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

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This study explores how young people participate in the construction of their learning disabilities and how the experience impacts their self-concept. None of the interviewees 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. Thematic analysis identified two key concepts that emerge from experiences of disablement in school systems: the importance of knowledge and the construction of identity through experiences in educational settings. A 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. Further, the nature and timing of children's participation in matters regarding them and their label of exceptionality in the Ontario education system are explored.

Within the scholarly literature there is a recent emphasis on the importance of participation of individuals with disabilities in the educational processes that affect them (McDonald, 2009; Prowse, 2009). This study aims to understand the 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. In the province of Ontario, where this study was conducted, students are formally identified as exceptional under Ontario Regulation 181/98. The regulation governs a process called the Individual Education Placement and Review Committee (IPRC), and is used if students are deemed to be *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....* (O. reg. 181/98, s. 11(1)). This study examines the effects of the identification process on identity formation for *exceptional* students. The aim of the study was to explore whether young people participate in the label construction of their learning disability, and how these experiences impact on young people's self-concept.

Researcher Perspective
The lead author of this article was identified with a learning disability at age eight. She had little participation in the identification process and construction of her disability in childhood and adolescence. The experience of being identified with a learning disability has strongly shaped how she sees the world and her perception of equity and inclusion. At times during her academic career she experienced segregation and had little participation or involvement in issues regarding her learning disability and label formation. This study is shaped by the lead author's experience and is contextualized within a children's rights framework, and the belief that children and young people should be participants in society.

The personal perspectives of the authors are informed by international standards for children's rights. The United Nations Convention on the Rights of the Child (UNCRC) outlines the child's right to participate, as is reasonable with age and maturity of the child (1989, Article 12). 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. Further

Article 12 states *the child who is capable of forming his or her own views [has] the right to express those views freely in all matters affecting the child and that the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly, or through a representative* (UNCRC 1989, Article 12)

Social Construction of Disability
Socially constructed categories of labels serve many purposes in society. The social model of disability emphasizes the responses that occur in a social context to an individual who is perceived as being disabled (Oliver, 1990). The social model emphasizes the social experience over the pathology of the individual. In this study, we focus on the construction of the disability label, which is the point at which there is a formal construction of the category of disablement. Foucault (1975) explains 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 one way in which these power structures are maintained and reproduced because certain labels are viewed negatively while others are viewed positively. The literature identifies long-term implications of disability 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 by 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 there are long-term negative effects of labeling which span from childhood to adulthood.

The findings of Higgins et al (2002) directly support the view that young people could 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 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 choose career and education routes that were vocational rather than university-based. Ingesson (2007) conducted semi-structured interviews with 75 teenagers and young adults. 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, while 80% felt that dyslexia negatively impacted school and school achievements. 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. These results clearly support the argument that labeling has a significant impact on an affected person's life trajectory in the education system.

The literature suggests that young people's participation in the construction of their disability may have positive ramifications for their self-concept. Additionally the literature indicates that young people with disabilities should be valued and given voice in the decisions that impact their lives now and in the future.

New Sociology of Childhood
The new sociology of childhood is described by Moss and Petrie (2002) as a social construction of children and young people which has emerged from ethical and political choices. They specifically critique the dominant modernistic discourse in British culture of children in a state of becoming adult and not recognized in their current state because they are *weak, poor and needy.* (p. 55). Moss and Petrie explain that assumptions of young people impact and shape public provisions and children's services. Drawing on Foucault, Moss and Petrie claim that norms are created and maintained within a society through the use of language and the creation of hierarchies. These Hierarchies ensure that children's knowledge is seen as less important or useful, which in turn impacts the identities children hold. Moss and Petrie (2002) reconstruct the term *active citizen* to incorporate a greater population inclusive of young people, and stretches the current narrow definition of an active citizen as an independent wage earner. 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. McDonald (2009) explains that social policy that relates to children serves to define childhood and childhood identities. 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 Right to Participate
While the right of children to participate in their own lives has been envisioned in law, several concerns are evident in practice. Davis and Watson (2000) critique the UNCRC in terms of their ambiguity towards children's competencies in representing themselves. Concerns about competency and maturity are significant determinants of whether or not children are 'invited' to participate in decisions that involve them (Davis & Watson, 2000). Research by Curtis, Dooley and Philips (2002), using data from the Canadian National Longitudinal Survey of Children and Youth, found variation between responses of parents and children for some outcomes such as the well-being of children with emotional disorders. However, they found a high degree of agreement between 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, Dooley & Philips, 2002). Curtis et al. (2002) highlight problems with assuming that parents know more about their child than the child themselves. The literature clearly identifies the importance of children's participation in label construction.

Understanding of the importance of children's own viewpoints has resulted in recent research that seeks to understand the unique perspectives of students who have disabilities. Shah (2007) studied preferences of students' with physical impairments for inclusive or specialized school programs. Singh and Ghai (2009) interviewed children about their understanding of the concept of disability and how it affected their social position and relationships to peers and family in India. Similarly, Najarian (2008) examined the self-identity of Deaf women and their educational experiences. She found that a positive identity was constructed through cultural identification with the Deaf community and in programs that supported educational success for the participants. Our study is embedded in this recent tradition of the importance of understanding experiences of disablement from the perspective of children and young people who have been identified as having disabilities.

Process of Constructing Identity
Identity is a complex multilayered and fluid construct. Much has been written about minority identities and the importance of building positive self-concept in childhood. In particular, several studies indicate that being identified as having a disability is an important psychological experience (Fewster, 2002;

Prowse, 2002; McDonald, 2009).

In a study of identity construction for individuals with autism, Bagatell (2007) found subjective views of identity. 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 and in the assessment process. Such inclusion would allow for individual differences to be explored so that specific needs and strengths could be highlighted.

Using auto-ethnography, Fewster (2002) documented his own experiences with and ethical concerns regarding the labeling of children and young people. He argues 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 to designate people as having a 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 concern is the objectification of the affected subjects. He believes that if 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) point to the importance of understanding local knowledge and understanding the individual instead of the socially constructed label that has been place upon them. 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.

The identification process has created a dichotomous discourse of *normalcy* and *disability* that may be applied to children from a very early age (Leiter, 2007). Categories of disabilities stress difference and dichotomize individuals rather than viewing everyone holistically. On a micro-individual level, Leiter (2007) found that individual attitudes were reflective of these mutually exclusive categories of *normal* and *disabled* and found that parents' views contribute to children being categorized by their disability. Similarly, Singh and Ghai (2009) found children were influenced by dominant discourses of *normality* and *disability*. Clearly there are underlying systematic constructions of disabilities which are central to individual constructions of identity. Categories and labels of disabilities are, therefore, socially created. Thus young people acquiring these labels should have a voice in their construction.

Context
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 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, Dworet and Weber (2008) state that a total of 7.12% of elementary school, and 12.93% of secondary school children in Ontario were labeled with exceptionalities in 2007. 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. 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*. While the policy framework described above is not inclusive of young children participating in the process of their own identifying as having a disability, there is an international rights discourse that includes the right of children to participate.

Method

The study provides local knowledge that draws on a small sample of individuals with learning disabilities and their role in the IPRC process. The study involved qualitative, in-depth semi-structured interviews, with four young people age 17 to 24. Each of the participants was attending either secondary or post-secondary educational institutions and continued to receive supports from their educational institutions. This age group was selected because they were considered old enough to articulate the complex experience of disability identity. They also had sufficient experience across multiple education settings to reflect on differences in treatment from different approaches to assessment and identification processes. One of the risks in asking adults to reflect on their childhood experiences is that there will be error in their recollection. While this affects the reliability of the facts in their anecdotes, the study is focused on the overall feeling that resulted from their experiences. The participants, as high school and University level students, are at an age when they are becoming aware of their own identities (which will be fluid over their life-span), and they are able to reflect on how their early experiences, from their own perspectives, have contributed to their self-concept.

The Participants

Participants were recruited by sending out a call for participants by email. The call asked for students from secondary and post-secondary institutions in the Greater Toronto Area who had been identified as having exceptionality in the category of learning disability through the formal IPRC process in public schools in the greater Toronto area. Interviewing young people was 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. A description of each participant is included below based on the description that each participant gave of themselves. We did not review formal assessments of each participant, but asked them to describe their own disability. The fact that each participant had been identified under the same category, as defined by the Ministry of Education, was to control for differences in service delivery that are likely for different pathological characteristics of disability.

Rita is a young woman 22 years of age. 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.

Greg is a 24 year old male who 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.

Erika is a 24 year old female who 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.

Rick 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.

Interviews

The interviews employed the natural flow of conversation with sharing from both interviewer and participant (Neuman, 2006). 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. The lead

author was the interviewer, and she shared personal experiences and answered specific questions from participants about the nature of her own disability to maintain a relatively neutral power dynamic between participant and researcher (Neuman, 2006).

The interview schedule is as follows:
1. Tell me about the first time you were identified with a disability?
2. Who was involved in explaining it to you?
3. Did you understand the information that was given to you?
4. Do you remember being a part of the IPRC meeting or any other meeting about your identification?
5. How did you understand this information at the time?
6. How has it impacted your life since?
7. Do you think your construction of your identity would have been different if you had been actively involved in the meetings about your disability?

Thematic analysis was 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 All interviews were transcribed and uploaded into a spreadsheet file. 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 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.

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. Consistent with standard coding methods, the findings will focus on the categories that emerged which have *sufficient data to establish the parameters of the category [and] to explicate its propertie*s (Charmaz, 2008, p.167). The frequency of coded themes is presented in Table 1. Two major themes emerge as primary themes: construction of identity and the importance of knowledge as central to participation. The primary themes are presented in the findings of the study with secondary and tertiary themes comprising the content of each of the primary themes. Analysis of the secondary and tertiary codes were used in the exploration of the properties of the two major themes.

Participation
Participants were asked to describe experiences they had with participation in the formal identification of their disabilities. Two key themes emerged from participants descriptions of participation in their own identification process and are described here. The first was that knowledge was central to their participation. The second was that the nature of participation was variable amongst the participants.

Participation in the Construction of the Label of Disability
Overall, the study aimed to understand the experience of participation in label construction for children with learning disabilities. The degree of participation in formal meetings such as IPRC, and IEP

meetings, psychological educational assessments, conversations with teachers, professionals and parents 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, Rita had no recollection of any conversations regarding her learning disability until much later in life, stating *They were all talking about me and writing papers and I didn't know*. The fact that there was limited participation is indicative of the current practice in Ontario special education. It is also interesting to note that the participation that did occur generally related to children being given knowledge.

Table 1. Primary and secondary themes

Primary	Secondary	Tertiary	Total Count
Construction of Identity	*Internal Truth of Self Concept About Disability (**Internal**)*	• Awareness of Difference • Effects on Behaviours • Evolution of Self Concept as an Individual with a Disability	53
	*External Truth of Self-Concept About Disability (**External**)*	• Discourses of Disability • Education system • Health Care System • Peers • Teachers • Parents	42
Knowledge as participation	*Knowledge of Disability (**Knowledge**)*	• Lack of Knowledge • Desire for More Knowledge • Acquired Knowledge	37
	*Participation in the Construction of the Label of Disability (**Participation**)*	• Yes • No • No Memory	52

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.

Erika felt that the experience of participation was beneficial to her overall self-concept and that her parent's more direct involvement was very useful when she was younger. However, she had some ideas about how the process of participation could be better.

> 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 disabilities. Because if the teacher is against children - 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 lack confidence like I had, or that shyness and that feeling of guilt that you have something like a disease or something (Erika).

Erika was not involved in the construction of her learning disability until much later in life. Retrospectively, she thinks 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.

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 I should have been a part more. Children should be a part of it and if I was told that when I was younger maybe things wouldn't have happened like this and maybe we would have found other strategies (Erika).

Rita received information about her learning disability after high school but reflected on the utility of children being part of the process at a younger age.

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 meetings. Maybe if I had an educational assessment done when I was younger and people told me that it's not ADD when I was ten instead of when I was 21, it might have been better (Rita).

Rita also spoke directly about children's right. She said, *it's kind of a right. It is your own mind right.... it was my right to receive*. Rita believed *it might have been better* referring to her self-concept.

While all participants value participation they acknowledge that certain conditions are necessary for participation to be a positive experience. For example Greg said *I think it could have been very useful. I don't know how you can present something that is that boring and jargony (sic) to a child and keep their interest. If you could do 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. Greg highlights the tension between the right to participate and the necessity for the process to be child friendly.

Knowledge
Knowledge of one's own disability was the link between self concept and participation. The basic purpose of most meetings and processes was to understand the child's disability and it was this knowledge of the specific learning disability of each participant that was central to their conceptions of participation. Knowledge was the first step in participation.

Rita said: *I can't tell if it's a good thing that I know [about my disability], or a bad thing that I know*. She often felt like it is *hindering in terms of my confidence [...] like the disability had just grown into a confidence issue. That's like the new disability*. Rita described how the construction of disability has become a part of her identity. However, Rita 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 viewed this experience as a child's misunderstanding, and felt intensely frustrated about the impact this lack of understanding had on her life.

I just remember reading stories that were meant 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 when I was in grade 6, I had a grade 3 reading level. And to think 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. I was reading books that were too immature for me, the content was very young (Rita).

Erika also lacked understanding 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 accommodations that benefit me.*

Three of the four participants were re-diagnosed before going to university. Each of them was interested to understand how their disability had changed and evolved.

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 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. (Rita)

Rita obtained the assessment not for school, but for *sheer curiosity*. Similarly Erika stated 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.

> *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, to re-evaluate where I am. It [My learning disability] will change as in it may lessen or maybe it will shift and I'll get new strategies. I myself, I think it's very important to find other skills and new information about yourself* (Erika).

There were two different occasions when Greg received information through his participation in a meeting regarding his learning disability. Greg transferred from one university to another after two years. At the first university Greg met with a psychologist who gave him information in a factual manner. Greg felt there was little room for him to discuss his disability, but provided prescriptive information. At the second university he attended, Greg received information via a mandatory class for students with disabilities, which was provided by the university as a credit towards his degree.

> *At the first university, it wasn't very good - like it wasn't done very well. I found, the 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 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, like we should put you on medication, because 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* no, I don't want to be on medication. That's not happening.

> *He broke it down by my IQ, like the different portions of my brain, and it didn't make any sense. I have a very good, IQ in... I don't know what, but in something to do with patterns I am way below average and it didn't mean anything to me at all. 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. I was just like I don't care and I didn't take advantage of many of the services that were available there at all.*

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. On the other hand, if the student feels like they are part of the process it can have a positive effect.

> *When I transferred to a different university, it was so much better. They had a class for people with learning disabilities and they made you go through your assessment step by step and you had to write a report on your assessment.*

> *It was sort of like a class, and in the class we talked about all these different learning disabilities. 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.*

This experience positively impacted Greg's behaviour and self-concept. Greg went on to say that he accessed more support services as a result of this experience.

Rita and Erika had similar positive experiences. They both received formal educational assessments after high school which greatly benefited them.

> *The psychologists was such a great guy. He said that disabilities - everybody has disabilities - that if you need glasses you put glasses on. 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 I don't remember the next day. So he's like, all you need is a computer, and that's your glasses.

Erika describes a second psychological assessment done before going to university:

The information made me aware of what I have. It changed me. I said to myself, I need to deal with this, and I need to find strategies to work with it. I think it's very important to get lots of information about your disability. I think it did help me. I think anyone who has an assessment should be informed, and informed about what accommodations they can have to make it easier on them.

Construction of identity
The most significant effect of the labeling process as described by participants was the effect on their own sense of self. An individual's perception of self is influenced by both internal and external factors. These factors are interconnected. Internal factors included awareness of difference, changing behaviours because of awareness of difference and an evolving sense of self-concept as an individual with a disability.

Internal constructions
The internal truths that constituted a component of identity had the highest frequency of coded statements of all themes.

All four young adult participants described a form of segregation from *typical or normal* classmates or activities which were seen as deviating from their peers.

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 (Rita).

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. I felt like I wasn't normal. I felt very, different from the other kids and that there was something wrong with me (Erika).

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 (Greg).

Rita revealed her confusion about how to integrate her disability into understanding of self. Writing essays was 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 (Rita).

Similarly Erika talked about her disabilities affecting her confidence and how this translated 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.* Erika also described 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 showed her reservations about the future:

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 (Erika).

Participants shared experiences about the evolution of their self-concept as an individual with a disability. Disability as part of their identity was not stable, but instead, shifted and changed over time. There was a tension between internal construction of disability and how the participants viewed their disability as changing and evolving. Rita said, *the fact that I haven't been in school for a while, changes*

my identity. I feel more confident with how I speak. Many of the difficulties Rita faced when she was younger were no longer as significant because she had learned useful coping strategies. She stated that the disability had become more of a confidence issue because she saw herself as a *wounded learner.*

Greg's self-concept evolved towards a negative view as a result of acquiring knowledge at university. Greg was not receiving formal educational support services. In his last years at high school, he worked closely with teachers who understood and accommodated his needs, but did not label or pathologize him. When he went to university Greg received the formal label of learning disability as a requirement for accessing the appropriate support learning services. Greg reacted negatively. He stated: *it bothered me a lot and I had a really hard time with it in University. I didn't like being labeled at all.*

Greg was much more comfortable with his disability in high school where he communicated took initiative with teachers without a formal label. His self-concept or internal truth was negatively impacted when he was required to have a formal identification at university. For Greg, acquired information negatively impacted self-concept and his internal truth.

Rick shared the difference between his experience when he was young and the present. Rick said,
> *When I was really young, I think I was kind of angry, even before I knew I had a 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. I guess 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.*

External influences
In addition to the internal experiences of disability, there are significant influences from external sources on the construction of identity as an individual with a disability. Both systemic constructions of disabilities and outsiders' construction of disabilities are important in understanding how these young people view their own identities. These external influences include general discourses of disability; their experiences in the education system or in health care, and their interactions with peers, professionals and family.

Rick 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 him, how others treat him, and that he believed without the label he would not be treated as different from his peers.

Erika explained that her disability influenced her sense of self-concept as being different. She said: *I had comments throughout my life, like* special needs*,* special ed*,* sped*. People knew you were different.* Social constructions of disability are common in society, and how participants viewed themselves was often in relation to how others viewed them, or how society constructed the label of disability.

Social segregation from *typically developing* peers was a common concern across the interviews. The manner in which the segregation was implemented in the education system 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.

Participants were also affected by their peers, teachers and parents' constructions of them as individuals with a learning disability. For example, Rick said:
> *A friend used to make fun of me about it. He used to tell me I couldn't read. He used to say,* you can't read – you go to reading clinic. *He was like* Can you read thisssss? *and I was like* yeah. *It was pretty painful really.*

Peer groups also had the capacity to improve an individual's self-concept. The following describes a group of students taking ownership of the experience of special education.

> *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. It was me and a bunch of boys and we used to spit down the stair well. On the way to reading clinic, we used to take a long, long, time and there were these 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 the third floor. We would try for 10 minutes to spit and it always hit the railings. So it was kinda like a cool thing. We were different, but it's okay as opposed to if someone makes fun of us. We had more camaraderie (Rick).

Teachers' constructions of disability greatly affected Rita:

I think that some teachers have this kind of attitude that they talk small to the kids with an LD. And they kind of 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 don't push them to try as much hard stuff. 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 (Rita).

Construction of identity is a complex phenomenon that is affected by both internal and external factors, which interact. This understanding of self also affects the manner in which the participants interacted with others. This complex construction of self was deeply embedded in participants' experiences in the identification process.

Discussion
These reflections from young adults about their own participation are consistent with other studies. Ingesson (2007) found that retrospectively adults felt 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 learning disabilities decrease and focus shifts to other strengths. The participants in this study described the benefits of participation in the construction of their learning disability, but the focus was clearly on accurate and helpful information, delivered with sensitivity in a manner that was understandable to them at their given age. The literature suggests that it is possible for young people – children - to participate in the construction of their learning disability labels (MacArthur, Sharp, Berni & Gaffney, 2007). Davis and Watson's (2000) study found examples of children with learning disabilities challenging notions of disability and empowering 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. Rita stated that *It was my right [to receive the assessment information].*

Increasing children's and young people's knowledge 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 active participation. This study indicates that the effects of the identification process are most keenly felt in terms of children's self-concept. Reciprocal and developmentally appropriate communication were seen as the most effective mechanisms for communication as Greg's experience at the two universities and Erika's experience with the second educational assessment illustrated. This study did not include children in its subject group and hence, it cannot be said that this would necessarily be how young children would view participation. However, the change that students experienced through the course of their education was an interesting finding that has been noted in other research (Fitch, 2003).

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 disability labels to a greater degree as they aged. The study also showed that self-concept changes and evolves over time, as children acquire knowledge and are subjected to external influences. These findings suggest that it 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 can result in children being motivated to participate in the management of their own education and the development of coping strategies, which are effective mechanisms for participation.

Higgins, Rashkind, Goldberg and Herman (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 (Erika, Rick). 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 an important theme

that emerged from the interviews in this study. 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. Similarly, none of the participants in this study spoke about their disabilities reaching the transformative stage. This study found evidence of the ongoing impacts of labeling on the participants' identity construction, from childhood into young adulthood, and evidence of the long-term negative effects of labeling (Erika, Rita). 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 the lack of knowledge still existed in young adulthood. As more knowledge was acquired, the participants' self-concept seemed to evolve. This research suggests that as more information is given to young people they may then be able to help construct more useful information, and reach the transformative stage that Higgins et al (2002) identified – where children see their learning disability as a positive in their lives and go beyond developing coping strategies to developing *thriving* strategies.

Conclusion

Interest in understanding the impact of child or young adult 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 an area of study which should be explored further. More research is needed to confirm the findings of this small 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 identity formation for children with disabilities. These preliminary results also suggest that such knowledge and positive self-concept encourages young people to better assess potential life opportunities.

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 during the process of identification. 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 actively participate in the planning of their own education, and to embrace their identity as a person with a learning disability.

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