, as well as interfering with the participant’s right to tell his own story, however incoherent it may be. Thus the authors recognized incoherence as part of a life story and in addition were able to see the value of participating in jointly creating a life story with these men, regardless of whether it fit within a dominant disability narrative, also highlighting the dialogical process of constructing a life story.

These competing views demonstrate the tension that is present when an active agent uses a cultural tool. Because there is often so much flexibility in how the tool is utilized, individuals tend to have different interpretations of the relevance of many features of the tool, in this case coherence. While some people value resolution and restitution in a life story, others may value the genuine experience of an individual,
regardless of the way it is told. In this way, dominant narratives are created that typically advocate for coherence as a salient characteristic of the story, while other (often counter) narratives fall outside that norm in search for other narrative ideals.

In addition to recognizing the value of incoherent stories in alternate disability identities, disability identities are being created based on tenets of interdependence. Harter et al. (2006) describe an art program created for people with disabilities (Freedom through Flight) in which the societal myth of independence is dispelled. Participants in this program learn alternate ways to understand each other, embrace each other’s differences and explore their interdependence. The authors describe how engaging with others through art helps to create a more internally cohesive identity, as well as contributing to the formation of a community. In this way, participants define an identity for themselves that is truly dialogical and formed through interaction with different others.

Garland-Thompson (2007) describes this process of interrelatedness when she explains how the disabled identity is formed. For her, the disability identity does not come out of experiences of personal struggle and facing adversity on one’s own; it comes from forging ahead with one’s team members and coming to terms with one’s disability as a member of a new community. For Garland-Thompson (2007), forming an identity “is a process that involves replacing stereotypical and oppressive conceptions of disability with different understandings rooted in the experience of a new embodiment” (pp. 118-119).

Meininger (2001) describes a concept similar to Garland-Thompson’s interrelatedness in his research on the care of persons with intellectual disabilities. In an
attempt to clarify the applicability of independence and the necessity of rights for persons with intellectual disabilities, he describes three different conceptions of autonomy using various metaphors. The metaphor of interest to the present discussion is the self as “story.” In this metaphor, the individual is seen as a character that is involved in finding himself through interactions with others. In this way of conceptualizing the self in relation to the world, dependence is not seen as a weakness, but rather as an “essential characteristic of all human beings” (Meininger, 2001, p. 246). The author speaks specifically about the term interrelatedness, and states that this is accomplished through both independence and dependence.

Finally, I would argue that there is another form of disability identity that is conveyed expressively. The “Freedom through Flight” initiative mentioned previously attempts to create a different experience of disability, one that rejects dominant discourses of disability, and allows impairment to be reconceptualised as something positive or simply as something different (Harter et al., 2006). In this way, disability is seen as only one kind of lived experience, and participants are given the space to express themselves creatively through the performance and exhibition of art. It is important to note the dialogical value of these art exhibitions, as visitors to the exhibit expressed to the disabled artists that they were able to relate to their experiences because they recognized facing experiences similar to the ones portrayed in the artwork. Therefore, the identities of both able-bodied viewer and disabled artist were created in the process of making and displaying the artwork.

Finally, Smith and Sparkes (2008b) reiterate the social function of stories for society as a whole. They believe that “society and culture speak themselves through an
individual’s story... [and that] people are born into a culture that has a ready stock of narratives from which they draw upon, appropriate, adapt, apply and perform in their everyday social interaction ” (p. 18). It is important to note that while these authors are not working within a mediated action framework, their analysis of narratives of disability readily suggests a family resemblance to that framework. It is apparent through Smith and Sparkes’ (2008b) description that individuals with disabilities are using narratives as a cultural tool to shape and form their identities as individuals.

Narrative Identity in Individuals who are Visually Impaired

Narratives have the potential to help individuals within a given society better understand themselves and their culture, regardless of their position within the culture. Whether individuals with disabilities are engaging dominant mainstream narratives in their identity formation, or stereotypical disability narratives, or whether they are striking out and creating their own identity that better represents their unique experiences, the influence of culture on these narratives is undeniable.

Upon examining the master narratives that are available within a certain culture, it is possible to see how the experiences of some individuals may not match these canonical stories. Very often, the stories that are told about and by people with disabilities further reify their marginalized status in society, as discussed previously. This is done by restricting or negating the stories that are available to certain individuals who belong to often marginalized groups.

Kate McLean (2008) refers to the restricting of narratives as the “silencing” of particular stories: “the explicit or implicit message that one’s stories, and consequently, one’s self, are not acceptable, interesting, or relevant, thus rendering one’s voice
unheard” (p. 1695). Conversely, she highlights that those who have personal narratives that match the dominant narrative are accepted by society as appropriate.

McLean (2008) offers an example of various groups of individuals, namely ethnic minority groups, women and homosexuals, whose narratives have been silenced throughout history. As an illustration of the privileging of certain identities over others, she points to the societal expectation that gays and lesbians must “come out”—in a sense formally announcing their deviance from the dominant narrative of heterosexuality. This illustrates the silencing of narratives, as these individuals become aware that their current selves and stories are not valued. It becomes apparent that their identities and narratives will only be legitimized if they fit into a recognized narrative category, in this case, homosexuality. This foregrounds important questions, such as “what narratives are told, why, and what [is] the consequence of having an untold self” (p. 1697).

Visual Impairment and Identity Formation, Touching the Rock: An Experience of Blindness, John M. Hull

The concept of silencing is applicable to a seminal text in the field of visual impairment and blindness. In 1990, John M. Hull wrote a memoir detailing his experiences of losing his vision over a prolonged period of time. His journaling covered a period of three years, and described various phases accompanying his profound loss, from anger to depression to acceptance. Most notable were examples in his story of how his experiences as a blind man no longer matched dominant narratives surrounding many roles that he felt had previously defined him, specifically the roles of father, husband and university professor.
The position that Hull felt was most disrupted by his blindness was the role he played as a father to his three children. This is best portrayed in the following quotation: “I have been marginalized as a father. My interaction with [my children] is now severely limited, and I am not the sort of father that I would like to be” (p. 143). This quote and others very similar to it throughout the autobiography highlight the tension that Hull felt in his relationship with his children. He described that he was acutely aware of the role a father should play in his children’s life and development, but also aware of how he didn’t measure up due to his blindness and the logistical and emotional barriers it presented. I would argue that his desire to be a certain kind of father to his children stems from pervasive ideas and discourses and narratives around what fatherhood should look like, primarily those depicting the father as strong, all knowing and independent.

However, throughout his narrative, the reader is able to see a transformation in Hull as he takes on different relationships with the dominant narrative of fatherhood. While he initially appears to be very withdrawn and despondent with his children early in his healing process, he learns to resist and reformulate the dominant narrative to some extent. This is evident when he originally withdraws from engaging with his son during his birthday party celebrations. He wasn’t able to see what gifts his son was receiving, didn’t know how to adapt the toys so they could play with them together, and therefore felt he couldn’t be part of the festivities. In a simple vignette, the reader is able to witness a reformulation of his role as a father, as he learns ways to adapt to the situation, such as interacting with his son one-on-one after the guests had left, and learning from his son what made each gift unique.
What is perhaps more interesting for the present discussion, however, is the ways in which Hull was not able to resist or reformulate the roles prescribed for him by certain master narratives. Throughout the entire story, it was evident that Hull was grappling with many issues surrounding his identity as a blind man. Because his transition to blindness was so gradual, Hull had trouble accepting the final, overarching title of "blind" into his self-concept. He made numerous comments about his loss of identity, his almost certain appearance as ignorant, his unavoidable marginalization and finally the capacity for blindness to return him to an infantile state in which he was robbed of his independence and masculinity. This is best summed up in his description of what it was like to have his sight robbed from him:

For if you take [predictability and familiarity] away, the blind person is transported back into the infantile state where one simply does not know how to handle the world, how to enter into it and to control it, how to exist in a relationship with that world, where the hard-won balance between trust and fear threatens to be upset, and one is overwhelmed by the thought that the world to which one seeks to be related is unrelatable to, because either it is unreal or unavailable. It is inhabited by beings to whom it does belong, the sighted. (Hull, 1990, p. 53)

The previous quotation, and especially the final sentence, highlights the incongruity Hull felt between the world he knew as a sighted man and the stories he felt he could tell about his life and his relationships as a blind man. Thus, it is apparent that while Hull is attempting to find his own identity as a blind father, husband and professor, his expectations and critiques of what it means to fulfil each of these roles is based on his
understanding of the dominant narratives of fatherhood, marriage and professional success.

Hull also highlights how the archetype of blindness does not necessarily have its own narrative, as it is always discussed in relation to light or being present: “this is what the archetype of blindness indicated, the lack of consciousness, the descent into sleep, the sense of nothingness, of becoming nothing. To be seen is to exist” (p. 60-1). In a subsequent passage he discusses his desire to find the antidote to this archetype, and postulates that the only force in opposition to darkness is light. He describes how his literal blindness may have activated the archetype of blindness within him; it is for these reasons that he often slips into a deep depression (Hull, 1990).

In many respects Hull (1990) portrays the tension that is present when individuals attempt to appropriate a cultural tool—in this case, master narratives—that do not fully describe their individual experience. Hull frequently mentioned that he was concerned with how he would be perceived by others and whether or not he would measure up to the ideals of fatherhood set forth by his culture. These examples show the constraining effect of a dominant narrative, in this case one pertaining to parenting, on people that do not identify with the dominant experience.

Risk-taking as a Foundational Adolescent Experience

Similar to the dominant narrative of parenting, the narratives associated with adolescence can be extremely prescriptive and, similar to discourses associated with disability, extremely marginalizing. Raby (2002) discusses how adolescents tend to be viewed as a homogenous group with essential characteristics; they are “dangerous, ungoverned and in need of control” (p. 430). Behaviour that is typically seen as “risky”
in adolescents includes smoking, drinking, drug use, sexual precocity, gambling and
dangerous driving (Lightfoot, 1997). Raby (2002) highlights five dominant discourses
that construct modern adolescence: the storm, becoming, at-risk, social problems and
pleasurable consumption. Of these five key discourses, all but one (pleasurable
consumption) deal with issues of youth risk-taking; three of these discourses (becoming,
storm and at-risk) will be discussed at length in the analysis section, as they relate
directly to the experiences and accounts of participants in the present study.

Raby’s (2002) conception of adolescence as a time of storm, the historic metaphor
put forth by G. Stanley Hall (1904), describes youth as genetically drawn towards risk,
experimentation and uncertainty. Similarly, the discourse of becoming highlights the
process of identity formation that adolescents go through on their journey to adulthood,
including the risks they take to form this identity. The discourse of youth at-risk describes
the various behaviours that youth engage in, such as taking drugs, drinking alcohol and
having unprotected sex; the motivations for these risky behaviours are seen to come from
a variety of sources: internal, peer-related and structural. Finally, the discourse of youth
as a social problem deals directly with the idea that adolescents who engage in risky
behaviours (disproportionately males) are a problem for their parents as well as the rest of
society.

By viewing popular discourses of adolescence through a lens of risk-taking, it
becomes apparent that risk-taking behaviour, whether or not accurately described by
adults and scholars, is an influential stage and descriptor of the adolescent experience. I
would argue that engaging in risky behaviours is one of the most important ways
adolescents actively construct their individual identities in today’s society. This may be
due to the nature of the activities themselves and the sense of maturity that is felt when adolescents choose to take part in activities that are typically adult-oriented (Lightfoot, 1997). Engaging in risky behaviours is a complex decision that has been shown to be dialogical in nature, follow certain cultural prescriptions, and assist in the burgeoning identity development of adolescents.

Risk-taking as a Dialogical Process

Just as telling one's story is a dialogical act, engaged in with various others, risk-taking behaviour is also dialogical in the sense that it is usually done in groups or with at least one other person, with meaning created through that interaction. As highlighted by Lightfoot (1997), identity construction is inherently contrastive, and taking risks as part of a group is a concrete way for adolescents to assert their place within their peer culture. This is due to the way in which taking risks mediates in-group and out-group relations by creating a shared history for group members.

Certain sub-groups of adolescents structure group membership and the identity of group members in terms of certain behaviours. For example, Lightfoot (1997) interviewed numerous teens and discovered various labels for the types of adolescent crowds and the behaviours engaged in by each group: “Preps smoke cigarettes, get drunk and stoned, and they have tried cocaine” (p. 135), for rednecks “alcohol and pot are the drugs of choice” (p. 136), and finally, “like punks, hippies are reputed to use drugs excessively, especially pot and LSD” (p. 137). While these are extremely stereotypical behaviours engaged in by individuals in a certain geographic region, one can appreciate the significance of belonging to a particular group or clique. Adolescents, as a whole,
tend to define themselves and their identities based on the people they spend their time with and the activities they engage in with the group’s members.

Relevant to the present discussion is the way in which each of the groups, or cliques, described previously uses risk-taking (or the lack of risk-taking) to define its identity. Some cliques characterized group membership according to the risky behaviour their members engaged in (e.g., rednecks drive cars fast and preps and hippies use drugs excessively), while other groups were defined by their lack of risk-taking (e.g., nerds are known for not taking risks and drammies spend their free time participating in school plays). Thus, within each of these categories, one’s propensity to take risks with other members of the group tends to define that individual’s identity; this highlights the dialogical quality of identity formation through risk-taking.

According to Gergen, Lightfoot and Sydow (2004), sharing in risk-taking adventures as part of a group is a way to narrate the identity of those involved, such that the risks taken and the reputations of the individuals involved are mutually affirming. Lightfoot (1997) highlights how group norms of deviance and aggression tend to promote interaction, affiliation and friendship among its members. Thus, risk-taking is one way in which adolescents identify with those around them. This dialogical process allows for the creation of similar stories among group members, and gives the group a shared history to discuss and narrate at later times.

Risk-taking as a Social Process

Risk-taking as a dialogical process takes place within certain culturally prescribed norms and expectations. In fact, DiBlasio (1986) highlights how cultural norms and expectations strongly influence risk-taking behaviour, as exposure to different groups of
people effectively shapes how adolescents view rules, laws and values, and whether they will act in law-abiding or law-violating ways. Thus the culture adolescents are immersed in, whether the larger culture or merely the culture of a particular sub-group, has a substantial effect on the choices individuals will make. As DiBlasio (1986) notes, this was evidenced by research highlighting that peer association and attitudes toward drinking and driving were a stronger predictor of an individual’s likelihood to be charged with a DWI (driving while intoxicated) than knowledge about the effects of this behaviour. In fact, Lightfoot (1997) discusses how adolescents’ conceptions of their own risk-taking behaviour, as well as their peers’, may be challenging the conventional view of adolescents, who are typically seen as in the throes of cognitive, social and emotional upheaval. Similar to more emancipatory counter-narratives of disability, she highlights how the current conception of adolescence may be changing due to the view that youth risk-taking behaviours are tied to developmental mastery, control and exploration. In this view, risks may be socially constructed as a positive developmental milestone that allows for individual growth, accomplishment and learning about life’s responsibilities (Lightfoot, 1997).

Thus, youth are using various counter-narratives at their disposal to define their experiences in a positive light, and are, in a sense, contributing to the reconstruction of a cultural narrative. This may be due to the fact that “teenagers, like adults, live in accordance with social meanings for which they are not responsible and which they may deplore” (Sustein, 2008, p. 151). While certain behaviours are expected of adolescents because of the culturally-relevant meanings that are attached to those behaviours, adolescents often appropriate those meanings in ways that resist dominant (adult)
conceptions. Understandably, then, a behaviour like adolescent risk-taking is likely to have contrasting valences within society: in general it is valued by one’s peers and condemned by adults.

Similarly, in a study on nurturing resilience in troubled youth, Ungar (2004) discovered that many behaviours that were conventionally perceived as dangerous, deviant and delinquent may in fact be examples of resilience. He describes youth who find ways to succeed on their own terms, regardless of whether their behaviour is accepted by caregivers. For example, “gang affiliation can be experienced by youth as an indicator of social maturity, a need for achievement, an appreciation for structure, and a system of beliefs relating to honour and duty” (p. 96), and “Squeegee Kids... have been made into thugs, rather than appreciated as entrepreneurs, their preferred construction of their role” (p. 97). In the previous examples, youth felt they were creating the strongest identity they could based on the resources they were offered. This highlights the subjective, socially-constructed nature of various identities and narratives, in this case risk-taking.

**Risk-taking as an Identity-Forming Process**

As discussed above, risk-taking as a culturally prescribed and dialogical act serves to assist in the formation of adolescent identity. Similar to Ungar (2004), Lightfoot (1997) has emphasized that society tends to hold two competing views of risk-taking: risks as trouble and risks as opportunity. Both of these views have the potential for identity development, as character is believed to be developed through risks and adventures. In this manner, risks tend to be sought for their capacity to challenge and educate. Many youth actually believe that taking risks offers them the possibility for
inner growth, independence and maturity (Lightfoot, 1997). In fact, as mentioned earlier, the social aspect of taking risks is probably the most significant motivator for engaging in these behaviours. Teens tend to believe that risky behaviour solidifies their place in a social order among their peers, as it serves as a declaration of their identity and generates a badge of peer group membership (Lightfoot, 1997).

Mitchell, Crawshaw, Bunton and Green (2001) offer another suggestion as to why risk-taking behaviour has the potential to transform an individual's character. According to the authors, North American culture has transitioned from a society built on social order to one based on taking risks. In a society where the dichotomy between the wealthiest and the poorest citizens is not as disparate as it was in the past, individuals strike out an identity based on the risks that they are able to take to advance their position in society. Therefore, whether it is risks taken in the business world, or risks that are more interpersonal in nature, the propensity for one to take risks is valued in today's society. From going out on a limb in one's job, taking chances on the stock market, to risky sexual encounters, taking risks is becoming a characteristic of modern society. Accordingly, one might expect narratives about risk taking to figure more prominently in narratives of identity—those of adults no less than those of adolescents. In this regard, it is important to keep in mind when studying the risk behaviour of adolescents that these individuals do not live in a vacuum; they both shape and are shaped by broader cultural discourses.

Visually Impaired Adolescents and Risk Taking: Planet of the Blind, Stephen Kuusisto

Similar to John M. Hull (1990), Stephen Kuusisto (1998) wrote a memoir of his experiences growing up as a person with a visual impairment. Because Kuusisto
describes his experiences from a very young age, the reader is given a very different perspective on various lifespan development issues that arose, namely fitting in with his able-bodied peers. In this sense, the idea of risk-taking assumed a different, more nuanced meaning, as individuals with visual impairments are not generally seen taking the same risks as their peers, but may be engaging in risky behaviour nonetheless.

Kuusisto (1998) describes what it was like to be a child growing up with a visual impairment, trying to gain acceptance from his peers. He gives the reader a picture of him riding his bicycle down the street, having no idea what lay ahead of him and being driven only by adrenaline. In this story, he falls but states that his only fear was being “found out” by the other children as a fraud. The following quotation highlights the lengths that Kuusisto went to to appear sighted and “pass as normal” among his peers:

I cycled from the age of ten until I was thirty. During my last decade it was occasional, more furtive, a headless activity like taking drugs. By my twenties, I knew it was injurious. As a child, I had only that graven need to resemble. (p. 9)

Kuusisto (1998) explains how his attempts to appear normal drove him to engage in numerous risky behaviours throughout his adolescence, including using illegal drugs, drinking excessively and transitioning from overweight to anorexic. This risky behaviour is evident in the following passage where Kuusisto describes his experiences of binging and purging.

I eat enormous cans of potato chips, whole boxes of cookies, entire cheeses, bins of plums, peaches... I am also more than a little stoned: glued together on Darvon, chocolate chips, bleu cheese straight from the foil. My flesh weighs me down like a rude sack of potatoes. (pp. 44-45)
I must sleep with the electric blanket on high. I’ve dropped below 105 pounds.
My mother begins to be alarmed. For a while my emergent thinness is
praiseworthy, I’ve been remade, I look convincingly refreshed, I seem to have
some friends. But now it’s clear I’m not eating.... Upstairs I’m free to be urgently
thin, inverted around my disappearance. My shrinking is an abstraction, just as I
am. Together we are a species. Down to bones, we’re at the height of our strength.
I want to be thinner. There’s no eloquence to it. (p. 56)

Articulated by both Hull (1990) and Kuusisto (1998), a loss of control over one’s
life and surroundings tends to be a common theme in stories told by individuals with a
visual impairment. Kuusisto (1998) portrays to the reader that his ability to manage how
he appeared to others, and thus his social identity, was how he instilled a sense of control
in his life when everything else seemed out of control. While disordered eating
behaviours are not typically seen in males, eating disorders as a whole are classified as
risk taking behaviour because of the health risks they pose (Igra & Irwin, 1996).

Research on risk-taking states that adolescents generally do not believe
themselves to be invincible, and in fact take risks purposefully to attain a goal (Fischhoff,
2008). Congruent with this idea, Kuusisto describes how taking various risks throughout
his adolescence served a purpose, namely allowing him to fit in with his able-bodied
peers. Whether it was riding a bicycle so he wouldn’t be found out, bingeing and starving
himself to cope with his ostracization and drastically change his physical appearance, or
taking drugs and alcohol to fit in with his peer group, each of his behaviours was goal-
driven and purposeful. Growing up in a time and place when even his own mother would
not utter the word “blindness” around her visually impaired son, Kuusisto took to the task
of forming his identity in the best way he knew how: fitting in with his peers by taking risks alongside them.

From the previous examples, it can be seen that risk taking is an almost universal adolescent activity that has the potential to transform an individual’s identity. Visually impaired adolescents are no different from sighted youth in their motivations to take risks. In fact, I would argue that the risks taken by people with a visual impairment are often more hazardous due to the practical issue of being unable to see. Even riding a bicycle becomes risky when one is not able to see what lies ahead on the road, let alone experimenting with drugs and alcohol—typically perceived as a pastime of able-bodied youth.

Purpose of the Present Study and Rationale

The purpose of the present study is two-fold:

1. To expand the applicability of mediated action as both a theoretical and empirical framework through analyzing the stories of a marginalized group of people who have not yet been studied in this context, namely, adolescents with a visual impairment.

2. To discern the tension present between the active agent and the cultural tool as adolescents with a visual impairment engage, appropriate, resist and transform the dominant narratives of disability and adolescence to make sense of their experiences, specifically those surrounding risk.

Mediated action as a framework has not yet been applied to the narrative identity formation of individuals with disabilities. While research has been conducted that uses mediated action to analyze life stories of various individuals (Tappan, 2000 & 2005;
Jones, 1999), its use with this population is novel and will contribute greatly to many fields of study, including psychology, disability studies and cultural studies by offering a tangible method to analyze the identity formation of people with disabilities in a way that does not privilege the social or medical models of disability, but rather advocates for a holistic, sociocultural approach.

A qualitative, narrative-based strategy will be used to study the experiences of this population. Narrative research as a whole is used very rarely in the study of persons with visual impairments, thus highlighting a further gap in the literature. Current literature in the field tends to focus on rehabilitation or educational intervention, using quantitative methods, while neglecting to investigate more subtle cultural expectations that may be placed on these adolescents by their peers, such as expectations about taking risks.

An individual’s engagement with the dominant narratives available for consumption has a seminal role in his or her identity formation. McAdams (2001) describes how narratives help to structure a life story, give it coherence, and assist in identity formation. In addition, actively formulating one’s identity is viewed as an especially formative task during the adolescent years, as adolescents are in the process of learning how to organize their experiences into an all-encompassing view of the self (Bamberg, 2004). However, despite the relevance of studying identity formation in this group, there is a paucity of research that focuses on the experiences of adolescents with disabilities. Research in the area tends to cater to the experiences of older individuals who make up the majority of those with a visual impairment (LaPointe, 2006).
Finally, as noted previously, risk-taking appears to be fundamental to the culture of adolescence; however, many sub-groups of adolescents have yet to be studied in this context, including those with a visual impairment. Research on visually impaired adolescents tends to focus on their purported lack of competence and acceptance among able-bodied peers descriptively—findings indicate, for example, that the size of their social networks tend to be smaller than their peers (Kef, 1997) and that they are seen as a burden on friendships (Mar & Sall, 1995)—but has failed to analyze how these youth behave socially with their peers during common adolescent activities, such as risk-taking.

For these reasons, the present study seeks to understand the ways in which the identity formation of visually impaired adolescents is affected by the dominant narratives of adolescence, most notably, risk-taking behaviours. The following specific questions will inform my analysis:

1. What kinds of narratives emerge when adolescents with a visual impairment discuss who they are?

2. Do adolescents with a visual impairment feel they are required to be a certain way or tell certain types of culturally-sanctioned stories about themselves?
   a. Do these narratives acknowledge the unique experience of visual impairment?
   b. Do participants resist, transform, or accommodate the culturally available narratives?

3. How does the discourse of adolescent risk-taking affect the identity development of adolescents who are visually impaired?
a. Do participants take part in the same types of risks as their peers? For what reason?

b. Does their visual impairment affect their ability to take certain risks?

c. Is risk-taking or telling stories about taking risks important to these adolescents? Why or why not?

   i. Is something else more important?
CHAPTER TWO: METHODOLOGY

Participants

Ten individuals (six female and four male) with a visual impairment were interviewed for the present study. Participants ranged in age from 15 to 20. My interest in interviewing individuals in this age range stems from my desire to gain the perspectives of adolescents specifically. Participants in this study were students who attended a school in Ontario that caters to individuals with a visual impairment. The only participation criterion was that participants were formally identified as visually impaired, as evidenced by their enrolment at a school for individuals with a visual impairment. There were no exclusion criteria for students wishing to participate, assuming they were able to communicate with the researcher.

Recruitment

After receiving approval from the Research Ethics Board at Brock University, I contacted the principal of a school in Ontario that caters to students with a visual impairment. I became aware of this school during conversations with friends who are visually impaired. When I contacted the principal, he informed me that I was required to complete an application to conduct research at this particular school; the application would be assessed by the relevant school board and the superintendent of the school.

Once approval was granted, I began to work with the principal of the school to determine the best way to recruit students. He felt that a daily announcement, delivered by him, would be the most effective as it would reach the greatest number of students. In total, the principal delivered the script that I prepared (see Appendix A) every morning.
for approximately two weeks. The script directed interested participants to the principal’s office to pick up the recruitment materials, which consisted of a letter of invitation and consent forms. I directed the principal to continue to advertise the study until the desired number of students came forward.

However, after approximately two weeks, it became apparent that the strategy of using a daily announcement was not sufficient to arouse interest in the students, as no students had come forth with their signed consent forms to participate. Thus, on one occasion, I traveled to the school to conduct an informal information session for any students who were interested in this research project. Students were informed once again over the loudspeaker that an information session about the study (which they were familiar with by this point) would be taking place in the library on a specified date at a specific time.

Attendance at the information session was excellent and, judging from students’ responses and engagement in the session, was successful in communicating a better understanding of the aim of the study and what would be required of them. While I was prepared at this session to give a formal presentation on the purpose and requirements of the study, it became clear that the best way to discuss the study would be to answer any questions the students had; thus the session had a very informal tone.

Throughout the session, students were very engaged in my research topic and had many questions for me, some relating to the study (“What if I don’t take risks at all?”), my research (“What school do you go to and what degree are you getting?”) and university as a whole (“What’s the difference between university and getting your Master’s?”), and other questions not related to the research at all (“How long did it take
you to get here?”). Overall, it appeared to be a great experience for both the students and myself, as it gave us an opportunity to meet and get to know each other on some level before the more formal process of interviewing took place. Subsequently, all ten participants were recruited after this session took place.

The principal was responsible for collecting the consent forms from the students and scheduling interview times that worked into each of the students’ class timetables. It should be noted that while the consent forms stated that only those students who were under the age of 18 get parental consent, the principal felt that all parents should be aware of the research project; in all but one case, parents returned signed forms even if their child was older than 18.

Once the scheduling process was complete and all forms were returned with the appropriate signatures, the principal contacted me and I traveled to the school for the interviews. All ten students were interviewed over two full days, four on the first day and six on the second. This compact interview schedule created the least amount of interference to the school and students.

Consents and other ethical issues

Due to the fact that the majority of participants were below the age of 18, the legal age of consent in Ontario, parental assent was required for most participants before the interview could take place. However, as mentioned above, the administration at the school requested that permission be gained from all guardians and students before the interview began, regardless of the students’ age. Parents and guardians were told that the purpose of this study was to discover the kinds of themes that are used in the stories that teens with a visual impairment tell about themselves; this would be accomplished by
asking their son or daughter specific questions about times that he or she may have taken
risks (see Appendices B, C, D & E for Parent and Participant Letters of Invitation and
Parent Consent and Participant Consent/Assent, respectively). School authorities
maintained the need to follow procedures around reporting any disclosures of abuse; this
requirement was shared with participants and parents as part of the consent process.

Regarding voluntary participation, every effort was made to ensure participants
understood that their participation was voluntary. Before commencing the interview, I
reiterated to participants that their participation was entirely voluntary, and they could
withdraw at anytime or decline to answer any question without penalty if they became
uncomfortable at any point. None of the participants withdrew and no one indicated that
they were uncomfortable answering any of the interview questions. Upon completion of
the interview, participants were offered a ten dollar gift card to Walmart for their
valuable contribution to this study; participants were aware of this incentive before
agreeing to participate. Finally, upon completing each interview, a feedback letter (see
Appendix F) was given to each participant outlining the purpose of the study and contact
information if they had any comments or concerns.

Procedure

Description of Setting

All ten interviews took place at the students’ school in one of two locations: a
conference room located in the main office of the school or in the principal’s office (as he
was not at school on that particular day and the conference room was in use). Participants
were given advance notice of their scheduled interview time, and if they were not at the
designated location on time, which was more often than not the case, they were called to
the main office over the loudspeaker. At this point, I asked participants if they would like to take my arm to be guided into the interview room; the majority agreed.

**Narrative Interview**

Once we were situated in the room, I described the study once again. All participants brought their consent form(s) with them and assured me that they were aware of what the forms stated. I went over the content of the consent form with each participant before the interview began, and asked each student if he or she had any questions before we began. I informed each participant that their voice was being recorded, and many students were interested in the recording device and asked to touch it to familiarize themselves with the equipment before we began. The interviews lasted on average 10 to 25 minutes.

At this point, a narrative, semi-structured interview was conducted with all ten participants. The decision to interview ten participants was made for two reasons. Sandelowski (1995) suggests that smaller numbers of participants are best when engaging in narrative interview research, as it allows the researcher to analyze the data in a more detailed way, by discerning the diversity within the narratives presented by each participant. Likewise, Bates (2004) advocates for interviewing each participant individually, as opposed to in a group setting, in order to create a more intimate research climate. An intimate research climate is essential for research that involves storytelling, as it allows the researcher to interact with the participant in a way that is conducive to discussing how the participant makes sense of their experiences and the greater environment.
The second reason for interviewing ten students came about after speaking with the superintendent of the school. It was decided that interviewing any fewer than ten students was potentially problematic for this particular school, as it could compromise the students’ anonymity and confidentiality due to the relatively intimate climate of the school. Therefore, interviewing ten participants was agreed upon, as this number provided a balance between the desire for an intimate research climate and the protection of the individual students.

Due to the narrative focus of these interviews, participants had a greater opportunity to choose the structure, content and focus of the interview to a degree, as the interview was partially open-ended. Bates (2004) claims that narrative interviewing offers the participant an opportunity to answer questions in everyday language, free from a formal, rigid line of questioning. According to Jovchelovitch and Bauer (2000), narrative interviewing is like a conversation between people, where the participants relate their experiences and bring in whatever they think is relevant. The researcher is then able to probe where necessary to guide the interviewee through the research topic (Bates, 2004). The necessity to probe participants was most evident as we discussed the question: “Do you engage in the same kind of risks as other people your age?” As discussed in the final section of this paper, participants experienced some confusion with the idea of “what other people their age do”. Thus, being able to probe the participant and guide them through the topics conversationally became valuable to the overall quality of the data.
Interview Protocol

The interview protocol for the present study was modeled after Gee, Allen and Clinton (2001), who also conducted a study on the factors that affect identity formation in adolescents. In this study, participants were asked various questions about their lives, homes, communities, interests and schools; this formed the “life part” of the interview. Following up on those questions, participants were then asked to comment on issues in society, for example abstract issues such as racism and sexism. Borrowing the methodological precedent set by Gee and colleagues, I chose to ask a series of “life” questions followed by “academic” or “society” (p. 176) questions, to discover the ways in which mediational means were engaged as participants discussed their identities in both concrete and abstract ways. The following specific questions were asked in the interview:

1. When people think about their identity or ask themselves the question “who am I?” they often choose to tell stories about themselves or their experiences. Can you tell me a story that reveals something important about who you are, about your identity?
   a. Do you feel your visual impairment is an important part of your identity?
   b. Do you think people expect you to be a certain way because of your visual impairment?
      i. What are these expectations?
      ii. Can you tell me more about how people may expect you to be?
      iii. Do people expect you to tell certain types of stories about yourself because of your visual impairment?

2. What kinds of behaviour do you—or people your age—consider risky?
a. Do you engage in the same kind of risks as other people your age?

b. Do you feel your visual impairment affects your ability to take certain kinds of risks?

3. Do you believe taking risks or telling stories about taking risks is an important part of being a teenager?
   a. If so, why do you think so?
   b. If not, what in your opinion is more important?
      i. Why is this more important?

Each of these questions was created strategically to examine every participants’ unique experiences with various discourses, keeping in mind Gee, Allen and Clinton’s (2001) abstract-to-personal style of questioning. The first set of questions (1) was created specifically to engage participants in a discussion about their identities, including whether or not their visual impairment enters into their sense of self, as well as offering participants an opportunity to discuss experiences they may have had with discrimination. Overall, these questions were created to discern how the youth perceived themselves and whether narratives of disability and/or discourses of adolescence were highlighted in the telling of their stories.

Based on extensive literature in the field, the second set of questions (2) dealt almost exclusively with the notion that taking risks is an important part of being a teenager and thus affects the identity formation of this group. The adolescents were asked whether they believed they took the same risks as other people their age to discover what activities they would cite as “risky” and whether they believed they engaged in this behaviour. Because an overarching theme of this study was to examine discourses of
disability highlighted in the introduction section, I also addressed the perceived limits their visual impairment places on risky behaviour.

Finally, the last set of questions (3) focuses on the positive social outcomes purported to come from taking risks, including the perceived benefit of discussing risk-taking with one’s peers (Lightfoot, 1997). I was interested in determining if adolescents with a visual impairment used storytelling about risks as a way to position themselves in a certain way with their peers. Ultimately, the last question in this set gave participants the opportunity to discuss what, if not risk taking, is an important part of growing up.

Once all ten interviews were complete, they were transcribed in full for analysis; approximately 40 pages of single-spaced text were produced and analyzed. Each participant was assigned a pseudonym in order to protect their identity in the final report. All ten participants indicated that they were interested in receiving feedback about this study upon completion. I collected the email addresses of nine participants in order to email a brief summary of findings and the phone number of one participant with the intention of reading the summary to her over the phone.

Data Analysis

Mediated Action

In keeping with the methodological precedent established by scholars in the field of mediated action research (e.g. Wertsch, Tappan, Brown and Jones), a sociocultural approach to data analysis and interpretation was adopted for the present study. Sociocultural analysis is a theoretical framework deeply rooted in the work of scholars highlighted throughout this paper, namely Vygotsky and Bakhtin, and which focuses its
analyses on the individual as well as his or her social, cultural and historic context (Wertsch, 2002).

Sociocultural analysis takes mediated action as a specific unit of analysis, as it promotes understanding of human action that is “inherently connected to the cultural, historical, and institutional contexts in which it occurs” (Wertsch, 2002, p. 18). As articulated throughout this paper, the foundational concept of mediated action states that two components constitute any human action: the “agent,” or the person who is doing the acting, and the mediational means or cultural tool that he or she is using to accomplish the action in question (Wertsch, 1998).

According to Wertsch (2002), “To be human is to use the cultural tools, or mediational means, that are provided by a particular sociocultural setting” (p.11). It is through the concrete use of these tools that the “irreducible tension” inherent in their use becomes salient. Therefore, mediated action as a theoretical framework highlights and deconstructs this tensile relationship through an analysis of mediational means engaged by the individual. Penuel and Wertsch (1995) elaborate on what it means to adopt a mediated action approach to understanding identity:

Taking mediated action as the unit of analysis ... allows us to ask a different set of questions about the way individuals use cultural tools to form an identity... In this approach, what we are attempting to interpret, explain, or analyze is meaningful human action, rather than either inner states of individuals or sociocultural processes, considered in isolation . . . . [T]he sociocultural framework asks us to focus on specific questions about the mediational means or cultural tools that people employ to construct their identities in the course of different activities and
how they are put to use in particular actions. When identity is seen in this framework as shaped by mediational means or cultural tools, questions arise as to the nature of cultural tools and why one, as opposed to another, is employed in carrying out a particular form of action. (p. 91)

While it could be stated that mediated action as a methodology does not provide a step-by-step guide to interpreting data like many other approaches, I would argue that therein lies its strength. According to Wertsch (1997), “a focus on cultural tools invites complementary, mutually informative analyses of the production and consumption of narrative texts” (p. 18) and negates the critique that identity research focuses only on cognitive nature of mental functioning, while ignoring the social nature (Tappan, 2000). Essentially, in its multidisciplinarity, this approach allows for a greater appreciation of the complexities of individual identity formation.

In keeping with the concept of multidisciplinarity, mediated action seeks to orient the researcher to the social and cultural tools being utilized regardless of the phenomenon under study, whether it be gender (Brown & Tappan, 2008), sexual risk (Jones, 1999), or moral identity (Tappan, 2000), as these constructs are at their core social ones and as such involve the use of mediational means. Exploring people’s use of those meditational means orients us the dialogical interchange that takes place between individuals and their world.

As an illustration of the applicability of mediated action as an analytical tool, Jones (1999), in his research on sexual risk, states that this approach allows researchers to identify the numerous cultural tools participants draw upon in the formation of their identities, such as discourses, ideologies and cultural practices. Jones notes that mediated
action shifts the focus of analysis from the identification, prevention and cataloguing of vulnerable people to a focus on identifying the tools that are available to individuals, whether they use these tools, and in what ways they use them.

Therefore, similar to research conducted by Tappan (2000, 2005), Wertsch (1997, 2002), Jones (1999) and Tappan and Brown (2008), much of my method was hermeneutic. In discussing the process of determining counter-narratives, Spreckels (2002) describes three forms of knowledge (common, ethnographic and theoretical) that are used when working hermeneutically with data—forms of knowledge that allow the researcher to arrive at complex conclusions about the subject matter in question. Van Vlaenderen (2001) further emphasizes the circular and dialectical nature of hermeneutic approaches to data analysis: “the hermeneutic circle implies that interpretation of a whole can only occur as a result of interpretation of its constituent parts and that these parts only make sense in the context of the whole” (p. 152).

Correspondingly, my analyses were based on my personal experience of general cultural discourses surrounding adolescence, risk taking, disability, and visual impairment (common knowledge), on conceptual formulations associated with the mediated action approach (theoretical knowledge), and on my engagement of the specific narratives provided by the adolescents (ethnographic knowledge). In keeping with the part-whole movement of the “hermeneutic circle,” my common and theoretical knowledge, while foundational for my initial efforts to understand and interpret the subject matter, was in turn shaped and reworked in light of the specific participant narratives I encountered.
The framework of mediated action is especially relevant when examining the experiences of adolescents with a visual impairment because of the role that discourse, a cultural tool, plays in individual and social functioning. By definition, a discourse is a set of ideas, metaphors and stories that are taken as truth within a culture (Lesko, 2001). Discourses “organize how we think, what we know and how we can speak about the world around us” (Raby, 2002, p.430). According to Davies (as cited in Lesko, 2001), during discourse formation, language and metaphor are joined with social understanding and linked with emotion. Thus, according to mediated action, discourses become the tools that are utilized by individuals in various and complex ways to make sense of their experiences.

Ultimately, utilizing mediated action as a methodology allows for a thorough analysis of the mediational means employed by the adolescents in the present study. The discourses that were called upon to narrate everyday meaning, the examples of double-voiced discourse present in their stories, and even the very identities of participants contained evidence of mediational means, an analytic category that orients us to the space between individual agents and their sociocultural setting (Wertsch, 2002). Once identified, these meditational means or cultural tools, in this case dominant discourses and narratives surrounding adolescence and disability, were deconstructed and analyzed to highlight the ways in which each participant uniquely resisted, transformed or appropriated them in a way that was congruent with his or her self-understanding.

While there are likely many relevant and effective sources one could use in a sociocultural analysis of identity formation, I have chosen to use three of Rebecca Raby’s (2002) five discourses of adolescence (becoming, storm and at-risk) in the present study.
The discourses of adolescence as becoming, a storm and at-risk offer an appropriate structure to analyze the way in which visually impaired adolescents rely on risk-taking to define their identity, as each discourse prominently foregrounds adolescent risk-taking experiences as seminal to the formation of one’s identity. I argue that these dominant discourses of adolescence, in addition to narratives of disability, are mastered, appropriated, resisted and transformed as adolescents with a visual impairment make sense of their experiences on their journey of identity formation.

In the following analysis, I will concretize the discourses of adolescence as analytical tools by offering examples of how they function in the world. Specifically, an analysis of popular Hollywood films illustrates how teenagers are typically portrayed as irrational, irresponsible and careless, which creates the impression that they are still in the process of “becoming” and are not yet able to take on adult roles (Stern, 2005). Likewise, interviews with pre-service teachers highlight the cultural assumption that adolescence is inherently a “stormy” developmental stage in which teens are wild, obnoxious and biologically driven by their hormones (Finders, 1998). Finally, Scott, Reppucci and Woolard (1995), through a discussion of the juvenile justice system, illustrate that youth are “at-risk” of jeopardizing their desired futures, and are therefore in need of surveillance and regulation.

Discourses of Adolescence

Rebecca Raby (2002) discusses five overlapping discourses that are commonly associated with adolescence and risk taking, three of which became especially salient during narrative interviews with participants; each of these will be discussed in greater detail in this section. For her part, Lightfoot (1997) describes discourses of risk-taking as
emerging from scholars such as Erikson, and particularly from his central thesis that adolescents engage in a period of “experimentation from which they emerge with a foothold on who they will become” (p. 20). This period of “locomotion” or constant movement toward something, often done by engaging in behaviour considered risky, is critical in the process of self-discovery and maturation (Erikson, 1963).

Adolescence as “Becoming”

Along this line of reasoning, the adolescent as “becoming” is the notion that adolescents have potential, but have not fully reached this potential. In a sense, they are frozen in time, neither rational, responsible adults, nor any longer children. During this time, according to the narrative of adolescence as becoming, self-discovery and identity formation through experimentation and risk taking are crucial in laying the foundation for adulthood.

In line with the idea that youth are irresponsible and not currently engaging in activities that will facilitate their becoming or springboard them into a desired adulthood, Stern (2005) analyzed the portrayal of adolescents in Hollywood films. In her analysis of the 43 mainstream films from 1999-2001 that featured teenagers as a central character, Stern (2005) discovered that modern Hollywood films “likely reinforce adults’ negative views and possibly work to distance adults from teens” (p. 23). For example, she found that while in reality the majority of teens are involved in volunteering and employment, fewer than five percent of film characters were depicted this way. On the other hand, a disproportionate number of youth were seen engaging in risk-taking activities that were self-serving, pleasure-seeking, and violent.
According to Stern (2005) "the virtual absence of depictions of teens as workers, volunteers, and caregivers may contribute to many adults’ beliefs that teens today are lazy, spoiled, and irresponsible" (p. 34). The caricatures of youth that the media presents reinforces the discourse of becoming (or of the failure to become), as it portrays youth as irrational, irresponsible and careless set against the ideal of adulthood. Because teens tend not to be portrayed in more “adult-like” roles, such as caregivers and workers, it is assumed by many that they are not capable of the maturity or responsibility necessary for these positions, thus reinforcing stereotypes that they may have the potential to take on these roles, but are not yet able.

Adolescence as a “Storm”

Paradoxically, however, while adolescents are expected to be acquiring and practicing the traits of adulthood, such as maturity and responsibility, they are viewed as unpredictable and biologically driven to take risks. As a result, it is expected that they will be drawn towards experimentation, while at the mercy of their raging hormones. This is the image of the adolescent as a “storm”. In the example that follows, Finders (1998) highlights that even the teachers who work closely with young adults assume that adolescents are overcome by irrationality and immaturity. It is precisely this view on adolescence that sustains the notion that adolescents are predisposed to risk taking and experimentation.

The idea of the immature and undisciplined teenager was examined in a qualitative study by Finders (1998) who asked pre-service teachers the question “What do you expect, anticipate, look forward to, and worry about in working with middle schoolers?” Responses to this question highlighted strong adherence to the dominant
cultural narrative of adolescence as a “storm,” as shown in the following examples: “I worry about the maturity level, as far as being or not being able to discipline them. I'm afraid they may be too obnoxious”, “I expect this age group to be pretty wild—with hormones surging and putting them in a certain state of mind” and “They have too much energy. With raging hormones and all. I don't look forward to having to tell Johnny to stay in his seat 10 times a day. I worry about liking them” (Finders, 1998, p. 252). These responses highlight the extent to which dominant assumptions about youth become integrated into our cultural narratives as fact, often leaving little room for reflection or reassessment of these beliefs.

Adolescence as At-Risk

Finally, in somewhat of a synthesis of the previous two discourses, the adolescent as “at-risk” is the view that the present day is a very dangerous time in which to grow up, especially due to the risks that teens commonly engage in, and adolescents must therefore be protected while undertaking the monumental task of forming their identities. Given these potential dangers, various techniques of surveillance and regulation become acceptable and are considered necessary (for examples, see McKay, 2005).

The view of adolescents as an “at-risk population” was concretized by Scott, Reppucci and Woolard (1995) in their evaluation of adolescents’ decision making opportunities in the legal system. The authors discuss that, premised on the notion of becoming, adolescents are viewed under the law as incompetent, immature and unable to fully comprehend the gravity their legal situation. Because of these paternalistic views, the legal system established a juvenile justice system that protects adolescents from the presumably immature and youthful choices they will make about their future. In this way,
youth who commit the same crimes as adults are treated as less mature and therefore less deserving of severe punishment (Scott et al., 1995). This conception that youth are at-risk of jeopardizing their desired futures extends into all important areas of an adolescent’s life, including restrictions on the ability to make decisions about medical treatment, employment, marriage and education (Scott et al., 1995).

As the previous examples demonstrate, adolescents tend to be seen as homogenous, with essential characteristics that emphasize risk-taking and consequently protection from risks as significantly important for the formation of their identities (Raby, 2002). However, as can be seen in the participant narratives in the following section, this essentialist conception of adolescence was continually challenged. Tension between participants’ experiences and the discourses available to describe these experiences, including dominant ideas surrounding disability, was evident throughout the interviews and was manifested in complex ways.

The tension between the participant’s experiences and the available discourses can be explained in part by the varying degrees of agency that each of the three discourses of adolescence allow for, because, as Raby (2002) states, there are fissures within each discourse that permit resistance. These opportunities for self-assertion and resistance begin to undermine the weight of these discourses as truth statements. Citing Vygotsky and Bakhtin and echoing foundational ideas by Wertsch, Holland (2001) advocates the necessity of studying agency as part of a sociocultural approach, as it addresses the paradox that humans are at once products of their social worlds yet still capable of producing remarkable improvisation. An analysis of the socially constructed
nature of identity, as it relates to risk taking, will be examined further in the results and analysis section on agency.

In the following section, I will begin by deconstructing the narratives of adolescents with a visual impairment, utilizing the three discourses of adolescence described above as analytical tools, while concurrently considering the effect of dominant discourses of disability, namely incompetence, dependence, failure and homogeneity described extensively in Chapter One. More specifically, each of these discourses will be used to analyze the responses and narratives offered by participants when asked to speak explicitly about their experiences with risk-taking. This analysis will yield insight into the specific ways in which adolescents with a visual impairment appropriate the culturally available tools at their disposal as a means to formulate their identity. Finally, as noted above, my analysis will highlight opportunities for agency within each of these discourses and the ways in which adolescents in the present study have attempted to assert their resistance.
CHAPTER THREE: RESULTS AND ANALYSIS

The purpose of the present study is to understand the ways in which adolescents with a visual impairment engage, appropriate, transform and resist the dominant narratives of adolescence and disability in their efforts to make sense of self-relevant experience, particularly as it revolves around taking risks. Accordingly, in this section I examine the reflections and narratives told by adolescents who are visually impaired in response to questions about their identity and the role that risk-taking plays in their lives. My analysis is organized around three prevailing discourses of adolescence, namely, becoming, storm, and at risk, which position youth simultaneously as unable to know their current selves, as slaves to their hormones and biology, and as necessarily in need of protection, respectively, and dominant discourses of disability, such as incompetence, dependence, failure and homogeneity.

Discourses of Disability

Initially, participants were asked to tell a story that revealed something important about who they were, about their identity. This was intentionally posed as a very open-ended question in order to allow participants to freely and candidly discuss their thoughts on their identity. DeFina (2009) advocates for the use of unspecific questions such as this, as these questions can lead to different narrative developments, as the account becomes a design created by the teller. In contrast to other questions posed later in the interview, this initial question did not explicitly raise the issue of disability or impairment.

While some participants initially discussed their visual impairment or health problems as a salient part of their identity, for most participants, their disability did not enter into their self-description. This is consistent with research by Watson (2002) who
determined that when asked what image comes to mind when thinking of one’s self, very few people with disabilities actually discussed their impairment as a salient part of their identity or even factored it into their sense of self. Congruently, most participants in the present study listed personality traits, unique skills, attributes and/or interests—rather than their impairment—when asked to talk about who they were.

Similar to the pattern reported in Watson’s (2002) study, participants in the present study felt their impairment was part of them, but only one of their many characteristics. Anna, for example, echoes this sentiment when she acknowledges her impairment, only after other, arguably more salient, aspects of her personality are discussed:

Anna: Umm, basically, well, I've been able to be in different sports; I'm very athletic. And, I've done many social activities, plus the choir, and I've been in many school plays, and I have performed in performances, like I performed in this year’s Christmas Carol-a-thon and I like to write and make up stories for people, and I'm also willing to help people whenever they need help.

Jessica: Is there maybe a story you can think of that really illustrates for us who you are?

Anna: Well, I'm a totally blind person, and I was blind from birth, and I first started using a cane when I was like in Kindergarten...

However, when asked specifically about the importance of their visual impairment as part of their identity, participant responses reflected two narrative themes: one which focuses on being burdened by a disabling society and another which identifies impairment as the cause of personal struggle. These templates for discussing disability,
examined in more detail in the following sections, were also noted by Watson (2002). He found that most participants described either the importance of their impairment in terms of its physical effect, meaning the daily experience of living in an impaired body, or its political effect in terms of discrimination and stigmatization.

*Disabling Society*

In the present study, those who cited a disabling society discussed difficulty dealing with other people’s perceptions of their impairment as well as problems interacting with people who didn’t understand them. This is shown in the following quotation where Josh discusses constantly worrying about being taken advantage of by others, in this case, getting the correct change back when paying with cash:

I think more of the challenge of being blind is not because of blindness itself, it’s because of people’s perceptions of it. So by that I mean the people who will not give you the same chance as everybody else because you’re blind, to the people who will try to take advantage of you... because I feel, unfortunately, I feel that I almost have to, metaphorically speaking, I have to wear a suit of armour when I’m out in public because I have to make sure that I’m protecting myself from people who underestimate us just enough that they think they can get away with stuff.

Josh speaks passionately about other people’s perceptions of him and other blind people and describes later in the interview that this treatment has compelled him to become “overprotective of [himself] and admit[ting] that people say [he] is even to the point of paranoid.” Throughout the interview, he spoke about the negative expectations other people place on him. He continually discussed feeling inferior and needing to prove
himself to others, whether it be to strangers in a coffee shop, video game enthusiasts online or even his parents.

The Bakhtinian notion of double-voiced discourse is useful here to understand the ways in which participants made claims that were aimed both at making a statement about the participant’s self, but also at addressing others expectations and hence at making a particular communicative impact. According to Bakhtin (as cited in Morris, 1994), double-voiced discourse is one that “is directed both toward the referential object of speech, as in ordinary discourse, and toward another’s discourse, toward someone else’s speech” (p. 105). Josh’s pointed awareness of the opinions of others is an illustration of double-voicing that occurs as he discusses overarching dominant discourses at play in his life. Josh’s statements serve two speakers and two intentions at the same time, each dialogically related to the other, almost as though the two speakers were interacting with each other (Dentith, 1995). On one hand, Josh argues that he is competent, but as a form of double-voiced discourse this focus on competence is also an address to others, and in particular a way of responding to others’ less than positive expectations for him as a blind individual. It is not enough to be competent; it is also necessary to convey the image and appearance of competence to others. In a sense, Josh must prove his competence to others and often goes to the extreme of protecting himself in public, while on the other hand he consistently acknowledges that others view him as inferior, thus often underestimating him. This tension-filled engagement with the actual and anticipated (and often antagonistic) views of others is a hallmark characteristic of double-voiced discourse and highlights Josh’s awareness of and efforts to dialogically engage and oppose the dominant discourse of disability as incompetence.
Watson (2002) highlights the dialogicality that is inherent in identity formation as he discusses the struggle one of his participants faced to create an identity through interaction: “by rejecting how others may see him and, through an interpersonal and social process challenging the narratives about him, he can adjust the ideas of others to fit with his own idea of his self-identity” (p. 515). Here Watson (2002) highlights the social nature of identity formation and reiterates earlier descriptions of identity that focus on the inherent cultural, discursive and interactional nature of self-definition (Barton, 2007; Kelly, 2005; Smith & Sparkes, 2008a, 2008b).

Participants in the present study also noted both implicitly and explicitly that their identity was being created through a constant dialogue with others, as seen in Josh’s previous quotation. This, however, is not a harmonious dialogue by any means. Josh’s response typifies Bakhtin’s notion of “internal” or “hidden” polemic. In this form of double-voiced discourse, the speaker’s “discourse is directed toward an ordinary referential object, naming it, portraying, expressing, and only indirectly striking a blow at the other’s discourse, clashing with it, as it were, within the object itself” (Morris, 1994, p. 107). Josh’s discussion about the caution he must exercise to protect himself “cringes with a timid and ashamed sideward glance at the other’s possible response, yet contains a muffled challenge” (Bakhtin, 1984, p. 205). Josh anticipates a hostile response from the other and responds based on this assumption; his resulting speech is as aggressive as it is fearful, as the other has ultimately affected not only the content of his response, but also how he tells his story (Tarulli, 2001).
The Disabled Identity

The subjugation and lowered expectations of people with a visual impairment expressed by Josh was described in vivid detail in a biography written about Mike May, a man who has been visually impaired since the age of three. In this quotation, Kurson (2008) describes a conversation May had with another individual who is visually impaired about the way in which they believe they are regarded within society:

The blind seemed groomed by the custodial establishment to lower their expectations, to become objects instead of actors, nouns instead of verbs. Neither could abide the deferring, postponing, waiting, dreaming, and sitting apart that seemed endemic to the lives of so many who had lost their vision. (p.76)

This sentiment further speaks to the societal constraints placed on individuals with a visual impairment in regards to how they are perceived and expected to be. The responses offered by participants in the following section highlights the tension that inevitably ensues when culturally available narratives regarding impairment don’t allow individuals to fully describe their experiences.

Because of the incongruence or tension between their experience and others’ perceptions of them, the majority of participants indicated that they felt they had to try harder to be recognized and accepted by others. In Sarah’s case, themes such as adaptation, acceptance and working harder to become a stronger person were discussed. Sarah’s rejection of the “disability narrative” discussed earlier, in which cultural storytellers tend to paint people with disabilities with the same brush by overemphasizing their homogeneity and propensity toward failure, is an attempt to bolster the image of people with disabilities by refusing to tell any stories about failure at all.
I think [my visual impairment is] maybe a lot of who I am. I think, you know, having to work a lot harder and having to try to do things a lot harder, even having to fail and pick yourself back up kind of makes you a stronger person because of your visual impairment.

In fact, in the final section of this paper in which agency is discussed, we will see that Sarah even goes so far as to state that sometimes when she has stories about failing, she simply "tries not to tell those stories." However, as Barton (2007) notes, adopting an identity based on achievement and being a strong person is still potentially damaging, as it does not do justice to the experiential complexities of people’s lives.

The pervasiveness of the “disability narrative” became apparent throughout the interviews in that even those participants who told me that their visual impairment was not an important part of their identity still evoked dominant disability narratives such as incompetence, dependence and homogeneity to describe themselves. Narratives organized around the themes of normality, competence and individuality emerged when participants were asked the question “Do you feel your visual impairment is an important part of your identity?” For example, Ashley negates the narratives of abnormality when she answers: “I just think of myself as a normal kid, living a normal life, but with some other medical issues, that’s basically what I think of myself as.”

Ashley’s response, and others like it, suggest that dominant narratives that are commonplace in literature and society as a whole—narratives of tragedy, frustration, failure and surrender (Emens, 2007)—are at once evoked and challenged within a single narrative. Specifically, when asked if others ever expected them to be a certain way because of their visual impairment, all but one of the participants told stories that
reflected the expectations contained in dominant discourses of disability, including commonly held conceptions about people with a visual impairment. These negative conceptions identified people with a visual impairment as dependent, incompetent, helpless, lacking a personality and slow. This awareness of the “disability narrative” is demonstrated in the following quotations by Sarah and Jason, which, in keeping with Bakhtin’s notion of double-voiced discourse, contain a muffled and ironically expressed challenge to this dominant narrative:

Well people probably expect that you can’t do very much for yourself, really. So, you know, you start doing things for yourself, you start acting like a normal human being, laughing at everyone else’s jokes, saying "Oh, I saw that movie; it was so funny" or you know, just enjoying the same things everyone else enjoys and they're like "Wow, you're actually like a normal person and you like to do normal things?" or you've, you know, cooked dinner, or like go around the mall or something and they realize, wait, you know, they're maybe not so different and then, you know. (Sarah)

People expect me to be some stupid guy who doesn't know what's what. Yeah, like expect, people think I'm, "Oh, this poor little blind person that can't do..." you know? They just think "Oh poor you, you're blind, let me help you, let me do this for you". (Jason)

Sarah’s use of the phrases “acting like a normal human being” and “you like to do normal things?”; no less than Jason’s reference to others who perceive him to be “some stupid guy who doesn’t know what’s what” and “this poor little blind person” suggest concrete, discursive embodiments of the “other’s” discourse, a discourse that is
ultimately rooted in the dominant disability narrative of incompetence and abnormality. Sarah and Jason are not ambiguous when they respond to how others perceive them, specifically stating that others expect them to be abnormal, lacking a sense of humour, unintelligent and incompetent. Thus, they have anticipated the negative response of others, and their response to my question reflects that awareness while simultaneously resisting and dismissing these conceptions.

Similarly, Anna’s response to the question of whether or not her visual impairment is an important part of who she is acknowledges and critiques discourses of disability as incompetence when she states, “No [my visual impairment is not an important part of who I am], because I think that if you're blind or not, I think I can do lots of things very well, like I can even figure skate... I feel like I can do just about anything no matter what disability I have.” Thus, by stating that her visual impairment is not an important part of her identity because she is able to do many things very well, she is rejecting the arguably common conception that people with a visual impairment cannot “do lots of things very well,” thus resisting the discourse of incompetence and creating a counter-narrative based on competence and ability.

The presence of disability discourses in the narratives of these youth is line with Raoul (2007), who states that “disease, disability, and trauma, while often having physical or biological causes and effects, are socially and psychologically constructed and part of a life story which changes because of them” (p.5). In this sense, both visual impairment itself and discourses surrounding it act as mediational means that affect one’s self-definition and relation to the world. This was seen in the previous examples from Anna, Sarah and Josh. Their identity relies on both a mastery of the discourse of
disability as incompetence, in the sense that they are aware of it and can reproduce it, but
their responses also constitute an explicit challenge to the discourse as well, particularly
through the creation of counter-narratives. In this way, disability becomes a lens through
which identity is created and viewed. However, similar to the discourse of adolescence as
“becoming” described in the next section, disability narratives also have the potential to
restrict and confine the way individuals define themselves.

Discourses of Adolescence

Adolescence as “Becoming”

“Being in the state of coming erases the ability of those in the state to describe or
know themselves and places the privilege and responsibility on adult experts to explain
adolescents” (Lesko, 1996a, p. 149). Common conceptions of adolescence place its
members in a tensile relationship with the freedom and protection of childhood, on the
one hand, and the responsibilities of adulthood, on the other. In this state of “becoming,”
adolescents are expected to undergo a process of self-discovery and identity formation
that focuses on who they will be as opposed to who they now are.

Similar to research by research by Stern (2005), who found that adolescents are in
fact more responsible and prosocially motivated than they are portrayed in popular
culture, participants in the present study had a complex and varied relationship with the
discourse of becoming, undermining the essentialist view of adolescence described
earlier. The majority of the time, participants appeared rational and responsible as they
described the behaviours they engaged in and their reasons for doing so. However,
ocasionally, they also subscribed strongly to the ideals of the discourse, most notably the
belief that they were still in the process of figuring out who they were, and therefore allowed themselves the time and space to figure things out.

Their tensile relationship with the discourse of “becoming” was, however, complicated further by societal expectations of people with a visual impairment. For example, attempting to assert independence became not simply an adolescent striving, but also an attempt to impress upon others the abilities possessed by people with a visual impairment. This is an example of intersecting discourses, a concept that will be elaborated throughout this section as I discuss participants’ encounters with “becoming.”

In fact, Lesko (1996b) highlights the way adolescents as a whole are devalued in today’s society and the emphasis that is placed on dependence and incompetence: “their dependence communicates their inequality, their ‘becoming’ status appears to legitimate it” (p.465). I would argue that adolescents who are visually impaired engage both narratives of disability and adolescence in the formation of their self-concept and identities, both of which emphasize dependence. It is precisely the way they engage these intersecting narratives that is of significance, as seen in the following discussion on independence.

Striving for Independence

Raby (2002) states that one of the paradoxes of youth as “becoming” is their desire to become more independent, while at the same time they are seen as dependent by others. Some adolescents in the present study used this position of “becoming” to their benefit, taking advantage of the time to figure things out, while others felt constrained by their inability to do things for themselves. However, as a whole, participants shared the understanding that gaining independence and/or appearing independent was of pivotal
importance to them. After speaking to these teens, I would argue that their desire for independence was more prominent than it is for other able-bodied adolescents, as both their age and disability place them in a position of dependence according to dominant discourses.

This intersection between discourses of disability and adolescence was illustrated best by Josh (see “Growing as a Person” below for narrative) when he described a time in which his mother told him he would have to leave his current school and move to a school that didn’t cater to people with a visual impairment. His narrative highlights the desperation he felt when he thought he might lose the opportunity to gain independent living skills that would assist him as a blind person while he was still young. Thus, he was convinced that due to both his impressionable young age and his disability, it was crucial that he gain a certain level of independence, so he didn’t “come out a charity case, a drain on society who knows very little.”

The view that an individual’s “disability,” more so than his or her “impairment,” causes problems functioning in society is in line with the social model of disability, a model according to which the effects of impairment are intensified by a society that does not properly accommodate an individual’s needs (Kama, 2004). Consider, for example, the following excerpt in which Emma talks about how her visual impairment inhibits her independence. She discusses how feelings of dependency are prominent in her life because of her disability:

And I am visually impaired and I'd say one of the biggest things it inhibits me to do is be more independent and travel. Doing stuff with friends, I can't just say "Oh, OK, let's do this tomorrow." I always have to know where we want to go to
see if I know how to get there. If I need a ride, I would have to arrange it with my mother, stuff like that.

In this quotation, Emma is acknowledging the dependent position she often finds herself in and how this affects her ability to interact with her peers. This vignette is significant, as it featured prominently in her response to the first interview question of the interview, “Can you tell me a story that reveals something important about who you are?” Her response makes it clear that she views herself as someone who desires independence, but finds herself constrained. Emma evokes both discourses of adolescence and disability in this excerpt; she has appropriated the discourse of adolescence as “becoming”, noting that adolescence is a time when youth begin to gain independence and freedom and are able to make plans with friends without restrictions, whereas her visual impairment and discourses surrounding disability place her in a position of reliance upon others.

In her own subtle way, Emma appears to be making a commentary on accessibility in society and her lack of options as a person with a visual impairment; however, due to its prominence in her response about her identity, it could be conjectured that she views her lack of options and dependence as a personal failure or a salient part of her identity.

Growing as a Person

In an effort to objectify the narrative of risk-taking for participants and in order to gauge their relationship with the discourse, the adolescents were asked about risk-taking as it relates to their identity formation, and more specifically about whether taking risks is an important part of being a teenager. Responses to this question were varied, with some participants believing it was important to take risks and some stating reasons why risk-
taking was not important to them at all. These responses will be discussed in greater
detail in the section on adolescence as a “storm”; however, what is most interesting for
the purposes of this section is the responses of participants who challenged dominant
discourses that emphasize risk-taking as important, and who stated that other aspects of
growing up were more important.

Participants discussed the importance of growing up, and many diverse themes
emerged: growing as a person, becoming skilled at various hobbies and developing
strong relationships with family and friends. Of particular interest is the theme “growing
as a person,” which highlights their relationship with the discourse of “becoming.” What
is notable here is how participants negotiate the paradoxical situation of striving for
independence while still acknowledging that their status as teenagers offers them the
unique opportunity and time to find out who they are. Here, Sarah discusses the
beneficial aspects of “becoming,” specifically the importance of taking some time to
think about who you are and where you’re going:

I think it's just important to, just figure out who you are and just take some time
and really think about, you know, step back from your life and just think about:
Am I where I want to be? Am I who I want to be? If I keep doing what I'm doing
now, is it going to make me happy? Like am I the person that I think I should be?

Similarly, Josh seems to ascribe to the belief that adolescence is the opportune
time to learn all he can, and offers a personal experience to make his point. Here in
particular is an excerpt from the lengthy narrative he recounted on the topic of leaving the
school he was currently attending because his family wanted to move outside the school’s
jurisdiction. In this story, he passionately states why he believes he needs to stay:
I thought, you know what, I was actually contemplating suicide because I thought, if I get dragged out... and miss out on years of training that I need to become a successful blind person, I thought, I might as well commit suicide because in a regular school, I'm going to come out a charity case, a drain on society who knows very little and [school name] has averted that disaster for me.

When asked how this relates to important milestones of growing up, we had the following dialogue:

Jessica: OK, so could you maybe bring that story back to the question of what is important to being a teenager? What would you say?

Josh: I think I was trying to relate that to, not only do I, you know, need to learn all I can, but I needed to be able to make that decision for myself.

In this quotation, Josh brings to light many of the issues discussed thus far. His story about potentially having to leave his school before he received the training and skills that he needed highlights his appropriation of the discourse of “becoming,” as Josh uses the discourse to his benefit as a method of convincing his mother to let him stay at the school. As a young man of only 16, he had internalized the belief that he was still growing into the person he is supposed to be, specifically a “successful blind person,” and that the school was necessary to help him in this quest. Thus, while literature may cite the importance of risk-taking for the majority of youth, Josh has made it clear that for him, other concerns, such as learning adaptive skills for adulthood may be more important.

What these participants both have in common is the understanding that their current selves, while not completely matured and rational, are still vital and powerful.
The next section on adolescence as a “storm,” however, is a contrast to the self-aware adolescent depicted in this section. This ambiguous period of adolescence that many teens use to their advantage when defining their identities often causes adults to be wary of them, believing their actions are biologically determined and unpredictable.

*Adolescence as a “Storm”*

Similar to the discourse of adolescence as “becoming,” adolescents in the present study had a multifaceted relationship with the discourse of adolescence as “stormy” and stressful. According to this discourse, teens are inherently inclined to take risks and experiment due to the physiological changes taking place in their pubescent bodies (Raby, 2002). Similar to the discourse of “becoming,” this “storminess” is often identified by adults, leaving teens in the position of trying to understand their seemingly irrational behaviours by trying to incorporate this trait into their burgeoning identities. Steinberg (as cited in Raby, 2002), on the other hand, speaks out against this view, arguing that it is exaggerated. He notes few teens are actually moodier that adults, deliberately oppositional, or experience an identity crisis, as seen in the narratives offered by participants.

At this point, it may be useful to revisit Wertsch’s distinction between the mastery and the appropriation of cultural tools, with particular reference to the discourse of adolescence as a “storm.” In some instances, participants in the present study appropriated the discourse, thus making it their own. This was seen in responses where the participant discusses the exhilaration of taking risks and the importance of doing these things before you have to “settle down” (Jason). However, it appeared to me that the majority of participants have simply mastered the discourse, meaning they were
aware of it, but did not necessarily accept it as their own. This was suggested by responses in which participants talked about the risks other teens were taking, while stating that they did not engage in such risks themselves. However, neither appropriation nor mastery guarantee a harmonious relationship with the cultural tool, and both ultimately allow for resistance or criticism of the discourse, as illustrated by participants throughout this section.

Although not all adolescents identify with the unpredictability and upheaval thought to be characteristic of their age, taking risks or refusing to take risks appears to be an important part of growing up. Mike May, a man with a visual impairment and the subject of an autobiography on the topic of human curiosity and adventure, supports the idea that experimenting and taking risks is the best way to figure out who you are: “the highest good for a person, blind or sighted, [is] in pushing forward in one’s chosen realm, not just because it [leads] to a fuller life but because it [seems] the way to know oneself” (Kurson, 2008, p. 76). Similar to some of the participants in this study, Mike May lived his life in a way that attempted to negate stereotypes of blind people any way he could. Throughout his life, he always took the road less travelled, which often involved taking risks, such as driving a motorcycle, joining the CIA and breaking records in downhill speed skiing. In fact, taking risks as a blind man and being recognized for them was so important to his self-definition that when offered the opportunity to undergo an operation that might restore his sight, he reflected:

May began to think a lot about who he was. Faced with the loss of his blindness, he could imagine a world in which the special things he did became routine, where catching buses in Europe was expected, where skiing moguls was ho-hum.
Vision for all its reported wonders, also made men ordinary, and it hit May that he didn’t necessarily want to be ordinary, that maybe he enjoyed or even thrived on the accolades and attention that came to him for being blind, and wondered why someone might choose to see if that meant no one would see him anymore.

(Kurson, 2008, p. 115)

In the following section, I will be describing how visually impaired adolescents defined risk, whether they engaged in the same kinds of risks as their peers and whether they felt that taking risks was an important part of being a teenager. Through this discussion it will become apparent that nearly all participants believed they took some risks in their everyday lives. The discourses and communication surrounding those risks, while qualitatively different than the risks commonly discussed in risk literature (for example, smoking, drinking, drug use, sexual precocity, gambling and dangerous driving [Lightfoot, 1997], which will be referred to from this point as “classic” risks), acted as a tool for the formation of their identities.

What Does Risk Mean to You?

Initially, to discern what adolescents considered “risk-taking” or “risky behaviour,” the participants were all asked the question, “What kinds of behaviour do you or other people your age consider risky?” Responses to this question were varied, and can be condensed into one of three themes. The first category includes “classic” or prototypical acts that most people would cite as risky, including getting in trouble (e.g., vandalism, robbery and pulling fire alarms) and compromising health and/or safety (e.g., drinking, smoking, drugs and sex with strangers). The second category includes examples that could be described as “everyday risks,” such as involvement in sports or athletics
(e.g., skiing, rollerblading and horseback riding), recreational activities (e.g., rollercoaster rides, climbing trees and eating spicy food) and worst case scenarios (e.g., drowning while fishing in a dam or falling while walking along a steep cliff). Finally, I have termed the last category “blind-specific” risks, as these situations, described often by participants, are uniquely dangerous or risky to individuals who are visually impaired. Responses from this category included safety concerns (e.g., crossing the street, getting hit by a football or going somewhere new) and fears of being taken advantage of (e.g., not receiving correct change when paying with cash).

Consistent with emerging literature on risk-taking (see Smith, Cebulla, Cox & Davies, 2006), the acts most adolescents cited as “risky” differed from “classic” examples of risk. While the majority of participants were able to describe the risks that “typical” teens might take, all participants stated that they themselves did not engage in these types of risk, rationalizing this choice with practical or logistical reasons as well as the belief that they were exercising good judgment. Their rationale for not engaging in typical risks will be discussed further in the next section on adolescents “at-risk.”

Subscription to the Ideology of Risk-Taking

The following example highlights a common theme found throughout the interviews. Here, Emma is able to pinpoint what could be considered risky behaviour, but quickly distances herself from the behaviour by asserting that she herself doesn’t engage in it:

Jessica: What kinds of behaviour do you, or other people your age, consider risky? So it doesn't necessarily have to be things that you've done, but when I say teenager and risk-taking, what comes to mind?
Emma: Ugh, drinking, drugs, not knowing- not telling parents where they are, not really caring who your friends are, oh going to parties that might not be safe.

That's about it.

Jessica: OK, and do you engage in the same kinds of risks as other people your age?

Emma: No, not really. I'm completely blind at night, so I never go out at night.

Jessica: No? That has an effect on it?

Emma: Yeah...

Our discussion highlights Emma’s ability to master the discourse of adolescence as a “storm,” in which teens are prone to drinking, irresponsibility and ambivalence, while also distancing herself from it. Her mastery of the discourse comes to light as she uses language consistent with adolescence as a “storm”, by listing “typical” teenage behaviour; her use of words like “not knowing” “not caring” “not safe” highlight the idea that the teens who engage in this behaviour are acting irrationally and aren’t making good choices. Throughout the interviews, it became apparent that the majority of participants had mastered the discourse of adolescence as a “storm,” as they were able to describe activities that could be considered risky; where they differentiated themselves was the degree to which they subscribed to the ideology of adolescence as a period when one engages in these “classic” examples of risk-taking. In the following quotation, James describes activities he considers risky in his own life, which would fit within the category of “blind-specific” risks noted earlier:
Well, [risk taking] can be as simple as crossing the street and getting hit by a car maybe, or taking a safe neighbourhood walk and getting jumped by some stranger 'cause you can't see them coming...

Likewise, in the following excerpt, Jason describes the things that he considers risky, some of which he takes part in, some of which he doesn’t:

Jason: ... eating the spiciest food, jumping off the highest diving board, you know- I do that. You know, just doing crazy things like stealing your parent’s car or breaking a window, or robbing a like, you know, doing something like that, vandalizing things, drinking alcohol.

Jessica: Those are really good examples. Do you engage in the same risks as other people your age?

Jason: Well, not all of them, but I did jump- I did belly flop off the high diving board of the [Name] Centre. I literally belly flopped off it. And I ate like hot curry stuff, so... And I did it to get a rush. I did it to go "Ohhhhh I'm livin' my life on the edge!"

The previous examples support findings by Smith et al. (2006), who state that while earlier literature on risk focussed on risk as static and categorical, such as the “classic” risks mentioned previously, studies on the topic currently conceptualize risk as “a dynamic phenomenon, located within cultures, structures, institutes and individual worldviews... includ[ing] a focus on ‘everyday risk’: the role of notion of risk in people's routine activities and life-planning strategies” (p.1).
Experimenting as a Developmental Milestone

Reflecting this research by Smith and colleagues (2006), youth in the present study appeared to take on a more nuanced relationship with both risk-taking and discourses that aim to describe and quantify risk-taking behaviours, such as the discourse of adolescence as a “storm.” In fact, Lightfoot (1997) exposes this nuanced relationship by presenting numerous narratives from her study on adolescent risk-taking. Through her analysis, Lightfoot (1997) was able to show that youth tend to subscribe to the belief that adolescence is in fact an important time for experimentation and taking risks, but that they expect personal and physical development will suppress this behaviour in the future. Thus by subscribing to progressive developmental narratives, it appears teens use their youthful status as justification for engaging in “irresponsible” behaviour before they are expected to take on a more conservative socially prescribed role. Thus, according to mediated action theory, the teens appear to be appropriating the discourse of adolescence as a “storm” and subscribing to the ideology of risk taking to make sense of their experiences. An awareness of the progressive developmental narrative was demonstrated by Jason:

Teenagers thrive on the exhilaration of taking risks and that's part of living up, like living it up, like living your life before you get a job, before you get things like kids or a wife, you gotta settle down, so live it up while you can.

Jason’s emphasis here on “living it up” before the responsibilities of adulthood begin highlights the extent to which he has appropriated discourses of adolescence, specifically a narrative of risk-taking into his identity. However, not all participants subscribed to this progressive developmental narrative as confidently as Jason did; most
found themselves trying to make sense of their contradictory experiences surrounding risk. On one hand, participants communicated that they did not take the same risks as their peers for various reasons, while on the other hand many discussed the positive aspects often cited in the literature of taking risks alongside their friends and telling stories about these experiences afterwards.

Therefore, as mediated action theory would predict, the discourse of risk taking serves a communicative function in mediating social relationships. In fact, Lightfoot’s (1997) study, in which adolescents were asked about the appeal of taking risks, found that a fair number of teens (15%) emphasized the social implications of taking risks; for example, “they impress friends; they create shared memories; they give you something to talk about laugh about later” (p. 100). Sarah highlights that being able to talk about risk-taking with friends is important because of the positive social rewards that can be gained:

People are always like "Oh, there was that one time I did this thing" and everyone so, you know, admires them because of that huge risk they took. Or it's just you know, a good story- it takes up the time, you know it's just interesting. And you know, sometimes it's good to bounce ideas off each other, sometimes you learn from each other.

Consider also the following excerpt from my interview with Ethan, in which he talks about how telling stories about risk-taking improved his friendships and allowed him to form strong relationships with his peers. Once again, his dialogue highlights a double-voiced quality; Ethan simultaneously describes the risks he has taken while consolidating social relationships with his peers:

[Talking about taking risks] is just I guess something to pass the time, and just
something to communicate about, so we know more about each other, and just to keep I guess communication flowing and our friendship going.

In the following interaction, Ethan evokes the discourse of disability as abnormality as well as narratives about developmental progress and mastery to narrate his experience:

Jessica: We are done all the questions. Is there anything you’d like to add about risk-taking or about your identity more generally?

Ethan: I think me taking risks helps me grow up kinda through the years.

Jessica: That's interesting. Can you elaborate on that a little bit?

Ethan: Well, umm, I guess as a blind person, you normally would not get on a bike and I used to ride a bike all the time....

Jessica: So you said that helped you grow up through the years? How so?

Ethan: I guess I like taking risks. I really do. Yeah, it has helped me grow up and I've learned new things because of me taking risks...

Ethan’s response is important for two reasons. The first is that his decision to discuss with me a time when he took a risk by riding a bike highlights Penuel and Wertsch’s (1995) notion that identity is first and foremost concerned with persuading others and oneself about who one is and what one values. Thus by portraying himself to me as someone who does things that “as a blind person, you normally would not [do],” we are co-constructing his identity through his understanding and rejection of the discourse of disability as abnormality. Secondly, his response is important because it further emphasizes the developmental progress narrative many youth subscribe to when discussing risk-taking. His assertion that risk-taking has “helped [him] grow up and...
learn new things” is consistent with research in the field (Lightfoot, 1997) on the perceived developmental benefits of taking risks as an adolescent. Likewise, talking about risks he has taken presents Ethan with a discursive venue to define his identity with his peers, as examined in the following section.

Social Benefits of Risk Taking

In keeping with the discourse of adolescence as “becoming”, participants in the present study who felt that taking risks was an important part of being a teenager believed that taking risks is a good way to find out who you are and adolescence is the ideal time to figure it out. In addition to discussing the positive social consequences of risk-taking, Lightfoot (1997) also discovered through interviewing teens that, interestingly, the number one reason they chose to take risks was because of the developmental implications involved in doing so; that is, most adolescents in Lightfoot’s (1997) study believed that risk-taking provides an unprecedented opportunity to learn about yourself and your abilities.

This perception of risk-taking as a positive way to forge one’s identity and gain experience in the world highlights the idea that risks may be constructed as positive developmental milestones that allow for growth, accomplishment and learning about life’s responsibilities (Lightfoot, 1997). Lightfoot focuses her discussion of risk-taking on the discourse of risk taking, more than on risks themselves when she states that “in tying risks, and indeed their very development, to issues of exploration, control, and mastery, the teenagers reconstructed our cultural narrative of adolescence” (p. 105). From here, she goes on to discuss the image of the adolescent as a “storm”: “In our culture, adolescence is considered a time of cognitive, emotional, and social upheaval. Individuals
tossed about by these revolutionary forces are expected to take risks (p. 105).” Her inclusion of the adolescent as a storm discourse here was intended as a contrast to the narratives of responsibility and independence offered as counter-narratives by her participants who believed they were actively constructing their identities, not being tossed about in a “storm.”

Gergen, Lightfoot and Sydow (2004) discuss further the possible identity functions of risky behaviour from a social constructionist perspective. They state that adolescent risk taking is not an individual behaviour, but rather a behaviour that emerges from relational processes. In this way, adolescent risk taking narrates the identity of those who are involved through shared adventures (Gergen et al., 2004). The discursive function of risk taking is apparent as risky behaviour becomes a communicative tool used to provide material for storytelling, allowing for a shared group history. Jason highlights the function of risk taking for him in the following dialogue when asked whether telling stories about taking risks was important to him:

Jason: No, just actually doing it is the most important. When other people are watching, like being in the spotlight, like "Wow! Everybody's cheering for me, everybody's watching me do this" and it feels so good.

Jessica: Why does it feel so good?

Jason: Because I'm being recognized for doing something and that's kind of what I want, I mean, you know, by kids at school. I'm not really recognized for doing anything, so when I actually do do something, I'm being recognized for it.

As Jason’s response highlights, doing risky things in front of his peers provides him with a platform to be recognized by those around him who might not otherwise
notice him. Through Jason’s example, it becomes clear how identity formation is a dialogical process that takes place between an individual and his social world (Gergen, Lightfoot & Sydow, 2004). This brings to light the notion that while biology may drive some risk taking behaviours, social context has a remarkable influence in determining behaviour (Lesko, 1996a).

The personal reactions and stories provided by participants in this section display the ways in which various discourses have acted as tools for mediating identity. In many ways, viewing discourses that define adolescence as a time when teens are meant to take risks constrained participants who felt that risk-taking did not define their experience and was not something they wanted to engage in. Often these individuals appropriated the discourse by creating a counter-narrative of risk-taking that allowed them to redefine what “risky” means by rejecting the behaviour of those who engaged in more classic risks. On the other hand, some participants, especially Jason and Ethan, discussed the benefits of being a teenager and having the freedom and opportunity to do things they couldn’t do once they became adults. Inevitably, discourses of disability interacted with discourses of adolescence and ideals of risk; this will be discussed further in the proceeding section.

I would also argue that in addition to suggesting adolescents are necessarily and uniformly vulnerable and “at-risk”, conceptions of blindness that stress dependence and helplessness compound these beliefs. As Raby (2007) states, as a whole adolescents’ conception as vulnerable and incompetent act to further “ignore their agency, fail to identify the ways that children and adolescents control access to their worlds and undermine the ability (and perceived ability) of young people to represent themselves”
The following section will look at adolescence as “at-risk” and the ways in which this concept is used to constraining and govern the actions of youth.

Adolescence as “At-Risk”

The discourse of adolescence “at-risk” is a synthesis of two of the discourses discussed previously, adolescence as “becoming” and adolescence as a “storm.” According to the discourse of adolescence as “at-risk”, the specific risks of the present (i.e., drugs, alcohol, depression and eating disorders) place youth at risk of jeopardizing their desired futures (Kelly, 2000; Raby, 2002), including getting married, buying a home, remaining in a stable job and “settling down” (Wyn, 2005, p. 27). This discourse overlaps with the discourse of adolescence as a “storm” in which youth are believed to be prone to take risks, but also with discourses of youth as “becoming,” in the sense that social control, discipline and protection, such as “increased surveillance of public spaces [and]... new interventions based on professional concerns about youth welfare” (McKay, 2005, p. 266) are viewed as necessary to assist these youth in reaching their full potential.

Two questions posed to participants in the present study uncovered their experiences of being perceived as “at-risk”: “Do you engage in the same kind of risks as other people your age?” and “Do you feel your visual impairment affects your ability to take certain kinds of risks?” These questions shed some light on the discourse by supplementing both research on discourses of disability as well as discourses of risk and the utility of risk taking for identity formation. It became clear through the examples participants gave when discussing their propensity towards risk that their disability already placed them within the category of “at-risk,” although this could be more accurately described as “vulnerable.” The impression of individuals with a visual
impairment as vulnerable is only compounded by ideas that youth as a whole need to be protected from the outside world as well as their own potentially bad decision making.

To illustrate, when asked whether they engaged in the same kinds of risks as their peers, all ten participants said that they did not; the majority of participants, seventy percent, believed their visual impairment accounted for this difference. Justifications for not taking these risks fell into one of two themes: practical limitations and good judgment. In terms of practical limitations, participants noted reasons such as not being able to see at night (which they believed to be a time when most risk-taking happens), being on medication, increased consequences and simply not being aware of the risks that other people their age take. A counter-narrative focussed on exercising good judgment was also present in most participants’ responses; the majority explicitly rejected taking part in certain behaviours, and felt good about themselves for doing so.

Exercising Good Judgment: “Having a Good Head on your Shoulders”

While the majority of participants were able to cite the specific risks that teenagers today are apt to take, what is interesting and relevant to the present study is the way in which these adolescents evaluated other teens who chose to take certain “classic” risks. While risk-taking and the discourse of adolescents “at-risk” are not equivalent concepts, it appears that youth in the present study equated these terms, as, for them, taking “classic” risks uniformly placed in them in the category of “at risk.” Therefore, having appropriated the discourse of adolescence as “at risk,” participants may be wary of exacerbating the vulnerability people with disabilities are assumed to possess.

The adolescents in the present study appeared to distance themselves from their cohort who are “at risk” of the negative consequences of risk by creating a new identity
or counter-narrative of someone who is responsible and exercises good judgment—as Sarah put it, someone with a “good head on their shoulders.” This reaction is consistent with literature that points to the fact that some youth use the discourse of adolescence as “at-risk” to regulate their own and others’ behaviour, often distancing themselves from the individuals who choose to engage (Raby, 2002).

In the following quotation, Ethan indicates his awareness of a risky behaviour that others his age might engage in, but quickly states that his knowledge of his abilities and limitations would prevent him from getting himself into a situation such as the one described:

I guess doing drugs would be [a risk that people my age take]. 'Cause if you're standing out, say on the street, you wouldn't catch me like, smoking a pipe or something, because I can't see if the cops are hiding there, or sitting there. Therefore, when sighted people—'sighties' as we call them—ummm, when they're standing there on the street corner, or where ever, at night in a park, they can- they have a better idea of if the cops are sitting there or not. Therefore I would probably end up in jail, and they wouldn't. But that's the thing.

This is consistent with responses Raby (2002) found in her study of teen risk taking. Like the youth in the present study, she discovered that some teens do in fact fall back on the discourse of youth “at-risk” to control their own and others’ behaviours, stating “several of the young women avoided certain other peers for fear of trouble, avoided walking alone at night for fear of assault, and had spent some time strategizing how to say ‘no’ to drugs” (p. 435). This avoidance of certain situations and certain others was undoubtedly a prominent theme among the majority of participants. In the following
quotation, when asked if her visual impairment affects her ability to take certain kinds of
risks, Sarah offers many reasons why she hasn’t engaged in most “classic” risks,
including social isolation, surveillance and risk factors:

Sarah: Well, I obviously can't drive, and I don't have all the same social
opportunities as other kids. Like going here, you know, you can't really get out
much, so I haven't really, you know, I've been going to this school for all my
highschool, so I haven't you know, gone to any crazy parties or anything very
much. I mean, who knows when I get back out into the real world for university
and highschool [laughs], who knows what'll happen, but I'm also not going to be
apt to take those risks because well, it's dark! I'm not going to be able to see. And
so I'm going to be more of a target.

Jessica: OK, that's interesting. Because it's usually dark when people are taking
risks?

Sarah: Yeah, or at least that kind of risk. So physical risks are something I think
that someone who is visually impaired, at least if they have a good head on their
shoulders, wouldn't be like apt to take.

Here, Sarah has referred to a more “classic” example of risk (going to a “crazy
party”), stressing that she is aware of what goes on in the “real world,” but that she is not
likely apt to take those risks because of the dangers they pose to her. Sarah justifies her
choice not to engage in many different kinds of risk using ideology from the discourse of
adolescence as an “at-risk” time, believing herself to be a “target” when referring to the
risks of today. Her interpretation of others’ behaviour and her refusal to take part serves
to further undermine the pervasiveness of the idea that all adolescents are uniformly “at
risk”; this sets Sarah up as powerful in determining the kinds of situations she will allow herself to be part of. A similar poignant response from Josh solidifies the concept of speaking out against one’s peers as a way to forge an alternative identity:

No, I don't [take the same risks as my peers]. I tend to kind of shun my peers, and I see a lot of things that they do not just as a risk to themselves, but as risk to our future, because the music people listen to, the kind of TV that many of my peers watch, that all kind of promotes the same things: you know, treat people who are different as inferior, violence is OK, sex for any reason is just fine even when it's over the top, you know, drugs are cool, and yeah, I don't partake. I don't even associate with most of my peers because I don't share the same set of morals that they do, and I can't conform to extremely loud music with those themes, so I see those kind of things as a huge risk.

It is interesting to see the ways in which many youth in the present study position themselves apart from other teens, even advocating for more parental control and surveillance of young people as Erika notes: “You know how some parents will let their kids just do whatever the heck they want? And those are the kids that are doing the graffiti on the roofs, smoking pot and marijuana and they're you know, taking signs off where the signs are supposed to be on”. Here, Erika has gone so far as to advocate for increased supervision of young people, highlighting the degree to which she has appropriated the discourse of adolescence “at-risk”; she subscribes so strongly to the ideology of the discourse that she appears to believe that the surveillance and supervision of young people is necessary and appropriate.
A final example from Sarah, highlighting the intersection of the ideology of making good decisions and the narrative of failure, emphasizes how feeling smarter than other teens is a way to negate the necessity to engage in risky behaviour and focus on other more important things in her life. For her, this belief acts to sustain an identity of someone who is above risk taking in the classic sense, but who still believes taking chances that might set her up for failure are necessary and a part of life:

Well, I'd say I'm probably smarter than the people who, you know, take those physical risks. I've, you know, made a choice not to do those- have those physical risks. But, I mean, I do take the same risks that set me up for failure because I mean that's a point of life- you have to take those risks. Failure is just a part of life, maybe it's a part of life for me more than for other people because things aren't as easy for me and failure is something you have to deal with, I mean you have to get up from.

As the previous examples demonstrate, youth in the present study had a complicated relationship with the discourse of adolescence as “at risk.” But whether it was due to their visual impairment, their informed choice not to engage in the same behaviours as their peers, or a combination of the two, these youth were not indebted to the discourse in a way that erased possibilities for agency. The following section will offer a final look into the narratives of these agentic adolescents, offering an analysis of their appropriation of these discourses as a means of identity formation.

**Agentic Potential within the Discourses**

Whether participants used the ideology of the discourses of adolescence to their advantage, took on a more nuanced relationship, or spoke out against the discourses as a
way to narrate their identity by creating alternate narratives, agentic potential was always present. It is in discussing this topic that the intersection between agency and tool use becomes salient. According to Raby (2002), agency is defined as “the ability to make choices, to reflect on and influence one’s own actions, and to potentially make change in the world around us” (p.442). On the other hand, according to mediated action, “agency goes beyond the individual, viewing it as integrated—and in tension with—the actor’s habitus, the mediational means employed and the social practices involved in constructing a mediated action” (Jones & Norris, 2005, p. 169).

Agency conceived through the framework of mediated action allows more possibilities for active agents to be involved in producing an outcome than traditional views that focus on individuals straining to wield power over their situation and actions. While Raby (2002) conceptualizes agency as resistance to the discursive formations in which people are embedded through fissures, mediated discourse analysis theorizes agency as a process of negotiation between “human actors, mediational means and the various discourses that circulate through them” (Jones & Norris, 2005, p. 170). It is precisely the negotiation or tension between the active agent and the discourse, rather than the individual attempting to break free or resist a discourse entirely—as seen in numerous narratives throughout this paper—that allows for agency.

However, as different as these two conceptions are, both Raby (2002) and proponents of mediated discourse analysis agree that agency is possible through concurrently appropriating or taking on many different identities. Raoul (2007) reinforces the idea of viewing one’s self through many different lenses, stating that simply acknowledging the influence of popular stories disseminated in our culture can be a
powerful way to minimize their impact. This can be seen in Ethan’s description of the expectations that are placed on him and how this limits his opportunity to show what he is capable of:

I guess people expect me to be all slow—well I am slow—but people expect that I can’t do this, or I can’t walk here or walk there, or do this for myself. But if they, like a bunch of people jump to that conclusion, then they’re never going to know, because you’re never going to get the opportunity to show them what you can and can’t do.

Ethan’s yearning to be viewed as a unique and competent individual reiterates the standpoint of Goodley and Tregaskis (2006), noted earlier, who discuss the importance of allowing for and accepting the multiple identities and narratives of people with disabilities. As Ethan states, there are times when he is slow and may be perceived as less competent than others, but there are times when he is more than capable, and he yearns for the opportunity to prove this to the people who hold negative expectations. Speaking out against the negative perceptions of others becomes a form of resistance, as Ethan is actively resisting a stable identity by rejecting the dominant narratives about people with visual impairments.

Sarah also speaks about the need for people with disabilities to be viewed as unique individuals who experience both success and failure as a part of their everyday lives. When asked if people expect her to tell certain stories about herself because of her visual impairment, Sarah discusses the common disability narratives of triumph and overcoming obstacles that people anticipate hearing from her and how this affects the way she tells stories about herself, specifically by telling only stories of accomplishment.
This admission is important, as it once again highlights the conscious awareness these adolescents have of the dominant cultural narratives that attempt (and arguably fail) to properly narrate their experiences.

Sarah: I guess there are the odd people who expect you to be overcoming obstacles, like you know those people you read about in Reader's Digest.
Jessica: ...Does that happen often?
Sarah: Not usually, I mean, sometimes I do have those stories, and sometimes I have the stories where I fail, and I try not to tell those stories and sometimes I do, depends on who it is.

It is in reading excerpts such as this that the idea of agency becomes salient. Sarah is actively choosing the stories she tells to others, but her choice is somewhat constrained in a tensile relationship with the discourses that surround her. This tension is inescapable, as all stories are always constrained in some way; however, this in no way diminishes her potential for agency. Her telling of stories, and ultimately aspects of her identity, become defined by other’s expectations, dominant discourses and language, all acting as mediational means. In this particular example, the stories Sarah chooses to tell are based on her relationship with both discourses of adolescence and disability.

This agentic potential present within these intersecting discourses is consistent with Roediger and Wertsch (2008) who state that tool use is “unique, even creative in some way” (p. 324), offering active agents choice in how they use the mediational means that are presented to them. Thus, while agency appears in the telling of narratives, this choice is always mediated by numerous aspects of one’s environment and culture,
emphasizing the compound unit of analysis favoured by Wertsch (1991) that focuses on “individual(s)-acting-with mediational-means” (p. 12).

Adolescence as “Becoming”

Primarily, while the discourse of “becoming” positions adolescents as vulnerable in a state between childhood and adulthood, agency can emerge in the active search for one’s own identity. Examples of this can include deciding what to do with one’s free time, whom to spend time with or what hobbies to pursue. This assertion of selfhood allows adolescents to try out new ways of being in an attempt to test their social power (Raby, 2002). This was demonstrated by Jason when I asked him what the most important part of growing up was:

Jason: Being me is the most important thing in the world, like... Yeah.

Jessica: Can you talk a little bit more about that?

Jason: ... there’s nothing more important than, like you know, listening to the music I like, watching the movies I like, being who I want to be, those are the three most important things.

Jessica: And why is that?

Jason: I don't know. I just like being me, I don't want to be some other person, I don't, you know, want to be a robot to some other person's ideas.

In this quotation, Jason portrays himself agentically as he speaks about the importance of being able to do the things he likes regardless other people because he is an individual and not “a robot to some other person’s ideas.” By stating this, he evokes a narrative of multiplicity in which people [with disabilities] are unique and, accordingly, distances himself from the discourse of disability as homogeneity. Shakespeare and
Watson (2001) echo this sentiment in the argument that “disability cannot be reduced to a singular identity: it is a multiplicity, a plurality” (p. 19). In short, Jason is more than just an instance of a type; he can’t be reduced to a category. Finally, his statement can also be viewed as a challenge to the idea of incompleteness that “becoming” sometimes suggests, as he highlights who he is, not who he will become.

Jason uses his interest in music and movies to set himself apart from others and assert his individual present self, not as an adolescent with a disability, but simply as “Jason.” Similarly, Josh has actively chosen the identity as an advocate for people who are visually impaired. In his experience, blind people are viewed as “bumps on logs” and unsuccessful. In the following narrative, he shows how it is important for him to post online videos of himself mastering video games as a way to bolster the image of blind people, this in an effort to create a counter-narrative of disability, or indeed even to question the very notion of impairment:

OK. I, in my spare time, I play video games, and I post videos of me succeeding in such games on Youtube to try and educate people to say "Hey, you know blind people aren't the bumps on logs that a fairly significant portion of society seems to think we are..." I put up with a lot of stuff from people on Youtube, anything from people saying, you know "You're not blind, why bother lying, looking for attention?" to "You're not effing blind you faggot, n-word" you know, whatever else, to people, you know, people taking my picture and posting vulgar videos and things trying to convince me to close my account and say "Ya, you're right, I'm not really blind". So I put up with a lot of that for the three years that I've been doing this on Youtube. But, I think when all is said and done, it's worth it,
because I'm helping people realize that I can be a successful human being. It's all in whether you choose to just sit on the couch and go boo hoo, or you choose to fight the odds.

Josh’s use of the internet as a tool for developing his identity highlights his ability to determine his present, vital self that is often negated in the process of growing up and disregarded entirely in the discourse of becoming. Agency is displayed in this regard in his active search to define himself as an advocate, both despite and because of other people’s negative views.

Adolescence as a “Storm”

The discourse of adolescence as a “storm”, on the other hand, traditionally offers limited opportunities for agency according to the literature (Raby, 2002). Because adolescents are viewed as biologically driven towards risky behaviour, it is assumed that they have little control over their actions during this period of their lives. I would argue, however, that participants in the present study emphasized that the risks you choose to take, and thus the developmental and social opportunities they provide, offer opportunities for agency. In the following quotation, Anna understands what is commonly meant by risk-taking behaviour, but insists that for her, risk-taking is not necessarily a dangerous act, has few negative consequences, and offers the opportunity to grow as a person:

Well, I consider risky as trying new things, and being part of something. Like sports, for example. I took the risk of being on the cross-country team and taking figure skating, and doing lots of fitness. I've taken the risk of doing things like that.
Thus, while her desire to experiment and try new things may be characteristic of her age, Anna describes how she exercises agency by choosing activities with positive rather than negative consequences.

*Adolescence as “At-Risk”*

Finally, the discourse of youth “at-risk” appears to offer adolescents the greatest opportunity to exercise their agency, as seen in interview responses. As noted, adolescents in the present study often used this discourse to self-regulate and distance themselves from the actions and behaviour of their peers, by subscribing to the alternate narrative of exercising good judgment. This was seen in their decisions not to go where risky behaviour is taking place and in choosing their friends wisely. Thus, agentic individuals viewed through a lens of “youth at-risk” appear very self-disciplined, often criticizing peers who do not have this same level of control (Raby, 2002). A final thought offered by Josh highlights the degree to which he distances himself from his peers:

> The only other thing I can say is, this group of teenagers, I think, the most important thing, and this has gone out the window completely almost, compassion. There's almost no compassion in people. I don't believe there's all that much compassion in people born after '80-'85. And I'm not saying everybody, but I think compassion is just gone.

In the previous sections, I have examined the extent to which visually impaired adolescents appropriated each of the three discourses of adolescence. As illustrated, their relationship with these discourses was complex and often times paradoxical. Many participants agreed with the importance of taking risks, but defined these experiences in unique ways. Most participants also distanced themselves from the risky behaviours of
mainstream youth, often speaking out directly against their choices. All participants seemed to agree that developing their present self, especially gaining independence, was of great importance. These adolescents spoke about themselves as dynamic, unique and competent, and utilized various cultural tools at their disposal, specifically discourses of adolescence and dominant narratives of disability to assist in defining their identity. Finally, an analysis of the agentic potential in each of these discourses revealed that as prescriptive and pervasive as these discourses may appear to be, examples of resistance and creative appropriation are evident.
CHAPTER FOUR: CONCLUSION

The goal of the present study was to illuminate the ways in which cultural tools mediate the identity formation of adolescents with a visual impairment. During interviews, it quickly became clear that the dominant discourses of adolescence and disability were the most salient tools used for this purpose. Participants provided narratives about all areas of their lives, from what they do with their friends, to traumatic events of the past, to how they actively work to bolster the image of blind people. Through these stories, it became clear that their relationship with the dominant narratives of adolescence and disability was complex; teens appeared to engage, appropriate, transform and resist the discourses as they carved out a unique identity.

Just as the identities of the adolescents that were examined in this study were multi-faceted and unique, they are also temporary. Each of these ten participants will continue to grow and change as they encounter different world views, experiences, people and new mediational means. Utilizing a sociocultural lens highlighted this quality in their narratives, as it accepts “the multiplicity, variability, and unfinalizability of one’s ... identity as being a fundamental characteristic of being human” (Tappan, 2000, p. 106).

This study was valuable as it added to the existing literature, albeit sparse, on adolescents with a visual impairment, in a way that allowed teens to speak freely and openly about their experiences, thus highlighting the mediational means that were relied upon for identity construction, foregrounding new definitions of risk, for example, the counter-narrative of “experimentation undertaken using good judgment.”

The significance of this study reaches far beyond the experiences of adolescents with a visual impairment, however. Mediated action as both a theoretical and
methodological framework takes the emphasis away from either the individual struggling to wield influence over his or her own actions on one hand, and constraining cultural forces, on the other. It has allowed me to take a more holistic approach to understanding the role that discourse, as a cultural tool, plays in the identity formation of these youth. Ultimately, I have attempted to argue that “identity, is, at its core, a mediated, dialogical phenomenon” (Tappan, 2005, p. 68).

Limitations

While every effort was made to design and execute a study that was thought provoking and rigorous, there are some modifications that may have improved the overall outcome of this study. In the following section, I will outline three areas of improvement, and the specific concerns that arose within each of these categories: participant selection and recruitment, disclosure and the interview protocol.

Participant Selection and Recruitment

It became clear throughout the process that the description used to promote this study over the loudspeaker at the school, which mentioned risk-taking, may have discouraged some students from participating and encouraged others. Because some students felt that they were not risk-takers or did not engage in risky behaviour, they may have assumed they would not be eligible to participate. This became clear to me in a conversation I had with Lindsay during the recruitment information session. She said that she would love to take part in the study, but because she felt that she doesn’t take risks, she thought I would not be interested in her responses. However, once I explained to her that this study was not simply for “risky” people, she was more than happy to sign up and did in fact end up taking part in the study. Thus, a limitation of the recruitment procedure
was that the aim of the study was not explained explicitly enough to students. Specifically, students should have been informed that I was interested in studying the importance of risk-taking on identity, and therefore I was interested in speaking to students who felt they took risks, as well as those who don’t feel that way. Had I described the study in this way, a slightly different (possibly less “risky”) sample of volunteers may have come forward to participate.

Disclosure

A limitation relating to disclosure may have surfaced in light of the question “What kinds of behaviour do you—or people your age—consider risky?” and the question that proceeded it, “Do you engage in the same kind of risks as other people your age?” Participants could have inferred that it would be socially desirable to deny risk-taking altogether, based on the order of these questions and the way they were phrased. Specifically, by first asking them about risk-taking in the abstract, participants were more likely to offer examples of stereotypical risks that were often exaggerated and far-removed from their typical activities; the expectation then may have been that they should deny engaging in these behaviours when the subsequent question was posed. Thus, it is possible, although not likely based on other contextual information gained from participants about their lives and typical activities, that denying risk-taking was a methodological artifact of the way the questions were phrased and ordered.

Interview Protocol

In terms of the interview protocol, some interview questions in particular may have caused difficulty for participants. The first problematic question required them to
tell a story about their identity, the second asked them to speculate about the risk taking
behaviour of other people their age.

I began the interview by asking participants the question, “When people think
about their identity or ask themselves the question “Who am I?” they often choose to tell
stories about themselves or their experiences. Can you tell me a story that reveals
something important about who you are, about your identity?” This question was
purposely expressed in a very ambiguous way that did not pertain to the issues of
impairment or risk-taking, this in an attempt to discover how participants perceived
themselves. The vagueness of this question, however, made some uneasy; this was
evident in some participants’ reluctance to answer. Jason, for example, was not clear on
what I meant by a story: “Umm, you mean like who I am actually? Like, what do you
mean about a story?”, and Erika also asks for clarification: “Can you give me a few
examples?” This final exchange with James further explicates the confusion experienced
by some of the participants:

James: You mean like my, umm, my something that I do, my interests?

Jessica: Well, when someone says “Who are you deep down? What makes you,
you?” what kind of story would you tell to really show them who you are?

James: Well, I umm, do you mean emotionally...?

Jessica: Anything. Anything you want.

Thus, it was evident that the way this question was phrased confused some
participants, as some were not clear on what I was looking for in terms of a “story” and
others were not familiar with the concept of “identity.” An additional complication arose
once participants clarified what I was asking them and began discussing their identities,
as the majority of participants did not engage a narrative discussion of “who they were,” but rather chose to list aspects of their personality. James’ response is typical of most participants in this regard: “Well, I am umm, I try to be eco-friendly, I’m honest, I’m good in academic studies.” The uneasiness participants experienced with the wording of this question and their unwillingness to offer a narrative when asked to do so is likely explained by the format and structure of the interview, as noted previously, rather than by causes intrinsic to the students themselves.

Susan E. Chase (2003) discusses how eliciting narratives from participants in interviews is complex and requires an altered conception of interviewing. According to her, it is crucial to ask for life stories within an interview if one wants to obtain narratives from participants rather than reports. Chase explains that stories (narratives) are “told to make a point, to transmit a message... about the world the teller shares with other people” (p. 274), whereas reports are typically collected by the researcher who also then assumes the burden of interpreting the report. To make this concept more concrete, narratives can be conceptualized as an animated story, whereas reports are simply an obligatory chronicle. Thus, Chase states that researchers must invite participants to tell their stories and take responsibility for the meaning of their talk, not by directing them to the research interest, but rather by directing them to their own experiences.

In the present study, I was limited by my adherence to the concept of the sociological interview. By this I mean that I felt responsible for laying the framework for participants in terms of what I was interested in researching, and then expected them to connect this to their experiences. According to Chase (2003), interview protocols can be ameliorated by providing the discursive and interactional conditions that arouse desire in
the participants to tell stories about their lives and experiences. Thus, had I engaged participants in a discussion about the discourses surrounding adolescence, disability and risk, I might have achieved a clearer sense of how these discourses impact their daily lives.

However, it should be noted that on many occasions I did in fact elicit very detailed and engaging narratives from participants during the entirety of the interviews. Ethan’s recollections of posting videos of himself on Youtube, as well as his story about potentially having to change schools, are excellent examples of narrative recollections recounted in this study. Ultimately, my inability to obtain narratives from participants in regards to the question “Can you tell me a story that reveals something important about who you are, about your identity?” has challenged my own assumptions about narrative and identity. While I assumed a discussion of identity would necessarily be narrative in nature, it became apparent that participants illustrated to me who they are throughout the entire interview. This is consistent with Tappan (2000) who describes identity formation not as a “core” sense of self, but rather as a story in which the narrator engages numerous mediational means, over time and during various life events, in order to create an identity.

Finally, it became clear throughout the interview that the participants did not have a clear sense of the behaviours “other people their age” engaged in. This became apparent as participants were asked “Do you engage in the same kind of risks as other people your age?” Ethan’s response sums up the sentiments expressed by most participants “I, umm, for me, I don’t really know what other teens are like, ‘cause I’ve never really hung out with the sighted crowd. Because I’ve been cooped up here [laughs].” Thus, it appears the
culture of risk present in the school these students attend may be fundamentally different than the risk-taking behaviours that are commonplace to other adolescents their age; however, even the difficulty experienced as a result of the question became a source of insight or interpretation, as discussed previously. This uncertainty about "what other people her age do" can be seen in Ashley’s response: “No, ‘cause I don’t cross the street without my cane. I go with my cane, or I go with a guide.” Here, Ashley does not even consider the things that other teens may do and only refers to her peers with a visual impairment as she discusses risk as crossing the street without a mobility aid. This question, however, provided useful information, such as alternate conceptions of risk, and provided me with additional insight into participants’ engagement with various discourses.

Overall, due to the semi-structured, conversational nature of the interview, issues surrounding the unclear phrasing of questions were dealt with on an individual basis as they arose. Sometimes I explained to participants that when I conceived this question, I intended it to mean “‘typical’ teenage behaviour,” for example “things you might see in movies” in order to move the interview forward if the participant was confused, whereas other times I simply went with the conception of risk that was put forth by the individual. This strategy elicited more useful data as it allowed the concept of risk (as it made sense to the individual participant) to become concrete enough that it could be discussed throughout the remainder of the interview. Thus, this strategy seemed to ameliorate problems inherent in the question and allowed me to move forward with discussions of their risk-taking behaviour.
Future Directions

The purpose of the present study was to explore the idea that humans are surrounded by discourses which act as tools that mediate their identity. Thus, future research should continue to study the mediational means that are undertaken by individuals both consciously and subconsciously for this purpose. As Tappan (2000) argues, sociocultural approaches to understanding identity formation are more useful than other cognitively-based interpretations, as they allow for the multiplicity and unfinalizability of narratives, qualities valued in disability (counter) narratives especially.

In addition, the field of mediated action as a whole would benefit from increased application of its framework and methods to other populations and fields of study. To date, researchers of mediated action have successfully applied the framework to the life stories of a former Neo-Nazi in the exploration of moral identity (Tappan, 2000) and, in the study of ideological development and forms of internalized oppression, to the autobiographical recollections of an African-American Nationalist leader (Tappan, 2005). The approach has also been used in the field of media studies (Scollon, 1998) and in discussing the sexual behaviour of homosexual males in China (Jones, 1999). I feel that by applying this theory more widely, it will allow for an alternate perspective on complex issues that allows both the reader and researcher to “live in the middle” by acknowledging the tension inherent between active agents and cultural tools.

An additional area of research that would benefit from future study is the field of visual impairment research, specifically research relating to adolescents. The paucity of research on teens with a visual impairment, especially research that is qualitative in nature, signals a need for increased attention to this population. The present study is the
first that I am aware of that specifically addresses risk-taking in adolescents with a visual impairment (see, however, Kef & Bos, 2006, for an examination of sexual behaviour in adolescents with a visual impairment).

While descriptive research on visually impaired adolescents tends to focus on issues derived from a deficit model of disability, such as research that illustrates their general lack of acceptance among able-bodied peers (Kef, 1997) and the assertion that visually impaired children are a burden on friendships (Mar & Sall, 1995), it has failed to analyze these issues using sociocultural approaches that consider both the individual as a social actor and the environment as a shaping force.

Furthermore, as I discovered through interviewing participants for this study, most teens with a visual impairment did not consider risk-taking (at least in the “classical” sense) to be important in their identity formation, and they often created counter-narratives of risk or denied it all together. Additionally, I found that while there have been studies that highlight the hyper-sexualized and overtly risky identity of many teens with a disability (see Cheng & Udry, 2002; Hollar, 2005), the teens I interviewed showed very little inclination towards these extreme behaviours. While it is possible that their denial of this behaviour could have been a consequence of the study’s policy on disclosure, I feel more research should focus on this discrepancy as it relates specifically to adolescents with a visual impairment. This is important, as it may be the case that adolescents with a visual impairment engage the dominant narratives surrounding risk and disability differently as they attempt to make sense of their experiences than other adolescents with a disability.
In addition, future research on risk-taking or identity formation in youth with disabilities should focus on different school environments. Because this study focused on teens who attended a school that specifically catered to individuals with a visual impairment, it was difficult to discern how the discourses in question would have played out in a different context. Interestingly, Moore and Polsgrove (1991) discovered that adolescents attending a school for the deaf tended to drink more alcohol on average than those who didn’t attend such a school, citing peer pressure as a driving force for this behaviour. Thus, in the future, examining the influence of peer pressure as well as different school environments would be advantageous.

Finally, greater attention should be paid to eliciting narratives as opposed to reports from participants, by cultivating in them a desire to tell stories about their lives and experiences. As noted by Chase (2003), participants are more likely to provide narrative accounts if the researcher takes the responsibility of “listening for gaps, silences, or contradictions and reiterating the invitation through questions that encourage fuller narration of the complexities of [their] stor[ies]” (p. 289). Attention to eliciting narratives would likely yield richer reports, providing participants with an ample chance to tell stories that highlight the ways in which they engage the discourses around them.
References


Watson, N. (2002). Well, I know this is going to sound very strange to you, but I don’t see myself as a disabled person: Identity and disability. *Disability and Society, 17*, 509-527.


Appendix A
Letter of Invitation Script

Volunteers are needed to participate in a study about risk-taking. A Master’s student, named Jessica Rathwell from Brock University in St. Catharines, is doing research on the stories that are told by teens who are blind or visually impaired.

As a participant in this study, you would be asked to meet with her for a 30-60 minute interview. She will ask you about questions about your identity, as well as questions about risks you may have taken and whether or not you think taking risks is an important part of growing up.

Your participation is extremely valuable, as it helps researchers understand the issues that are important to you as an individual. You will be offered a ten dollar gift certificate to Walmart to thank you for your time.

If this interests you, please go to the principal’s office to pick up a letter of invitation that gives you a few more details about the research. Included on this sheet is an email address where you can reach Jessica to ask her any questions you may have about the study.

Thank you very much for considering taking part in this research project.
Appendix B
Letter of Invitation to Participate in Research for Guardians

May, 2010

Title of Study: Mediated Action, Narratives of Risk-taking, and Identity Formation in Adolescents with a Visual Impairment

Principal Student Investigator: Jessica Rathwell, MA student, Department of Child and Youth Studies, Brock University

Faculty Supervisor: Dr. Donato Tarulli, Associate Professor, Department of Child and Youth Studies Brock University

I, Jessica Rathwell (MA candidate, Department of Child and Youth Studies, Brock University), invite your son/daughter to participate in a research project entitled: Mediated Action, Narratives of Risk-taking, and Identity Formation in Adolescents with a Visual Impairment.

The purpose of this study is to attempt to discover the kinds of themes that are used in the stories that adolescents with a visual impairment tell about themselves. I will be asking your son/daughter specific questions about their identity and their views on risk taking.

Your son/daughter is being asked to participate in an individual interview. His/her participation should take 30-60 minutes. He/she will meet one-on-one with myself, Jessica Rathwell, and talk about the kinds of risks teenagers take, and whether he/she feel that taking risks is important to him/her.

Your son/daughter’s participation is important, as it will help us understand the themes and issues that adolescents with a visual impairment feel are important in constructing their identities. His/her participation in this study is completely voluntary, and he/she may choose not to participate or withdraw his/her participation at any time. Your son/daughter will be offered a ten dollar gift certificate to Walmart to thank him/her for participation.

This research project is operated with the assistance of [name] School.

If you have any questions about your son/daughter’s rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any other questions, please feel free to contact me.

Thank you,

Principal Student Investigator:
Jessica Rathwell
MA student, Department of Child and Youth Studies
Brock University

Email: jr08--@brocku.ca

Faculty Supervisor:
Dr. Donato Tarulli
Associate Professor, Child and Youth Studies
Brock University
Phone: (905) 688-5550 ext: 4513
Email: dtarulli@brocku.ca

This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board (file # 09-140 TARULLI).
Appendix C
Letter of Invitation to Participate in Research for Participants

May, 2010

Title of Study: Mediated Action, Narratives of Risk-taking, and Identity Formation in Adolescents with a Visual Impairment

Principal Student Investigator: Jessica Rathwell, MA student, Department of Child and Youth Studies, Brock University

Faculty Supervisor: Dr. Donato Tarulli, Associate Professor, Department of Child and Youth Studies, Brock University

I, Jessica Rathwell, invite you to participate in a research project entitled: Mediated Action, Narratives of Risk-taking, and Identity Formation in Adolescents with a Visual Impairment.

The purpose of this study is to discover what kinds of themes and issues you feel are important for understanding your identity. In particular, I am interested in your thoughts and stories regarding risk taking.

You are being asked to participate in an individual interview. Your participation should take 30-60 minutes. You will meet one-on-one with myself, Jessica, and talk about the kinds of risks teenagers take, and whether you feel that taking risks is important to you.

Your participation is important, as it helps us as researchers to understand the issues that are important to adolescents with a visual impairment. Your participation in this study is completely voluntary, and you may choose not to participate or withdraw your participation at any time. You will be offered a ten dollar gift certificate to Walmart to thank you for your time.

This research project is operated with the assistance of [name] School.

If you have any questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905 688-5550 ext 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me.

Thank you,

Principal Student Investigator:
Jessica Rathwell
MA student, Department of Child and Youth Studies
Brock University
Email: jr08--@brocku.ca

Faculty Supervisor:
Dr. Donato Tarulli
Associate Professor, Child and Youth Studies
Brock University
Phone: (905) 688-5550 ext: 4513
Email: dtarulli@brocku.ca

This study has been reviewed and received ethics clearance through Brock University’s Research Ethics Board (file # 09-140 TARULLI).
Appendix D
Guardian Consent to Participate in Research (for participants under the age of 18)

Project Title: Mediated Action, Narratives of Risk-taking, and Identity Formation in Adolescents with a Visual Impairment

Principal Student Investigator: Jessica Rathwell
MA student, Department of Child and Youth Studies
Brock University
Email: jr08--@brocku.ca

Faculty Supervisor: Dr. Donato Tarulli
Associate Professor, Child and Youth Studies
Brock University
Phone: (905) 688-5550 ext: 4513
Email: dtarulli@brocku.ca

May, 2010

INVITATION
Your son or daughter is invited to participate in a study that involves research. The purpose of this study is to attempt to discover the kinds of themes that are used in the stories that teens with a visual impairment tell about themselves. I will be asking your son/daughter specific questions about times that he/she may have taken risks. This research project is operated with the assistance of [name] School.

WHAT’S INVOLVED
As a participant in this project, your son/daughter will be asked to meet one-on-one with myself, Jessica, to talk about the kinds of risks teenagers take, and whether he/she feel that taking risks is important to him/her. Participation will take approximately 30-60 minutes of his/her time, and his/her responses will be tape-recorded.

POTENTIAL BENEFITS AND RISKS
The possible benefit of participating in this includes helping me as a researcher understand the issues that are important to adolescents with a visual impairment. In addition, your son/daughter will offered a ten dollar gift certificate to Walmart. There also may be risks associated with participation, however for this project, the risks are very minimal. Because he/she is discussing experiences in which he/she took risks, as well as aspects of his/her identity, he/she may experience slight discomfort.

CONFIDENTIALITY
The information your son/daughter provides will be kept confidential. His/her name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. Prior to the final draft publication of the MA thesis of the Principal Student Investigator, the administration at [name] School has the right to remove any anonymous quotation at their discretion.

Data collected during this study will be stored at Brock University in the Child and Youth Studies Department. Data will be kept until completion of the project, after which time it will be destroyed. Access to this raw data will be restricted to myself (Jessica Rathwell) and my Faculty Supervisor, Dr. Donato Tarulli.

DISCLOSURE
Because your son/daughter is under the age of majority, if any abuse is suspected towards him/her or if he/she reports instances of self-injurious behaviour, we as researchers have an obligation to report this to the relevant authorities. Therefore his/her responses would not remain confidential in this instance.

In addition, the researcher reserves the right to report any major transgressions against the code of conduct in place at [name] School to the school authorities.
VOLUNTARY PARTICIPATION
Participation in this study is voluntary. If your son/daughter wishes, he/she may decline to answer any questions or participate in any component of the study. Further, he/she may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which he/she is entitled.

PUBLICATION OF RESULTS
Results of this study may be published in professional journals, presented at conferences and will be included in the MA thesis of the principal student investigator. Feedback about this study will be available to you and your son/daughter if you are interested.

CONTACT INFORMATION AND ETHICS CLEARANCE
If you or your son/daughter have any questions about this study or require further information, please contact the Principal Student Investigator or the Faculty Supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University, file # 09-140 TARULLI. If you or your son/daughter have any comments or concerns about his/her rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM
I agree to allow my son/daughter to participate in this study described above. I understand that because my son/daughter is under the legal age of majority (18), my signature is required before my son/daughter can participate in this study. My son/daughter will however sign a participant assent form, indicating their desire to participate as well.

I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time. In addition, my son/daughter may withdraw their participation at any time as well.

Name of minor (please print): ____________________________________________

Name of parent (please print): ____________________________________________

Signature of Parent: ____________________________________________ Date: ____________________
Appendix E
Participant Consent/Assent to Participate in Research

Project Title: Mediated Action, Narratives of Risk-taking, and Identity Formation in Adolescents with a Visual Impairment

Principal Student Investigator:
Jessica Rathwell
MA student, Department of Child and Youth Studies
Brock University
Email: jr08--@brocku.ca

Faculty Supervisor:
Dr. Donato Tarulli
Associate Professor, Child and Youth Studies
Brock University
Phone: (905) 688-5550 ext: 4513
Email: dtarulli@brocku.ca

May, 2010

INVITATION
You are invited to participate in a study that involves research. The purpose of this study is to attempt to discover the kinds of themes that are used in the stories that teens with a visual impairment tell about themselves. I will be asking you specific questions about times that you may have taken risks. This research project is operated with the assistance of [name] School.

WHAT'S INVOLVED
As a participant in this project, you will be asked to meet one-on-one with myself, Jessica, to talk about the kinds of risks teenagers take, and whether you feel that taking risks is important to you. Participation will take approximately 30-60 minutes of your time, and your responses will be tape-recorded.

POTENTIAL BENEFITS AND RISKS
The possible benefit of participating in this study includes helping me as a researcher understand the issues that are important to you as a teenager with a visual impairment. In addition, you will be offered a ten dollar gift certificate to Walmart. There also may be risks associated with participation, however for this project, the risks are very minimal. Because you are discussing aspects of your identity and your views on risk-taking, you may experience slight discomfort.

CONFIDENTIALITY
The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study; however, anonymous quotations may be used. Prior to the final draft publication of the MA thesis of the Principal Student Investigator, the administration at [name] School has the right to remove any anonymous quotation at their discretion.

Data collected during this study will be stored at Brock University in the Child and Youth Studies Department. Data will be kept until completion of the project, after which time it will be destroyed. Access to this raw data will be restricted to myself (Jessica Rathwell) and my Faculty Supervisor, Dr. Donato Tarulli.

DISCLOSURE
If you are under the age of majority and any abuse is suspected towards you or if you report instances of self-injurious behaviour, we as researchers have an obligation to report this to the relevant authorities. Therefore your responses would not remain confidential in this instance.

In addition, the researcher reserves the right to report any major transgressions against the code of conduct in place at [name] School to the school authorities.
VOLUNTARY PARTICIPATION
Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS
Results of this study may be published in professional journals, presented at conferences and will be included in the MA thesis manuscript of the Principal Student Investigator. Feedback about this study will be available to you if you are interested.

CONTACT INFORMATION AND ETHICS CLEARANCE
If you have any questions about this study or require further information, please contact the Principal Student Investigator or the Faculty Supervisor using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University, file # 09-140 TARULLI. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

ASSENT (for participants under the age of 18):
I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time. I understand that because I am under the legal age of majority (18), the signature of my legal parent or guardian is required before I participate in this study (included in a separate form).

Name: ____________________________

Signature of Parent: ____________________________ Date: ________________

CONSENT (for participants over the age of 18):
I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name (please print): ____________________________

Signature of Participant: ____________________________ Date: ________________
Appendix F
Feedback Letter

Dear Participant,

I would like to thank you for your participation in this study. As a reminder, the purpose of this study is to explore the stories visually impaired teens tell about their lives and the role risk taking has in constructing their identities.

The data collected during the interviews will contribute to a better understanding of how visually impaired teens like yourself feel about risk taking as an important teenage activity. Please remember that any data pertaining to you as an individual participant will be kept confidential, except for the special circumstances noted in the consent form.

After all the data are collected and analyzed, I will begin the long process of writing the final chapters of my thesis which will discuss all of this information. After the completion of my thesis, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me at the email address listed at the bottom of the page. If you would like a summary of the results, please let me know. When the study is completed, I will send it to you. The study is expected to be completed by the Fall of 2010.

As with all Brock University projects involving human participants, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at Brock University. Should you have comments or concerns resulting from your participation in this study, please contact the Office of Research Ethics at Brock University (905 688-5550 ext 3035, reb@brocku.ca). In addition, if you experienced any distress as a result of this interview, either the researchers of this study or your school can help you to identify appropriate support services.

Thank you so much again. It has been a pleasure working with you.

All the best,

Jessica

Jessica Rathwell
M.A. Student, Child and Youth Studies Department
Brock University
jr08--@brocku.ca