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"If only I had known...": young peoples participation in the construction of their learning disabilities

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"IF ONLY I HAD KNOWN...": YOUNG PEOPLES PARTICIPATION IN THE
CONSTRUCTION OF THEIR LEARNING DISABILITY LABELS.

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Abstract

This paper explores how young people participate in the construction of their learning disabilities and how the experience impacts their internal truth, and self-concept. The results show that none of the interviewee subjects in the study participated in the Identification Placement and Review Committee (IPRC) meetings conducted in Ontario. The interviewees did participate in a variety of other forums such as psychological testing, university development centers, and conversations with family members, and teachers. Analysis of coded qualitative interviews reveals four major themes that were interwoven: internal truth of self-concept about disability; external truths of individuals of self-conceptualization about disability; knowledge of disability; and participation in the construction of the label of disability. The children's rights framework and the new sociology of childhood are used to explore the construction of self-concept for children and young people with disabilities, and the nature and timing of their participation in matters regarding them and their label of exceptionality in the Ontario education system.

Key words: Self-concept, Participation, Learning Disability, Exceptionality, Young People, Construction of Labels

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Introduction

Within the scholarly literature there is evidence of a relationship between the self concept of an individual with disability and their level of participation in the processes surrounding the construction of their label of disability. This paper will explore themes of active student participation in the label formation and its impact on self-concept. This study will focus specifically on young people's experiences in Ontario with the Individual Placement and Review Committee (IPRC) process, in which young people are formally labelled with exceptionality. This study will not focus on the IPRC process. Instead, it will explore whether young people are participating in the process of constructing their labels of learning disabilities and how these experiences or lack of experiences impact their internal truth and self-concept of an individual with a disability.

Exceptionalities are formally defined by Ontario Regulation 181/98 (an amendment to the Education Act, 1998, regulation amended in 2005) as "a pupil whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program...." (s. 11(1)). The terms disability and exceptionality in this paper specifically refer to learning disabilities, the designation which has been attributed to all of the participants in the study. Interviews with four young adults diagnosed with learning disabilities and designated as having an exceptionality under the category of learning disabilities were conducted using a grounded theory approach to identify themes emerging from the interviews (Glaser & Strauss, 1967). Individual and systemic issues will be identified and common themes in experiences will be explored.

The research question posed in the study is, "Do young people participate in the

label construction of their learning disability, and how do their experiences impact their lives?"

Researcher Perspective

This particular study has relevance to me as I was identified with a learning disability at age eight. I had little participation in the identification process and construction of my disability in childhood and adolescence. I am a young woman of Irish/Canadian decent. I am middle class, and have lived predominantly in Toronto since birth. The experience of being identified with a learning disability has strongly shaped how I see the world and my perception of equity and inclusion. At times during my academic career I was in a segregated classroom in school and had little participation or involvement in issues regarding my learning disability and label formation. The framework of children's rights resonates strongly with me and therefore drives much of my world view and understanding of children and young people as active participants in society. I view knowledge as subjective, and believe that people's experience and local truths are multilayered and complex (Estenberg, 2002).

Theoretical Framework

There are three frameworks that will be drawn upon in this study. A children's rights framework will be used, as well as Foucauldian theory and finally the new sociology of childhood, which seeks to explain the social and cultural construction of children and young people and their place in society (Moss and Petrie, 2002). These frameworks are outlined below in relation to the topic of young people's participation in the construction of identity with experience of their learning disabilities.

Children's Rights Framework

The United Nations Convention on the Rights of the Child (UNCRC, 1989) outlines children's fundamental rights. Canada signed and ratified this convention in 1989. Article 12 of the Convention outlines the child's right to participate and the right to form his or her own views and to express them freely in all matters affecting him/her, as is reasonable with age and maturity. Article 29 of the UNCRC states that "the education of the child shall be directed to the development of the child's personality, talents and mental and physical abilities to their fullest potential" (Article 29,Section 1(a)). Article 23 highlights that children with a disability have the right to enjoy a full and decent life, with conditions that ensure dignity, promote self-reliance and facilitate the child's active participation in the community. This document challenges the notion that children are incompetent and in need of protection which are assumptions that have been the norm in society. The UNCRC provides space for children to participate in matters that are of concern to them and that will directly impact them. As a result, this international convention supports the inclusion of children and young people in the construction of their disabilities.

Foucauldian Theory

Foucault (1979) traced the history of the construction of knowledge and how power and knowledge are used to construct Truths in society. Truth with a capital 'T' refers to large scale Truths that are presented as dominant ideologies and norms in our society and accepted as 'common sense'. Foucault (1979) explores the shifting uses of language and discourse within modernity that have created a need to measure, categorize and order such things as our views, ideas and behaviours. Foucault (1979) specifically

examines language and its roles in producing Truths. In this study, Foucauldian theory is used to critically examine young peoples' current status in society, and to understand the mechanisms in place that control and oversee them. Foucauldian theory explores how knowledge is ordered in a hierarchal manner, where some knowledge is viewed as more important or useful than other knowledge. This ordered knowledge impacts identity and some people are seen as more important or useful. People's identities become ranked, differentiated, and categorized in a hierarchy.

Foucault (1975) examined the nature and properties of discipline and how the formation of a disciplined society was created. Foucault (1975) understands discipline as part of the processes and events in history, economics, the judiciary, politics, education, and sciences. Discipline is a fundamental technique for maintaining order in society. Every system of power needs to insure discipline to sustain itself. Traditionally feudal power was used to maintain order. There were a number of drawbacks to feudal power, the key one being economic costs. Since the feudal age, new mechanisms of sustaining power have been implemented. The term "panoptic modality of power" is Foucault's term for the process by which individuals learn to govern themselves in accordance with the norms of society this is also referred to as governmentality.

Gallagher (2008) uses Foucauldian theory to understand the social construction of disability, and to explore the implication of labeling children with disabilities, as well as how children's participation or lack thereof in the process may have specific outcomes for the individual. He clearly explains that the nature of power is something that is exercised and not possessed. Power only exists when it is put into action, and is specific to the context that it is occurring in. Therefore Gallagher (2008) understands that no

power is exercised in the same way with the same outcome. He describes power, according to Foucauldian analysis, as a net-like organization never concentrated in one area. Gallagher (2008) uses Foucauldian analysis to highlight the effects of participatory incentives and the value in studying the effects and outcomes of participation rather than the intentions of providing participation. For instance that it is not useful to study the intentions of inviting young people to participate in matters regarding them, but instead to study the outcomes of inviting young people to participate.

New Sociology of Childhood

Moss and Petrie (2002) explore social constructions of children and young people which have emerged from ethical and political choices within a larger framework. Drawing on Foucault's theories, Moss and Petrie (2002) deconstruct assumptions of children and young people represented in society as 'Truths'. They specifically critique the dominant modernistic discourse in British culture of children as child in a state of becoming adult and not recognized in their current state because they are "weak, poor and needy" (p55). Moss and Petrie (2002) explain that assumptions of young people impact and shape public provisions and children's services in Britain.

Moss and Petrie (2002) reconstruct the term "active citizen" to incorporate a greater population inclusive of young people. This stretches the current definition of active citizen that narrowly defines it as an independent wage earner (Moss and Petrie, 2002). Everyone, not only young people, is dependent on care and this dependency should not be used to take away rights as citizens. Moss and Petrie (2002) argue that a discourse focusing on children's rights, instead of one constructing children as having needs, will help adults treat and conceptualize children and young people as citizens,

without over emphasizing their developmental needs.

Moss and Petrie (2002) provide a framework that challenges and dismantles modernistic views of children and young people. A shift in discourse from the need to protect, control and oversee children and young people with disabilities to one of full participation in society as a citizen would significantly disrupt the agenda of social institutions. Moss and Petrie (2002) identify social services for children and young people as sites of grooming, surveillance and control whose objectives are to produce new generations of productive citizens for society's economy. Institutions become sites of governmentality where children learn to govern themselves in accordance with societal values and norms. Children's services are driven by economic pressures instead of the best interest of the child, which better enables children to become adults who may fulfill their duties as working members of society during their peak working lives. Participation of children and young people would encourage children to be more active about their rights and citizenship. Moving towards an educational model that incorporates the voice of young people may begin to change young people's roles in society and perceptions of them as passive recipients of knowledge.

The above three theories – UNCRC, Foucauldian, and new sociology of childhood will be drawn upon for the scope of the study. They shape how the research was conducted and will be referred back to with regards to the results.

<center>Literature Review</center>

This section will review some of the literature on the social creation of labels. Three central themes that emerged in the literature are who knows what is best for the child, the process of constructing identity, and the implications for the individual child

with a label.

The IPRC Process in Ontario, Who Knows Best

A common discourse of childhood is that parents know what is best for their children. This is evidenced in Ontario Regulation 181/98 s.5(2) which positions parents to speak in the best interests of their children. This position reflects our cultural perspective regarding the inclusion of young people in the creation of their labels. Ontario Regulation 181/98 entitles parents, as well as pupils 16 years of age or older to attend IPRC meetings. In addition, any pupil who has had an IPRC is required by law to also have an Individual Education Plan (IEP) which is to be updated yearly with parents and professionals (O. Reg. 181/98, s. 6). The IEP has its own policy (Ministry of Education, 2000).

The Toronto District School Board (2007) reports that 79 percent of 16 year olds were not invited to participate in their Identification, Placement, and Review Committee (IPRC) meetings. Sixteen is the age at which young people in Ontario are deemed legally entitled to participate in these meetings. Yet a vast majority of students are not being included. Bennett and Weber (1999) state that a total of 7.27% of elementary school, and 12.12% of secondary school children in Ontario were labeled with exceptionalities in 1997. Decisions made in the IPRC process result in the creation of disability labels, referred to as "exceptionality", that become a significant part of a young person's identity throughout their academic career. It should be noted a designation of "exceptionality" within the school system, is not the same as a diagnosis of disability by a medical or psychological professional. Educational designation often follows diagnosis. However, diagnosis of disability is not necessary for a designation of exceptionality in the school

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system. For many people, including the participants in this study, the two processes are not necessarily distinct.

Ontario Regulation 181/98 excludes young people under the age of 16 from their IPRC meetings reinforcing the devaluation of young peoples' voices in the construction of their disability. The language that is used throughout IPRC policy highlights the dichotomy between typically developing children and those with exceptionalities. Leiter (2007) critiques this type of language which is also present in federal and state legislation in the United States (US). The Ontario Education Act, US legislation and state policies use language that creates mutually exclusive categories between "normalcy and disability".

Davis and Watson (2000) critique the UNCRC and selected Scottish national laws in terms of their ambiguity towards children's competencies in representing themselves. Davis and Watson (2000) highlight the disconnect between policy and practice for children with disabilities because their right to be included is often overlooked and denied. Data was used from an ethnography, which took place in school settings and discussed how adults viewed and judged competency in children with disabilities. Davis and Watson (2000) uncover the socially constructed notion of competency and how it is measured, by whom, and in what situations. They looked at how competency in children with disabilities was defined, and what happened when children did and did not participate and contribute to the assessment process. The researchers found examples where children with disabilities challenged notions of disability and were able to empower themselves by making decisions and participating in issues that were affecting them. Davis and Watson (2000) provide tangible examples of how adults and young

people can work together to dismantle notions of disability and incompetency.

The issues of competency and maturity are significant determinants of whether or not children are 'invited' to participate in decisions that involve them. Davis and Watson (2000) bring to light some of the issues that both policy makers and professionals need to address in order to create a more equitable and respectful education system. Davis and Watson's (2000) study informs this research project by pointing out how some language, such as best interests, used in laws and policies is ambiguous and lacks guidelines. Some of these terms are present in Canadian law and policy; therefore, they may be contributing to the lack of progress that is occurring in Canada on the children's rights and inclusion agenda.

Ideologies of children with disabilities that are shaped by law and policies are present here in Canada. A Canadian study by Curtis, Dooley and Philips (2002) assesses whether the parent or the child knows what is in their best interest of the child. The data are drawn from the Canadian National Longitudinal Survey of Children and Youth, and used to examine to what extent parents and children (age 10-11) agree on the child's well-being. There was some difference between the answers of parents and children for less observable outcomes like emotional disorders. There was a high degree of correlation between the answers of the parents and children for observable traits, like academic performance. However, there was a significant discrepancy in the answers of children and their parents with regards to the child's well being. Curtis et al. (2002) highlight problems assuming that parents know more about their child than the child themselves. This research supports the topic under investigation because the inclusion of young people actively creating and adapting their labels in the IPRC process allows children to speak

for themselves.

Process of Constructing Identity

Bagatell (2007) explores the process of constructing identity for individuals with autism. She conducted a qualitative ethnography over a period of nine months and found that the discourse of disability holds negative connotations. Bagatell (2007) explored how identities are adapted, negotiated, and resisted through personal agency. Such identities were found to be fluid, conflicting, and multilayered. The qualitative auto-ethnography by Fewster (2002) documents his own experiences with and ethical concerns regarding the labeling of children and young people. His major arguments are that the Diagnostic Statistical Manual IV (DSM IV) has become the controlling system through which services are funded and provided. He questions the categories created by disability and the modernist assumptions on which they are based. He states that labels are constructed by the power elite and are used to maintain the social and moral order. Fewster's (2002) fundamental issue with the DSM IV is its objectification of the affected subjects. He believes that if such individuals were treated with love, curiosity, and compassion, there would be far fewer diagnoses and labels confining and separating people from one another in society.

Both Fewster (2002) and Bagatell (2007) take issue with the way in which the process of identity is constructed. Fewster (2002) critiques the system of labeling and the discourse of disability, while Bagatell (2007) explores the process of constructing identity. He argues that the process of creating an identity for individuals with disabilities can be challenging due to negative discourses of disability. Bagatell (2007) describes how individuals negotiate these labels and maintain personal agency. Both researchers point to

the importance of understanding local knowledge and understanding the individual

instead of the socially constructed label. Individuals with disabilities should be included

in meetings where labels are created because current standards often do not view

individuals holistically. The individual is able to give professionals valuable information

to develop more effective programs and Individual Education Plans (IEPs, Ministry of

Education, 2000). Such inclusion would permit the individual to assume the role of

expert, thus making them a part of their identity construction. These two studies illustrate

that labels are generalized, and that to truly understand people, professionals must

provide an opportunity for everyone to participate in the construction of disability labels.

Bagatell's view is very similar to Fewster's (2002) and identifies alternatives to the

medical model of categorization and the pathologizing of disability. Bagatell (2007)

provides examples and the opportunity to meet and view individuals with disabilities as

equals. Fewster (2002) identifies the weaknesses in the current system that can be

corrected by applying humanitarian values such as respect, love, and compassion instead

of academic or medical solutions that put barriers between people.

Bagatell (2007) and Fewster (2002) are important to this study because they

address the multiple social processes through which identities are formed and draw on a

power analysis to understand the process of identity construction in our society. Bagatell

(2007) uses a Foucauldian analysis from the constructivist perspective that emphasizes

the role of discourse and power relationships within the social production of identity. Her

qualitative study focuseson the deficit-driven assumption that, for individuals with

autism, social interaction and communication are difficult and therefore identity

construction holds little value. Her findings show that, despite these assumptions, the

construction of identity is very important to individuals with autism.

Bagatell (2007) focuses primarily on a single subject, a 21-year-old male. Her research clearly shows the uniqueness and subjectivity of people, and supports the inclusion of individual voices in the assessment process. General labels about a group of individuals do not reflect individual capabilities and potential life trajectories. In Bagatell's (2007) study, individuals with autism want to be included in social interactions. Such inclusion would allow for individual differences to be explored so that specific needs and strengths could be highlighted.

Leiter (2007) examined the social creation of developmental disability labels on both a micro and macro level as observed in Early Intervention programs in Massachusetts, USA. Leiter's (2007) study explores the assumptions embedded in the assessment process. The goal of the study was to understand the creation process of developmental disabilities in early intervention programs and the categories that these interventions support. Qualitative findings supported the theme of dichotomizing "normalcy and disability" on a macro- policy level. US Federal and state policy create categories of "normal" and "disability" that are mutually exclusive. Categories of disabilities stress difference and dichotomize individuals rather than viewing everyone holistically. On a micro-individual level, the article analyzed the adult's views of impairment and how these views contribute to the social creation of "disabled" and their children being categorized by their disability. Leiter (2007) critiques the pathologized constructed notion of disability as a problem with the assumption that disabilities must be rehabilitated. Leiter (2007) views underlying systematic constructions of disabilities to be central to change.

Leiter (2007) informs my research as it supports the notion that categories and labels of disabilities are socially created, thereby creating space for the argument that young people acquiring these labels should have a voice in their construction. This notion is similar to the viewpoints of Bagatell (2007) and Fewster (2002). Leiter's (2007) study also points to an area in which Canada still struggles: pathologizing the ideologies that inform policy, as seen in Ontario Regulation 181/98 which excludes young peoples' voices in constructing their disabilities.

Tregaskis (2000) notes a lack of research in the area of non-disabled individual's perceptions of disability. Tregaskis (2000) suggests that progress in the disability movement is difficult when there is little research done on attitudes and perceptions towards disability amongst non-disabled individuals and how dominant ideologies and assumptions regarding disability are constructed and maintained. Understanding and researching dominant ideologies is critical if we are to change the current systems which are exclusionary. Tregaskis (2000) notes that the problem is not with individuals with disabilities or people without disabilities but instead the socially constructed notion and relationship of the binary construction of disability versus normality, the problematic constructions of disability as 'other' and 'dependant'.

Implications for Individuals' Self-concept

The socially constructed categories of labels serve many purposes in society. As discussed above, Foucault (1975) explains the construction of identities and how knowledge and power are used to create categories of identities, some of which hold more power than others. Labeling is another way in which these power structures are maintained and reproduced because certain labels are viewed negatively while others are

viewed positively. Two studies examine the long-term implications of labeling and the individuals' lack of understanding and self identification with their label. Higgins, Rashkind, Goldberg, and Herman, (2002) conducted a mixed methods longitudinal study exploring the process by which participants are 'coming to terms with their learning disability' and the social and emotional impact of being labelled as learning disabled.

Higgins et al. (2002) determined levels of success operationalizing them as IQ scores, average income, and number of job changes. The ten-year follow-up study used mostly quantitative measures to determine that half of the individuals were 'successful'. In the 20-year follow-up study, extensive qualitative interviews were conducted in addition to continuing the quantitative measurements. The tests and interviews were organized into themes that explored the awareness of difference individuals felt throughout their lives, particularly their academic related differences, non-academic differences, normative and adaptive value judgments, the labeling event, understanding and negotiating the label, compartmentalization, and finally transformation. Success was determined by the researchers and not by the participants themselves.

Higgins et al. (2002) found that labeling is detrimental to children. Participants described a process of becoming aware of their "differences", understanding and negotiating their differences, the compartmentalization of their learning disability, and finally, the transformation of their learning disability into something positive in their lives. Higgins et al (2002) found that individuals who were typically successful also had higher correlations of acceptance of their disability. However, relatively few individuals had reached the level of transformation where the label was seen as a positive influence in their lives. The study indicates ongoing life impacts of labeling, from childhood into

adulthood, and long-term negative effects of labeling. Higgins et al. (2002) noted that a lack of information was evident at the stage where people were understanding and negotiating the label

The findings of Higgins et al (2002) directly support the view that young people may benefit from being included in the construction of their disability as the majority of individuals after a 20-year study had yet to reach the transformative stage. The researchers did not explicitly state why this stage was not attained by most participants, but their findings demonstrate a need for approaches to conceptualizing labels for individuals with disabilities. The findings suggest that in order to reach the transformative stage, the disability needs to not only be accepted but viewed as a positive attribute in one's self-concept. This shift in perception may change the way society understands and relates to disability, and how the individual constructs their self-concept.

Similarly, Ingesson (2007) documents how young people with dyslexia reported lower levels of self esteem than their peers and how they were more likely to chose career and education routes that were vocational rather than university-based. These results clearly support the argument that labeling has a significant impact on an affected person's life trajectory in the education system.

Ingesson (2007) conducted semi-structured interviews with 75 teenagers and young adults. The mean age of these individuals was 19 years old. They were asked retrospective questions about their experiences growing up with dyslexia. The study found that the first six years after diagnosis were the lowest period of self esteem and that self esteem steadily increased with age throughout school to post secondary education or into the workforce. Of the 75 participants, 40% felt that dyslexia had negatively

influenced their self esteem "quite a lot" or "very much", while 80% felt that dyslexia impacted school and school achievements "quite a lot" or "very much". Ingesson's (2007) findings demonstrate that retrospectively adults felt that they had little information about their disabilities in the first six years of diagnosis. With time and understanding, some of the negative impacts of their disabilities decreased and participants began to focus on their other strengths.

The literature suggests that young people's participation in the construction of their disability may have positive ramifications for their self-concept. Three themes emerged in the literature: who knows what is best for the child; the process of constructing identity; and implications for the individual child with a label. These themes all point to the notion that young people with disabilities are valuable members of society and should be given a voice in the decisions that impact their lives now and in the future.

Methodology

Rational

This study builds on the current literature regarding Canadian children's participation in the construction of their disability label. There is not a significant amount of research done in Canada on participation using a children's rights framework; much of the research is international, such as; Davis and Watson (2007) and MacAurthor (2000). Therefore this research will explore issues of children's participation in the construction of their disabilities in a Canadian context that has not previously been studied. The results of this study may be used to bring awareness to teachers and parents about facilitating participation within the current system, using the IPRC meetings as a possible place to start. The study will explore how young people are participating in the construction of

their disability and how experiences of participating/ not participating impact self-concept.

Approach and Strategy

The study provides local knowledge that draws on a small sample of individuals with disabilities and their role in the IPRC process. Transcriptions of interviews where subjects describe their school experiences form the data for this study. The study uses qualitative in-depth semi-structured interviews with four young people age 17 to 24. The analysis strategy used in the study is grounded theory as understood by Newman (2006). In grounded theory micro level events and experiences are explored which may have implications at the macro level. This study seeks to explore the link between individual experiences with IPRC meetings and the formation of self-concept. A grounded theory strategy is one where data is collected without a hypothesis. Instead, as seen in this study there is an exploration in the area of interest: young peoples' participation in the construction of their disability. All interviews were transcribed. After the data was collected, open coding was used by reading through transcripts of the interviews several times, allowing codes and themes to emerge naturally. Specific findings were identified through a subsequent review of the primary, secondary and tertiary codes. Using these codes, an exploration of themes and relationships was undertaken. A discussion of the findings provides possible implications for the IPRC process and for the individual's construction of their disability label. This method of analysis is consistent with the theoretical frameworks being used.

Participants

The rational for involving individuals' with experiences in the IPRC process was

necessary in order to answer the proposed questions in the study: Do young people participate in the label construction of their learning disability, and how do these experiences impact young people's self-concept? Involving such participants is consistent with the rational and underlying theoretical frameworks of this study, which is that children should be active participants in the construction of their disability label. All subjects - 4 young people aged 17 to 24 years - were identified as having a disability/exceptionality in the category of learning disability through the formal IPRC process in public schools in the greater Toronto area.

Recruitment

Recruitment of young adult participants was drawn from my contacts who participated in the public special education system in the greater Toronto area using a non-random, purposive, snowball sampling technique. Formal e-mails were sent to the contacts describing this study and inviting them to participate on a voluntary basis. Individuals who received this e-mail were also asked to forward the information to any other individuals who met the subject criteria and who might be interested in participating. Precautions were taken to ensure that individuals would not feel obligated to participate on the basis of having a previous relationship with the researcher. Distance and professionalism was maintained by using formal e-mail communication and guidelines stressing the voluntary nature of the study. Participants could to choose to reply or not. Four individuals responded. E-mail and telephone communication was used to determine the date and location of the interviews.

Data Collection

Data collection was achieved in a face-to-face interview with each participant

during which they were asked about their memories and experiences with the construction of their learning disability in the school system. The interviews employed the natural flow of conversation with sharing from both interviewer and participant (Newman, 1996). This method allowed the flow of the interview to be guided by the participant, with the interviewer inviting each participant to share information at their discretion. Flexible interview questions guided the interviewer to support the general direction of the discussion. I shared many personal experiences and answered specific questions from participants about the nature of my own disability to maintain a relatively neutral power dynamic between participant and researcher (Newman, 1996) creating a safe environment for the participants.

The interviewer provided sympathy and encouragement to the participant as he/she disclosed difficult experiences. The interviewer supported these experiences with sympathetic responses such as "that must have been hard for you" and maintaining eye contact, active listening, and making use of follow up questions such as "tell me more about that experience?" or and "how did that influence your self-concept?"

The interviews took place over a three-week period. The interviews were held in private locations convenient for the participant. Four participants requested that their interviews take place in their homes, and one took place in a private location at Ryerson University. Ensuring an appropriate setting for the interview increases the individual's comfort level and ability to contribute to an effective interview (Newman, 1996). Participants were given choice in finding a comfortable setting for them to help reduce the power differential between researcher and participant.

A digital tape recorder was used to record interviews. Interviews lasted from 20

minutes to 45 minutes. To allow the narratives and experiences of the participants to be heard, direct quotes are presented in the research paper (Esterberg, 2002).

Ethical Considerations

The key potential problem that was addressed was subjects feeling uncomfortable due to the subject matter of disability. As seen in the literature, disability is often seen as a difficult topic to speak about, which may have led to the participant feeling shy or slow to warm up. To minimize the effect of subjects feeling uncomfortable with discussing their disability I openly shared my experiences of disability prior to and throughout the interview to allow for a more equal sharing of information and power. This seemed to work reasonably well and participants often asked more about my own experiences with disability which led to participants disclosing more about their personal experiences with disability. Participants were given an information sheet about the study in advance and were asked to sign a consent form in order to satisfy the ethical concerns of the Ryerson Board of Ethics. (Please see Appendix 3).

Data Organization

Narratives from the interviews were transcribed from the digital recorder and stored on a password protected computer in a word file using coded names. The recorded audio files were downloaded onto a computer in the Early Childhood Studies department in a password-protected file that was only accessible to researcher and supervisor. Consent forms were stored in a locked filing cabinet only accessible by the researcher. The participants participated in semi-structured interviews lasting from 20-45minutes. Seven semi structured questions were prepared beforehand and used to guide the interviews (Please see Appendix 4). The researcher had prior training on qualitative

interviewing through a formal research methods class, as well as extra training specific to the topic under investigation with the MRP supervisor. All data will be discarded after two years from the completion date of this project. Audio files will be deleted and consent forms will be shredded.

Data Analysis and Interpretation

Grounded theory techniques (Glaser &Strauss, 1967) were used to analyze data through coding methods as outlined in Newman (2006). This consisted of three stages: open coding; axial coding; and selective coding. All transcripts were uploaded into a spreadsheet file where each statement from the interviews was inserted into a separate row, allocated a reference number and labeled by participant. The resulting database was then subject to review and analysis. Each statement was read in isolation a number of times and assigned a thematic code. In an iterative process each new statement read was assigned either a previously identified code or a new code. In this way, all statements were coded and the final list of codes was developed. The justification for each theme was documented on the same row of the text being analyzed in the spreadsheet file in order to rationalize the construct validity of each code. Consistency of the application of each theme and subtheme to the data was ensured by reviewing the documented rational for each part of the transcripts and comparing the rational to the definition of each theme and subtheme. As new themes emerged, the entire database of text from the transcripts was revisited to ensure completeness and consistency.

Once all of the codes had been identified, they were organized into a structure that included primary, secondary and tertiary themes. This structured coding method allowed identification of sub-themes that were internally consistent with the overall primary

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themes. Frequency of the themes and subthemes by participant were calculated from the spreadsheet (see Appendix 2). The frequency data provided information about which themes were most predominantly discussed across the interviews and therefore may have been most important to the participants. However, all of the codes identify important concepts related to participation in the identification process.

Trustworthiness of the Data

As the research is based in a post-modern paradigm, it holds certain assumptions about notions of Truths. Within this paradigm the findings are viewed as subjectively viewed, limited and partial (Esterberg, 2002). The researcher does not attempt to present the findings as Truths. Instead findings are presented as specific and socially constructed, according to context, location, time and subjective experiences of those who participated in the research.

This research is based on the lived experiences of four young people disclosed in individual semi-structured interviews. The data was quantified using a spread sheet to develop a coding structure and to track the frequency of statements in each theme. This structure ensured internal consistency in the theoretical conclusions drawn from the data. Using direct quotes, in the analysis and discussion ensures that the participants' voices are preserved. Patterns and themes are discussed and explored by the researcher, but no attempt at uncovering Truths was made. The researcher had a previous history with each participant, which may have induced the participants to disclose more information and share more experiences because they were familiar with the researcher's personal experiences with learning disabilities. Building trust with the participants provides a mechanism for ensuring face validity in participants' responses.

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Findings

The findings in this study emanate from the overarching themes which arose from a detailed review of the transcripts of the qualitative interviews. These overarching themes were divided into primary, secondary and tertiary themes. After the initial readings of the transcripts, working definitions were constructed for each theme in order to provide a basis for identifying all other relevant quotes in the transcripts and ensuring consistency of coding. Each theme and subtheme was assigned a code. Specific quotes were tagged with the appropriate code or codes and a quantification of the occurrences of the codes was undertaken.

Using grounded theory to analyze the data, four major themes emerged followed by secondary themes and tertiary themes. The primary themes were internal truths, external truths, knowledge regarding disability and participation (see Table 1.1).

Table 1.1. Coding structure for primary, secondary and tertiary themes.

Primary	Secondary	Tertiary
External Truth of Self-Concept About Disability **(External)**	• Discourses of Disability • Education system • Health Care System • Peers • Teachers • Parents	• Supportive • Unsupportive
Knowledge of Disability **(Knowledge)**	• Lack of Knowledge • Desire for More Knowledge	
	• Acquired Knowledge	• Supportive • Unsupportive
Participation in the Construction of the Label of Disability **(Participation)**	• Yes • No • No Memory	• Useful • Not useful • Retrospective
Internal Truth of Self Concept About Disability **(Internal)**	• Awareness of Difference • Effects on Behaviours • Evolution of Self Concept as an Individual with a Disability **(Evolution)**	

The Participants

Names of all people and individual schools were changed to pseudonyms to protect the identity of individuals participating in this study. Names of school districts remain the same because they are large and it would not be possible to identify the individuals from that information.

RM is a young woman 22 years of age. She was educated in the Toronto public school system. She was diagnosed with a learning disability/exceptionality in elementary school. She received speech and language services as well as attending Special Education and Reading Clinic. She received special education until the end of grade 11 at which time she transferred to an alternative school. At 20 years of age, for her own interest, she undertook another formal psychological educational assessment. It outlined her learning disability as being predominantly in the area of working memory, memory processing and motor skills.

GP is a 24 year old male who was educated in the Toronto public school system. He was diagnosed with an exceptionality in grade 3, after he was observed having difficulty reading and writing. Initially, he was in a French immersion program but he switched to the English stream of education. He received support from Special Education and Reading Clinic until the end of grade 10 at which time he transferred to a school without special education services. He also accessed educational support services at two different universities after having undertaken another psychological educational assessment in his first year of university.

EA is a 24 year old female who was educated in the York Region public school system. She was identified as having an exceptionality in elementary school. She moved

to Israel during grade 4 to grade 8 where she again was identified as having a learning disability. She received educational support services in Canada and Israel. She then came back to Canada in grade 9 and continued to receive support from a special education program. At 18 years of age, she had another psychological educational assessment done and accessed support services for students with disabilities throughout her university education.

RK is a 17 year old male currently enrolled in the Toronto public school system. He was diagnosed with Attention Deficit Disorder, behavioral problems, and a learning disability at a young age, and attended a program at a psychiatric facility. He then transferred to a public school where he was segregated in a classroom with individuals with specific needs until the end of grade 5, at which time he attended a special education classroom on a part-time basis.

Internal Truths.

Internal truths are an individual's perceptions about self-concept, specifically how they view themselves. The Internal Truths theme is divided into three subthemes: Awareness of Difference; Effects on Behaviours; and Evolution of Self-concept as an Individual with a Disability. The theme of Internal Truths had the highest frequency of coded statements of all the primary codes.

Awareness of Difference.

Awareness of Difference is a subtheme that emerged under the primary theme of Internal Truths. All four participants who were young adults with disabilities discussed Awareness of Difference and how it related to their individual truths or self-concept. The following excerpts illustrate the theme of Awareness of Difference, which was often

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understood by participants when subjected to a form of segregation from "typical or normal" classmates or activities which were seen as deviating from their peers.

> RM: I remember the teacher used to come in and call for the three people in the class individually and we had to get up and walk out of the class. So - not only did we know we were different, but everybody in the class knew we were different and that's sort of – that's when I realized I wasn't the same as the rest of them.

> EA: I don't remember exactly how I felt, I remember feeling weird that my friends were progressing differently than me, and I was like behind. And I was not at the same level as my friends in reading. My friends were reading chapter books and I was still reading like even like a children's book still, in grade 1, 2. I [was] reading tons, but I wasn't reading a chapter book like they were, because I couldn't. And really in grade 4, I started reading properly. But, um, I remember my friends were given the opportunity to go into a different program, a gifted program in a different school. So I started losing some of my friends, and I had to stay in the same school. And that bothered me also. You start seeing a difference.

> GP: I felt embarrassed about my learning disability when I was in first year, and second year university too. And then I just stopped caring after a while, but I didn't want people to know I had a learning disability, because it made me feel stupid, and I thought that they would think that I was stupid as well.

> RK: When I first went to Hillberg Elementary [School] I was like fully in this LD [Learning Disability] class. And then I went part time near the end, and in Hillberg [Elementary School] it was part time, but I went there for the whole day but I was part LD [Learning Disabled] and part ah…. regular or whatever. And then like around grade 7 or 8, I stopped being LD [Learning Disabled] and I started being like [a] regular class [student].

> EA: I felt like I was embarrassed by it [her learning disability]. I felt like I wasn't normal. I felt very, different from the other kids and that there was something wrong with me. Um, that I am not smart and it started making me less confident with myself, shyer and quieter. In [a] school setting I am very quiet. At home or with my friends I am very comfortable. I wouldn't share with a lot of people. I just, it made me, um, it was just, it did affect my life. It does affect my life still. I still have a hard time with it.

These four excerpts deal specifically with Awareness of Difference. They highlight segregation, as being in a separate classroom, or being treated differently from their peers. Feelings of 'embarrassment' and of 'difference' are also referred to. All quotes include references to differences from peers and/or deviation from the norm. They

all appear to be associated with a negative impact on self-concept, except for the quote by RK. RK shows that he noticed being in the LD [Learning Disabled] class verses the regular class but he does not discuss his self-concept. Both GP and EA speak about how they feel currently and how their Awareness of Difference still impacts them, many years after leaving high school.

Overall it would appear that Awareness of Difference is an important factor in the construction of an individual's self-concept. In the final quote by EA she states that this Awareness of Difference also impacted her behaviour. She states: "it started making me less confident with myself, shyer and quieter. In [a] school setting I am very quiet". This illustrates the next subtheme of Internal Truths: Effects on Behaviour.

Effects on Behaviour

The subtheme, Effects on Behaviour, is associated with the primary theme of Internal Truths and Self-concept. This code often occurred with the codes: Acquired Knowledge about the nature of their learning disability; Lack of Knowledge; and Other People's or Society's perceptions of them. Under the subtheme of Effects on Behavior the observed quotes illustrate how the participants' self-concept may have affected their activities or perceived opportunities as a result of being aware of being a person with a learning disability.

> RM: So I can't tell if it's like, a good thing that I know [about my disability], or a bad thing that I know, but it's definitely in the back of my mind when I have to spell anything. I have such bad spelling anxiety. I can't spell, if someone's looking over my shoulder, and I have to type something, in like, Google search. It's [like I am] done [in]. But if there's no one there, I can spell okay, like figure it out. But if someone's watching me I can't spell at all, like writer's anxiety. Or [when] I was once, playing I went to a bar and we had to play a dictionary game. And I was with people I didn't know and you had to say a word out of the dictionary, and make up a definition, of the word. And one of them is not true …or all of them are not true and one is right and you have to guess which one is

right. But like, you know, [I] think of a word, a funny word, nobody knows. But I couldn't do it. I just quit. It took me. I wrote something and I scribbled it out, and I couldn't write anything [be]cause I couldn't. I was afraid they would judge me on my bad grammar, and so, it was kind of like hindering, in terms of my confidence more than ah, anything else, like the disability. The disability has just grown into like a confidence issue. That's like the new disability.

This quote illustrates how multilayered and confusing labels of disabilities become. For example RM states: "so I can't tell if it's like, a good thing that I know [about my disability], or a bad thing that I know". She states that she often feels like it is "hindering in terms of my confidence […] like the disability had just grown into like a confidence issue. That's like the new disability." This final statement shows how the construction of disability has become a part of her identity, which impacts her confidence and subsequently her behaviour.

The quote below by RM, provides another example of how she feels about her disability and the confusion she faces in terms of understanding how it impacts her as well as how it affects her confidence and her behaviour. She says "blame it on the disability" exemplifying how at times her concept of herself with a disability prevents her from working in academic areas of interest. She reveals her confusion of not completely accepting and her lack of understanding of her disability.

> RM: So I still have it embedded in me. And I dunno if it's in my head or not. I dunno if I could use it as an excuse more, because I have been told I have disabilities or because I never knew exactly what they were. And so I just have this thing, where if I can't do it, it's not my fault, sort of mentality... like always blame it on the disability and that always sort of hindered me from working too, and at other things. Like writing essays were always really difficult. And I can't tell if it's because I can't write essays or because I have a disability or because I have no confidence to write an essay, because I was told I have a disability. And I blame it on the disability that I don't even know what it is. So it's this, it's really confusing. Did I just have problems reading as a kid and it's sort of affected me for my life. And it's sort of like, I don't even know what it is really. It's hard to explain.

Similarly to RM, EA finds that her concept of an individual with a disability affects her behaviour. EA talks about her disabilities affecting her confidence and how this translates into a fear: "I find I still, I am afraid I am not saying something smart enough, or good enough, or my vocabulary isn't good enough". This impacts her public speaking. EA explains how her learning disability affects her behaviour at times in the following quote:

> EA: I am embarrassed of my oral skills still, cause I find I still, I am afraid I am not saying something smart enough, or good enough, or my vocabulary isn't good enough. Because when I was younger I was told that I am not at par with the other people and then after that, differences in language and the stop of English, the pause of English and Hebrew, and coming back in grade 9. I am very afraid to speak publically, with people that are. I am stronger of a writer, I feel that, I feel.

EA also describes a fear of the future, a fear of entering the work force and feeling like she would not be suited to certain jobs because of her construction of self. The following shows how she has reservations about opportunities for the future.

> EA: Umm, yeah that's a big fear. One of my big fears is that, how am I going to go about in the work force? What kind of job would suit me right now? Will I be able to get accommodations? Not every job even knows what that is, or does that. It's a big deal. But I think for myself because I know what is best for me, that I will find my own strategies to find a job and work with that.

Overall participants spoke in depth about: how the construction of their disability impacted their behaviour and their self-concept and internal truth; and that their learning disabilities were very much a part of their identities. As RM stated: "So I still have it embedded in me."

Evolution of Self-Concept as an Individual with a Disability

Participants shared experiences about the evolution of their self-concept as an individual with a disability (subtheme Evolution of self-concept) over time. This

subtheme of disability was not stable, but instead, shifted and changed over time. There was a tension between the subtheme of Effects on Behaviour and the theme of Internal Truth of self-concept as about disability. At times the constructed label was a fixed part of the individual's identity and conflicted with the subtheme of Evolution of the self-concept as an individual with a disability. The following quotes (from RM, GP and RK) are useful in discerning how the participants view their disability as changing and evolving over time.

> RM: Umm, ah, the fact that I haven't been in school for a while, also, changes my identity. I feel more confident with how I speak. Since I [have] been out of school and expressing myself, um ah. I remember it was just, it was about 2 and a half years ago when I got this [psychological education assessment] done. And I remember walking out after everything was done, after two weeks of like every weekend - six hours a day. And I remember him just telling me, what happened. What it [the disability] is. I remember walking out and being relieved and really happy, and kind of just laughing. I was talking to Dylan [my boyfriend] on the phone and I was like I cannot believe it. I can't believe it, that I had trouble reading when I was a kid and it turned into something else. It's created a whole new disability. So I am just kind of bitter about it. But laughing about it and just really relieved too. That it's something that I can generally overcome, it's umm … something that is, ah, greatly emotional [as] opposed to only physical.

This excerpt demonstrates how RM's self-concept and understanding of her disability and identity as an individual with a disability changed when she received new information about her disability. She expresses relief, as she understood the nature of the disability as being something she could work with and "generally overcome". As she grew older many of the difficulties she faced when she was younger were no longer as significant because she had learned useful coping strategies. She states that the disability had become more of a confidence issue because she saw herself as a "wounded learner".

In the following quote, GP's self-concept evolves towards a negative view as a result of acquiring knowledge at university. GP was not receiving formal educational

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support services. In his last years at high school, he was working closely with teachers who understood and accommodated his needs, but did not label or pathologize him. When he went to university the formal label of an individual with a learning disability was placed on him again as a requirement for accessing the appropriate support learning services. GP reacted negatively. He stated: "it bothered me a lot and I had a really hard time with it in University. I didn't like it [being labeled] at all."

> GP: Yeah I went about it [speaking to teachers and getting accommodations] on my own. And then when I went to university. It was like oh well you have a learning disability and I guess that, it was something I had had all my life, and that it was just like oh, I am going to learning center for this area or this class and it wasn't a big deal. And then all of a sudden [in high school] I didn't have it. And then I was labeled with it again [in university], and it bothered me a lot and I had a really hard time with it in university. I didn't like it [being labeled] at all.

GP was much more comfortable with his disability in high school when he was communicating with teachers and taking the initiative to communicate what he needed without a formal label. His self-concept or internal truth was negatively impacted when he was required to be labeled with a learning disability in order to receive support and services from the university. For GP, acquired information negatively impacted self-concept and his internal truth.

RK shares his experiences of the difference between his internal truth or self-concept of an individual with a disability when he was young and now a teenager. He reflects on how this self-concept of 'disability' impacted him and how he coped by "being funny". RK speaks about how he no longer feels the same about his disability as "it's not really so much a part of me, as it was". He reflected about how he now focuses on his strengths. This he finds is better for him.

RK: Ah when I was really young, I think I was kind of angry, even before I knew I had it [learning disability], or whatever. But after that, I think that I always tried to be funny or whatever. And that's how I coped, I think. When I went to Hillberg [Elementary School], I think it was more [of an issue], but the whole thing wasn't as big of an issue. Um, but at Cresmount [Elementary School] too, it was kind of like I used comedy. Not so much anymore. … I think that it's not really so much a part of me, as it was. I see myself as it's not really there. I guess it's, it's about becoming more confident and having hobbies and stuff helps a lot. Like you don't focus on it. You don't care, and if you focus on your strengths it's better.

The quotes demonstrate the ever changing nature of self-concept of an individual with a disability, and how this label changes and evolves with time, knowledge and experiences. New experiences, knowledge age and maturity seem to shape how individuals identify with their learning disabilities. The label of learning disabilities does not appear to be permanent of stable, changes a great deal over time.

External Truths of Self-Concept about Disability.

External Truth of Self-concept about Disability (External Truth) refers to both systemic constructions of disabilities and outsiders' construction of disabilities. The subthemes for External Truth are: Discourses of Disability; Education System/ Health Care System; Peers; Families, and Teachers. External Truth seems to impact self-concept as an individual with a disability and includes the outsiders' perceptions of the disability, the treatment of the person (viewed as learning disabled) and how society's systems defined disability.

Discourses of Disability.

The theme of Discourses of Disability had relatively few coded statements from the interviews indicating that this was not a dominant theme for participants. The following are examples of how discourse was noted as being a part of the construction of a disability label by the participants.

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RK: Ummm, I don't think they should call it learning disability because if you think about it, it's like disabled people. It's like, it's like someone ...less than...who doesn't have something else. They shouldn't call it that. I dunno, I just think that some things are stupid. They should just call it something else...

RK speaks about his frustrations with the definition and social construction of the term "learning disability" and "special education". He spoke about how these labels create differences that make children feel bad or excluded. In other parts of his interview, he refers to teachers' perceptions of how these labels will change, how others treat him, and how he believes that without these labels such differences wouldn't occur.

EA speaks about how the discourse of her disability influenced her sense of self-concept as being different. She says: "I had comments throughout my life, like 'special needs', 'special ed', 'sped'. They always... people saw, people knew you were different." Social constructions of disability are common in society, and how participants view themselves was often in relation to how others viewed them, or how society constructed the label of disability.

Education System and Health Care System.

Under the primary theme of External Truth, the Education System and Health Care System were subthemes that emerged from the participants' experiences with learning disabilities, as documented in the transcripts of their interviews. The following quote illustrate how the education system is set up to categorize and define students with learning disabilities as being different.

RK: Well Crestmont [Elementary School] wasn't the greatest school because they like had the LD [Learning Disability] class, in this like tower. Ahahahah, no, no actually like it was fully in a tower, and you had to like walk up these stairs, and it was one of the only classes in this area, and it was like everyone knew where it was. And it had like a stigma, like you know... and that sucked. But other than that ,yeah, Crestmont [Elementary School] wasn't like the greatest school for that.

The program was alright but the kids outside it didn't really understand it and stuff, so it was, hard. But at Hillberg [Elementary School], it wasn't really ever an issue, no one ever said anything like that. No one cared as much.

Social segregation from 'typically developing' peers was a common theme to emerge in coding. The manner in which the segregation was implemented in the education and health care systems was generally viewed as unsupportive of the individuals' ability to access services. Segregation, often made the participant more aware of being different, and appears to have negatively impacted their sense of self-concept and internal truth.

Peers, Teachers and Parents.

Participants were also affected by their peers, teachers and parents' constructions of them as individuals with a learning disability. The following quotes demonstrate experiences of how others' impacted the self-concept of participants.

> RK: Damion … [a friend] used to make fun of me about it, he used to tell me I couldn't read. Ahah he used to be like, you can't read – you go to reading clinic, ahahaha, when we were playing cello together. And he was like "can you read thisssss" and I was like "yeah". Ahaha. it was pretty painful really.

Peer groups also had the capacity to benefit and improve an individual's self-concept. The following demonstrates how individuals with disabilities normalized the experience of special education, making it a "cool kid hang out".

> RK: I think it was like some cool kids went there. It was like the cool kid hang out. Like I think Lance was in it at one point. Like me and Lance, and he was this big raver at the time and Justin … [another friend]. It was me and a bunch of boys and we used to spit down [the stair well]. There [It] was like this. On the way to reading clinic, we used to take a long long time and there were these like stairs going up. And if you spit at the top of the stair sometimes you can make it so it doesn't hit any of the railings from like the third floor. And we would like try for like 10 minutes to spit and it always hit the railings. So it was kinda like a cool thing. It changed into more like anarchy. Oh, like [we] were different, but it's okay as opposed to if someone makes fun of us. We had more … camaraderie.

The next two quotes provide examples of experiences with teachers. The first quote speaks to the issue of mis-diagnosis, which is also related to the subtheme of Lack of Information. The teacher's construction of disability greatly affected RM and RK, and how they viewed themselves and their constructions of self-concept.

> RM: Because I had teachers, I told people I had ADD [Attention Deficit Disorder] and I told myself I had ADD [Attention Deficit Disorder] because people told me that and I believed them. So I don't know if I used that as an excuse or whatever. I am just kind of bitter how like liberal they were with diagnosing me and how much I could be affected by that [label]. Imagine someone told you – you had [Attention Deficit Disorder] you know. Imagine someone told you, you were tone deaf, and you can't listen to music [or] you can't sing [because] you're tone deaf. And then you join a choir and you realize you're not tone deaf. [For] Your entire life you thought you were tone deaf and you're fine. Like, how much shit have you missed?

> RK: Yeah for sure, but also I think that also some teachers, have this kind of attitude that they talk small to the kids with an LD [Learning Disability]. And like they kind of, like think that if you're like this then you're not going to be able to do [the] harder stuff. That they think they are just like helpless and stuff, and like [the teachers] don't push them to try as much hard stuff like. Ummm It's [a] really stupid perception and negative. A lot of kids that have learning disabilities are just as intelligent as or even more than other people. There's no difference [in terms of intelligence].

The two quotes above speak to the teachers' perceptions and constructions of individuals with disabilities. RM and RK demonstrate frustration about their teacher's perceptions of them, and explain how these perceptions impact their educational experiences. These two examples support the view that outsiders have the ability to impact an individual's self-concept of disability.

Knowledge of Disability.

Knowledge of Disability (Knowledge) is a primary theme that was identified during the coding process. It is associated with three sub-themes: Lack of Knowledge;

Desire for More Knowledge; and Acquired Knowledge. The theme of Knowledge was closely related to the theme of Participation in the Construction of the Label of Disability (Participation) because they often appeared together in the coding process.

Lack of knowledge.

> RM: Well um, I just remember reading stories that were meant from [for] people a lot younger than me, and not liking the stories and feeling really [bad]….. and them telling me what level reading I was in. So like when I was in grade 6, I had [was at] a grade 3 reading level. And to think, to think at that time that you had a brain of a grade 3 in grade 6 wasn't true - it was just the reading level of someone in grade 3 and younger, and that was the difference [not my intelligence]. I was reading books that were too immature for me, the content was very young.

RM was not told about the nature of her disability. She was not given child friendly appropriate information for her reading level and, as a result, she concluded that her brain was underdeveloped compared to her peers. She views this experience as a child's misunderstanding, and feels intensely frustrated about the impact this lack of understanding has had on her life. EA further illustrates the existence of a lack of a clear understanding of the nature of her learning disability: "…with my disability I don't find it to be very defined and I myself still don't understand it. I know that I need certain, like, accommodations that benefit me".

Desire for More Knowledge.

Another subtheme to emerge under the primary theme of Knowledge was Desire for More Knowledge. The following quotes demonstrate the participants' desire to understand and learn more about their learning disability. Three of the four participants were re-diagnosed before going to university and discussed the fact that they were very interested to understand how their disability had changed and evolved, and how they have learned new coping strategies.

RM: Yeah, psychological educational assessment, I had one when I was a kid, and that's when I sort of got into [it]. And then I had one after I finished high school, just out of sheer curiosity,[and] because I was told I had ADD [Attention Deficit Disorder]. And I had been told I had dyslexia. And I have none of that. I have memory problems and organizational problems. Any[way] they said that, more so [or less], I am a very wounded, ah, learner. He said that before that, most even more than your disabilities, you [are] just very scared and wounded.

This quote clearly illustrates RM's drive to learn more about her learning disability. She obtained the assessment not for school, but for "sheer curiosity". Similarly EA states that in the future she would like to be diagnosed again, in order to benefit from having a better understanding of her disability and to develop useful coping strategies.

EA: Yeah I think so, I actually do want to get re-diagnosed: to see if I have improved; to see if things have changed; to see if I am doing the right thing - kinda, to re-evaluate where I am. I think it's very useful for people, because of all the unconfidence [misunderstanding] and all that stuff that is mixed up in my life. I think it's very important to keep going with it. I don't think it will disappear. I think it is a part of me and my identity and it is something I should follow with.

EA: It [My learning disability] will change as in it may lessen or maybe it will shift and I'll get new [coping] strategies. I myself, I think it's very important to find other skills and new information about yourself.

Acquired Knowledge.

The theme of Acquired Knowledge often appears with Participation throughout the coding process. Acquired Knowledge has the potential to change self-concept, affect behaviour and limit perceived opportunities. There were two different occasions when GP received information through his participation in a meeting regarding his learning disability. GP transferred from one university to another after two years. At the first university GP met with a psychologist who gave him information in a factual manner. GP says he felt there was little room for him to engage in a conversation. The discussion offered more prescriptive information. At the second university he attended, GP received

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information via a mandatory class for students with disabilities, which was provided by

the university as a credit towards his degree. The following is his account.

> GP: Yeah they broke it [the assessment] down for me. Um and [at the first]
> university, it [the process of providing help] wasn't very good - like it wasn't
> done very well. I found, the guy [psychologist] sorta... bad. Well, the
> psychologist took me into his office and was like you have this disability. It's
> kind of like ADD [Attention Deficit Disorder]. We think you would benefit from
> taking some kind of drug, and I was like umm, ah, that's really not what I want to
> do. You know, and I got really pissed off at that point and I just stopped listening
> to anything he was saying. And he was all contradictory [confusing], like we
> should put you on medication, ummm [be]cause we think you have ADD
> [attention Deficit Disorder], but you don't actually have ADD [Attention Deficit
> Disorder]. But you should be on medication anyways and I was ahhhh, no, I don't
> want to be on medication. That's not happening.

> GP: Yeah, well he [the psychologist] was saying, [be]cause he broke it down by
> my IQ, like the different portions of my brain, and it didn't make any sense. It
> was like okay, I have a very good, IQ in... I dunno what, but in something to do
> with like patterns and I am way below average, in stuff to do with reading and it
> didn't mean anything to me at all. It was like okay you tell me, I have a high IQ
> here and not there, and it was like I just didn't really like the way it was presented.
> It didn't really work for me, so I just got upset about it.

> GP: ...and I was just like I don't care and I didn't take advantage of many of the
> [support] services that were available at [the first university] at all. I didn't. I got
> really angry at his assessment and was like, I don't want to deal with this. I don't
> want anything to do with this anymore.

In the first quote GP speaks about how the first university attempted to deliver

information about his learning disability in order to provide him with useful support

services. He stated that the approach was "not working for him" that he "really did not

like the way it was presented". GP referred specifically to how the information was given

to him. He went on to state that "I didn't take advantage of many of the [support] services

that were available at [the first university] at all", which demonstrates how this

experience actually affected his behavior. GP stated "I got really angry at his assessment

and was like, 'I don't want to deal with this', 'I don't want anything to do with this

anymore'". The above excerpts illustrate the powerful impact that the delivery of

information can have on a person with a learning disability. It also reveals how this

impact can result in adversely affecting behaviour and increasing resentment.

> GP: Then when I went to [the second university], it was so much better. They had
> a class for people with learning disabilities and they made you go through your
> [educational] assessment step by step and you had to write a report on your
> assessment.

> GP: Well it was sort of like a class, and in the class we talked about all these
> different learning disabilities and they – we had to bring in. I am not sure which
> test it was – which ever test I had at university - we had to bring in our assessment
> and the teachers looked over it. And then they went over it with you, and they
> broke it down with you. And you had to write something about what your learning
> disability was, and there were other portions of the course too, but that was the big
> benefit of it. And it made me a lot more comfortable with the fact that I do have a
> learning disability and I learn a certain way.

> GP: Yeah it's the only place I've ever heard of a program like that too and it was
> good. You had to take it [the course] if you had a learning disability. You had to
> take this course.

The experiences GP had at the two universities were very different, but clearly

illustrate how the manner in which information is delivered impacts behaviour. At the

second university GP attended a mandatory class with peers with different types of

disabilities where they learned together about their respective learning disabilities. He

completed a project regarding his specific learning disability to understand the nature of it

and how it affected him. He also consulted with professors who "looked over it, and then

they [teachers] went over it with you, and they broke it down with you". This experience

positively impacted GP's behaviour and self-concept. GP stated that "that was the big

benefit of it, and it made me a lot more comfortable with the fact that I do have a learning

disability and I learn a certain way." He went on to state that he accessed more support

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services as a result of this experience. When asked whether he would have liked to have

this information earlier in his academic career he said:

> GP: Yeah I probably would have [liked to have this class in high school]. I would
> have understood a little bit more [about my learning disability]. I probably would
> have, ah, developed better coping strategies [sooner] because I mean, because
> everything I have really developed that I use now, has been since ah, since I was
> at [the second university] and because I really started to explore it [my learning
> disability] and break it down. And um, yeah, in high school I probably would
> have done better in high school if I'd have had it [the better understanding of the
> learning disability] then.

RM and EA had similar positive experiences. They both received formal

educational assessments after high school which greatly benefited them.

> RM: He [the psychologists] put it like really, he was such a great guy. I wish I
> was friends with him. I wanted to like have a drink with him, because he put
> everything - he made everything - he made sense of everything. He said that
> disabilities - everybody has disabilities - that if you need glasses you put glasses
> on. Some glasses, and some people need outside materials to help them with their
> disabilities. I have poor motor skills he said. I can't write very fast and I am too
> visual. So if something doesn't look nice, then I discard it. And my short term
> memory is great, so all these complications turn into the fact that I am really bad
> at taking notes and that I think I'll remember something, and [then] I don't
> [remember] the next day. I understand when things come to me immediately and
> then I forget the next day. And I can't write notes [be]cause my [poor] motor
> skills. So he's like, all you need is a computer, and that's your glasses. Some
> people need their glasses right here and some people need glasses on their head or
> in their ears, and some, and yeah everything made sense. And he knew my brain.
> He knew how to describe things for me. Ah he said that, um, I am like a funnel
> and like, ah, information is being poured into the top of my head which is the
> open mouth for the funnel and my hand is the bottom part of the funnel. And you
> just [as] information keeps pouring [in] and it overflows because the bottom half
> isn't as big [able to deal with the flow of information] as the top half and
> [because] I am writing [too slowly] and I am getting [only some of] the
> information. And then it [the flow of information] overflows and my short term
> memory can't handle it. And that['s it] exactly. I was like OH YEAH! I can see
> that makes sense.

In the quote below, EA describes a second psychological educational assessment

done before going to university and reveals how she received the information:

EA: It [the information] made me aware of what I have. It [the information] changed me. I said to myself, I need to deal with this, and I need to find [coping] strategies to work with it. I was hadn't been a part of it [the meeting about her learning disability in school], and if I didn't know exactly what it [the learning disability] was, I probably would have just gotten word of mouth [information about the nature of my learning disability] from my parents. I probably would have not taken it as seriously.... But, it [the information from the second assessment] .... Did help me.

EA: I think it's very important to get lots of information about your [learning] disability. I think it [the information] did help me. I think anyone who does have one [an assessment] should be informed, and informed about what accommodations they can have to make it easier on them. But I, it's' hard, it's hard to talk about it [the learning disability] ...

Participation in the Construction of the Label of Disability

Participation in the Construction of the Label of Disability includes participating in formal meetings such as IPRC, and IEP meetings, psychological educational assessments, conversations with teachers, professionals and parents. There were four sub-themes under Participation in the Construction of the Label of Disability (Participation): Yes - the participant participated; No - they did not participate; No Memory of participation; and finally Retrospective Reflections About Participation.

Yes- I participated/No –I did not participate/ No Memory of Participation.

The degree of participation varied in each participant's case. None of the participants participated in their IPRC meetings and there was limited memory as to participating in the development of the Individual Education Plans (IEP) with the Special Education professionals. Three of the four participants described how their parents spoke for them throughout the IPRC process and how their parents asked the participants questions about their experiences and feelings. The fourth, RM had no recollection of any conversations regarding her learning disability until much later in life, stating "Yeaaah... they were all talking about me and writing papers and I didn't know".

Three of the four subjects spoke about participating more in the construction of their disability labels, as they got older. These three participants all had psychological educational assessments after they graduated from high school at which time they were active participants in the process.

Retrospective.

The sub-theme of Retrospective reflection on the theme of Participation occurred frequently as participants spoke about what they would have liked to have done with regards to participating in the construction of their disability at an earlier age. The quotes below illustrate that Participation at an earlier age might have had a positive impact. EA felt that the experience of participation was beneficial to her overall self-concept and that her parent's involvement was very useful at a young age. There were other examples of participation in Acquiring Information, which will be explored in subsequent sections.

> EA: I would probably do the same approach as my parents, but I would probably advocate for my child to be a part of their diagnosis, and to talk about it. Talk about how they're feeling and what's going on in class, and constantly be in touch with the teacher, and be aware that the teacher knows what the disability is and what the teacher's assumptions and views are on [learning] disabilities. Because if the teacher is against children like that - like I've had a bad experience with teachers - so I don't want my child in that classroom. I don't want my child to have the unconfidence [lack of confidence] that I had, or that shyness and that feeling of guilt that you have something like a disease or something.

> EA: …and um, and if my parents hadn't explained to me a little about what a learning disability was or what was going on with me at that time, I probably would have had even more questions and felt even more ashamed about it. So I think that it [the assessment process] should have [been more inclusive], I should have been a part [of the meetings and exchanges with professionals] more. I don't remember exactly so it's hard to tell, but maybe the reason I don't remember is because I wasn't a part of it [the assessment process], right. It would have been more meaningful and memorable at that time if I had [been a participant]. Children should be a part of it … and that if I was told that [about the nature of my disability] when I was younger maybe things wouldn't have happened like this and maybe we would have found other [coping] strategies. I have no idea, but it makes me question, I don't even know my specific …. [disability].

Here EA reveals the fact that she wasn't involved in the construction of her learning disability until much later in life. She is thinking retrospectively how things might have been and how life would have been different if she had received the information about her learning disability earlier and had participated more actively at an earlier age. Below RM speaks about how she received the information about her learning disability after high school and how she might have liked to receive it earlier. The following quote reveals a Retrospective subtheme.

> RM: Yeah I would have liked that, yeah. It would have given the child an opportunity to say what they do [like] and what they don't like, and how they feel. It's hard to say to a teacher, you know when you're a kid, how you feel and you don't really have a say. It's hard to remember though. That was a long time ago, so I don't really know if I could have even gone to these [IPRC process] meetings. I don't know … So maybe if I had it [an educational assessment] done when I was younger and people told me that it's not ADD [Attention Deficit Disorder] when I was ten instead of when I was 21, it might have been better … Yeah it's kind of a right. It is your own mind right.. ahahah, you know … it was my right [to receive the assessment information].

RM strongly states that she felt it would have been beneficial for her to receive information about the nature of her learning disability earlier in life. She specifically makes references to the fact that she understands it may be difficult for children to speak to teachers and other professionals when they are young, and therefore alludes to the fact that such conversations need to happen in a child friendly way. The final sentence in her quote really speaks to children's right. She states that it was her right to have information about her learning disability "Yeah it's kind of a right. It is your own mind right .... it was my right". RM believes it was her right to receive this crucial information earlier in life, and she believes "it might have been better" referring to her internal truth and self-concept.

This section provides statements that are the most contradictory to the overall hypothesis of the study that participation is positive. While all participants value participation they acknowledge that certain conditions are necessary for participation to be a positive experience. For example GP "I think it could have been very useful, I don't know how you can present something that is that boring and jargony to a child and keep their interest. Ahaha, if you could do it that, that would be very useful for kids with learning disabilities" This is an example of some of the limitations of the current IPRC process. The nature of the meetings may have to change in order for young people to really understand the discussion that is occurring. GP highlights the tension between the right to participate and the necessity for the process to be child friendly.

Discussion

The following four themes were found to be the most prominent in the findings.

1. Young people have limited experiences participating in their construction of disability.
2. Retrospectively young adults illustrated they would have liked to participate more in the construction of their disabilities.
3. External constructions of 'disability' have an impact on individual's self-concept.
4. The relationship between knowledge and participation and its impact of Internal Truth and self concept as individual with disability.

These four themes of Participation, Retrospective, External Truths and Knowledge are discussed with reference to the literature, future direction and implications.

Participation

Young people in this study did not participate in the IPRC process as described in Ontario Regulation 181/98 (2005). There was also little memory of participating in the

Individual Education Plan (IEP) meetings. There was, however, evidence supporting the need for child friendly, direct and frequent communication between parents and children with regards to the child's learning disabilities. This finding is supported in the literature under the theme of "who knows best" as parents, teachers, and other professional are predominantly making the decisions for young people in regards to the programming and other educational decisions and matters surrounding disability. This research supports the findings by the Toronto District School Board (2007) that 79% of 16 year olds are not being invited to participate in the IPRC meetings. Although participation was limited in the early years, this study observed increased participation over time. Recall that three of the four participants all took part in an educational assessment after high school (EA, GP and RM). The research also revealed that the effectiveness of the participation – internalization of the new information followed by a positive behavioural change – was impacted by the setting and the manner in which the information about the nature of their disability was delivered. Recall GP's experiences at the two different universities. No literature that supported this observation was found.

Retrospective

Retrospectively young adults reflected on how they would have liked to participate more actively in the construction of their learning disabilities. Ingesson (2007) found that retrospectively adults feel they had little information about their learning disabilities in the first six years of diagnosis. Ingesson (2007) also found that with time and understanding, some of the negative impacts of their learning disabilities decreased and participants began to focus on their other strengths. This study's current findings directly support the Ingesson (2007) finding. All participants clearly discussed their

desire to participate more in the construction of their learning disability and the need to receive more information related to the nature of their learning disability. The literature suggests that it is possible for young people – children - to participate in the construction of their learning disability labels. Davis and Watson's (2000) study found examples where children with learning disabilities challenged notions of disability and were able to empower themselves by making decisions and participating in meetings and decisions affecting them. Furthermore the United Nations Convention on the Rights of the Child (1989) supports this study's finding that children could have participated in the construction of their learning disability labels either directly or through their parents. RM stated that "It was my right [to receive the assessment information]". The UNCRC and the new sociology of childhood support the notion that children are competent and would be able to meaningfully contribute to the constructions of their learning disabilities labels.

External Truths

This study provides evidence that the external construction of learning disability labels has an impact on an individual's self-concept. This observation is applicable to both systemic and outsiders' constructions of external truths (Appendix 2). Some findings were consistent with Foucauldian (1975) theory of govermentality, the process whereby one governs oneself according to the norms of society. This is evident in the data where some participants felt bad or diseased at a young age (see excerpts for EA under Retrospective). This is also evident with the subtheme of Effects on Behaviour in which participants describe how they were challenged and how they modified their behavior because of their self-concept as "individuals with learning disabilities". Specifically, the participants would often avoid taking risks and had lower levels of confidence in respect

of performing various tasks (e.g. writing essays - RM, spelling words in a game – RM, public speaking - EA). This observation supports the Foucauldian theory that identities are constructed by dominant ideologies and knowledge in society and, that some identities are valued more by society and some less so, resulting in the arrangement of identities in hierarchical categories as explored by Foucault (1979). This explains why individuals labeled with learning disabilities felt 'different' or 'embarrassed' and changed their behaviour to support this socially constructed notion of learning disability. One participant even expressed concern over her ability to find a job because society lacks a good understanding of individuals with a learning disability (EA).

Leiter's (2007) major argument was that the Diagnostic Statistical Manual IV (DSM IV) has become the controlling system through which support services are funded by society and provided to individuals. This study's findings are consistent with Lieter's (2007) argument in that some of the participants discussed how support services and accommodations were dependent on the provision of relevant and current labels through a formal diagnosis. For example the participants had to have recent psychological educational assessments before being granted accommodations and access to university support services (GP). In some cases, these assessments proved beneficial, in later years, by imparting relevant information to the participants about the nature of their learning disabilities, which impacted self-concept and acted as a stimulus for behaviourial change leading to the development of useful coping skills. In other cases these assessments reinforced the categories of an individual with a learning disability and led to adverse behaviours by the participant and negative stereo-typing by peers. Recall GP's experiences at the two different universities where each of these circumstances occurred.

Fewster (2002) questions the categories created by disability and the modernist assumptions on which they are based. He states that labels are constructed by the power elite and are used to maintain the social and moral order. I believe that what Fewster (2002) highlights is an important concern. From the findings it could be hypothesized that with increased participation of children and young people in label construction, meetings and other formal processes, labels may begin to be more subjective and evolve over time as the individual grows and changes. Therefore labels would not be seen as negative and fixed aspects of individuals' identities, but instead they would be shifting evolving and transforming.

A change in the type of language used in the IPRC policy is in order, such that the language does not highlight difference, but instead focuses on viewing the individual holistically. This will promote the inclusion of young people in their IPRC meetings and may diminish the negative impacts of labeling thereby better enabling young people with disabilities to co-construct their titles of disability while creating a space for multiple empowering identities to emerge as described by Moss & Petrie, (2002) Davis & Watson (2000) and Howe & Covell (2001).

Bagatell (2007) explored how identities are adapted, negotiated, and resisted through personal agency. This study found evidence of Bagatell's (2007) observations in that the identities of the subjects were found to be fluid, conflicting, and multilayered. External and internal truths were intertwined, difficult to differentiate and impacted the participants in a variety of ways in terms of their identity formation. For example, GP resisted his psychological educational assessment at the first university he attended. GP refused services and ignored his label, dissociating himself with it. This example shows

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how individuals resist and negotiate labels when it is not "working" for them, as stated by GP.

Knowledge and Participation

Increasing children's and young people's knowledge of the nature of their learning disability and increasing active participation in the construction of their learning disability label has the potential to impact internal truth, self-concept as "individuals with learning disabilities" and behaviour. This study provides evidence that the manner in which the information about the nature of the learning disability is provided has an impact on how the individual accepts and uses the information. Participation was seen to be most beneficial with reciprocal communication and partnership in a developmentally appropriate manner. Recall GP's experience at the two universities and EA's experience with the second educational assessment. This study did not include children in its subject group and hence, it cannot be said that this would necessarily be how children would view participation.

Gallagher (2008) noted the importance of studying the effects of participating rather than studying intentions. Participants in this study were engaged in construction of their learning disabilities labels to a greater degree as they aged. The study also shows that their self-concept changed and evolved over time as they acquired knowledge and were subjected to external truths. The data does not clearly demonstrate causality, but does suggest the existence of a relationship. The research also appears to suggest that motivated participation with the appropriate professionals gives the individual an opportunity to challenge and manage the demands or ideologies placed upon them by developing useful coping strategies. These findings suggest that providing a child

friendly setting and communication is important to ensure young people feel comfortable to communicate and share their knowledge for the purpose of better understanding the nature of their learning disability. This results in effective participation.

Higgins et al. (2002) found that labeling is detrimental to children. Participants described becoming aware of their "differences" and how they felt bad or like a person with a disease (EA, RK). Higgins et al (2002) documented the process of understanding and negotiating differences, the compartmentalization of learning disability, and finally, the transformation of learning disability into something positive in people's lives. This evolution of disability was a very significant finding in this paper's research. The evolution of disabilities was found to be influenced by acquired knowledge, participation and external truths. Higgins et al (2002) found that relatively few individuals had reached the level of transformation where the label was seen as a positive influence in their lives. Higgins et al (2002) findings are consistent with this study's research findings because none of the participants spoke about their disabilities reaching the transformative stage. Both Higgins et al (2002) and this study found evidence of the ongoing impacts of labeling on the participants' lives, from childhood into young adulthood, and evidence of the long-term negative effects of labeling (EA, RM). Higgins et al.'s (2002) study noted that a lack of information was evident at the stage where people were "understanding and negotiating the label". This study provides similar evidence. Most participants discussed the lack of information as an issue and in some cases this lack of knowledge still exists as a young adult (RM). As more information was acquired, the participants' self-concept seemed to evolve (GP). This research suggests that as more information is given to young people about the nature of their learning disability in an appropriate manner, and about

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what the possible implications might be on their lives, they may be able to construct more useful labels, and reach the transformative stage that Higgins et al (2002) identifies – where they see their learning disability as a positive in their lives and go beyond developing coping strategies to developing "thriving" strategies. RK's comments hint at this when he says "…if you focus on your strengths it's better". RK also says about the term "learning disability": "They shouldn't call it that. I dunno, I just think that some things are stupid. They should just call it something else…".

Author's Reflection

My own evolution of my learning disability label and transformation of 'an individual with a learning disability' changed over the course of this project. This is an important factor to note. Through my journey of academic qualitative research about disability and self concept my understanding of disability has changed. Through my active participation in researching theories, frameworks, literature and engaging in qualitative conversations with others about experiences of learning disabilities I have acquired new awareness and understandings of my own self concept as an individual with a learning disability. The process of analyzing the data and writing up the finings inspired me and changed my thinking about my own construction of disability. These changes will continue throughout my life.

As stated in the introduction, I had no formal participation in IPRC meetings as a young person and limited participation in IEP meetings. Increased participation came later as I had to take ownership of my learning disability as I moved away from home to university where I had to access services myself.

A learning disabilities specialist in a university student center told me that due to

the nature of my learning disability, I would be unable to become a teacher. I had a strong reaction to this information, and was angry. Thankfully another external influence, a first year professor, balanced this negative construction of my learning disability when he taught me about social construction theory. We discussed at length the construction of the term learning disability, and how it affected individuals. We spoke about my own strengths and how barriers in conventional society need not apply and that by utilizing my strengths I could still achieve my dreams whatever they may be.

The second part of my evolution of my learning disability label or self-concept as an individual with a learning disability came in my fourth year of university. That is when the idea for this research paper came to me. I was taking a class in narrative therapy and I was asked to do a personal assignment, identifying a personal fear that had influenced my life. I chose the theme "being scared and limited by my self-concept as an individual with a learning disability". With the help of a professor I mapped out all the areas that this construction of self challenged me on a daily basis. I looked back at when I overcame this construction of self and when the construction was destabilized, allowing a new construction of self to emerge. I identified people in my life who supported notions of individuals with learning disabilities in need of assistance and those people who promoted the new construction as a unique individual. I wrote letters thanking those individuals in my life who had supported me when I was younger to acknowledge their love and support and to ask them to join me in a new construction of me as an individual with unique skills and strengths. This process allowed me to move into an acceptance stage of understanding my learning disability as described by Higgins et al (2002). Finally this current project has allowed me to really begin to unpack my learning

disability and understand more collectively through others' experiences. This process has begun to move me into the transformative stage as explained by Higgins et al.(2002) Like Higgins, I see my learning disability as something that I am proud of, and that has shaped my experiences in a positive way and encouraged me to grow and seek opportunities I otherwise would not have had. Through exploration of my own construction of my learning disability, I developed the idea for this current research project.

Therefore, it may be that if more information were given to young people in this stage as explored in the current study, through conversations and participation about the implication and uses of the label, perhaps more individuals would be able to reach the "transformative" stage where they see their learning disability as something that has been positive in their life.

Limitations

The findings for this study may not be generalized to a larger population because the study did not use a representative sample. The learning's are limited in their application to the wider world because they are drawn from the experiences of only four individuals. The results do provide a glimpse into the importance of parental support in shaping self-concept at an early age, which can have an impact even in young adulthood. The participants' memory gaps as to the various events in their early lives coping with a learning disability and the resulting label add subjectivity to the data. These memory gaps may account for incomplete information regarding the nature, timing and quality of their participation in the IPRC process and any subsequent pertinent events. Interviews with parents might have produced more complete information and additional themes may have arisen resulting in different or conflicting findings. Future research should address this

gap by including parents' experiences and viewpoints about their recollection of the

children's experiences and the nature of their children's participation.

Participants were asked to respond retrospectively to questions about whether

participation in formal events would have provided them with different experiences and

access to knowledge. Retrospective answers introduce more subjectivity into the data

collected.

Future Direction

Future studies may wish to build upon this research by interviewing children and

young people who are currently being labeled in the education system. Such studies could

explore what these experiences mean to children at the time of identification of their

learning disability or exceptionality. Future studies may include interviewing children

who have participated in child friendly IPRC meetings to further our understanding of the

impact of such participation on a child's construction of self-concept. Parent interviews

would provide additional valuable insight into the construction of children's external

truth. Curtis et al. (2002) illustrate how parents lack sufficient information to speak solely

on behalf of their children. Therefore, including children in the process would add value

to these meetings. However, the report highlights the importance of the parent's voice in

the assessment process and identification of disabilities. It reinforces the notion that both

the parents' and child's opinion and knowledge need to be represented and addressed.

Interest in understanding the impact of child participation is growing in Canada and

internationally. Examination of the current Ontario education policies and practices of

inclusion of young people in the IPRC meetings and process is also an area of study,

which should be explored. More research is needed to confirm the findings of this limited

study which suggest that increased information and participation of young people in the construction of their learning disability label may have a positive impact on self-concept. These preliminary results also suggest that such knowledge and positive self-concept encourages young people to better assess potential life opportunities which often encourages them to develop more effective coping strategies to effect desired life outcomes. These results need to be explored in a larger more specific and directed study given the potential significant benefits. Finally, it would be useful to explore what factors need to be in place for individuals with a learning disability to move into the transformative stage where they take ownership of their learning disability and the related label, focus on their strengths and develop thriving strategies.

Conclusion

The study supports policy changes for the inclusion of children and young people in the construction of their learning disability and related labels through more effective participation in IPRC process, meetings and the development of Individual Education Plans. The study supports the notion of children and young people being active participants in the construction of their internal truth and identity as an individual with a learning disability. It also supports notions of children as competent and interested in matters that affect them. Young adults have a desire for more knowledge and when they acquire more knowledge in an appropriate reciprocal manner their self-concept evolves and transforms in a beneficial way through development of more effective coping strategies. This research supports change for individuals at the local level as well as at a systemic level at sites of the construction of disability. Finally, this research supports changing the term "learning disability" and the related discourse.

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Appendix 1

Research Questions

Questions for adult participants who were identified with a learning disability when they were younger

Tell me about the first time you were identified with a disability?

Who was involved in explaining it to you?

Did you understand the information that was given to you?

Do you remember being a part of the IPRC meeting or any other meeting about your identification?

How did you understand this information at the time?

How has it impacted your life since?

Do you think your construction of your identity would have been different if you had been actively involved in the meetings about your disability?

Questions for parents about the experiences of their child identified with a learning disability

Tell me about the first time you were told that your child was identified with a disability?

Tell me about how you explained this to your child and how they reacted?

Do you believe that your child would benefit from being a part of the meetings where teachers, professionals, and caregivers discuss the needs of your child and programs and services that will be accessible to them?

(If so) Is there anything about the current IPRC process that you would like to see changed in order for your child to participate in the meetings?

Appendix 2

Count of Occurrences of Various Codified Themes and Subthemes Across Interviews

Description		Interviewee				Grand Total
Primary	**Secondary**	**RM**	**GP**	**RK**	**EA**	**Total**
External	Outsiders Construction	2			2	4
	Systemic Construction	1	1		4	6
	Education System	5		2		7
	Teachers	4		2	5	11
	Peers			3	3	6
	Family				1	1
	Health Care System			1		1
	NA		2		1	3
	Discourse of Disability	3				3
External Total		**15**	**3**	**8**	**16**	**42**
Internal	Difference				3	3
	Evolution	4	8	8	6	26
	Awareness of Difference		1	10	1	12
	Effects on Behaviour		2	3	5	10
	NA			1	1	2
Internal Total		**4**	**11**	**22**	**16**	**53**
Knowledge	Lack of Knowledge		1	5	2	8
	Desire for More Knowledge		1	5	3	9
	Acquired Knowledge		6	5	5	16
	NA		1		3	4
Knowledge Total			**9**	**15**	**13**	**37**
Participation	No Memory	3		2	1	6
	Retrospective	3	2	5	5	15
	Process		1	1		2
	Desire for More Knowledge			1		1
	No, I did not participate	2	2	3	1	8
	Yes - I participated	3	7	2	8	20
Participation Total		**11**	**12**	**14**	**15**	**52**
Grand Total		**30**	**35**	**59**	**60**	**184**

Letter of Information

My name is Elizabeth Savaria I am conducting a research study for my Master's Research Paper (MRP) in Early Childhood Studies. This study is being supervised by Kathryn Underwood from the School of Early Childhood Education at Ryerson University.

The scope of this study is to explore the IPRC (Individual Placement and Review Committee) process in Ontario Schools. The IPRC process is the formal meeting professionals and parents schedule to determine a label for child and deiced what accommodations and services that child will have access to. The study explores the role that young people have in the IPRC process. In this study, with you present, I will ask your child about their experience with the IPRC process and their perspective on the decision about the identification of their needs within a category of "exceptionality[1]"..

The study will be made up of one semi-structured interview with questions relating to the participants experiences with the IPRC and their inclusion and exclusion in the process. Participants will parents with children who have gone through the IPRC process, young adults who have been through the IPRC process and children themselves. The interview will be 45-75 minutes in length.

If you and your child choose to participate in the study your identities will be protected, and any information share with the researchers will not be traced back to you or your child. The information gathered will be strictly protected and locked in a secure location at Ryerson University with access to data and information strictly protected. You and your child will have the right to withdraw at any time during the study, and your data will be destroyed.

What you and your child will gain from being part of this study is a chance for personal reflection and sharing of experiences of the IPRC process. You and your child will be contributing to research that may shape policies and practices in regards to children and young people with disability and their participation in the IPRC process. I cannot guarantee, however, that you will receive any benefits from participating in this study.

All information collected will be kept confidential. The minimal risks involved in participation in the study are that speaking about sensitive and personal issues may be uncomfortable. Children in any study are particularly sensitive; I will have a very high standard for ensuring their comfort. If your child feels shy or shows

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[1] Exceptionality is the term used by the Ministry of Education to define categories of disability, such as learning disability, autism, low vision, etc. in the province of Ontario. I will have a copy of the Ministry document identifying these categories with me when we meet.

discomfort, I will stop the interview. You as a parent or guardian may be present throughout the interview, and may terminate the interview if you feel your child is uncomfortable or you are uncomfortable with the interview.

Your child will be asked if s/he want to take part, and will not be required to do so if s/he is shy or unwilling. Also, s/he may stop at any time without penalty. You and your child may withdraw consent at any time. If you do not give permission, or if your child does not want to participate, it will not affect your child's care in any way. By participating in the study there are no direct benefit to you or your child. The interview will be audio taped.

<u>Questions about the Study</u>: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

Elizabeth Savaria
MA Student
(647) 207-3824
elizabeth.savaria@ryerson.ca

Kathryn Underwood PhD
Assistant Professor School of Early Childhood Education
1-416-979-5000 ext 2519
kunderwood@ryerson.ca

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

> Research Ethics Board
> c/o Office of the Vice President, Research and Innovation
> Ryerson University
> 350 Victoria Street
> Toronto, ON M5B 2K3
> 416-979-5042

Consent Form

Investigators:

I am conducting a research study for my Master's Research Paper (MRP) in Early Childhood Studies. This study is being supervised by Kathryn Underwood from the School of Early Childhood Education at Ryerson University.

Purpose of the Study:

The scope of this study is to explore the IPRC (Individual Placement and Review Committee) process in Ontario Schools. The IPRC process is the formal meeting professionals and parents schedule to determine a labelidentify additional learning needs of for a child, and to identify a category of "exceptionality" according to the Ministry of Education's criteria for identification and to and decided what accommodations and services that child will have access to. The study explores the role that young people have in the IPRC process. In this study, with you present, I will ask your child about their experience with the IPRC process and their perspective on the decision about the identification of their needs within a category of "exceptionality". I would also like to interview you as a parent about your experience with this process.

Description of the Study:

The study will be made up of one two semi-structured interviews with questions relating to the participants experiences with the IPRC and their inclusion and exclusion in the process. The interview with your child will be 45-7530 to 60 minutes in length. Techniques will be used to interview children that are consistent with their preferred method of communication. I would also like to interview you about your experience in this process. The interview will take between 60 and 90 minutes.

Confidentiality:

If you and your child choose to participate in the study your identities will be protected, and any information shared with the researchers will not be traceable back to you or your child. The information gathered will be strictly protected and locked in a secure location at Ryerson University with access to data and information strictly protected. You and your child will have the right to withdraw at any time during the study, and your data will be destroyed.

Risks and Benefits of the Study:

What you and your child will gain from being part of this study is a chance for personal reflection and sharing of experiences of the IPRC process. You and your child will be contributing to research that may shape policies and practices in regards to children and young people with disability and their participation in the IPRC process. I cannot guarantee, however, that you will receive any direct benefits from participating in this study.

All information collected will be kept confidential. The minimal risks involved in participation in the study are that speaking about sensitive and personal issues may be uncomfortable. Children in any study are particularly sensitive. For this reason, I will be particularly conscientious about; determining your child's level of comfort during the interview.

Voluntary Nature of Participation:
I will have a very high standard for ensuring their comfort. If your child feels shy or shows discomfort, I will stop the interview. You as a parent or guardian will be present throughout the interview, and may terminate the interview if you feel your child is uncomfortable or you are uncomfortable with the interview.
I understand that my child will be asked if s/he want to take part, and will not be required to do so if s/he is shy or unwilling. Also, s/he may stop at any time without penalty. I may withdraw my consent at any time. If I do not give permission, or if my child does not want to participate, I understand that it will not affect my child's care in any way. By participating in the study you understand that there are no direct benefits to me or my child. I understand that the interviews will be audio taped.

I have read and understood the letter describing the proposed study.

I understand that my child and I will be asked questions about the IPRC process and his/her perspective on the decision about identification.

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

Elizabeth Savaria
MA Student
(647) 207-3824
elizabeth.savaria@ryerson.ca

Kathryn Underwood PhD
Assistant Professor School of Early Childhood Education
416-979-5000 ext 2519
kunderwood@ryerson.ca

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.
Research Ethics Board
c/o Office of the Vice President, Research and
Innovation

Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

_____

Name of Participant (Guardian) please print

_____   _____

Signature of Participant (Guardian)   Date

_____   _____

Signature of Investigator   Date

Note: If this consent agreement is being developed to obtain parental permission, the signature line should be labelled "Parent/Guardian of Participant." In addition, include a line that would be used by the parent/guardian to indicate the name of the child for whom they are giving permission.

_____   _____

Signature of Participant or Parent/Guardian   Date

_____

Name of Child (print) if applicable